



EUROPEAN CONFERENCE ON FASD 2018

SEPTEMBER 24-26, 2018
H4 HOTEL (FORMERLY RAMADA),
ALEXANDERPLATZ, BERLIN

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Please use the following references as each day has been given its own code:

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| Monday, 24.09.18 | 2761102018037341009 | (6 points) |
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Fifth European Conference on FASD

24 to 26 September 2018

Berlin, Germany



www.eufasd.org

Conference Chairperson: Gisela Michalowski

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Conference Chairperson: Gisela Michalowski

European Conference
Fetal Alcohol Spectrum Disorders

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The **EUROPEAN FASD ALLIANCE** was founded in February 2011 to meet the growing need for European professionals and NGOs concerned with FASD to share ideas and work together. The EUROPEAN FASD ALLIANCE is a nonprofit international organization registered in Sweden.

Our Goals are

- To support the member associations in their efforts
- To improve the quality of life for all people with Fetal Alcohol Spectrum Disorders and their families
- To increase awareness of the risks of drinking alcoholic beverages during pregnancy.

The EUROPEAN FASD ALLIANCE will also act as a liaison centre

- To collate and disseminate information to its members
- To stimulate international collaboration on research projects on the origins management and prevention of Fetal Alcohol Spectrum Disorders
- To encourage national associations to exchange and share their projects and experiences
- to foster the foundation and development of new national FASD Associations.

The Board

- Chair: Diane Black (Netherlands)
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Hans Spohr (Germany)

The Council of Lifelong Experts

- Lee Harvey - Heath (England)
Lena Larsson (Norway)
Donna Ross (Scotland)
Karl Wittgard (Sweden)

Monday, September 24, 2018

Posters should be posted on 24th before 10:30 a.m. and be removed on 26th at 1 p.m.

| | |
|---------------|--|
| | Welcome |
| 9:00 – 9:20 | Gisela Michalowski, Mirjam Landgraf, Diane Black |
| 9:20 - 9:30 | [1] Thierry Maillard A tribute to Dr. Lemoine and the recognition of FAS |
| | |
| | |
| | Plenary Session 1: Prevention |
| | Session chairs: Ed Riley, Ken Warren |
| 9:30 - 9:50 | [2] Peggy Murray FASD prevention internationally – How far have we come? |
| 9:50 - 10:10 | [3] Sylvia Roozen Developing systematic FASD prevention programs |
| 10:10 - 10:30 | [4] James Fitzpatrick Scaling up FASD prevention with at-risk communities |
| 10:30 - 11:00 | <i>Coffee break and poster viewing</i> |
| 11:00 - 11:20 | [5] Leana Olivier FASD prevention in rural and urban settings |
| 11:20 - 11:40 | [6] Nancy Poole Multilevel FASD prevention guided by virtual national research network |
| | |
| 11:40 - 12:45 | Plenary Session 2: What's happening in my country? |
| | Session Chairs: Martha Krijgsheld, Gisela Michalowski (5 min presentation each) |
| | [7] Romania: Teodora Ciolompea Benefits of a new prevention and intervention program for population at risk for FASD |
| | [8] Spain: Oscar Garcia-Algar Foetal Alcohol Spectrum Disorder (FASD) in adopted children from East Europe countries in Spain |

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| | [9] Netherlands: Martha Krijgsheld What's happening in the Netherlands |
| | [10] United Kingdom: Michelle Bond Establishing a Local Assessment Pathway for FASD within a Community Child Development Service |
| | [11] Scotland: Sarah Brown What's Happening in My Country – Scotland, UK |
| | [12] France: Catherine Metelski FASD: What is happening in France? |
| | [13] Slovenia: Matej Kosir, Marjetka Hovnik-Kersmanc What is happening in Slovenia? |
| | [14] Poland: Katarzyna Okulicz-Kozaryn Looking for the agreement on the Polish guidelines for diagnosis of Fetal alcohol spectrum disorder |
| | [15] Australia: Elizabeth Elliott My Country 5 Minute Update--Australia |
| | [16] Finland: Sari Somer Support groups for young FASD Adults |
| | [17] Slovak Republic: Veronika Šebeková Multidisciplinary teams platform and screening algorithm indicating the presence of FASD by preschool children in the system of early intervention in Slovak republic |
| 12:45 - 13:45 | <i>Lunch</i> |
| 13:45- 15:15 | Parallel Sessions A: Carers, Prevention, Biomarkers |
| 15:15 - 15:45 | <i>Coffee break</i> |
| 15:45 - 17:15 | Parallel Sessions B: Adults, Diagnosis, Professionals |
| 17:20 – 18:20 | Prevention: Discussion & Audience engagement – toward an international collaboration Chairs: Edward P Riley, Kenneth Warren, Peggy Murray, Sylvia Roozen, James Fitzpatrick, Nancy Poole, Leana Olivier, Gerjo Kok, Leopold Curfs |
| 17:20 – 18:20 | <i>Poster Presentations</i> |

Tuesday, September 25, 2018

| | |
|---------------|---|
| 8:30 | Opening Marlene Mortler (Drug Commissioner of Germany) |
| | |
| | Plenary session 3: Biology of FASD / Diagnosis |
| | Chairs: Oscar Garcia, Diane Black |
| 8:40 - 9:10 | [18] Keynote: Michael Kobor Epigenetics in Human Fetal Alcohol Spectrum Disorder – Opportunities and Challenges |
| 9:10 - 9:40 | [19] Keynote: Miguel Del Campo Use of MRI and EEG in the Fetal Alcohol Spectrum Disorders |
| 9:40 - 10:00 | [20] Luis Castillo A new App: VisualFASD (a Foetal Alcohol Spectrum Disorder dysmorphology assessment tool) |
| 10:00 – 10:30 | <i>Coffee break and poster viewing</i> |
| | |
| | Plenary session 4: Prognosis, Legal issues |
| | Chairs: Ilona Autti-Ramö, Teodora Ciolompea |
| 10:30 – 10:50 | [21] Rabya Mughal Sleep, Anxiety and Behaviour in children on the Fetal Alcohol and Autism Spectrum |
| 10:50 - 11:10 | [22] Niina-Maria Nissinen Mental and behavioral disorders among young people with prenatal substance exposure - ADEF Helsinki research project (Alcohol or Drugs Exposure During Fetal Life) |
| 11:10 - 11:30 | [23] Kathrin Bohmert Sleep Problems in children with FASD – frequent, but frequently overlooked |
| 11:30 - 11:50 | [24] Raewyn C Mutch and Hayley Passmore Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia |

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| 11:50 - 12:00 | Questions |
| 12:00 - 13:00 | <i>Lunch</i> |
| | |
| | Plenary Session 5: Living with FASD |
| | Session chairs: Leopold Curfs, Philippa Williams |
| 13:00 – 13:10 | [25] Gisela Michalowski Film of German adults with FASD |
| 13:10 - 13:25 | [26] Claudia Koster Adult with FASD from the Netherlands |
| 13:25 - 13:40 | [27] Gaby Mitrani Personal Story – Mother from Israel |
| 13:40 – 14:00 | [28] Leana Olivier What happened to them? |
| 14:00 - 14:20 | [29] Jennifer Shields Social Workers' Experiences of Supporting Looked-After children Exposed to Alcohol In-Utero; an Interpretative Phenomenological Analysis |
| 14:20 - 14:40 | [30] Zameer Mohamed Carer stress in Fetal Alcohol Spectrum Disorders: Data from the UK National Specialist clinic |
| | |
| | Plenary Session 6: Intervention |
| | Session chairs: Raja Mukherjee, Peggy Murray |
| 14:40 – 15:00 | [31] Ilona Autti-Ramö ICF as framework for understanding the needs of a person with FASD |
| 15:00 - 15:20 | [32] Ira J. Chasnoff Educational and behavioral interventions for children and youth with FASD |
| 15:20 - 15:50 | <i>Coffee break</i> |

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| 15:50 - 17:05 | Parallel Sessions C: Legal issues, Professionals, Prognosis |
| 17:10 – 18:00 | <i>Poster Presentations</i> |
| 17:10 – 18:15 | Business meeting General Assembly of the Member Organizations |
| 19:00 – 23:00 | Gala dinner <i>Including presentation of poster prizes</i> |

Wednesday, September 26, 2018

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|---------------|---|
| 8:45 | Opening |
| | Plenary Session 7: Stigma |
| | Session chairs: Mirjam Landgraf, Alison Frieling |
| 9:00 - 9:30 | [33] Hans Spohr Reflections about the difficulty of FASD to be accepted in the community and worldwide |
| 9:30 - 10:00 | [34] Ken Warren PAE Research Impact for the Treatment and Prevention |
| 10:00 - 10:30 | [35] Arjan Bos The social stigma of fetal alcohol spectrum disorders: From theory to interventions |
| 10:30 - 11:00 | <i>Coffee break</i> |
| | Plenary Session 8: International cooperations |
| | Session chairs: Gro Løhaugen, Elizabeth Elliott |
| 11:00 – 11:30 | [36] Edward P. Riley Collaborative Initiative on FASD (CIFASD): An update on current research |
| 11:30 – 11:50 | [37] Mariann Skar |

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| | Policy Developments and action at EU level |
| 11:50 – 12:00 | [38] Diane Black, Kathy Mitchell FASD Global |
| 12:00 – 12:10 | [39] Mirjam Landgraf One World FASD Network |
| 12:10 – 12:20 | Announcement of Election Results: Diane Black New Board for 2018 to 2020 |
| 12:20 – 12:30 | Announcement of EUFASD 2020: Gro Løhaugen |
| 12:30 – 12:40 | Closing remarks: Gisela Michalowski, Diane Black, Mirjam Landgraf |
| 12:40 | End |

Parallel Sessions A1 Monday early afternoon

13:45 - 15:15 [40] Raja Mukherjee
Workshop (90 min): Assessing the Neurocognitive function(?) in people with FASD: Subtleties of presentation and lessons from two European FASD specialist clinics for diagnosis and management

Parallel Sessions A2 Monday early afternoon

Secondary disorders

Chairs: James Fitzpatrick, Alison Frieling

13:45 - 14:00 [41] Anne M. Koponen
Mental and behavioral disorders among young people with prenatal substance exposure - ADEF Helsinki research project (Alcohol or Drugs Exposure During Fetal Life)

14:00 - 14:15 [42] Michel Spodenkiewicz
Time to catch up with the secondary psychiatric disabilities of FASD in France

14:15 - 14:30 [43] Katarzyna Dylag
Prevalence of urinary system defects among patients with fetal alcohol spectrum disorders

- 14:30 - 14:45 [44] Kate M Fleming
Alcohol consumption in pregnancy and childhood hearing and neurodevelopmental problems in the UK: analysis from the Millennium Cohort Study
- 14:45 - 15:00 [45] Sarah Brown, Jennifer Shields
Risk Assessment in FASD – Why Paediatricians Need CAMHS Training.
- 15:00 - 15:15 Discussion

**Parallel Sessions A 3 Monday early afternoon
Prevention**

Chairs: Ilona Autti-Ramö, Denis Lamblin

- 13:45 - 14:00 [46] Kathleen Tavenner Mitchell
Reducing Stigma towards Birth Mothers and their Children with FASD in Healthcare Providers
- 14:00 - 14:15 [47] Heike Kramer
Pregnant - my child drinks as well! Alcohol - No sip. No risk!
Successful school FASD primary prevention before pregnancies
- 14:15 - 14:30 [48] Nancy Poole
Evaluation of HerWay Home: Promising approaches and outcomes of an FASD prevention program for substance-using women with complex, social determinants of health issues
- 14:30 - 14:45 [49] Bérénice Doray
The FASD Resource Center in Reunion Island: Back to 2 years of activity
- 14:45 - 15:00 [50] Denis Lamblin
The SAFTHON, First International Solidarity Movement for the prevention of Fetal Alcohol Spectrum Disorders
- 15:00 – 15:15 Discussion

**Parallel Sessions A 4 Monday early afternoon
Biology and Prevention**

Chair: Diane Black and tbc

- 13:45 - 14:00 [51] Sarah Brown
Genetic testing in FASD assessments – What lessons did we learn?

- 14:00 - 14:15 [52] Marta Astals-Vizcaino
Epigallocatechin Gallate (EGCG) to Improve Cognitive Performance in Foetal Alcohol Syndrome (FAS) Children
- 14:15 - 14:30 [53] Rose Schmidt
Discussing multiple substances by multiple providers, as a key FASD prevention strategy
- 14:30 - 14:45 [54] Stefania Bazzo
"Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders (FASD): from prevention to evaluation": an e-learning program for health professionals in Italy
- 14:45 - 15:00 [55] Louise Gray
Reducing alcohol use by women who are pregnant, planning or could be: using social media campaigns to raise awareness
- 15:00 - 15:15 [56] Giuliana Moino
Prevention of alcohol consumption during pregnancy and promotion of healthy lifestyles in Italy: an "experiential laboratory" of participatory education.

Parallel Sessions A5 Monday early afternoon

Adults

Chairs: Gisela Michalowski, Jan-Peter Siedentopf

- 13:45 - 14:00 [57] Lina Schwerg
Introducing the BSI-FASD – A Screening Instrument for Adults with FASD
- 14:00 - 14:15 [58] Betteke Maria van Noort
Psychiatric symptoms and quality of life in adolescents and adults with fetal alcohol spectrum disorder: results from a longitudinal observational study
- 14:15 - 14:30 [59] Nadine Beck
Criminal behavior and substance abuse in adolescents and adults with fetal alcohol spectrum disorder
- 14:30 - 14:45 [60] Björn Kruse
Concept of an inclusive FASD-Outpatient Clinic: Experiences and Proposals

14:45 - 15:00 [61] Jessica Wagner
Attitudes towards a late FASD diagnosis

15:00 - 15:15 Discussion

Parallel Sessions B 1 Monday late afternoon

15:45 - 17:15 [62] Philip May
Workshop (90 min): Physical Growth and Traits of Children with Fetal Alcohol Spectrum Disorders (FASD) and Maternal Risk Factors in the General Population of the United States: Summary Results from the Collaboration on FASD Prevalence (CoFASP)

Parallel Sessions B 2 Monday late afternoon

Diagnosis

Chairs: Gro Løhaugen, Oscar Garcia

15:45 - 16:00 [63] Michael Suttie
Introducing Objective 3D facial Analysis into the FASD Clinic Workflow

16:00 - 16:15 [64] Zameer Mohamed
Comparisons of the BRIEF Parental Report and Neuropsychological Clinical Tests of Executive Function in Fetal Alcohol Spectrum Disorders: Data from the UK National Specialist Clinic

16:15 - 16:30 [65] Jennifer Shields
Neuropsychological Profiles in Scottish Children Affected by Prenatal Alcohol Exposure

16:30 - 16:45 [66] M. Zimmet
Paediatrician reported FASD in Australia: over-representation of children in out-of-home care and Indigenous children

16:45 - 17:00 [67] Magdalena Borkowska
Neuropsychological assessment of children with Fetal Alcohol Spectrum Disorders in Poland

17:00 - 17:15 Discussion

Parallel Session B 3 Monday late afternoon

15:45 - 17:15 [68] Dianne Wesselink
Workshop (90 min): Raising and educating children with FASD

Parallel Session B 4 Monday late afternoon *outside of congress center* *Diagnosis*

15:45 - 17:15 [69] Björn Kruse
On-site workshop (90 min)
Visit to a Berlin diagnostic clinic: diagnostic approach in adults.
Note that since this visit is off-site, it is at your own risk and any problems are not covered under the insurance of the conference center.

Parallel Sessions B 5 Monday late afternoon *Professionals*

Chairs: Leopold Curfs, Teodora Ciolompea

15:45 - 16:00 [70] Mirjam N. Landgraf
The German guideline for diagnosis of FASD and the knowledge of German health professionals and parents about FASD

16:00 - 16:15 [71] Marsha Wilson
Lessons Learned: the development of a model of an online FASD Training project

16:15 - 16:30 [72] Fiona McGruer
Service Evaluation of the Fetal Alcohol Assessment and Support Team in NHS Ayrshire and Arran, Scotland

16:30 - 16:45 [73] Heather Jones
FASD Hub Australia: a novel resource for clinicians, caregivers, researchers and policy-makers

16:45 - 17:00 [74] Jocelynn L. Cook
The evolution, priorities and highlights of the latest FASD research in Canada

17:00 - 17:15 Discussion

Parallel Sessions B 6 Monday late afternoon
Professionals

15:45 - 17:15 [75] Matej Kosir
Workshop (90 min): How to inform policy- and decision-makers about evidence-based alcohol policy

Parallel Sessions C 1 Tuesday afternoon
Intervention

Chairs: Leana Olivier, Sylvia Roozen

15:50 - 16:05 [76] Linda Wason-Ellam
Interactive Dynamic Assessment: A longitudinal study of a diagnostic and mediation tool for school-age learners with FASD

16:05 - 16:20 [77] Osman Ipsiroglu
Is Iron Deficiency hindering Precision Medicine in Individuals with FASD?

16:20 - 16:35 [78] Michelle Stewart
A Strengths-Based Research and Interventions: Workshop & Discussion of Community and Family Resources

16:35 – 17:05 Discussion

Parallel Sessions C 2 Tuesday afternoon
Legal issues / prognosis

Chairs: Mirjam Landgraf, Ira Chasnoff

15:50 - 16:05 [79] Hayley M Passmore
Improving the management of young people with Fetal Alcohol Spectrum Disorder in an Australian detention centre

16:05 - 16:20 [80] Alan Price
The impact of traumatic childhood experiences on cognitive and behavioural functioning in children with prenatal alcohol exposure (PAE)

- 16:20 - 16:35 [81] Elizabeth Carlson
Prenatal alcohol exposure and its relation to intelligence, executive functions, and antisocial and prosocial outcomes
- 16:35 - 16:50 [82] Raja Mukherjee
Polysubstance abuse and its impact on FASD diagnosis and outcomes: Data from the UK National Specialist FASD clinic
- 16:50 - 17:05 Discussion

Parallel Sessions C3 Tuesday afternoon

Carers

Chairs: Katarina Wittgard, Martha Krijgsheld

- 15:50 - 16:05 [83] Fiona McGruer
Parent, Carer and Professionals' Perspectives on FASD Services in Scotland
- 16:05 - 16:20 [84] Elizabeth A. Russell
FASD and the 12 steps for Birth Mothers
- 16:20 - 16:35 [85] Alan Price
Experiences of adoptive parents of children with FASD and a history of traumatic experiences in the UK
- 16:35 - 17:05 Discussion

Parallel Session C4 Tuesday afternoon

Professionals

- 15:50 - 17:05 [86] Heike Hoff-Emden
Workshop (75 min): Coaching Manual - A Guide for Caregivers of People Affected by FASD

Parallel Session C5 Tuesday afternoon

Prevention

- 15:50 - 17:05 [87] Gerjo Kok
Workshop (75 min): Prevention campaigns for Fetal Alcohol Spectrum Disorders (FASD)

European Conference on FASD 2018

Monday, September 24 to Wednesday noon, September 26, 2018
H4 Hotel (formerly Ramada), Alexanderplatz, Berlin

Marlene Mortler,
Drug Commissioner of the Federal Government, Member of Parliament

Ms. Michalowski, Ms. Black, Ms. Landgraf,
Distinguished Ladies and Gentlemen,

Thank you very much for the invitation to attend this important conference! As the Drug Commissioner of the Federal Government, I attach great importance to the topic of FASD. We are dealing here with children and families who need very special help and support. This is why I made FASD the topic of my first major Annual Meeting as Commissioner on Narcotic Drugs.

Up to 10,000 children are born with FASD every year in Germany. Alcohol consumption during pregnancy has a significant impact on the health of the unborn child. It can lead to lifelong physical and mental damage, as well as to behavioural disorders in the child. Persons with FASD are impaired for their entire life, whereby the greatest problems often have to do with handling day-to-day activities. Living a 'normal' life is possible only for very few young people and adults with FASD.

This is why it is important to collect reliable knowledge on FASD and to pass it on. This international congress here in Berlin is making a major contribution in this direction.

In organising this congress at international level, FASD Deutschland has succeeded in bringing together an incredible number of persons who deal with FASD, both professionally and privately, to exchange experience and share new findings – always with the aim of finding even better ways to help persons with FASD and their families. I wish to thank you wholeheartedly for this, and for the excellent job you have made of organising this congress. I have great respect for such an extraordinary achievement on the part of a self-help organisation. This also applies to the scientific direction of the congress who, in addition to their 24-hour job in clinics and practices, have succeeded in putting together an excellent scientific programme.

From the day I took on this office, I have been avidly involved in the prevention of FASD, improving its diagnosis and more actively supporting those affected.

I was happy to support the drafting of the FASD Diagnosis Guideline. It is a vital component in giving significantly more affected children and young people the opportunity to receive optimum treatment and support through early diagnosis. It is my hope that the S3 Guideline will be applied widely and I am delighted the publication of English and Spanish versions of the Guideline are available here. I urge you to take this important guideline home with you, in your individual language, so that the knowledge of FASD in your country can be deepened and children can receive targeted assistance based on a sound diagnosis.

One thing fills me with great pride. In February 2016, the manual 'Fetal Alcohol Spectrum Disorder – what next?' (*Fetale Alkoholspektrumstörung – und dann?*) was published. It was the first manual on FASD published in Germany that is aimed directly at those affected. Its goal is to help persons with FASD better handle their everyday life. It not only provides information on the disorder itself, it also gives practical tips for living together with other people.

The possibilities available for supporting persons whose lives are affected by this disorder are still not yet sufficiently well known. Very often there is a lack of knowledge on the relevant social legislation in force. This is why we have commissioned a brochure to provide comprehensive information on the legal questions that arise when caring for persons with FASD. What rights do I have? Where can I claim them?

These resource persons, on whom people with FASD depend, also need concrete assistance and support. They will need competent and comprehensive assistance to be able to make family life with persons with FASD successful. I am fortunate to have the opportunity to support the publication of a manual that offers targeted assistance in solving the problems, both big and small, that occur in day-to-day life with persons affected by FASD.

Ladies and Gentlemen,

As you can see, in Germany, FASD is also politically on the agenda – not on its own, but embedded in diverse activities that we launched in recent years.

However, in the coming days, we will be dealing very specifically with FASD. I am sure that you will be able to further our joint efforts to improve the situation of persons affected by FASD and all of those who take care of them.

I wish all of the participants of this congress an intense exchange and interesting insights that will give impetus to your work and day-to-day interactions.

[1] A tribute to Dr. Lemoine and the recognition of FAS

Thierry Maillard

SAF Océan Indien, Saint- Louis, Reunion Island

On March 25, 1968, Dr. Lemoine published the conclusions of a thesis on 127 cases of abnormalities observed in children of alcoholic mothers. This publication did not receive the attention it deserved. It took another five years with Dr. Smith & Jones and Ann Streissguth's publications to hear, for the first time, about Fetal Alcohol Syndrome (FAS). These authors helped the world recognize the work of this Frenchman from Nantes who was ignored by his colleagues.

The aim of this presentation is to use the history of Dr. Paul Lemoine to celebrate 50 years of the history of FAS, recall the difficulties we still encounter in our countries to talk about the consequences of alcohol on the fetus and make the recommendations credible : 9 months 0 alcohol.

[2] FASD prevention internationally – How far have we come?

Peggy Murray

National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health (NIH), 5635 Fishers Lane, Bethesda, MD 20892-9304, United States

Background: Over the course of the 45 years since the subject of Fetal Alcohol Spectrum Disorders (FASD) began to attract medical and research attention, we have made some important advances in understanding this disorder. Many studies have been undertaken to develop diagnostic guidelines, establish FASD prevalence estimates, studying mechanisms of pathogenesis, develop evidence-based interventions, and many more. In this presentation, an overview will be provided on international FASD prevention efforts and discuss ways to move forward in this field.

Methods: Review of scientific literature and key informant interviews.

Results: There are effective intervention strategies identified in the literature, however, critical gaps remain, especially in strategies to deal with alcohol drinking culture and women's response, reducing stigma so that women with alcohol use disorders are more likely to seek and receive help, and identification of ways to facilitate provision of comprehensive services to women and families.

Conclusion: While there are important advances in the identification of effective FASD prevention strategies, there are specific areas for improvement. A research strategy for prioritization of new studies in this area is needed, as well as development of targeted communication to policy makers worldwide on what is already known about effective and ineffective approaches.

[3] Developing Systematic Prevention Programs for Fetal Alcohol Spectrum Disorders (FASD)

Sylvia Roozen^{1,2}, Gjalte-Jorn Y. Peters^{1,3}, Gerjo Kok^{1,2}, David Townend^{1,4}, Ger Koek^{1,5}, Jan Nijhuis^{1,6}, and Leopold Curfs^{1,7}

¹ Governor Kremers Centre, Maastricht University Medical Centre+, The Netherlands

² Department of Work and Social Psychology, Maastricht University, The Netherlands

³ Faculty of Psychology and Education Science, Open University of the Netherlands

⁴ Department of Health, Ethics & Society, Maastricht University, The Netherlands

⁵ Department of Internal Medicine, Division Gastroenterology, Hepatology, Maastricht University Medical Centre+, The Netherlands

⁶ Department of Obstetrics & Gynaecology, Maastricht University Medical Centre+, The Netherlands

⁷ Department of Genetics, Maastricht University Medical Centre+, The Netherlands

⁷ Department of Genetics, Maastricht University Medical Centre+, The Netherlands

Background: The complexity of intervention development is sometimes overlooked in health promotion. This is for sure the case concerning FASD. Evidence-based health promotion intervention aimed at the field of FASD is a complex process. The complexity lies within an in-depth description of interventions and their development. The field of FASD needs to use systematic approaches for adapting evidence based behavioural interventions. Lessons can be learned from a framework that has been applied in various other health promoting fields; namely Intervention Mapping (IM). IM provides planners with a systematic method for decision making in each phase of developing a programme to influence changes in behavioural and environmental conditions.

Methods: The IM framework is a six step systematic approach for designing, implementing and evaluating health promotion programmes employing existing theories and evidence of behaviour and social change. The needs assessment as part of intervention planning concerning FASD was studied through multiple systematic literature reviews up to February 2018.

Results: Results of the systematic literature searches will be presented and specific recommendations for prevention efforts will be discussed.

Conclusion: The Intervention Mapping framework is useful as a blueprint for designing, implementing, and evaluating an intervention model for FASD. The quality of analysis of needs assessment needs further improvement. Studying the psycho-social determinants of behavior is often neglected although it is a fundamental step.

[4] Scaling up FASD prevention with at-risk communities

Fitzpatrick JP, Oscar J, Carter M, Councillor, J, Symons, M, Bruce, K, Wagner, B, Walker, R, Pearson, G.

Telethon Kids Institute, Perth, Australia

Background

Australian Aboriginal communities documented the prevalence of FASD (194 per 1000 children), and prenatal alcohol exposure (PAE) (55% high risk drinking). In response a broad FASD strategy was implemented in two regions: Fitzroy Valley (FV) and Pilbara. Strategy aims are to reduce PAE, and deliver FASD diagnostic clinics and school-based treatment programs.

Methods

FASD strategies were implemented in the FV pop~4,500 (2008-2015), and Pilbara pop~60,000 (2015-2020). *Prevention* includes a) Mass media campaign and general health promotion activities b) Training of local health service providers to deliver targeted health promotion c) Support of pregnant women and their partners at-risk of alcohol use in pregnancy d) Postnatal support of women's social and emotional wellbeing. *Diagnosis* is delivered by PATCHES Paediatrics, a multidisciplinary outreach school-based FASD service. *Treatment* to improve self regulation/executive function is delivered through an RCT of the Alert Program, in nine schools in the FV (n~250 children) and six schools in the Pilbara (n~250 children).

Results

Alcohol use in pregnancy reduced from 65% in 2010 to 18% in 2015 (FV midwife data). Community awareness of FASD (95%), and intent of participants to stop drinking if pregnant (~80%) or to support others not to drink (~90%) has been documented in interviews with ~800 participants aged 18-80. FASD clinics are delivered throughout the Fitzroy Valley and Pilbara regions. The Alert Program pilot intervention (one school, n=24) improved caregiver/teacher-rated executive functioning using the BRIEF ($p<.05$); and behavioural regulation SESBI ($p<.05$) and ECBI ($p<.05$). A further 14 schools will receive this intervention from 2016-2020.

Conclusions

It is possible to achieve FASD prevention, diagnosis and treatment within 5 years at a population/regional level. There is hope, and a roadmap for success for communities and governments seeking to address this complex public health issue.

[5] FASD prevention programmes in rural and urban settings in South Africa

Leana Olivier

CEO Foundation for Alcohol Related Research (FARR), Research fellow: Department of Molecular Biology and Human Genetics, Faculty of Health Sciences, University of Stellenbosch, South Africa

Background

FARR has done 14 FASD prevalence studies in rural and urban communities in 5 of the 9 provinces in South Africa. Rates between 27 – 282/1000 have been reported. Many of these studies took place in poor resourced, rural communities with little, if any, access to relevant services. Knowledge and skills pertaining to FASD management and prevention are lacking in professionals leading to underreporting and poor service provision. Myths and incorrect information are rife. FARR therefore implements 3 year FASD awareness, prevention and training programmes in all the research sites, thereby building capacity and facilitating the community, as well as local service providers' resilience and ability to prevent FASD.

Methods

1. FASD Prevalence Study provides information about the extent of the FASD and related problems in the community
2. Findings in the above-mentioned are used to adapt FARR's awareness programmes targeting the entire community (as per the IOM model). This includes a variety of programmes and engagement with the media.
3. Prevention programmes, such as the Healthy Mother Healthy Baby Programme, are implemented to support pregnant women to have healthier pregnancies (with a focus on alcohol harm reduction) and healthier babies. Babies are assessed at 9 months of age.
4. Training programmes are offered to professionals (health workers, educators, social workers, etc.) and other service providers in the area.

Results

The presentation will provide an overview of the above-mentioned interventions and the techniques that are used. It will also refer to the engagement with stakeholders such as government departments, tertiary institution and corporates.

[6] Multilevel FASD prevention guided by virtual national research network

Nancy Poole

Centre of Excellence for Women's Health and CanFASD Research Network, Vancouver Canada

Background:

The CanFASD Research Network supports a prevention research arm, which links researchers, practitioners, policy analysts and birth mothers across Canada's vast geography, and catalyzes coordinated action on FASD prevention. The Prevention Network Action Team is known internationally for developing a 4 level prevention model which is designed to reach women at different levels of risk, and is linked to alcohol policy, diagnosis and intervention efforts.

Methods:

The Prevention Network Action Team employs 4 key methods

Network building - A network of researchers and research collaborators (who have policy, service provision and experiential wisdom) share expertise and skills on a monthly basis via a 75 minute webmeeting.

Research – Network participants build multidisciplinary research teams and conduct research together. This research falls into the following pillars: clinical, population health, health service and policy research.

Collaborative knowledge exchange – Network participants develop and implement strategies for moving "research into action" through a wide range of knowledge exchange mechanisms

Influencing policy and service provision - Network participants work with local, regional and national governments and organizations to guide service and policy improvements

Results: - This presentation will provide specific Canadian examples of evidenced studies and projects related to media campaigns (directed to all society), brief interventions (with all women of child bearing years and their partners) and specialized support programs (reaching pregnant women at highest risk & new mothers and their children). The ways in which the Network applies the above-mentioned methods, and enacts the principles of trauma-informed, harm-reduction-oriented and integrated women/child centred approaches will be highlighted.

[7] Benefits of a new prevention and intervention program for population at risk for FASD

Teodora Ciolompea; Mihaela Anca Iliescu, Tudor Gheorghe from
Saint Stelian Drug Addiction Evaluation and Treatment Centre, Bucharest, Romania

Background: Despite the fact that FASD appears in 0.25 cases per 1000 births in the Romanian population, medical and social care services are not able to provide quality care for the population at risk due to the lack of training in this area.

Method: We present a multi-focus program that combines an awareness campaign to reduce alcohol use during pregnancy with professional training for medical staff and social services to introduce a community clinical prenatal and neonatal screening protocol and medical follow-up after birth at least for the first year of life for the newborns exposed to alcohol during pregnancy.

A short questionnaire was presented to professionals. In your practice, do you have any cases with FASD or suspicion of FASD? What do you know about medical services that can be provided for persons with FASD?

Results: A state-funded program was developed for one year, focused on targeted prevention educational Interventions for professionals working with the population at risk for FASD. The 6-step targeted intervention consists of the following:

- Identify community at risk,
- Identify professionals serving communities at risk;
- 3-day training for professionals;
- Producing educative-informative materials for the targeted population to assess medical-social services;
- Organize and information-communication session with local opinion leaders from the community, key persons, families having a child with FASD, NGOs working with families and children in need for medical care. Introduce to them through local advertisement and community meetings, the new medical and social services for people with FASD--from screening to diagnosis and treatment;
- Working with local NGOs for prevention activities to raise awareness on target population regarding risk of drinking alcohol and pregnancy.

Conclusion: This multi-focus community program combining awareness campaign for the population at risk and professional training to introduce a clinical prenatal and neonatal screening and one-year medical follow-up for children exposed to alcohol during pregnancy is a real chance for early detection for FASD and also an effective method to reduce prenatal exposure to alcohol.

[8] Foetal Alcohol Spectrum Disorder (FASD) in adopted children from East Europe countries in Spain

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Background: The purposes of this investigation were to determine the prevalence of FASD between children adopted from East Europe countries (Russia and Ukraine) in Barcelona (Spain).

Methods: In a population-based, prospective, observational, multidisciplinary, cross-sectional, cohort study of 238 children between 7 and 18 years old and adopted from East Europe countries (Russia and Ukraine). Children were assessed at least 2 years after adoption, from pediatric, neuropsychological, and somatometric perspectives, using 2016 Hoyme's criteria.

Results: Fetal alcohol spectrum disorders, that is, fetal alcohol syndrome (FAS), partial FAS, and alcohol-related neurodevelopmental disorders, were identified for 48% of children; FAS was found for 18%, partial FAS for 16%, and alcohol-related neurodevelopmental disorders for 14%. Alcohol-related birth defects were found for 1% of children.

Conclusion: Fetal alcohol spectrum disorders were common in this long-term follow-up study of children adopted from orphanages in East Europe countries. Maternal alcohol consumption during pregnancy has long-lasting adverse effects, causing structural, behavioral, and cognitive damage despite a radically improved environment. However, we can't forget the neurodevelopmental deleterious effects of abandonment during first months or years of life, that add to effects of prenatal exposure to alcohol.

[9] What's happening in the Netherlands

Martha Krijgsheld

Chairperson of the FAS Foundation of the Netherlands

Background: The FAS Foundation of the Netherlands was established in 2002 with the following goals: Warning the general public of the dangers of alcohol use in pregnancy; support families with good information, if possible with a scientific source; advocacy (government); promote scientific research.

Methods: We try to meet these goals by spreading information, promoting peer contact, and maintaining contacts with other NGOs in the Netherlands and worldwide. In the last two years we have been asked to participate in projects from the Dutch government to develop a knowledge synthesis, and to improve knowledge of GPs.

Results: We have trained a group of volunteers to give information and lessons in schools, adoption organisations, foster care, and other groups of interested people. We support special groups, including parents of children with FASD, adults with FASD, and birth mothers. We have a lively facebook account with a lot of interaction and good information about FASD. In 2017 we introduced a FASDpas, a special card for (young) adults to help them explain FASD in complicated situations.

Discussion: We are continually building up our networks and expanding knowledge of FASD in the Netherlands. On complicating factors is that, due to changes in the laws (decentralization of special care), it is more difficult to get a good diagnoses. As is the case in other countries as well, we are constantly trying to counter misinformation about alcohol and pregnancy that appears on internet, television, etc.

[10] Establishing a local assessment pathway for FASD within a Community Child Development Service

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Background: A local assessment pathway for FASD was set up in Brighton and Hove in 2016. Prior to this, children with antenatal exposure to alcohol and neurodevelopmental concerns were seen for assessment within the service, but there was no standard method of assessment and in some cases no clear outcome. It was felt that it was possible to improve and standardise assessment and diagnosis of FASD within existing resources.

Method: The Washington 4-digit code (Astley SJ et al) was used as the assessment method. Paediatricians and a psychologist from the service underwent online training and a clinical pathway was established.

A baseline audit was completed and results were compared with children who were subsequently seen as part of the pathway. A service user questionnaire was developed and sent to parents and carers whose children had been assessed using the new pathway.

Results: Documentation of the four key areas for FASD diagnosis was improved for children assessed as part of the new pathway. The time taken to reach diagnostic formulation was also improved and outcomes were clearer.

For a small number of more complex children (particularly those without facial features) it was difficult to reach a diagnostic conclusion within an acceptable timeframe using available resources (a key issue was limited access to psychology assessments during the audit timeframe).

The service user questionnaire showed that in general parents and carers were happy with the assessment process, and found the assessment helpful. Suggested areas for improvement included clear information about the assessment process for parents and carers, additional follow up and post diagnostic support.

Conclusion:

1. It was possible to improve assessment for FASD within in a child development service without significant extra resources.
2. A small number of more complex children would benefit from a referral to a more specialist service with increased access to a variety of standardised tests.

[11] What's Happening in My Country – Scotland, UK

Sarah Brown

Scottish Government-Funded Fetal Alcohol Advisory and Support Team (FAAST), Rainbow House, Ayrshire Central Hospital, Scotland, UK.

The Scottish Government (SG) is firmly committed to the FASD agenda. This has been policy driven, with '*Changing Scotland's Relationship with Alcohol: A framework for action*' published in 2009. A whole population approach has been adopted, aimed at reducing consumption, supporting affected families and communities, and improved treatment and support for alcohol-related issues. Improving outcomes for Children Affected by Parental Substance Misuse (CAPSM) is a priority and funding has been made available to support initiatives such as:

New Developments:

- Scottish (SIGN) FASD Diagnostic Guideline (commenced 2016)
- FASD Diagnostic Pathway (launched 2017)
- Minimum unit pricing for alcohol (introduced May 2018)
- Funding extension for Fetal Alcohol Advisory and Support Team (until March 2020)
- UK-wide FAS Surveillance Study (tbc)

Ongoing work:

- SG FASD Advisory Group liaison with important stakeholders e.g. Educational Psychology, Preconceptual (Nutrition) Care Group, Legal Services, Education, Social services, Voluntary Groups
- Support for Research: biomarkers, neurodevelopmental phenotype of FASD, carer and professional perspectives on FASD, UK prevalence research
- FASD Awareness/Training: online resources, seminars and interactive education sessions (by Manitoba team), twice yearly Clinician's forum for training, peer support and service development.
- Fetal Alcohol Assessment and Support Team – service pathway development and research remit. Additional funding will enable a pilot of multi-agency working to develop FASD knowledge and support hubs aimed at improving services for affected individuals and families. The team will also be available to provide national consultancy to raise awareness and support service development.
- Within local health boards FASD-specific initiatives are increasing e.g.: pre-pregnancy and pregnancy advice services; appointment of a FASD Programme Manager driving service development in prevention, identification, diagnosis and support.

[12] FASD : What is happening in France ?

Catherine Metelski, Antoine Bourely
Association "Vivre avec le SAF", France

Background: FASD was ignored in France for 40 years. Awareness is finally growing thanks to two NGOs: In 2008 Dr Lamblin founded "SAF France" a medical association, and in 2012, we created "Vivre Avec le SAF" (Living with FASD), an NGO of concerned parents. We have grown to more than 150 families, with a majority of adoptive parents. We have created a website, support documents in French (brochures, posters) and a "Guide for Parents and Caregivers", adapting many Canadian documents to the French context.

Our activities: We are helping create a network of neuropsychiatrists able to diagnose the disease. We currently know one to three specialists per region. We will take the same steps to create a network of psychiatrists to support adults with FASD. We have created six regional antennas to foster closer contacts between our members and better contacts with local professionals. We hold regular conferences to raise awareness among professionals around us: school teachers, medical doctors, but also job centres, the Police, and the Justice System. The last conference we co-organized in the Ministry of Health in Paris (Sept 6, 2017) gathered 260 people, including the Minister herself.

Results and perspectives: The Ministry of Health has announced steps to increase the visibility of the logo on alcohol containing bottles. Two Resource Centers have been created for diagnoses and support. One has started operating, and now has more than a year of experience. A very active medical team is also working in Paris. The government seems to favour an approach where all neurodevelopmental diseases (Autism, Down Syndrome, FASD,...) will be treated together. The President and his wife seem really concerned.

Conclusion: One lesson at this point: the Government only reacts to the pressure of families and citizens: let it grow !

[13] What's happening in Slovenia?

Marjetka Hovnik-Keršmanc, *National Institute of Public Health (NIPH), Slovenia*

Matej Košir, *Director of the Institute for Research and Development "Utrip", Slovenia*

Background: On the 9th of September 2014, the National Institute of Public Health (NIPH) marked the FAS International Day for the first time in Slovenia (as part of a project co-financed by the Ministry of Health in period of 2013-2014). As part of the project, NIPH carried several key messages regarding alcohol exposure in pregnancy or during breastfeeding through traditional and social media, stands in larger cities, calls to health professionals and students, video campaigns etc. Institute "Utrip" joined the international campaign "Too Young To Drink" which was launched in 2016 by EUFASD and many international partners. Youth Association "No Excuse" (in collaboration with the NIPH) developed and conducted a joint social media campaign in 2016 with thematic hashtag. Since 2014, several activities have been implemented, but mostly in relation to 9th of September, the FAS International Day.

Methods: Main activities were focused on information and awareness campaigns in media, particularly social media (2014-2017), conducting surveys among health professionals and women of childbearing age (by Utrip and NIPH). Several conferences, workshops and lectures have been conducted in previous years by NIPH for health professionals and students, women of childbearing age and staff in restaurants, bars and pubs as well.

Results: The activities of NIPH that take place in Slovenia are shown as examples of good practices in the prevention of alcohol exposure in pregnancy in the WHO publication from 2016. In addition, Utrip and No Excuse reached relatively good media coverage with campaigns in 2016 and 2017, especially through social media (Facebook and Twitter).

Discussion: In September 2018, NIPH is planning to organize an expert meeting to mark the 2018 FAS International Day by inviting NGOs. There is a need for more consistent and coordinated national action with more relevant key stakeholders (e.g. Ministry of Health, NIPH, NGOs, health professionals etc.) which would not be focused only on 9th of September and media campaigns. Significant progress has been made in previous years, so there is a potential for improvement and better coordinated results.

[14] Looking for the agreement on the Polish guidelines for diagnosis of Fetal alcohol spectrum disorder

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Background: According to different estimates alcohol consumption during pregnancy in Poland ranges from 15% to 40% and the prevalence of FASD is not lower than 2% among schoolchildren. In spite of these alarming data and growing interest of specialists, broad, professional discussion on the national standards of FASD diagnosis has been missing in our country. Therefore, the State Agency for Prevention of Alcohol Related Problems (PARPA) in cooperation with The Warsaw Medical University and St Louis Children's Hospital in Krakow initiated the project aimed at reaching the professionals' agreement on the standards for FASD diagnosis in Poland.

Methods: The basic assumption is to base Polish standards on the world most popular diagnostic guidelines, i.e. IOM (Hoyme et al., 2016), Washington (Astley, 2004) and Canadian (Cook et al., 2016). In accordance with the *Appraisal of Guidelines, Research and Evaluation, version II* (AGREE II) approach, the multi-professional experts panel will discuss recommendations concerning key aspects of FASD diagnosis presented in the above mentioned guidelines. The process of agreeing on the Polish standards will consist of several steps, starting from the elaboration of the questionnaire to collect experts opinions on the quality of each recommendation, completing the list of stakeholders to be questioned and looking for the experts consensus.

Results: As the work is in progress, the only result to be mentioned now, is the Polish version of the AGREE tool (questionnaire). The Polish experts opinions on the key recommendations of the IOM, Washington and Canadian guidelines will be presented during the conference.

Conclusion: At this stage, the networking opportunities the EUFASD conference offers and the possibility of adding broader European perspective to our project, might be more than useful, leading to high quality national guidelines.

[15] My Country 5 Minute Update--Australia

Elizabeth Elliott, Carol Bower, Narelle Mullan, Louise Gray
FASD Centre of Research Excellence, Australia

Background: Following the 2012 national government inquiry into FASD, the Australian Government recognised the need for a decisive, coordinated national response. This resulted in FASD gaining in recognition as an issue of public health concern. A number of milestone achievements followed.

Method: Key initiatives include:

1. A national FASD Technical Network to advise governmental policy;
2. Development and roll out of the Australian Guide to the Diagnosis of FASD;
3. Increased diagnostic capacity across Australia through new services;
4. Establishment of a national website - FASD Hub Australia - an information repository for health professionals, researchers, policy makers and families;
5. Establishment of a National FASD Register;
6. Establishment of an Australian Centre of Research Excellence (funded by NHMRC);
7. Funding for a dedicated parent/ caregiver helpline and support service through NO-FASD, Australia;
8. Development and distribution of FASD educational resources for Aboriginal and Torres Strait Islander communities and service providers;
9. National consultation to develop a 10-year strategic plan to address FASD for 2018-2028.

Results: In the presentation we will provide a status report on achievements relating to FASD in Australia. Advances in prevention, diagnosis, clinical management and non-clinical interventions will be noted, gaps identified and future directions outlined.

Conclusion: Despite significant progress in addressing FASD in Australia, significant needs remain particularly in capacity to provide diagnostic and clinical services and support for individuals across the lifespan.

[16] Support groups for young FASD Adults

Sari Somer

FASD Coordinator of FAIDD, Finland

Background: FAIDD has been organizing support groups for young adults with FASD since 2009. FAIDD has led three groups and mentored a fourth group, which was led by another organization.

Introduction: Young adulthood is an especially challenging stage in life for people with FASD. It holds many challenges concerning study and work, independent living and relationships. Foster care services in Finland generally end at the age 21. This is a problem for adults with FASD, who mature later than their peers and have a disability. Support groups have been attended by adults of ages 18-30.

Results: Young adults with FASD have profited a lot from support groups. They have engaged well in group activities, gained peer support, explored their life stories together and formed long lasting relationships with other group members. Support groups have helped them move on with their lives, look to the future, face adulthood challenges and reach dreams.

Conclusion: Because of the excellent results, we hope that support groups for young FASD adults will be a permanent part of the foster care system in the future. While more intervention research is needed to show effectiveness, support groups have already shown us (group members, their carers and group leaders) that a small, effective intervention given at the right time can make a huge difference in the life of young FASD adults. In 2013, the sponsor of FAIDD has assigned us a recognition award for the effectiveness of support groups for young FASD adults.

[17] Multidisciplinary teams platform and screening algorithm indicating the presence of FASD by preschool children in the system of early intervention in Slovak republic

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Centre for Diagnosis, Prevention and Therapy of FAS, Catholic University in Ružomberok, Slovakia

Background: Fetal Alcohol Spectrum Disorder (FASD) covers the range of effects of prenatal alcohol exposure, such as neurovascular and other FAS-specific medical findings and its range of intensity and visible signs. The strength of measurements depends, among other things, on the quality of diagnostic tools or multidisciplinary skills, so the aim is to offer recommendations for the FASD screening to capture, protect and intervene most accurately and objectively for effected children in the Slovak Republic.

Methods: The investigation was done on 173 children, 3-7 years of age. The authors used a questionnaire along with their own concept of monitored domains - pre-school capability, anthropometry (head perimeter, height, weight and filtrum), hearing processing (calibrated audiometer), speech, selected cognitive components, motor system (T-239, Ozero`s test) and sensor profile.

Results: In regular population screening, we detected 16,76% of children who showed a delay (from 10 to 3 ‰), 19,65% in weight, and 10,98% in the perimeter of the head. Up to 30.058% of the children had a filtrum value 3 to 4. The sample also showed decline in cognitive functions: attention - 6.36%, visual perception - 10.98%, approach for work - 23.12%, sociability - 39.31%, speech - 45.67%. Hearing was weakened by 58.38% and gross and fine motor by 49.71% of children. Sensory processing was weakened in only 8 children - in emotional response, movement, touch and oral processing. The severity of alcohol exposure was not investigated.

Conclusion: The results define the basic screening criteria and the basic distribution algorithm of the child caught in the healthcare system of Slovakia. Slovak specialists are not yet trained in screening, prevention, and today they are unable to co-ordinate medication of interventions with other professionals, so there is an urgent need to network early (0-7 yr.) intervention actors into active childcare with the FASD in Slovakia.

[18] Epigenetics in Human Fetal Alcohol Spectrum Disorder – Opportunities and Challenges

Michael S. Kobor

This presentation will highlight the emerging role of epigenetics in fetal alcohol spectrum disorder, touching on three related key topics. First, Dr. Kobor will discuss the fundamental biology of epigenetics at the interface between environments and the genome and in the context of the developmental origins of health and disease concept. Second, select examples from multidisciplinary human population studies will illustrate how early life adversities such as poverty and family stress can become embedded into our genome, using a “society to cell” paradigm. Third, recent epigenetic signatures of human fetal alcohol spectrum disorder provide opportunities to understand biological pathways relevant for neurodevelopment or to serve as a biomarker for improved diagnosis of at-risk populations. In turn, the challenges of this approach will be discussed from biological, social and ethical perspectives.

[19] Use of MRI and EEG in the Fetal Alcohol Spectrum Disorders

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The Fetal Alcohol Spectrum Disorders diagnostic categories are based on the assessment of patient's growth, dysmorphic facial features and neurobehavioral profile. Structural or functional impairment of the brain including abnormal brain MRI and seizures of abnormal EEG are contributors to the diagnosis of FASD as reflections of the brain damage that occurs in FASD. (Hoyme et al. 2016 revised IOM guidelines). Given the neurobehavioral phenotype of FASD is complex and variable, objective measures of brain damage such as MRI and EEG are useful to support and understand objective deficits in FASD.

We prospectively performed clinical assessment, brain MR imaging clinical evaluation of seizures and EEG in 62 patients with FASD. The most frequent findings on MRI were hypoplasia of the corpus callosum and/or of the cerebellar vermis. Additional findings were vascular anomalies, gliosis, prominent perivascular spaces, occipito-cervical junction and cervical vertebral anomalies, pituitary hypoplasia, arachnoid cysts, and cavum septum pellucidum. Fourteen children showed EEG anomalies, including slow background activity and interictal epileptiform discharges, focal and/or generalized, and 3 of them had epilepsy. In one patient, seizures were first detected during the EEG recording and one case had an encephalopathy with electrical status epilepticus during slow sleep (ESES). Focal interictal discharges in our patients did not imply the presence of underlying visible focal brain lesions in the neuroimaging studies, such as cortical dysplasia or polymicrogyria. Brain defects on MRI and abnormal EEG were demonstrated both in patient with FAS and in those with non-FAS categories of FASD. (Boronat et al. 2017)

Disproportionate volume reductions in the basal ganglia, corpus callosum (CC) and hippocampus have been reported in children with prenatal alcohol exposure (PAE). PAE is associated with decreases in subcortical volumes and decreases in callosal volume may be a marker and/or play a role in fetal alcohol-related impairment in cognitive function seen in childhood. Recent shape analysis studies which combined facial regions with the caudate nucleus (CN), and with the corpus callosum (CC), better identify those with FAS. CN asymmetry was reduced for FAS compared to controls and is strongly associated with general cognitive ability, verbal learning, and recall in those with prenatal alcohol exposure. (Suttie et al. 2018)

The use of functional MRI for the study of FASD indicates that localized alterations in neural activity, aberrant fronto-parietal network synchrony, and poor coordination of

neural responses with regions outside of this network may help explain spatial working memory deficits in individuals with a history of heavy PAE. (Biffen et al. 2017)

The overall contributions of MRI and EEG to the diagnostic clinical evaluation and management of FASD justify their use in the clinic. Treatment of clinical and subclinical seizures and may help improve cognition and behavior in these patients. The identification of specific differences in brain MRI, with particular emphasis on brain volume and fMRI studies may increasingly inform brain deficits specific to some patient with FASD, and help design targeted interventions and educational supports. These tools may also provide objective measures of response to these interventions and understand their correlation with measures of learning and behavior impairment and improvements.

[20] A new App: VisualFASD (a Foetal Alcohol Spectrum Disorder dysmorphism assessment tool)

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Background: FASD diagnosis by health professionals is easy in an expert setting, but paediatricians are not well trained in clinical practice in our sociodemographic environment. However, a new clinical challenge is raised: massive adoption of children coming from East Europe countries, where alcohol consumption during pregnancy is very important, especially between women with socioeconomic problems that produces the international adoption of their children. This situation supposes the need of develop diagnostic expertise in busy pediatricians.

Methods: To develop an expert App tool for the first screening assessment by health care workers in front of children with a risk or suspicion of FASD.

Results: The App has been developed and is going to be validated next months. First results show a very easy use, with good correlated results to classic assessment of these children using 2016 Hoyme's criteria.

Conclusion: A mobile App could be very useful for assisting primary health care workers, psychologists, etc. in cases of FASD risk in adopted or non adopted children.

[21] Sleep, Anxiety and Behaviour in children on the Fetal Alcohol and Autism Spectrum.

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The Institute of Education, University College London.

Background: Sleep is one of the last remaining 'mysteries', the precise mechanisms and reasons for which are not known to science. When measured in both neurotypical and non-neurotypical populations, sleep quality has shown correlations with cognitive functions such as language, behaviour, mood and memory consolidation. Much of what we know about sleep comes from the study of such relationships. Sleep disruptions are prevalent in children with FASD, particularly sleep disorders and problems related to melatonin, cortisol and circadian rhythm. This study examined the relationship between sleep, behaviour and anxiety in 6-16 year olds with FASD.

Methods: Sleep, behaviour and anxiety were measured in a sample (n=91) group of 6-16 year olds with FASD, through a series of caregiver reports. (the Child Behaviour Checklist, Spence Anxiety Scale and the Child Sleep Habits Questionnaire). A typically developing group (n=36) and a comparison Autism group (n=33) were also recruited.

Results: Children with FASD showed shorter sleep duration, more night waking, sleep onset delays, daytime sleepiness and sleep disordered breathing than typically developing controls. Regression analysis showed that a proportion of the variance in behaviour and anxiety - particularly attention ($p=0.001$), aggression ($p=0.002$) and emotional reaction ($p=0.021$) - was attributable to sleep. Children with FASD displayed higher levels of sleep disturbances than children with Autism, however typically developing children showed a higher correlation coefficient between sleep and behaviour.

Conclusion: The sleep architecture reported here was consistent with previous findings in FASD sleep studies however this is the first to measure sleep as a comparison between FASD and Autism. It is also the first to measure sleep, anxiety and behaviour in individuals with FASD. These results indicate that attention, conduct and emotion in relation to sleep disturbances are areas for further exploration in these populations.

[22] Mental and behavioral disorders among young people with prenatal substance exposure - ADEF Helsinki research project (Alcohol or Drugs Exposure During Fetal Life)

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Background: A majority of children with prenatal alcohol exposure are exposed to illegal drugs, as well. Moreover, many of them live in traumatic caregiving environment at least the first years of their life. Despite that, the effects of exposure to both alcohol and drugs, and trauma, on the overall developmental outcome of these children have not been well studied.

This study investigates 1) the nature and extent of mental and behavioural disorders (ICD-10, F00-F99) among young people with prenatal substance exposure, and 2) the association of the dual exposure to substances and traumatic experiences with these disorders.

Methods: The women with substance abuse problem during pregnancy were first identified in the maternity clinics of health care centers of Helsinki metropolitan area and referred to special antenatal clinics of Helsinki University Hospital (N=3) where pregnancies were followed. All children born to them during that time (1992-2001, N=638) are included in this study. The matched control group consists of 1914 unexposed children born to women with no evidence of substance misuse in any of the national health and social welfare registers. Data for this register-based case-control cohort study were collected linking medical records with register data from the national registers by using a unique identification number. Analysis: risk indexes, comparisons, incidence and prevalence figures, and multivariate logistic regression.

Results: The data collection was completed in the beginning of 2018. First results on mental and behavioral disorders will be presented.

[23] Sleep Problems in children with FASD – frequent, but frequently overlooked

Kathrin Bohmert¹, Osman Ipsiroglu², Angelika Schlarb³, Barbara Schneider⁴, Dorothee Veer⁵

All authors will be presenting

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Background: Sleep problems are commonly reported in children with FASD, resulting not only in difficulties with cognition, behavior and general health, but also reducing quality of life for children, families and caregivers. Specific knowledge and thorough assessment of sleep problems associated with FASD are therefore essential. Nevertheless, screening, diagnosing and treating sleep disorders in children with developmental disorders remains a challenge in clinical practice. To approach this topic, we conducted an online survey regarding the assessment and treatment of sleep disorders in children with developmental disorders.

Objectives: 1. To collect information how Developmental Centers in Germany assess and treat sleep problems in children with developmental disorders 2. To highlight different approaches to develop individualized therapies.

Outline of the symposium: Symposium with a panel discussion.

Contributions: 1. Dr. Dorothee Veer presents results of an online questionnaire that was sent to all developmental centers (Sozialpädiatrische Zentren, SPZ) in Germany, concerning assessment and treatment of sleep disorders in children with developmental disorders. Results showing a high awareness of sleep problems and high affinity to melatonin treatment, but only little knowledge about standardized assessments as validated questionnaires, sleep logs and therapies. Also, standardized treatment guidelines are lacking. 2. Barbara Schneider will present results from the German Pediatric Sleep Working Group regarding recommendations on the use of melatonin in children with sleep disturbances. 3. Prof. Angelika Schlarb will present short and long term effects of Cognitive Behavioural Therapy for insomnia (CBT-I) in groups for children and caregivers. 4. Kathrin Bohmert will talk about successful sleep hygiene intervention in a therapeutic living community. 5. Prof. Osman Ipsiroglu will discuss a new precision medicine approach to sleep disturbances associated to movement disorders and iron deficiency.

[24] Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia

Raewyn C Mutch^{1,2,3}, Carmela Pestell^{1,4}, **Hayley M Passmore**^{1,2} on behalf of the Banksia Hill Study team¹

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⁴*School of Psychological Science, The University of Western Australia, Perth, Australia.*

Background: Neurodevelopmental impairments due to FASD can predispose young people to engagement with the law. Canadian studies identified FASD in 11%–23% of young people involved with justice services, but there were previously no data for Australia. This presentation will discuss the first study to estimate the prevalence of FASD among sentenced young people in Australia.

Methods: Multidisciplinary assessment of all young people aged 10–17 years 11 months and sentenced to detention in the only youth detention centre in Western Australia occurred from May 2015 to December 2016. FASD was diagnosed according to the Australian Guide to the Diagnosis of FASD.

Results: 99 young people completed a full assessment (88% of those consented; 60% of the 166 approached to participate); 93% were male and 74% were Aboriginal. 88 young people (89%) had at least one domain of severe neurodevelopmental impairment, and 36 were diagnosed with FASD, a prevalence of 36% (95% CI 27% to 46%). The majority of young people with FASD had severe impairment in academic, attention, executive functioning and/or language domains.

Conclusions: This study, in a representative sample of young people in detention in Western Australia, has documented a high prevalence of FASD and severe neurodevelopmental impairment, the majority of which had not been previously identified. These findings highlight the vulnerability of young people within the justice system and their significant need for improved diagnosis to identify their strengths and difficulties, and to guide and improve their rehabilitation. The translational outcomes of this research, including the development of training resources for the custodial workforce, and the implications for all aspects of the youth justice system will be discussed.

[25] The FASD Film Project, Fulda 2018

Gisela Michalowski

FASD Deutschland e.V., Germany

This year saw the third weekend break for adults with FASD accompanied by a caregiver. The event was held from July 26th - 29th 2018 at the youth hostel in Fulda and one item on the agenda was the film for the European Conference on FASD in Berlin.

The first step was to define what message the German adults with FASD want to get across. In a brainstorming session a whole wealth of ideas were put forward and the participants decided it would be a good idea to use a symbol or image to represent the effects of pre-natal alcohol exposure on the individual. There were the usual "typical" suggestions - a house shifting on cracked foundation, a brain etc. but it was actually thanks to the weather that a brilliant idea came up! On this stifling hot afternoon, everyone looked longingly out of the window at the trees ...

That was it: a tree. A tree with its roots submerged in alcohol, bearing goods fruits on one side and rotten fruits on the other. The good fruits stand for everything people with FASD can achieve or have achieved. The rotten fruits stand for the negative things that can happen to someone who has FASD. The group of adults with FASD set to work, literally putting pen to paper and they also began to draw "their tree" using coloured pencils.

[26] Living with FASD

Claudia Koster

I am a 38 year old Female with FasD, got the official diagnoses in 2010. I have been struggling allot with several areas in life. I was "different". I would like to give a sneak peak into the problems i walked into, and what i need from society to thrive and be a valuble part

After the diagnoses it was very hard to find the right care, the world is so high paced and always changing that i just can't keep up.

My conclusion after 8 years of having the diagnoses is that there is no knowledge on how to care for adults with FasD, I am putting a lot of effort into sharing my story, explaining to parents what they can try, letting other adults know, it is part of their FasD. This is mostly on Facebook and on a groupchat on whatsapp.

Having more science based information can make me a better spokesperson, but i am focusing on how we People with FasD need more help. The disability is more than bad behavior or a low IQ.

I have been asked to speak at some educational events in the past, but they keep being cancelled because of lack of signups.

I did do a talk for my local government about how a hidden disability can exclude you from society. They were shocked, and a bit in disbelief on how poor the care was. After evaluating and checking the facts they did agree it has to change.

[27] Personal Story

Gaby Mitrani

Mother, Israel

Three years ago, on Israel Independence Day, my 21 year old son was diagnosed with FASD. At that instant, I was both enlightened as well as devastated. I was enlightened because finally the last piece of the puzzle who is "Ido" (my son) fit into place so that we could finally see the picture that had been eluding us for so long. But at the same time, I was also devastated, since this meant that Ido had a permanent, incurable condition. From that moment, my life turned upside down and it has become my life-long project to disseminate and spread as much information as I possibly can about FASD to professionals, doctors, colleagues, parents and social workers who are searching for answers in a dark void. As a social worker with many years of experience, I am sure that as my knowledge of FASD continues to expand, I will be able to help many who are searching for answers and have yet to find them.

This is my personal story and I would like to share it with you.

[28] What happened to them?

Leana Olivier^{1,2}, Chanelle Lombard¹, Lian-Marie Drotsky¹, Jaco Louw¹, Denis Viljoen^{1,2}
¹The Foundation for Alcohol Related Research (FARR), ²Department of Molecular Biology and Human Genetics, Faculty of Health Sciences, University of Stellenbosch, South Africa

Background: South Africa has the highest reported Fetal Alcohol Spectrum Disorder (FASD) prevalence rates in the world, ranging between 27/1000 to 282/1000 in some communities. To date 14 FASD Community Prevalence Studies have been done, but little is known about the impact of this disorder on the lives of the diagnosed children and their families.

Methods: In the first of its kind study in this country, 43% of the original clients who were diagnosed with FASD in 2002 – 2003 in a remote rural area, as well as 48% of their controls, were found, examined and interviewed. Interviews were also conducted with 49,5% of the biological mothers/caregivers who participated in the original study. Researchers were blinded to the previous diagnoses of the participants.

Results: The presentation will focus on the findings of the dysmorphological assessment of these young adults with confirmed FASD, as well as their life experiences over the past 15 – 16 years compared to their controls. Findings obtain from the interviews with the mothers/caregivers will also be discussed.

Conclusion: Information obtained from this study is currently used to guide further research and service delivery by government departments in this community, as well as adolescent and adult populations in other high-risk communities in South Africa.

[29] Social Workers' Experiences of Supporting Looked-After children Exposed to Alcohol In-Utero; an Interpretative Phenomenological Analysis

Louise Gordon & Jennifer Shields

The Scottish Government-funded Fetal Alcohol Advisory and Support Team (FAAST), Rainbow House Community Paediatrics, Ayrshire Central Hospital, NHS Ayrshire and Arran, Irvine, Scotland.

Background: Fetal Alcohol Spectrum Disorder (FASD) is an umbrella-term describing life-long disabilities that can result from alcohol exposure in-utero. The Scottish Government estimates >10,000 children and young people are affected by FASD. Children with FASD are over-represented within fostering and adoption services, but few studies explore Social Workers' views of FASD and the impact upon children and families. This is the first study in Scotland to examine this question.

Methods: We explored Social Workers' experiences of supporting children with prenatal alcohol exposure within Adoption Services in Scotland. 5 social workers were recruited for semi-structured interviews. Understanding of FASD, confidence discussing a diagnosis with potential adoptive parents, and the personal, professional and emotional impact of working with affected children were explored. Interviews were transcribed verbatim. Themes were elicited using Interpretative Phenomenological Analysis.

Results: There were four super-ordinate themes identified: 1) lack of knowledge/awareness 2) dealing with uncertainty 3) impact of the diagnosis & 4) vulnerability. Experiences of the adoption process were classified: 1) social worker's experience 2) perceived experience of adoptive parents & 3) of the child with FASD. Distinct subordinate themes identified within each of these three groups offered valuable insights.

Conclusion: All interviews detailed the complex interaction effects which occur between worker, prospective families and affected children during the adoption process. Perceived inadequacy of knowledge and uncertainty around the negative impact of FASD played important roles in the child's journey through adoption services. Experiences, attitudes and decisions of the Social Worker are pivotal to adoptive parents' and ultimately the child's journey. Given the Scottish initiatives to increase identification and diagnosis, the impact of this on other services should be carefully considered.

[30] Carer stress in Fetal Alcohol Spectrum Disorders: Data from the UK National Specialist clinic

Zameer Mohamed, Alex Carlisle, Alex Livesey, Raja Mukherjee
National Specialist FASD Clinic, Surrey & Borders NHS Foundation Partnership Trust, Surrey, UK

Background: Previous research in FASD has started to look at the unique stress that is placed upon carers of children with Fetal Alcohol Spectrum Disorders (FASD). The goal of this research was to analyse outcomes from carer stress questionnaires (i.e. from carers of children with an FASD diagnosis in the UK) to better understand the nature of this stress.

Methods: 88 carers of children with FASD, aged 6-12, completed the Parental Stress Index (PSI). Descriptive statistics, regression analysis, ANOVA, and question by question analysis were all carried out in order to investigate the exact nature of stress in carers of children with FASD.

Results: Five out of the six Subscales in the Child Domain were in the clinically significant range for stress, with the exception of the Reinforces Parent Subscale. In comparison, none of the Parent Domain Subscales were in the clinically significant range for stress. Regression analysis showed that two Subscales in the Child Domain and one Subscale in the Parent Domain contributed significantly to the overall stress reported by parents on the PSI. Only the parent-child attachment Subscale in the Parent Domain showed a significant difference in stress between age groups of carers.

Conclusion: Overall there is significant stress in carers of children with FASD. Aspects in both sides of the child and parent relationship dyad contribute to overall stress of carers, in all carer age groups. This suggests the needs of caregivers with FASD are wide ranging, and should be a noteworthy target for intervention.

[31] ICF as framework for understanding the needs of a person with FASD

Ilona Autti-Rämö

The Social Insurance Institution, Helsinki, Finland

A tool to enhance communication and to identify a wider perspective on the individual needs and goals of rehabilitation is the International Classification of Functioning, Disability and Health (ICF) and its version for Children and Youth (ICF-CY) (WHO, ICF 2001; WHO, ICF-CY 2007). The ICF consists of 5 components: body structure and function, activity, participation, environment and personal factors and they are further divided into domains and categories. Professionals are often focused on detailed descriptions of children's abilities within the examination room (eg. anamnestic information, professional evaluations) and of the physical examination (e.g. dysmorphic features, growth). Less emphasis is given to the activities and possibilities to participate in their natural environment. In terms of the ICF-CY, the professionals evaluate the child's capacity (what he/she can do at his/her best), not what the child actually does in her/his real life (performance). The ICF framework helps to keep participation and environmental aspects in mind and emphasizes that rehabilitation is not about "fixing" the child but providing the child with possibilities to live an active, participatory life – each with an individual flavor. With this presentation I want to shift the focus from diagnostic criteria towards understanding what are the needs of individual persons with FASD. In addition the barriers and facilitators for participation will be discussed.

[32] Educational and behavioral interventions for children and youth with FASD

Ira J. Chasnoff

NTI Upstream and University of Illinois College of Medicine, Chicago, Illinois, USA

Background: Children and adolescents with FASD frequently are challenging to families and school personnel. Behaviorally, poor impulse control, poor judgement, and deficits in social skills in combination with slower information processing and memory deficits result in the young person with FASD's having significant academic difficulties. The purpose of this presentation is to demonstrate how to address behavioral and educational issues at home and school through an integrated approach to behavior and learning.

Methods: Through a prospective approach, 50 families with children with FASD, ages 5 to 18 years, were enrolled in a prospective study to test a computer-based behavioral management system. The study was guided by a central hypothesis: An interactive behavior management system can improve child behavior and family function. The families were trained in the use of the system and completed an age-appropriate Child Behavior Checklist and the Parenting Stress Index at baseline and 6 months and 12 months after enrollment. In addition, a literature review was undertaken to assess educational strategies that specifically address learning deficits in children and adolescents with learning difficulties related to FASD.

Results: Data at both follow up points demonstrated significantly fewer disruptive behaviors and lower total behavioral problem scores for the children, and families experienced significantly less disruption and stress and increased feelings of competence. The most promising educational strategies are a positive teacher-student relationship ($d=.72$), direct instruction ($d=.84$), and behavior management ($d=.93$).

Conclusion: *At the conclusion of this session, participants will be able to:*

1. Describe a progressive, step-wise strategy for managing behavioral difficulties in adolescents with FASD
2. Name three educational strategies that can be used to promote learning in children and adolescents with FASD.

[33] Reflections about the difficulty of FASD to be accepted in the community and worldwide

Hans-Ludwig Spohr

Two remarks

- 1. History of Attitudes towards drinking in Pregnancy** (NIAAA: Kenneth Warren)
For the majority of the 20th century teratogenicity of alcohol was unknown; the pervasive belief held well into the 1970s, that there was no risk to either mother or fetus from prenatal alcohol.
After describing FAS in 1973 it posed a major challenge to changing physicians and public attitudes on alcohol and pregnancy.
- 2. “You can’t handle the truth”, medical Paternalism and prenatal alcohol use** (C.Gavaghan, 2009 : Ethicist, school of Law ,Glasgow)

What is the difficulty of FAS to be accepted in the Community?

- Changing spectrum of FASD
- FAS-diagnosis only possible by clinical evidence; no pathognomonic signs, no test etc.
- 1973 a small group of typical FAS with facial dysmorphism described by D.Smith
- Later on :“Partial FAS”(and the picture of the ice-berg); emerging of “Adult FAS”
- Increasing number of affected patients 1:1000 life-born children in 1990 to 1:100 in 2016
- The majority of adult patients is undiagnosed today
- Varying FAS- guidelines in different countries
- Increasing number of FAS- phenotypes seen in rare molecular-genetic diseases
- Still today FAS is thought to be a fashionable complaint among many medical doctors

Facit:

- In 2009 an international FASD- Symposium with US FAS-researchers took place in Berlin.
- Ten years later the 3rd Congress of “European FASD-Alliance” in Berlin presents intensive research activities worldwide and hopefully we expect an international FASD-Society. This is a huge progress in research and understanding of FAS.

But daily work and confrontation with this disease is much more difficult and somewhat disappointing; it will take probably “more than a generation” until FAS will be accepted by the community and worldwide.

[34] Research Impact on Treatment and Prevention

Kenneth R. Warren

There are significant segments of our modern history during which alcohol was viewed as posing no risk to either the fetus or the overall process of gestation. At the extreme, one accomplished investigator interpreted his observation on decreasing litter size and weight in animals exposed to alcohol vapor as a strengthening of the species by eliminating weaker individuals. Skepticism related to research findings surrounding prenatal alcohol exposure (PAE) is not a new phenomenon but has followed other reports since the 17th century. Even today, this skepticism exists in many countries across the world. The consequence has been to limit the degree of attention that should have already been applied to FASD prevention, and limited focus on addressing treatment needs of affected individuals. With respect to prevention, the time is appropriate to look to the public health campaigns that have both succeeded and failed and adopt the models that have shown success in reaching the population most at risk. For PAE, this would be youth and young adults and their communication vehicle is most often social media. The efforts required for treatment differ in that neuro-behavioral and physical impairments must be addressed. Research has made inroads on understanding the mechanisms by which FASD injury arises and this research needs to expand to further uncovered approaches to ameliorate these deficits.

[35] The social stigma of fetal alcohol spectrum disorders: From theory to interventions

Arjan Bos

Open University, the Netherlands, Faculty of Psychology and Educational Sciences

FASD is a highly stigmatized condition. Birth mothers of children with FASD are blamed for their child's prenatal exposure to alcohol and are stigmatized for their past behavior. Public beliefs about young persons with FASD are also negative: people tend to anticipate life trajectories towards involvement in crime, alcohol and drug use. The public stigma of FASD may lead to self-stigma. Mothers of children with FASD may experience self-blame and individuals with FASD may internalize negative beliefs about FASD. In this presentation different types of stigma will be discussed (public stigma, self-stigma, stigma-by-association and structural stigma). For each type of stigma the available literature on fetal alcohol spectrum disorders will be reviewed. Moreover, this keynote lecture will focus on awareness of stigmatization and specific strategies to reduce FASD related stigma. The state-of-the-art knowledge on reducing stigmatization will be highlighted.

[36] Collaborative Initiative on FASD (CIFASD): An update on current research

Edward P. Riley

San Diego State University, San Diego, CA, USA

Background: The impact of prenatal alcohol exposure is a global public health issue, with an estimated 119,000 children born worldwide every year with FAS. Considering the full spectrum of effects (FASD), more than a half a million individuals per year are impacted by such exposure. CIFASD was funded over a decade ago as a multisite, international consortium to characterize the range of outcomes from prenatal alcohol exposure utilizing a multidisciplinary approach.

Methods: This presentation will focus on current research findings and ongoing projects within CIFASD. Our current aim is to improve the screening, diagnosis, and characterization of FASD across the life span utilizing integrated data from the face, brain, behavior, and biomarker variables. We are assessing factors that may be involved in imparting risk or resiliency to FASD. Finally, recognizing the mismatch between the number of individuals with an FASD and the availability of health professionals to deal with those individuals, we are exploring eHealth technologies, so that our research can be more broadly disseminated.

Results: In this plenary, the use of telemedicine and facial recognition will be discussed as ways to improve access to diagnosis and for their potential in rapid low-cost screening. Related to screening is a new computerized algorithm utilizing both physical and behavioral features to assess FASD risk. We are also investigating the use of an evidenced based family intervention that can be delivered over a cell phone or tablet. As one of the key obstacles in diagnosing FASD is the alcohol exposure history, we are developing biomarkers of exposures and assessing genetic factors that might influence outcomes. Finally, we are investigating long-term health outcomes in individuals with an FASD.

Conclusions: FASD is a complex disorder, but progress towards understanding and dealing with this issue can be made using a multidisciplinary collaborative approach.

[37] Policy Developments and action at EU level

Mariann Skar, European Alcohol Policy Alliance, Belgium

Background: The European Alcohol Policy Alliance (EUROCARE) is an alliance of non- governmental and public health organisations across Europe advocating for the prevention and reduction of alcohol related harm. Member organisations are involved in advocacy and research, the provision of information and training on alcohol issues, and services for people whose lives are affected by alcohol problems.

Eurocare's missions is to promote policies that prevent and reduce alcohol related harm. Our message regarding alcohol consumption is that "less is better".

Methods Eurocare has for the last 28 years been actively advocating for the prevention and reduction of alcohol related harm. Eurocare has a unique position of being a European organisation with committed members across Europe working specifically on one risk factor – alcohol. Eurocare's main policy areas – such a price and taxation (increase in taxes and minimum unit pricing), regulation of marketing (including sponsorship and product placement), protection of young people (age limits and advertisement), comprehensive product labeling (ingredient listing and health information labels), work on chronic diseases (e.g. cancer) – all contribute to Member States efforts to reduce inequalities and create sustainable health systems.

Eurocare generates, disseminates and facilitates exchange of best practices and capacity building in alcohol policy through its membership (59 members in March 2018) across 24 European countries, newsletters, website, events and cycle of policy debates. It is playing an effective role in civil dialogue processes at the EU level, through active participation in a number of established networks like European Health Policy Forum, DG Trade Civil Society Dialogue, DG AGRI Civil Society Dialogue and DG Connect Pilot Community of Better Self- and Co-Regulation, and Better Internet for Children, as well as the expert group on prevention in OECD and work closely with World Health Organisation.

Eurocare will present latest policy developments and their relation to the topic of FASD.

[38] FASD Global

Diane Black¹, **Kathy Mitchell**², Jan Lutke³

¹ *EUFASD Alliance, Landskrona, Sweden*

² *NOFAS, Washington, D.C., US*

³ *International FASD Research Conferences, UBC, Vancouver, Canada*

Background: Many countries have organizations providing evidence-based information on alcohol and pregnancy and supporting families living with FASD. However there are many areas of the world where information is scarce and resources are nonexistent. Furthermore, there are numerous small organizations without access to evidence-based information and materials for prevention and support. Therefore, we decided to develop FASD Global, whose mission is to unite organizations around the world working on FASD prevention, intervention and treatment.

Methods: FASD Global was launched in February in Ribeirao Preto, Brazil, together with the launch of a website www.fasdgloba.org.

Results: FASD Global will become an international on-line community where FASD-oriented organizations, charities, government agencies, service providers, FASD advocates and educators, and individuals and families living with FASD can find reliable evidence-based information, share ideas, and locate resources. FASD Global is supported by a Scientific Advisory Committee of top researchers around the world.

Conclusion: We believe that FASD Global will fill a gap providing high-quality, evidence-based information about FASD, but are not primarily involved in research and in supporting organizations concerned with FASD around the world.

[39] One World FASD Network

Mirjam N. Landgraf ^{1,2}, Kajal Chhaganlal ^{2,3}, Denise Carvalho ^{2,4}, Birte Rahmsdorf ^{1,2}, Florian Heinen ^{1,2}

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⁴ Universidade Federal do Paraná (UFPR), Curitiba, Brazil

Background: The aim of establishing a One World FASD Network is to evaluate the existent knowledge about FASD in different countries and continents, to estimate the prevalence of alcohol use in pregnancy and of FASD in different populations and to raise awareness about the potential harm of intrauterine alcohol exposure for the unborn child.

Methods: In 2015, representatives of 19 countries from 4 continents associated to the Center for International Health (CIH LMU Munich) agreed to build a FASD network. A steering group consisting of participants from Germany, Mozambique and Brazil was established. The partners of Mozambique and Brazil were trained regarding (early) diagnosis, differential diagnosis, everyday life functioning, therapy and prognosis of children with FASD. The cooperation partners and the German experts performed joint workshops and lectures about FASD in Beira (UCM, Mozambique) and in Curitiba (UFPR, Brazil).

Results: In 2016 101 professionals (doctors of general medicine, pediatrics, neuropsychiatry, child and adolescent psychiatry, gynecology, neurology, psychiatry, dentistry; nurses, occupation therapists, psychologists) and 194 students (nursing, psychology, medicine, occupational therapy) could be reached by joint workshops and lectures about FASD in Beira and in Curitiba. In 2017 307 students (medicine, psychology, nursing) were educated in Beira. The German guideline for diagnosis was summarized in a pocket guide FASD which was translated in English, Spanish, French and Portuguese. It was distributed to the 19 members of the One World FASD Network and published as electronic version at the CIH homepage.

Conclusion: There is strong need for better awareness of the severe complications of intrauterine alcohol exposure. The first step was the establishment of a network, the development of a diagnostic guideline and its dissemination in multiple countries all over the world.

[40] Assessing the Neurocognitive function(?) in people with FASD: Subtleties of presentation and lessons from two European FASD specialist clinics for diagnosis and management.

Raja Mukherjee(1), Gro C.C. Lohaugen (2), Alexandra Carlisle(1), Alexandra Livesey (1),

1. UK Nation FASD specialist behaviour clinic, Gatton Place, Redhill, UK

2. Regional Competence Center for children with prenatal alcohol and/or drug exposure in the South-Eastern Norwegian Health trust. Sørlandet Hospital, Arendal, Norway

The broad neurocognitive deficits associated with Fetal alcohol spectrum disorders are generally well known and established. Research over the last 30 years have identified deficits in intellectual function, memory, executive function, adaptive ability as just a few of the areas that are impaired in this group. These functional deficits are corroborated by structural and functional brain scanning data highlighting that interconnectivity remains an issue. Despite this, there remains very few highly specialist neuro psychological centres that are regularly assessing the broad neurological and neurodevelopmental profile associated with FASD in Europe. This means that the subtleties of presentation across a range of tools remains uncertain to many. These lead to diagnostic and therapeutic quandaries.

This workshop will be led by specialist psychologists and practitioners from two of the most established clinics in Europe based in Norway and UK. Both offer comprehensive assessment of individuals. The workshop will highlight and present practice-based knowledge and emerging data from these clinics as to which neuropsychological tests are most sensitive and most useful in identifying the range of deficits seen. The facilitators will share clinical experience of which test offer the most utility from a diagnostic perspective but also therapeutically. Daily life and educational intervention planning will also be discussed. These will be combined with case discussions and facilitated presentations to answer some of the more difficult and subtle issues found with FASD diagnosis and management. Based on the extensive experience of these two centres is hoped that those attending the workshop will gain a better understanding of how to assess this complex condition at local, regional and national level requirements.

[41] Mental and behavioral disorders among young people with prenatal substance exposure - ADEF Helsinki research project (Alcohol or Drugs Exposure During Fetal Life)

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4. *The Social Insurance Institution of Finland, Helsinki, Finland*

5. *Department of Obstetrics and Gynecology, Helsinki University Central Hospital, Helsinki, Finland*

Background: A majority of children with prenatal alcohol exposure are exposed to illegal drugs, as well. Moreover, many of them live in traumatic caregiving environment at least the first years of their life. Despite that, the effects of exposure to both alcohol and drugs, and trauma, on the overall developmental outcome of these children have not been well studied.

This study investigates 1) the nature and extent of mental and behavioural disorders (ICD-10, F00-F99) among young people with prenatal substance exposure, and 2) the association of the dual exposure to substances and traumatic experiences with these disorders.

Methods: The women with substance abuse problem during pregnancy were first identified in the maternity clinics of health care centers of Helsinki metropolitan area and referred to special antenatal clinics of Helsinki University Hospital (N=3) where pregnancies were followed. All children born to them during that time (1992-2001, N=638) are included in this study. The matched control group consists of 1914 unexposed children born to women with no evidence of substance misuse in any of the national health and social welfare registers. Data for this register-based case-control cohort study were collected linking medical records with register data from the national registers by using a unique identification number. Analysis: risk indexes, comparisons, incidence and prevalence figures, and multivariate logistic regression.

Results: The data collection was completed in the beginning of 2018. First results on mental and behavioral disorders will be presented.

[42] Time to catch up with the secondary psychiatric disabilities of FASD in France

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Background: 50 years after Paul Lemoine's pioneer description in 1968 of the adverse effects of alcohol on the developing fetus, a lot has changed in the recognition and comprehension of Fetal Alcohol Spectrum Disorders (FASD) worldwide. France has largely contributed to prevention efforts but is lacking national recommendations for assessment of children with FASD. This lack of information on FASD particularly affects French child psychiatry, while we know nowadays the importance of psychiatric secondary disabilities and comorbidities. These issues such as attention deficiency, behavioral or emotional dysregulation impact severely the quality of life and lead child psychiatrists to be often at the forefront of medical care of these patients. Time to catch up !

Methods: This communication aims to show the actions of the first French FASD Diagnostic Center in its advocacy missions and collaboration with child psychiatry services on Reunion Island. We focus on improving both recognition and access to adapted psychiatric care for children with FASD.

Results: Fundamental knowledge on children with FASD deserve to be shared with psychiatric services: (1) Issues concerning access to care. (2) Assessment of comorbidities whose recognition can have an impact on social functioning and quality of life. (3) Targeted multidisciplinary developmental assessment to adjust psychiatric therapeutic interventions (4). Care for siblings and parents' mental health. (5) Individual preventive strategies of FASD.

Conclusion: A collaborative work with families, partners from child psychiatry services and the resource centers can optimize access and quality of psychiatric care for children with FASD, particularly through adapted early targeted intensive care interventions.

[43] Prevalence of urinary system defects among patients with fetal alcohol spectrum disorders

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Background: The teratogenic effect of alcohol on the developing fetus is well studied, however the system that is mostly affected is central nervous system. The effect of alcohol on other systems including genitourinary system remains controversial. Data from the animal studies suggest an increased rate of genitourinary system defects among individuals with prenatal alcohol exposure. On the other hand, Taylor et al. in a human cross sectional study did not demonstrate an increased prevalence.

Methods: The study was conducted as a cross-sectional study. 100 patients of St. Louis Children Hospital age 1 month-18 years-old, diagnosed with FASD were included in the study. All patients had an abdominal ultrasound done, serum creatinine level measured and blood pressure (twice) taken.

Results: Congenital kidney defects were observed in 31% of the patients. Duplication of pelvicalyceal system, dilatation of the pyelocalyceal system, renal pyramids overgrowth, partially external renal pelvis. Two patients (2%) were diagnosed with congenital hydronephrosis, one (0.5%) had renal medullar cysts and one had a horseshoe kidney. Abnormal bladder (atonic bladder, decreased bladder volume, elongated-in-shape bladder, abnormal bladder perystalsis was observed) in 7% of the patients. Urethra defect (hypospadiasis) was observed in 1 patient.

Conclusion: Congenital genitourinary system defects are more prevalent among FASD patients, however the majority of the defects are not clinically significant.

[44] Alcohol consumption in pregnancy and childhood hearing and neurodevelopmental problems in the UK: analysis from the Millennium Cohort Study

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Background Fetal Alcohol Spectrum Disorders (FASD) is the leading preventable cause of disability in children in the UK. Identification and diagnosis of FASD is poor, with many children receiving diagnoses of other neurodevelopmental deficit (including Attention Deficit Hyperactivity Disorder -ADHD), but no FASD diagnosis. FASD is associated with a large number of comorbid conditions, including an 80-fold increased risk of sensorineural hearing loss. Using a contemporary UK birth cohort we examined the association between maternal alcohol consumption in pregnancy, hearing problems at age 3 and later ADHD.

Methods Analysis of the UK Millennium Cohort Study (MCS), based on 9,179 children participating in 3 survey sweeps (9 months, 3, 7 years old). The main outcome was parental-reported hearing problems, at age 3. We also examined self-reported diagnosis of ADHD at age 7. Incident rate ratios (IRRs) and 95% confidence intervals (CI) were estimated using Poisson regression, according to maternal drinking in pregnancy in units per week (categorised as none, 1-7, 8-14 and 15 or more) adjusted for measures of childhood socioeconomic conditions. Analyses were conducted using Stata/SE with svy commands to account for the sampling design and attrition.

Results At age 3, 1,328 children (14.4%) had reported a hearing problem with the most common of these being otitis media and unspecified hearing loss. Children of mothers who reported drinking 15 or more units per week of alcohol in pregnancy were twice as likely to have hearing problems compared to mothers who reported never drinking in pregnancy (aIRR1.9(95%CI[1.07,3.39])). Risk of ADHD diagnosis at age 7 was also elevated in children of mothers who drank 15 or more units per week though this was not statistically significant at the 5% level (aIRR2.79(95%CI[0.91,8.57])). Children with hearing problems at age 3 were 3.5 times more likely to have a diagnosis of ADHD at age 7 (aIRR3.49(95%CI[1.92,6.32])).

Conclusions In a representative UK child cohort we found a significant prevalence of parental reported hearing problems at age 3 which was associated with high maternal alcohol consumption in pregnancy. Hearing problems were associated with a higher risk of ADHD. The self-reported nature of both alcohol consumption and hearing problems is the primary limitation of this study. Maternal alcohol consumption is rarely captured in child health records in the UK making follow-up of potentially exposed children difficult. Further investigation in children with hearing loss could lead to earlier diagnosis of neurodevelopmental conditions, including FASD, and provide opportunities to intervene and improve outcomes.

[45] Risk Assessment in FASD – Why Paediatricians Need CAMHS Training.

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Background: Children affected by prenatal alcohol exposure (PAE) present to a variety of health services. UK FASD assessment is coordinated by Paediatrics or Child & Adolescent Mental Health Services. Over 90% of PAE-affected individuals experience comorbid mental health disorders, with high rates of both externalising and internalising symptoms. Mood disorders, including increased suicide risk, may be less apparent to Paediatricians.

Methods: Risk was assessed in 36 children with PAE. The Children's Depression Inventory (CDI) was used in 22/36 children and data was converted to z-scores. We recorded i) responses to items asking about suicidal ideation, ii) if children required formal risk assessment, and iii) if children were referred on to CAMHS in relation to risk. 32/36 carers were administered the Strength and Difficulties Questionnaire (SDQ) to record externalizing and internalizing behaviours. SDQ data was converted to z-scores.

Results: (1) Children affected by PAE do not score significantly highly on the CDI but do score significantly highly on the SDQ. Although known mental health risk was an exclusion criteria for FAAST involvement, (2) 11 children (30.6%) required a full formal risk assessment. (3) 5 children were referred to CAMHS (13.9%), 3 in regards to mental health risk (8.3%), and 2 in regards to risk due to impulsive behaviour (5.6%). (4) Of those who completed the CDI, 31.8% of children stated that they had thought about suicide and 4.5% wanted to complete suicide.

Conclusion: Paediatricians must be aware that children affected by PAE are at high risk of mental health difficulties. Risk requires in-depth assessment and is not typically apparent in screening. Screening should be utilized as a 'conversation starter'. Paediatricians may require Mental Health First Aid and CAMHS risk assessment training. If children known to CAMHS are referred to Paediatrics for FASD consideration, we would recommend that shared care is maintained.

[46] Reducing Stigma towards Birth Mothers and their Children with FASD in Healthcare Providers

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Background: Stigma associated with drinking during pregnancy is common, yet the reasons that women may drink while pregnant are not widely recognized or understood. The effect of stigma is far-reaching with profound impacts, particularly the biological mother and her entire family. Yet little work has been done taking into account the voices of those who are most impacted by the effects of alcohol consumption during pregnancy, the individuals who have lived experience. Some pediatricians believe that an FASD diagnosis stigmatizes the child. Research to change stigma suggests that *contact* intervention with people with a lived experience is effective. To investigate if contact intervention was effective the Centers for Disease Control funded an anti-stigma program with the University of California, San Diego, NOFAS, and the Illinois Institute of Technology that sought to: 1) to prevent alcohol-exposed pregnancies among reproductive age women and 2) to prevent FASD. The program aimed to increase obstetrician-gynecologists to universally screen for alcohol use among their pregnant patients using a validated screening tool and pediatricians to universally screen their patients for prenatal exposure to alcohol.

Methodologies: A community based participatory program (CBPP) that included community members (birth mothers, parents, and individuals with FASD) and two primary care systems. Four focus groups provided qualitative data on the nature of FASD stigma issues. The data informed the development of a formal birth mother training curriculum, evaluation, and an anti-stigma program manual.

Results: Trained birth mothers presented to the UCSD Reproductive Medicine and Pediatrics teams.

Conclusion: Evaluations showed an increase in both of the medical teams to be more likely to discuss alcohol use with their patients, use screening for alcohol use and were more likely to screen for possible FASDs.

[47] Pregnant - my child drinks as well! Alcohol - No sip. No risk! Successful school FASD primary prevention before pregnancies

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Background: Although the clinical picture FASD was described 45 years ago, there is still a lack of knowledge in the general population about the effects of alcohol consumption during pregnancy. In Germany, alcohol consumption during pregnancy affects an estimated 10,000 newborns every year. A FASD education program in schools does not yet exist in Germany and there is nothing in the school curriculum. FASD should be clearly addressed in advance of pregnancies and this repeated multiple times over the course of schooling. The medical information lessons performed by members of the Medical Society for Health Promotion (ÄGGF) are ideally suited for this purpose. Since 1952, physicians have been visiting schools to provide pupils with gender-sensitive information about many topics relating to sexual and reproductive health. The Federal Ministry of Health therefore commissioned the ÄGGF to carry out a FASD primary prevention project in schools.

Methods: In 2015, the ÄGGF, the incorporated medical association of health support, launched the first nationwide school project 'FASD Primary Prevention before Pregnancy' supported by the Federal Ministry of Health for all pupils of eighth grade and higher. Over the course of three years (2015-2018) 1200 events (most of them realized as 90-minute medical information sessions for one school class each) were held, more than 20,000 participants were reached. Pupils comprised 90 % of participants, while the remaining 10% were teachers, parents, doctors, medical personnel and other individuals operating in a knowledge-spreading capacity. An accompanying randomized monitored evaluation with a waiting control group was carried out by the Institute of Therapy Research in Kiel, Germany (IFT-Nord) in 130 school classes (65 classes intervention group and 65 classes waiting control group).

Results: The students of the intervention group showed significant knowledge improvement on the topic of FASD following participation in the school project. Furthermore, the results show huge interest among pupils as well as positive behavioral intentions in relations to later pregnancy and also the further spreading of received information. Special didactic FASD materials were rated as helpful and important by the students.

Conclusion: FASD primary prevention before pregnancy for pupils is necessary, highly feasible and effective. School provides the best access to reliably reach young people. Special didactic materials are very helpful and effective for knowledge transfer.

[48] Evaluation of HerWay Home: Promising approaches and outcomes of an FASD prevention program for substance-using women with complex, social determinants of health issues

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Background: Based in Victoria, BC, Canada, HerWay Home (HWH) is a multi-service drop-in and outreach program for pregnant women and new mothers who use or have used substances and who may also be affected by mental illness, trauma and/or violence. Key philosophical underpinnings of HWH include: harm reduction; being relationship-based and trauma-informed. This paper presents highlights of HWH's comprehensive evaluation (2015-2017).

Methods: Phase 1 of the evaluation focused on the implementation of HWH, identifying promising practices and early outcomes for clients and their families. Phase 2 focused on assessing longer-term outcomes for women and their children, service partners, and systems. The evaluation employed a mixed-method design, involving: interviews with 60 people (28 clients; 26 service partners; 6 staff); review of program data; document review; and a social return on investment (SROI) analysis.

Findings: HerWay Home is achieving key outcomes and is being implemented in ways that are highly consistent with its guiding principles. Significant outcomes for clients included improved mental well-being; quitting or substantially reducing substance use; feeling supported; retaining/regaining custody of their infant/child(ren); and feeling hopeful. More than 75% of infants were healthy at birth and 83% were not substance-affected. The SROI showed strong cost savings and social value created in relation to the outcomes examined. Promising approaches included the importance of: a harm reduction approach in helping women to achieve their goals; a non-judgemental, relational approach; and relationship-building between HWH staff and community partners.

Conclusion: This session provides an opportunity to learn about holistic programs reaching pregnant women and new mothers with substance use and related health and social care challenges and about approaches to evaluation that capture the complexity of such multi-service programs for women and their children/families.

[49] The FASD Resource Center in Reunion Island : Back to 2 years of activity.

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Concerning about 1 in 100 births, Fetal Alcohol Spectrum Disorder (FASD) is the most common cause of neurocognitive disorders and difficulty of social insertion. However, screening, diagnosis and management of these patients remain difficult due to a lack of knowledge of professionals and difficulties to approach these patients and their families.

Reunion Island has been implicated for a long time in the prevention and the management of FASD. Reunion Island is one of the French overseas department, in the Indian Ocean between Madagascar and Mauritius. Its population exceeds 800,000 inhabitants and the annual birth number is about 14,000. In 2004, Ms. Anne-Marie Payet, as Senator of Reunion Island, defended the implementation of a warning logo on all bottles of alcoholic drinks marketed in France; Reunisaf association between 2001 and 2012 developed an innovative process of prevention and support for these families, focused on the concept of “to move towards”.

The FASD Resource of Reunion Island, managed by the medicosocial Foundation “Père Favron” in partnership with the University Hospital is the central link of the new experimental Action Plan against FASD. It is funded by the Regional Health Agency of Indian Ocean (ARS-OI) and the Interministerial Mission against Drugs and Addictive behavior (MILDECA). Its missions are multiple : 1 - to identify and put together the different actors of health, medico-social and social sectors, but also of education and Justice, to coordinate the formation of the different professionals and the information of the general public , 2 - to identify and facilitate the diagnosis and care of the families in synergy with regional health networks about perinatality and addiction and the diagnosis center recently set up at the University Hospital, 3 - and finally to promote research with the creation of a cohort of patients.

After two years of activity, we will present the different actions of our Resource Center, its strengths, but also its limitations and areas for improvement. For example, more than 3,000 health students and 500 professionals have been trained since 2016.

This Center is the first one created in France; it should serve as a model to encourage the creation of other centers, in both metropolitan France and other overseas territories.

[50] The SAFTHON, First International Solidarity Movement for the prevention of Fetal Alcohol Spectrum Disorders

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Background: The consequences of alcohol consumption during pregnancy afflict a minimum of 1 % of the global population. It is the major cause of mental disability and non-genetic social maladjustment and it is so preventable. Fetal alcohol consumption generates more than 400 comorbidities that will express throughout life. Yet they remain unknown to most professionals from health and social services, education, justice and from politics. Most countries worldwide are concerned with fetal alcohol consumption. In any country, as soon as a woman consumes alcohol: fetal alcoholism is present. Many governments are not aware of this public health issue and, above all, of the stakes associated with it (health, social, justice, economy, education). Its prevention can avoid many illnesses, academic failure, delinquency and also bring significant savings to the countries. Reunion Island became a model for France as it has initiated the logo of prevention for all alcoholic beverages, a logo now adopted by many countries worldwide.

Methods: To promote the prevention of FASD we launched the 1st SAFTHON (FASTHON), in september 2017, emanating from the experience of Reunion Island. Its purpose was to create a strong regional, national and international solidarity movement to facilitate collective awareness of FASD.

Its goals:

1/ to develop collective awareness of FASD by increasing the knowledge of the general public

2/ to encourage institutions and individuals to join us in this fight against a huge Public Health issue and for equal opportunities of life.

3/to collect funds to support projects on the ground concerning:

*Women in difficulty with alcohol

*The lives of all people impacted by fetal alcohol consumption

*The struggle of families facing FASD issues

Results: This first edition of the SAFTHON that occurred on September 8-9, 2017, was promising: we collected funds to develop projects on the ground, and overall, we were followed by more than 40 million viewers. This event made a lot of noise.

For the second edition of the SAFTHON in 2018, all 107 french departments will follow

the path opened by Reunion Island and copy our original model. These departments represent more than 350 000 professionals working for families, childcare, including foster families and serving the defense of the rights of women and children. Some amongst you asked us to create an International Committee for the next SAFTHON. We launched a survey and presented this project in Vancouver at the 8th International FASD Conference.

Conclusion: This presentation will share with you development, impact and results that occurred recently from this global action.

[51] Genetic testing in FASD assessments – What lessons did we learn?

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Background: The prevalence of FASD in the UK is poorly defined, but estimated at 1-4% (Popova, 2017). When considering a diagnosis of FASD, review by a clinical geneticist has been advocated. In Scotland our resource of 1 clinical geneticist per 330,000 must be used judiciously and review of every FASD case is impractical.

Methods: 36 children were assessed and genetic testing considered. Genetic testing/array CGH (aCGH) was requested if any of the following were present - dysmorphic features outwith FASD spectrum, microcephaly, structural malformation, family history of learning disability or recurrent miscarriages (recommended by Clayton-Smith, 2012).

Results: 36 children attended for assessment. 26 (72%) received a diagnosis of FASD. Alcohol history unknown in 8. Marked facial features present in 12 (facial features score of 4, Astley, 2004; further 9 children had a score of 3). 4 known to be microcephalic at birth (unknown in 14 children). 14 microcephalic at time of assessment. 28 underwent genetic testing - 25 had a normal aCGH and 3 had an abnormality detected. The abnormalities detected were (1) loss at 2q13, (2) loss at 6p25.1, (3) gain at 15q11.1-11.2. These were discussed with a geneticist, but not thought to be wholly responsible for the presenting phenotype.

Conclusion: We propose that all children assessed for FASD undergo genetic testing. This reflects recommendations that an aCGH is a first line test in individuals with developmental difficulties (Miller 2010), has cost-saving implications (Sagoo, 2014), and is now readily available. An aCGH is particularly important for those in whom marked facial features (all 3 facial features) are used as a proxy for prenatal alcohol exposure (Cook et al, 2016). If the aCGH is negative, discussion with a geneticist is still recommended. Where there is a paucity of information regarding the family history an aCGH is warranted. An abnormal aCGH should always be discussed with a clinical geneticist.

[52] Epigallocatechin Gallate (EGCG) to Improve Cognitive Performance in Foetal Alcohol Syndrome (FAS) Children

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Background: The flavonoid epigallocatechin gallate (EGCG) is a modulator of neuronal plasticity useful in other neurodevelopmental diseases. A recent study showed that EGCG is a promising tool for cognitive and health related quality of life improvement in Down's syndrome. The objective is to determine the efficacy of EGCG as a therapeutic candidate for the improvement of cognitive performance in FAS patients.

Methods: Pre and post study, non randomized, controlled and without placebo, to evaluate the efficacy of EGCG. It is a pilot study in a cohort of 40 FAS children, between 7 and 14 years old. An oral dose of 9 mg/Kg/day will be administered during 1 year, with 6 control visits until 6 months after finishing the treatment. Several cognitive and neuropsychological tests were used before, during and after the antioxidant therapy (WISC-IV, NEPSY-II, CBCL 6-18).

Results: (1) No side effects were found, clinical or biochemical. (2) Several domains of cognitive and neuropsychological tests improved with a statistically significant result: work memory, oral comprehension, perceptive reasoning, outsourced behavior.

Conclusion: EGCG could be a promising therapeutic tool for symptomatic treatment of FAS children. A double blinded clinical assay is going to be initiated next months.

[53] Discussing multiple substances by multiple providers, as a key FASD prevention strategy

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Background - Reaching all women of childbearing years through brief, respectful conversations about alcohol is a key FASD prevention strategy. In countries like Canada, as rates of binge alcohol drinking by women continue to increase, plans to legalize cannabis use are underway, and use of prescription pain medication is at crisis proportions, new opportunities for enhancing discussion of alcohol and these other substances become available. This session will describe approaches to implementing brief intervention/support with women and their partners, on four substances (alcohol, tobacco, cannabis and prescription opioids) in ways that expand the reach and efficacy of alcohol interventions. Further it will highlight how brief intervention can be employed by all those who work with women in the perinatal period, not only physicians.

Methods: An environmental scan of existing brief intervention practices was conducted in Fall 2017 in Canada. Twelve regional sessions were conducted across the country with multi-disciplinary experts from professional health and social care organizations. These sessions were supported by a literature review which included academic literature published between 2004 and 2017 identified using EBSCOHost Research Databases, and grey materials (e.g. practice guidelines) identified through targeted web searches.

Results: Current and evidenced brief intervention practices and resources being utilized in Canada were compiled. Ideas for expanding the delivery of brief, integrated, and trauma-informed support on alcohol, tobacco, cannabis and prescription opioids, and for including service providers beyond physicians in these practices will be provided.

Conclusions: The findings from this study and the resources created based on these results: enhance understanding about the health consequences of legal substance use in the preconception and perinatal periods; promote practice change that supports prevention of FASD; and increase efforts to implement collaborative discussion on substance use by a range of practitioners.

[54] “Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders (FASD): from prevention to evaluation”: an e-learning program for health professionals in Italy.

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Background: In 2017, the Italian Local Health Authority no.2 “Marca Trevigiana” – Treviso, Veneto Region [AULSS2] developed a mandatory e-learning program on FASD for health professionals, called “Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders (FASD): from prevention to evaluation”. The aim of the program is: 1) to provide all health professionals in the area of the AULSS2 with theoretical knowledge and updates on the harmful effects of alcohol consumption in pregnancy; 2) to provide knowledge on the assessment of the risk related to alcohol use during pregnancy; 3) to promote awareness of prevention models for the health of women and children, in relation to the harm due to prenatal alcohol exposure. This program is carried out with the collaboration of the team of professor Mauro Ceccanti from La Sapienza University (Rome, Italy) and the participation of the Canterbury Christ Church University (UK).

Methods: The program is delivered in e-learning mode with tutoring support, and has a total duration of 6 hours. It consists of five training modules: 1) general information on FASD; 2) epidemiological aspects; 3) strategies and methods to assess a newborn at risk for prenatal alcohol exposure; 4) prevention of FASD: from traditional models to community empowerment; 5) clinical practices to evaluate and take charge of women at risk for alcohol use during pregnancy. The program includes an innovative method of pre and post evaluation of knowledge and opinions, developed according to the “action-research” approach. The program is going to be implemented in 2018.

Expected results and conclusions: The e-learning program is going to train about 1,500 health professionals in the area of Treviso, and it is planned to make it available to more professionals in the Veneto Region. This program will provide professionals with systematic knowledge and competence, that are expected to facilitate and support the development and implementation of an integrated and efficient system for FASD prevention, diagnosis and treatment, which is currently still missing in Northern Italy.

[55] Reducing alcohol use by women who are pregnant, planning or could be: using social media campaigns to raise awareness

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The National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD, Australia)

Background: The harm caused to an unborn infant by in-utero alcohol exposure was first identified in English-speaking literature in 1973. Despite this, alcohol-exposed pregnancies continue to be a global problem. In Australia, almost 50 % of pregnancies are unplanned and 80% of women consume alcohol. This leads to approximately 50 - 60% of women consuming alcohol during pregnancy. Health messages through traditional communication channels have had some impact but the use of newer digital communication platforms needs to be explored. There are over 17 million active Facebook accounts, 5 million Instagram accounts and 3 million Twitter accounts in Australia. This presents opportunities to create compelling campaigns to reach identified target groups, in this case women aged 18-40 and their support networks. On average 75% of these women log onto Facebook once per day and 51% log on several times per day.

Methods: We will examine a range of strategies used in social media campaigns in public health, including the design, development, delivery and results of campaigns.

Results: Approaches used were non-traditional, use humour, positive images and reach mainstream to create intrigue and discussion across social channels. Campaign results included an audience reach of over 200,000 for \$2500 USD spent. Social media presents opportunities to raise awareness about the risks associated with alcohol exposed pregnancies to targeted stakeholders. This can be done at low cost with considerable reach and impact can be tracked.

Conclusion: The presentation is designed for people who are not social media professionals but recognise the potential of social media. The prevention of FASD is intimately linked to combatting the reach of global alcohol conglomerates who use social media skilfully to advertise to their target markets. Effective health promotion must also use these media to develop a larger share of voice and compete effectively for audience.

[56] Prevention of alcohol consumption during pregnancy and promotion of healthy lifestyles in Italy: the experiential laboratory “MITOSI”.

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Background: in 2017, the Veneto Region (Italy) inaugurated an “experiential workshop” called “MITOSI”, aimed at offering pregnant women the opportunity to learn and experiment healthy lifestyles (proper nutrition, adequate physical activity, abstention from alcohol and smoking). The target are women within the 3rd month of pregnancy. The workshop is located in one hospital in Venice. It is proposed and managed by midwives, who received a specific training on the issue.

Methods: the workshop lasts one day and begins with physical activity (a walk from Venice train station to the hospital). Each group consists of a maximum of 12 women. The experience then continues in specially designed rooms of the hospital, according to the following sequence: 1) Reception and introduction; 2) Workshop “alcohol” (women have the opportunity to: A - acquire information on an idea of non-commercial beverage, made of natural ingredients and based on healthy principles as “zero alcohol / few fats and sugars / use natural and fresh ingredients”, as well as on the risks of alcohol use to the unborn child. B - experience empowerment, by reproducing a FASD-awareness action, integrated with the use of social media in real time). 3) Workshop “healthy nutrition”; 4) Workshop “physical activity”; 5) Workshop “Relax and music therapy” (suggested as an alternative to tobacco smoke). The workshop ends with the administration of a questionnaire.

Results: until now, 90 midwives were trained to manage the program and 30 women attended the workshop. Surveys completed after attending the training or participating in the workshop revealed an excellent level of satisfaction, both in professionals and among women, in terms of quality of the training and efficacy of the program. The experience is ongoing.

Conclusions: the “experiential workshop” is a promising approach to empower pregnant women and prevent the harmful effects of prenatal exposure to alcohol, in association with the promotion of the other key healthy lifestyles during pregnancy.

[57] Introducing the BSI-FASD – A Screening Instrument for Adults with FASD

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Background: In Germany there is a significant gap between the suspected prevalence of adults with Fetal Alcohol Spectrum Disorder (FASD) and the number of people with actual diagnosis of this disorder. This gap results in severe impacts on the psychosocial outcomes of adults affected by FASD, who lack the medical diagnosis that would make them eligible to receive needed services. One reason for this gap is the considerable cost of the FASD diagnostic process. To address this need, our current research aims to develop an efficient screening tool for FASD that can be easily implemented. Thus we developed the Biographical Screening Interview for people with suspected FASD (BSI-FASD). The objectives of our research are as follows: (1) develop a valid translation and adaptation of the English *Life History Screen* (Grant et al., 2013); (2) pretest the translation with an adult affected by FASD to ensure comprehensibility; and (3) evaluate the reliability of the BSI-FASD for use as a screening tool for the identification of FASD in German adults.

Methods: The study includes 112 participants recruited from: an alcohol rehabilitation clinic; our own FASD-Fachzentrum; a self-help group for people affected by FASD; and from members of FASD-Deutschland. All participants in our research have been administered the BSI-FASD and have been referred for FASD diagnosis or have already been diagnosed with FASD.

Results: The BSI-FASD is able to correctly identify people affected by FASD. Our results of this research show high values for both sensitivity (87.5 %) as well as specificity (93.7 %). Areas which illustrate significant differences between people affected by FASD and people without an FASD diagnosis include: maternal alcohol use, education, employment and income, living situations, mental health, and day-to-day behaviors.

Conclusion: The BSI-FASD can be an efficient and economic screening tool that can be easily administered in any setting. It can help close the diagnostic gap, as it reliably identifies individuals with suspected FASD who should be referred to further diagnostics.

[58] Psychiatric symptoms and quality of life in adolescents and adults with fetal alcohol spectrum disorder: results from a longitudinal observational study

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Background: Alcohol consumption during pregnancy has far-reaching biological, psychological and social consequences. Long-term effects of fetal alcohol-spectrum disorder (FASD) into late adolescence and adulthood are largely unknown, but the limited research suggests a negative prognostic outcome.

Methods: Retrospective, longitudinal study aiming to assess childhood factors and current outcomes, i.e., psychiatric symptomatology, quality of life (QoL) and functional level in a cohort of adolescents and adults (current age ≥ 16 years). Psychiatric symptoms were assessed via self-report with the Brief Symptom Inventory (BSI). QoL was examined via the Life Satisfaction Questionnaire. Other variables, such as current employment, education level, or living situation, were assessed via multiple-choice and open-ended questions. Patients were compared to general population levels and the different diagnostic groups were compared to each other (fetal alcohol syndrome (FAS), partial FAS (pFAS), alcohol-related neurodevelopmental disorder (ARND)).

Results: Altogether, 137 patients (age=26.3 (range=16-60) years; 45% female) participated in the study. Overall psychological distress was significantly higher vs the general population. Specifically, anxiety, hostility and paranoid ideation levels were affected. General life satisfaction was lower in FASD patients than in the general population. Moreover, patients with FAS ($n=81$) reported less satisfaction with life compared to patients with pFAS ($n=47$).

Conclusion: The under recognized and understudied population of adolescents and adults with FASD remain largely affected by the disorder on important levels of daily life. Although it remains unclear if these long-term effects are direct or secondary consequences of FASD, these patients should be identified early and receive targeted interventions as well as appropriate support in order to improve the identified measures of unsatisfactory outcome.

[59] Criminal behavior and substance abuse in adolescents and adults with fetal alcohol spectrum disorder

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Background: Fetal alcohol spectrum disorder (FASD) is an increasingly recognized public health issue worldwide and until now, little is known about its negative outcomes in late adolescence and adulthood. Clinical descriptions suggest major problems with adaptive behavior, including criminal behavior and substance abuse behavior in patients suffering from FASD. These problems seem related to neurocognitive impairments and negative life experiences.

Methods: In a retrospective longitudinal study, data was collected via self-report including standardized questionnaires. For information about childhood, including trauma experience, the Childhood Trauma Questionnaire was used; substance abuse and criminal behavior was assessed by open-ended questions and the Comprehensive Misconduct Inventory.

Results: Altogether, 126 patients with FASD participated in the study (median age: 24 years, range 17 – 60; 55.6% male, 44.4% female). Only 6.3% of the study cohort reported no criminal behavior and 33.3% reported no substance abuse behavior. Patients were statistically more likely to show criminal behavior when diagnosed with partial fetal alcohol syndrome (pFAS) compared to alcohol-related neurodevelopmental disorder (ARND). Moreover, experience of slight versus no emotional neglect during childhood resulted in higher odds for criminal behavior in patients with FASD. Experiencing severe versus no physical neglect during childhood increased the odds for substance abuse in FASD-patients almost 5-fold.

Conclusion: Physical and emotional neglect during childhood increased the risk for substance abuse and criminal behavior respectively in patients with FASD. Moreover, a diagnosis of pFAS seems increase the odds of showing criminal behavior.

[60] Concept of an inclusive FASD-Outpatient Clinic: Experiences and Proposals

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Background: FASD persists into adulthood. Many persons with FASD are diagnosed in childhood, many of them receiving a good support to cope with their specific problems. An unknown number of children is not diagnosed and did not receive specific support. To be able to give this support and to receive monetary support from the social insurance system, a sustained diagnosis must be made. In Germany, there was no outpatient clinic that offered these examinations paid by health insurance.

Methods: We set up an inclusive FASD-outpatient clinic in spring 2015 attached to our outpatient clinic for persons with mental retardation and psychiatric comorbidities. The staff consists of two physicians, one neuropsychologist, one educator and a secretary. Moreover, there is a close cooperation with the clinic with social workers and many kinds of occupational therapies.

Our clinical workup consists of a standardized enrolment-procedure, an extensive anamnestic workup, neuropsychological evaluation, medical and neurological examination and computer supported evaluation of facial stigmata. After that, we do an interdisciplinary case-conference in which we discuss the findings and the diagnosis. After that, we invite the patient and his caregivers for explanation of findings and diagnosis. If necessary, patients and caregivers can make further appointments. Moreover, we plan to establish a therapeutic group-program.

Results: Persons are sent to us from several public-service institutions as well as from foster parents. Some make appointments for themselves or are sent to us from FASD-Deutschland. About a quarter of patients comes from our own institution, either from the inpatient- or the outpatient-clinic. About 70% have a learning disability, 30% a mental retardation. About three quarter of the patients have a FASD-diagnosis (about 40% ARND, 20% FAS and 15% pFAS), one quarter has no FASD-diagnosis.

With our actual amount of staff, we can not offer as much diagnostic procedures as requested, so we have a waiting-list for an examination for FASD.

Conclusions: The inclusive FASD-outpatient clinic is well established. Further offers for examination and therapy are needed.

[61] Attitudes towards a late FASD diagnosis

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Background: Persons with FASD deal differently with this diagnosis, especially when they are diagnosed as adults. For a lot of patients a late FASD diagnosis is considered to be helpful in order to receive further treatment and health care as well as social insurance benefits. Other patients suffer from a shock and react depressed. Therefore it is necessary to discuss and learn about the specific aspects of possible consequences and develop support strategies after the diagnosis.

Methods: In this pilot study, we will report the results of a mixed methods design. We included 20 semi-structured interviews by experts of FASD, ADHD, autism and mental disabilities and patients with FASD and similar deficits. Semistructured interviews were conducted, transcribed and qualitatively analysed using thematic analysis. Data reduction, coding and analysis were facilitated by Maxqda qualitative data analysis software version 12. Additionally, several standardized questionnaires were used and combined to assess personality aspects (NEO-FFI) and health issues (WHO-QOL, SF-12).

Results: Not only the diagnosis itself, but consequences afterwards were regarded differently by experts and patients in some aspects. As FASD is not included in the ICD-10, knowledge about FASD for further treatment and support is limited compared to other diseases. This was seen as a problem especially associated with the FASD diagnoses by experts and patients. Labeling associated with the diagnosis was reported more often by adults with FASD. Possible consequences of the FASD diagnosis such as guilt reduction at court or the wish to receive benefit retirement pay were seen skeptical by the experts rather than patients. For the patients, the direct link to alcoholism of their mothers was also a difficult aspect of the diagnosis. Altogether, the FASD diagnosis was reported to be more ambivalent and negative compared to other diseases.

Conclusion: Compared to other diseases adults with an FASD diagnosis and their caregivers must put more effort in getting help after the diagnosis. Further aspects have to be discussed such as ethical implications concerning stigmatization and legal issues.

[62] Physical growth and traits of children with Fetal Alcohol Spectrum Disorders (FASD) and maternal risk factors in the general population of the United States: summary results from the Collaboration on FASD Prevalence (CoFASP)

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Background: Physical and neurobehavioral traits of children with fetal alcohol spectrum disorders (FASD) in general populations are not well known or well described in the literature. The Collaboration on FASD Prevalence (CoFASP) is an initiative funded by the U.S. National Institute on Alcohol Abuse and Alcoholism (NIAAA) to establish the prevalence and characteristics of diagnoses of FASD in general populations of the United States (USA).

Methods: All first grade children enrolled in public/private schools in 3 regional communities of the USA were the subjects of this study (N=8737). For two years at each site, children who were provided consent to participate (56%) were screened for height, weight, and head circumference and some children were randomly-selected from school enrollment lists as candidates for normal controls. The small children and all randomly-selected children were given dysmorphology exams and neurobehavioral testing. Also, their mothers were interviewed about known maternal risk factors.

Results: This presentation will report physical traits of 1,350 children from regional populations who were typically-developing (controls, n=1220) and children with fetal alcohol syndrome (FAS, n=23), partial fetal alcohol syndrome (PFAS, n=61), or alcohol-related neurodevelopmental disorder (ARND, n=46). The traits discussed for controls as well as diagnosed children will be: growth and development, cardinal features of FASD, other dysmorphology and minor anomalies. Select maternal risk factors will include: alcohol use prior to and during pregnancy, drug use, socioeconomic status, and childbearing history. Drinking prior to conception correlates significantly with prenatal drinking ($r=0.251$, $p<.001$). Average week of pregnancy recognition is significantly later for mothers of children with FASD (7.6 vs. 5.5).

Conclusion: The traits of many children with FASD in the general population of the USA are different from those described in clinic-based studies.

[63] Introducing Objective 3D facial Analysis into the FASD Clinic Workflow

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Background: The facial gestalt of fetal alcohol syndrome (FAS) has long been established with diagnosis heavily reliant on the identification of the three cardinal features: a smooth philtrum, a thin upper lip, and narrow palpebral fissures. Currently, the screening software used to identify facial features associated with prenatal alcohol exposure uses 2D photographs and includes some elements of subjective assessment. Our previous studies using objective 3D facial analysis have shown accurate discrimination between individuals with FAS and controls and have also identified facial dysmorphism across the FASD spectrum. We aim to transfer these techniques into the FASD clinic workflow for direct use by the clinician.

Methods: Individuals referred to the UK National Foetal Alcohol Spectrum Disorders clinic, run by Dr Raja Mukherjee, were scanned using a handheld high-resolution 3D facial camera. For each individual, dense surface modelling analysis produced facial heat maps of normalised differences delineating facial dysmorphism, surface curvature analysis showing degree of philtrum smoothness, and discrimination test results showing the individual's placement relative to FAS and control means.

Results: Our 3D face screening software, *FaceScreen*, provides a set of tools for the objective assessment of facial dysmorphism. The software prototype generates reports summarising individual facial presentation using a selection of techniques. These techniques detect even the most subtle facial differences described as 'minor anomalies' in the literature.

Conclusion: Assessment of subtle facial features associated with prenatal alcohol exposure is often overlooked, and is particularly challenging when an individual lacks criteria for a FAS diagnosis. Our techniques provide a surface-based analysis of facial dysmorphia utilising the precision of 3D imaging. Emerging 3D camera technologies based on smartphone and tablet will reduce the cost and complexity of 3D imaging and hence provide a viable option for future placement in FASD clinics.

[64] Comparisons of the BRIEF Parental Report and Neuropsychological Clinical Tests of Executive Function in Fetal Alcohol Spectrum Disorders: Data from the UK National Specialist Clinic

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Background: Extant literature is sparse with regards to the relationship between caregiver reports and neuropsychological tests of executive functioning in Fetal Alcohol Spectrum Disorders (FASD). The goal of this paper was determining the clinical utilities of executive functioning measures used in the UK national FASD clinic. We examined relationships between outcomes on the Behaviour Rating Inventory of Executive Function (BRIEF) and the Delis-Kaplan Executive Function System (D-KEFS), as part of an ongoing service evaluation. Profiles of executive functioning measures were reported in order to contribute to delineating a profile of executive dysfunction in FASD.

Methods: Caregivers of 49 people with FASD completed the BRIEF, and 61 people with FASD were administered the D-KEFS. Outcomes were compared to normative means. Pearson's Correlations were also carried out between both measures.

Results: The BRIEF showed a profile of clinically significant elevations in all three Index scores and seven out of the eight Scale scores. Several D-KEFS tests showed below average executive functioning. Pearson's Correlations between all eleven BRIEF scales and the eighteen selected D-KEFS subscales showed little relationship.

Conclusion: Both executive function measures have separate clinical utility in demonstrating executive function deficits in FASD. The sample population used in this study also show a similar pattern to FASD populations internationally, suggesting a similar neuropsychological profile is seen in the UK. However, caregiver reports display little relationship to neuropsychological tests. These measures likely monitor different aspects of executive functioning in different settings. Future research should focus on identifying tests that better relate findings from clinical settings to that of real world behaviour.

[65] Neuropsychological Profiles in Scottish Children Affected by Prenatal Alcohol Exposure

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The Scottish Government-funded Fetal Alcohol Advisory and Support Team (FAAST), Rainbow House Community Paediatrics, Ayrshire Central Hospital, NHS Ayrshire and Arran, Irvine, Scotland.

Background: Children with prenatal alcohol exposure (PAE) may exhibit impaired neurodevelopment in multiple domains. Difficulties include borderline range cognitive ability, poor memory, impaired motor and language skills, and marked executive dysfunction (Kodituwakku, 2009). Further elucidation of the neuropsychological and functional profiles of affected individuals brings us closer to establishing a phenotype of FASD. This phenotype may inform efficient identification and assessment of affected individuals.

Methods: We extracted data for ~100 children assessed in relation to PAE by Ayrshire Child Health. This comprised assessment of eight brain domains: structure, cognition, motor/sensory function, language, memory, attention, executive function, adaptive function and social perception. Standardised assessment scores were converted to z-scores. Analysis was undertaken to i) determine relationships between domains ii) explore potential phenotypes characterising PAE iii) consider how, in future, this may inform assessment.

Results: Preliminary results indicate: 1) current sample typically scored 1-1.5 standard deviations (SD) below population norms in cognition, with 21% below -2SD - Intellectual Disability range. 2) Adaptive functioning was largely -2SD below the mean 3) Executive functioning was highly impaired and was significantly correlated with adaptive functioning (BADS-C $r=0.55$, $p=0.03$; BRIEF-2 Parent $r=0.76$, $p=0.0001$). Adaptive function did not correlate with cognition, however cognition and executive function are correlated (BADS-C only $r=0.53$, $p=0.02$). Further analysis will clarify these interactions.

Conclusion: Correlations between executive function and adaptive function in the context of low average cognition is indicative of a potential neuropsychological correlate within FASD. Our data will contribute to international samples to elucidate a potential neurodevelopmental phenotype of FASD, thus informing identification and assessment protocols.

[66] Paediatrician reported FASD in Australia: over-representation of children in out-of-home care and Indigenous children

Zimmet M ^{1,2}

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Background: Recent diagnostic patterns of Fetal Alcohol Spectrum Disorder (FASD) in Australia are unknown.

Methods: Prospective national surveillance (2014-2017). Paediatricians reported children (<15 years) diagnosed with FASD according to national diagnostic guidelines to the Australian Paediatric Surveillance Unit.

Results: 36 paediatricians reported 302 cases, of which 258 met diagnostic criteria. Most FASD cases (70%) were diagnosed by paediatricians at new specialist FASD clinics. Reporting rates doubled since the previous reporting period (2001-2004) with a similar ratio (1:3) of 3 versus less than 3 sentinel facial features (SFF). All cases had severe neurodevelopmental impairment most commonly in Language, Academic Achievement or Attention domains, with almost one quarter (23%) microcephalic. 67% of cases were male, 56% were Indigenous (compared to 3% of the general population), and 58% lived in out-of-home-care in contrast to 20% who lived with their birth parents.

Conclusions: Increasing FASD diagnoses by Australian paediatricians suggests better recognition of the spectrum, coinciding with new national guidelines and specialised diagnostic clinics. Yet FASD is likely underdiagnosed given high drinking rates in pregnancy rates (~60%). Our data highlights the challenges in identifying non-Indigenous children with FASD and those living with birth parents, indicating the need for ongoing clinician education. A national case register will enable epidemiological monitoring.

[67] Neuropsychological assessment of children with Fetal Alcohol Spectrum Disorders in Poland

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Background: In accordance with diagnostic guidelines of the Fetal Alcohol Spectrum Disorders – FASD (Cook et al., 2015), neurodevelopmental disorders caused by PAE may be recognized if severe dysfunctions are observed in at least three of the following areas: motor skills; neuroanatomy/neurophysiology; cognition; language; academic achievement; memory; attention; executive function (including impulse control and hyperactivity); affect regulation; adaptive behaviour, social skills or social communication. Each domain should be assessed separately, whenever possible – with the use of standardized tools. Authors define a severe impairment when the measure is ≥ 2 SDs below the mean.

Methods: Scoping review of neuropsychological assessment, that can be used in the FASD diagnosis in Poland.

Results: In Poland there is a variety of neuropsychological tools, that can be used in the FASD diagnose among children. The main problem which appears during the assessment process is the deficiency of the neuropsychological assessment standards. As a result, reliability and accuracy of FASD diagnosis remains questionable.

Conclusion: In general, adequate diagnosis and neuropsychological assessment of a child with FASD requires use of proper diagnostic methods. Specificity of disorders connected with prenatal exposure to alcohol is a great challenge in face of deficit of neuropsychological assessment standards for children in Poland.

[68] Raising and educating children with FASD

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Prenatal alcohol exposure causes brain damage. Curing FASD is still is not possible, so raising affected children is all about caring and dealing with the results of the prenatal exposure. Understanding the underlying cause helps us to adapt the environment for the child or adult with FASD and to give better care. Children and adults with FASD often find it difficult to understand what they should do, and may not be able to carry out tasks. However, environmental adaptations and good support can help. This workshop is about the environmental modifications which might help them achieve success. It's about looking for minor signs, having patience and giving them 'yes' instead of 'no' from a practice based point of view.

[69] On-site workshop: Visit to a Berlin diagnostic clinic: diagnostic approach in adults.

(Note that since this visit is off-site, it is at your own risk and any problems are not covered under the insurance of the conference center.)

Björn Kruse, Jessica Wagner

Background: In Germany as in other countries, many persons with FASD are not diagnosed in childhood. Due to their typical neuropsychological deficits, they experience many problems in everyday life. They would need to get specialized support on the basis of a sustained diagnosis. In Germany, there was no place for a specialized diagnostic approach for adults on a regular basis.

Methods: We established an FASD-outpatient-clinic for adults with and without mental retardation. Our approach includes

- differentiated neuropsychological examination
- medical examination, including
- photodiagnostic evaluation
- interdisciplinary case-conference
- detailed explanation of the diagnosis and its implications to the patient and his caregivers
- further supportive appointments
- therapeutic groups are in preparation

Results: We present our practical approach in an on-site workshop in the Evangelisches Krankenhaus Königin Elisabeth Herzberge. (The hospital can be reached by public transportation from the conference-site within 25 minutes.) Furthermore, we want to get into an interactive discussion about possibilities, limitations and future of making the diagnosis FASD in adults. A special focus will be the inclusion of persons with and without mental disabilities.

Conclusion: The aim of the workshop is to get into intensive exchange of experiences to further develop the diagnostic procedures in adults with suspected FASD.

[70] The German guideline for diagnosis of FASD and the knowledge of German health professionals and parents about FASD

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Background: The development and distribution of the German S3 guideline for the diagnosis of FASD was a major step to raise awareness about FASD among professionals in Germany.

The objective of our study was to evaluate the knowledge about FASD among different professionals in the health and social system and among parents with children with FASD in Germany.

Methods: A questionnaire with 20 items about FASD was sent by post to all children's hospitals (n=287), all hospitals for child and adolescent psychiatry (n=173), all social paediatric centres (n=162), all neuropaediatricians in private practice (n=129) and all youth welfare offices (n=672) in Germany. Furthermore a link to the questionnaire as online version was put in the member's newsletter by 14 relevant professional societies. Besides, the questionnaire was distributed personally to the attendees of the annual national FASD conference (n=363).

Results: Altogether 428 persons took part in the survey. 273 participants were professionals and 155 parents of children with FASD. More than 95% of the professionals and parents knew that alcohol consumption during pregnancy constitutes a risk for the child. The prevalence of maternal alcohol consumption and of FASD was underestimated. Approx. 70% of the professionals knew which disorders belong to FASD but only a small proportion of the professionals determined the correct characteristics of the different FASD. Most professionals had difficulty choosing effective components of intervention for children with FASD. Regarding the long-term outcome professionals were also very insecure.

Conclusion: Professionals in the German health and social system are aware of FASD but underestimate the level of damage and the negative impact on every day functioning of the affected patients.

[71] Lessons Learned: the development of a model of an online FASD Training project

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Background: Douglas College, with funding provided by the Victoria Foundation developed an on-line training program to provide province wide FASD Training in British Columbia, Canada. Douglas College staff, headed by Marsha Wilson, consulted with experienced leaders in the fields of FASD, disability management, curriculum design as well as with individuals with FASD and caregivers, to develop on-line training modules covering aspects of FASD throughout the lifespan. Modules included: FASD Fundamentals, Primary and Secondary Disabilities, Strategies and Solutions, Family Matters, and Circles of Strength. An additional module, developed by Marsha and an individual with FASD, focused on FASD across the Lifespan. The Family Matters modules also contained a face to face workshop component. Currently community based workshops are being developed on the Impact of FASD on indigenous communities in Canada and world-wide.

Results: Access to the training program was provided to 253 family members and front line workers from various sectors. Seventy-four per cent of the 184 participants completing a course evaluation, rated the training as exceeding their expectations. Ninety-seven per cent felt they gained knowledge about FASD even though 87% of the participants were experienced FASD front line staff. Many participants indicated that following the training, they would take a different approach in their practice of working with self-advocates and families living with FASD.

Conclusion: Overall evaluation of the on-line training was positive. Current approaches are being developed to enhance cultural sensitivity in the training. Upon review, a number of lessons were learned about the development of online curricula. These lessons will be the focus of this presentation.

[72] Service Evaluation of the Fetal Alcohol Assessment and Support Team in NHS Ayrshire and Arran, Scotland.

Fiona McGruer & Jennifer Shields

Scottish Government-funded Fetal Alcohol Advisory and Support Team (FAAST), Rainbow House Community Paediatrics, Ayrshire Central Hospital, NHS Ayrshire and Arran, Irvine, Scotland.

Background: There is a critical need to develop FASD assessment and support services in Scotland given an estimated UK prevalence of 2-6% (Popova et al, 2017; Lange et al, 2017). From 2015 - 2018, the FAAS Team piloted an assessment, diagnosis, and support pathway for children affected by prenatal alcohol exposure; based upon the Canadian model (Cook et al, 2016).

Methods: We utilised the trident method to evaluate the FAAS Team process, outcomes and stakeholder perspectives (Ellis & Hoggard, 2006): 1) Process i) analysis of inputs provided by FAAST versus treatment as usual (TAU), 2) Outcomes i) administered a pre/post questionnaire battery measuring quality of life, mood and behaviours ii) recorded supports provided to children & families, 3) Perspectives i) undertook qualitative interviews with carers and educational professionals ii) administered questionnaires to carers and professionals. In addition we recorded training delivered using pre/post questionnaires to measure training impact.

Results: The pilot provided input to ~180 children. (1) Process: NHS Ayrshire & Arran is the first Scottish health board to implement FASD assessment within CAMHS/Community Paediatrics via multidisciplinary assessments and interventions with education and social care colleagues. (2) Outcomes: Quality of life, mood and behaviour did not change during assessment processes, however all cases were enabled to access education and community input. (3) Perspectives: themes from qualitative interviews indicated parents “finally felt heard” & professionals understood the needs of the child. Ongoing strategies were highlighted as an area of need. Training was delivered to over 5000 individuals across Scotland.

Conclusion: The FAAST process led to implementation of FASD assessment in TAU settings. The trident approach yielded information on necessary components of the assessment process, expected outcomes, and inputs required to support children and families affected by FASD in Scotland.

[73] FASD Hub Australia: a novel resource for clinicians, caregivers, researchers and policy-makers

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Background: Historically, on-line information focussing on different aspects of FASD was available on Australian websites, but it was a challenge to find current, reliable, locally relevant information. Our aim was to develop a 'one-stop shop' for information, resources, tools, services, research and publications about FASD in Australia.

Methods: To identify information needs and ideas for FASD Hub content, face-to-face and telephone interviews were conducted with Australian health and other professionals, parents and carers, researchers, government, and policy makers. This informed the development of key user journeys, functional design and content. Content (text, video, interactive) was developed by the Project Team with advice from the FASD Hub Working Group and key stakeholders. Following the launch of the FASD Hub an online survey evaluation was conducted and email feedback and web analytics collected.

Results: The FASD Hub was launched on 9 September 2017. It hosts information about education and training opportunities; news; Australian research, resources and publications; links to support groups and a clinical services directory. The majority of responses to the online survey (n=49) were from health professionals (54%) and parents/carers (33%). Most respondents found that the site was easy or very easy to use, met their needs very well or extremely well, and was trustworthy and evidence-based. Participants provided positive feedback and suggestions for additional content. The website was accessed by 90 people per day, 24% of users accessed the site from a mobile or tablet device, and 28% were repeat users.

Conclusion: The national FASD Hub, the first of its kind internationally, offers improved access to high quality information and resources in one central location and will increase awareness and responsiveness to the needs of people living with FASD and enable the national dissemination of tools, resources and information to a range of stakeholders.

[74] The evolution, priorities and highlights of the latest FASD research in Canada

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Background:

Recent epidemiological studies estimate prevalence rates as high as 2-5%, suggesting that FASD is a public health problem of epidemic proportion and translating into over a minimum of 350,000 affected individuals in Canada. It has also been estimated that the total cost of FASD to Canada is \$4B/year.

National agreement on themes and priorities is essential to direct resources, to catalyze research efforts and partnerships and to provide key information to policy-makers, program delivery and best practice development that will lead to research support that will ultimately improve outcomes of those affected by FASD. Because of the engagement of stakeholder/partner organizations, stakeholder/partner-initiated “spin-off” projects followed, including development of evidence-based Clinical Practice Guidelines, online educational programming, and creation of a Prevention Framework. Research Leads of the Canada FASD Research Network are sharing new and emerging policy-relevant research findings in diagnosis, prevention, and intervention.

Methods: In 2002 and again in 2012, two National multi-disciplinary workshops of experts were held in Canada to take stock of the FASD-related research landscape, with the goal to gain consensus on multi- and cross-disciplinary FASD research priorities. Each workshop hosted 75 participants. Thematic-based discussions included basic science, prevention, diagnostics, intervention and prevalence, with Indigenous Health, gender and ethics crossing all themes. Gaps and research priorities were identified, strengths and weaknesses of the Canadian FASD research field were discussed and opportunities for new and innovative research were explored. In collaboration with regional, provincial and national partners, the Canada FASD Research Network has expanded, aligned and evolved its focus to address Canada’s research priorities in the FASD field.

Thematic properties were not different over the 10 year period; Screening and Diagnosis, Interventions, Treatment, Prevention, Development of Best Practices, Biomarkers, prevalence.

Canadian capacity for biomedical, clinical and population research focused on FASD has increased and knowledge translation in the field has significantly expanded.

Conclusion: This information formed the foundation of a National FASD Research Agenda that set evidence-based priorities to improve FASD-related outcomes and catalyzed research in areas that are important to Canadians. Research results provide the basis for the development of effective treatment and management for FASD as well as to induce effective program and policy development.

[75] How to inform policy- and decision-makers about evidence-based alcohol policy

Matej Košir

Institute Utrip, Slovenia

Background: Advocacy skills are essential for the public health researchers and practitioners to potentially influence policy- and decision-making processes for better health-related policies. Those skills are important especially in those public health areas where so-called “unhealthy” industries are influential and/or (at least) want to be important stakeholders in the field (such as alcohol and tobacco industry).

Methods: Recognizing this need, Institute Utrip developed a series of advocacy trainings, especially for researchers and practitioners in the field of alcohol and tobacco policy. . The workshop provides a template for researchers and practitioners to build advocacy skills and increase the role of public health professionals in setting evidence-based alcohol policy.

Results: Outcomes include an increased competence for such advocacy as forging stronger relationships with policy- and decision-makers and other key stakeholders in the field, advocating for the use of research to inform policy- and decision-makers about evidence-based policies, providing expert testimony, writing position papers, press releases and social media posts, and committing to ongoing advocacy

Conclusion: Researchers and practitioners need to become more relevant to policy- and decision-makers, and a workshop focuses on that aim.

Structure of the workshop:

- ⇒ Short introduction of the workshop
- ⇒ Advocacy for evidence-based alcohol policy: definitions, aims & objectives
- ⇒ Coalition building / developing effective coalitions
- ⇒ Making the case for evidence-based alcohol policy with media advocacy
- ⇒ How to organize advocacy course / workshop (to spread the knowledge and skills to other potential advocates)
- ⇒ Developing effective advocacy plan (group work)
- ⇒ Questions and discussion

[76] Interactive Dynamic Assessment: A longitudinal study of a diagnostic and mediation tool for school-age learners with FASD

Linda Wason-Ellam

University of Saskatchewan, Saskatoon, Canada

Background: There is a sizable body of research on how children learn to read and write. However, the development of these skills and assessments that are predecessors to conventional reading and writing abilities for FASD readers remain absent. Struggling readers with an existing diagnosis of FASD often lack the implicit processes and tacit knowledge that underpins reading. The objectives of this longitudinal study were as follows: **1.** To design a dynamic assessment model applied during learning, which identifies specific cognitive problems underlying language and reading skills for readers with FASD. **2.** To identify interactive multimodal strategies (drawing, photography, digital images, concept mapping, or storyboards) with graduated prompts that are developmentally appropriate and brain compatible. **3.** To focus learners' attention, maximize working memory, foster meaningful connections with prior schema, which enhance connections in neural networks.

Methods: **1.** To track 54 struggling readers with FASD, grades 2 to 4 over a ten-year period. **2.** To present dynamic assessment as a diagnostic tool that measures thinking, visualizing, predicting, meaning-making, and problem solving as an active teaching tool aimed at modifying cognitive functioning.

Results: **1.** Visual mediational strategies used within the dynamic assessment study were closely related to successful academic and social learning processes in school and to other life contexts. **2.** The qualitative measuring of diagnostic and formative information for higher order thinking skills, and deficient cognitive functions that are responsible for literacy learning difficulties were implemented.

Conclusion: Introducing visual strategies that facilitate learning through reading or writing tasks were effective in providing "an explicit record of learning" as readers and writers with FASD used memory pegs for specific functions within literacy tasks.

[77] Is Iron Deficiency hindering Precision Medicine in Individuals with FASD?

James Connor¹, Alison Frieling², Osman Ipsiroglu³ Karen Spruyt⁴, Dorothee Veer⁵
(all authors will be presenting and are members of the International Iron Conundrum Research Consortium)

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² *FASD Deutschland e. V.*

³ *H-Behaviour Research Lab, BC Children's Hospital Research Institute, Department of Pediatrics, University of British Columbia, Vancouver, Canada*

⁴ *Laboratoire de Physiologie intégrée du système d'éveil CRNL □ INSERM U1028 □ CNRS UMR 5292, Université Claude Bernard Lyon 1, Hospices civils de Lyon, France*

⁵ *Neuropädiatrie, Sozial-Pädiatrische Ambulanz- und Therapie Zentrum, SPATZ; Mep-pen, Germany*

Background: Iron deficiency (ID) is prevalent in both developed and developing countries. Low socioeconomic status is a major risk factor for having ID, particularly when children have neurodevelopmental/-psychiatric conditions (e.g. FASD). ID affects brain development, aggravates disruptive behaviours inherent to these conditions, and interacts with the effects of psychotropic drugs. We have started to decode disruptive behaviours according to characteristic movement patterns and behaviours observed in these children using video recordings. Analysis of these 'H-Behaviours' (hyperactivity / hyper-/hypoarousability in the wake state, hyper-motor-restlessness in the sleep state) can potentially be used as a biomarker to indicate response to iron supplementation and psychotropic drugs and personalize medicine.

Objectives: To review (1) associations of ID/metabolism with the pathophysiology of FASD genesis; (2) ID-scoping review results and H-Behaviour presentations; (3) challenges in clinical practice from the perspectives of families and clinicians, and introduce (4) the methodology of the proposed EU - Precision Medicine Study, which will focus on effects of iron supplementation.

Outline of parallel session: *Format:* Symposium with a panel discussion. *Contributions:* (1) Dr. James Connor will present cellular/molecular mechanisms by which cells regulate their iron status and how alcohol intake during pregnancy can lead to iron mismanagement in the brain of the fetus and offspring. (2) Dr. Osman Ipsiroglu will present results of scoping literature reviews on the associations of ID and FASD, and show video examples of H-behaviours. (3) Ms. Alison Frieling and Dr. Dorothee Veer will present challenges experienced by families and clinicians, which hinder Precision Medicine. (4) Dr. Karen Spruyt will present the **participatory research methodology** of the proposed EU-Canada grant with a focus on the concept of **n=1 studies**, which will support the **Precision Medicine** model our Iron Conundrum Research Consortium proposes.

[78] A Strengths-Based Research and Interventions: Workshop & Discussion of Community and Family Resources

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¹University of Regina and Canada FASD Research Network, CANADA

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³FASD Network of Saskatchewan, CANADA

Background: Recent research indicates that individuals with FASD have an average life expectancy of 34 years with a leading cause of death being suicide. Concurrently, Fetal Alcohol Spectrum Disorder, unlike many other disabilities, has a tangible absence of strengths-based approaches to understanding and studying the disability and experiences of those who have FASD. This project was conceived to specifically identify strengths-based approaches to the disability and lead to a project that can help address social isolation and loneliness. Developed in 2015, the project started with the premise that people with disabilities like FASD are experts, and can hold the artistic and imaginative potential necessary in improvisation such as: impulse, imaginative narrative, and spontaneity. This session will include a discussion of the background and findings of the project along with a sample workshop to demonstrate the games in practice.

Methods: The project was developed in collaboration with individuals that have disabilities, their support networks (including caregivers, mentors and support staff), researchers, socially-engaged artists, music therapists, Indigenous knowledge keepers and educators, and community organizations. This a community-driven, participatory research project that allowed for this consultation process to inform key areas for investigation and exploration. Following this consultation process, a pilot study was designed and launched in 2016 in two settings (a clinical site and a community agency). The pilot study ran in 2016 and demonstrated a clear potential to positively impact participants. Support staff from service delivering organizations also participated in and benefited from the project. The benefit to workers was an unintentional outcome but cross-beneficial in that this is a high-turnover industry and serving individuals benefit greatly from continuity in who delivers their care and supports. Following the pilot study, a new series of workshops were hosted to test the capacity for transferability between settings in Winter 2017.

Results: The project has demonstrated preliminary findings in the areas of: sleep, relaxation, trauma and social isolation. Concurrently, the workshop is also understood to be a community-driven resource that is opening up opportunities to better understand/gain new understandings about FASD through improvisational play. The toolkits developed, and the workshops, are low-barrier resources to counter social isolation and to draw on the strengths individuals have. Outcomes have included the distribution of the

tool and outreach to four countries and use in multiple settings. In addition to the community resource, a family resource used for foster parent training has been developed and both a school-based toolkit and a family resiliency toolkit are currently in development.

Conclusion: This project has become the backbone of a longer-term project focused on community-driven research working in direct collaboration with families and individuals impacted by FASD. Given the outcomes from pilot and feasibility phases, a series of resources were developed and released to help address social isolation and misunderstandings surrounding the disability. Concurrently, individuals with FASD have been involved at all stages from project design to facilitating workshops.

[79] Improving the management of young people with Fetal Alcohol Spectrum Disorder in an Australian detention centre

Hayley M Passmore^{1,2}, Raewyn C Mutch^{1,2,3}, Sharyn Burns⁴, Jonathan Carapetis¹, Guy Hall⁵ and Carol Bower¹

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Background: Health and justice professionals across Australia are urging for an increase in services to better support young people with fetal alcohol spectrum disorder (FASD) involved with the justice system. Knowledge of FASD among young people sentenced to a period of detention is increasing, with a prevalence study ascertaining that 36% of young people sentenced to detention have FASD, and 89% are severely impaired in at least one area of neurodevelopmental function. However, to date there has been no investigation into the capacity of custodial staff to identify and manage young people in Australian detention centres with FASD or similar impairments, nor has there been published interventions aiming to develop environments appropriate for those with FASD in detention.

Methods: The current knowledge, attitudes, experiences and practices relating to FASD and neurodevelopmental impairments among the custodial workforce at the only youth detention centre in Western Australia were determined using mixed methods. This data informed the development and evaluation of training resources (a series of short, educational videos) aiming to upskill the custodial workforce in the management strategies most appropriate for young people in detention with such impairments.

Results: A lack of specific knowledge, inadequate training, and inconsistent information-sharing processes have previously reduced the ability of the custodial workforce to care for youth with FASD and other neurodevelopmental impairments. The training resources were influential in increasing staff knowledge and awareness of impairments, and their receptiveness to adapting management strategies according to the needs of young people in their care.

Conclusion: Given the high rates of impairment among young people in detention in Australia, all staff involved in the care of detained young people should receive comprehensive training about neurodevelopmental impairments and appropriate management strategies.

[80] The impact of traumatic childhood experiences on cognitive and behavioural functioning in children with prenatal alcohol exposure (PAE)

Alan Price¹, Penny Cook¹, Sarah Norgate¹, Raja Mukherjee²

¹ *School of Health Sciences, University of Salford, United Kingdom*

² *Surrey and Borders NHS Trust, United Kingdom*

Background: The cognitive and behavioural functioning of children with PAE or trauma, including abuse and neglect, can be similar in presentation. Since a high number of children with PAE also have a history of trauma, it is necessary to separate the effects of each exposure, to understand how the two exposures can interact, and to predict the developmental trajectory of children with both exposures.

Methods: An online survey was distributed via social media and completed by the carers of 245 children with PAE, mostly from the USA, UK and Canada. The survey assessed trauma, empathy, behavioural difficulties, and comorbid conditions. Separately, a lab study at the University of Salford compared intelligence, executive functioning and brain activity between a group of children with PAE and trauma, PAE only, and typically developing controls.

Results: Children with PAE had high levels of trauma and comorbid conditions, low empathy, and high levels of behavioural difficulties. There was a weak positive relationship between trauma and behavioural difficulties, and no relationship between trauma and empathy. Children with PAE had IQs in the normal range and there was no significant impact of trauma.

Conclusion: As expected, there appears to be greater harm associated with dual exposure compared with PAE alone, but differences may be relatively subtle. It may be the case that PAE is more damaging to development than trauma, but larger studies and prospective cohorts are required to properly assess this. More confidence can be attached to the conclusion that PAE causes cognitive and behavioural deficits independently of trauma.

[81] Prenatal alcohol exposure and its relation to intelligence, executive functions, and antisocial and prosocial outcomes

Elizabeth Carlson¹, Aamena Kapasi¹, Jacqueline Pei¹, Tara Anderson², Mansifeld Mela²

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Background: Prenatal alcohol exposure is related to deficits in both intelligence and executive functioning. Less is known about the development pathway of these deficits, and the subsequent trajectory toward antisocial and prosocial behaviours. The objective of this study is to explore the relation between prenatal alcohol exposure and cognitive functions in the prediction of antisocial and prosocial behaviours.

Methods: Data from the prospective Avon Longitudinal Study of Parents & Children (ALSPAC; N = 15,445 live births) will be analyzed. Cognitive data from 7354 of these children was collected. Questionnaires were administered to the mothers throughout their pregnancies to examine a variety of factors including prenatal alcohol use. Children's cognitive functions (including intelligence and executive functions), and prosocial and antisocial behaviours were assessed from ages 8-15.

Results: Structural equation modeling will be used to examine how prenatal alcohol exposure (timing and amount) relates to the development of intelligence and executive functions, and whether intelligence mediates the development of executive functions in the prediction of antisocial and prosocial behaviours. Findings will be discussed.

Conclusion: Results from animal studies support the connection between prenatal alcohol exposure and neurodevelopmental disruptions; however, ethical considerations prohibit experimental exploration of this relation within humans. We must be tentative in our interpretation of findings from retrospective research used to explore the relation between prenatal alcohol exposure and neurodevelopmental disruptions due to considerations such as recall bias. Prospective longitudinal data such as those explored here, provide us with the best opportunity for understanding developmental trajectories for children exposed to alcohol in utero.

[82] Polysubstance abuse and its impact on FASD diagnosis and outcomes: Data from the UK National Specialist FASD clinic

Raja Mukherjee, Zameer Mohamed, Alex Carlisle, Alex Livesey

National Specialist FASD Clinic, Surrey & Borders NHS Foundation Partnership Trust, Surrey, UK

Background: Previous literature has suggested a link between alcohol use and additional use of various substances. However, research is scarce in considering the complexities and differences in aetiologies between children exposed to prenatal alcohol abuse alone, and those exposed to effects of prenatal polysubstance abuse. The goal of this study was to delineate as far as possible the effects of polysubstance abuse, in a UK cohort of children with Fetal Alcohol Spectrum Disorders (FASD).

Methods: Data was analysed for 91 cases of FASD seen in the UK national specialist clinic (52.7% Male, 47.3% Female, mean age = 11 years). Children with FASD were differentiated into groups by either having prenatal alcohol exposure only (PAO), or additional prenatal polysubstance abuse (PPA). ANOVA was conducted to explore any group differences on scores on the Weschler Intelligence Scale for Children (WISC), Short Sensory Profile (SSP), and the Developmental Behaviour Checklist (DBC).

Results: Initial exploratory analysis revealed that the PAO group had significantly lower (thus more impaired) mean scores on the Verbal Comprehension Index and specific subtests on the Working Memory Index of the WISC. However, the PPA group show more sensory difficulty. Additional analysis will be completed to consider any further neurodevelopmental differences between groups.

Conclusion: Preliminary results indicate some aetiological differences between PAO children and PPA children. Children in the PAO group may have specific areas of cognitive weakness compared to the PPA group, namely in Verbal Comprehension and in aspects of Working Memory. The PPA group may have more difficulty with aspects of sensory processing. More analysis will be conducted to try to further delineate the effect of different prenatal drugs in addition to alcohol on children. Clinical outcomes and explanations are considered in relation to behaviour, mental health, educational and social development of children with FASD.

[83] Parent, Carer and Professionals' Perspectives on FASD Services in Scotland

Fiona McGruer and Jennifer Shields

The Scottish Government-funded Fetal Alcohol Advisory and Support Team (FAAST), Rainbow House Community Paediatrics, Ayrshire Central Hospital, NHS Ayrshire and Arran, Irvine, Scotland.

Background: Parent & carer involvement is a crucial element of the design and delivery of FASD services. Previous qualitative work, which elucidated experiences of parenting a child affected by prenatal alcohol exposure (e.g. Watson et al., 2013; Michaud & Temple, 2013) touched upon barriers to accessing assessment. In the current context of emerging care pathways for FASD in Scotland, and as part of the FAAST service evaluation, we aimed to gather multiple perspectives in respect to FASD assessment services.

Methods: We recruited parents, carers and professionals of children who accessed assessment by the FAAS Team and offered the opportunity to participate in semi-structured interviews. Participants were asked broad questions regarding the process of accessing assessment, assessment process, feedback and resulting outcomes of this. Questioning focused on the individuals' lived experiences and reflections. Interview recordings were transcribed verbatim and analysed using Interpretative Phenomenological Analysis (IPA).

Results: This qualitative method ascertained parent, carers and professionals' experiences of the pilot service, perceptions of FASD diagnosis and of accessing FASD support services in Scotland. Thus far, this dataset represents views of biological parents (of both sexes), adoptive parents, kinship carers, foster carers and professionals. Emergent themes include: (1) The 'fight' to be heard and access services in Scotland, (2) the experience of being heard in the pilot service, (3) stigmatisation of the parent/carer and child by the diagnosis & (4) protection of the parent/carer and the child by the diagnosis.

Conclusion: The design and delivery of future services should be strongly informed by the experiences of all stakeholders, particularly parents and carers. We must be mindful of the challenges in accessing FASD services & the impact of this in Scotland. Further research is required in regards to positive and negative impacts of the diagnosis.

[84] FASD and the 12 steps for Birth Mothers

Elizabeth [Anne] Russell

Russell Family Fetal Alcohol Disorders Association Australia

Background: Over the years Anne has analysed very closely what steps helped her come through the difficult times. She condensed and clarified them and turned them into steps much like the 12 Steps of AA. It has been said that a diagnosis of FASD is a diagnosis for two, yet birth mothers do not often receive the support they need to overcome their guilt and shame. They face guilt, remorse and often misunderstanding from others serving to intensify their negative feelings. Stigma is a persistent scourge in the life of every birth mother.

Methods: These 12 Steps have been used in Australia in a pilot program as the established guidelines for a face to face support group for birth mothers. Similar to AA, each member talks about whatever they feel is important to them at the time. The meetings are fortnightly and do not replace counselling.

Results: The 12 Steps for Birth Mothers, have been used in the birth mothers group for the last 4 months. They have been embraced by the 5 mothers in the group and are in front of each member during the support group meeting. The 5 mothers are at different stages in their acceptance. The participants of this group have agreed that_ that the negative feelings have alleviated somewhat, and they generally feel less concerned about what other people may think and more inclined to pass on their knowledge, experience, strength, and hope.

Conclusion: Birth mothers need to have support after diagnosis. Counselling is important; however it may be that some women need to have the support of other birth mothers in the same way that alcoholics need the support of other alcoholics in AA.

[85] Experiences of adoptive parents of children with FASD and a history of traumatic experiences in the UK

Alan Price¹, Penny Cook¹, Sarah Norgate¹, Raja Mukherjee²

¹ *School of Health Sciences, University of Salford, United Kingdom*

² *Surrey and Borders NHS Trust, United Kingdom*

Background: Children with FASD or a history of traumatic experiences including neglect and abuse can be challenging to care for, due to their social, emotional, and behavioural difficulties. Dealing with these problems can cause high levels of stress, and potentially affect siblings and extended family as well as parents. This qualitative study sought to investigate the impact on families of behavioural difficulties in children with FASD and trauma.

Methods: 12 semi-structured interviews were conducted with adoptive parents of children with FASD. Questions focused on behavioural, emotional and social difficulties, issues at school, and daily living experiences. Participants had taken part in a previous study, where history of trauma was assessed. Roughly half of the participants' children had a history of trauma.

Results: Participants described a range of behavioural, social and emotional difficulties. Having extended family members, such as grown-up children, who could babysit was reported to be helpful. Participants reported wanting an education health and care plan (EHCP) for their child, but accessing this service was difficult. Despite the study aim to investigate behavioural problems, participants spent more time describing the stress caused by a lack of awareness, support and services for FASD. Participants felt frustrated at having to fight for support, and having to educate professionals about FASD.

Conclusion: This study was designed to investigate the impact of children's behavioural difficulties on their adoptive parents. Behaviour in children with FASD and trauma is challenging, but the lack of understanding and support available appears to be the most substantial issue faced by parents in the UK.

[86] Coaching Manual - A Guide for Caregivers of People Affected by FASD

Heike Hoff-Emden

Social Pediatric Centre (SPZ) Leipzig, Germany

Background: Challenging behaviours cause stress for individuals with FASD and their caregivers. During anamnesis foster/adoptive parents identified the social environment as a major external stressor. Negative experiences/reactions were mainly attributed to the lack of knowledge about FASD. As a result, a parent group was established for coaching.

Methods: Coaching sessions led by an FASD expert. Topics included: Basic facts about FASD; practical advice to manage challenging behaviours; home/school/job situations; advice on aspects of social law; stress reduction, identifying resources and coming to terms with FASD. Stress levels were lowered; parents developed a more positive attitude towards children affected by FASD. Knowledge, results and ideas were compiled in a coaching manual.

Results: The manual is multidimensional, aimed at professionals who train caregivers of individuals affected by FASD. The topics are basic knowledge about FASD; viewpoints of individuals and their caregivers affected by FASD; identifying causes of primary stress and understanding specific patterns of behaviour; how to identify resources and encourage caregivers to accept help/support; creating a lifelong support programme or a **5 digit code for life**.

1-Medical check-ups to identify physical abnormalities and co-morbid conditions; 2-Neuro psycho-logical diagnostics/check for trauma-related problems/test and evaluate social behaviour; 3-Co-ordinate treatment/forms of therapy; 4-Determine the level of social participation or isolation/work to improve it; 5-Create a network for life.

Conclusions: Parental coaching can be seen as the key to stress reduction **for everyone involved:** parents/caregivers, those affected by FASD and the social environment. The manual is a tool for professionals. It is imperative that families raising children with FASD register with a specialist FASD centre. **The Federal Drug Commissioner has provided funding for this project and the manual is now available free.**

[87] Workshop prevention campaigns for Fetal Alcohol Spectrum Disorders (FASD).

Gerjo Kok^{1,2}, Sylvia Roozen^{1,2}

¹ *Governor Kremers Centre, Maastricht University Medical Centre+, The Netherlands*

² *Department of Work and Social Psychology, Maastricht University, The Netherlands*

Discussion Leaders: Gerjo Kok & Sylvia Roozen

Workshop Purpose: The aim of this workshop is to provide participants with evidence-based insights and tools for systematic development of effective interventions related to alcohol consumption during pregnancy and FASD prevention. In addition, awareness for the various sources of alcohol related messages and the commercial aspects of campaigns will be discussed.

Workshop Activities: The development of effective prevention campaigns is not easy and the complexity is often overlooked. Program planners often do not use a systematic approach and choose methods intuitively versus derived from evidence. For example, scary pictures are often used in health promotion to discourage unhealthy behavior. These so-called "fear appeals" to discourage behaviors such as drinking during pregnancy, are ineffective. A better approach is to send out positive messages that deliver new and valid arguments, increase social support and improve people's skills. In order to do so, program planners benefit from using a planning strategy or framework such as Intervention Mapping. A brief description of Intervention Mapping will be discussed, including practical applications to secure effectiveness.

Necessitates: All participants are invited to bring along their prevention campaign materials (e.g. posters) which are used in their own institute or country.

Speaker information



Dr. Miguel del Campo is a medical geneticist at Rady Children's Hospital-San Diego and an associate professor at UC San Diego.

After graduating from the Universidad Complutense de Madrid in Spain, Dr. del Campo went on to complete additional training at the Hospital Universitario La Paz and the Universidad Autonoma de Madrid. He followed this training with a fellowship in genetics and dysmorphology at the University of California San Diego, a Ph.D. in pediatrics from the Universidad Autonoma de Madrid, and postdoctoral training at the Salk Institute for Biological Studies.

ical Studies.

Dr. del Campo cares for patients with dysmorphologic, genetic, and teratologic conditions and his current research interests include: Fetal Alcohol Syndrome (FAS), limb defects and HOX signaling pathways, Williams syndrome, autism, prenatal diagnosis through comparative genomic hybridization, and Marfan syndrome and other connective tissue disorders. Additionally, he actively participates in various national and international organizations as well as support groups for parents with children with genetic disorders and FAS disorders.



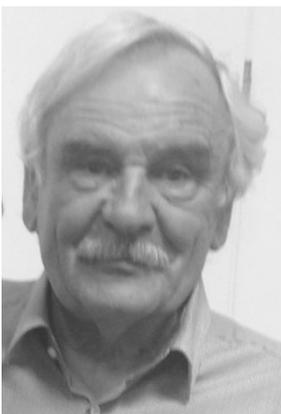
Dr. Michael S. Kobor is a Professor in the Department of Medical Genetics at the University of British Columbia (UBC). Dr. Kobor has received many distinctions, including a Tier 1 Canada Research Chair in Social Epigenetics, the Sunny Hill BC Leadership Chair in Child Development, and an appointment as Senior Fellow of the Canadian Institute for Advanced Research (CIFAR) Child and Brain Development Program. A champion for translational research, he serves as the Lead for the “Healthy Starts” Theme at BC Children’s Hospital.

Dr. Kobor’s own research is focused on illuminating the mechanisms by which early life environments get “under the skin” to affect health and behaviour across the lifespan.



Edward P. Riley received his Ph.D. in Psychology in 1974 from Tulane University and did a postdoctoral fellowship at the Center for Alcohol Studies, Rutgers University. He is currently a Distinguished Professor of Psychology and the Emeritus Director of the Center for Behavioral Teratology at San Diego State University. He has authored close to 300 scientific papers and reviews, primarily on the effects of prenatal alcohol exposure. He served as Chair of the U.S. National Task Force on FAS/FAE from 2000-2004 at the request of the U.S. Secretary of Health.

He is a Past-President of the Research Society on Alcohol (RSA), the Fetal Alcohol Study Group of the RSA, the Behavioral Teratology Society, and the International Society for Biomedical Research on Alcoholism. He has served as a member of the U.S. National Institute on Alcohol Abuse and Alcoholism Council and as a member of the Behavioral and Social Advisory Council of the ABMRF/The Foundation for Alcohol Research. He served on the Expert Panel for the U.S. Substance Abuse and Mental Health Service Administration's FASD Center for Excellence and previously served as Chair of this advisory group. He has received numerous awards for his scholarship and contributions to the alcohol field, including the RSA Distinguished Researcher Award, the National Organization on Fetal Alcohol Syndrome Research Recognition Award, and most recently the Frank Seixas Award from the RSA. His work on FASD has been funded continually since 1978 by the National Institute on Alcohol Abuse and Alcoholism. He currently directs the Collaborative Initiative on FASD, an international, multisite consortium funded by NIAAA.



Prof. Dr. Hans-Ludwig Spohr. The pediatrician and neuropsychiatrist Prof. Spohr was the director of the children's hospital of the DRK Kliniken Westend until 2005. In 2009 the 'FASD-Zentrum' at the Charité – Universitätsmedizin Berlin was founded with the support of the 'Foundation for Disabled Children.'



Dr. Kenneth R. Warren has been associated with the field of birth defects for 46 years and in the areas of FAS and FASD for 44 years. At the National Institute on Alcohol Abuse and Alcoholism (NIAAA), Dr. Warren initiated the programs supporting research on prenatal alcohol exposure (PAE) shortly after the initial reports on the existence of the fetal alcohol syndrome (FAS) were published from France and the United States. He organized the first international conference on FAS which was held in February 1977. The recommendations emerging from that conference led to the issuance of the first health advisory on drinking in pregnancy that was issued by the U.S. federal government on June 1, 1977, the first such advisory anywhere in the world. Dr. Warren was a contributing writer and the editor of the internal report that was required to seek approval for the issuance of the advisory, and he authored the advisory's language. Given the state of the knowledge existing at that time, this advisory was restrained in its approach: advising against heavy drinking in pregnancy and recommending consumption at no more than 2 U.S. standard 14 gram drinks per day. With more emerging research and a Congressional recommendation for an updated advisory, Dr. Warren prepared background materials and language for the 1981 U.S. Surgeon General's Advisory on Alcohol and Pregnancy which stated that the most prudent course was to avoid alcohol when pregnant or seeking pregnancy. Dr. Warren continued to lead and contribute to the FAS and FASD field throughout his NIAAA career, which ended in June 2018. Academically, Dr. Warren received a Ph.D. in Biochemistry from Michigan State University in 1970 and undertook postdoctoral studies at UCLA and the University of Michigan (the latter in lipid biochemistry and birth defects). Administratively, among the many positions Dr. Warren has held in NIAAA, most notable are serving as the Director of the Office of Scientific Affairs from 1984 to 2006; serving as Executive Secretary of the National Advisory Council on Alcohol Abuse and Alcoholism during those same years; serving as NIAAA Deputy Director from 2008 to November 1, 2015; and as Acting Director 2008-January 2014.



Dianne Wesselink,

Health Psychologist for Children and Adults in Gelre Hospitals, Location Zutphen, the Netherlands

Dianne Wesselink studied pedagogy at Utrecht University till 1995. After several jobs in mental healthcare, in 2001 she received her Dutch BIG registration as a Healthcare Psychologist for Children and Adults and started working for the Gelre Hospitals, Location Zutphen, in the east of The Netherlands. In 2006 together with Rudi Kohl, pediatrician, she founded the FAS clinic in this hospital. From all over the country children and their caretakers come for diagnosis of Fetal Alcohol Syndrome. Meanwhile they also diagnose adults with FASD.

In 2013 Dianne took a short sidestep to another employer: Autimaat, an institution for autism assistance and care. In 2014 she went back to her former employer Gelre Hospitals and is still working here as a child psychologist for both the clinic, outpatient clinic and FAS clinic. Her work consists of diagnosis and treatment of children and young adults with inter alia somatic unknown complaints, chronic diseases, anxiety for medical operations and trauma as well as FAS patients.

Dianne has been trained in EMDR, Cognitive Behavioral Therapy, Sensorimotor Psychotherapie and Hypnosis.

Dianne lives in her birth region The Achterhoek in the east of the Netherlands together with her partner and two teenage daughters, a cat and three ponies.

Posters

General Poster Viewing Monday and Tuesday morning

Special Poster Presentations Monday and Tuesday evening

| Poster Presentations Monday 17:20 (parallel groups 1 – 3) | | | |
|---|------------|-------------|---|
| 2 minutes presentation and 1 minute discussion for each poster | | | |
| Prevention | | | |
| Presentation Monday 17:20 Group 1 | | | |
| P01 | Doray | Bérénice | Epidemiology of Fetal Alcohol Syndrome on Reunion Island. Contribution of the registry of congenital malformations of Reunion Island 2003-2015. |
| P02 | Fiorentino | Daniela | Alcohol consumption and awareness of dangers of drinking while pregnant: a preventive intervention in Senior High School |
| P03 | Howlett | Helen | Alcohol screening in pregnancy: an opportunity for support and education? |
| P04 | Kalberg | Wendy O. | Identification of Early Life Predictors for Fetal Alcohol Spectrum Disorders |
| P05 | O'Mahony | Mary Teresa | Calling time on pre-natal alcohol exposure: time to screen for alcohol in pregnancy |
| P06 | Ramage | Kaylee | Overcoming barriers to disclosure of alcohol use among pregnant women: a qualitative study |
| P07 | Schölin | Lisa | A qualitative study exploring midwives' attitudes and practices of advising pregnant women about alcohol |
| P08 | Schölin | Lisa | The conversation matters: a qualitative study exploring the implementation of screening and brief interventions in antenatal care in Scotland |

| Professionals | | | |
|--|---------|------------|--|
| Presentation Monday 17:20 Group 2 | | | |
| P09 | Burn | Rachel | A Multi-disciplinary Fetal Alcohol Spectrum Disorder (FASD) Awareness Training programme for Professionals and Caregivers in Ayrshire and Arran |
| P10 | Shields | Jennifer | Professionals' Changing Knowledge, Confidence and Attitudes on Fetal Alcohol Spectrum Disorder (FASD) within Health and Social Care Partnerships in Ayrshire, Scotland |
| P11 | Burslem | Fiona | Communicating Brain Domains - A Positive, Visual (and Quick) Method for Multidisciplinary Team Feedback |
| P12 | Doray | B er enice | Knowledge and practices of Health Professionals concerning Fetal Alcohol Syndrome in Reunion Island (France) |
| P13 | Green | Courtney | Knowledge and Attitudes of Service Providers in Canada about Fetal Alcohol Spectrum Disorder |
| P14 | Green | Courtney | Knowledge and Attitudes of Healthcare Providers in Canada about Fetal Alcohol Spectrum Disorder: Has Anything Changed in 15 Years? |
| P15 | Howlett | Helen | A survey of health care professionals' knowledge and experience of Fetal Alcohol Spectrum Disorder (FASD) and alcohol use in pregnancy |

| Caregivers | | | |
|--|---------------|---------|--|
| Presentation Monday 17:20 Group 2 | | | |
| P16 | Spodenkiewicz | Michel | Foster and biological parent's perspectives on actual difficulties of children with FASD: results from a prospective exploratory study from the first French FASD Diagnosis Center on Reunion Island |
| P17 | Tremblay | Melissa | Researching Community-Based Initiatives that Serve Individuals with FASD |

Biology / Basic researchPresentation Monday 17:20 **Group 3**

| | | | |
|-----|--------------------|----------------|---|
| P18 | Baggio | Suelen | Pharmacological modulation of behavioral and neurochemical profile in an adult zebrafish FASD model |
| P19 | Blanck-Lubarsch | Moritz | An analysis of malocclusion associated with fetal alcohol spectrum disorder (FASD) using the peer assessment rating index (PAR) |
| P20 | Carito | Valentina | Changes in fetus morphology by second trimester ultrasound in pregnant women with positive levels of urine Ethylglucuronide |
| P21 | Dylag | Katarzyna Anna | Prenatal alcohol exposure reduces 5-HT concentration in mouse intestinal muscle and mucosa. |
| P22 | Ehrhart | Friederike | Gap analysis of knowledge in molecular pathways leading to Fetal Alcohol Spectrum Disorders |
| P23 | Fiore | Marco | A normalized cut-off for urinary ethylglucuronide for the assessment of alcohol consumption during pregnancy: comparison between biochemical data and screening questionnaires. What is the best indicator? |
| P24 | Fratte | Antje | FASD and immunodeficiencies. Specific immunological examinations as a component of FASD-diagnostic evaluations. |
| P25 | González Rodríguez | Isela Iveth | Abnormal cortisol awakening response in teenagers associated to mother's alcohol problematic |
| P26 | Huang | Ruobing | Towards analysing the effect of alcohol exposure on the fetal brain using 3D neurosonography: building age-specific fetal brain atlases |

PrevalencePresentation Monday 17:20 **Group 3**

| | | | |
|-----|--------|------|--|
| P27 | Becker | Gela | FASD in Residential Care Facilities for Children and Adolescents who Cannot Live at Home: A Pilot Study to Estimate Prevalence |
|-----|--------|------|--|

Poster Presentations Tuesday 17:10 (parallel groups 4 – 6)

2 minutes presentation and 1 minute discussion for each poster

DiagnosisPresentation Tuesday 17:10 **Group 4**

| | | | |
|-----|-----------------|----------|--|
| P28 | Blanck-Lubarsch | Moritz | 3D-Analysis of philtrum depth in children with fetal alcohol spectrum disorder (FASD) |
| P29 | Broccia | Marcella | A Danish fetal alcohol spectrum disorders definition |
| P30 | Kalberg | Wendy O. | Neurobehavioral Profiles of Children with Fetal Alcohol Spectrum Disorders (FASD) in the General Population of the United States: Results from the Collaboration on FASD Prevalence (CoFASP) |
| P31 | Liberadzki | Paweł | Initial assessment of the possibility of using a 3D scanner in the diagnosis of FASD syndrome |
| P32 | Merino-Elia | Ana | Profile of children seen for Clinical assessment for Fetal Alcohol Spectrum Disorder (FASD) in a General Neurodevelopmental Clinic- Challenges and gaps in service provision |
| P33 | Socanski | Dobrínko | Fetal alcohol spectrum disorder in a clinical setting at a child neuropsychiatric department |
| P34 | Scott | Louise | Is there a Rationale for Applying Paediatric Brain Injury Diagnostic Techniques to FASD Diagnosis? |
| P35 | Svensson | Leif | Anthropometry in FASD - a longitudinal study |
| P36 | Wenzel | Philipp | How short is a "short palpebral fissure"? Reference values of palpebral fissures in children and adolescents with and without Fetal alcohol syndrome (FAS) |
| P37 | Williams | Carrie | Growth trajectories in Fetal Alcohol Spectrum Disorder; Implications for future research. |

ComorbiditiesPresentation Tuesday 17:10 **Group 5**

| | | | |
|-----|-----------|-------------|---|
| P38 | Chasnoff | Ira | Co-occurring vs. multi-occurring mental health diagnoses in children and adolescents with FASD |
| P39 | Dirks | Henrike | Substance use and psychiatric comorbidities in adult FASD patients |
| P40 | Feldmann | Reinhold | Fetal alcohol spectrum disorders as a risk factor for an increased consumption of drugs and media in adolescence |
| P41 | Fernandes | Ana Cecília | Auditory manifestations in children exposed to alcohol during pregnancy as assessed by otoacoustic emissions |
| P42 | Ipsiroglu | Osman | Iron Deficiency and Neurodevelopmental Disorders (ADHD, autism, and fetal alcohol spectrum disorder/FASD - A Scoping Review |
| P43 | Ipsiroglu | Osman | Iron Deficiency and Sleep - A Scoping Review |
| P44 | Simões | Humberto | Assessment of auditory function in schoolchildren exposed to alcohol during pregnancy |

| Therapy | | | |
|---|------------|-----------------|--|
| Presentation Tuesday 17:10 Group 6 | | | |
| P45 | Kowalska | Katarzyna | Efficacy of Repetitive Transcranial Magnetic Stimulation (rTMS) in Treatment of Children with FASD - Study Protocol. |
| P46 | McNeil | Allison Lavinia | Developmental trajectory of adaptive functioning in individuals with FASD/PAE: Impacts of service use |
| P47 | Rutherford | Jessica | Let's make learning fun: Developing a learning programme for children with Foetal Alcohol Spectrum Disorders using the animation film making process |
| P48 | Unsworth | Kathy | Developing an FASD Framework for the Canadian Workforce: A Model for Implementation |

| Adults / Prognosis | | | |
|---|---------|-------------------|---|
| Presentation Tuesday 17:10 Group 6 | | | |
| P49 | Cook | Jocelynn | Using Screening, Diagnosis and Data to Improve Outcomes in FASD: Canada's National Database |
| P50 | Francke | Lisa | Neurocognitive impairments in adult FASD patients |
| P51 | Wagner | Jessica Christine | Neuropsychological outcome in adults with FASD and a mental disability. |

[P01] *Epidemiology of Fetal Alcohol Syndrome on Reunion Island. Contribution of the registry of congenital malformations of Reunion Island 2003-2015.*

Bérénice Doray^{1,2,3}, Laure Tiverne², Bénédicte Bertaut-Nativel⁴, Hanitra Randrianaivo⁴, Barbara Delmotte¹, Karine Josse¹, Stéphanie Sotaca¹, Thierry Bafinal¹, Stéphanie Robin⁵, Justine Lanneaux⁵, Augustin Rousselle⁵, Marilyn Tallot⁵, Marilyn Jacquemont⁵, Alizé Payet⁵, Lucie Rebourg⁵, Sonia Henkous⁵, Lucie Rebourg⁵, Nathalie Penard⁵, Marine Gayet⁵, Agnès Cudenet⁵, Michel Spodenkiewicz^{5,6,7}

1 – Centre Ressources ETCAF Fondation Père Favron – CHU de La Réunion - France

2 – CIC 1410 - CHU de La Réunion - France

3 - Centre de Référence Anomalies du Développement et Syndromes Malformatifs Sud-Ouest Occitanie Réunion – Site Constitutif de La Réunion - France

4 – Registre de Malformations Congénitales – CHU La Réunion - France

5 - Centre Diagnostic ETCAF – CHU La Réunion - France

6 – Pôle de Santé Mentale, CHU Réunion, Saint-Pierre, La Réunion, France

7 – CEPOI EA 7388, UFR Santé, Université de la Réunion, Saint-Pierre, La Réunion, France

Introduction: Fetal Alcohol Spectrum Disorder represents a major public health problem. Concerning about 1 in 100 births, it is the most common cause of neurocognitive disorders and difficulty of social insertion. Fetal Alcohol Syndrome (FAS) is the most severe form including growth retardation, dysmorphic syndrome, malformations, neurocognitive and behavioral disorders.

Patients and Methods: A population-based retrospective study was performed from data of the Registry of Congenital Malformations of Reunion Island. All cases with FAS were recorded among live births (anomaly detected during the pregnancy or after birth up to the 12th month of life), stillbirths after 22 weeks of amenorrhea and terminations of pregnancy (whatever the term of pregnancy) whom mothers lived and gave birth in Reunion Island between 2003 and 2015.

Results: 122 cases were registered. The total prevalence was 6 per 10,000 births with a number of births between 4 and 14 per year. This population was composed of 115 livebirths, 2 stillbirths and 5 terminations of pregnancy. The diagnosis was performed prenatally in 31% of the cases, at birth in 61% and during the first year of life in 8%. The majority of cases (72%) were born in the south of the Island, 3% of cases were born at home. Maternal vulnerability factors were identified, including pregnancy not declared or declared late (14 cases), pregnancy not well monitored (17 cases), anonymous birth (1 case), but also mothers out of care, previous foster children. Concerning malformations, brain malformations were the most frequent (70%) including 12 cases of microcephaly

and 6 cases of agenesis of the corpus callosum. The other frequent anomalies were cardiac malformations (30%), cleft lip or cleft lip palate (15%), renal malformations (9%). Fetal growth restriction was identified in 61% of the cases, severe in 50% of the cases.

Conclusion: These results confirmed

1 – the high prevalence of FAS in Reunion Island, evaluated at 6 per 10,000 total births; if this result was lower than the usual prevalence of 10 per 10,000, it can be explained by the restrictive criteria for inclusion in the registry: only the most severe cases with a well-known maternal alcohol use were registered. Nevertheless, this prevalence was much higher than that recorded by other French registries or European registries. Does this result reflect a truly higher prevalence on Reunion Island or rather a better diagnostic ability from professionals educated for a long time about this entity? Similarly, is SAF really more frequent in the South of the Island or is it only the consequence of more experienced professionals? If this last hypothesis is true, the improvement of knowledge, using training programs offered by the FASD Resource Center of Reunion Island should lead to remove this difference in the future.

[P02] Alcohol consumption and awareness of dangers of drinking while pregnant: a preventive intervention in Senior High School

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Latium Regional Center for Alcohol – “Sapienza” University of Rome, Rome (Italy)

Background: Prevalence of FAS in European Region has been estimated at 37.4 per 10,000 (Italy 82.0 per 10,000) while the prevalence of alcohol consumption during pregnancy in the same region is 25.2% (Italy 33.1%). In Italy, only 50% of citizens completely agree that alcohol consumption in pregnancy can increase the risk of birth defects. Objective of this study was to enhance awareness about the risk related to alcohol consumption in pregnancy among young people.

Methods: an informative session about Fetal Alcohol Spectrum Disorder (FASD) and risks related to alcohol consumption in pregnancy was delivered to students attending the last year of a Senior High School in the metropolitan area of Rome (Italy). The session was preceded and followed by the delivering of an anonymous questionnaire investigating style of alcohol consumption and knowledge about FASD. Drinking style was investigated through the three questions of the WHO's questionnaire AUDIT-C. Two additional questions were added to the questionnaire delivered two months after the informative session, to investigate intention to pass the information received to pregnant women in personal environment and intention to drink when pregnant.

Results: 191 students participated in the informative session (female = 49.2%; male 50.8%; mean age 17.9). Among females, 10.2% scored positive to the AUDIT-C; 9.6% declared to binge once a month. 27.7% of females had at least heard about FASD and 46.8% could correctly describe it: these percentages increased, respectively, to 88.6% and 64.9% after the intervention. 94.3% declared to be intent to pass the information received to others. Among female students who could not define FASD correctly, 42.4% scored positive to the AUDIT-C. After the informative session, all of them declared the intention not to drink during a future pregnancy.

Conclusion: style of alcohol consumption in female young population leads to an increased risk of giving birth to affected children in future: spreading information at an early stage is important to enhance awareness about the risks related to alcohol consumption in pregnancy.

[P03] Alcohol screening in pregnancy: an opportunity for support and education?

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2 The Medical School, Newcastle University, Newcastle upon Tyne, UK

3 Institute of Health & Society, Newcastle University, Newcastle upon Tyne, UK

Background: Providing antenatal and postnatal support for women who drink alcohol in pregnancy is only possible if those at risk can be identified. However, screening will only be helpful if women feel comfortable with the method used.

Methods: We conducted a survey of pregnant women and their partners to investigate self-reported beliefs and practice regarding drinking during pregnancy and the acceptability of screening.

Results: One-hundred and seventy-one pregnant women and 41 partners participated. 89.5% of pregnant women believed women should abstain from alcohol consumption, although only 40.9% reported not drinking in pregnancy. Of 96 women who reported drinking in pregnancy all but six stopped drinking when they found out they were pregnant. 87.2% of women and partners who responded would consent to blood biomarker analysis. Confusion over what level of alcohol is safe and using screening as an opportunity for education and support emerged as key themes from free-text responses.

Conclusions: Most women viewed screening for alcohol in pregnancy positively, although its acceptability in the small number of women who continue to drink is unclear.

[P04] Identification of Early Life Predictors for Fetal Alcohol Spectrum Disorders

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⁴*Stellenbosch University, Department of Psychiatry, South Africa*

⁵*The University of North Carolina, Nutrition Research Institute, USA*

Background: Fetal Alcohol Spectrum Disorders (FASDs) occur when fetuses are exposed to alcohol in utero. Diagnosis of FAS in infancy and early childhood is difficult, and no clear criteria have been established for an early-childhood diagnosis. Diagnosis in the infant is rarely attempted, because of the lack of documented specificity of the phenotype in the newborn. Yet, identification and referral within the first few months of life may represent the most crucial time in the affected child's life for initiation of early intervention services. The objective of this study was to determine a potential diagnostic protocol for children in infancy and early childhood.

Methods: Children from newborn to 60 months of age were followed to determine the physical and developmental trajectories that characterize the alcohol-exposed population in this stage of life (N=199). The mother/child dyads were enrolled through antenatal clinics. This cohort included children prenatally exposed to alcohol, as well as children who were not prenatally exposed. Three methodologies were used to approach this issue: (1) growth and standardized dysmorphology assessment; (2) standardized developmental assessments; (3) and digital photography. All methods were applied at the following ages of the children: 6 weeks, 9 months, 18 months 42 months and 60 months.

Results: This longitudinal investigation of dysmorphology and development of a cohort of children who were prenatally exposed to alcohol and controls revealed that early behavioral factors and dysmorphic features can help identify alcohol-affected children as early as 6 weeks and 9 months respectively. General developmental milestone assessment began to reveal differences with children prenatally alcohol exposed between 9 and 18 months of age.

Conclusion: Children prenatally exposed to alcohol are at risk for later developmental and learning issues. Early diagnostic tools are imperative to drive early intervention services.

[P05] Calling time on pre- natal alcohol exposure: time to screen for alcohol in pregnancy

Mary Teresa O'Mahony

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Background: Pre-natal alcohol exposure, cause of Foetal Alcohol Spectrum Disorders (FASD), is a major adverse determinant of public health. It is necessary to increase awareness and provide women with a consistent message that pregnancy needs to be alcohol free to prevent FASD. This health education is necessary but insufficient to prevent cases of FASD. This proposal to screen for alcohol during pregnancy is intended to provide more information to the pregnant woman, to promote abstinence.

Methods: The condition: prenatal alcohol exposure; the test: maternal urine test for ethyl gluconoride; the treatment: brief intervention with agreed patient pathways; and the screening programme were evaluated against established criteria for population based cancer screening programmes.

Results: Prenatal alcohol exposure is an important health condition with known epidemiology and outcome. Any positive urine test for ethyl gluconoride in pregnancy is significant. Women accept urine testing during pregnancy but whether testing for alcohol is acceptable needs confirmation. Screening and brief intervention is effective in reducing alcohol intake in adults. Agreed patient pathways for harmful and dependent alcohol use are inadequately resourced. Resources released through the prevention of even a modest number of cases of FASD would cover the cost of screening and patient follow-up. It is ethical to screen.

Discussion: A motion *That the Irish Medical Organisation (IMO) supports screening for alcohol in pregnancy* was carried at the IMO AGM on 5th April 2018. This is an important initial step working towards the institution of screening for alcohol in pregnancy for women in Ireland.

[P06] Overcoming barriers to disclosure of alcohol use among pregnant women: a qualitative study

Kaylee Ramage

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Background: Women who consume alcohol during pregnancy experience significant discrimination from peers, family, and healthcare providers that may impact their choice to seek support during their pregnancy. Women who continue to drink alcohol after they know they are pregnant face additional stigma as compared to women who stop drinking upon pregnancy recognition. There is a need to break down stigma surrounding alcohol consumption during pregnancy to better identify and support women who continue to use alcohol during pregnancy, thereby working to prevent new cases of FASD.

Methods: This study conducted qualitative interviews with women who use alcohol after pregnancy recognition and service providers who work with these women. Questions focused on childhood and life experiences, reasons for and patterns of alcohol consumption during pregnancy, barriers and facilitators to disclosure, and best practices for harm reduction. Ethics approval for this project was obtained from the Health Research Ethics Board of Alberta.

Results: Women who continued to consume alcohol during pregnancy experienced significant discrimination from healthcare providers and their social networks which precluded seeking help during their pregnancy. Furthermore, stereotypes about who was at risk for an alcohol-exposed pregnancy affected healthcare providers' choices to ask women about their alcohol use during pregnancy and referral to resources. Women identified several leading practices for promoting disclosure of alcohol use and for harm reduction around alcohol use during pregnancy.

Conclusion: Stigma and discrimination are continuing issues affecting the disclosure of alcohol consumption during pregnancy. Creating a safe space for disclosure is necessary to allow women who need support to come forward during pregnancy, ultimately reducing the incidence of alcohol-exposed pregnancies.

[P07] A qualitative study exploring midwives' attitudes and practices of advising pregnant women about alcohol in England and Sweden

Lisa Schölin

Research Fellow, School of Health in Social Sciences, University of Edinburgh, United Kingdom

Background: The harm caused by alcohol exposure during pregnancy are well-known, but a 'safe' threshold for alcohol consumption has not been established. Until 2016, the recommendation for pregnant women in England was to avoid alcohol and only consume small amounts if they chose to drink, whilst in many other countries abstinence has featured as the key recommendation for some time. The current study aimed to explore midwives' views on alcohol use in pregnancy and advising pregnant women about alcohol in England and Sweden, within the context of differing guidelines on drinking during pregnancy.

Methods: Sixteen qualitative semi-structured interviews were conducted with midwives working in Liverpool, England (n=7) and Örebro County, Sweden (n=9) in 2014. Data were analysed inductively, using thematic analysis with thematic networks.

Results: The findings show that all midwives believed pregnant women should be advised to not consume any alcohol during pregnancy, but highlighted the need to tailor their approach to the individual. A recognised key issue in both countries was exposure before the pregnancy is known to the woman. English midwives acknowledged that drinking small amounts may not cause harm, whereas Swedish midwives believed any amount of alcohol was associated with risk. Midwives believed discussing alcohol is part of their role as a health professional, but clear protocols with routine questions for all women was perceived to aid asking about alcohol consumption.

Conclusions: Cultural context appears to be an important factor to consider in preventing alcohol exposure during pregnancy as it may influence health professionals' views of risk. Further work should expand on the current study to understand the implications of cultural context for prevention research, training, education and maternal health care practice.

[P08] The conversation matters: a qualitative study exploring the implementation of screening and brief interventions in antenatal care in Scotland

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Background: The use of screening and alcohol brief interventions (ABIs) in antenatal care is an important strategy to prevent harm caused by alcohol exposure during pregnancy, despite less robust evidence of effectiveness than in primary care settings. There is however limited understanding of how ABIs are implemented within antenatal care, and what facilitates successful implementation. This study aimed to explore the implementation of a national ABI programme in antenatal care in Scotland.

Methods: Qualitative interviews were conducted with implementation leaders in eight Scottish health boards in 2013. Interviews were analysed using thematic analysis and the practical robust implementation and sustainability model (PRISM) was used as a conceptual framework for understanding of differences in implementation across health boards, perceived setting-specific barriers and challenges.

Results: In several health boards, reported alcohol use during pregnancy was lower than expected, which led them to pay special attention to optimizing the way in which they enquired about women's alcohol use. Strategies focused on improving disclosure and facilitate dialogue, including exploring pre-pregnancy drinking habits instead of current alcohol use. Adapting the intervention to local context, including the choice of screening tool, and ensuring acceptability and support at practice level were important facilitators for routine implementation.

Conclusions: This study suggests that acceptability and adaptability of interventions are important components to successfully screen and deliver ABI within routine maternity care. Furthermore, the experiences from Scotland indicates that main priorities are to develop strategies and protocols that encourage an open dialogue and builds a trusting relationship between pregnant women and midwives.

[P09] A Multi-disciplinary Fetal Alcohol Spectrum Disorder (FASD) Awareness Training programme for Professionals and Caregivers in Ayrshire and Arran.

Rachel Burn¹, Lorna Fulton²

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² *Scottish Government-Funded Fetal Alcohol Advisory and Support Team (FAAST), Rainbow House, Ayrshire Central Hospital, Scotland, UK.*

Background: Ayrshire and Arran has embraced the Scottish Government 'No Alcohol, No Risk' message for some time. Awareness of FASD is increasing in this region. Professionals ability to provide support to children and families affected by FASD is dependent upon their own knowledge. Our training programme aimed to i) change knowledge, understanding and attitudes of professionals around alcohol use during pregnancy and FASD and ii) provide professionals and caregivers with strategies to support individuals affected by FASD.

Methods: Our training calendar was distributed across NHS Ayrshire and Arran and the Health and Social Care Partnerships via email. Full-day training covered attitudes around alcohol and pregnancy, alcohol units, the importance of delivery of ante-natal Alcohol Brief Interventions (ABI), fetal development, how alcohol affects fetal neurodevelopment, FASD definition, FASD prevalence, information on assessment and diagnostic pathways, and a presentation on lived experience by an affected young person. Half-day training comprised information on strategies and approaches to support affected individuals and the local support group. Paper evaluation questionnaires were administered following training.

Results: The training calendar was fully booked within weeks. We have now trained over 5000 individuals. Evaluations revealed increased knowledge and understanding. Qualitative evaluation data highlighted the importance of making FASD training mandatory for staff working across the Health and Social Care Partnerships, including Education. As a result, bespoke training sessions were delivered to specific staff groups including Health Visitors, Early Years staff, Child Protection teams and Social Work.

Conclusion: Our specific training programme, conducted with the aim of improving awareness and knowledge around FASD, was effective and resulted in professionals being able to provide advice, guidance and support to children and families affected by FASD.

[P10] Professionals' Changing Knowledge, Confidence and Attitudes on Fetal Alcohol Spectrum Disorder (FASD) within Health and Social Care Partnerships in Ayrshire, Scotland.

Jennifer Shields, Fiona McGruer, James Anderson

Scottish Government-funded Fetal Alcohol Advisory and Support Team (FAAST), Rainbow House Community Paediatrics, Ayrshire Central Hospital, NHS Ayrshire and Arran, Irvine, Scotland.

Background: Assessment and diagnosis of Fetal Alcohol Spectrum Disorder (FASD) in multidisciplinary teams is a relatively recent endeavour in Scotland. Assessment is dependent upon professionals' awareness of FASD and confidence in how to formally identify, assess, and support individuals. Early identification is associated with reduction in adverse outcomes. This research aimed to i) establish a benchmark of Ayrshire-based professionals' knowledge, confidence, and attitudes in relation to FASD and ii) determine whether this changed following the three-year pilot Fetal Alcohol Assessment and Support Team (FAAST), who delivered pan-Ayrshire training to approximately 5,000 multiagency professionals.

Methods: We emailed a cross-sectional online questionnaire to Ayrshire professionals from health and social care partnership services working alongside individuals with FASD (n=144). This elicited self-reported knowledge, confidence, and attitudes and respondents' demographic data. We issued shorter versions of this survey to attendees before and after FAAST training. The cross-sectional online questionnaire was repeated following the conclusion of the FAAST pilot's work to measure change across the partnerships.

Results: Prior to the FAAST pilot training, professionals rated their knowledge and confidence regarding FASD as low. However, a large proportion of those professionals support individuals with suspected FASD. Data from training questionnaires revealed increases in knowledge and confidence after training. We anticipate lasting changes in professionals' knowledge, confidence, and attitudes in supporting individuals with FASD in our second questionnaire (currently with ~70 respondents) when compared to our initial benchmark taken in 2015.

Conclusion: A targeted awareness and diagnostic training programme can improve professionals' knowledge, confidence, and attitudes around FASD; supporting the development of pathways and services for this group.

[P11] Communicating Brain Domains - A Positive, Visual (and Quick) Method for Multidisciplinary Team Feedback

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² *Public Health, NHS Ayrshire and Arran, 48 Lister Street, Crosshouse Hospital, Kilmarnock Rd, Crosshouse, Kilmarnock, Scotland, UK.*

Background: FASD diagnosis is assessed through a multidisciplinary approach, using standardised testing where appropriate (Cook et al. 2016; Astley, 2004). A comprehensive multidisciplinary team (MDT) formulation report is complex and can be a lengthy process. To reduce the time families wait for feedback and to maximize understanding, our team developed a one page visual report to summarise the child's profile of strengths and difficulties. This can be used with the patient, family, educational and support staff.

Methods: Two versions of the report were developed: one for the young person and one for adults with whom assessment findings were shared. Both versions feature a basic graphic representing the brain, with 'domains' and functional areas labeled. The terminology used is easily understood and represents the areas assessed by the MDT. During the feedback discussion, the young person is taken on a 'journey' around their brain. To ensure the feedback was positively framed, a 'medal' sticker was awarded to each brain area (gold, silver, bronze). In the adult version of the report, green, orange and red stickers were used. The sticker used represented assessment findings, where gold (green) represented within -1 standard deviation (SD) from the mean, silver (orange) represented -1 to -2 SD from the mean, and bronze (red) represented -2 SD or more.

Results: Feedback ascertained in clinic indicated children and carers found it useful to have information presented visually and valued the brevity of the information. Understanding strengths and difficulties enabled children and carers to implement strategies without delay. A more comprehensive, formulation-based report followed this in due course.

Conclusion: We found that the visual report feedback method was well-received due to its simplicity, ease of understanding, speed of delivery, and appeal to children. This method can easily be adapted for different sites and services, and for different assessment protocols.

[P12] Knowledge and practices of Health Professionals concerning Fetal Alcohol Syndrome in Reunion Island (France)

Bérénice Doray^{1,2,3}, Nelly Maroudin Viramale⁴, Barbara Delmotte¹, Karine Josse¹, Stéphanie Sotaca¹, Thierry Bafinal¹, Stéphanie Robin⁵, Justine Lanneaux⁵, Augustin Rousseau⁵, Marilyn Tallot⁵, Marilyn Jacquemont⁵, Alizé Payet⁵, Lucie Rebourg⁵, Sonia Henkous⁵, Lucie Rebourg⁵, Nathalie Penard⁵, Marine Gayet⁵, Agnès Cudenet⁵, Michel Spodenkiewicz^{5,6,7}

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5 - Centre Diagnostic ETCAF – CHU La Réunion - France

6 – Pôle de Santé Mentale, CHU Réunion, Saint-Pierre, La Réunion, France

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Aim of this study: Fetal Alcohol Spectrum Disorder represents a major public health problem. Concerning about 1 in 100 births, it is the most common cause of neurocognitive disorders and difficulty of social insertion. Fetal Alcohol Syndrome (FAS) is the most severe form including growth retardation, dysmorphic syndrome, malformations, neurocognitive and behavioral disorders and concerns one in 1,000 births. The purpose of this study was to identify current knowledge, diagnosis, prevention, and intervention practices related to fetal alcohol syndrome (FAS) among pediatricians (P), gynecologists (G), general practitioner (GP) and midwives (M).

Patients and Methods: Three questionnaires were developed by the Resource Center of Reunion Island; they were inspired by the study published in *Pediatrics* 2006.118 (3):e657-68. They were distributed in 2016, by e-mail from the regional perinatal network or before training sessions organized by the Resource Center. The questionnaires included four parts, divided into about 20 questions. Some questions were different depending on the type of professional. The first part concerned general information, allowing to draw the profile of the professionals. Then global knowledge was evaluated, following by prevention and taking care. The last part concerned training of the professionals.

Concerning prevention, only 51% of G and M and 36% of P and GP declared to systematically inform teenage girls and women of childbearing age about the risks of prenatal alcohol exposure. During pregnancy, the necessity of abstinence was well-known by 98.5% of professionals; 85% of G, M and GP declared to ask systematically for alcohol consumption, 5% sometimes and 2% rarely or never.

Nevertheless, in daily practice, if fetal restriction was diagnosed, FAS was systematical-

ly suspected by only 18% of M, 42% of G and 47% of GP. Only 13.5%, 37.5% and 42% of them declared always asking the patient about alcohol consumption. To explain this result, professionals said he did not think about FAS for lack of knowledge in 35% of cases, for fear of stigmatizing in 32%, for lack of time in 20%, and for lack of interest in 7%.

21% of P and GP believed they were well prepared to diagnose a child with FAS, 12% felt somewhat prepared, 52% not well prepared, and 12% not prepared.

Similarly, 9% of P and GP felt well prepared to follow and care for a child with FAS, 15% somewhat prepared, 46% not well prepared and 24% not prepared.

Conclusion: This study demonstrates correct theoretical knowledge of the effects of prenatal exposure to alcohol among pediatricians, gynecologists, general practitioners and midwives in Reunion Island.

[P13] Knowledge and Attitudes of Service Providers in Canada about Fetal Alcohol Spectrum Disorder

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Background: In 2001-2002, the Public Health Agency of Canada facilitated a survey to examine knowledge and attitudes of physicians and midwives across Canada towards Fetal Alcohol Syndrome (FAS) and alcohol use during pregnancy. The results provided important insight and informed educational initiatives for health care professionals. However, despite their important role in women's health, other service providers have not been asked similar questions, nor have their screening and referral/intervention practices been determined.

Methods: A Canada-wide online survey was developed and widely disseminated in both English and French using the Survey Monkey tool. Questions were developed and finalized by an expert committee comprised of representatives from the partner associations and informed by a comprehensive literature review. Data were analysed using descriptive statistics.

Results: In total, 1,842 responses were collected. Data suggest that while service providers recognize that Fetal Alcohol Spectrum Disorder (FASD) is an identifiable syndrome (88%) and recommend abstaining from alcohol during pregnancy (98%), some believe that there are often more pressing issues (e.g., homelessness, food security, mental health) to address when caring for pregnant women (39%). Many service providers are unaware of standardized screening tools for alcohol use during pregnancy (45%), and are unclear if screening tools are effective in identifying problematic drinking (48%). 67% provide brief intervention when any alcohol use is reported during pregnancy and 43% refer to harm reduction services. Lack of resources that can be provided to women remains a concern for 85% of the service providers.

Conclusion: Together these data highlight gaps in knowledge and practice that must be addressed for service providers to effectively care for women in the area of alcohol use during pregnancy. More education and training, including resources for women, are needed.

[P14] Knowledge and Attitudes of Healthcare Providers in Canada about Fetal Alcohol Spectrum Disorder: Has Anything Changed in 15 Years?

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Background: In 2002, a large Canadian study collected information from health care professionals (a random sample of 5,361 paediatricians, psychiatrists, obstetricians and gynaecologists, midwives and family physicians) to determine their current levels of knowledge and attitudes towards Fetal Alcohol Syndrome (FAS) and alcohol use during pregnancy. The survey findings provided baseline information for assessing the effectiveness of educational initiatives and policy in the area of health care professional practice.

Methods: Since that time, a flurry of public and professional awareness campaigns and materials have been developed, as well as diagnostic guidelines for fetal alcohol spectrum disorder and it was anticipated that knowledge and attitudes have evolved. So 15 years later, the objective of this project was re-evaluated and an expanded online survey was administered to determine changes in practice, confidence and competence of healthcare professionals in managing these cases, including their needs around resources, education and supports. (N=713)

Results: New data suggest that more healthcare professionals recognize that FASD is an identifiable syndrome (94% vs 84%) and more recommend no alcohol during pregnancy (92% vs 87%), although similar proportions believe that the effects of alcohol on the fetus remain unclear (25%). Fewer care providers report using a standardized screening tool for alcohol use during pregnancy (42% vs 62%, and fewer (87% vs 94%) believe that prenatal alcohol exposure is a risk for permanent brain damage. 60% provide brief intervention when any alcohol use is reported during pregnancy and 66% refer to harm reduction services (vs 53% in 2005). Insufficient resources in the practice setting was cited as the reason for not providing intervention. When asked about non-pregnant women, less than half in 2005 said they discuss alcohol use with all women of childbearing age, but 71% said that they do in the new survey. Lack of treatment and educational resources that can be provided to women remains a concern for over half of the respondents.

Conclusions: Together these data suggest that the inability of science to provide an absolute threshold for safety and harm is still a deterrent to the advice that health providers give to their patients about alcohol use during pregnancy. More education and training, including resources for patients are needed, despite the investments that have been made over the past 15 years.

[P15] A survey of health care professionals' knowledge and experience of Fetal Alcohol Spectrum Disorder (FASD) and alcohol use in pregnancy

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Background: FASD is the leading known cause of preventable learning disability in developed countries. Screening for alcohol use early in pregnancy can facilitate the identification of women in need of support. However, only a small percentage of UK children with FASD are diagnosed. This may be partly due to a lack of FASD awareness by National Health Service professionals.

Methods: We developed an online survey to determine healthcare professionals' (midwives, health visitors, obstetricians, paediatricians and general practitioners) knowledge and opinions.

Results: There were a total of 250 responses to the survey's (78 midwives, 60 health visitors, 55 obstetricians, 31 paediatricians and 26 general practitioners). 58.1% of paediatricians had diagnosed FASD and 36.7% worried about stigmatisation. 54.8% of paediatricians had received FASD training compared to only 21.3% of midwives. This was directly reflected in variable knowledge levels across the professions.

Conclusions: We identified a need for training in FASD and alcohol screening in pregnancy to improve awareness and recognition by professionals. Clear referral routes and care pathways are needed in the UK to optimise outcomes.

[P16] Foster and biological parent's perspectives on actual difficulties of children with FASD: results from a prospective exploratory study from the first French FASD Diagnosis Center on Reunion Island

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Background: The result of the pioneers' advocacy for the recognition of adverse effects of alcohol on the fetus, new health policies and a strong international network of experts of Fetal Alcohol Syndrome Disorder (FASD) lead in 2017 to the creation of the first FASD Diagnostic Center in France on Reunion Island.

This center conducts a multidisciplinary, both medical and paramedical, developmental assessment. Its mission is to diagnose and formulate individualized therapeutic proposals. It also has to respond to families' concerns and difficulties in raising children with FASD.

This exploratory study aims to identify the main difficulties met by foster and biological parents of children diagnosed within the FASD Diagnostic Center on Reunion Island.

Methods: Prospective study including foster and biological parents of 50 children aged from 6 to 18 years old diagnosed with FASD. A questionnaire about actual difficulties and concerns about their children was given to all participants. Data were analyzed with a mixed qualitative and quantitative analysis.

Results: 45 participants have been included. (1) The majority of accompanying adults were foster mothers (2) In order of frequency, the main concerns were: behavior and attention issues at home; adjustment and learning problems at school; issues with access to psychiatric care. Participants experienced helplessness and isolation with a strong feeling of misunderstanding for biological mothers.

Conclusion: These results are consistent with the current scientific literature. Psychiatric secondary disabilities appear to be the main difficulties reported by the parents. There is a strong need for a standardized and systematic assessment of major psychiatric comorbidities in all children with FASD. Close collaboration between diagnostic centers, FASD resource centers and local psychiatric care actors should improve the access to care. Setting up parent's groups and information meetings on FASD could meet the families' concerns.

[P17] Researching Community-Based Initiatives that Serve Individuals with FASD

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The pressing need exists for research approaches that effectively engage hard to reach populations such as individuals with FASD. It is arguably ethically imperative for researchers to recruit participants who have been exposed to the greatest risks and/or who have the greatest needs, although these populations can be particularly difficult to engage.

This presentation will provide a discussion of the opportunities and challenges that arise with researching community-based programs and projects that serve individuals with FASD. Individuals with FASD often have complex, interconnected needs for support, and this can present unique challenges. This presentation will share innovative strategies and relationship-based approaches for researching community-based initiatives that serve people with FASD. In particular, the presenter will bring to light how employing flexible, creative, and participatory approaches can enhance research by providing spaces for hard to reach participants to share their experiences, thereby culminating in findings that are usable by stakeholders. We will also explore how, by building trusting relationships, the research process itself can serve to generate changes in programs that serve hard to reach groups. In addition to sharing strategies that have worked well to engage hard to reach groups, we will discuss some of the challenges that may be encountered. For example, the presentation will touch on the difficulties in researching programs that are geographically dispersed, balancing the need to establish relationships with hard to reach groups with the need to preserve rigor in our research, and managing competing expectations from multiple stakeholder groups while maintaining trusting relationships. By sharing this information, we will generate dialogue and broaden understanding of how innovative research methods and practices can be applied to community-based initiatives that serve hard to reach groups such as people with FASD.

[P18] Pharmacological modulation of behavioral and neurochemical profile in an adult zebrafish FASD model

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Background: Fetal Alcohol Spectrum Disorder (FASD) is a syndrome with neurological and behavior impairments. Our recent findings indicates social behavior impairment, anxiety like behavior and reduced role brain glutamate uptake in a milder form of FASD in adult zebrafish model. The objective of this study was modulate those alterations using buspirone, an anxiolytic compound, and ceftriaxone, an up-regulator of glutamate-uptake system.

Methods: Milder form of FASD was accessed by zebrafish larvae 24 h post-fertilization were exposure to low concentrations of ethanol (0.0%, 0.1%, 0.25%, 0.5% and 1%) during 2 hours. After 4 months the animals were submitted to novel-tank paradigm, social interaction task and their role brain was used to access glutamate-uptake activity. All parameters were modulates by pre-treatment with buspirone at the doses of 25, 12 e 6.25 mg/kg, (i.p.) 10 minutes before the behavior test, and ceftriaxone 300mg/kg (i.p.) once a day during 6 days. In the sixth day the brain were removed and the glutamate uptake was performed.

Results: An ethanol dose dependent reduction of time spend in the conspecific zone compared to control was observed in social task. All FASD groups presented higher time spend in the bottom zone of the novel-tank paradigm. Only animals treated with ethanol 1% during development presented a higher latency to the top zone, an indicative of anxiety-like behavior. Animals from the group ethanol 1% treated with buspirone presented a similar profile behavior as control group in both tasks. The ceftriaxone treatment increased the reduced levels of role brain glutamate-uptake observed in the FASD animals (Ethanol 0.5% and 1%).

Conclusion: Embryonic alcohol exposure disrupts social behavior and increases anxiety behavior phenotype, which are positively modulated by buspirone. Ceftriaxone returned brain glutamate uptake to control levels, however this drug did not affect the impairment behavior.

[P19] An analysis of malocclusion associated with fetal alcohol spectrum disorder (FASD) using the peer assessment rating index (PAR)

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Background: Malocclusion in patients with fetal alcohol spectrum disorder (FASD) has so far been described in case reports with reliable evidence for associations pending. The purpose of this study was thus to investigate possible associations between malocclusion and FASD.

Methods: 30 patients with FASD and 30 patients of a healthy control group were examined according to defined inclusion and exclusion criteria. The extent and type of malocclusion was quantified with the PAR index and its 11 components based on an analysis of orthodontic plaster models. In addition, anthropometric data such as gestational age, body weight and height at birth as well as present body weight, height and head circumference at examination date were assessed.

Results: The PAR index showed significant differences between the groups ($p=0.002$) with malocclusions more pronounced in FASD patients. Particularly differences in the upper transversal dimension with a higher prevalence of crossbites could be found ($p=0.018$). Anthropometric data revealed a significantly lower body weight ($p<0.001$) and height ($p<0.001$) at time of birth, but not at the present examination date (weight: $p=0.329$; height: $p=0.496$), whereas head circumference was significantly lower than in controls ($p<0.001$). When relating weight and height measures to age using percentile curves of physiological growth, clinically relevant discrepancies could be found.

Conclusion: Our results show that malocclusion can provide additional evidence for FASD diagnosis. When FASD is diagnosed in a child, early referral to an orthodontist seems advisable in order to stimulate maxillary growth and consequently prevent further malocclusions.

[P20] Changes in fetus morphology by second trimester ultrasound in pregnant women with positive levels of urine Ethylglucuronide

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Background: The early discovery of fetal alcohol spectrum disorders (FASD) is a crucial issue to better address more comprehensive interventions for the mother and infant. Ethylglucuronide (EtG) is an ethanol metabolite and EtG is used as a biomarker of alcohol drinking also during gestation. EtG can be detected in the blood and in several biological matrices including urine, hair and nails. Other different strategies to reveal alcohol use during pregnancy are commonly used as screening questionnaires, including AUDIT-C, T-ACE/TACER-3, TWEAK and food habit diary. In this study, we investigated in pregnant women the association between EtG presence in the urine and markers of the physical features characteristic of FASD by prenatal ultrasound in the second trimester of gestation. We also correlated these data with the AUDIT-C, T-ACE/TACER-3, TWEAK and a food habit diary.

Methods: Forty-four pregnant women in follow up at the ambulatory of Gynaecology and Obstetrics of the Sapienza University Hospital "Policlinico Umberto I" of Rome, Italy, were enrolled and examined for ultrasound investigation. Urine samples were provided by pregnant women immediately after the routine interviews. EtG determinations were performed by Enzyme Immunoassay with a cut-off established at 100 ng/mL according to previously established methods.

Results: Data show that 15 of the enrolled pregnant women overcame the EtG cut off (34.09%).

ANOVA data revealed that the fetuses of the positive EtG pregnant women had significantly longer Interorbital Distance (IOD) and also significantly increased Frontothalamic Distance (FTD) measured as the distance between the inner surface of the frontal calvarium and the posterior margin of the thalami ($p < 0.02$). Quite interestingly no direct correlation was found between EtG data and both food diary and Audit-C. However, a significant concordance was observed between urinary EtG and T-ACE ($r = .317$; $p = .047$) and between urinary EtG and TWEAK ($r = .496$; $p = .001$).

Conclusions: Some ultrasound measurements were associated with positive EtG urine levels as selected facial and neurobiological features of FASD. This study provides clinical evidence that the diagnosis of maternal alcohol consumption during pregnancy by urine EtG may disclose FASD related damage in the fetus.

[P21] Prenatal alcohol exposure reduces 5-HT concentration in mouse intestinal muscle and mucosa

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Background: The influence of prenatal alcohol exposure on the serotonergic system in the brain has been well studied, however its influence on the serotonergic system in the gastrointestinal system remains unknown. The objective of the study was to use a mouse model of pre-natal alcohol exposure to investigate the effects on serotonin and its metabolites and precursors in colonic tissue.

Methods: This study used treatment of mouse breeding harems with 5% ethanol with saccharin via drinking water throughout pregnancy and compared the results with a saccharin control group. Tryptophan, serotonin (5-HT) and 5- hydroxyindoleacetic acid (5-HIAA) concentrations were measured in the longitudinal muscle myenteric plexus (LMMP) and mucosa of intestinal tissue by high-performance liquid chromatography (HPLC).

Results: Decreased 5-HT concentrations in mucosa and LMMP (females only) were observed in prenatally exposed mice compared to controls. Increases in mucosal and LMMP tryptophan concentration were only observed in prenatally exposed female mice.

Conclusion: In conclusion, prenatal alcohol exposure causes a decrease in conversion of tryptophan to 5-HT in both muscle and mucosa although the effect is more pronounced in females. The observed sex difference may be related to changes associated with the estrous cycle.

[P22] Gap analysis of knowledge in molecular pathways leading to Fetal Alcohol Spectrum Disorders

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Background: Exposure to alcohol (ethanol EtOH) may cause mild to severe damage to the development of an unborn baby. Alcohol and its teratogenic effects have been studied extensively. Nevertheless, the pathways leading from the damaging agent to the broad variety of physiological and psychological symptoms are not yet fully understood. The aim of this study is to provide an overview of our current understanding of molecular pathways leading to a FASD.

Methods: A systematic literature search on the teratogenic effects of prenatal alcohol exposure was conducted using various databases. The existing knowledge was summarized and gaps of current knowledge have been identified.

Results: The pathways leading from EtOH to FASD start with the metabolism of EtOH to acetaldehyde. Apart from the toxicity of EtOH and acetaldehyde itself, during this process oxidative stress is generated in form of different oxygen radicals. This does not only deplete radical scavenger mechanisms but also triggers deleterious downstream pathways influencing gene expression and epigenetic imprinting. Examples for pathways involved are SHH pathway, AKT/mTOR, apoptosis, neurotransmitters, retinol signaling, cytoskeleton and cell adhesion, cholesterol homeostasis and DNA damage pathways. Many of these are known to be involved in central nervous system development.

Conclusion: The biggest gaps in knowledge at the moment are the lack of a clear (human) dose-consequence relationship, potentially involved susceptibility genes, epigenetic consequences (also in further generations), data driven downstream pathway analysis, and reliable biomarkers to detect both, susceptibility and exposure. Priority should be given to improve our current understanding of the pathophysiology of FASD. A big potential lies in the use of integrated data analysis within metabolites/ metabolomics, gene expression, epigenetics, genetic/genomic, and linked data to overcome this gap.

[P23] A normalized cut-off for urinary ethylglucuronide for the assessment of alcohol consumption during pregnancy: comparison between biochemical data and screening questionnaires. What is the best indicator?

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Background: Ethylglucuronide (EtG), a product of ethanol metabolism, is commonly used as a marker of alcohol consumption and can be identified also in urine. Fetus can be harmed by alcohol drinking during pregnancy, so, is important to reveal any form of use and abuse during this period. For this reason, different detection strategies have been planned, including that of using screening questionnaires as the AUDIT-C, T-ACE and TWEAK. This study intends to compare biochemical data with the outcome of questionnaires, plus a food diary routinely in use in our Hospital, and to define a cut-off value for EtG in random urine spot samples, normalized for the amount of creatinine excreted.

Methods: Random urine samples were collected from 214 pregnant women immediately after the interviews. EtG was quantified using an enzyme immunoassay and urinary creatinine was assessed using an enzymatic colorimetric method. Women that had not exhaustively answered to one of the questionnaires, or that refused to provide urine sample were excluded. At the end, only 182 women had a complete set of data and were considered for this study.

Results: A normalized cut-off at 105 mg/g of urinary creatinine was established using the 90th right sided percentile of the population of pregnant women who declared no alcohol units consumed per month before pregnancy (n=54). Our data show that 20.3% of the pregnant women in study was over the established normalized cut-off value. A moderate concordance (unweighted $k=0.47$) was found between the normalized cut-off and the cut-off proposed by the test manufacturer (100 ng/mL). Poor to null concordance (unweighted $k<0.2$) was found between EtG data and all of the alcohol screening interviews, these last showing, on average, lower levels of alcohol consumption.

Conclusions: This study provides evidences that the assessment of maternal alcohol consumption during pregnancy, only indirectly estimated with questionnaires and food diary, can produce misleading ratings.

[P24] FASD and immunodeficiencies. Specific immunological examinations as a component of FASD-diagnostic evaluations.

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Background. Individuals with an FASD diagnosis often show elevated rates of infectious diseases in early childhood. This suggests that the immune system may be affected by prenatal alcohol exposure. Furthermore, higher rates of comorbidity between FASD and diseases of the immune system have previously been described, i.e. in rheumatic and other autoinflammatory diseases.

Objective. In this study we examine whether immunodeficiency is verifiable in children with an FASD diagnosis and whether an FASD-specific pattern can be shown. Specific parameters may be identifiable and should be considered when examining FASD patients' immune status to detect treatable immunodeficiencies in time. This can help in improving diagnostic and therapeutic procedures for children with an FASD in regards to immunodeficiency.

Material and methods. All patients were diagnosed at the FASD Center of SPZ Leipzig. In cooperation with the ImmunoDeficiencyCenter Leipzig at St. Georg Hospital we currently examine children who are diagnosed as FASD and present with increased rates of infections. The study will include 20 children with established FASD diagnosis. A control-group consisting of children without an FASD diagnosis will be included as well. During our study we will perform:

- A collection and evaluation of clinical data, specifically anamnesis of infections (questionnaires),
- Immunological laboratory testing, i.e. phenotyping of immune cells.

Results. The study is performed prospectively and we will report on first trend results.

[P25] Abnormal cortisol awakening response in teenagers associated to mother's alcohol problematic

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Background: Prenatal alcohol exposure (PAE) can lead to a range of neurodevelopmental changes, which could affect systemic functioning and drive to dysregulation of the hypothalamic–pituitary–adrenal (HPA) axis. PAE is associated to changes and deficits in cognitive and academic skills. The aims of this study were: (1) to analyze the association of cortisol awakening response in 12 years old children with positive alcohol diagnosis using the ICD-10 research criteria to assess any diagnosis of harmful use or alcohol dependence in pregnancy; (2) To evaluate the association of cortisol awakening response in 12 years old children with mother's positive screening using the AUDIT-Total score questionnaire, which was used to identify alcohol problematic use.

Methods: From the longitudinal prospective study INFANTO-ALCOHOL, a subsample included 76 mothers and their 12-year-old children prenatally exposed to ethanol and controls. The AUDIT questionnaire was used to assess current alcohol consumption problems. Salivette saliva samples for circadian and CAR (cortisol awakening response) cortisol analysis were collected from all children and analyzed by radioimmunoassay method.

Results: (1) A positive correlation between mother's AUDIT positive and 12 years-old child salivary cortisol awakening response (CAR). (2) There was a strong association of ICD diagnosis for both diagnosis of harmful use and alcohol dependence with the levels of CAR.

Conclusion: The study results indicated a possible relevant association between levels of cortisol awakening response and mother's AUDIT total score. Pregnant women with a positive alcohol dependence or harmful use ICD diagnosis are more likely to heavily consume alcohol in pregnancy. Considering the known role of cortisol in the stress response and sleep regulation, we postulate that PAE, even in the absence of a clinical FASD diagnosis is implicated in developmental psychopathological relevant mechanisms.

[P26] Towards analysing the effect of alcohol exposure on the fetal brain using 3D neurosonography: building age-specific fetal brain atlases

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Background: Studies have shown that prenatal alcohol exposure can cause structural brain abnormalities in early stages of fetal development. Although ultrasound has been used for decades as the main modality to examine prenatal health, little attention has been given to investigate alcohol-related effects on fetal brain development using fetal neurosonography. This might be explained by the low signal-to-noise ratio, the arbitrary position of the fetal head, and the difficulty in interpreting complex fetal brain anatomies.

Methods: As a pilot study, this work focuses on investigating fetal neurosonography of healthy subjects from a large population to build a reference model to facilitate future disease-related studies. We use cutting-edge image analysis and deep learning techniques to exploit the sonographic patterns contained in fetal neurosonograms. A 3D convolutional neural network is built to simultaneously detect within a 3D volume six key fetal brain structures: the cerebellum, thalamus, lateral ventricle, cavum septum pellucid, brain stem and eye. Via omni-supervised learning, the model scales from 200 annotated training examples to 3,500 unlabelled volumes without further human intervention.

Results: Experiments demonstrated the established framework successfully boosted the localization accuracy from 2.07 ± 1.65 mm to 1.76 ± 1.35 mm on a hold-out validation set. Furthermore, we aligned the fetal brains of 4,044 subjects using the six automatically detected key fetal brain structures as landmarks. The aligned volumes are grouped based on their gestational age (range from 20 to 30 weeks) to produce age-specific brain atlases.

Conclusion: The proposed model can assist in evaluating fetal brain development directly in utero. Our future study aims to apply this tool on prenatal alcohol exposure cases, and compare them against the established brain atlases.

[P27] FASD in residential care facilities for children and adolescents who cannot live at home: a pilot study to estimate prevalence

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Background: Approx. 95,000 children and adolescents live in residential care facilities in Germany, 74,000 in foster care. Whilst FASD has long since been a topic of discussion in the foster care system its importance has only recently been recognised in the residential care system. A meta-analysis for Europe quotes prevalence of FASD in children at approximately 2%. An international meta-analysis in foster families estimates the prevalence of FASD to be 30% to 52%. There are no figures on prevalence for children in residential care. The Diakonische Werk Berlin-Brandenburg-schlesische Oberlausitz (DWBO) realised the potential danger of not dealing with this subject and launched a survey on FASD.

Methods: A standardized online questionnaire was sent to all 35 DWBO residential care facilities (approx. 2,200 placements). Discussion rounds were set up with facility managers. The following questions were asked: Is FASD a subject you are familiar with? How many cases of FASD are you aware of?

Results: 21 out of 35 residential care facilities participated (63%). The majority (62%) had either not tackled the subject of FASD at all or had not gone into any depth. Eight facilities cared for 27 children or adolescents already diagnosed with FASD at the time the survey was carried out. This leads to an estimated prevalence of 4.4% in the participating residential care facilities.

Conclusion: The prevalence of FASD estimated in this survey in children's residential care homes is higher than the prevalence in the general population, but lower than the rate determined for children in foster care. This is probably due to the fact that knowledge of FASD is greater in foster families than in the residential care system and many FASD cases in residential care will presumably go undetected. At the moment our focus is on FASD awareness and on the impact of FASD in the residential care system. A follow-up study including FASD screening and diagnostics is planned.

[P28] 3D-Analysis of philtrum depth in children with fetal alcohol spectrum disorder (FASD)

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Background: The diagnosis of FASD is complex and a high number of unreported cases are assumed. With our study, we aimed to analyse metric differences concerning philtrum depth at different measuring points in FASD children compared to a healthy control group using 3D measuring methods.

Methods: The FASD-group consisted of 25, and the control group (c-group) of 30 children. Sex and age at examination date as well as measurements of body length, weight and head circumference were recorded. In addition a 3D facial scan was taken. The philtrum data were extracted from the 3D-measurements and the metric depths at defined measuring points P1-P4 were determined.

Results: The philtrum depths for the single points P1 ($p=0.025$), P2 ($p=0.001$), P3 ($p<0.001$) and P4 ($p=0.001$) differed significantly between the collectives, with the control group showing ≈ 0.4 mm greater measurements at each of the respective points compared to the FASD-group. The deepest measurements were found at P2 (0.59 mm) and P3 (0.41 mm).

With respect to the mean of head circumference there were also significant differences to be found when comparing FASD and c-group ($p=0.001$).

Conclusion: Head circumferences and philtrum depths in children with FASD are significantly smaller compared to healthy controls and therefore indicators for the respective diagnosis. Using 3D methods, significant differences in philtrum depth can be quantitatively detected and therefore provide additional evidence in verification of FASD diagnosis.

Using the presented method, percentile curves for philtrum depths could be developed.

[P29] A Danish fetal alcohol spectrum disorders definition

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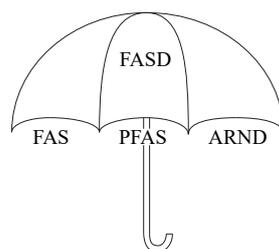
Background: Fetal alcohol spectrum disorders (FASD) is an umbrella term of a continuum of disabilities due to prenatal alcohol exposure. Yet, we do not have an international consensus of the definition of FASD and the diagnostic criteria of the conditions. Since 1994, the International Classification of Diseases has covered the most severe condition of FASD; fetal alcohol syndrom (FAS), but without specifying diagnostic criteria.

The Danish Paediatric Society has described the first Danish definition of FASD with specific diagnostic criteria for the conditions. The aim is to introduce a common understanding of FASD among professionals, to implement an evidence-based relevant and easily applicable diagnostic tool and to align examination and follow-up.

Methods: Based on existing guidelines and evidence-based literature, a national guideline on FASD was made in close collaboration with psychologists, the Danish Child and Adolescent Psychiatric Association and leading Danish researchers in the field.

Results: The Danish FASD definition consists of three conditions; FAS, partial fetal alcohol syndrom (pFAS) and alcohol-related neurodevelopmental disorder (ARND). The diagnostic criteria for FAS are at least one structural or functional anomaly of the brain, three facial characteristics and deficit of growth. For pFAS the criteria are at least one structural/functional anomaly of the brain and two facial characteristics. For ARND, at least one structural/functional anomaly of the brain. Confirmation of intrauterine alcohol exposure is a criteria to establish pFAS and ARND conditions.

Conclusion: The Danish definition of FASD and the diagnostic criteria of the conditions have turn out to be crucial evidence-based diagnostic tools for alignment and establishment of a standardization in clinical settings. The danish FASD guideline has been well-received. Based on this Danish FASD definition, a new ongoing Ph.D. project will quantify the problem of FASD in Denmark.



[P30] Neurobehavioral Profiles of Children with Fetal Alcohol Spectrum Disorders (FASD) in the General Population of the United States: Results from the Collaboration on FASD Prevalence (CoFASP)

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Background: The Collaboration on FASD Prevalence (CoFASP) was an initiative funded by the U.S. National Institute on Alcohol Abuse and Alcoholism (NIAAA) to establish the prevalence and characteristics of different FASD diagnoses in four regions of the United States (USA). The protocol for assessing neurobehavioral abilities under this initiative was set a-priori and based on criteria established in the 2016 diagnostic scheme set forth by Hoyme et al. This session will report on neurobehavioral results of the CoFASP children from three of the four regions.

Methods: All first grade children enrolled in public and private schools in three regional communities of the USA were the subjects of this study (N=8737). Children whose families provided consent were either enrolled because of small physical size (height, weight or head circumference) or as randomly-selected controls. A battery of tests was used to assess overall cognition, executive functioning, visual-spatial skills, working memory, learning and behavior. A total of 1,350 children were tested.

Results: In this presentation we will discuss the battery of tests chosen for the study and report on the results of the neurobehavioral testing. The results convey the complexities of the neurobehavioral profiles that emerged with this population. A total of 1220 controls and 23 diagnosed with fetal alcohol syndrome (FAS), 61 diagnosed with partial fetal alcohol syndrome (PFAS), and 46 diagnosed with alcohol-related neurodevelopmental disorder (ARND) will be discussed. Heat maps and scatter plots exemplifying the complexities of the testing profiles by functional area and diagnosis will be shared.

Conclusion: The variability of neurobehavioral deficits in the alcohol-exposed population is great. When making a diagnosis of FASD, that variability and complexity should be considered.

[P31] Initial assessment of the possibility of using a 3D scanner in the diagnosis of FASD syndrome

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Background: It happens that alcohol absorbed by a child during the prenatal period influences the shape of his face. For this reason in the diagnosis of this syndrome anthropomorphic measurements are taken. They are usually made using the traditional measuring tools. Not all parameters can be measured in this way, some of them are assessed qualitatively. The result of the qualitative study depends on the skills of the specialist. The aim of our research was to compare the results obtained using the 3D scanner we built with these coming from the traditional measurement.

Methods: The 3D scanner used consists of two structural light projectors and three cameras. It is able to scan the face in an angle close to 180°. Its resolution is 0.05 mm and is at least a order higher than the traditional measuring instruments. Using the scanner were investigated 60 people. At the same time, measurements were taken for these people using a vernier caliper. The palpebral fissures length, the distance between the pupils and the depth of the philtrum were measured. Because in the case of the depth of the philtrum there is no traditional method that could be used to measure it the obtained data were compared with the qualitative description.

Results: The study made it possible to compare the results obtained using the scanner with the results of measurements using the traditional methods. Statistical analysis indicates that they are in most cases convergent. For several children the differences were greater. They were small children who are difficult to precisely measure.

Conclusion: The use of a 3D scanner simplifies and shortens the examination and enables the measurement of parameters which until now have only been described qualitatively. This solution seems appropriate for screening studies for the early diagnosis of FASD.

[P32] Profile of children seen for Clinical assessment for Fetal Alcohol Spectrum Disorder (FASD) in a General Neurodevelopmental Clinic- Challenges and gaps in service provision

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Background: There is increasing awareness of children with suspected FASD in neurodevelopmental clinics and the community. This, alongside a paucity of national specialist services highlights the need for the development of comprehensive local FASD specialist services.

Methods: Cohort members were identified as having been referred for assessment of FASD, 2011 to 2017, through clinical service records.

Results: 43 children, (22 female), were seen for FASD assessment. In 63%, (n=27), the diagnosis was confirmed or highly likely. In 28%, (n=12), the child did not currently meet diagnostic criteria but FASD remained a potential diagnosis. In 4 children FASD was not thought likely. Of the 27 children with confirmed or likely FASD, 13 (48%) had full or partial facial features of FAS and 14 (52%) had no facial features. Average age at diagnosis was 7.8 years (95% CI 6.8, 8.8). Almost 80% of the cohort had a co-morbidity; ADHD, ASD and microcephaly being most frequent, but multiple other mental health co-morbidities were seen. Microcephaly was more common in children with unconfirmed diagnosis, (P=0.02). All children underwent facial feature assessment. Only 35% of the cohort had a face-to face cognitive assessment. Half the cohort had adaptive functioning assessment using ABAS-2 questionnaire. Only 8 of the cohort were successfully referred to a tertiary FASD diagnostic service, all of whom had complex presentations, and all of whom received a diagnosis (FAS n=1; FASD n=7). The mean time to diagnosis was 9 months (5.7, 12.3). The mean number of times seen was 3.5 (2.6, 4.4).

Conclusion: Over a 7 year period, a substantial number of children were seen in a neurodevelopmental clinic for FASD assessment. These children had complex presentations including multiple co-morbidity requiring in-depth assessment. Without specialist services such children are often seen multiple times and given multiple diagnostic labels without a clear identification of their primary problems.

[P33] Fetal alcohol spectrum disorder in a clinical setting at a child neuropsychiatric department

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Background: Children with Fetal Alcohol Spectrum disorder (FASD) have often neuropsychiatric comorbidities, but the presence of FASD in child psychiatry patients is not systematically studied. We investigated the number of clinical manifestations of FASD in a selected child psychiatry population suspected to have FASD.

Methods: Total sample included 45 children (58% male) between the ages of 6 month and 16 years prospectively evaluated at the Child Neuropsychiatric Department between 2015 and 2018. FASD diagnoses were made using the 4-Digit Diagnostic Code. The children were divided into two groups according to confirmed or not confirmed history of maternal exposure to alcohol, and clinical manifestations of FASD were analysed.

Results: Of the 45 children with suspected FASD, an unknown history of maternal exposure to alcohol during pregnancy was found in 21 cases (48%). All 8 internationally adopted children had lack of confirmed prenatal alcohol exposure. Of the other 13 cases, 6 were children from foster care. In confirmed use of alcohol group, Partial Fetal Alcohol Syndrome was registered in one case, Static encephalopathy /Alcohol-Exposed in 4 children and Neurobehavioral Disorder/Alcohol-Exposed in 10 children. In non-confirmed use of alcohol group, some features of FASD were found in 15 children (equivalent to Static encephalopathy /Alcohol-Exposed in 1 case and Neurobehavioral Disorder/Alcohol-Exposed phenotypes in 14 cases).

Conclusions: FASD diagnosis in a child psychiatry setting indicates children at risk who need help and specialized interventions for their complex problems, although many of them have unknown prenatal exposure to alcohol.

[P34] Is there a Rationale for Applying Paediatric Brain Injury Diagnostic Techniques to FASD Diagnosis?

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Background: As a diagnostic community, we continue to refer to those who suffered prenatal alcohol exposure (PAE) as having a permanent brain injury. However, we do not necessarily rely on the methods or tools commonly used in diagnosing other forms of paediatric brain injury (PBI). There appears to be a number of areas of overlap with respect to diagnosis and outcome between these diagnoses. Review of the PBI literature indicates that there is much to offer the FASD diagnostic process, especially as they share the diagnostic gold standard of relying on a multi-disciplinary team.

Methods: Reviewing the PBI literature we devised & updated test lists for diagnosing FASD for different age groups and used them over the last 8 years. The PBI literature as well as specific training in diagnosing PBI also provided specific techniques (i.e.: use of base rates, understanding variability in outcome, etc). Using data from within our practice, which specializes in diagnosing all forms of paediatric brain injury (whether prenatal or postnatal or traumatic, developmental) as well as 2 community based FASD Teams we compare the outcomes, diagnostic processes, and specific tests which best allow the determination of brain injury from PAE in children as young as 2.5 years up to 18 years.

Results: (1) Areas of overlap are more common than expected. (2) Methods of diagnosis proved to be the same regardless of the cause of the brain injury. (3) Differences between the groups shed light on the neurodevelopmental trajectory. (4) Differences in specific recommendations are required.

Conclusion: The Diagnosis of PBI has much to teach those of us diagnosing FASD from the particular methods used to understanding some fundamental differences in outcome (e.g.: challenges integrating strengths in FASD). Implementing the PBI processes improved our diagnostic acuity.

[P35] Anthropometry in FASD - a longitudinal study

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Department of Ophthalmology, Skaraborg Hospital, Skövde, Sweden.

Background: Longitudinal studies of individuals with Fetal alcohol spectrum disorders (FASD) are warranted. In a previous report, 71 children adopted to Sweden from Eastern Europe were assessed five years post adoption. FASD according to IOM-criteria 2005 were identified in 52% of children (n=37). Diagnostic categories were Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (PFAS) and Alcohol related neurodevelopmental disorders (ARND). The children were called for a follow up as young adults.

Methods: 32 of 37 individuals with FASD were attained for follow-up with physical and neurological examination (20 FAS, 8 PFAS, 4 ARND) as young adults.

Results:

Table. A cohort of children with FASD followed anthropometrically from child- to adulthood. First assessment (n=37) at a median age of 8 years and the second assessment (n=32) at median age of 23 years. All measurements are presented in mean percentile of the group.

| FASD | Weight | Height | Head circumference |
|-----------------------------------|--------|--------|--------------------|
| Children n=37 mean age 8 years | | | |
| FAS (21) | 8 | 10 | <1 |
| PFAS (10) | 41 | 25 | 32 |
| ARND (6) | 43 | 29 | 27 |
| Adults n=32 mean age 23 | | | |
| FAS (20) | 33 | 10 | 16 |
| PFAS (8) | 33 | 36 | 50 |
| ARND (4) | 39 | 16 | 60 |

Conclusion: Growth restriction accompanying FAS persist into adulthood for height and head circumference but there is a slight catch up for head circumference. The number of PFAS and ARND-cases were too few for drawing conclusions.

[P36] How short is a “short palpebral fissure”? - Reference values of palpebral fissures in children and adolescents with and without Fetal alcohol syndrome (FAS)

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Background: The fetal alcohol syndrome (FAS) includes among others the facial dysmorphic feature of short palpebral fissures (PF). According to international FAS guidelines short PF are one of the key physical markers for identifying children with FAS. To date, there are no German reference values of palpebral fissures both in healthy children and adolescents and in children and adolescents with FASD.

Methods: In a controlled study, we intend to measure PF of 1200 children and adolescents with FAS (age range 0 to 18 ys) and 1200 healthy children. The measurement will be made by a device called "2WIN" produced by Adaptica S.r.l. in Italy. The 2WIN is a binocular video-refractor and vision measuring instrument that uses dynamic retinoscopy by infrared light. It also can measure distances in the face of test subjects like the PF or the pupil distance.

Results: The study protocol was presented to the local ethic committee. We expect to present preliminary data at the Berlin conference.

Conclusion: FAS diagnostic guidelines suppose the presence of short PF in FAS patients. German PF norms, however, are lacking. Our study may help to define normal PF and short PF in German children and adolescents. Furthermore, the classic measurement methods of PF by rulers are error-prone. The measurement by a device like the 2WIN are more exactly and reliable.

[P37] Growth trajectories in Fetal Alcohol Spectrum Disorder: Implications for future research.

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Background: Growth restriction in FASD is widely known. However, growth trajectories in affected children have not been well characterised.

Methods: Weight and height measurements, including those from birth were extracted from clinical notes of 39 children seen in a general neurodevelopment clinic for assessment of FASD. Using both WHO and UK growth reference data, growth centiles and Z scores were calculated where data were present. Growth trajectories were classified as previously described by Carter et al 2013; 1) Small for gestational age at birth with poor postnatal growth 2) Small for gestational age with catch up growth 3) Appropriate for gestational age with poor postnatal 4) Appropriate for gestational age with poor postnatal growth. Occipito-frontal circumference for weight and height was also examined.

Results: Of the 39 children (20 female), 32 had birth weight available. 15 (47%) were small for gestational age (SGA) at birth. 7 (47%) children with SGA displayed catch up growth and 8 (53%) did not. 17 children (53%) were appropriate weight for gestational age at birth, the vast majority of whom continued to grow along an appropriate trajectory (>10th centile). Very few children had poor growth trajectories with an onset after infancy. Of the 7 children who did not have birth weight available, all had adequate post-natal growth. Growth centile data and individual trajectories will be presented graphically.

Conclusion: A high proportion of this cohort were born small for gestational age. This concurs with data from similarly exposed cohorts. More than half of children born SGA displayed catch-up growth, but a significant proportion did not. Very few children showed growth stunting postnatally. This study shows abnormal growth trajectories in a significant proportion of children and highlights the need for further investigation, taking into account potential confounding factors including maternal and safeguarding issues.

[P38] Co-occurring vs. multi-occurring mental health diagnoses in children and adolescents with FASD

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Background: A high rate of co-occurring mental health disorders among children and adolescents with FASD has been documented. However, it is important to distinguish between conditions that are co-occurring (implying a direct association with an index disease) and multi-occurring (meaning any co-occurrence of separate disorders). The purpose of this study was to explore the association of biological factors related to alcohol exposure and environmental factors related to out-of-home placement with specific psychiatric diagnoses.

Methods: 119 foster and adopted children (63 with FASD and 56 with no prenatal exposure to alcohol) underwent a medical/dysmorphia examination and a comprehensive psychological evaluation. A series of predictive discriminant analyses (PDA) was used to assess prenatal exposure patterns and child welfare system factors as predictive factors of mental health diagnoses: Attention Deficit Hyperactivity Disorder (ADHD), Anxiety Disorder, and Mood Disorder.

Results: The prevalence of ADHD was significantly greater in the children with FASD, while the non-exposed children had a significantly higher rate of mood disorders. Prenatal alcohol exposure and number of prior placements were the significant predictors for ADHD. The significant predictor variables for Anxiety Disorder were a history of abuse and a shorter time in current placement. For Mood Disorder, a lack of alcohol exposure and a shorter time in current placement were the significant predictors.

Conclusion: Child welfare system factors as well as biological factors significantly contribute to the occurrence of ADHD, while risk of a Mood or Anxiety Disorder is related to environmental factors. There are opportunities for systems change, especially as related to frequency and duration of placements in the child welfare system, that may help prevent the occurrence of mental health disorders in both alcohol- and non-exposed children in out-of-home placement.

[P39] Substance use and psychiatric comorbidities in adult FASD patients

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Background: Fetal alcohol spectrum disorders (FASD) are a group of developmental disabilities related to maternal alcohol consumption during pregnancy. FASD is a life-long lasting condition with various neurocognitive impairments and deficits in daily-life functioning. Research also indicates that FASD patients have an increased prevalence for substance use, substance related disorders and other psychiatric disorders. In Germany, data on adult FASD patients and their mental health are rare. The study aims to describe substance use patterns and psychiatric comorbidities in adult FASD patients.

Methods: In 2017, a FASD specific consultation-hour for adults has been established at the LVR-Hospital Essen. Structured clinical interviews regarding substance use and current as well as lifetime mental health are an essential part of the diagnostic process. Most patients attending the consultation-hour consented to analyze their diagnostic data for research purposes. Patients of at least 18 years of age, sufficient German language abilities and no acute psychotic disorders are included. In a next step, patients with intellectual disabilities, not related to FASD, will be assessed as control group.

Results and Conclusion: Data collection is still in process, 30 patients are already included. Preliminary results can be presented in September 2018.

[P40] Fetal alcohol spectrum disorders as a risk factor for an increased consumption of drugs and media in adolescence

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Background: Studies indicate an increased prevalence of a clinically relevant consumption of alcohol, nicotine and illegal drugs among patients with fetal alcohol spectrum disorders (FASD). Media consumption in FASD patients may show characteristic features of addictive behavior as well. The present study aims to verify the link between FASD and consumption of drugs and media.

Methods: Caregivers of 44 patients (age M = 15.75 y, SD = 2.54 y; range = 11–20 y) and 44 healthy controls (age M = 15.70 y, SD = 2.45 y; range = 11–21 y) were instructed to fill in a questionnaire about their children. These questionnaires contained information about demographic data, drug consumption and the use of media.

Results: There was an increased regular and earlier alcohol consumption in controls (46%) if compared to the FASD patients (23%). Adolescent persons diagnosed with FASD did not start smoking earlier, but the number of smokers in this group (25%) was higher, only 5% of the controls smoked regularly. Contact with illegal drugs was limited to cannabis (18% in both groups). Patients spent much time with media (median 5h/day, range 0–15 h/day), as did controls (median 4h/day, range 0–15 h/day).

Conclusion: In summary, there was no major difference between teens with and without the diagnosis FASD consumption of drugs and media in adolescence. This result may be explained by a protective environment as controls and adolescents with FASD lived within stable (foster-)families.

[P41] Auditory manifestations in children exposed to alcohol during pregnancy as assessed by otoacoustic emissions

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Background: Over the years, there have been many reports of marked deficits, including sensory impairments, in children with significant prenatal alcohol exposure. However, some of these impairments may also be observed in certain psychiatric disorders, such as autism spectrum disorder (ASD). Otoacoustic emissions can provide information on the sensory component of hearing. The aim of this study was to compare transient otoacoustic emissions in children with significant prenatal alcohol exposure, children with ASD, and children with neurotypical development.

Methods: This observational cross-sectional study included 21 children exposed to alcohol during pregnancy, 12 children with ASD, and 11 children with neurotypical development. All study participants had auditory thresholds within the normal range and no middle ear disturbances. Cochlear function was evaluated using transient otoacoustic emissions. The total responses and responses according to frequency band in each ear were compared between the three study groups.

Results: There was no statistically significant difference in the total response of the transient otoacoustic emissions between the groups. However, the amplitude of the transient otoacoustic emissions at frequencies of 1000 Hz and 1400 Hz was higher in the group exposed to alcohol during pregnancy than in the control group.

Conclusion: Cochlear function at the frequencies of 1000 Hz and 1400 Hz is different in children with prenatal alcohol exposure from that in children with neurotypical development.

[P42] Iron Deficiency and Neurodevelopmental Disorders (ADHD, autism, and fetal alcohol spectrum disorder/FASD - A Scoping Review

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Background: While there are many studies documenting the role of iron deficiency (ID) in neurodevelopmental disorders (NDD), the interaction between ID and NDD is not very well understood and iron supplementation is rarely considered as a primary therapeutic approach. In this scoping review, we investigated 1) the effects of iron deficiency on the severity of neurodevelopmental disorders, and 2) whether iron supplementation improves symptoms.

Methods: Scoping review of 34 studies published between 1994 and 2016 using “iron deficiency anemia” AND “ADHD” OR “autism” OR “FASD” as search terms in various biomedical databases.

Results: Attention deficit hyperactivity disorder (ADHD) was investigated in 23 studies and 3 systematic reviews, autism spectrum disorder (ASD) in 8 studies, while none of the studies focused on fetal alcohol spectrum disorder (FASD). In association studies, a positive association with iron deficiency was found in 13/18 ADHD, and 4/8 ASD studies. In treatment studies, iron supplementation was beneficial in 4/5 ADHD studies, which included one RCT.

Conclusion: Most of the studies indicated a correlation between ID and ADHD. Due to the search criteria, two FASD studies were not included in this review. Their results revealed that young children whose mothers drank heavily were more likely to be diagnosed with iron deficiency compared to controls. In light of the results for ADHD and knowing the role of iron deficiency in neurodevelopmental disorders, iron investigation and supplementation should be considered in children and adolescence with FASD. In addition, data should be collected in order to create evidence.

[P43] Iron Deficiency and Sleep - A Scoping Review

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Background: Up to 80% of children and adolescents with FASD have insomnia. Over the last 20 years, experimental studies have show deleterious effects of prenatal alcohol exposure on brain iron status. In this review, we investigated 1) the effects of ID on symptom type and severity of sleep disorders, and 2) whether iron supplementation improves symptoms.

Methods: Scoping review of 94 studies published between 1972 and June 21, 2016 using terms such as "iron deficiency anemia" and "sleep" in biomedical database search engines.

Results: We did not find any studies that described comorbid FASD and sleep disorders. However, restless legs syndrome (RLS) was investigated in 75 articles (73 primary studies and 2 systematic reviews), Periodic limb movements in sleep (PLMs) in 8, Sleep disordered breathing (SDB) in 3, and General sleep disturbances (GSD) in 8. In association studies, a positive association with iron deficiency was found in 30/43 RLS, 3/8 PLMs, 2/2 SDB, and 5/6 GSD studies. In treatment studies, iron supplementation was beneficial in 29/30 RLS, 1/1 SDB, and 2/2 GSD studies. Out of the 33 treatment studies, six were RCTs all of which were conducted in RLS populations with 5/6 showing a therapeutic benefit of iron supplementation. For association studies in pediatric populations, 1/1 RLS, 1/1 SDB, 2/5 PLMs, and 4/5 GSD studies found positive associations. For treatment studies in pediatric populations, 6/6 RLS and 2/2 GSD studies demonstrated a benefit of iron supplementation.

Conclusion: Although we found no studies that focused on FASD specifically, findings from our scoping review suggest that iron screening and supplementation would be beneficial for children/youth who present with comorbid FASD and sleep disorders. Future studies should be conducted that explore the link between FASD, sleep disorders and iron deficiency.

[P44] Assessment of auditory function in schoolchildren exposed to alcohol during pregnancy

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Background: The consumption of alcohol by pregnant women causes abnormalities on fetal growth and development, including structural and functional changes in the Central Nervous System. Changes in hearing sensitivity have been well studied, but the involvement of the auditory central nervous system still needs more research. Our objective is to study peripheral and central hearing function in school-age children with prenatal exposure to alcohol.

Methods: The participants were 45 children of both genders between the ages of 13 and 14. They were allocated into two groups based on whether they were exposed to (EG) or not exposed (NEG) to alcohol during pregnancy. The following tests were performed: pure tone audiometry, acoustic immittance, transient otoacoustic emissions (T-OEA), auditory brainstem responses (ABR), late auditory evoked potentials, long-latency auditory evoked potential (LLAEP) and event-related auditory potential (ERAP), registered in Cz and Pz, with comparative analysis between groups.

Results: Only one child of EG had unilateral mixed hearing loss. The other participants were found to be in normal hearing thresholds with tympanometric curve type "A" being predominant, and contralateral acoustic reflex being present. There were no differences between the cochlear function and behavioral auditory processing assessment. Although the ABR results have been suggestive of change in neural synchrony at the brainstem, the difference between groups was not confirmed. For the LLAEP, the EG showed lower amplitudes for P2, at the Pz deriving electrode; the EARP P3a component had larger amplitudes in EG, at Cz. The comparison between the active electrode was possible to record a greater identification of the P3 components with double peak for the electrode in Pz.

Conclusion: Pregnant alcohol use in any trimester was associated with changes in neural synchrony at the brainstem as well as in the identification of P2 and P3a components.

[P45] Efficacy of Repetitive Transcranial Magnetic Stimulation (rTMS) in Treatment of Children with FASD – Study Protocol.

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Background: The proportion of children with ADHD symptoms is significantly higher among patients with FASD than in general pediatric population (49-94% vs. 5%). Symptoms observed in ADHD and FASD such as increased reactivity, attention disorders, difficulties with inhibition of the reaction, are associated with abnormalities in the neurotransmission of dopamine and norepinephrine. Repetitive transcranial magnetic stimulation (rTMS) is a non-invasive therapeutic method used in many neurological and psychiatric disorders. Research shows that its use (especially in prefrontal areas) is connected, among others with an increase in the secretion of dopamine and its metabolites. The use of rTMS in ADHD give promising therapeutic results. Considering the similarity of cognitive and behavioral symptoms in FASD and ADHD, similarity in neurotransmission disorders with a worse response to the use of stimulants in FASD group, it seems reasonable to attempt to use rTMS in the treatment of patients with FASD.

Method/design: Open label pilot study including 10 patients , age 7-12 with diagnosis of FAS, pFAS, ARND (canadian criteria). Included patient will undergo 5-days rTMS therapeutic sessions (low frequency 1Hz, 1200stimuli/day).Cognitive and behavioral assessment will be administered before and 7 days after finishing therapy.

Discussion: This study is designed to examine the therapeutic efficacy of rTMS among children with FASD presenting symptoms similar to those occurring in ADHD.

[P46] Developmental trajectory of adaptive functioning in individuals with FASD/PAE: Impacts of service use

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Background: Researchers agree that individuals with FASD/PAE frequently experience difficulty developing appropriate adaptive skills, such as deficits in social skills, communication, and living skills. Service use (e.g., counseling, support groups) among this population is also high. However, little is known about the developmental trajectory of adaptive skills within this population. Additionally, the impact of service use on adaptive skill development is largely unexplored.

Methods: The following research questions were explored: What is the developmental trajectory of adaptive functioning in individuals with FASD/PAE? What impact does service use have on development of adaptive skills in individuals with FASD/PAE? Children previously diagnosed with FASD ($n = 14$) or PAE ($n = 2$) were assessed at time one (M age = 13 years) and again at time two (M age = 18). During both assessments parents completed the Adaptive Behaviour Assessment System (ABAS-II) and participated in a semi-structured interview exploring services used by the participants and their families.

Results: Results of the ABAS-II will be analyzed at the group and individual levels to outline changes in adaptive functioning across both time points. Interview data will be used to describe the quantity and type of services used by participants and their families. The relationship between service use and adaptive functioning at both time points will be highlighted.

Conclusion: Results will be used to discuss the importance of considering the developmental trajectory of adaptive functioning when designing and implementing interventions for individuals with FASD/PAE. Ways in which this information can be used to tailor interventions will be included. Information regarding the quantity and type of services used by individuals with FASD/PAE and their families will be discussed.

[P47] Let's make learning fun: Developing a learning programme for children with Foetal Alcohol Spectrum Disorders using the animation film making process

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Background: This paper discusses the development of a specifically designed learning programme which focusses on the use of the animation film making process as an educational tool for FASD affected individuals. The film making process requires a slow progression through the development of the chosen topic, such as the passage of time for example. Each task entails significant repetition and the entire process is an interactive experience for the animator (which in this case would be the participant). The film making process can require the use of the animators visual, auditory and kinaesthetic learning pathways which enables the process to be adapted to target a single learning approach or multiple.

Methods: With consideration of existing strategies such as the Math Interactive Learning Program developed by Claire Coles and colleagues at Emory University, and Social Stories developed by Carol Gray, a specifically designed programme has been developed to lead the participant through the production of an animated film. The process has educational elements of the chosen topic embedded at every opportunity, targeting each of the participants learning pathways. The chosen topic of this study surrounds the concept of time, for which participants will animate their daily routine of brushing teeth, with themselves as the character and their bathroom as the scene. A clock will be animated to display the passage of time as the actions take place and the scene will be produced for morning and evening to reinforce the understanding of this process being completed twice daily. Participants will also narrate their actions to act as a voice over for their film and produce sound effects (the brushing sound) which will play for the duration of 2 minutes.

Results: The expected results upon testing this programme is that the animation film making process can further the understanding of a specific topic, when the programme is designed to meet the needs of the individual due to the hands on, immersive approach to learning. It is expected that participants will engage with this approach to learning and respond positively to producing a short film which can be viewed as a visual reminder when brushing their teeth in the future.

Conclusion: Further research is to be carried out to explore the use of this programme with different topics and larger participant groups to gain full understanding of the level of success. Understanding money and values of is a desirable future topic to explore.

[P48] Developing an FASD Framework for the Canadian Workforce: A Model for Implementation

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The Canada FASD Research Network

Background: Adequate services and supports are neither available nor accessible for many Canadians affected by FASD. Without appropriate and timely intervention, there is an increased risk of adverse outcomes and secondary disabilities including mental health problems, addictions, incarceration and maladaptive behaviours. Unfortunately, substantial inequalities in how services are accessed and delivered across different geographic regions make it difficult to support individuals with FASD and their families. Front-line workers and service providers are often not sufficiently equipped to effectively engage with individuals and families affected by FASD, and they require specific education and training to provide insight into the manifestations of FASD in their specific context, as well as evidence-based guidelines for best practice.

Methods: In collaboration with key experts and partners, this project will create a targeted Workforce Development Framework. A Needs Assessment was conducted related to FASD knowledge and practice in the identified target workforce sectors. This occurred via an online survey to members of the target sectors. Focus groups were also conducted with various stakeholders. Data generated from the Needs Assessment and the background literature review formed the foundation of on-line accredited training modules and peer-training sessions.

Results: 525 survey responses were collected and analyzed to develop a novel mechanism for education and training that includes models of peer professional training and accessible resources to assist in addressing knowledge gaps, enhance practice and improve outcomes for those providing services to individuals with FASD as well as those with FASD themselves.

Conclusions: The Framework will provide a systematic approach to education and training resources on FASD to promote knowledge mobilization and best practice, general enough to provide a standardized approach and materials, but malleable enough to allow for customization to different sectors. A strategic, evidence-based FASD-informed workforce will assist to equip staff across systems to deliver quality treatment, supports, and services for individuals with FASD.

[P49] Using Screening, Diagnosis and Data to Improve Outcomes in FASD: Canada's National Database

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Background: This paper presents results from the Dataform project, the 1st nationwide study of individuals diagnosed with FASD in Canada. Dataform collected information on demographics, neurobehavioural profile, co-morbidity, medication use, treatment recommendations, post-natal and prenatal exposures. Information will be used to improve outcomes in FASD by identifying red flags for screening, better understanding support needs, and developing new approaches to intervention.

Methods: Researchers identified FASD diagnostic centres across Canada and each received a letter outlining the project and an invitation to participate. Representatives from participating clinics attended an online session to discuss processes and potential data elements. A secure, web-based data form was designed to enter information commonly generated and collected by clinics. The form was completed online by staff from clinics. Descriptive analyses were used on aggregate data.

Results: Twenty-six clinics across the country participated. 656 individuals were assessed and 79% received a diagnosis of FASD. The mean age of diagnosis in the pediatric group was XXX and in adults was XXX ;males and females were equally represented; 8% had all 3 sentinel facial features. PAE was confirmed in 95% of those who received an FASD diagnosis. Growth impairment was not associated with FASD. 72% of the sample has 3 or more functional brain domains impaired and prenatal exposure to cannabis (26%), nicotine (41%) and cocaine (16%) was common. Individuals with FASD had a more legal issues, school problems, and often lived outside of the biological home. Those diagnosed as adolescents or adults used more substances, had a higher propensity for mental health issues, and took a number of medications. Depression and anxiety problems increased with age and the most common recommendation for children was behavioural therapy, and for adults was coaching and support. Behavioural and learning issues were found to be strong indicators for screening and referral.

Conclusions: Knowledge about FASD and its implications may improve outcomes in treatment and intervention. Detailed knowledge of the FASD population in Canada will also help to clinically describe the population and to identify red flags for referral and diagnosis.

[P50] Neurocognitive impairments in adult FASD patients

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Background: Fetal alcohol spectrum disorders (FASD) are a group of developmental disabilities related to maternal alcohol consumption during pregnancy. FASD is a life-long lasting condition with various neurocognitive impairments and deficits in daily-life functioning. Data on neurocognitive impairments in adult FASD patients are rare. FASD-specific neuropsychological patterns in adults are not yet identified. The study aims to describe neurocognitive impairments regarding intelligence, attention, executive functioning and memory in a German sample of adult FASD patients. Results might help to develop diagnostic guidelines for adults.

Methods: In 2017, a FASD specific consultation-hour for adults was established at the LVR-Hospital Essen. A detailed neuropsychological assessment is an essential part of the diagnostic process. To assess global intelligence, executive functioning, attention deficits and certain aspects of memory German versions of *Wechsler Adult Intelligence Scale (WAIS)*, *Tower of London (ToL)*, *Test of Attentional Performance (TAP)* and *Auditory Verbal Learning Test (AVLT)* are applied. Most patients attending the consultation-hour consented to analyze their diagnostic data for research purposes. Patients of at least 18 years with sufficient German language abilities and no acute psychotic disorders are included. In a next step, patients with intellectual disabilities, not related to FASD, will be assessed as control group.

Results and Conclusion: Data collection is still in process, 30 patients are already included. Preliminary results can be presented in September 2018.

[P51] Neuropsychological outcome in adults with FASD and a mental disability

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Background: Mental disabilities are common with people with FASD in about one third of the patients. If a mental disability is known, further neuropsychological tests are often omitted as they are not needed in order to diagnose FASD. Nevertheless, further tests are often the basis for following treatment and counseling. Therefore, it is relevant to discuss the possibilities and limitations of additional testing in this group of patients.

Methods: In this pilot study, neuropsychological performance of 20 patients with FASD and a mental disability were compared to 20 patients with FASD and a learning disability or a normal IQ. All patients were diagnosed at our outpatient FASD-clinic in Berlin. A variety of standardized neuropsychological tests were administered to evaluate the CNS-score, including a verbal learning and memory test (VLMT), the developmental test of visual perception for adolescents and adults (DTVP-A), a word fluency test, a computer-based test battery to test attention and executive functioning (TAP) and IQ-scores (WAIS-IV).

Results: Although people with a mental disability show generally more deficits in different neuropsychological domains, a similar variety of strengths and difficulties can be detected in both groups. Half of the patients showed a rather homogeneous neuropsychological profile whereas the others displayed a heterogeneous profile in both groups. The areas mostly impaired were attention followed by executive functioning and maths in both groups. Language and visual perception were more often deficient with people with FASD and a mental disability.

Conclusion: Especially adults with FASD and a heterogeneous neuropsychological profile are at risk to suffer from excessive demands by others. In these cases, counseling can be a helpful tool for a better understanding. Nevertheless, additional testing can also be exhausting and a confrontation with one's deficits. Therefore, a test session in the group of patients with a known mental disability should be included if possible, but more individualized and more efficient.

Exhibitors

(in alphabetical order)

I - Books, Brochures and Other Media

The German Federal Centre for Health Education (BZgA)

Since its foundation in 1967 as a federal authority in the portfolio of the German Federal Ministry for Health, the Federal Centre for Health Education (BZgA) has fulfilled the task of publishing information concerning prevention and the promotion of health concerns. In its function as a competence center for health promotion it develops together with co-operation partners strategies to strengthen health education and prevention as well as implementing them in various campaigns and activities.

For the European Conference on FASD from 24–26 September 2018 and the German Conference on FASD from 28–29 September 2018, the BZgA has prepared informational materials on the subjects of alcohol consumption during pregnancy and while nursing which will be available at the BZgA booth.

More information on select themes and campaigns may be obtained at:

www.sexualaufklaerung.de

www.kenn-dein-limit.de

www.rauchfrei-info.de

www.kindergesundheit-info.de

www.fruehehilfen.de

Contact:

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CanFASD (Canada FASD Research Network) Vancouver, BC, Canada

Mr. Edward Swatschek – Manager, Corporate Services and Communications

Website: canfasd.ca

Email: info@canfasd.ca

FASD Deutschland e.V. Lingen, Germany

N.N. (Members of the organisation team)

Website: www.fasd-deutschland.de

Email: info@fasd-deutschland.de

NTI Upstream Portland, OR, USA

Dr. Ira J. Chasnoff (NTI Upstream and University of Illinois College of Medicine, Chicago, Illinois, USA)

Website: www.ntiupstream.com

Email: info@ntiupstream.com

II - An Exhibition to Visit

FASD-Netzwerk Nordbayern e.V., Braeuningshof, Germany

"ZERO" is a project sponsored by the German Federal Health Ministry.

Originally designed and presented in German, this exhibition has now been adapted for an international public, especially for this conference - thanks to the generosity of the Federal Health Ministry which has kindly provided funds for translation and all other costs involved.

"ZERO" is here for the entire conference - an interactive exhibition in a dome tent we call "the walk-in womb". Experience 40 weeks of pregnancy from the perspective of the unborn child: look, touch and listen. Learn about pregnancy, alcohol and FASD. Listen to people with FASD - how it effects their lives. Enjoy this special exhibition, a mobile prevention campaign aimed at a young public.

Dr. Heike Kramer and/or Dr. Gisela Bolbecher from FASD-Netzwerk Nordbayern will be available to take your questions during the breaks and at lunch time. Please feel free to visit "ZERO" at any time that suits you.

Website: www.fasd-netz.de

Email: info@fasd-netz.de



The Reichstag



Federal Government



TV Tower



Brandenburg Gate



Siegessäule - triumphal column

We wish you a pleasant time in Berlin!