



EUROPEAN
FASD
ALLIANCE

PROGRAM

EUFASD 3 CONFERENCE

Rome, October 20 to 22, 2014



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Table of content

Conference chair, scientific and local planning committees 2

Conference program: 3-11

Monday 3

Tuesday 5

Wednesday 7

Paralell Sessions A, B 8

Paralell Sessions C, D, E 10

Paralell Sessions F, G, H 11

Abstracts [1-61] 12-72

Abstracts Posters Monday [1-23] 73-96

Abstracts Posters Tuesday [1-25] 97-122

Attendee list 123-127

EUFASD3 Conference

Rome, October 20 to 22, 2014

CONFERENCE CHAIRMAN: Mauro Ceccanti

Scientific planning committee

Tatiana Balachova
Diane Black
Magdalena Borkowska
Oscar Garcia-Algar
Ilona Autti-Rämö
Denis Lamblin
Raja Mukherjee
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Marina Romeo
Luigi Tarani


Program EUFASD3 Conference

Rome, October 20 to 22, 2014

Monday, October 20, 2014



08:30	Registration desk opens
09:00 – 09:15	Welcome Mauro Ceccanti
09:15 – 11:00	Plenary Session I: Prevention Session chair: Raja Mukherjee
09:15 – 09:45	[1] Ken Warren, USA Alcohol and Pregnancy in History and Art: Were There Missed Clues Along the Way?
09:45 – 10:05	[2] Marianne Virtanen, Norway Alcohol free pregnancy – A successful campaign in Norway
10:05 – 10:25	[3] Jocelynn Cook, Canada Screening for FASD and risky drinking in substance abuse and mental health centres: a Canadian pilot study
10:25 – 10:45	[4] Marjetka Hovnik Keršmanc, Slovenia Raising awareness on hazardous consequences of alcohol to the unborn child – a pilot project from Slovenia
10:45 – 11:00	Questions and Discussion
11:00 – 11:30	Coffee break and poster viewing
11:30 – 13:00	(Continuation of Plenary Session I) Session chair: Oscar Garcia-Algar
11:30 – 11:50	[5] Samantha Marchant, UK Birth mother's report
11:50 – 12:10	[6] Tatiana Balachova, USA The population health impact of small effects: a clinical trial of a brief physician intervention to reduce prenatal alcohol exposure in Russia
12:10 – 12:30	[7] Patrizia Riscica, Italy An international campaign to raise awareness of FASD
12:30 – 12:50	[8] Christina Chambers, USA The impact of micronutrient supplementation in alcohol-exposed pregnancies on gestational age and birth size
12:50 – 13:00	Questions and Discussion



13:00 – 14:00

Lunch and poster viewing

14:00 – 15:35

Plenary Session II: Diagnosis/Recognition
Session chair: Ed Riley

14:00 – 14:45

[9] Keynote lecture: Peter Hammond, UK
3-D facial imaging

14:45 – 15:05

[10] Phil May, USA
FASD prevalence and characteristics in Italy: Is this pattern similar to others in Europe?

15:05 – 15:25

[11] Katarzyna Okulicz-Kozaryn, Poland
FASD prevalence among school children in Poland

15:25 – 15:35

Questions and Discussion

15:35 – 16:05

Coffee break

16:00 – 17:15

Plenary Session III:
Use of video for FASD education and awareness

16:05 – 16:35

[12] “FASD: Do you know it?” (Daniela Fiorentino, Italy)

16:35 – 16:55

[13] “Living with FASD” (Liv Drangsholt, Norway)

16:55 – 17:15

[14] “Sensitive Souls” (Anje Dalhoff, Denmark)

Tuesday, October 21, 2014

08:30

Registration desk opens

09:00 – 09:05

Welcome

09:05 – 10:45

Plenary Session IV: Education and intervention
Session chair: Leopold Curfs

09:05 – 09:25

[15] Edward Riley, USA

Speculations and food for thought: what happens when children with FASD become adults?

09:25 – 09:45

[16] Raja Mukherjee, UK

An exploration of neurodevelopmental profiles in children and adults with FASD: findings from a national clinic

09:45 – 10:05

[17] Michaela Thomas, adult with FASD, UK

My journey so far

10:05 – 10:25

[18] Claire Coles, USA

Reducing disruptive behavior using the gofar program in children with FASD

10:25 – 10:45

Questions and Discussion

10:45 – 11:15

Coffee break and poster viewing

11:15 – 12:55

(continuation of Plenary Session IV)
Session chair: Marco Fiore

11:15 – 11:35

[19] Magnus Landgren, Sweden

Academic and social implications for children adopted from eastern Europe diagnosed with FAS – a 15-year follow-up

11:35 – 11:55

[20] Joanne Rovet, Canada

Self-regulation therapy induces neuroplastic change in children with FASD

11:55 – 12:15

[21] Teresa Jadczyk-Szumilo, Poland

Assessment of right hemisphere language functions in children with FASD


12:15 – 12:35

[22] Osman Ipsiroglu, Canada

Screening for sleep problems can become part of standard practice in FASD diagnosis and treatment

12:35 – 12:55

Questions and Discussion



13:00 – 14:00

Lunch and poster viewing

14:00 – 15:00

EUFASD Alliance General Assembly
with election of new board

15:00 – 16:30

Parallel Sessions A, B, C and D
(see end of document)

16:30 – 17:00

Coffee break

17:00 – 18:00

Parallel Sessions E, F, G and H
(see end of document)

Wednesday, October 22, 2014

08:30	Registration desk opens
09:00 – 09:05	Welcome
09:05 – 10:45	Plenary Session V: Ethical issues Session chair: Peggy Murray
09:05 – 09:25	[23] David Townend, The Netherlands Legal and ethical questions posed by FASD
09:25 – 09:45	[24] Ilona Autti-Rämö, Finland The ethics of access to diagnostics
09:45 – 10:05	[25] Nancy Poole, Canada Screening and testing for prenatal alcohol exposure: balancing ethics, effectiveness, and public health policy
10:05 – 10:25	[26] Denis Lamblin, France How the prevention of FASD contributes to compliance with the international rights of the child
10:25 – 10:45	Questions and Discussion
10:45 – 11:15	Coffee break and poster viewing
11:15 – 12:05	Continuation of Plenary Session V Session chair: Diane Black
11:15 – 11:35	[27] Tiziana Codenotti The future of FASD prevention in Europe
11:35 – 11:55	[28] Margaret Murray Joining Forces: Using Global Health Policy to Address Fetal Alcohol Spectrum Disorders in Europe and North America
11:55 – 12:05	Questions and Discussion Announcement of election results (Gisela Michalowski) Announcement of next conference (Raja Mukherjee) Closing remarks (Mauro Ceccanti)
12:30	End

Parallel Sessions

A Prevention

Session chair Magdalena Borkowska

[29] Daniela Fiorentino, Italy

Comparison of three different methods to evaluate alcohol consumption in pregnancy

[30] Oscar Garcia-Algar, Spain

Advances in the development of novel antioxidant therapies as an approach for fetal alcohol syndrome prevention

[31] Rosanne Kristiansen, Norway

Screening pregnant women for alcohol use before and during pregnancy

[32] May Olofsson, Denmark

Family centers in Denmark

[33] Patrizia Musacchio, Italy

Continuing education as a key element for universal prevention

[34] Sylvia Roozen, The Netherlands

Improving health promotion related to FASD: A systematic literature review

B Adoption issues

Session chair: Ilona Autti-Rämö

[35] Luigi Tarani, Italy

FASD in adopted children from Eastern European countries

[36] Laia Martinez Ribot, Spain

Information on FASD during the adoption process and FASD diagnosis in adopted children in Spain

[37] Natalia Barcons, Spain

FASD in Eastern European adopted children in Spain

[38] Stephanie Toutain, France

Children with special needs, adopted through the French Agency for Adoption in Europe, between 2007 and 2010

C Medical understanding

Session chair: Jessica Wagner

[39] Popova, Svetlana, Canada

Comorbidity of Fetal Alcohol Spectrum Disorder: A systematic literature review and meta-analysis

[40] Erikson Felipe Furtado, Brazil

Mother's T-ACE positive screening associated with abnormal cortisol in 12-year old children

[41] Luigi Tarani, Italy

Seizures in fetal alcohol spectrum disorders: Evaluation of clinical, electroencephalographic, and neuroradiologic features in a pediatric case series

[42] Jennifer Thomas, USA

Dietary nutrient intake is associated with hyperactivity among children with prenatal alcohol exposure

[43] Jenny Rangmar, Sweden

Follow-up study on neuropsychological and psychosocial functioning in adults with fetal alcohol syndrome

D The Keys to FASD Success

[44] Session leader: Jeff Noble

E Prevention: community efforts

Session chair: Thierry Maillard

[45] Jan-Peter Siedentopf, Germany

Detection of alcohol consumption in pregnancy: a comparison of current practice and recommendations given in Vienna, Austria and Berlin, Germany

[46] Denis Lamblin, France

A new plan for France

[47] Deborah Rutman, Canada

Evaluating FASD prevention and support programs: How value-based program evaluation supports planning, practice, and program implementation

[48] Kathleen Mitchell, USA

Organizing and creating a collaborative unified voice of FASD prevention

[49] Daniela Fiorentino, Italy

A FASD awareness campaign

F Diagnosis

Session chair: Luigi Tarani

[50] Lori Vitale Cox, Canada

TES Diagnostic Wheel for FASD and related conditions

[51] Jocelynn Cook, Canada

The revised and updated diagnostic guidelines for Fetal Alcohol Spectrum Disorder (FASD): Best practice recommendations

[52] Miguel Del Campo Casanelles, Spain

Training for the recognition of physical features of FASD

[53] Annet Toornstra, The Netherlands

School children at risk of prenatal alcohol exposure in rural Southwest Ukraine; assessment according to the 4-digit code and a neurodevelopmental test battery

[54] Katarzyna Anna Dylag, Poland

Conclusions after one-year-long experience of first multidisciplinary FASD diagnostic center in Poland

G Raising and educating children with FASD

Session chair: Tatiana Balachova

[55] Deborah Rutman, Canada

Becoming FASD informed: strengthening practice and programs working with children, youth and adults living with FASD

[56] Heike Hoff-Emden, Germany

Rehabilitation for children with fetal alcohol spectrum disorders (FASD) - a unique opportunity to create a holistic forecast

[57] Sandra Knuiman, The Netherlands

Parenting stress and overreactivity in adoptive families with FASD

[58] Inger Thormann, Denmark

How to minimize secondary disabilities

[59] Linda Wason-Ellam, Canada

A longitudinal study of school-age learners with FASD

[60] Elena Varavikova, Russia

Making the future for FASD management in Russia

H Awareness project: Discussion & Evaluation by Participants

[61] Session leaders: Stefania Bazzo, Kathleen Mitchell, Patrizia Riscica, Giuliana Moino, Diane Black, Francesco Marini, Lana Popova

ABSTRACTS

[1 – 61]

[1]

Alcohol and pregnancy in history and art: Were there missed clues along the way?

Kenneth Warren

National Institute on Alcohol Abuse and Alcoholism, National Institute of Health, USA

For most of the 20th century alcohol was considered to be a substance that could be ingested throughout pregnancy without posing any potential harm to the developing fetus. The change in this viewpoint to one of recognition that prenatal alcohol could cause lifelong adverse consequences on offspring is often attributed to astute clinical observations made by researchers in Roubaix, France, and Seattle, Washington, U.S., in the late 1960s and early 1970s, respectively. But a look at history reveals that there was a general knowledge among some in the medical community and public officials from at least the 18th century to the very early 20th century (pre-1920) of adverse effects of alcohol in pregnancy, even if it did not include exact knowledge of fetal alcohol spectrum disorders. We can see the evidence for the existence of FASD in pre-20th century art, literature and medical society documents. The event responsible for the seeming mid-20th Century amnesia on alcohol and pregnancy was the worldwide alcohol prohibition movement and reaction to the failure of this social experiment in countries where it was implemented. Those who work on FASD prevention must still strive to overcome inaccurate attitudes and beliefs on alcohol and pregnancy, particularly with groups, communities, and countries where the greatest degree of misinformation exists.

[2]

Alcohol-free pregnancy – a successful campaign in Norway

Marianne Virtanen

Norwegian Directorate of Health

Objectives: A recommendation of “no alcohol in pregnancy” was included in the Guidelines for Pregnancy Care in 2005. The Directorate of Health started a campaign to inform about the recommendation and its background two years later. All pregnant women should be aware of the recommendation and abstain from alcohol from the beginning of the pregnancy, even though it usually requires a change in lifestyle.

Materials and methods: The main target group was women in childbearing age, but their partners were also targeted. The campaign used several information channels: campaign film on tv and cinema, internet, advertisements, journalist seminars, expert opinions and information material at the health centers, GPs, etc.

Results: The message is very well known among the target group and they support it strongly (96 %). Annual surveys show that pregnant women do not drink after a positive pregnancy test. The population in general has become more restrictive to alcohol use in pregnancy. The campaign won a top Sabre-award in its category (measurement and evaluation), and was rated as one of the 50 best campaigns in the world last year.

Conclusion: This campaign has reached the desired outcome. The following conditions have supported its outcome: dissemination of information over a long period of time, extensive scientific references, support from medical experts on FASD, engagement of an excellent film, PR, information and market research staffs, and financial resources to make the campaign visible.

[3]

Screening for FASD and risky drinking in substance abuse and mental health centres: a Canadian pilot study

Jocelynn L. Cook¹; Sterling K. Clarren¹; Katrina Kully-Martens²; Carmen Rasmussen²; Hasu Rajani²; Dorothy Badry³

¹Canada Fetal Alcohol Spectrum Disorder Research Network, Canada; ²University of Alberta; ³University of Calgary

Objectives: FASD often co-occurs with substance abuse and mental health issues; however, traditional treatment approaches have not been successful. Individuals with FASD have higher rates of mental health problems compared to the general population (up to 90% in some studies), and are also at significantly higher risk for developing substance abuse problems. Treatment modifications within mental health and substance abuse services may support successful outcomes for individuals with FASD. The goal of this pilot study was to provide tools and a process for identification of those who may have FASD or who may be at risk for having a child with FASD within existing mental health and/or substance abuse treatment centres.

Methods: Four large programs were selected for implementing training and screening. All programs were linked to diagnostic centres and training was provided related to screening for FASD and/or alcohol consumption during pregnancy. Programs incorporated treatment practices developed for individuals with FASD and provided outreach support to identify others with potential FASD.

Results: Preliminary data suggest that screening tools for alcohol use during pregnancy and for FASD can be successfully incorporated into existing substance abuse and mental health practices, with appropriate training and support. Referral pathways for support and/or diagnosis can be implemented, and services can be better targeted to benefit individuals with FASD.

Conclusions: These data reveal a promising approach to preventing FASD and improving outcomes for those already affected. This model can be adapted and implemented within international substance abuse and mental health facilities to increase successful outcomes for individuals with FASD and for those at-risk.

[4]

Raising awareness on hazardous consequences of alcohol to the unborn child – a pilot project from Slovenia

Marjetka Hovnik Keršmanc¹, Maja Zorko¹

¹National Institute of Public Health Slovenia

Slovene population studies show that hazardous drinking is rising among young females and that we lack programmes for early identification and management of hazardous drinking among women who are pregnant or are planning pregnancy. In response, a pilot project was developed (2013) and carried out (2014) in the south-western region of Slovenia (Gorenjska region). The project aims at raising awareness on hazardous consequences of alcohol to the unborn child and encouraging women not to drink alcohol when planning pregnancy, during pregnancy or when breastfeeding.

Phases of the project are as follows:

1. Assessing attitudes pregnant women and their partners have on alcohol consumption during pregnancy/lactation and knowledge of its harmful effects to the unborn child. Survey among 297 visitors of schools for future parents was carried out.
2. Empowering health professionals to raise awareness among women of childbearing age on the effects of alcohol in pregnancy. A one-day expert meeting was organised. The topics were: epidemiological data, standard units of alcohol beverages, how alcohol affects the foetus, view of gynaecologists and paediatricians on FASD, how to follow a conversation with pregnant women/nursing mothers/women of childbearing period.
3. Raising awareness in the general public and among women of childbearing age about the risks of prenatal alcohol exposure. The health education materials were developed and distributed to health institutions, pharmacies, higher education institutions, student homes, student clubs, social work centres, libraries and others. On FAS day, 9 September 2014, we plan a press conference and a booth.

The project will end in November 2014.

[5]

Birth mother's report

Samantha Marchant

London, UK

I am a birth mother to Stanley who is now 10 years old. Stanley has PFAS.

Stanley goes to a special school but is struggling academically and socially. He finds it difficult to form friendships. He doesn't like change and has a paranoid persecutory complex. He has sensory processing problems. He is good at making things and can show good problem solving skills. He is very hyperactive and has poor short term memory. I would like to talk about my journey and also the educational journey I've had with my son, getting right school and support.

I have been sober 10 years and a single parent to 3 sons; my younger sons (2) and (3) don't have FASD. I am active in trying to raise awareness, have appeared on radio, TV, and in magazine articles hopefully educating people on the effects of drinking while pregnant and the lifelong implications of it, not only for a child affected by FASD but the whole family and society around them. I also work with NOFAS UK doing joint articles and media.

[6]

The population health impact of small effects: a clinical trial of a brief physician intervention to reduce prenatal alcohol exposure in Russia

Tatiana Balachova¹, Mark Chaffin¹, Barbara Bonner¹, Galina Isurina², Larissa Tsvetkova², Elena Volkova³,

¹Department of Pediatrics, College of Medicine, University of Oklahoma Health Sciences Center, Oklahoma City;

²Psychology Faculty, St. Petersburg State University, St. Petersburg; ³Nizhny Novgorod State Pedagogical University, Nizhny Novgorod

Objectives: Maternal alcohol consumption during pregnancy can result in adverse pregnancy outcomes. The problems are completely preventable by avoiding alcohol use during pregnancy. Randomized clinical trials are needed to evaluate interventions for different settings and populations. This study was aimed at evaluating a brief intervention to reduce the alcohol-exposed pregnancy (AEP) risk in Russia, a country with one of the highest alcohol consumption levels in the world.

Materials and methods: A dual-focused brief physician intervention (DFBPI) was designed based on two interventions (Fleming et al., 2008; Floyd et al., 2009) modified to be deliverable by OB/GYN physicians. The intervention consisted of two face-to-face, 5-minute sessions incorporated in routine clinic visits. 767 non-pregnant women, aged 18–44 years, at risk for an AEP were recruited for the study and 72 participants became pregnant during the course of the study.

Results: Physicians can deliver DFBPI during clinic appointments. The AEP risk reduced in both conditions with a stable time effect. Larger changes in drinking amounts, especially prior to pregnancy recognition in the intervention group compared to control. The effect of the intervention on early pregnancy abstinence was significant and remained robust over the 12 month follow-up period.

Conclusion: The effect of the intervention on overall drinking was small in size, but given that the intervention was very brief, requires limited cost or effort, and potentially can be delivered to large numbers of women at OB/GYN clinics routinely, it has a significant impact on the population and provides important public health benefits.

[7]

An international campaign to raise awareness of the risks of drinking in pregnancy

Patrizia Riscica

Health Authority of Treviso, Italy

Background: The EUFASD Alliance, together with the Local Health Authority of Treviso and Fabrica, the communication research centre of Benetton group (Italy), has developed an international communication campaign, launched on September 9, 2014.

Objectives: The aim of the campaign is to create global awareness of the risks of drinking alcohol during pregnancy. The campaign involves entities involved in FASD prevention around the world and facilitates each country to empower their own communities.

Methods: The project consists of a global communication campaign applying theoretical models of social marketing to health promotion to spread a coherent and univocal health message. An action of integrated communication is achieved through a network of partners, with active participation of the citizens. The campaign is adaptable to different countries or areas based on the available resources.

Various modes of communication are used, including traditional and unconventional communication tools, social media, and specific tools of social marketing. During this campaign, healthcare professionals distribute educational materials to women.

Results: Preliminary results of the campaign will be provided during this presentation.

Conclusion: This project will empower local health authorities and NGOs in their efforts to raise awareness; support nascent organizations and networks in areas where there is currently little or no action on FASD prevention; create a network to share materials and best practices; stimulate positive debate among professionals and the public; provide opportunities to compare and evaluate the effectiveness of techniques in various countries and cultures; create solidarity in communities; and, finally, contribute to effective reduction of alcohol-exposed births.

[8]

The impact of micronutrient supplementation in alcohol-exposed pregnancies on gestational age and birth size

CD Chambers¹, CD Coles^{1,2}, JA Kable³, CL Keen⁴, JY Uriu-Adams⁴, KL Jones¹, L Yevtushok⁵, N Zymak-Zakutnya⁶, W Wertelecki^{1,7}, & and the CIFASD

¹Department of Pediatrics, University of California San Diego; ²Departments of Psychiatry and Behavioral Science and ³Pediatrics, Emory University School of Medicine; ⁴Department of Nutrition, University of California, Davis; ⁵Rivne Oblast Medical Diagnostic Center OMNI-Net Center; ⁶Khmelnysky Regional Perinatal Center OMNI-Net Center; ⁷Department of Medical Genetics, University of South Alabama

Objectives: To explore the potential benefits of vitamin/mineral supplements taken in pregnancy in reducing the impact of prenatal alcohol exposure on fetal growth and gestational age at delivery, a clinical trial was conducted in Ukraine.

Materials and methods: Women who consumed moderate-heavy amounts of alcohol in early pregnancy and low/unexposed controls were recruited in pregnancy on average in the 2nd trimester, and were assigned to no supplements, a multivitamin/mineral supplement, or a multivitamin/mineral supplement plus choline for the remainder of pregnancy. Gestational age at delivery, birth weight, length, and head circumference were measured.

Results: A total of 553 women participated in the trial, 270 of whom were in the high-risk group and 283 of whom were in the comparison group. Among those in the alcohol exposed group, women who were assigned to the multivitamin/mineral supplement had infants with significantly higher birth weight and birth lengths than those assigned to the no supplement group ($P's < 0.05$). Women assigned to the multivitamin/mineral supplement plus choline delivered infants at significantly later gestational age and had infants with larger head circumferences at birth than those assigned to the no supplement group ($P's < 0.05$). There was no significant effect of any micronutrient supplementation on any of the growth measures or gestational age in the low/no alcohol group.

Conclusion: Multivitamin/mineral supplementation with and without additional choline may have a beneficial effect on fetal growth and gestational length. This could represent an important intervention in women who have already consumed substantial amounts of alcohol before recognition of pregnancy.

[9]

3-D facial imaging

Peter Hammond

UCL Institute of Child Health, London

The facial effects of prenatal alcohol exposure have been a key element of the diagnosis of fetal alcohol syndrome (FAS) since David Smith and Kenneth Jones coined the term in 1974. In the following four decades, combinations of manual and technology based approaches have been developed to assist non-specialists in assessing facial dysmorphism in general and in diagnosing FAS in particular.

The talk will describe recent uses of 3D photogrammetry and associated computerised techniques to recognise these facial characteristics even when they are more subtle or incomplete as in the broader fetal alcohol spectrum disorders. Obstacles to clinical introduction of the techniques and possible approaches to their removal will be discussed.

[10]

FASD prevalence and characteristics in Italy: Is the pattern similar to others in Europe?

Philip A. May

Nutrition Research Institute, Gillings School of Global Public Health, Kannapolis, North Carolina, USA

The rates of fetal alcohol spectrum disorders (FASD) vary widely from one population to another. And, to a lesser degree, the physical and cognitive/behavioral characteristics of the children and maternal risk factors identified also vary from one population to the next. This presentation will provide the attendees with an overview of findings from two population-based study samples of first grade children and controls carried out in the Lazio region of Italy by scholars from the University of Rome ("La Sapienza") and several universities from the United States (USA).

In the Italian studies, the rate of fetal alcohol syndrome (FAS) was documented to be between 4.0 and 12.0 per 1,000 children, and total FASD was estimated to affect at least 2.3% to 6.3%. These rates exceed what for many years had been estimated for the western world (Europe and North America). The methods of the study will be reviewed, and the specific findings among the children with various diagnoses of FASD and mothers in the Lazio studies will be compared and contrasted to similar studies of several communities in the USA, Croatia, and South Africa. Findings from this research may have important implications for countries throughout Europe. FAS and total FASD may be far more common than previously believed in Europe and the USA. Furthermore, some of the specific characteristics of the children with FASD and the maternal risk factors for FASD may differ with culture and social class.

[11]

Polish study on FASD prevalence among schoolchildren

Katarzyna Okulicz-Kozaryn¹, Magdalena Borkowska¹, Jolanta Terlikowska¹,
Krzysztof Brzozka¹

¹The State Agency for Prevention of Alcohol-Related Problems (PARPA), Warsaw, Poland

Objectives: The main objective of the study is to estimate the prevalence of FASD among children aged 7-9. The study is conducted in a frame of the WHO International Collaborative Research Project on Child Development and Prenatal Risk Factors with a Focus on FASD and is based on an active case ascertainment approach (2012).

Materials and methods: 113 regular and special schools (with in total > 2500 eligible students) from 4 voivodeships with differentiated prevalence of alcohol exposure during pregnancy were randomly selected. In the first stage, children growth deficits and behavioral/learning problems were assessed. In the second stage, data from biological mothers; neuro-psychological evaluation and dysmorphological measures were collected. Diagnosis of FAS, FASD and ARND were formulated by the diagnostic teams based on the Canadian Guidelines (Chudley et al., 2005).

Results: Preliminary results, based on the assumption that ALL children with FASD from eligible sample participated in the study, indicate that estimated rate of FAS among Polish children is no lower than 6/1000, pFAS rate is at least – 8/1000 and ARND – 14/1000.

Conclusion: This study provides first estimates of FASD prevalence in Poland, showing maybe not higher than in other EU countries, but significant rates of disorders associated with prenatal alcohol exposure. Until now these diseases have been ignored by Polish health-care system. Epidemiological estimates provide strong argument for developing procedures and services to support individuals affected by alcohol during prenatal life.

[12]

FASD: Do you know it?

D. Fiorentino¹, R. Ciccarelli² F. Cereatti¹ G. Coriale¹ P. Ciolli³ F. De Rosa¹
R. Sanseverino⁴ M.C.M. Scamporrino¹ S. Solombrino¹ L. Tarani⁵ M. Ceccanti^{1,6}

¹Lazio Regional Center for Alcohol, Rome, Italy; ²SITAC Italian Society for Alcohol Treatment, Rome, Italy; ³Department of Gynaecology- Obstetrics and Urological Science, Sapienza University of Rome; ⁴ASL RMB Alcohol Treatment Unit, Rome, Italy; ⁵Paediatric Department, Sapienza University of Rome, Italy; ⁶Clinical Medicine Department, University of Rome "Sapienza", Italy

Objectives: This is a 20-minute educative documentary about FASD, suitable for enhancing awareness and knowledge of the risks related to alcohol consumption in pregnancy and the damages it causes. It has been conceived for use in Continuing Medical Education courses and professionals' training in general and antenatal classes. But it could be used also in schools in science and biology curricula.

Materials and methods: The dvd tells the story of Cristina and her two-year-old child Giuseppe. Cristina consumed some alcohol during pregnancy and is now taking Giuseppe to the paediatrician to exclude damages for having been exposed to alcohol in uterus. While there, Cristina thinks back to the moment in which her gynaecologist suggested to her to give up drinking. She remembers also a counselling session she had with a psychologist. The dysmorphology exam and the counselling sessions with the gynaecologist and the psychologist are shown. Then Italian experts are interviewed about important issues like epidemiology, prevention, and neuropsychology. The DVD language is Italian with English subtitles.

Results: The DVDs are currently distributed during Continuing Medical Education courses held by the Lazio Regional Center for Alcohol and the SITAC Association for alcohol treatment. So far, 400 DVDs has been printed but, as they can be freely duplicated, their distribution is potentially higher.

Conclusion: Still, in Italy little is known about the risks of alcohol consumption in pregnancy both in health professionals and general population. Easily accessible instruments like this educative DVD can contribute to the enhancement of awareness.

[13]

Documentary film: eye-opening FASD project in Norway

Sveinung Wiig Andersen, Liv Drangsholt, Hilde Evensen Holm

KoRus-Sør, Borgestadklinikken, Regional Center for drug and alcohol dependence, Norway

During the last 5-6 years KoRus-Sør has been involved in education and communication projects about FASD. Producing the documentary film “Born with FASD” has been one of the latest tasks.

In the film, we see Fredrik, Jacob, Veronica and their foster/adoptive families. All three were born with FASD and are sharing some of their experiences living with FASD. Jacob is 12 years old and is struggling with learning disabilities. School and homework are hard. Fredrik (14) is a very open person about living with FAS and he states this is the key to gain support in the local community. Veronica (21) is a young girl who has gone a long way with struggle and hardships, but is now working at the local nursing home.

Professor/pediatrician Jon Skranes and neuropsychologist Sidsel Bruarøy also share their knowledge in the documentary.

We have successfully used the film in our seminars about FASD. The response is extremely good!

The film has three parts:

1. Living with FASD (14 min)
2. School and education (8 min)
3. Looking forward (14 min)

The mission of the film project: The main target groups for this film are both family/caretakers and professionals. We have experienced that there is a lack of knowledge about FASD in Norway, and our hope and aim is to contribute to more knowledge and openness about FASD.

[14]

Using the power of video to raise awareness of FASD

Anja Dalhof

Danish Doc Production

Video can help establish awareness and understanding for people with FASD. I am making a film, "Sensitive Souls," which shows the serious consequences children suffer when alcohol is used during pregnancy.

The film is directed to everybody but especially to foster families, social workers and the entire health care system.

In 1992 I made a film about FAS. This film, "High Hopes," was about the newborn Cecilie, who was born with FAS. In cooperation with psychologist Inger Thormann, who worked at the orphanage where Cecilie lived, I completed this film about Cecilie's struggle against the consequences of her prenatal exposure.

Six years later I made another film about Cecilie when she was about to start school. In this film it was clear that she was isolated and marginalized from her classmates.

In 2012 once again Cecilie, at that time 21 years old, became a protagonist in my new film "Sensitive Souls." I followed Cecilie in her daily life as a young woman. This material is interwoven with the footage from 1992 and 1998. Two other young people with FAS also participate in the film.

The film shows these young people's lives, feelings and thoughts, showing how they suffer from the effects of alcoholism. The film also shows the successes when they are met by understanding and insight from other people, and on the contrary, how serious the consequences can be if children do not receive the necessary help from the beginning.

I hope this film will help raise awareness of the dangers of drinking in pregnancy.

[15]

Speculations and food for thought: What happens when children with FASD become adults?

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Objectives: Children with an FASD grow into adults, yet the literature provides little information concerning long-term health or behavioral consequences. Animal data suggests that individuals with FASD may be more prone to certain diseases. Limited data in humans suggests that in certain cases, individuals with an FASD may display some improvement in their functioning as they mature into the mid years of adulthood. This presentation will speculate on both of these issues, based upon information about fetal programming and brain development.

Methods: Literature was searched using terms of “fetal alcohol” and adults over the age of 19. Similarly, a search for animal studies and long-term health related outcomes. Finally, information on trajectories of brain development was reviewed.

Results: Long-term consequences of prenatal alcohol exposure (PAE) are understudied, but the available work confirms that FASD is a life-long condition. Animal studies report a number of medical issues involving hypertension, insulin resistance, and immunological disorders. More optimistically, brain imaging studies show different trajectories of regional brain development in individuals with FASD compared to typically developing controls. Regional brain maturation may be delayed in FASD, and that as the individual reaches the mid stage of early adulthood years this maturation, especially of white matter may improve the person’s functioning.

Conclusions: While very little research has been done on the long-term effects of PAE, FASD is typically a life-long condition. Preclinical data suggests that PAE is associated with health risks as the person matures. However, regional brain maturation may be delayed or atypical in FASD, and that there is a possibility for an improvement in functioning in adulthood. If these speculations are correct, it is imperative to provide health promotion strategies and protective environments during the protracted period of brain maturation.

[16]

An exploration of neurodevelopmental profiles in children and adults with FASD: findings from a national clinic

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Objectives: The diagnosis of wider disorders under the FASD spectrum remains for many a complicated process. This paper presents the neurodevelopmental profiles that have been identified from those seen in the clinic diagnosed under this umbrella.

Materials and methods: The first 70 cases passing through the clinic were assessed using a range of measure. Areas assessed include IQ, executive function, social communication and associated disorders, attention, impulsivity, communication, pragmatic understanding, sensory profile, functional ability and behaviour rating. In all cases genetic factors, neglect, other prenatal drugs, prematurity and early neglect were accounted for as far as possible. Neurodevelopmental profiles and correlation between findings were explored using quantitative tools to try to identify specific profiles found in FAS and ARND.

Results: Due to the development of the clinic not all cases had all tests completed. Initial findings highlight a disorder that has particular deficits with the use of language combined with executive deficits. The more taxing assessments involving a combination of brain processes such as number letter sequencing were identified as problem areas rather than simple sequencing or shifting problems alone. Further sensory processing identified primarily deficits with auditory filtering and sensory seeking behaviours. When taken alongside an impulsive and inattentive presentation without necessarily hyperactivity raises the question about the validity of some ADHD hyperkinetic diagnoses in this group. Language processing and verbal working memory rather than numerical memory were found to be more in deficit with a large proportion needing to speak out loud to process information. These have behavioural implication that warrants further exploration. Further evaluation will take place and will be presented in Rome.

Conclusion: Our clinic has through careful evaluation of each case, spending two days per person, begun to understand and identify not only markers that will help with diagnosis, point to an understanding of the underlying neurological processes that explain behaviour in affected individuals. These will be explored and presented further in Rome.

[17]

My journey so far

Michaela Thomas, adult with FASD

London, UK

My name is Michaela. I am 25 and have been diagnosed with FAS. Although it was diagnosed when I was 3, I only found out 4 years ago. I am a mother to a 5-yr-old son who has been living with my aunt for 18 months, but we are working towards him coming home.

I was in the care system until I was 21. In the last year I have become more involved in raising awareness about FASD, attending parliament on FAS day '13 with FASD UK. I'm finding my voice and want to educate and raise more awareness of the many adults who are going unsupported and possibly undiagnosed. I'm hoping to work with care leavers and young women with FASD to help them work with the leaving care team, social workers and putting in place supports that weren't there for me.

[18]

Reducing disruptive behavior using the GOFAR program in children with FASD

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Objective: GOFAR was designed to improve self-regulation and adaptive skills in children with FASD.

Methods: The intervention has 3 components: (1) a “serious” computer game that teaches a metacognitive control strategy; (2) parent behavioral regulation training; and (3) Applying metacognitive strategies to learn adaptive skills. The FAR learning strategy teaches children to **F**ocus and make a plan, **A**ct the plan, and **R**eflect back on their actions. 30 participants were randomized to 3 groups: (1) GOFAR Computer Game; (2) Faceland Computer Game; (3) No-Intervention Controls. In both intervention groups 5 sessions of parent training and child computer training (Phase 1) were followed by 5 “applied” sessions (Phase 2). The GOFAR group learned the FAR strategy using a computer game while the FACELAND game group focused on identifying emotions. Disruptive behaviors, including temper tantrums, poor frustration tolerance, impulsivity, destructiveness, aggression, and attention problems, were assessed before enrollment, after Phase 1, and after Phase 2.

Results: Using repeated measures ANOVA, a significant treatment group by time point effect was found on disruptive behavior ($F(4,36)=2.903, p < .035, \text{partial } \eta\text{-squared}=.24$), even when interval between pretest and post-test, child’s age, and IQ were controlled. Post hoc comparisons indicated no change in controls while the GOFAR group showed significant improvements in disruptive behavior after Phase 1 and the FACELAND group showed significant improvements in disruptive behavior after Phase 2.

Conclusion: Results suggest that instruction in the FAR metacognitive learning strategy, via computer or parent-child therapy sessions, resulted in significant reduction in disruptive behaviors.

[19]

Academic and social implications for children adopted from eastern Europe diagnosed with FAS – a 15-year follow-up

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In a previous report 71 children adopted from eastern Europe were medically assessed 5 years post adoption to families in western Sweden.¹ FAS was found in 21/71 (30%) children. A follow-up was commenced in 2014, approximately 15 years later.

Method: A structured telephone interview covering questions concerning social context, adaptation, school, and health, including visual/ophthalmological aspects, was carried out with parents of the adoptees while contacting for a clinical follow-up. Psychosocial outcome data from the first 17 interviews are presented.

Results: Seven males and ten females with a mean age of 21 years were interviewed. Only 3/17 had completed nine-year compulsory school, 8/17 had incomplete grades, 6/17 had been educated in schools for children with intellectual disability. One young man had attempted university studies for a year. All but one, were still living with their parents. Two of the parental couples were divorced. All young adults were still dependent on their parents for practical life issues such as economy, food and clothing. None belonged to a society/organisation for recreational activities. Eleven young adults out of seventeen had had contact with legal authorities, mainly as victims; four girls reported being sexually victimized outside family. All but three had more or less regular contact with a medical doctor, mostly a psychiatrist because of ADHD. Half of the young adults wore glasses.

Conclusion: Despite optimal change for a better milieu, children adopted from eastern Europe at a mean age of 3 years and diagnosed with FAS at 8 years of age had significant academic and social difficulties 15 years later.

[20]

Self-regulation therapy induces neuroplastic change in children with FASD

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Rationale: Children with FASD demonstrate core deficits in inhibitory-control and emotion-regulation aspects of executive function (EF) and abnormal neural systems underlying these skills. Recent studies indicate the Alert Program for Self-Regulation® is efficacious in improving EF skills but associated changes in neuroanatomy were not examined.

Methods: Participants were 37 children with FASD and 20 typically developing controls (TDC) aged 8-12 years. All were tested at baseline and 14 weeks later (posttest). FASD group was randomized to receive the 12-week Alert program after baseline (TXT, n=18) or on study completion (delayed treatment group or DTC, n=19). At both assessment periods, all children received a comprehensive EF evaluation and neuroimaging scan that included structural sequences and functional MRI (fMRI) using a Go/No-Go paradigm. Structural MRI data were analyzed via voxel-based morphometry, cortical-thickness, and deformation-based morphometry techniques. For fMRI, the contrast of interest was the difference in activations between No-Go and Go trials.

Results: Relative to DTC, TXT showed significant improvement in inhibitory control and emotion regulation but not other EF aspects (working memory, planning, attention) as well as fewer externalizing behavior problems. TXT also showed increased grey matter in frontal lobe structures relevant for inhibitory control and increased cortical thickness in frontal and temporal cortices; the proportion of subjects indicating change on DBM was significant only in TXT. On fMRI, TXT showed greater change than other groups in key frontal structures supporting inhibitory control and emotion regulation (right middle and left medial frontal gyri).

Conclusion: Alert therapy induces neuroplastic change in FASD.

[21]

Assessment of right hemisphere language functions in children with FASD. Using spectroscopy to examine CNS in children with FASD

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Purpose: The study focused on assessing children with FASD in terms of their right hemisphere language functions such as: drawing conclusions based on indirect information, sense of humour, understanding metaphors, and linguistic prosody. Additionally CNS was examined using proton MR spectroscopy.

Material and methods: Participants of the study included 124 children with FASD and 52 controls. The group with FASD consisted of: 62 children with FAS, 34 children with pFAS, and 28 children with ARND. Diagnoses were based on assessment of primary dysmorphies. The group was varied in terms of age and gender. All children were tested using Wechsler Intelligence Scale and RHLB-PL. These tests were followed with MR and HMRS examinations. Statistic results were obtained using analysis of covariance (ANCOVA).

Results: Children in the clinical group scored lower in all RHLB-PL tests. Even if normal IQs were identified with Wechsler's Scale, results scored by children with FASD in language tests were significantly different from those obtained by their peers in the control group.

Conclusion: Assessment of right hemisphere language functions may help understand developmental deficits in children with FASD. RHLB – PL tests may be helpful for Polish psychologists in performing neuropsychological assessment of children with FASD. HMRS examination is an effective tool for identifying CNS changes in children with FASD.

[22]

Screening for sleep problems can become part of standard practice in FASD diagnosis and treatment

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Objectives: Growing evidence supports that early intervention in sleep problems can improve outcomes. Undiagnosed sleep disorders can lead to a negative cascade of difficulties during development. We focus on the need for sleep studies in those with prenatal alcohol exposure (PAE) and equip participants with the tools needed for implementing the new version of a Screening Tool (Vancouver Polar BEARS).

Materials and methods: The BEARS is well reviewed (2004, Owens *et al.*), however, clinical experience demonstrates additional impact on the family from any child sleep problem. Devised additional questions to measure family & child stress caused by potential undiagnosed sleep problems. As sleep screening is not yet routine in FASD diagnosis/treatment, devised questions to determine what other diagnoses and treatments (pharmaceutical and behavioural) were attempted before sleep was considered as a factor. To be efficacious, a new tablet format was used, which allows user & practitioner flexibility (e.g.: parents complete in waiting room; can immediately look up definitions of words/phrases) (Results summary/areas for further investigation).

Results: Indicated that the new questions and format are easy to use and the system quickly tabulates useful practitioner information. Tablet format gathers information prior to an office appointment or while the family is in waiting room. The results allow FASD professionals to determine when and if polysomnography/other forms of sleep evaluation are required. Beginning to understand the degree to which an undiagnosed sleep problem affects the child and family. And to delineate additional stress on the family system by the number of other treatments attempted before sleep was considered.

Conclusion: This new form of sleep screening provides excellent results. We can easily train community partners so that screening can occur early in the process. The Vancouver Polar BEARS is therefore an useful adjunct in the understanding of sleep disorders in FASD.

Legal and ethical questions posed by Fetal Alcohol Spectrum Disorder (FASD)

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The extent of the potential risk to the developing foetus posed by the use of alcohol by the mother during pregnancy is increasingly understood, although the precise nature of the threat requires a great deal of further work. Whereas Foetal Alcohol Spectrum Disorder (FASD) is increasingly researched and acknowledged in some places, for example, South Africa, in Europe it is not as firmly on the agenda. It is therefore interesting in its own right. Equally, as more is understood about genomics, FASD becomes an example of other questions about the impact of parental behaviour on the embryo and foetus.

FASD poses a number of difficult ethical and legal questions. Two will be addressed in this paper:

1. Prevention. As it becomes clearer that some patterns of alcohol consumption during pregnancy can have severe long-term effects for the child, is intervention ethical in pre- and proscribing behaviour to women in pregnancy? This is set against the challenge of the concept of the status of the 'future child' in moral philosophy, and the practical problem of the seemingly contradictory positions that prevention would require when considered against many jurisdictions' construction of abortion.
2. Proportionality. It is apparent that there are risks through the use of alcohol, and compared with other risks - for example, from tobacco or other drug use during pregnancy - the risks from alcohol are high. However, whilst the risks are not fully understood, and the potential for discrimination and disproportionate responses are high, FASD poses again the question, how can Laws be framed to create an appropriate balance of precaution and proportionality when risks are not fully understood?

This paper is based on normative reflection of the issues drawn from the systematic literature review discussed in the paper proposed for the conference by Roozen et al. It considers the legal issues from the perspective of the Dutch (Civil Law) and the UK (Common Law) traditions, and the ethical issues from Kantian, Utilitarian, and Virtue Ethics perspectives.

[24]

The ethics of access to diagnostics

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Access to diagnostic procedure is a crucial part of care pathways and treatment processes. A diagnosis has moral and practical consequences in requiring treatments or other modes of care.

Diagnostic procedures tend to obtain substantial symbolic value. This symbolic value may also influence the evaluation, demand and practical application of these tests in a manner that may challenge justice in their distribution (e.g. the tests are not used for those with largest expected health gains). One also needs to ask the question who is qualified to diagnose FASD?

Existing resources of diagnostic facilities differ between countries and within a country. Why is FASD a more welcome diagnosis in one country than in another? Accepting the suggested prevalence of FASD (at least 1/100) requires that resources to diagnose it are provided – yet this is not the case in any western country. Is there a possibility that access to diagnostic and therapeutic facilities is constrained by inequalities having to do with geography, gender, ethnic background, or insurance – or local interest and expertise?

In most cases patients have a right to autonomy, i.e. right to be self-governing agents. The practical challenge with all diagnostic tests is that in order to be fully autonomous, the patient should also understand all consequences of the possible diagnosis. As there exists no consensus on diagnostic criteria, and the cut-off limits are arbitrary, the possibility of a false positive and a false negative has to be kept in mind.

[25]

Screening and testing for prenatal alcohol exposure: balancing ethics, effectiveness, and public health policy

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Objectives: Confirmation of prenatal alcohol exposure can be key to establishing an accurate diagnosis of FASD and early diagnosis may allow for interventions that reduce the development of secondary disabilities associated with FASD and that support women who may be at risk of having another child with FASD in the future. This context has led to increased attention to different approaches to screening and testing of pregnant women and new mothers for alcohol use. This presentation will examine the evidence for different approaches to screening and testing and emerging ethical issues associated with each approach.

Materials and Methods: Different approaches to screening and testing will be reviewed, including validated screening tools (e.g., T-ACE, TWEAK), motivational interviewing approaches, and meconium testing. Research on women's perspectives on screening and testing will also be presented.

Results: Research has shown that because of the punitive and judgmental social and legal positions that society generally takes towards pregnant women who use alcohol and drugs, positive test results often lead to child welfare involvement. Certain approaches to screening and testing can lead to trust and confidentiality concerns between women and health care professionals. Questions have also been raised about targeted versus universal screening.

Conclusions: Screening and testing for prenatal alcohol exposure can play an important role in reducing alcohol-exposed pregnancies by providing opportunities for frank and safe discussion and information-sharing about alcohol use during pregnancy and for providing early intervention and support. However, there are a number of challenging ethical areas which require further exploration and attention.

[26]

How the prevention of Fetal Alcohol Syndrome Disorders contributes to compliance with the international rights of the child

Denis Lamblin

SAF France

This intervention will

- Highlight the close links between the prevention of Fetal Alcohol Spectrum Disorder and compliance with international children's rights.
- Raise the issue, in developed countries, but also in developing countries, confronted often without knowing it, to one of the most important and preventable causes of social inequality and injustice.
- Give strong arguments.
 - To acknowledge this issue which affects more than a million babies worldwide every year.
 - Implement actions supported by the World Health Organization and the United Nations Organisation, as is done for AIDS and Hepatitis C, and is registered in the Millennium Plan.

[27]

The future of FASD prevention in Europe

Aleksandra Kaczmarek

Eurocare

[28]

Joining forces: using global health policy to address Fetal Alcohol Spectrum Disorders in Europe and North America

Margaret M Murray

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As the focus of global health policy moves from infectious disease to non-Communicable Diseases (NCD's) associated with lifestyle risk factors such as unhealthy diet, lack of physical activity, tobacco use and the abuse of alcohol, an important opportunity presents itself for the international FASD community. No longer is the incidence and prevalence of a disease the driving factor in health policy – now, the burden of the problem is the most important consideration.

Fetal alcohol spectrum disorders cause lifelong issues for the affected individual, family, and community that carry a huge burden for societies in high, middle, and low income countries. The FASD research and advocacy organizations in Europe and North America have an opportunity to work collaboratively to develop an international FASD prevention, treatment and research agenda and see that it is well placed on the global health policy agenda.

[29]

Comparison of three different methods to evaluate alcohol consumption in pregnancy

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Objectives: (1) To investigate alcohol consumption in pregnant women (2) To make a comparison among different methods of investigating alcohol consumption in pregnancy.

Materials and methods: A questionnaire evaluating alcohol consumption was delivered, through a semi-structured interview, to women admitted to the delivery ward of a big hospital in Rome. Alcohol information was gathered through three different methods. The first one was a weekly diary evaluating both food and beverages consumption. Then the WHO's AUDIT test for the detection of problematic drinking was embedded in the questionnaire. Finally, the T-ACE test for screening at risk drinking in pregnancy closed the interview. The participation was voluntary and the questionnaire anonymous.

Results: All the women approached (N= 123) accepted to be interviewed. As results from the weekly diary, 31.7% admitted at least some drinking during pregnancy and 2.6% drank more than 1 drink per occasion. Frequency of drinking. Data from the AUDIT showed that 24.4% drank, hence showing a difference compared to the diary ($p < 0.01$). Any of the screened women scored positive for risky drinking neither through the AUDIT nor the T-ACE. Nonetheless, 2.2% answered they needed more than 2 drinks before feeling high (the cut-off point to the T-ACE question about tolerance; it scores 2 points).

Conclusion: This pilot study showed that different methods of investigation get different answers. Answers obtained through the weekly diary and the T-ACE question about tolerance produced higher percentages of consumption and risk, probably because they are able to avoid the effect of social stigma. This has to be taken into consideration, as an accurate evaluation of alcohol consumption during pregnancy is mandatory to prevent foetal alcohol effects.

[30]

Advances in the development of novel antioxidant therapies as an approach for Fetal Alcohol Syndrome prevention

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Background: Ethanol is the most common human teratogen, and its consumption during pregnancy can produce a wide range of abnormalities in infants known as fetal alcohol spectrum disorder (FASD). The major characteristics of FASD can be divided into: (i) growth retardation, (ii) craniofacial abnormalities and (iii) central nervous system (CNS) dysfunction. FASD is the most common cause of non-genetic mental retardation in western countries. Although the underlying molecular mechanisms of ethanol neurotoxicity are not completely determined, the induction of oxidative stress is believed to be one central process linked to the development of the disease. Currently, there is no known effective strategy for prevention (other than alcohol avoidance) or treatment.

Methods: In the present review we will provide the state of art in the evidence for the use of antioxidants as a potential therapeutic strategy for the treatment using whole-embryo and culture cells models of FASD.

Conclusion: We conclude that the imbalance of the intracellular redox state contributes to the pathogenesis observed in FASD models and we suggest that antioxidant therapy can be considered a new efficient strategy to mitigate the effects of prenatal ethanol exposure.

[31]

Screening pregnant women for alcohol use before and during pregnancy

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Objectives: Health Authorities in Norway have an ongoing trial in some municipalities of screening all pregnant women in prenatal care for alcohol use before and during pregnancy, using elements from the international screening tools TWEAK and Audit-C, with some adjustments. The screening is intended to provide a base for an in depth conversation about alcohol and fetal development, and alcohol use during motherhood. The main goal is to reduce or eliminate alcohol related damages to the fetus. In this study, we have looked into how useful midwives and pregnant women find this tool.

Materials and methods: 6 municipalities participated for 5 months in 2013/2014. The midwives collected all the screening-forms, a total of 254, which we analysed. 129 pregnant women, who had been screened, received a web-based questionnaire about the screening. 70 (54 %) answered this questionnaire. Finally we interviewed the midwives in each of the 6 municipalities.

Results: Results indicate that the midwives experience a more structured way of bringing up the topic of alcohol use and possible damages with all pregnant women when they have this structured form as a base for the conversation. They also experience that this form helps them to bring up the topic in a non-judgemental way. They do not experience that the form helps to reveal women with severe problems with alcohol, but they see the screening and the conversation as an important way to influence the pregnant women in a positive direction concerning alcohol consumption. The pregnant women themselves find the information about alcohol and possible damages to be a very important message in the prenatal care. Many of the pregnant women also answered that the conversation and screening would affect their drinking habits for the rest of the pregnancy (24.3 %), during the period when they have small children (26 %) and also later in life (23.6 %).

Conclusion: A tool that ensures that the topic of alcohol use and pregnancy is discussed with all pregnant women during prenatal care in a non-judgemental and non-moralistic way is embraced both by the midwives and the pregnant women. The screening influences the pregnant women not to drink during pregnancy, and also make them reflect about drinking habits later in life. The screening does not increase the probability of revealing women with severe drinking problems during pregnancy, but the screening reveals risk drinking amongst some of the women before pregnancy.

[32]

Family centers in Denmark. A specialized, multidisciplinary and comprehensive program for pregnant women using alcohol or other substances and their children up to the age of 6 years

May Olofsson

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The aim of the program is to prevent FASD and other congenital injuries as a consequence of substance use during pregnancy. The pregnant women are given counsel on the effect of alcohol and other substances on the fetus, help to stop drinking alcohol and using drugs, prenatal care, help to social and psychological problems. All children are followed by a child psychologist and a pediatrician from birth to school age.

The program collaborates with the social services and the child care protection system. In Denmark we now have similar programs at the 5 major hospitals throughout the country and we also have a nationwide Center for Prevention of FASD and other congenital substance effects on children. In the program we use licensed diagnosis of alcohol for pregnant women as well as children (and licensed diagnosis of other substances). In all labor and delivery departments we utilise a questionnaire for screening the use of alcohol and other substances during pregnancy.

Data from all the Family Centers are recorded in a database including medical, psychological and social data from early pregnancy and to school age of the child. The database will allow us in the near future to evaluate and assess the program of the Family Centers and to conduct research within the field of prevention and treatment of FASD.

[33]

Continuing education as a key element for universal prevention

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Objectives: (1) to enhance health professionals' knowledge and competencies regarding the risks related to alcohol consumption in pregnancy and, consequently, (2) to inform women about these risks. A special focus on the training process is made.

Materials and methods: Among a FASD universal prevention initiative, health professionals were trained through Continuing Medical Education and an awareness campaign was started to inform women about the risks of drinking during pregnancy, in a Health District in Rome, Italy (ASL RMD). An official agreement protocol among the ASL RMD, the Lazio Regional Center for Alcohol and SITAC (a no-profit organization working on alcoholism) has been signed, to ensure a successful initiative. After the training, all the women attending obstetric facilities were interviewed about their alcohol consumption and knowledge of FASD. Then, informative pamphlets and posters were distributed and appended. A second questionnaire was delivered, to test the retention of the preventive message.

Results: 14 nurses, 13 gynaecologists, 12 psychologists, 8 obstetricians and 5 social workers were trained. 550 pamphlets were distributed and 25 posters appended. 248 pregnant women were interviewed, 13,3% admitted drinking during pregnancy while 68,1% did not know anything about FASD. Further results from the post intervention questionnaire will be discussed.

Conclusion: Risks related to alcohol exposure during pregnancy remain an alarming major health issue, as still 13,3% of pregnant women drink. Preventive efforts are necessary and health workers' education is a key element to lower this number. To ensure the quality of the training, only 52 health workers were admitted, into two courses, while many other application forms had been received, this proving that there is a strong interest toward the issue, that is essential to address.

[34]

Improving health promotion related to Fetal Alcohol Spectrum Disorder (FASD): the need for a framework

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Background: Alcohol use during pregnancy is one of the leading preventable causes of intellectual or developmental disability. Fetal Alcohol Spectrum Disorder (FASD) is the non-diagnostic umbrella term used to characterize the full range of damage caused by prenatal alcohol exposure, varying from mild to severe, and encompassing a broad array of physical defects and cognitive, behavioral, emotional, and adaptive functioning deficits. This situation clearly warrants intervention. 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. Bartholomew, et al. (2011) designed such a systematic framework 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.

Method: 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. This framework was used in the present study.

Results: The results of the first step (e.g. the needs assessment or situation analysis of the problem concerning FASD) will be presented from a systematic literature review.

Conclusion: The Intervention Mapping framework is useful as a blueprint for designing, implementing, and evaluating an intervention model for FASD. The first step in this process showed that current data about prevalence remains insufficient.

FASD in adopted children from eastern European Countries.

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Objectives: Alcohol consumption in pregnancy and thus the risk of FASD in the newborn is also influenced by the social culture of drinking as well as the personal history of the woman. In Europe alcoholism is an extremely widespread problem especially in Eastern Countries. The purpose of this study was to verify if this fact can be reflected in the cases of children with FASD at the Observatory of "Policlinico Umberto I" in Rome through the phenomenon of adoptions.

Materials and methods: From 2012, 18 children examined at the Observatory for suspected FASD have received a definitive diagnosis. This was made on the basis of the revised IOM criteria through the execution of a paediatric-dysmorphologicalevaluation and a neuro-psychological evaluation after a structured interview with parents.

Results: On 18 children diagnosed with FASD, 14 (77.8 %) were adopted, all of them from Eastern European Countries (11 from Russia, 1 from Kazakhstan, 1 from Ukraine and 1 from Latvia); only 4 were born in Italy. In regards the specific diagnosis in the group of adopted children were detected 9 cases of FAS (64.3 %), 4 of PFAS (28.6 %) and 1 of ARND (7.1 %); in the group of Italian children there were 2 cases of FAS (50 %) and 2 of ARND (50 %).

Conclusions: The comparison of our study with the work of May PA *et al.* (2006) shows that FASD in Italian children has a slighter manifestation than the one in adopted children, since the difference of diagnosticated FAS among the two studies.

[36]

Information on FASD during the adoption process and FASD diagnosis in adopted children in Spain

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Objectives: Specific information regarding FASD is only rarely given to adoptive parents. However, most parents seek information read the medical records, and engage in specific consultations on the health risks in general and the health of their future children aswell. We aimed to compare the information gathered by the families with the outcome of their children in terms of a specific diagnosis of FASD and its multiple associated problems.

Methods: We studied 34 families We designed two separate questionnaires: the first addressed the information provided before the adoption, during the process, and even after the arrival of the child, the second addressed their children´s problems, their feelings about those problems and the information gathered during adoption. This data was compared with the diagnoses of their children within the FASD spectrum according to the IOM criteria and their specific cognitive and behaviour problems.

Results: The information on FASD provided during adoption is scarce and very inaccurate, the preadoptive consultations based on pictures and videos often do not identify FASD. Moreover, after the adoption, many of the medical consultations performed fail to identify the problem and result in great delays in diagnosis and specific care. The parents feel lost and mislead, and believe the pre-adoption information process is not accurate nor transparent.

Conclusion: The information systems during the adoption process often fail to identify FASD. There is a need for improvement because the families seek information and feel deceived.

[37]

FASD in eastern European adopted children in Spain

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Objectives: Children adopted in Eastern European countries tend to have higher rates of behavioral problems, aggression and social relationship difficulties, learning difficulties, Attention Deficit disorder and prescription of medication, according to research results from the AFIN Research Group, confirming those results obtained internationally.

Starting from the situation obtained in the research results of the group, and the international literature, research on FASD within Eastern European adopted children has been taking place in order to determine whether these children have physical, functional and a neuropsychological profile compatible with a diagnosis of Fetal Alcohol Spectrum Disorder (FASD).

Materials and Methods: A total sample of 75 children (aged 6-18) have been assessed following the Canadian Guidelines for FASD diagnosis. The following variables measuring neuropsychological phenotype through assessment instruments have been taken into account: Visual-motor functioning; cognitive functioning, executive functions, memory and abstract reasoning; Communication and verbal aptitude assessment; Academic proficiency; Attention deficit disorder / hyperactivity; Adaptive behavior, social skills.

The assessment methodology included one full day assessment with: Parents interview and questionnaire filling out; the neuropsychological assessment and the physical examination.

Results: Results obtained suggest the presence of FASD within the Eastern European adoptees in Spain in high prevalence. Till date, preliminary results indicate that 21 over 30 show a neuropsychological FASD profile. Full sample data will be presented.

Conclusion: Difficulties to obtain data from the biological mothers about alcohol consume during pregnancy lead to misdiagnosis and arise the importance of obtaining a compatible FASD neuropsychological profile in order to adequate interventions with these children.

[38]

Children with special needs, adopted through the French agency for adoption in Europe, between 2007 and 2010

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Objective: This oral presentation aims at presenting on the one hand, the socio-demographic characteristics of the adopting parents of the French Agency for Adoption who chose to adopt children with “special needs” from Europe between 2007 and 2010, and on the other hand, the medical check-ups of these children given to potential parents.

Methods: We used two databases for our statistics (authorization Cnil 1205018): the first one was provided by the French Agency for Adoption and the second results from our analysis of the files for adoption. The files of 300 children adopted in Europe between 2007 and 2010 were examined, including those of 134 children with special needs.

Results: The parents of the children with specific needs adopted through the Agency are older and include more single women. The children increasingly tend to carry specific pathologies. Since three quarters of the children come from the former USSR, the major health risk is fetal alcohol syndrome.

Conclusion: In spite of the trend common to all these countries to propose more children with specific needs for adoption, it is extremely difficult to trust the contents of the medical reports on the children. To make up for this lack of reliability, the French Agency for Adoption has created ways to inform foster parents as well as a medical support center.

Comorbidity of Fetal Alcohol Spectrum Disorder: a systematic literature review and meta-analysis

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Objectives: Fetal Alcohol Spectrum Disorder (FASD) is related to numerous comorbidities due to the permanent effects of prenatal alcohol exposure on the fetus; however, the existing comorbid conditions and their prevalence among individuals with FASD remain to be established. Therefore, using the existing epidemiological and medical literature, the current study aimed to: 1) identify the comorbid conditions that occur among individuals with FASD, and 2) estimate the pooled prevalence of comorbid conditions found to occur among individuals with Fetal Alcohol Syndrome (FAS).

Materials and methods: A systematic literature search of studies reporting on the comorbidity among individuals with FASD was conducted using multiple electronic bibliographic databases according to standardized international protocols (i.e., Preferred Reporting Items for Systematic Reviews and Meta-Analyses). All comorbid conditions were coded according to the International Statistical Classification of Diseases and Related Health Problems, tenth revision (ICD-10). The pooled prevalence of disease conditions found to occur among individuals with FAS was estimated using the Mantel-Haenszel method, assuming a random-effects model.

Results: Over four hundred comorbid conditions were identified to occur among individuals with FASD. The most prevalent comorbid conditions among individuals with FASD were *Congenital malformations, deformities and chromosomal abnormalities* (Q00-Q99) and *Mental and behavioural disorders* (F00-F99) of the ICD-10.

Conclusion: The results support the link between FASD and multiple comorbid conditions, highlighting the importance of assessing prenatal alcohol exposure as a significant clinical risk factor for comorbidity.

[40]

Mother's T-ACE positive screening associated with abnormal cortisol awakening response in 12-year-old children

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Objectives: The identification of pregnant women at risk for giving birth to FASD children is a major concern in public health. In this sense, many controversial results have contributed to a somewhat sceptical attitude towards the confidence on early identification and intervention using short questionnaires. One typical argument refers to the lack of evidence for pathological consequences of light and moderate drinking directly related to alcohol drinking. Despite of the general acceptance of the public health relevance of FAS, some questioning remains on the relationship between light and moderate drinking to child mental health development. Longitudinally psychoneuroendocrinological effects of fetal alcohol exposure could explain the vulnerability for an abnormal psychological development of the child. This study aimed to analyze the association of cortisol awakening response in 12 years old children with positive screening using the T-ACE short questionnaire for risky drinking in pregnancy.

Materials and methods: Subjects included 67 mother-child pairs recruited from a community cohort followed since the third trimester of pregnancy. All children were in the same age group (12 years old). 56 mothers were found as negative T-ACE cases in third trimester of pregnancy and 11 were found as positive cases (cut-off point ≥ 2 ; standard drink = 14g). *Salivette* saliva samples for circadian and CAR (cortisol awakening response) cortisol analysis were collected from all children.

GLM repeated measures were performed for comparisons between and within groups.

Results: Results indicated that groups differ significantly with regard to their pattern of cortisol awakening response. Children from T-ACE positive mothers showed higher basal cortisol levels at wake time. Neither current mother alcohol drinking or current mother behavioural problems influenced the results.

Conclusion: T-ACE positive screening in pregnancy was associated with an abnormal cortisol awakening response and higher basal cortisol at wake time in 12 years old children.

[41]

Seizures in Fetal Alcohol Spectrum Disorders: evaluation of clinical, electroencephalographic, and neuroradiologic features an a pediatric case series

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Seizures are observed with a frequency of 3-21% in children with fetal alcohol spectrum disorders (FASD). However, clinical, neuroradiologic, and electroencephalography (EEG) features are poorly described. In this study, 13 patients with FASD and epilepsy or seizures were identified retrospectively from the databases of seven Italian pediatric neurology divisions. Eleven children were affected by epilepsy, and two had at least one documented seizure. Both generalized and focal seizures were observed. EEG showed diffuse or focal epileptic activity; two children developed electric status epilepticus during sleep (ESES). Structural brain anomalies, including polymicrogyria, nodular heterotopia, atrophy, and Arnold-Chiari type 1 malformation, were discovered in almost 50% of patients. Control of seizures was not difficult to obtain in 11 cases; one patient showed pharmacoresistant epilepsy. EEG and clinical follow-up are recommended in children with FASD and epilepsy, since severe conditions requiring aggressive treatment, such as in ESES, may develop. Neuroradiological evaluation is warranted because several types of brain anomalies could be associated with maternal alcohol consumption during pregnancy.

[42]

Dietary nutrient intake is associated with hyperactivity among children with prenatal alcohol exposure

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Background: It is well known that prenatal alcohol exposure impairs neurocognitive development. However, relatively little is known about the nutritional status of children with FASD and how this might influence cognition and behavior. This study evaluated dietary nutrient intake of children with FASD and its relationship with neuropsychological performance.

Method: Participants were children with confirmed histories of heavy prenatal alcohol exposure (5-10 years, $N=55$). Dietary intake data was collected using the Automated Self-Administered 24-hour Recall for the previous day; 36 nutrients and minerals were analyzed. Inattention, hyperactivity, and impulsivity were measured using the Quotient ADHD System.

Results: Observed nutrient intakes were compared to U.S. dietary intake data from similar-age children (NHANES 2007-2008) and to the Dietary Reference Intakes. Relative to the national sample, children with FASD consumed lower levels of protein, omega-3 fatty acids, magnesium, potassium, zinc, vitamin C, vitamin K, niacin, and choline. Moreover, their diets were likely inadequate for fiber, omega-3 fatty acids, potassium, calcium, vitamin K, vitamin E, and choline. Ten nutrients were significantly related to increased hyperactivity on the Quotient.

Conclusions: These findings indicate that children with FASD do not meet recommended intake levels for several nutrients and have poorer nutritional status compared to similar-aged children. Additionally, lower nutrient intake in this population was associated with poorer neurobehavioral performance. Preclinical data have shown that supplementation with several nutrients, including choline, vitamin D, and omega-3 fatty acids, may attenuate alcohol-related cognitive impairment. Thus, these data support that nutritional supplementation may improve cognition in children with FASD.

[43]

Follow-up study on neuropsychological and psychosocial functioning in adults with Fetal Alcohol Syndrome

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Fetal alcohol syndrome (FAS) is the adverse outcome caused by a mothers' alcohol consumption during pregnancy. FAS could be divided in primary disabilities – the neuropsychological, congenital disabilities, and secondary disabilities – possible adverse outcome when the individual is interacting with the environment.

Aim: Examine the effects of prenatal alcohol exposure on neuropsychological (primary disabilities) and psychosocial functioning (secondary disabilities) in adults with FAS.

Methods: Study group was 79 adults, mean age 32 years (between 18 and 47) with a verified FAS-diagnosis. Data was obtained by semi-structured face-to-face interviews covering: health, illicit drug/alcohol use, family and psychiatry. Neuropsychological tests on cognitive and executive functions were performed. Additionally, data was obtained by record-linkages between registers from Swedish authorities on education, employment, dependency on public welfare and trouble with the law.

Results: As children, 82% of the individuals with FAS were placed in out-of-home-care, as adults 71% lived as singles, 65% dependent on public welfare, 33% had been treated for mental health problems, 47% were prescribed medications for mental health problems. Performance on neuropsychological were poor, but they hadn't experienced trouble with the law or drug problems.

Conclusion: Primary disabilities remain and as symptoms of the secondary disabilities, many of the adults with FAS have mental health problems and do not live an independent adult life. Protective factors in their lives have been early FAS-diagnosis, social and financial support that protected them from troubles with the law and drug problems.

[44]

The keys to FASD success

Jeff Noble

FASD Forever

As professionals, we have found the answers to explain what FASD is, how it affects fetus development and what it looks like across the lifespan. However, there continues to be little research and practical work around supporting the FASD person and the caregivers that support them. The Keys to FASD Success will provide participants with an intensive overview of the realities of raising/caring for someone with FASD and the unique demands and challenges that professionals and systems often overlook. Participants will learn about practical, research based theories and strategies that will focus on the FASD caregiver and building capacity through mentorship and (non-traditional) support systems.

Research and evidence has shown time and time again that a stable placement is the number one success factor for those with an FASD. Providing caregivers with adequate, appropriate and accessible support, education, training and respite opportunities will increase their capacity to care and provide a long lasting home to someone with an FASD; thus providing people with an FASD a more useful (and successful) future, while saving governments and health care systems millions of dollars in unnecessary costs, ie. placement breakdown, staffing, housing, etc.

Participants will be provided with an opportunity to learn about:

- The Keys to FASD Success: *Training, Coaching, Respite and Grief and Loss*
- Shifting their thinking from labeling behaviours, and instead focusing on the realities of an invisible brain-based physical disability through a strengths based, brain-age approach
- Strategies and interventions that community service agencies and front line staff can use to build better and long lasting rapport and working relationships with the FASD primary caregivers
- Normalizing the experience of the FASD Caregiver and acknowledge the unique challenges of supporting someone with a brain based disability.
- Developing appropriate services and support systems for FASD Caregivers

[45]

Detection of alcohol consumption in pregnancy: a comparison of current practice and recommendations given in Vienna, Austria and Berlin, Germany

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Objectives: Despite of a variety of standardized questionnaires for the detection of alcohol consumption during pregnancy, underreporting of alcohol consumption during pregnancy is common. The aim of our study was to acquire data on the methods applied to detect alcohol use in pregnancy and to compare the advice given concerning alcohol consumption in pregnancy.

Materials and methods: Based on a telephone survey in 73 obstetric offices in Vienna and Berlin the recommendations for alcohol drinking during pregnancy, the use of a standardized questionnaire to obtain medical history, the number of alcohol consuming pregnant women and the further procedure with these women were determined.

Results: In Vienna only 59% of the interviewed persons advised the pregnant women to completely abstain from alcohol. The amounts of alcohol that were considered harmless were not precise and sometimes even reaching risky levels. None of the interviewed obstetric offices was using any of the recommended questionnaires for alcohol-screening. The further procedure for pregnant women, who were consuming alcohol, varied substantially.

Conclusion: None of the recommended questionnaires to detect alcohol consumption in pregnancy were used in clinical practice in Vienna or Berlin. Recommendations given by obstetrical caregivers do not reflect our current knowledge about the detrimental effects of alcohol consumption in pregnancy.

[46]

A new plan for France

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SAF France

In 2014, SAF France changes its strategy with a system based on three priorities, that it wants to develop in the coming years to improve the collective awareness and prevention program. Firstly, a major overhaul of awareness campaigns for the general public and professionals starting from the analysis of good practices on social networks (strategy and some tools will be explained). Secondly, a major training plan for professionals in health, social and education services. Thirdly, setting up Resource Centers for the diagnosis and support of at-risk populations

[47]

Evaluating FASD prevention and support programs: how value-based program evaluation supports planning, practice, and program implementation

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Objectives: This presentation shares findings from a three-year project that created common evaluation frameworks and identified promising methods and tools for FASD prevention programs serving pregnant women and mothers, and supportive programs for youth and adults with FASD.

Methods: Following an extensive review of existing methods and indicators of success used by FASD programs, we created three visual evaluation Maps, which include: theoretical foundations of programs; activities and program outcomes; and client, community and systemic outcomes. We then held consultations across Canada for feedback. We tested using the Maps in Years 2-3, when we provided evaluation support to five FASD-related programs in three regions of Canada. In spring 2014, we launched the project's website, which offers practical information, tools and resources (www.fasd-evaluation.ca).

Results: In this session, we will discuss key elements of the Maps and website and will show how these resources can be used as tools for program planning, training and evaluation. Project findings indicate that the Maps provide a visual way to show the links between program theory, program activities, and outcomes. The evaluation Maps also resonate with staff, funders, policy makers, and clients, and facilitate conversations about the complexity of FASD.

Conclusions: We focus on evaluation because of our strong belief that evaluation can improve policy, programming and practice. The resources developed through this project support capacity of community organizations to undertake evaluation. Furthermore, they offer a common framework for planning or conducting evaluation across programs, communities and countries.

[48]

Organizing and creating a collaborative unified voice of FASD prevention and support

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Objectives: NOFAS has successfully organized 41 national and international affiliates. NOFAS serves as a liaison to all federal agencies that address FASD, FASD researchers and has partnerships with key professional groups such as the American College of Obstetrics and Gynecology (ACOG) and American Academy of Pediatrics (AAP). Creating an environment of collaboration, communication and unity results in successful FASD prevention, legislation, and support for individuals and their families living with FASD.

Materials & Methods: NOFAS invited grassroots FASD groups across the U.S. join them to create change and awareness of FASD. The NOFAS affiliates communicate monthly and meet annually for FASD Hill Day and the NOFAS Affiliate Summit.

Results: Successes include securing legislation and appropriations, formation and participation of FASD task forces, partnering and sharing of materials and resources, fund raising, and collaborative media events. All share a common goal: to prevent FASD. Creating an inclusive, open system strengthened both NOFAS and their affiliates.

Conclusion: NOFAS and their 41 affiliates continue to evolve, grow and change. NOFAS affiliates are a creative, enthusiastic group that have conducted research, facilitated public awareness, and work together to monitor the government agencies that address FASD and to mobilize policy makers, professional groups, and systems of care. As Aesop taught us, *“United we stand, divided we fall”*.

[49]

A FASD awareness campaign

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Objectives: This paper describes a universal preventive intervention aimed at enhancing risk awareness related to alcohol consumption in pregnancy, both in health professionals and women.

Materials and methods: Two main health districts, in the Rome area, were chosen to disseminate an awareness campaign to prevent FASD. Six different stages were planned: (1) conception and realization of pamphlets and posters, taking into account psychosocial studies on persuasion mechanisms; (2) creation of a 20-minute educative documentary including information and showing counselling sessions with a pregnant, currently drinking woman and the dysmorphology exam; (3) delivery of two Continuing Medical Education courses addressed to gynaecologists, obstetricians, nurses, pediatricians, psychologists and social workers; (4) administration of questionnaires to pregnant women attending obstetric facilities, to investigate alcohol consumption and information on FASD; (5) dissemination of pamphlets and posters in obstetric facilities; (6) administration of final questionnaire to control campaign penetration.

Results: 87 health professionals were trained, and 1700 pamphlets and 50 posters were disseminated in health facilities. DVDs containing the documentary were delivered to all course attendees. Results from the questionnaire (N = 340) showed that 14.4% of pregnant women drank, 26.6% kept on drinking once pregnant, 69.9% were not able to correctly describe what foetal alcohol syndrome is and 17.8% were not given advice about drinking during pregnancy by health professionals. Chi squared test showed that women told not to drink more probably did not drink compared to those told to limit quantities ($p < 0.05$); while women who could correctly identify FAS tended to abstain once pregnant ($p < 0.05$). Results from the final questionnaire will be also discussed.

Conclusion: In Italy, information about risks related to alcohol consumption in pregnancy are not widespread yet, neither in professionals nor in pregnant women. Pregnancy represents a fertile moment for disseminating health preventive messages as women are highly motivated to protect their babies' health and take into great account professionals' advice. Hence, universal preventive initiatives, such as spreading of information and giving health advice, represent cost-effective interventions, among the non-clinical population.

[50]

Re-balancing the wheel-the two eyed seeing, tes diagnostic wheel for FASD and related conditions

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Objectives: FASD is a complex condition that affects all aspects of an individual's development. It is a condition that is embedded in a generational and social-cultural context. Research indicates there may be an epigenetic, generational component that may affect the expression of the primary condition of FASD as well as the secondary conditions that follow. Recent research also indicates that certain mental health conditions may actually be part of the trajectory of the primary FASD condition rather than secondary to it. None of the widely used FASD diagnostic systems, 4-Digit Diagnostic Code, Canadian Guidelines, Institute of Medicine or Hoyme's revised IOM Criteria, have a framework to consider the generational, social-cultural context of the condition or the secondary disabilities related to it. The objective of this work was the development of an FASD assessment tool that includes such a framework in order to improve FASD service delivery in a community setting

Materials and methods: The TES, Two-Eyed Seeing, diagnostic wheel, includes a structured approach to the assessment of generational risks as well as secondary disabilities. It was developed as a clinical tool for an FASD diagnostic team providing a system based approach to diagnosis, intervention and prevention within the context of individual's family and community culture.

Results: This system approach to FASD assessment and intervention has contributed to improved FASD service delivery in the small indigenous community in Atlantic Canada where it was developed. It aligns more closely with traditional ways of approaching health and well-being and was especially helpful in terms of the provision of system based interventions for affected individuals as well as differential diagnosis of adolescents and young adults. In 1999-2000 3.4 % of the school age population was diagnosed with FAS. In 2013-14 of school age population 0% diagnosed with FAS. FASD has not been eliminated but rates have decreased significantly.

Conclusion: The TES Wheel provides a multidimensional framework for FASD diagnosis and intervention and has proven useful in FASD service delivery in a community context especially in regard to older youth and adolescents living with their birth mothers or extended families.

[51]

The revised and updated diagnostic guidelines for Fetal Alcohol Spectrum Disorder (FASD): best practice recommendations

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Objective: FASD is the most common type of developmental disability worldwide. Since releasing the 2005 Canadian diagnostic guidelines for FASD, gaps and inconsistencies have emerged. The goal of this presentation is to provide an overview of the Canadian diagnostic guideline revision projects, with a specific focus on infant and adult diagnostic criteria and recommendations, and introduction to the updated neuropsychological assessment domains.

Materials and Methods: In 2012, the Public Health Agency of Canada tasked the Canada Fetal Alcohol Spectrum Disorder Research Network with the role of leading the update and revision project of the diagnostic guidelines for FASD. A steering committee of international experts was created to oversee and synthesize input from the broader FASD community via surveys, workshops and consultations.

Results: The updated guidelines reflect current, evidence-based practices for diagnosis of FASD and are based on widespread consultation with expert practitioners as well as research and community partners in the field. These guidelines intend to address the concerns and gaps identified by the larger FASD community, with representation from applicable facets of health and social service disciplines. Ultimately, there was unanimous agreement that the diagnostic process continues to involve a comprehensive bio-psychosocial approach including history, physical examination and neurodevelopmental assessment that require a multidisciplinary approach.

Conclusion: It is anticipated that the updated guidelines will improve diagnostic practices and management for individuals with FASD and their families. These guidelines may also provide an opportunity to engage with international researchers and clinicians in the hopes of developing a global approach to FASD diagnosis.

Training for the recognition of physical features of FASD

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Objectives: Efficient accurate recognition of the physical phenotypes of FASD is still restricted to some experts caring for affected patients. Training onsite with patients could be a successful method to improve the accuracy of the physical diagnoses made by other professionals and to identify their needs.

Methods: A cohort of 36 children, suspected to have FASD participated. As a first step to define their specific IOM diagnostic category, physical exams were performed by two experts. All patients accepted being reexamined and taken pictures by a diverse group of 12 medical professionals, whose previous knowledge was assessed. The exam sheet included the three facial features and all items of the dysmorphology score (Hoyme et al). The examiners performed the measurements, plotted in the curves, calculated the scores and defined the IOM categories. The training consisted of four sessions: a talk was given after the first, and onsite help as well as critical review of pictures during the other three.

Results: The accuracy of the measurements, the interpretation of the dysmorphic features and the knowledge of the precise categories of the IOM criteria all significantly improved during and after the training. The interpretation of other dysmorphic features and recognition of genetic syndromes was the most inaccurate of all aspects evaluated.

Conclusion: This method of training proved efficient to extend knowledge on physical recognition of FASD. It is currently being compared with training using a DVD filmed after these results were analysed and the specific needs identified in this study were addressed.

School children at risk of prenatal alcohol exposure in rural southwest Ukraine: assessment according to the 4-digit code and a neurodevelopmental test battery

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Background: There is no adequate knowledge about Fetal Alcohol Spectrum Disorder (FASD) in a hard-to-reach rural area in Southwest Ukraine. Ukraine is among the countries with the highest alcohol consumption per capita (WHO).

Method: Screening in two schools grade 1-9, consisted of diagnostic guidelines from the FASD 4-digit code with accompanying photographic software, fixed assessment of 9 tasks from the Cambridge Neuropsychological Test Automated Battery (CANTAB®), the Naglieri Non-verbal Ability Test (NNAT), a basic mathematics ability test (Tempo Toets Rekenen), a Trail Making Test, and qualitative measures (observation lists and self-reports) for ascertainment of pre-natal alcohol exposure.

Results: Enrolled were 262 children. Over 21% of the school-going children function at an intellectual deficient range (NNAT, N=195). Mathematics results (N=192) reveal 84% and 62% of students in the respective schools score more than 20% below standardised age expectations in basic computations.

Collected data, including growth and facial dysmorphology, reveal that 6% of the participants, who are at risk of Prenatal Alcohol Exposure (PAE) according to the 4-digit code show significant cognitive impairment. Compared to age matched controls, participants with high possibility of prenatal alcohol damage exhibited longer reaction and decision-making times and more errors in CANTAB® tasks (N= 185), suggesting severe problems with attention. These participants also show significant impairments in memory, spatial working memory and planning. The combined data suggest significant executive function deficits at varying levels.

Conclusions: Expanded screening and designing preventive interventions are needed in this rural area.

[54]

Conclusions after one-year-long experience of the first multidisciplinary FASD diagnostic center in Poland

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Objectives: The first multidisciplinary FASD diagnostic center in Poland containing both in-patient and out-patient services was started in June 2013. Our objectives were to provide Polish patients with the best care based on scientific evidence.

Materials and methods: During one year of the center's existence sixty-four children were seen either in clinic or at the hospital's department. All the patients were seen by a pediatrician, pediatric neurologist and psychologist. Each patient had a brain MRI scan, which in some cases revealed abnormalities .

Results: Diagnosis of FAS was made for eighteen patients, while pFAS was diagnosed in eleven cases. The majority of the patients presented with either adoptive or foster parents, only in five cases was it a biological parent who started the diagnostic process. Prenatal alcohol exposure was confirmed in thirty-one patients but it was not possible to determine the quantity of the alcohol consumed by the patients' mothers during pregnancy. Parameters such as neurocognitive test results, speech disorders and failure to thrive occurrence, types of abnormalities found in MRI scan and dysmorphic characteristics were analyzed.

Conclusion: Creation of a multidisciplinary FASD diagnostic center is the first step to improve care for children with FASD diagnosis. Both physicians and other specialists engaged in the care are still studying the matter and pointing to the future development of the center's importance. Our greatest hope is to make changes in the Polish public healthcare system so that children with FASD can get the best care fully refunded by the government.

[55]

Becoming FASD informed: strengthening practice and programs working with children, youth and adults living with FASD

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Objectives

- To expand evidence-based knowledge about what is an 'FASD-informed' approach
- To increase understanding about why an FASD-informed approach matters – i.e., what are the service-related barriers faced by people living with FASD and what are positive outcomes of FASD-informed programs
- To strengthen capacity regarding planning and evaluation of FASD-informed programs

Methods: This session shares findings from the author's multiple research and evaluation projects over the past decade, including qualitative studies of parents who have FASD, substance-using women with FASD, and youth with FASD. Through these projects, dozens of people with FASD participated in interviews focusing on experiences with services, as did over 60 service providers working in programs serving people with FASD. Comprehensive literature reviews regarding promising approaches also were conducted.

Results: The session will present synthesized findings about FASD-informed practice: what it is; why it is centrally important in working with youth, women or adults who may have FASD; what are the experiences and social determinants of health challenges that people with FASD face that affect their accessing and successfully engaging in services; and how FASD-informed program evaluation frameworks and processes can facilitate program planning and aid in demonstrating impacts of health, prevention and support services.

Conclusion: An FASD-informed approach uses knowledge about how FASD may affect a person in potentially all areas of life and also recognizes that for people with FASD, other issues such as trauma may be present. The approach then puts in place adaptations to maximize participants' access to and success within the program.

[56]

Rehabilitation for children with Fetal Alcohol Spectrum Disorders (FASD) - a unique opportunity to create a holistic forecast

Heike Hoff-Emden

KMG-Reha-Center Sülzhayn, Sülzhayn, Germany

Objectives: There is a need and desire of foster parents and people affected by FASD to find a place where you are informed about FASD and can participate in the tailored therapies. Based on these facts children and youths with FASD were recorded from July 2012 in the neurological Rehabilitation Clinic. In addition to the multimodal programme which consists of Neuropsychology, Occupational Therapy, Psychomotoric Therapy, Neuro-Education, School, Music Therapy and job-related Therapy, seminars aimed at handling the symptoms were conducted for parents and kids. In addition, a detailed social medical report was created.

Materials and methods: The rehabilitation results are evaluated in terms of the change achieved in dealing with the symptoms of the child by means of structured interviews with the caregivers in 5 families and by means of a questionnaire in 30 families.

Results: Positive changes were always described relating to the comorbidities, behavioral problems and the family dealing with FASD issues. The exchange with other foster parents was considered to be very constructive.

Conclusions: The inpatient rehabilitation provides a unique opportunity for multi-professional observation, therapy and resource discovery and the creation of a prospective socio-medical assessment and Neuropsychological testing. This measure is evaluated very positively. For the FASD affected the meeting with physically disabled children is an important experience for the development of social skills. In addition the clinic carries out follow-up networking, evaluation of results, training opportunities about FASD as well as cooperation with the judiciary system.

[57]

Parenting stress and overreactivity in adoptive families with a child with a Fetal Alcohol Spectrum Disorder

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Objectives: Children adopted from Central Eastern European countries show relatively high rates of behavioural problems and Fetal Alcohol Spectrum Disorders (FASD). Parenting these children may be associated with higher levels of parenting stress, which may be related to more negative parenting behaviour. In this study, we examined associations between child externalizing problems and parental overreactivity, mediated by parenting stress, in a sample of adoptive families with a high prevalence of FASD.

Materials and methods: Participants were 79 Dutch adoptive families who adopted a child from Poland at 2.9 years (SD=1.5). At the time of the study, children were 8.6 years old (SD=2.9). Adoptive parents answered the Nijmegen Child-Rearing Questionnaire, the Parenting Scale, and the Child Behaviour Checklist. Multi-group mediation analysis was performed for adoptive parents of children with a FASD diagnosis (21%), suspected FASD (26%), and no suspicion of FASD (53%).

Results: A strong association was found between externalizing problems and parenting stress for all groups. The association between parenting stress and overreactivity, and the indirect relation between externalizing problems and overreactivity through parenting stress were significant for adoptive parents of children with suspected FASD or no FASD suspicion, but not for parents of children with a FASD diagnosis.

Conclusion: Although adoptive parents of children diagnosed with FASD are confronted with child externalizing problems, which is strongly related to parenting stress, for these parents parenting stress was not related to overreactivity. Possibly a clear diagnosis gives adoptive parents more understanding for the child's FASD-related challenges, enabling them to better adjust their parenting behaviour.

[58]

How to minimize secondary disabilities

Inger Thormann

Denmark

I will give my presentation in connection with Anja Dalhoff's presentation of the trailer for the film "Vulnerable Souls", as my talk will revolve around the three persons portrayed in the film: Gigi, Cecilie and Jonas. They have all developed secondary disabilities; for the two girls these secondary difficulties overshadow their primary difficulties.

For example, Gigi contacted her case worker for help. Gigi explained that she had a brain injury and was unable to perform the job was assigned. Gigi insisted on her disability and explained that she suffered from FASD. The caseworker did not know anything about the implications of FASD and insisted that she give the job a try.

Later Gigi was offered a job in a supermarket. Turning down the job would mean losing her benefits. So Gigi showed up. There was a sale going on, and there were lots of shoppers who crowded Gigi, asking questions that she could not answer, and there was music playing on the sound system. She felt invaded and overstimulated and sought refuge in the lavatory.

Recurring experiences of this nature do something to a person, and disrespectful treatment due to ignorance gradually erodes a person's self-esteem.

Secondary damage cannot be prevented completely, but it can be minimized. In my presentation I will offer specific proposals for action. I will refer to chapters from Ann Streissguth and Jonathan Kanter's book "Overcoming Secondary Disabilities", including "Parent Advocacy in FAS Public Policy Change", as well as my own experiences.

[59]

A longitudinal study of school-age learners with FASD

Linda Wason-Ellam

Objectives: This longitudinal research examines a dynamic assessment model for 103 learners (ages 6-12 years and 3 university students) applied while learning through multimodal mediation strategies (art, photography, and digital images) identifying specific processes underlying language and reading skills for struggling learners with FASD from Aboriginal backgrounds. The study utilized interactive prompts, developmentally appropriate and brain compatible, to focus learners' attention, maximize working memory, foster meaningful connections with prior schema and enhance connections in neural networks that are socially constructed and aimed at modifying cognitive functioning.

Methods: There is a need to study the literacy tasks requisite within the classroom learning experiences of children with FASD using participatory observation, recording predictable patterns and analysing the content of a learner's oral, written and pictorial responses. This essential knowledge informs the moment-to-moment instructional decisions by knowing what a learner can almost do, can do independently or in collaboration, or understands incompletely. Recognizing these patterns focuses teaching on meaningful instruction.

Results: Results indicated the successes in the literacy journey of children with FASD in the elementary school. Dynamic assessment has emerged from both theoretical conceptions about brain plasticity and cognitive needs to find adequate and prescriptive diagnostic tools to determine the modifiable learning of children with FASD applied during "authentic learning experiences."

Conclusion: This work measures diagnostic and formative information, a visible and explicit record of learning processes, both higher order thinking strategies and deficient cognitive functions that are responsible for learning achievements or areas of possibility with struggling learners with FASD.

[60]

An analysis of current difficulties and ethical questions in FASD prevention in Russia

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FASD prevention in Russia came in a new phase. It is moving from denial to an established matter of discussions in TV programs, on the Internet, in newspapers and. What are the current difficulties and ethical questions that should be addressed? There are following important issues facing our Coordinating Committee for Alcohol Harm and FASD prevention in Moscow: quality relation with media; building up collaboration for prevalence study in Russia; ethical collaboration and work with adoptive parents; strengthening relation with the medical, social professionals and teachers. We are in search of the solutions and will appreciate an exchange of experience on these issues with other experts.

[61]

International campaign to raise awareness of FASD: a workshop to facilitate the communication network

The EUFASD Alliance, together with the Local Health Authority of Treviso and Fabrica, the communication research centre of Benetton group (Italy), has developed an international communication campaign, launched on September 9, 2014. The aim of the campaign is to create global awareness of the risks of drinking alcohol during pregnancy through active involvement of the various organizations dealing with FASD prevention around the world.

The project consists of a global communication campaign applying theoretical models of social marketing to health promotion to disseminate a coherent and univocal health message. The campaign is adaptable to different countries or areas based on the available resources. The campaign is spread through a network of partners, with active participation of the citizens in all the countries involved.

This interactive session is targeted especially to the various current and future stakeholders involved in the campaign. The aim of the session is two-fold: first, to provide an occasion to discuss the first results of the campaign in the countries that have already launched it, the strategy used, and cultural specificities; and second to provide suggestions to the organizations who have not already started the campaign, but are planning or would like to do it in their own country.

ABSTRACTS
Posters Monday
[1 – 23]

[M1]

UK guidelines on consumption of alcohol in pregnancy: professional and public confusion. (Mothers may be inadvertently putting their babies at risk of FASD)

Background: The current UK guidelines for consumption of alcohol in pregnancy, advocate avoidance of alcohol, but the guidelines go on to state that if you choose to continue to drink alcohol, then this should be limited to 1-2 units of alcohol once or twice a week.

Midwife survey: Only 77% of midwives in our survey (n=35) displayed a correct knowledge of the UK guidelines. Interestingly, when asked what they would recommend to their friends or family, 83% recommended complete abstinence.

Only 59% felt 'comfortable' or 'very comfortable' asking about maternal alcohol consumption.

Conclusion: There is significant professional confusion over the current guidance, and it is likely that public confusion is greater. Research is needed into public understanding of these guidelines.

Anecdotal experience has shown us that members of the public can believe they are staying within the current guidelines by consuming 1-2 drinks per week (equivalent to 3-7 units per week), and therefore unknowingly be putting their babies at risk of developing fetal alcohol spectrum disorder.

Recommendation: research is urgently needed into public understanding of the current guidelines in the UK. This is potentially a major public health concern.

[M2]

A local comparison of knowledge between health, social and education professionals

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¹Red Balloon Training & Consultancy, Chesterfield; ²National FASD Specialist behaviour clinic, Surrey and Borders Partnership NHS Foundation Trust

Objectives: It is 7 years since the BMA published 'Fetal Alcohol Spectrum Disorders - A guide for healthcare professionals' (BMA, 2007). It was noted that 'the lack of knowledge and understanding of FASD among healthcare professionals means they often do not feel competent to make a diagnosis'. It also notes that there is a lack of specific guidance on diagnosis, referral and treatment in the UK.

According to the BMA Guide (2007) UK Health departments should produce guidance for healthcare professionals in the UK on the identification, referral and diagnosis for the full range of FASD' Also that the treatment of FASD requires the implementation of tailored management programmes and specialised support in the provision of healthcare, education and specialised support in the provision of healthcare, education and social services'. Training of Foster Carers, conducted by Red Balloon, suggests that an apparent lack of knowledge in Social Workers, Teachers and Medical Professionals means that they face a 'brick wall' in terms of getting a diagnosis, receipt of or delivery of an appropriate service, in both the short and the long term. This seemed to be especially so in cases where no facial features were observed.

Method: The purpose of this study is to look at 3 types of professionals identified as lacking in knowledge by Foster Carers, specifically Social Workers, Teachers and GP's. We sought to address the question as to whether there appears to be a training provision gap based on profession. This study will be conducted as part of an evaluation of the training provision provided by Red Balloon Training to help address this current gap. Thirty-five GP's, 35 children and families Social Workers and 35 Secondary School teachers, fully qualified in their profession, will be approached to participate. Contact initially by direct mail and subsequently by attendance at a team meeting. Questionnaires have been developed through information provided by Foster Carers, feedback obtained from prior training and wider literature. Questionnaires will be filled out during the meetings. Frequency data will be analysed using Microsoft Excel package. Qualitative data will be analysed thematically.

Results: Data collection is currently ongoing and will be analysed prior to the conference. Data presented at the conference.

Conclusions: At this point conclusions cannot be drawn. To be presented at the meeting in Rome.

[M3]

Paternal alcohol exposure in the mouse alters brain NGF and BDNF and induces ethanol intake preference in male offspring

Carito V, Ceccanti M, Coccorello R, Ciafrè S, Giacobazzo G, De Nicolò S, Tirassa P, Chaldakov G, Fiore M

Objectives: Ethanol exposure during pregnancy and/or lactation may induce marked cognitive and physiological deficits in the offspring. However, the role of the paternal alcohol exposure (PAE) prior to mating on offspring cognition and neurobiology have not received much attention. The purpose of the present study was to examine whether PAE may disrupt the levels of Nerve Growth Factor (NGF) and/or Brain Derived Neurotrophic Factor (BDNF) and affect ethanol preference and ethanol susceptibility in the male offspring.

Materials and methods: After a period of habituation to ethanol consumption, male stud CD1 mice received 11% ethanol (dissolved in water) for 90 days as their only source of liquid. Mating time was 1 hour without liquids. Only male offspring were used. When adult, animals were assessed for their ethanol preference by a conditioned place preference (CPP) paradigm. NGF and BDNF levels were evaluated by ELISA assay.

Results: PAE elicited differences on NGF levels in several brain areas, such as frontal cortex, striatum, olfactory lobes, hippocampus and hypothalamus. We found also BDNF alterations in frontal cortex, striatum and olfactory lobes. Notably, these changes resulted to be associated with a higher susceptibility to the rewarding effects of ethanol mostly evident at a concentration of 0.5g/kg but ineffective in non PAE animals. Higher ethanol concentrations (1.5g/kg), however, produced an aversive response in PAE animals.

Conclusion: This is the first study to demonstrate that: i) PAE affects NGF and BDNF in the mouse brain; ii) PAE may induce ethanol intake preference in the male offspring.

[M4]

Exploration of maternal alcohol consumption, nutrient intake and dietary patterns

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Background: Ethanol can cause damage to the developing fetal brain and tissues, largely through oxidative stress-related mechanisms(1) and perturbation of DNA methylation pathways(2). Results from animal models have suggested that alcohol consumption in the presence of inadequate maternal nutrition may increase the risk of adverse health outcomes for the infant(3).

Objectives: To explore associations between alcohol consumption patterns, and the intake of dietary methyl donors and antioxidants during pregnancy, and to derive maternal dietary patterns associated with alcohol consumption levels, drink preference and drinking patterns prior to and during pregnancy.

Methods: Data was collected as part of the Avon Longitudinal Parent and Children cohort study (ALSPAC). At 8, 18 and 32 weeks gestation women provided details of alcohol consumption, and at 32 weeks gestation women completed an FFQ. 12,035 women provided alcohol and dietary data. Alcohol consumption was categorized as 0, <1, 1-6, 7-14, 15+ units per week. Mean daily intakes of methyl donor nutrients and antioxidants were calculated from UK and US dietary composition tables (4,5). Reduced rank regression (RRR) was performed to derive dietary patterns associated with intakes of dietary methyl donors and antioxidants, and dietary patterns were analysed for relationships with alcohol consumption using multiple linear regression models, adjusted for sociodemographic characteristics.

Results: Data has been analysed and results are being obtained. The following results will be presented; a description of the population according to alcohol consumption and nutrient intakes, the relationship between alcohol consumption and nutrient intakes, and the dietary patterns derived and their associations with alcohol consumption.

[M5]

Preventing Effects of Prenatal Alcohol Exposure with Maternal Nutritional Supplements: Developmental Effects on 6-Month-Old Ukrainian Infants

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Objectives: Although many women continue to drink in pregnancy, there are, as yet, no reliable methods for preventing effects of prenatal alcohol exposure (PAE) on child development. Fetal alcohol spectrum disorders (FASD) are more often reported in disadvantaged populations, like those in emerging democracies, where environment, including suboptimal nutrition during pregnancy, may potentiate teratogenic effects of PAE. Accordingly, we evaluated the potential benefits of gestational supplementation with micronutrients, including choline, at two OMNI-Net sites in Western Ukraine, Khmelnytsky and Rivne.

Methods: Alcohol-using and nondrinking women were randomized in mid-pregnancy to micronutrient/mineral supplement groups: None, Multivitamins, (MMV), Multivitamin plus Choline (MMV+C). At 6 month follow-up, infants (N= 367) were evaluated with the Bayley Scales of Infant Development (2nd ED; BSID-II) yielding standard scores for Mental Development Index (MDI), and Psychomotor Development Index (PDI).

Results: Generalized Linear Regression was used to evaluate the impact of: 1) Alcohol group, 2) Multivitamin assignment (MMV) and 3) Choline supplementation on child outcomes while covarying Testing Site, Socioeconomic Status, Parental Age, Child Sex, Cigarette Use, and prerecruitment supplements. For PDI, Alcohol group and MMV did not contribute to Motor outcome, but Choline approached significance with choline users having lower scores, $X^2_{(1)}=2.67, p=.10$. For MDI, MMV supplementation significantly improved cognitive outcome ($X^2_{(1)}=4.69, p<.03$). In a second analysis, amount of alcohol per day preconceptually also was significantly related to outcomes at six months.

Conclusion: Alcohol dose and timing affect 6-month infant cognition and MMV supplementation may reduce the negative impact of alcohol use during pregnancy on specific developmental outcomes.

[M6]

Prevention of FASD in Giyani district, South Africa

Liv Drangsholt

KoRus-Sør, Borgestadklinikken, Regional Center for drug and alcohol dependence, Norway, Blue Cross, Norway

Objectives: South Africa is known to have one of the highest rates of FASD in the world. Blue Cross Norway partnered with Blue Cross South Africa started in 2010 a project in the Giyani province aiming to reduce drug and alcohol uptake by teenager. The rate of FASD has not been estimated in this district, but alcoholism, substance abuse and teenage pregnancies is a common problem in the Giyani district.

The objective of our small project was to implement a FASD prevention program in the already existing project. A psychologist and a social worker (Liv Drangsholt) from KoRus – Sør was engaged by Blue Cross Norway.

Materials and methods: First phase: We prepared materials home in Norway during summer 2013, such as power point presentations, brochures, t- shirts with pictograms etc. The local workers in Giyani made appointments for us with local social services, schools etc.

Second phase : The two employees from KoRus-Sør visited Giyani the two last weeks of October. The program included the following:

- A one-day seminar for several local projects including the Blue Cross project. Powerpoints, t-shirts and brochures were shared.
- Teaching in two local schools, grade 8 and 9.
- A meeting with the chief of a local village and a public meeting in the same village.

The local workers from the Blue Cross project attended all our meetings, and learned to use the prevention materials we had prepared, including powerpoint presentations.

Third phase: The local workers continue the work in the Giyani district. They now have appointments with 12 local health centres, and have visited several schools with the program.

Conclusion: We have experienced that it is possible to implement FASD prevention programs in a simple and inexpensive way if we work with already existing projects.

[M7]

Assessment of a novel murine model of Foetal Alcohol Syndrome using acute administration of angiotensin IV

Sara Fidalgo, Paul Gard

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Introduction: Angiotensin IV (ang IV) induces improved cognition in several rat and mouse paradigms. The mechanism of action of ang IV on learning and memory is unclear but it is known to interact with insulin-regulated aminopeptidase (IRAP) to inhibit its aminopeptidase activity and enhance its facilitating effects on glucose uptake.

Aim: to assess the effects of ang IV in a low-dose alcohol exposure as a novel mouse model of foetal alcohol spectrum disorders (FASD). Current models of FASD use high chronic prenatal alcohol exposure (up to 20% alcohol in drinking water).

Methods: C57BL/6 mouse breeding harems were given a 2-bottle choice of either water and saccharine (0.66mg/ml) or water and saccharine containing 5 % ethanol *ad libitum*. Control animals received water only. After weaning, off-spring received water only. The effects of ang IV (5µg/kg, s.c.) on learning and memory was assessed in the offspring at 2 months using the novel object recognition test.

Results: In control and saccharin-treated progeny ang IV caused a significant improvement in learning and memory ($p < 0.05$); there was no such effect in alcohol-treated animals. Post-mortem analysis of brain IRAP enzyme activity demonstrated that ang IV inhibited the aminopeptidase activity in the water control and saccharine progeny but was without effect in the alcohol-treated progeny, this was coupled with increased ER stress.

Conclusion: These results demonstrate that low dose ethanol exposure *in utero* attenuates the pro-cognitive effects of the endogenous peptide ang IV, possibly by inducing conformational changes in the brain enzyme IRAP.

[M8]

Maternal ethanol consumption during pregnancy: prenatal exposure diagnosis, neonatal screening and postnatal follow up

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Background. Prevalence, underdeclaration, severe effects on neurodevelopment (fetal alcohol syndrome), and associated expenditure of prenatal ethanol exposure are well known.

Objectives. (1) To study the measurement of prenatal alcohol exposure: questionnaire and biochemical screening techniques. (2) To design and to implement a prenatal diagnosis and a neonatal screening protocols of prenatal ethanol exposure. (3) To design and to implement an intervention protocol and follow up of exposed newborns.

Methods. Prospective study including mothers and newborns prenatally exposed to ethanol, in the hospital of the PI: 200 pregnant women for the prenatal diagnosis, 200 couples of mothers and newborns for the neonatal screening, and 50 children prenatally exposed to ethanol for the follow up during 1 year. A questionnaire about consumption and exposure to tobacco, alcohol and drugs of abuse during pregnancy, was administered, and in biological samples (maternal hair from the first trimester and after childbirth, meconium and cord blood) fatty acid ethyl esters (FAEE), EtG/EtS and phosphatidylethanol (PEth) of ethanol and drugs of abuse, was analyzed by liquid chromatography coupled with tandem mass spectrometry and by immunoanalysis.

Results. (1) Prevalence of prenatal alcohol exposure in Barcelona has decreased from previous cohort study. (2) A clinical prenatal diagnosis and neonatal screening protocol and follow up of alcohol fetal exposure was implemented. (2) Brief intervention during pregnancy was shown to be effective in reducing prenatal exposure to ethanol by alternative matrices analysis.

Conclusion. Intervention and screening protocols during pregnancy and at birth are effective in reducing prenatal exposure to alcohol.

[M9]

Ethanol exposure during zebrafish embryogenesis alters neuronal differentiation in the spinal cord

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Background. The exposure of the human embryo to ethanol results in a spectrum of disorders involving multiple organ systems, including impairment of the central nervous system (CNS) development. The zebrafish is now emerging as a powerful organism for the modelling and study of human diseases, becoming an alternative model for the evaluation of chemicals and drug toxicity.

Methods. In order to evaluate the teratogenic effects of acute ethanol exposure during early embryonic development, we analyzed the effects in neurogenesis, neuronal differentiation and hindbrain patterning using zebrafish transgenic lines. These expressed fluorescent proteins in specific neuronal populations and neural territories.

Results. Zebrafish embryos exposed to ethanol displayed small eyes and/or a reduction of body length, phenotypical features similar to the observed in human embryos exposed prenatally to ethanol. A small reduction in rhombomeric domains was observed, although neuronal specification is not altered. However, we analyze the effects in specific neuronal subpopulations such as motoneurons, sensory neurons or differentiated neurons showing different effects. First, there is no effect in motoneuron specification, although these upon ethanol treatment display shorter axons. Second, there is a decrease in the population of sensory neurons and fully differentiated neurons upon ethanol exposure, mainly due a decrease in cell proliferation and subsequent apoptosis during neuronal differentiation.

Conclusion. These findings indicate that although first steps of neurogenesis were not grossly affected, neuronal cell differentiation was down-regulated by early alcohol exposure during zebrafish development. These results establish the use of zebrafish embryos as an alternative research model to elucidate the molecular mechanism(s) of ethanol-induced developmental toxicity at very early stages of embryonic development.

[M10]

Case Management: supporting pregnant women to stop drinking or to drink less

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Objectives: Children's physical, behavioural and cognitive development are negatively affected by maternal drinking during pregnancy, particularly when binge drinking occurs. Many characteristics associated with FASD are caused by drinking during the first trimester. This study sought to support heavy drinking pregnant women in a South African community to stop drinking or reduce their drinking.

Materials and methods: Women recruited from antenatal clinics were invited to participate in Case Management (CM) for 18 months. Data on the drinking characteristics of 41 pregnant women were collected at baseline, and 6, 12 and 18 months. Data were analysed using SPSS version 19.0.

Results: In this community, of 250 women who were interviewed, 143 offspring had FASD. Binge drinking was the norm amongst women who drank, with about 40% of women bingeing over weekends. One study participant said after a weekend's bingeing, she could only feel her unborn baby moving again by Thursday.

When comparing baseline data of women who entered CM to data 6 months after intake, results indicated a decline in number of drinks consumed over weekends, significantly lower peak blood alcohol concentrations at 6 and 18 months follow-up, and a reduction in AUDIT scores from 19.8 at intake to 9.7 at the 6 month follow-up.

Conclusion: Through CM a pregnant woman with high-risk drinking behaviour can be sufficiently supported to stop drinking or to drink less and, consequently, reduce her risk of giving birth to a child with FASD.

[M11]

The Impact of Micronutrient Supplementation in Alcohol-Exposed Pregnancies on Information Processing Skills in Ukrainian Infants

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Objectives: The role that micronutrients play in ameliorating the impact of prenatal alcohol exposure was explored in a clinical trial conducted in the Ukraine. Cardiac orienting responses during a habituation/dishabituation learning paradigm were obtained from 6-12 month-olds to assess neurodevelopmental outcome.

Materials and methods: Women who differed in prenatal alcohol use were recruited during pregnancy and assigned to a group (None, Multivitamin/Minerals, and Multivitamin/Minerals plus Choline). Ten trials were used for the habituation and 5 for the dishabituation condition. Heart rate was collected for 30 sec prior to stimulus onset and then 12 sec post-stimulus onset. Difference values (ΔHR) were computed for the first 3 trials of each condition and aggregated for analysis.

Results: Choline supplementation resulted in a greater magnitude of response on the visual habituation (Wald Chi-Square=10.9, $p < .001$) and dishabituation (Wald Chi-Square=7.3, $p < .007$) trials and the latency of the response was reduced in both conditions (Habituation: Wald Chi-Square=9.0, $p < .003$; Dishabituation: Wald Chi-Square=4.9, $p < .027$). Change in choline level was positively related ($r = .19$) to ΔHR during habituation trials and DMG levels predicted ΔHR during habituation trials ($r = .23$) and speed of both responses (Habituation: $r = -.20$; Dishabituation: $r = -.18$). A trend was found between DMG and ΔHR on the dishabituation trials ($r = .19$).

Conclusion: Choline supplementation during pregnancy may provide beneficial impact to neurodevelopmental functioning in alcohol-exposed pregnancies and changes in nutrient status of the mother suggested that the mechanisms may be through the breakdown of choline to betaine and then to DMG.

[M12]

Preventing FASD: Surveying Youth Knowledge and Attitudes about Alcohol Use, Sex, and Pregnancy

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Objectives: FASD is, in theory, preventable. Several recent prevention efforts have attempted to educate youth about the cause of FASD in order to reduce future occurrences. However, these educational interventions have given little attention to implementing programs that address prevention of FASD while also considering teen lifestyles and challenges. As such, current programs are likely ineffective. This project aimed to: 1) document baseline student knowledge about sex and alcohol use; 2) identify misconceptions related to sexual activity and alcohol; and 3) develop insight into how best to support prevention of FASD within school settings.

Materials and methods: Participants were recruited through the Wellness, Resilience, and Partnership Project (WRaP), which is a program that includes in-school success coaches who support youth and educate them about FASD. Approximately 3000 secondary school students (ages 12 to 18) from 8 schools completed an online questionnaire consisting of Likert-type and open-ended questions regarding their knowledge, attitudes, and behaviors surrounding alcohol use, sex, pregnancy, and FASD.

Results: Data collection will continue until the end of the present school year (June 2014). Descriptive data highlighting student knowledge, beliefs, and attitudes about substance use, sex, pregnancy, and FASD — as well as gaps in knowledge and how student viewpoints vary by age and gender — will be presented. Qualitative data regarding participant perspectives about strengths, gaps, and experiences with current prevention initiatives will also be discussed.

Conclusions: Information from this study will be used to facilitate the development of more effective programs to educate youth about making healthy decisions and preventing high risk behaviors. It will also help inform researchers and educators about the best ways to engage adolescents in prevention practices.

[M13]

Rural Community Engagement and Fetal Alcohol Spectrum Disorder

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Fetal Alcohol Spectrum Disorder is a very complex disorder involving both prevention of the disorder and treatment or services to those impacted. In most jurisdictions around the world FASD has been developed in urban settings often following a strong medical model. In rural Canada as well as other places, addictions issues and substance abuse increases in rural communities as compared to larger urban communities.

Can rural communities address the complexities of FASD? Can rural communities develop and deliver effective services?

The Lakeland Centre for FASD is a rural based regional NGO that has been able to become a leader in developing services for prevention and service delivery in small rural setting, less than 100,000 residents over a 300km radius area. This session will break down some of the stereotypes of rural communities and highlight how the strengths of rural areas can work to bringing awareness of FASD and service delivery. The Lakeland Centre for FASD provides multi-disciplinary diagnostic services for children and adults, post diagnostic outreach services, education, resource development, summer camp for kids with FASD, intensive outreach support to high risk women, and a residential alcohol/drug treatment program specializing in pregnant women. How has all of this been developed? And sustained for the last 20 years?

This is an example of a model that has established itself in the community and has been duplicated in other areas across Canada.

[M14]

The U.S. National Organization on Fetal Alcohol Syndrome (NOFAS): 25 years

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Objectives: NOFAS was the pioneer in FAS and remains the U.S. national organization focused on FAS. NOFAS has orchestrated every hearing and briefing held on FASD. NOFAS serves as a liaison to all federal agencies that address FASD, FASD researchers, families living with FASD and has partnerships with key professional groups.

Materials & Methods: There has been much progress in the U.S. NOFAS has been involved (or aware) of all U.S. FASD activities for 25 years and has a timeline of past and current FASD activities, media, awareness campaigns, legislation, research, curriculum, parent groups, intervention and promising models for individuals with FASD, and outreach to birth mothers.

Results: Successes in the U.S. include 4 evidence based intervention models, the American Academy of Pediatrics has produced an FASD Toolkit, the Centers for Disease Control is prioritizing getting screening for alcohol a standard practice of care in primary health, FASD is now listed in the DSM, and the American Bar Association passed an FASD Resolution. Current problems in the legal system include recent laws that will incarcerate women for drinking.

Conclusion: The U.S. is making great strides in community and professional advocacy, but has a long way to go in addressing the stigma, blaming, and the over-simplification of FASD prevention.

[M15]

Empowering conversations to prevent alcohol-exposed pregnancies: multi-sectoral training for service providers in British Columbia, Canada

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Objectives: In 2013-2014, the BC Ministry of Health received one-time funding for FASD prevention. In collaboration with the BC Centre of Excellence for Women's Health, education sessions were conducted for health and social service providers across BC's six health authorities. The purpose was to expand participants' knowledge, skill, and expertise to help women avoid alcohol use during pregnancy and when planning a pregnancy. This presentation provides an overview of the education initiative, including outcomes, challenges, and lessons learned.

Materials and Methods: Face-to-face practice-based learning sessions were held in the six health authorities. Web based evidence-based learning resources were developed by a research team and disseminated to participants prior to training. Post training webinars further supported practical skills and learning development.

Results: Empowering service providers with current messaging and evidence and in motivational interviewing approaches to engage women and their support networks in the conversation around alcohol use in a range of settings and contexts was emphasized. Although resource constraints impacted training participation, the sessions supported the broader provincial strategies addressing substance use in BC, including FASD prevention and improving alcohol policy.

Conclusions: This educational initiative successfully engaged and empowered provincial health and social service providers working with women of childbearing age in a range of sectors. Lessons learned may be relevant to other alcohol brief intervention initiatives, development of continuing education resources and programs, and research knowledge translation to support practice change.

[M16]

Teaching FASDs in the Social Work University Curriculum: A pilot study

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Objectives: FASDs are not generally taught in the Social Work curriculum at universities in England. Yet, social workers routinely work with service users who use alcohol and/or have been impacted by its effects. This presentation will focus on a pilot study to include FASDs content in the Social Work University curriculum.

Materials and methods: The author taught a two-hour FASDs curriculum to Bachelors' and Masters' level Social Work students during 2014 at a university in England. The training focused on an overview of FASDs including treatment across the lifespan for persons with FASDs, screening, diagnosis and assessment of FAS, and the role of social workers in screening and brief intervention for women of child bearing age.

The curriculum was based upon the author's previous work as former Social Work Curriculum Expert for the Frontier Regional FASD Training Center (funded by the US Centers for Disease Control and Prevention) in which her team and she developed training for social work students and professionals that is now available nationally in the USA. With permission, she adapted the training to the British context. The author also adapted pre and post training questionnaires which evaluated students' knowledge about FASDs and stigmatizing attitudes.

Results: Twenty-four social work students completed the pre-post evaluation questionnaires. University Ethics Board approval was received. Preliminary findings revealed that there were gains in students' pre to post knowledge and decreases in stigmatizing attitudes.

Conclusion: Recommendations for including FASDs content in Social Work and Allied Health University courses will be provided.

[M17]

“Everyone knows you shouldn’t drink when you’re pregnant” – A comparative study of experiences of alcohol advice during pregnancy among new parents in England and Sweden

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Objectives: Although most countries recommend abstinence from alcohol in pregnancy, guidelines can vary. For example, in Sweden an exclusive abstinence policy is endorsed whereas in the UK abstinence is recommended, but women are also informed to limit their intake if they choose to drink. This study aimed to explore new parents’ experiences of alcohol advice and its influence on knowledge, attitudes and drinking practices in pregnancy.

Materials and Methods: Semi-structured interviews were conducted with a convenience sample of new parents living in Merseyside, UK (N=21) and Örebro County, Sweden (N=19). Data was analyzed using framework analysis.

Results: Preliminary results indicate that both Swedish and UK parents recognized alcohol use in pregnancy as harmful, with English parents being more familiar with specific effects such as Fetal Alcohol Syndrome. Both samples suggested that midwives could inform more about specific risks with drinking. Structured screening was apparent in Swedish antenatal care as all women recalled receiving an alcohol assessment and subsequent abstinence advice at the initial visit. Interviews with English women suggested more variation in assessment and advice, with some parents expressing confusion or inconsistencies with advice received. The clear abstinence advice provided in Sweden could explain Swedish parents’ stricter alcohol attitudes and greater abstinence during pregnancy.

Conclusions: Parents lacked specific information about alcohol risks in antenatal care. Preliminary results suggest abstinence during pregnancy is more established as a general attitude in Sweden; perhaps reflecting overall public health policy. Providing consistent and informative advice about specific risks with drinking may prevent prenatal alcohol exposure.

[M18]

Midwives's knowledge, practice and attitudes regarding assessment and advice about alcohol consumption during pregnancy?

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Background: Drinking, smoking, obesity and sedentary behavior have adverse health implications for infant and maternal health and wellbeing. Midwives have a key role in identifying, advising and managing women during pregnancy yet practice varies widely across England and Wales. It is unclear to what extent midwives discuss sensitive topics such as drinking, smoking, weight, diet and exercise with women during antenatal visits, whether they provide structured advice and support to change unhealthy behaviors, and what the barriers are to providing public health-related advice to pregnant women.

Objectives:

1. Establish what midwives know about recommended advice regarding drinking, smoking, diet and exercise; the effects of alcohol, smoking, obesity and sedentary behavior on the health of women and their babies, and how they might assess this during routine antenatal care.
2. Determine in what contexts midwives discuss drinking, smoking, diet and exercise with women, how they do this, and what they do if they are concerned about these factors.
3. Explore midwives' views on discussing drinking, smoking, diet and exercise with women and the difficulties they see in doing so, and the training and support they need to fulfill this public health role.

Methods: The study utilises a mixed methods design comprising two phases: a web-based questionnaire survey involving a random sample of members of the Royal College of Midwives in England and Wales, followed by semi-structured interviews with a purposive sample of questionnaire respondents.

Results: Data for the questionnaire phase of the study has been gathered and analysed and will be presented.

[M19]

Multidisciplinary hospital unit focused on pregnancy care, child testing and social treatment in cross-sectorial coordination

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The unit offers treatment and guidance to those families using medicine, alcohol or other drugs during their pregnancy.

We also follow those children that have been exposed to addictive medicine, alcohol or drugs during pregnancy until they start school.

Now as a permanent feature in the Danish health system as of 1 January 2015, the “family unit” or “familieambulatoriet” combines the efforts of midwives, paediatricians, obstetricians, psychologists and social workers in effort to guide, and offer extra services, to these families in a complex healthcare system.

The unit also initiates cross-sectorial coordinated meetings with the various governmental, regional, municipal and private bodies both before and after birth.

The workshops primary focus will be on the need for cross-disciplinary and cross-sectoral efforts, in order to give the children and families that use addictive medicine, alcohol or drugs the most useful coordinated care and healthier children that develop and flourish.

The workshop will be a brief introduction and cases with cross-sectional focus.

[M20]

A comparison of maternal risk factors for fetal alcohol syndrome disorders in Italy and South Africa

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Objectives: Research in a region in Italy, where moderate drinking during meals in a well-nourished and well-educated population is believed to be the predominant pattern, has shown that the prevalence of Fetal Alcohol Syndrome Disorders (FASD) is higher than previously estimated. This raises questions about the perceived risk of prenatal drinking and other maternal risk factors for FASD in this population, especially when compared to the Western Cape Province of South Africa (SA) where the norm of binge-drinking over weekends has produced the highest measured prevalence of FASD globally.

Materials and methods: In both areas population-based, active case ascertainment studies were used to find FASD cases through structured outreach in first grade populations. Institute of Medicine (IOM) criteria were used to identify children with FASD. Retrospective interviews were completed in separate studies using similar methods with 39 mothers of children with FASD in Italy and 158 in SA.

Results: In SA FASD is significantly correlated with low socio-economic status, binge drinking over weekends, advanced maternal age, and high gravidity and parity. In Italy, except for educational level, few differences were found between mothers of children with FASD and normal controls; however, current drinking was much higher in mothers of children with FAS. In both communities mothers of children with FAS more often reported drinking in all three trimesters.

Discussion: One plausible explanation for low levels of alcohol consumption found in Italian mothers is underreporting. This and other possibilities will be explored further in this poster utilizing data from both studies.

[M21]

FASD collaboration roundtable (FCR): a model for community education and development

Marsha Wilson, Elizabeth McWilliams Hewitt, Cheryl McIntee

FASD Collaboration Roundtable, Langley, BC, Canada

The FCR is a group of professionals from varied disciplines who work collaboratively on an annual education and community development campaign. The FCR, with a passion for those that live with FASD and their families, has a cross-sectoral and multi disciplinarian representation of members; justice, private sector, education, health, Indigenous people groups, non-governmental organizations.

Using a budget based on revenues generated, the groups' mandate is to provide relevant, evidence based information and deliver education reflective of the felt needs of the community. The FCR designs and delivers a one day educational forum which builds on emerging knowledge and evidence based strategies and supports.

Over the course of 6 years, the forum has grown to have an audience of 300 parents and practitioners. Each year speakers, including those who live with FASD, present on a specific topic via lecture, small group presentations and experiential learning. The event is hosted by a local community college and students from the Child and Family Studies Faculty provide child care and respite to parents throughout the forum.

The FCR is an enduring model for a public education campaign that can be replicated in various urban communities. It builds upon current infrastructures typically in place in urban settings, such as: government agencies, educational institutions, non-profit organizations, self-advocate groups and informal parent networks.

[M22]

Improving knowledge and practice behaviors in medical and allied healthcare providers: updates from the Great Lakes FASD Regional Training Center

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Objectives: The adverse effects of alcohol consumption during pregnancy represent a significant public health risk. Many physicians and other medical professionals feel inadequately prepared to provide appropriate services to reduce the risk of an alcohol-exposed pregnancy or provide clinical diagnosis and appropriate care for individuals affected by fetal alcohol spectrum disorders (FASD). The overarching goal of this Center was to increase knowledge and improve practice behaviors of medical and allied health practitioners and students around the prevention, identification, and treatment of FASD.

Materials and methods: Utilizing the content of the *FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice* (Centers for Disease Control and Prevention, 2009) the Center conducted over 400 trainings during the past six years reaching over 9,000 participants. Data from evaluated trainings that occurred during the second round of funding (N=1300) are reported.

Results: Training activities were effective in significantly increasing participant knowledge about FASD from pre-training to both post-training and 6-month follow-up. Significant increases were also seen in confidence levels for screening, educating and referring women who drink at risky levels as well as diagnosing and treating individuals at risk for FASD. Finally, clinician feedback resulted in the development of a resident training model to increase competence in diagnosis.

Conclusion: Medical and allied health care providers increased their knowledge and confidence in the prevention, diagnosis and treatment of FASDs. Physician feedback and identification of barriers to practice change were identified, and led to the creation of a resident training model.

[M23]

Challenges in Determining the Prevalence of FASD Affecting Children in Care

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Objectives: Determining the prevalence of FASD is challenging. However, it is critical to measure the number of individuals who are affected with the condition in order to plan for their service needs. Measuring FASD prevalence requires consistent diagnostic criteria, community awareness to screen affected individuals for assessment, and defining the population in question, among other considerations.

Children in the care of child welfare agencies are considered to be at high risk for FASD, as parental substance misuse brings many families to their attention. Research into the prevalence of FASD affecting children in care is at a beginning stage. In this study, methodologies to determine the prevalence of FASD affecting children in care in three Canadian provinces were employed, in order to establish baseline data toward a consistent, national approach to FASD prevalence measurement for this high-risk population.

Materials and methods: The study actively sought information about children in care, diagnosed with or suspected of having FASD, by accessing existing child welfare administrative databases. All children in care in Alberta, Manitoba and Ontario were intended for inclusion, although the challenges in ensuring common definitions, populations, and database information revealed many challenges in determining the prevalence of FASD for this population.

Results: Several challenges were encountered in this project, aiding in the identification of issues to be addressed in future prevalence studies. Despite limitations, prevalence rates of more than 10% were determined for each province.

Conclusion: This study confirmed that FASD is a significant issue affecting children in care in three Canadian provinces.

ABSTRACTS
Posters Tuesday
[1 – 25]

[T1]

Using computerised facial analysis software to determine features associated with FASD in newborn babies

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Objectives: To determine the feasibility of using facial analysis software to analyse the three characteristic facial features of Fetal Alcohol Syndrome: palpebral fissure length (PFL), lip thinness (ULC) and philtrum smoothness, in newborn babies. To develop normal reference ranges for these features in this population.

Materials and methods: Three standardised digital photographs were taken of healthy term babies. Gestational age and birth weight were noted. Mothers completed a lifestyle questionnaire including questions about alcohol consumption before and during pregnancy. Photographs were analysed using facial analysis software (University of Washington, Seattle) to measure PFL and lip thinness. Philtrum smoothness and ULC were assessed on a 5-point rank scale.

Results: 87 babies were recruited. Mean gestation was 39.7 weeks, mean birthweight 3470g. The mean PFL was 16.3mm (SD 1.2), mean ULC 61.1 (SD 1.29). The mean ranks assigned for philtrum and ULC was 3. 67% were exposed to alcohol in early pregnancy, reducing to 19.5% in late pregnancy.

Conclusion. A complete set of photographs was possible in over 2/3 of babies, indicating that this technique is feasible in this age-group. Increased success would come from repeat attempts, and demonstrate that can play a part as useful tool in the clinical diagnosis of FASD. Values for PFL are smaller than those previously published using direct measurement³. This potentially could lead to over-recognition of reduced palpebral fissure length using this method (and hence overdiagnosis of features associated with FASD). Normal ranges for upper lip thinness (ULC) have not previously been published in this age-group.

³Jones, K. Palpebral fissure length in newborn infants. *J pediatr* 1978; 92: 787

[T2]

From research to real life: When FASD is FASD and not something else?

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The current estimate for the prevalence of FASD in western countries (1/100) may be an underestimate and thus the launch of FASD screening and diagnostic programs is well understood. Special attention has been focused on adolescents and young adults with neurobehavioral and psychosocial problems without a prior FASD diagnosis, especially in the juvenile court. However, the secondary adverse effects of a postnatal living environment and the possible hereditary origin of neuropsychological symptoms may be easily forgotten as the interest in the screening and diagnostic procedures increases.

The etiology of neurobehavioural deficits is difficult to define if one or both of the parents has no education past secondary school, has minor or major difficulties in their reading and writing performance, has difficulties in keeping the jobs and has a long history of smoking and alcohol abuse – often along with drugs. Even more difficult it becomes if the child has been taken into custody and has been witnessing a row of adverse events during her/his life course.

There is no doubt that prenatal alcohol exposure can have have detrimental and lifelong effects on the developing brain. However, the mere information on prenatal alcohol exposure should not justify that a child, adolescent or adult with neuropsychological deficits in three brain domains is given the diagnosis of FASD. In individual cases it's important to consider what are the persistent long-term neurobehavioural consequences of intrauterine alcohol exposure and differentiate these from those caused by adverse life events or which may be of hereditary origin.

[T3]

Prevalence rates of prenatal alcohol exposure from detection of phosphatidylethanol in dried blood spots

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Objectives: Identifying infants at risk for developing FASD requires confirmation of maternal drinking during pregnancy or detection of prenatal alcohol exposure. Detection of the direct alcohol biomarker, phosphatidylethanol (PEth), in dried blood spots has been shown to be a feasible and sensitive method to screen newborns at risk for prenatal alcohol exposure.

Our laboratory has analyzed dried blood spot cards for detection of PEth in both prospective and retrospective studies to determine prevalence rates of prenatal alcohol exposure in multiple populations.

Materials and methods: Dried blood spot cards were collected and analyzed for detection of PEth in three different populations: (1) from 135 newborns born at the National Social Security Perinatology Unit in Montevideo, Uruguay; (2) from 250 anonymous samples from a Midwestern state; and (3) from 346 newborns born at the Charleston Area Medical Center (CAMC) Women and Children's Hospital in West Virginia.

Results: In the public health care hospital in Montevideo where alcohol consumption during pregnancy is commonly reported, PEth was detected in 107 samples (79%). In our analysis of 250 anonymous newborn dried blood spots from a Midwestern state, where reported alcohol consumption is less frequent, PEth was detected in 10 samples (4%). At the CAMC Women and Children's Hospital in West Virginia, where the population of mothers is of lower socioeconomic status and alcohol consumption during pregnancy is of concern, PEth was detected in 68 samples (19.7%). Further results will be presented in Rome.

Conclusion: Detection of PEth in dried blood spots is an effective method to examine prevalence rates of prenatal alcohol exposure during late pregnancy. Results from our studies indicate that the prevalence rates of PEth detection in newborns vary significantly among different populations in the United States and abroad.

[T4]

Polish system of networking and diagnosing of FASD

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Krzysztof Brzozka

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Objectives: The issue of FASD is known and targeted in Poland by many different nongovernmental organizations, foundations and state organizations including PARPA. Even though there is still a huge lack of knowledge, good practises and common system of diagnosing FASD. We still do not know the prevalence of FASD across Polish children but the first step to estimate its prevalence among children aged 7-9 years old was taken.

Materials and methods: To follow the need of networking and to have the information about the methods of diagnosing, therapy and methods of prevention used around the places involved in FASD issue, PARPA started to organize cyclical meetings with all the cooperating institutions. From the questionnaire addressed to all respondents of mentioned organizations we have received/built overview of the current situation and raised all the lacking issues connected with FASD.

Results: Most of the organizations involved in FASD issue concentrate on diagnose and therapy. The diagnoses of FASD set by individual organizations are very often based on different methods of diagnosing and not homogenous.

Conclusion: We are facing lack of standards in diagnose of FASD. We are missing the psychological tools to measure and to study the central nervous system disabilities. There is shortage of knowledge about FASD among medical staff and rarely they are involved in diagnose. The primary goal is to involve and train the medical staff, what will start from the autumn this year.

[T5]

Consultation about alcohol and other lifestyle habits in early pregnancy

Eli Margrete Fjelde

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Objectives: Antenatal care is an important arena for preventing FASD. 6 of 10 women in Norway report that healthcare professionals does not inform about consequences of alcohol use in pregnancy (2013). The aim of the project was to develop a consultation about alcohol and other lifestyle habits in early pregnancy, in order to provide all women with information that enables them to make informed decisions.

Material and methods: The intervention took place in 8 health centers in the county of Rogaland, including 364 women. The consultation was carried out within 9 weeks of gestation. It concerned healthy lifestyle habits in pregnancy with particular focus on alcohol, but also topics such as smoking, nutrition and physical activity. The TWEAK questionnaire was used as a basis to talk about alcohol use. The counselling approach relies on the basic elements of motivational interviewing (MI). The women and the midwives were interviewed about their experiences of the consultations. The feasibility of the project was also investigated.

Results: Both the pregnant women and the midwives were positive to the consultation, and considered that there is a need for this type of information early in pregnancy. The evaluation revealed some structural challenges, such as lack of communication between doctors and midwives and limited capacity in community midwifery.

Conclusion: Early consultation about alcohol and other lifestyle habits can be a useful approach to enable women to make informed choices during pregnancy. However, there is a need to work with the structural limitations and to study the effects of the intervention.

[T6]

Fetal alcohol exposure in third trimester of pregnancy more associated with birth anthropometrical parameters in a Brazilian sample

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Objectives: to characterize the alcohol consumption pattern during pregnancy and to evaluate the relationship between fetal alcohol exposure and birth anthropometric data.

Materials and methods: After delivery, data were collected from 160 hospitalized women from a public obstetrical clinic in the city of Ribeirão Preto, Brazil. Birth weight, birth length, head circumference, and chest circumference were obtained from medical records and the information about frequency and quantity of alcohol consumption during the first, second and third trimester were obtained from the mothers by means of face-to-face structured interviews in the immediate postpartum. The questionnaires T-ACE and AUDIT were employed as screening instruments.

Results: 50 participants were T-ACE positives (cut-off ≥ 2) and 34 participants AUDIT positive (cut-off ≥ 8). Frequencies of 18.7%, 11.2% and 8.1% of pregnant women that drank three or more standard drinks (12 grams of alcohol) in the first, second and third gestational trimester, respectively. An inverse statistically significant Spearman correlation was found between standard drinks per occasion in third trimester and birth length ($\rho = -0.236$; $p = 0.003$), as well for chest circumference ($\rho = -0.233$; $p = 0.003$).

Conclusion: The findings suggest a greater susceptibility for alcohol effects on birth anthropometrical parameters in third trimester.

[T7]

Diagnostic expansionism: the challenge of characterizing alcohol embryopathy

Gisela Michalowski

FASD Deutschland

A so-called S3 clinical guideline for FAS (S3 being the highest quality grade in Germany) has now been released. Its implementation has led to an increase in the number of paediatricians, for example those working in centres for social paediatrics now able to diagnose FAS.

The conference documentation from last year's symposium was recently published – the third volume in this series. In September this year the annual symposium will take place in Dresden and preparations are, of course, well underway.

At the end of May we spent a long weekend combining 4 days' training and fun for the whole family. The main theme of the lectures, seminars and discussion rounds for adults was "Even Small Steps Lead to Success" whilst the children enjoyed supervised group activities. 160 participants were lucky to get a place. It was the biggest group we've had so far! The event was fully booked within 7 hours of registration opening!

The closed online support group continues to grow in size and welcome new members as do the regional support groups who meet throughout Germany; in fact in some areas, new groups have recently formed. The group leaders are especially trained to hold lectures, organise workshops, give interviews etc. i.e. to share their expert knowledge of FASD.

FASD is international so we must be too! We not only partner and keep in touch with other German organisations we also maintain relations with groups from abroad and attend as many international congresses as possible.

The motto "knowledge is power" is a good one for our work; only by spreading knowledge on FASD can we gain the power to help those affected.

We can see first positive results but we still have a long way to go!

[T8]

Longitudinal Studies with a Cohort of Infants and Toddlers Prenatally Exposed to Alcohol in South Africa

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Objectives: Diagnosis of Fetal Alcohol Spectrum Disorders in early childhood is difficult and no empirically-developed diagnostic criteria exist. This study aims to develop early diagnostic criteria for FASD in actively ascertained cohort of infants and toddlers in the Western Cape Region of South Africa (N=199), and evaluate the effectiveness of an early intervention program in a sub-sample of children. Preliminary results of the longitudinal study and methods used in the early intervention programs are discussed.

Materials and Methods: The study employs data collection to develop infant/toddler diagnostic criteria, growth and standardized dysmorphology assessment of children at birth, 6 weeks, 9 months, 18 months, 42 months and 60 months respectively; standardized developmental assessment – at the same intervals; and digital photography. An early developmental intervention, that includes support for the child and family, is being evaluated in a select number of children from the longitudinal cohort (N=48).

Results: Preliminary findings from the longitudinal cohort indicate that alcohol-exposed children have significantly poorer outcomes on some of the items of the Brazelton Neonatal Behavioral Assessment Scale and The Bayley Scales of Infant Development, at each time period, with variation in dysmorphology noted over time in children who are alcohol exposed.

Discussion/Conclusion: These findings have important implications for diagnosis of FASD in infants and toddlers.

[T9]

Importance of a network of services in the care of the child with FASD and family: a single case study

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Objectives: The diagnosis and treatment of FASD is a complex process and often could be very difficult due to missing or poverty of network services in the care of the child with FASD and family. Nevertheless, there is a growing demand for diagnosis and treatment in adopted children especially from Eastern Europe (Landgren, 2010; Lange, 2013). In this study, we considered the negative effects of no treatment on neurodevelopment and adaptive functioning of FAS child.

Materials and methods: The child was diagnosed at the FASD Center of Policlinico Umberto I in Rome. He was 25 months, born in Russia and living in Italy for 5 months from the FAS diagnosis at the Policlinico. Griffiths Mental Development Scales (GMDS) and Vineland Adaptive Behaviour Scale (VABS) were performed and repeated 15 months after.

Results: The child was identified as having a neurodevelopmental and adaptive functioning delays. His GMDS total developmental quotient was very low (TDQ=50) and equivalent age at VABS composite scale was 16 months well below age expectation at 25 months. After 15 months from the first assessment, the neurodevelopmental and behavioural profile was no better. His TDQ was very low (<68) and equivalent age at VABS composite scale was 22 months significantly below age expectation at 40 months

Conclusion: The adoptive parents got early a diagnosis but then failed to find services, very few in Italy, able to treat FASD child and family. Educational and therapeutic interventions are the only known means of rehabilitation for FASD. Without treatment, the reduction of the primary and secondary FASD disabilities could be very difficult.

[T10]

Pharmacotherapy and Sleep Problems impacting the Quality-of-Life of children with Fetal Alcohol Spectrum Disorders (FASDs)

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Introduction: In the absence of effective treatments for FASDs, interventions mostly rely on rehabilitation, cognitive behavioural therapy, and pharmacotherapy with antipsychotics, antidepressants and psycho-stimulants. Treatments may be partially beneficial; yet, results are inconsistent for various reasons (e.g. missed sleep problems, SPs). Given the essential role of sleep in cerebral functioning and the detrimental clinical consequences of SPs, we investigated quality-of-life (QoL) in children with FASD and SPs, who have been on/off pharmacotherapy.

Methods: As part of an intervention program at the University of the Fraser Valley (Strength-Based Interventions for Fetal Alcohol Spectrum Disorders) involving children (n=40; 6-12 years old) with confirmed FASD diagnoses, caregivers completed a functional sleep/wake-assessment survey exploring SPs, medications, and QoL utilizing a scale of 1-10 (min/max).

Results: 55% of the children (n=22/40) were prescribed medications in their life history, with 91% on stimulants, 73% on non-stimulants, and 50% on antipsychotics. Furthermore, 59% (n=13/22) had stopped medications for missing effects and/or side effects (not surveyed further) and 41% (n=9/22) were still on medications at time of evaluation. Children with SPs and on medications had the lowest QoL (5.7; n=7/40); children with SPs and no medications had higher QoL (8.3; n=9/40). Children with no SPs had the highest QoL: 9.0 for those on medications (n=2/40), and 9.5 for those who stopped medications (n=4/40).

Conclusion: In children with an FASD diagnosis, SPs seem to directly impact QoL. Additionally, pharmacotherapy seems to negatively affect QoL. This observation and the medication stoppage rates raise concerns about pharmacotherapy among children with FASDs.

[T11]

The sudden discovery of Fetal Alcohol Syndrome by an adoptive mother and the creation of the first French association of families affected by FAS and FASD

Faudou Sourisse Véronique

Vivre avec le SAF, Videlles, France

One evening in november 2011, Véronique Sourisse, adoptive mom to Una, born in Latvia, suddenly discovered the three letters “F.A.S” on Google: three letters that would be permanently engraved in her life.

Véronique remembers that moment clearly: it was very late at night and, her computer on her lap, she sought an answer to her questions. The day before, the school psychologist was clear: “Your daughter is no longer making progress. In fact, she is actually regressing.” Harsh words that destroyed 10 years of hopes.

Since her arrival in France at the age of 18 months, Una has suffered from hyperactivity, behavioral disorders but also disturbing cognitive gaps. Una was treated by many medical specialists, but nobody could explain to Véronique where were her daughter’s difficulties came from, or give her concrete advice on caring for her.

With the only actual diagnosis being “a mental delay of three years,” Véronique then began to fight every day to try to understand the disability of her daughter. She instinctively tried various strategies to assist with her scholastic progress. She attempted to reduce the behaviors that caused her daughter to be isolated from her peers.

It was not until the age of 12 that Una was finally diagnosed with FASD, thanks to the perseverance of her mother. That same year, 2011, at a symposium, Véronique met Cathy Metelski, an adoptive mother of a son also diagnosed with FAS as an adolescent. Driven by the same anger at having lost so much time, together they created the first French association for families affected by Fetal Alcohol Syndrome, “Living with FAS”.

[T12]

FASD in the context of cumulative risk: results of a pilot cumulative risk diagnostic clinic.

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Objectives: Research on adverse child outcomes has focused on single etiologic variables, yet negative outcomes result from the complex interplay between multiple factors including negative experiences or exposures and the absence of protective factors. Cumulative risk models assume that individuals exposed to more risk factors are more likely to experience adverse outcomes. Individuals with prenatal alcohol exposure frequently have other negative exposures that impact their developmental, behavioral or mental health profile. We describe a pilot clinic developed collaboratively between the Alberta Children's Hospital and Calgary and Area Child and Family Services, where a cumulative risk model was used to development a comprehensive diagnostic and intervention planning clinic.

Methods: Children in foster care with severe developmental and behavioral difficulties were identified from an existing collaborative service. At intake, diagnostic needs were reviewed, and assessment provided related to functional need. Assessment options included review by a child abuse specialist, developmental pediatrician or developmental psychiatrist, or developmental assessment including an FASD assessment.

Results: Seventeen children were assessed, and the majority had multiple significant risk factors. All children had complex functional deficits. Integrated assessment was seen as beneficial by child welfare workers and foster parents as it provided a unified understanding of a child's functional needs and associated etiologic variables.

Conclusion: A cumulative risk diagnostic model for children presenting with multiple risk factors provided a more comprehensive understanding of the diagnostic profiles and intervention needs of this population. The success of this pilot was contingent on collaboration between clinicians within health and child welfare.

[T13]

Iatrogenic Harm? Poly-pharmacy and over-medication in children and youth with an FASD and/or prenatal substance exposure

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Objectives: In children and youth with FASDs and/or PSE who face multiple challenges, sleep problems (SPs) often remain unrecognized. Given the complex course of their lives and mental health co-morbidities, current clinical explanatory models are often daytime focused and may not acknowledge SPs. Therefore, we prospectively investigated challenging/disruptive sleep/wake behaviours in children and youth with FASDs/PSE.

Materials and methods: After analyzing previous assessments, diagnoses and therapeutic suggestions, we conducted functional 'Sleep/Wake-Behaviour Assessments' of the patient and if applicable, birth parents/siblings. This is a clinical practice strategy based on narrative schema and therapeutic emplotment, utilizing qualitative interviews and incorporating caregivers' contributions and if possible, conducted videosomnography at home, the natural setting where sleep occurs.

Results: Familial Wills Ekblom Disease and Sleep Disordered Breathing were the most frequent causes for SPs (WED: n=37/37; SDB: n=14/37). The majority of patients had been previously medicated for daytime problems. Consequently, SPs were also targeted with (up to 18) medications without investigating the underlying cause. Use of psychostimulants started <6yrs (youngest patient: 2.5yrs), frequently leading to neurologic/behavioural, and antipsychotics to metabolic Adverse Drug Reactions. Medication indices vary from 2 (<6yrs) to 5.2 (>10yrs). Treating the underlying SP helped to reduce and/or wean off antipsychotics/psychostimulants in all cases.

Conclusion: Deficits in the diagnostic recognition of chronic SPs among children with FASDs/PSE result in psychotropic substances as the mainstay of therapeutic interventions and fragmented care. We propose a clinical practice strategy acknowledging exploration of challenging sleep/wake behaviours and a database for exploring the dimension of the problem.

[T14]

When do we lose them? Challenging/disruptive sleep/wake behaviours in adolescents with Fetal Alcohol Spectrum Disorders

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Introduction: The familial neurological condition, Willis Ekbom Disease (WED or Restless Legs Syndrome), which can mimic ADHD and cause insomnia, non-restorative sleep and subsequent sequelae, has never been investigated in children and youth with an FASD.

Participants and methods: We report four adolescent patients with an FASD and WED diagnosis. The case analyzes were visualized on Life-Trajectory-Graphs; x-axis showing: age and the corresponding diagnoses, pharmaceutical/non-pharmaceutical treatments and main symptoms to medications as described by caregivers; y-axis showing: services provided at the universal, specialized, regional and quaternary tier service levels.

Results: All patients presented with chronic SPs from very early childhood caused by WED, which had not been recognized as WED but as ADHD. All were diagnosed with multiple mental health co-morbidities and treated with 4-18 medications in various combinations per patient, including: hypnotics, stimulants, anti-psychotics, anti-depressants, anti-seizure, blood pressure medications and medications labelled as 'food-supplements'. All patients experienced several severe adverse drug reactions with *emergency admissions to paediatric or mental health facilities*; in 3/4 cases the family setting broke down.

Conclusion: Retrospective analysis of clinical worst-case scenarios depicted cause-effect-interactions and the consequential cascade to a spectrum of developmental paediatrics and mental health diagnoses and in consequence, inappropriate medications due to missed or neglected SPs. Our current understanding is that WED can confound all developmental paediatric and mental health diagnoses, and missed WED diagnosis may lead to inappropriate medication cascades. We suggest a database for monitoring side effects and differentiating 'harmless' side effects from major adverse drug reactions.

[T15]

Lessons learned from a cohort of birth mothers to children with FASD: The NOFAS Circle of Hope (COH)

Kathleen Tavenner Mitchell

National Organization on Fetal Alcohol Syndrome (NOFAS), Washington, DC, USA

Objectives: The Circle of Hope (COH) is a peer mentoring program designed to support birth mothers. Women that have used alcohol or other drugs while pregnant are likely to drink in their next pregnancy if they are not educated or provided support. Membership has expanded to over 600 members and includes state, agency, and international COH affiliations. Successes include the peer mentorship, intervention and referral to treatment, the Women in Recovery Summits, and the speaker's bureau. In 2012 COH members were surveyed and 92 women responded.

Materials & methods: The 32 question survey sought to capture a factual profile of the characteristics of women that have drank while pregnant. Respondents included women from America, Europe, Canada and Australia.

Results: The confidential survey provided an opportunity to collect an honest report of alcohol and other exposures from a cohort of women that are viewed as being difficult to obtain information from. Women reported on their beliefs, behaviors and lifestyles and birth outcomes.

Conclusion: Understanding why women drink while pregnant is an important first step in reducing the stigma and developing prevention messages. Their stories are important in developing models of intervention and policy. The bond between birth mothers has global reach. Countries from across the seas can be connected to work together to support women to prevent FASD.

[T16]

The NOFAS K-12 FASD prevention curriculum: an evidence-based model for educating school age populations on FASD

Kathleen Tavenner Mitchell

National Organization on Fetal Alcohol Syndrome (NOFAS), Washington, DC, USA

Objectives: According to the U.S. Surgeon General early education about healthy lifestyle choices and behaviors is the most effective method to address major health concerns. The NOFAS curriculum is designed to engage students and raise awareness about drinking during pregnancy. The emphasis of the curriculum is on alcohol, addiction to alcohol and how alcohol can effect fetal development. The lessons include the skills of making decisions, setting goals, and carrying out action plans to meet those goals.

Materials and methods: The curriculum includes four modules (K-2, 3-5, 6-8, and 9-12) and each includes lesson plans and educational materials. Methodologies include a DVD, FASD Brain model, youth book, and puzzles.

Results: The curriculum is easily integrated into several different units in a standard health curriculum. For instance, in the U.S., an average high school health curriculum is broken down into several units including, *Alcohol Tobacco and Drugs*, *Reproduction and Pregnancy*, *Health Promotion and Disease Prevention* covering a wide range of topics. A variety of instructional strategies and methods are essential in addressing the many needs and interests of students.

Conclusions: The curriculum has been disseminated across the U.S. and worldwide. The evaluations reported that both teachers and students enjoyed the methodologies and both increased awareness about drinking and pregnancy after receiving the lesson.

[T17]

Evaluation of the effectiveness of a national clinic for behaviour in children and adults with FASD

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National FASD Specialist Behaviour Clinic, Surrey, UK

Objectives: The National FASD clinic in the UK was established in 2009. Since then it has grown both in terms of numbers seen but also the types of service delivered. In order to develop the next stage of the service it was deemed important to understand the benefits and deficits of the current service.

Materials and methods: The last 50 cases attending the FASD clinic in Surrey were written to with a standardised questionnaire. Likert scales from strongly agree to strongly disagree were linked to questions related to the clinic running. These ranged from the effectiveness of the service to help the individual and whether they would recommend the service to also looking at waiting times, post diagnostic support and the benefits of the reports sent.

Results: The data is currently being collected. Provisional findings suggest that for the majority the service met their expectations and was staffed by experts who understood both the needs of the individual affected and that of carers. It was also a service that would be recommended to others. It also highlighted the struggle that those seen had in many cases to secure funding for a referral and that where there was a lack of local understanding following up and implementing the recommendations. Where the individual had been forced to attend, for example via court referral, their impression of the service was not necessarily as positive as the impact was less. Further evaluation will take place and will be presented in Rome.

Conclusion: It is clear that the clinic is delivering what it pertains to in terms of expertise and diagnostic thoroughness. Unfortunately it is clear that individuals need to engage with the process for the greatest benefits to be seen and also increased local post diagnostic provision is needed if the findings of the assessment are to have the greatest impact. Where it was available significant changes to the individuals' lives were seen.

[T18]

Social development in Fetal Alcohol Spectrum Disorders: an analysis of social deficits and interventional approaches

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Objectives: Impaired social development is a core deficit of FASD. Severe social impairments persist with age and negatively impact multiple areas of functioning. This review critically evaluates the existing literature on social skill deficits and current interventions for social problems. We hypothesized that social problems manifest differently across stages of development and remain pronounced throughout life.

Materials and methods: Empirical and review studies were ascertained via a computer-based search of PubMed and Web of Science search engine. Searches included different combinations of a main set of keywords: FASD, Prenatal Alcohol Exposure, social skills, social cognition, intervention, treatment, adaptive behaviour and social behaviour. Archival searches from published review papers were also conducted.

Results: Social development including social interactions, adaptive behaviours and social cognition are impaired throughout life. Neonates and infants show significantly impaired arousal states and atypical or delayed developmental behaviours, while older children experience marked difficulties with interpersonal interactions. In adolescence, social impairments often manifest in delinquent and defiant behaviours that continue into adulthood. By working with the affected individual and the caregiver, successful programs are able to address the unique developmental needs of the FASD population. Although progress is reported in several programs, interventions directly targeting social skills are scarce and none have addressed issues regarding the changing trajectory of social issues with time.

Conclusion: Existing literature points to a distinct pattern of problematic social skills that contribute to later secondary disabilities. While early intervention is suggested to prevent compounding problems, the efficacy of current approaches is limited.

[T19]

Fetal Alcohol Spectrum Disorder: UK Birth Mothers' Experiences.

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¹St George's University of London.

²UK National FASD specialist Behaviour Clinic, Surrey and Border's Partnership NHS Foundation Trust

Objectives: There has been little research into the experience of birth mothers of children with FASD and no published work of this kind in the UK. The primary objective was to explore the experiences of birth mothers of children diagnosed with FASD living in the UK. It aims to build on the limited research that has been carried out primarily by Salmon (2008) in Canada. It also takes into consideration research done on adoptive carers of children with FASD (Mukherjee, accepted for publication December 2012).

Materials and methods: This is a qualitative study consisting of individual semi-structured interviews of 5 women who have given birth to children who have been diagnosed with FASD. Women were accessed through the national FASD clinic in Oxted, Surrey, UK and through the European Birth Mothers Support Network. Interviews were audiotaped and transcribed verbatim. N-vivo software was used to manage the data. First then second cycle coding processes were applied to the data. Further thematic analysis was then carried out.

Results: The women reported experiencing a sense of inevitability that they would have children with FASD based on their problems with drinking. However, a tension exists between this feeling of a lack of control versus the choice the women perceive they have in terms of whether to drink or not. Life is described as a series of battles – the battle against alcohol, the battle to obtain a diagnosis, the battle to manage their own emotions in particular their guilt, the battle to get their children the right support. Through the battles there is a sense of hope and greater purpose – life for the mothers becomes about being the best advocate they can be for their child and about raising greater awareness of FASD in both professionals and the public.

Conclusion: FASD is sometimes described in the literature as being completely preventable. This study challenges this concept in some based on the women's experiences and invites us to explore how best we can support these women.

[T20]

The complexity of FASD, drug addiction and parenting skills

Hege Renée Welde, Hilde Moan Ingebrigtsen

Lade Addiction Treatment Centre, Trondheim Norway

Objectives: Lade Addiction Treatment Centre offers longterm inpatient treatment during pregnancy and to families with addiction including FASD. Patient problem complexity is a challenge for the treatment system and child welfare services. How can we meet the treatment needs of these families?

Materials and methods: In the project “Building a life” the department (1) developed and implemented a tool called “The Circle of Functioning” that describes levels of functioning in ten life areas (including parenting skills) (2) developed competence in mentalization based therapy and (3) implemented a model focusing on early housing. The project included a 22 year old pregnant woman admitted without consent, diagnosed with FAS. Evaluation of the project and the clinical case is the topic of the presentation.

Results: “The Circle of Functioning” is a useful tool to assess parent functioning and understand the dynamics of how different areas of life influence each other. It gives a picture of risks and protection factors for the child. A mentalization-based approach and planned leave during treatment is reported to be of great importance in preparing for life outside of the institution. Results and experiences from the project will be presented with examples.

Conclusion: It is possible to work with the complexity of FASD, drug addiction and parenting skills within this framework. Long term treatment, building trust in relationships and working with several areas of life is crucial.

[T21]

World Impression

Betteke Vredeveld

Netherlands

I am a social work student from the Netherlands and the owner of Worldimpression. Since September 2013 I have been working in South Africa. I have worked closely with children suffering from FASD. I started a project to photograph children with FASD over the whole world and I started in South Africa.

If the mother drinks during the pregnancy there is a chance that the child will be born with FASD. Drinking alcohol during the pregnancy can affect the development of the unborn baby. FASD can be recognized by behavioural problems, learning difficulties, development delay and you can also see it in the face; small eyes, a flat cheekbone and a thin upper lip. FASD is a preventable disease if the mother not drinks alcohol during the pregnancy, the child will not be born with FASD. FASD is 100% preventable and 100% irreversible.

I started Worldimpression a year ago. I became fascinated with this syndrome and I believe that it is important to make people more aware of it. I started thinking what I could do as an individual to give this subject more attention. So I had the idea to take photos of children with FASD over the whole world. I started taking photos in the townships here in South Africa of children with FASD. The results were amazing!

So what I did is I combined my social work skills and passion for photography and started this beautiful project.

[T22]

FASD prevention. What is happening in France?

Denis Lamblin

SAF France

To recognise this problem in France, SAF France began in 2008 a program of actions based on regional, national and international conferences. It is clear that its impact regarding the identification of FASD is low to very low. In 2014, SAF France analyses the different causes of this relative failure and explains how it plans to change its strategy.

[T23]

FASD in Israel

Yehuda Senecky

Child Development and Rehabilitation Institute, the national FASD clinic, Schneider Children's Medical Center of Israel, Sackler School of Medicine, Tel-Aviv University, the Israeli Anti-Drug Authority

Since the last conference in Barcelona there have been many changes and developments in the field of FASD in Israel. Early this year we opened in collaboration with the Israeli Anti-Drug Authority the national FASD clinic to serve the whole country. Together with the Israeli Medical Association and many medical societies we published a Clinical Guidelines on the topic of FASD which was distributed among all professionals.

We are involved in the media in disseminating information to the public and professionals and in our parliament in an attempt to change legislation. In collaboration with "Motherisk" in Toronto we opened a telephone counseling for pregnant and breastfeeding women regarding alcohol consumption during pregnancy and lactation. In the last day of awareness (9/9/2013) we had a national conference with the participation of the Israeli Minister of Health. On this occasion we were declared as a national clinic and FASD as a significant problem. This year we are planning to mark the international day of awareness by joint activities with the Ministry of Health and the Israeli Anti-Drug Authority.

[T24]

What do we know and do about FASD in Slovenia?

Sanela Talić

Institute for Research and Development "Utrip", Slovenia

FASD is a relatively new topic in Slovenia and the problem is very underrated in opinion of key experts in the field of alcohol. There is virtually no epidemiological data, screening studies, prevention programmes or public education campaigns. System of diagnosis of FASD does not exist as well. Our institute started to work in this field based on the experience that many young women are not aware of the possible consequences of drinking alcohol during pregnancy. Recently, we decided to conduct a survey among young women and health professionals about their attitudes towards alcohol consumption during pregnancy and knowledge about the possible occurrence of FASD in children.

The results of the survey will be presented on the conference for the first time. Furthermore, the Ministry of Health has recently awarded a grant to one of the regional public health institutes for the development of specific prevention activities and materials as well as guidelines and recommendations for preventive work in primary care regarding alcohol, pregnancy and FASD. This development is rather promising and at the time of the conference the project will produce some outputs which will be presented too. Finally, our institute is very active in the field of advocacy for better alcohol policy at national and European level and there are several issues related to alcohol, pregnancy and FASD on the policy agenda right now which will be presented as well.

[T25]

France: Parents Create an Association to Help People Live with FASD

Antoine Bourély

Association “Vivre avec le SAF”, La Tour D’Aigues, France

FASD rediscovered: originally discovered in France, FASD was ignored by the authorities during 40 years. In 2008 Dr Lamblin founded “SAF France”, a medical association, bringing his experience acquired in La Réunion. Conferences have been organized every year, the last one in Paris in June 2013.

FASD awareness in France - A daunting task:

- FASD prevalence was measured in Roubaix: 2 % of live births.
- It is hard to find 10 medical doctors able to diagnose FASD in France.
- Institutions exist to help kids with FASD, but not for teens or adults.
- Projects are being debated to create FASD centres.

Our history: In 2011, adoptive parents with affected kids met in FASD conferences. They created in April 2012 an Association to help their kids cope with FASD, and quickly grew to 50 families: mostly adopting parents, but also foster care and natural families.

Why a parent’s association:

- Parents know their kids better than doctors, because they live everyday with them.
- The experience with other diseases has shown that only the lobbying by parents could create a government response.

Our project: we got funding by the Government to create a set of tools to increase awareness and provide people with recipes: a web site, specialized brochures, a manual for parents, videos. A lot of information in English comes from North America, but very little was available in French. This French speaking knowledge base will be very useful for parents.



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