



9th International Conference on ADOLESCENTS AND ADULTS WITH FETAL ALCOHOL SPECTRUM DISORDERS

Review, Respond, and Relate
Integrating Research, Policy, and Practice
Around the World



The Hyatt Regency, Seattle, WA



Website

GENERAL INFORMATION

Despite thousands of published articles on FASD, limited research focuses specifically on adolescents and adults with FASD. As individuals diagnosed with FASD age, the “need to know” across a broad spectrum of areas continues to be critically important for identifying clinically relevant research questions and directions that will impact their day-to-day function and health outcomes.

Building on the work of eight previous conferences*, we aim to examine relevant global research, programs, and policies. What can we learn from practice-based evidence? What does existing or emerging research tell us? Are the results transferable from country to country and/or from laboratory and clinical studies to real life? Are there clinical implications of results from any of these areas of which we should be aware? What are the changes in our thinking, practice, and directions that will be required to improve outcomes? What are the implications for the future?

We hope you can join us at this interactive conference and be at the forefront of addressing these relevant global issues.

*This conference, previously held in Vancouver and hosted by University of British Columbia's Interprofessional Continuing Education, has been moved to Seattle, the birthplace of the FASD diagnosis in North America. FASD United has taken on the task of putting on this unique global FASD conference in close conjunction with the International Adult Leadership Collaborative (ALC) of FASD Changemakers, a group of talented and dedicated individuals with FASD who are leaders in the community.

LEARNING OBJECTIVES

- Connect the identified needs of community workers, healthcare providers, professionals in the FASD field, families, and individuals with FASD with the research community
- Gain insight into emerging research findings and how they might better assist ethical policy and decision-making and the development of integrated and collaborative approaches across systems
- Examine practice-based evidence, projects, and programs to understand the potential connections to research and potential longitudinal studies
- Engage in knowledge exchange and dialogue through multidisciplinary sessions, networking, and hearing from the direct experience of individuals with FASD and families

WHO SHOULD ATTEND?

This multidisciplinary conference will be of interest to the audiences listed below, as well as anyone working towards an advanced understanding in the field of FASD.

- Addiction Specialists
- Administrators/Managers
- Child Welfare Professionals
- Clinicians
- Community Members
- Educators
- FASD Specialists
- Family Members/Caregivers
- Individuals with FASD
- Justice/Legal
- Physical and Mental Health
- Physicians/Nurse Practitioners
- Policy Makers
- Program/Support Services
- Researchers
- Scientists
- Students/Trainees

PROFESSIONAL CREDITS

A certificate of attendance will be prepared for all registrants including pre-approved continuing education credits where appropriate. Please refer to [our website](#) for updates on credits.

LOCATION & TRAVEL

The Hyatt Regency Seattle | 808 Howell St, Seattle, WA

Please reserve your room at a special rate of \$229.00 + taxes until March 20, 2024 for single/double occupancy. Please book [online here](#) and specify that you are booking under “FASD 2024 Conference”. Or please call toll-free: 1.800.233.1234 (North America) or 1.402.592.6464 (International) to reserve.

The Hyatt Regency Seattle is conveniently located to many public transportation options, including the Link Light Rail (2 blocks away). Please visit [here](#) for more information.

GENERAL INFORMATION

REGISTRATION INFORMATION

Register before/on **February 14, 2024** to save up to \$100 on registration. The tuition fee includes conference materials, refreshment breaks, and two lunches. We encourage you to register online (the most secure method) at the [conference website](#). Please visit the website for further ways to register, as well as cancellation/refund/transfer guidelines. If you need assistance in registering, please contact registration@fasdunited.org.

REGISTRATION FEES

EARLY-BIRD RATES

BEFORE/ON FEBRUARY 14, 2024

Full Conference (April 11-14)	\$795
Pre-conference (April 11)	\$150
Main Conference (April 12 - 14)	\$745

REGULAR RATE

AFTER FEBRUARY 14, 2024

Full Conference (April 11-14)	\$895
Pre-conference (April 11)	\$200
Main Conference (April 12 - 14)	\$795

SPECIAL RATES

Individual with FASD	\$0
*Parent Pre-conference (April 11)	\$100
*Parent Main-conference (April 12-14)	\$400
**Student Pre-conference (April 11)	\$100
**Student Main conference (April 12-14)	\$400

All rates are quoted in USD.

*Available only for parents/guardians of individuals with FASD who do not work in the area of FASD.

**Available only for full-time students. A copy of valid student photo ID must be sent with your registration. Please email a copy to registration@fasdunited.org after registering to qualify for this rate.

If you are a **speaker, sponsor, or exhibitor**, please refer to registration rates provided by Jo Votolato, Conference Director.

CALL FOR POSTERS

The Call for Posters (with the possibility of being upgraded to a 15-minute oral paper presentation) is available. Please visit our [website](#) for more details.

SPONSORS & EXHIBITORS

If you wish to sponsor or exhibit this conference, please visit our [website](#) to download the sponsorship and exhibit prospectus.

CODE OF INCLUSION

This Code of Inclusion serves as a guide outlining our expectations for all participants who attend this conference. By embracing the principles below, we aim to foster an open dialogue in a safe and progressive environment, most notably for individuals with FASD. Upholding the Code of Inclusion is the responsibility of all who attend the conference:

1. Use of non-stigmatizing language & visuals

- Centering on the living experience of the FASD community, and those diagnosed with FASD and their families, can do more good than focusing only on alcohol use during pregnancy.
- Promoting dignity and respect of individuals with FASD, their caregivers, and those who use alcohol during pregnancy, can be accomplished through use of person first language, avoidance of blame assignment and avoidance of stigmatizing visuals (e.g. avoid fear-based images).
- Focusing on research and fact-driven information, while also avoiding politicization and segmentation of issues, can reduce stigma and heighten accuracy.
- (If applicable) Emphasizing messages of support and education, rather than complete prevention of alcohol use during pregnancy can provide a message of hope rather than one of defeatism.

2. Commitment to equity & inclusivity

- Aiming toward use of non-technical language can enhance inclusiveness and equity. Technical language and abbreviations that border on "professional jargon," without explanation, may unintentionally exclude persons without similar training from the conversation.

3. Respectful disagreement towards different viewpoints

- Any professional field, especially as it develops consensus and responds to emerging evidence, will generate different viewpoints. Respect towards all perspectives, with balanced and calm presentation of evidence, are encouraged.

PROGRAM-AT-A-GLANCE

	THURSDAY APRIL 11	FRIDAY APRIL 12	SATURDAY APRIL 13	SUNDAY APRIL 14
8:00	8:00 - 8:30 Registration			
9:00	8:30 - 10:00 Pre-conference: PC1 or PC2	8:30 - 10:00 Welcome Remarks, Plenary	8:30 - 10:00 Remarks, Plenary	8:30 - 9:15 Remarks, Plenary
10:00	10:00 - 10:30 Break (April 12, 13: exhibits, posters)			9:40 - 10:10 Break (exhibits, posters)
11:00	10:30 - 12:00 PC 1 or PC2 continues	10:30 - 12:00 Breakout Session A	10:30 - 12:00 Breakout Session C	10:10 - 11:40 Breakout Session E
12:00	12:00 - 1:00 Lunch (on your own)	12:00 - 1:00 Lunch (provided), exhibits, posters	12:00 - 1:30 Lunch (on your own), exhibits, posters	11:40 - 12:40 Lunch (provided) Exhibits, posters
1:00	1:00 - 2:30 PC 1 or PC2 continues	1:00 - 2:30 Breakout Session B	1:30 - 3:00 Breakout Session D	12:40 - 2:30 Remarks, Plenary, Starfish Award & Closing Ceremonies
3:00	2:30 - 3:00 Break (April 12, 13: exhibits, posters)			2:30 Adjourn Safe travels!
4:00	3:00 - 4:30 PC 1 or PC2 continues	3:00 - 4:30 Remarks, Plenary	3:00 - 3:30 Break, exhibits, posters	
5:00			3:30 - 5:00 Remarks, Plenary	

TEEN & ADULT STREAM

WHAT IS IT?

The teen & adult program contains both educational and social activities. It is open **ONLY** to teens and adults who have FASD or believe they do. It is **NOT** open to other family members.

This is meant to be a safe place for teens and adults to learn about FASD from those who have become mentors and leaders and who have overcome many difficulties but who still struggle daily with different things – those who really understand and know the struggles those attending with FASD are experiencing. It is place where they can meet others like themselves, talk about things, ask questions, learn a thing or two, and experience belonging.

WHEN IS IT?

- Friday, April 12, Saturday, April 13, Sunday, April 14

WHO PLANS IT? AND HOW MUCH IS IT?

The stream is planned, organized, and run by the **International Adult Leadership Collaborative of FASD Changemakers** (see page 7).

The teen and adult program, as well as the rest of the main conference, is **free for individuals with FASD**.

MORE INFORMATION ON THE TEEN & ADULT STREAM, INCLUDING SCHEDULE, CLICK [HERE](#).



CONFERENCE COMMITTEES

PROGRAM PLANNING COMMITTEE

Jan Lutke, Conference Chair,
Vancouver, BC

Jo Votolato, Conference Director,
FASD United, Washington, DC

Heather Carmichael Olson, Ph.D.,
Clinical Professor, Division of Child and
Adolescent Psychiatry, Department of
Psychiatry and Behavioral Sciences,
University of Washington School of
Medicine, Seattle, WA

Michael Charness, MD, Chief of Staff,
VA Boston Healthcare System; Faculty
Associate Dean, Professor of
Neurology, Harvard Medical School;
Associate Dean, Professor of
Neurology, Boston University School
of Medicine, West Roxbury, MA

Peter W. Choate, RCSW, Ph.D., Clinical
Social Worker, Professor, Social Work
Mount Royal University, Calgary AB

Dan Dubovsky, MSW, FASD Specialist,
Independent Contractor, Philadelphia, PA

Bill Dunty, Ph.D., FASD Research
Coordinator and Program Director,
Division of Metabolism and Health
Effects, National Institute on Alcohol
Abuse and Alcoholism, National
Institutes of Health, Bethesda, MD

Brenda Knight, Registered Psychologist,
Private Practice, Vancouver, BC

Christine Loock, MD, FRCPC, FAAP,
Developmental and Social Pediatrician,
Associate Professor, Department of
Pediatrics, University of British
Columbia, BC Children's Hospital &
Sunny Hill Health Centre for Children,
Vancouver, BC

Rajesh Miranda, Ph.D., Professor,
Department of Neuroscience and
Experimental Therapeutics, College of
Medicine, Texas A&M University Health
Science Center, Bryan, TX

Christie Petrenko, Ph.D., Research
Associate Professor, Mt. Hope Family
Center, University of Rochester, New
York, NY

Edward Riley, Ph.D., Distinguished
Research Professor, Center for Behavioral
Teratology, San Diego State University,
San Diego, CA

Joanne Weinberg, Ph.D., Professor and
Distinguished University Scholar, Emerita,
Department of Cellular & Physiological
Sciences, University of British Columbia,
Vancouver, BC

LOCAL PLANNING COMMITTEE

Jan Lutke, Conference Chair,
Vancouver, BC

Jo Votolato, Conference Director,
FASD United, Washington, DC

Jennifer Wisdahl, Chief Operating
Officer, FASD United, Washington, DC

Allison D. Brooks, Ph.D., Licensed
Psychologist, University of Washington
Fetal Alcohol Syndrome Diagnostic and
Prevention Network; Clinic Director,
Brooks Powers Group, Seattle, WA

Paul Connor, Ph.D., Clinical
Neuropsychologist/Licensed
Psychologist Private Practice, Des
Moines, WA; Courtesy Clinical
Assistant Professor, University of
Washington, Psychiatry and Behavioral
Sciences, Fetal Alcohol and Drug Unit,
Seattle, WA

Carolyn Hartness, Fetal Alcohol
Spectrum Disorders/Reentry
Consultant/Trainer, Seattle, WA

Susan (Astley) Hemingway, Ph.D.,
Professor of Epidemiology and
Pediatrics, Schools of Public Health and
Medicine, University of Washington,
Director WA State Fetal Alcohol
Syndrome Diagnostic & Prevention
Network, Seattle WA

Tracy Jirikowic, Ph.D., OTR/L, FAOTA,
Professor | Department of Rehabilitation
Medicine; Program Director, Division of
Occupational Therapy; Co-Director,
Program in Rehabilitation Science, UW
Medicine, University of Washington,
Seattle, WA

Kay Kelly, Project Director, FASD Legal
Issues Resource Center; Research
Coordinator, Multisite Study of Prenatal
Alcohol Exposure: Effects of Inflammation
and Endocrine Dysfunction in Adulthood,
Brain Maturation in Adults with FASD,
Addictions, Drug & Alcohol Institute
(ADAI)/Fetal Alcohol and Drug Unit
(FADU), University of Washington/ School
of Medicine/Psychiatry, Seattle, WA

Michelle Kuhn, Ph.D., Assistant
Professor of Psychiatry and Behavioral
Sciences, University of Washington
Medical School; Attending Psychologist,
Seattle Children's Hospital, Seattle, WA

Annette Kunzman, MBA, President,
FASD Network of Southern California;
Member, FASDNow!, a California
Alliance, Manhattan Beach, CA

Natalie Novick Brown, Ph.D., Clinical
Assistant Professor, University of
Washington, Seattle, WA

Erin Olson, Ph.D., Clinical Associate
Professor, Psychiatry & Behavioral
Sciences, University of Washington School
of Medicine; Psychologist, Fetal Alcohol
Syndrome Diagnostic & Prevention
Network, Institute on Human Development
and Disability University of Washington;
Attending Psychologist, Autism Center,
Seattle Children's Hospital, Seattle, WA

Joanne Sparrow, Ph.D., Licensed Clinical
Psychologist in Private Practice (Redmond,
WA) and Special Projects Coordinator –
Families Moving Forward Program (Seattle
Childrens Research Institute), Seattle, WA

Karen A Steele, Attorney, Salem, OR

Susan Stoner, Ph.D., Research Associate
Professor, Ann Streissguth Ph.D. Professor
of Fetal Alcohol Spectrum Disorders;
Addictions, Drug & Alcohol Institute;
Department of Psychiatry & Behavioral
Sciences; University of Washington School
of Medicine, Seattle, WA

CONFERENCE COMMITTEES

INTERNATIONAL ADVISORY COMMITTEE

Sabrina Agnihotri, Trainee Representative; MD/Ph.D.,PGY-5, Department of Psychiatry, University of Toronto, Toronto, ON

Dorothy Badry, Ph.D., RSW, Professor, Faculty of Social Work, University of Calgary, Calgary, AB

Tatiana Balachova, Ph.D., Health Scientist Administrator/Program Director, Division of Epidemiology and Prevention Research (DEPR); Scientific Coordinator and Executive Secretary, Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD), National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, Bethesda, OK

Claire Coles, Ph.D., Professor, Department of Psychiatry and Behavioral Sciences; Director, Maternal Substance Abuse and Child Development Program (MSACD), Emory University, Atlanta, GA

Paul Connor, Ph.D., Clinical Neuropsychologist/Licensed Psychologist Private Practice, Des Moines, WA; Courtesy Clinical Assistant Professor, University of Washington, Psychiatry and Behavioral Sciences, Fetal Alcohol and Drug Unit, Seattle, WA

Lori Vitale Cox, Ph.D., Director Elsipogtog Eastern Door Centre; Adjunct Professor UBC Faculty of Medicine, Department of Pediatrics, Rexton, NB

Elizabeth Elliott, Professor, Discipline of Child and Adolescent Health, Faculty of Medicine and Health Science, University of Sydney; and Consultant Paediatrician, The Sydney Children's Hospitals Network, Westmead, Australia

Carmen Enache, MD, Ph.D., Senior Consultant, Obstetrics and Gynecology, Emergency Clinical Hospital, Bucharest, Romania

Erikson Furtado, MD, Ph.D., University of Sao Paulo, School of Medicine of Ribeirao Preto, Department of Neurosciences and Behavior, Division of Psychiatry, Child & Adolescent Psychiatry and Mental Health, Alcohol & Drugs Program – PAI-PAD Ribeirão Preto, Brazil

Mary Kate Harvie, Judge, Provincial Court of Manitoba, Winnipeg, MB

Susan (Astley) Hemingway, Ph.D., Professor of Epidemiology and Pediatrics, Schools of Public Health and Medicine, University of Washington, Director WA State Fetal Alcohol Syndrome Diagnostic & Prevention Network, Seattle WA

Heike Hoff-Emden, Dr.med, Leader, FASD Centre, Central Germany/Leipzig Leipzig, Germany

Parker Holman, Senior Lab Demonstrator, Anatomy, Department of Kinesiology; Adjunct Professor, Department of Psychology, Brock University, St. Catharines, ON

Kay Kelly, Project Director, FASD Legal Issues Resource Center; Research Coordinator, Multisite Study of Prenatal Alcohol Exposure: Effects of Inflammation and Endocrine Dysfunction in Adulthood, Brain Maturation in Adults with FASD, Addictions, Drug & Alcohol Institute (ADAI)/Fetal Alcohol and Drug Unit (FADU), University of Washington / School of Medicine/Psychiatry, Seattle, WA

Denis Lamblin, MD, Developmental Pediatrician, President SAF FRANCE; President and Delegate Director, Local & Regional Networks, International SAFTHON (FASTHON), Reunion Island, France

Philip May, Ph.D., Research Professor, Gillings School of Global Public Health, University of North Carolina at Chapel Hill-Nutrition Research Institute, Kannapolis, NC

Valerie McGinn, Ph.D., Clinical Neuropsychologist, Department of Population Health, University of Auckland, Auckland, New Zealand

Kathleen Mitchell, Senior Vice President of FASD Prevention and Recovery Services, FASD United, Washington, DC

Leana Olivier, Chief Executive Officer, Foundation for Alcohol Related Research (FARR), Cape Town, South Africa

Moira Plant, Professor Emeritus, Alcohol & Health Research Unit, University of the West of England, Bristol, UK; Adjunct Professor, Curtin University, Edinburgh, UK

Svetlana (Lana) Popova, Senior Scientist, Institute for Mental Health Policy Research, Centre for Addiction and Mental Health; Associate Professor, Epidemiology Division, Dalla Lana School of Public Health, University of Toronto; Associate Professor, Factor-Inwentash Faculty of Social Work, University of Toronto; Graduate Faculty Associate Member, Institute of Medical Science, University of Toronto, Toronto, ON

Jon Skranes, Professor, Child Neurology and Rehabilitation, Department of Clinical and Molecular Medicine, Faculty of Medicine and Health Sciences, Norwegian University of Science and Technology (NTNU), Trondheim; Head of Child Habilitation Unit and Senior Consultant, Regional Competence Center for Children with Prenatal Alcohol/Drug Exposure, Dept. of Pediatrics, Sørlandet Hospital, Lillesand, Norway

Paula Stanghetta, Facilitator, Coach, Trainer, Paula Stanghetta & Associates Inc., Kitchener, ON

CONFERENCE COMMITTEES



FASD LEADERSHIP COMMITTEE: INTERNATIONAL ADULT LEADERSHIP COLLABORATIVE (ALC), FASD CHANGEMAKERS

Myles Himmelreich, ALC FASD Changemaker, Vancouver, BC

CJ Lutke, ALC FASD Changemaker, Vancouver, BC

Katrina Griffin, ALC FASD Changemaker, Vancouver, BC

Emily Hargrove, ALC FASD Changemaker, Paducah, KY

Justin Mitchell, ALC FASD Changemaker, Vancouver, BC

Anique Lutke, ALC FASD Changemaker, Vancouver, BC

Maggie May, ALC FASD Changemaker, Ireland

Jacob Dedman, ALC FASD Changemaker, Australia

Jessica Birch, ALC FASD Changemaker, Australia

Nury van Beers, ALC FASD Changemaker, Netherlands

Kim Dokter, ALC FASD Changemaker, Netherlands

Byron Jones, ALC FASD Changemaker, New Zealand

Gina Schumaker, ALC FASD Changemaker, AK

Shannon Butt, ALC FASD Changemaker, Ottawa, ON

Justin Shepherd, BFA, ALC FASD Changemaker, Vancouver, BC



Remember that no one is born a **CHANGEMAKER**. It is something you become when you see a problem, then dare to become part of the **SOLUTION**.

MELINDA GATES



The VERDICT IS IN YOUR COURT:



ADVANCING JUSTICE FOR INDIVIDUALS WITH FASD
ACROSS JUDICIAL SYSTEMS



Despite alarming prevalence and concern, there is a persistent lack of understanding regarding how to effectively accommodate individuals with FASD when they have justice encounters. Recent strides in scientific research and collaborative efforts involving judges, lawyers, probation officers, social workers, researchers, and other professionals have challenged legal principles and fostered a growing recognition of the pressing ethical and moral imperatives to identify FASD and respond accordingly.

Please join us in this session with justice and non-justice professionals to foster dialogue, share strategies and tools, and disseminate recent research into accessible information for use in courts and community. The lack of accommodation, for individuals with a recognized disability, raises social justice concerns as their access to justice (at all levels) is severely impacted which can lead to unjust outcomes including loss of personal freedom, loss of parental rights, and/or prolonged justice engagement. From sensory challenges to delayed processing, FASD can present myriad challenges to individuals. The over-representation of individuals with FASD in the criminal justice system as well as family and child welfare courts presents an alarming issue with the potential for intergenerational impacts.

To advance access to justice, this workshop will be organized around three key questions:

- How can the different judicial systems better respond with heightened awareness and effectiveness regarding all parties, including victims, defendants, and witnesses in the criminal court, and the children and families related to a person with FASD in the family court?
- What are key strategies community workers/supports can use to help support individuals with FASD who are justice-involved?
- How can justice professionals and those disciplines adjacent to them better share evidence-based practices to further our collective understanding of the complexities of FASD and appropriate accommodations so as to more effectively support individuals to stay in community?

This one-day workshop will bring together leading justice, community and research voices to explore proven, promising and exciting practices for an interdisciplinary audience. We will share information across sectors to build overall capacity to support individuals with FASD inside and outside the courtroom. After this exciting one-day session, participants will be able to:

- Explain the ways in which FASD can present particular challenges for individuals with FASD and justice professionals in different courtroom settings
- Understand barriers to justice as they present in criminal, family, and child welfare courtroom settings
- Demonstrate new language and understanding of how to implement proven practices to better support individuals with FASD in community and justice settings
- Describe the proven best practices showcased in this session and apply them in diverse court settings in your own communities

The detailed schedule for this day, including break times, will be released soon. Please note that there is no lunch provided on this day.

LET'S TALK: PCI

The SCIENCE & FUNCTION OF MEMORY



A REAL WORLD APPROACH: EVIDENCE, EXPERIENCE AND THE WISDOM IN THE ROOM



LET'S TALK: PC2

FASD was first clinically identified over 50 years ago, and international research continues to provide a very large, growing and diverse body of scientific evidence about the impact of prenatal alcohol exposure on the brain and body. Of particular importance, however, to teens and adults with FASD and those who live and work with them is the impact of alcohol on the area of memory. Memory is the critical building block or cornerstone of cognition, thinking, learning and the application of accumulated knowledge which has been retained – when it is required, where it is required, for whom it is required, how it is required, as it is required, and why it is required, on demand over time. The practical use of knowledge is always memory-based, and when memory is impaired, the ability to function effectively in real life in a fast-paced world is impaired. No one can function well in a vacuum of information. So, how is what science knows translated into use and how can this usage benefit teens and adults with FASD and their parents/caregivers?

Using the expertise of research clinicians, Adult Leadership Collaborative (ALC) members and the wisdom in the room, delegates will discuss how the science of memory, its assessment, test interpretation and use in everyday life can be better understood. Can it be better assessed in an ecologically valid manner and what are the implications for function going forward?

Learning Objectives

- Review the theory and science behind memory, specifically in relation to memory in adolescents and adults with FASD
- Consider how impaired memory relates to everyday activities in expected function in those with FASD
- Examine roles in understanding and supporting memory functioning
- Explore the concept of an “interautonomous approach” to effectively communicate about memory in different environments and systems
- Discuss the gap between formal memory assessment and real life demands
- Consider meaningful and realistic strategies and functional support by everyone involved, including parents and caregivers

FACILITATOR:



PAULA STANGHETTA
Facilitator, Coach, Trainer, Paula Stanghetta & Associates, Kitchener, ON

WELCOME REMARKS:



JAN LUTKE
Conference Chair, Vancouver, BC

OPENING & CLOSING REMARKS: NOTHING ABOUT US WITHOUT US...



MYLES HIMMELREICH
Changemaker, Vancouver, BC



CJ LUTKE
Changemaker, Vancouver, BC




KATRINA GRIFFIN
Changemaker, Vancouver, BC



EMILY HARGROVE
Changemaker, Paducah, KY

EXPERT SPEAKERS:



JULIE KABLE
Ph.D., Associate Professor, Department of Psychiatry and Behavioural Sciences and Pediatrics, School of Medicine, Emory University, Atlanta, GA



JACQUELINE PEI
Ph.D., RPsych, Professor, Department of Educational Psychology; Assistant Clinical Professor, Department of Pediatrics, University of Alberta, Edmonton, AB

The detailed schedule for this day, including break times, will be released soon. Please note that there is no lunch provided on this day.



8:00 - 8:30 Registration

8:30 - 9:10 Conference Welcome & Opening Remarks



TOM DONALDSON

President & CEO, FASD United, Washington, DC



JAN LUTKE

Conference Chair, Vancouver, BC

& FASD Adult Leadership Committee



MYLES HIMMELREICH

Changemaker, Vancouver, BC



CJ LUTKE

Changemaker, Vancouver, BC



KATRINA GRIFFIN

Changemaker, Vancouver, BC



EMILY HARGROVE

Changemaker, Paducah, KY

Special Welcome (to be announced)

Remarks: *Nothing About Us Without Us - Life as I Live It*
Maggie McHugh (Maggie May), Changemaker, Ireland

9:10 - 10:00

MORNING PLENARY

PRELIMINARY RESULTS FROM FASD CHANGEMAKERS LAY OF THE LAND SURVEY #2: **WHAT REALLY MATTERS? LIFE AS WE LIVE IT**

Myles Himmelreich, Changemaker, Vancouver, BC
CJ Lutke, Changemaker, Vancouver, BC
Katrina Griffin, Changemaker, Vancouver, BC
Emily Hargrove, Changemaker, Paducah, KY

- Discuss why this survey was developed
- Identify key findings from the survey
- Consider the implications of the preliminary survey results and areas requiring further research

10:00 - 10:30 Break: exhibits open and poster viewing

“
Coming together is a
BEGINNING.
Keeping together is
PROGRESS.
Working together is
SUCCESS.

HENRY FORD —”



10:30 -
12:00

BREAKOUT SESSION A

Each session will have a
25% interactive component.

A1

4 oral papers (15 minutes & Q&A)

A1a Electroencephalographic Results in Children with FASD
Katarzyna Dyląg, MD, Physician, Faculty of Medicine, Jagiellonian University; St. Louis Children Hospital, Krakow, Poland

A1b Sex Differences in Cognitive and Behavioral Effects of Prenatal Alcohol Exposure in a Rat Model
Shameena Bake, Ph.D., Assistant Professor, Department of Neuroscience and Experimental Therapeutics, Texas A&M Health Science Center, Bryan, Texas

A1b Weaving Indigenous and Western Worldviews within the Assessment and Diagnosis of FASD
Kara Te Whata-Maynard, PGDip, Learning Support Psychologist, Ministry of Education, New Zealand

A1c The Meaning of Resiliency in Aboriginal Adults with FASD
Melanie Samaroden, BA, BEd, Masters Student, Counselling Psychology, Athabasca University, Edmonton, AB

A2

2 x 45-minute sessions & Q&A

A2a (45 minutes) Diversity, Equity and Belonging: Inclusive Strengths-based Approaches to Address FASD in Urban Indigenous Communities

Christine Loock, MD, Social Pediatrician, University of British Columbia; Responsive Intersectoral, Community Health, Education, and Research (RICHER) Initiative, Vancouver, BC
Wanda Pelletier, FASD Key Worker Program YWCA Crabtree Corner; Project Coordinator, United Families for our Future FASD Project, Vancouver, BC

- Discuss inclusive, empowering approaches developed with individuals and families living with FASD in indigenous urban underserved settings
- Discuss approaches to changing the narratives surrounding FASD developed with persons with lived experience
- Discuss common themes in other urban, rural and other underserved settings internationally

A2b (45 minutes) Accessible Strategies for Training Pediatric and Adult Primary Care Providers in FASD Diagnosis and Care
Lynn L. Cole, DNP, Clinical Associate Professor, University of Rochester School of Nursing, University of Rochester, New York, NY
Christie Petrenko, Ph.D., Research Associate Professor, Mt. Hope Family Center, University of Rochester, New York, NY

- Describe the strengths and challenges of the primary care landscape in care of adults with intellectual and developmental disabilities
- Discuss Project ECHO (Extension for Community Healthcare Outcomes), as a model of care to expand access to care for individuals with chronic complex conditions
- Discuss use of Project ECHO in training primary care providers about FASD and other developmental disabilities in pediatrics and opportunities in adult care

A3

90-minute session, only open to delegates who attended the pre-conference session #1 (page 8)

Follow-up to PS1: The Verdict in in Your Court: Advancing Justice for Individuals with FASD Across Judicial Systems

For those who attended PC1, this breakout session will focus on issues specifically of interest to parents and/or caregivers of individuals with FASD as it relates to the judicial systems. Please only select this session if you attended PC1.

A4

90-minute session

Implementing an FASD Assessment and Strengths and Strategies Approach in a Substance Use Treatment Agency and a Behavioral Health Agency

Dan Dubovsky, MSW, FASD Specialist, Independent Contractor, Philadelphia, PA
Summer Krochta, LCSW, Vice President of Programs, Children's Service Center, Wilkes-Barre, PA

- Describe a process of identifying individuals who have a likely FASD
- Discuss a strengths and strategies approach for supporting these individuals
- Examine barriers to implementing screening and modifications in treatment settings
- Identify benefits of this screening and strengths and strategies approach



A5

90-minute session

What Are You Afraid of? – Addressing the Biggest Fears of Receiving and Accepting an FASD Diagnosis

ALC members

TBD

A6

90-minute session

Practice-Based Evidence FASD Support Groups in Ontario: What Makes Them Work and How Augmenting Groups and Individual Sessions with Acceptance Commitment Training Can Impact Outcomes

Angela Geddes, CYC, MSW, RSW, YTT, Researcher, Social Worker, Private Practice, Elgin County, ON

- Demonstrate the importance of working alongside individuals with FASD and their caregivers to develop and deliver supports tailored to their needs
- Collaborate and develop partnerships with community agencies, sharing expertise and resources, while building skills and capacity
- Identify the unique and key elements of support groups that are considered effective in addressing the wellbeing of individuals with FASD and their caregivers
- Practice and further discover the benefit of Acceptance Commitment Therapy/Training (ACT) for all: facilitators, group and individual participants

12:00 - 1:00 Lunch (provided), exhibits, and posters

Parent Lunch (provided): In past conferences, parents have appreciated to the opportunity to come together at these events to connect with other parents who are raising a child, youth, or adult with FASD. For those parents who have children/adults living with FASD and are registered to attend the main conference, we are happy to announce that this lunch is arranged for you. If you are interested in attending, please sign up when registering for the conference. You will receive more information closer to the conference about this lunch.

1:00 - 2:30

BREAKOUT SESSION B

Each session will have a 25% interactive component.

B1

4 oral papers (15 minutes & Q&A)

B1a Choline, One-Carbon Metabolism, and Prenatal Alcohol Exposure
Susan Smith, Ph.D., Deputy Director, UNC Nutrition Research, University of North Carolina, Kannapolis, NC

B1b Ultrasound imaging of ciliary arterial blood flow as a potential ocular biomarker for brain effects in adult offspring prenatally exposed to alcohol
Marisa Pinson, BS, Graduate Assistant Researcher, Neuroscience and Experimental Therapeutics, Texas A&M Health Science Center, Bryan, TX

B1c Metabolic and Cardiovascular Diseases in a Retrospective Cohort of Adults with FASD
Olivia Weeks, Postdoctoral Research Fellow, Division of Cardiology, Boston Children's Hospital, Harvard Medical School, and Brigham and Women's Hospital, Boston, MA

B1d Embryonic Alcohol Exposure in Zebrafish Predisposes Adults to Cardiomyopathy and Diastolic Dysfunction
Olivia Weeks, Postdoctoral Research Fellow, Division of Cardiology, Boston Children's Hospital, Harvard Medical School, and Brigham and Women's Hospital, Boston, MA

B2

4 oral papers (15 minutes & Q&A)

B2a Planning Healthy Outcomes with Caregivers of Individuals with FASD: Caregiver Perceptions and Beliefs
Vannesa Joly, BA, Graduate Research Assistant, Department of Educational Psychology, University of Alberta, Edmonton, AB

B2b Disruption of Circadian Clocks in Children with FASD
Dipak Sarkar, Ph.D., DPhil, Board of Governors Professor, Director, Endocrinology Program; Distinguished Professor, Department of Animal Science, The State University of New Jersey, Rutgers, New Brunswick, NJ

B2c FASD in Canadian Criminal Cases: A Case Law Review
Kaitlyn McLachlan, MA, Ph.D., Assistant Professor, Department of Psychology, University of Guelph, Guelph, ON

B2d Rural and Remote Programming: Changing Pathways for Youth Living with FASD
Wanda Beland, BEd, Executive Director, NWR FASD Society-Mackenzie Network, High Level, AB



B3

90-minute session

FASD and Justice

Andrea Kotlar, Executive Director, FASD Network of Saskatchewan, Saskatoon, SK

Shana Mohr, Training and Programs Manager, FASD Network of Saskatchewan, Saskatoon, SK

- See how harm reduction can work in the justice system
- Recognize trauma informed care and the role FASD plays in criminal occurrences
- Work with lawyers to create an FASD-informed approach to representing their clients

B4

90-minute session

FASD as a Brain/Body Disorder: A Social Determinants of Health Perspective

Peter W. Choate, RCSW, Ph.D., Clinical Social Worker Professor, Social Work Mount Royal University, Calgary AB

Dorothy Badry, Ph.D., RSW, Professor, Faculty of Social Work, University of Calgary, Calgary, AB

- Use the proposed FASD Social Determinants framework for policy and clinical practice development
- Develop language and positions to engage colleagues in changing to strengths and capacity perspectives
- Integrate social determinants and human rights creating foundational advocacy positions that can be used in various forums intersecting with people with FASD
- Locate capacity building in case plans developed with clients

B5

90-minute session

FASD and Policy Implications Among Offenders in a Federal Psychiatric Facility

Mansfield Mela, MBBS, FWACP, FRC Psych, MSc, FRCPC, Professor and Forensic Psychiatrist, Department of Psychiatry, University of Saskatchewan, Saskatoon, SK

- Compare the rates of and contributing factors to FASD in correctional and non-correctional populations
- Recognize the importance of applying a similar research approach as the current study in other patient populations in order to improve public safety

B6

Open only to parents & caregivers
90-minute session

Parenting Children and Adults with FASD: Recognizing the Joys and Adjusting to What You Can and Cannot Change

Dan Dubovsky, MSW, FASD Specialist, Independent Contractor, Philadelphia, PA

Brenda Knight, Registered Psychologist, Private Practice, Vancouver, BC

- Identify positive aspects of raising your child
- Describe challenges of meeting the needs of the child or adult
- Increase your coping skills
- Recognize the need to reduce your isolation

2:30 - 3:00

Break, exhibits, and posters





3:00 - 3:10 Remarks: **Nothing About Us Without Us - The Health of Adults with FASD: What Can We Expect?**
 Jessica Birch, ALC FASD Changemaker, Australia

3:10 - 4:30

AFTERNOON PLENARY

FACILITATOR:

EXPLORING HEALTH OUTCOMES IN ADULTS WITH FASD



BILL DUNTY

Ph.D., FASD Resource Coordinator and Program Director, Division of Metabolism and Health Effects, National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, Bethesda, MD

Evidence from the Atlanta and Seattle Research Study Sites



CLAIRE D. COLES

Ph.D., Professor, Department of Psychiatry and Behavioral Sciences; Director, Maternal Substance Abuse and Child Development Program (MSACD), Emory University, Atlanta, GA

- Provide an overview of the impact of prenatal alcohol exposure on adult health and immune function
- Identify areas of risk and resilience
- Discuss the implications of the results for improving medical care and treatment options

Evidence from the Canadian Research Study Site



CHARLIS RAINEKE

Ph.D., Assistant Professor, Department of Psychology, Brock University, St. Catharines, ON

- Provide an overview of the impact of prenatal alcohol exposure on adult health and immune function
- Identify areas of risk and resilience
- Discuss the implications of the results for improving medical care and treatment options

The Potential for Severe Cerebrovascular Outcomes in Adulthood Due to Prenatal Alcohol



FARIDA SOHRABJI

Ph.D., Distinguished Professor and Department Head; Director, Women's Health in Neuroscience Program, Department of Neuroscience and Experimental Therapeutics, Texas A&M University, Bryan, TX

- Recognize that prenatal alcohol exposure (PAE) is a risk factor for adult cardiovascular diseases
- Recognize sex differences in stroke outcomes in PAE adults

Preliminary Results on the Study of the Cardiovascular Risk in Adults with a History of Prenatal Alcohol Exposure



JULIE KABLE

Ph.D., Associate Professor, Department of Psychiatry and Behavioural Sciences and Pediatrics, School of Medicine, Emory University, Atlanta, GA

- Identify relative risk for cardiovascular disease in adults with FASD
- Discuss the role that lifestyle and environmental factors play in mediating cardiovascular outcomes in adults with FASD
- Review the importance of early screening for cardiovascular disease and vascular functioning in individuals with FASD



8:00 - 8:30 Registration

8:30 - 8:40 Remarks: Nothing About Us Without Us - Housing: The Absence of Which is the Absence of Everything
Justin Shepherd, ALC FASD Changemaker, BFA, CA

8:40 - 9:40

MORNING PLENARY

FACILITATOR:

A SYSTEMATIC AND PERSON-CENTERED HARMONIZING FRAMEWORK FOR HOUSING INDIVIDUALS WITH FASD: EXPERIENCES AND TRANSLATIONAL RESOURCES



BRENDA KNIGHT

Registered Psychologist,
Private Practice, Vancouver, BC



JACQUELINE PEI

Ph.D., RPsych, Professor, Department of Educational Psychology; Assistant Clinical Professor, Department of Pediatrics, University of Alberta, Edmonton, AB



ELIZABETH CARLSON

MA, Doctoral Student, School and Clinical Child Psychology Program, University Of Alberta, Edmonton, AB

- Apply a harmonizing housing framework and use accompanying translational resources to support individuals with FASD in meaningful ways. These actionable resources are intended to aid service providers, caregivers, and individuals with FASD by promoting understanding and facilitating meaningful goal attainment
- Recognize current housing provision practices, identify current successes, and demonstrate knowledge on how to adapt programming to better meet the needs of individuals with FASD

9:40 - 10:00

REPORT

PROGRESS REPORT FROM THE INTERNATIONAL CONSENSUS COMMITTEE ON THE RESEARCH CLASSIFICATION OF FASD



MICHAEL CHARNESS

MD, Chief of Staff, VA Boston Healthcare System; Faculty Associate Dean, Professor of Neurology, Harvard Medical School; Associate Dean, Professor of Neurology, Boston University School of Medicine, West Roxbury, MA

- Understand the basic clinical elements that contribute to a diagnosis of FASD
- Identify the similarities and differences in the three principal diagnostic systems that are used most widely to diagnose FASD
- Recognize the challenges for the field in working with different diagnostic systems

10:00 - 10:30 Break, exhibits, and posters

10:30 -
12:00

BREAKOUT SESSION C

Each session will have a
25% interactive component.



C1

4 oral papers (15 minutes & Q&A)

C1a Recommendations Towards Neuropsychological Assessment, Therapy and Post-Diagnostic Activities Based on Proposition of Polish Diagnostic Guidelines of FASD

Magdalena Borkowska, MSc, Researcher, The National Center for Prevention of Addictions (KCPU) Department of Prevention and Public Education, Warsaw, Poland

C1b Mood and neurotic disorders among youth with prenatal substance exposure: A longitudinal register-based cohort study

Niina-Maria Nissinen, Ph.D. Student, MPH, MSc, Folkhälsan Research Center, Tampere University, Tampere, Finland

C1c Assessment and Outcome Profiles in an Adult FASD Clinic: Building on a Successful Pilot and Moving Forward

Paul Jerry, Ph.D., RPsych, Professor and Psychologist, Faculty of Health Disciplines, Athabasca University, Medicine Hat, AB

C1d Healthcare Utilization and Characteristics of Individuals with FAS: A descriptive population-based cohort study in Ontario

Danijela Dozet, MPH, Research Analyst, Institute for Mental Health Policy Research, Centre For Addiction And Mental Health; Ph.D. Student, Institute of Medical Science, Faculty of Medicine, University of Toronto; Toronto, ON

C3

90-minute session

Systemic Advocacy: Creating Change through Community Connection and Co-creation

Sarah Levine, MA, Senior Project Lead, BC Representative for Children and Youth, Victoria, BC

Myles Himmelreich, Co-researcher, BC Representative for Children and Youth, Victoria, BC; FASD Changemaker, Mentor, FASD Consultant, Speaker, Vancouver, BC

Jennifer Charlesworth, Representative for Children and Youth of British Columbia, Victoria, BC

Karen Bopp, Executive Advisor, Children and Youth with Support Needs, BC Representative for Children and Youth, Victoria, BC

Dawson Jones, Youth Research Participant, BC Representative for Children and Youth, Victoria, BC

- Hear from the lived experience of children and youth diagnosed with FASD and how those voices have informed the Representative for Children & Youth's systemic advocacy work
- Identify the different tools to be used in systemic advocacy work and how community-based research uplifts these tools
- Identify barriers to systemic change
- Shift patterns in complex systems

C2

Open only to mental health clinicians
90-minute session

Integrating Knowledge, Experience and Approaches to Mental Health Treatment for Individuals and Families Living with FASD

Dan Dubovsky, MSW, FASD Specialist, Independent Contractor, Philadelphia, PA

Brenda Knight, Registered Psychologist, Private Practice, Vancouver, BC

- Examine underlying issues that contribute to mental health concerns
- Review issues related to the utilization of evidence-based practices in mental health treatment
- Reflect on your standards of practice
- Discuss the importance of professional self-care

C4

Film: 90-minute session

(Film premiere) '8 Keys for Adults with FASD': Seven adults with fetal alcohol spectrum disorders telling their stories, challenges, strengths, and strategies for success

Produced and Distributed by the Alaska Center for Fetal Alcohol Spectrum Disorders

- Identify a broad range of impacts & challenges that are associated with prenatal alcohol exposure and FASD
- Describe a range of strategies that can be helpful to those who experience an FASD
- Explore their own reaction to the stories shared by the adults in the film, from the panel, and questions from audience members



90-minute session

Holistic Support for Adolescents with FASD: From Disability Processing to Relationship-Building to Adaptive Living Skills

Janis Yue, OTS, Master's Student, Occupational Therapy, University of Southern California, Los Angeles, CA

- Identify challenges with self-efficacy that adolescents with FASD often experience
- Describe how challenges with self-efficacy can result in poor outcomes for adolescents with FASD
- Apply sensory and arts-based strategies to support self-efficacy for adolescents with FASD



90-minute session
(Two parts: I & II)

Susan (Astley) Hemingway, Ph.D., Professor of Epidemiology and Pediatrics, Schools of Public Health and Medicine, University of Washington, Director WA State Fetal Alcohol Syndrome Diagnostic & Prevention Network (FASDPN), Seattle, WA

(Part I) Comparison of The 4-Digit Code 2004, Canadian 2015, Australian 2016 and Hoyme 2016 FASD Diagnostic Guidelines When Applied to the Records of 1,392 Patients

- Recognize the key contrasts and similarities in the diagnostic criteria between the 4-Digit Code, Canadian 2015, Australian 2016 and Hoyme 2016 FASD diagnostic guidelines
- Recognize the key contrasts and similarities between the measurement tools (Lip-Philtrum Guides; direct versus photographic measurement of facial features; palpebral fissure length normal growth charts) utilized by the 4 systems
- Discuss the magnitude of discordance in diagnoses generated by the 4 systems
- Identify the ethical and clinical implications of the diagnostic nomenclature

(Part II) FASD in Washington State: A 50-Year Reflection

- Showcase the accomplishments of WA State in the 50 years since the University of Washington coined the term FAS in 1973
- Demonstrate how legislative support, interagency collaboration, centralized data collection, and use of an evidence-based FASD diagnostic system (4-Digit Code) has been key to the 30-year success of the FASDPN
- Demonstrate the value of adopting a single diagnostic system: we can now compare the WA and AK 4-Digit Code FASD diagnostic outcomes and prenatal exposures of thousands of patients diagnosed across both states over 3 decades
- Demonstrate how the FASDPN diagnostic model/tools has been adopted in 35 countries, most recently through the Polish Instytut of FASD

12:00 - 1:30

Lunch (on your own), exhibits, and posters

1:30 - 3:00

BREAKOUT SESSION D

Each session will have a 25% interactive component.



4 oral papers (15 minutes & Q&A)

D1a A Thematic Analysis of Strengths and Protective Factors in Youth with FASD and Criminal Legal System Involvement

Chantel Ritter, MSc, Ph.D. Student, Clinical Child and Adolescent Psychology, University of Guelph, Guelph, ON

D1c Results from the Randomized Controlled Efficacy Trial of the Families Moving Forward Connect App for Caregivers Raising Children with FASD

Christie Petrenko, Ph.D., Research Associate Professor, Mt. Hope Family Center, University of Rochester, New York, NY

& two oral paper sessions (to be confirmed)



90-minute session

Implementing a Screening Assessment, and Intervention Protocol to Identify Youth with FASD Within Michigan's Department of Health and Human Services

Katherine Fitzpatrick, MA, Coordinator, SED and Neurodevelopmental Disorders, Michigan Department of Health and Human Services, Lansing, MI

Dan Dubovsky, MSW, FASD Specialist, Independent Contractor, Philadelphia, PA

- Describe the screening, assessment, and implementation process to identify youth with FASD
- Discuss the importance of utilizing a strengths assessment for youth and their family members
- Identify barriers to implementing the protocol



D3

90-minute session

A Community Initiative to Increase Well-being and Reduce Recidivism in Youth Offenders with FASD

Sam Galloway, Practice Manager, START Taranaki, Kaponga, Taranaki, New Zealand

Her Honour Judge Lynne Harrison, RGON, LLB, District Court Judge, Taranaki District Court, New Plymouth, New Zealand

Valerie McGinn, Ph.D., Clinical Neuropsychologist, Department of Population Health, University of Auckland, Auckland, New Zealand

- Identify what leads to increased well-being and better outcomes for recidivist youth offenders with FASD
- Apply this type of community initiative in your own community to build productive crime free lives and achieve success for youth with FASD

D5

90-minute session

Essential Lessons from Medical Assessments of Adults at FASD Diagnostic Clinics: What I Needed to Learn in Order to Understand Symptoms and Improve Patient Outcomes

Roderick Densmore, MD, Physician, Okanagan Valley FASD Assessment And Support Society, Salmon Arm, BC

- Identify questions that screen for common—but often undiagnosed—FASD-related sensory "invisible disabilities. One example: safety in traffic is at risk if difficulties predicting where a moving object (such as a car) will be in a few seconds time are not recognized.
- Effectively advocate for their patient when suicide risk seems to be underestimated by other professionals
- Use a framework developed by psychologist, Dr. Novick Brown, to understand if sexually inappropriate behavior requires involvement of the criminal justice system or not
- Identify additional strategies and tools that can save time and increase accuracy of assessments

D4

90-minute session

FASD Across the Lifespan Research Including a Report on Adolescent Deaths and Serious Injuries with Prenatal Substance Exposure/FASD in Child Advocate Reports in Canada: A Systematic Review

Dorothy Badry, Ph.D., RSW, Educator, Faculty Of Social Work, University of Calgary, Calgary, AB

- Review current research evidence and literature on the state of practice issues for adolescents with FASD
- Consider the issues of child deaths and serious injuries as reported by child advocates across Canada, contributing to a recognition of the serious need for FASD informed practice in child protection

D6

90-minute session

New Directions for FASD: Perspectives from Australia, USA, and Canada

Elizabeth Elliott, AM, MD, MPhil, MBBS, FRACP, FRCPCH, FRCP, Child and Adolescent Health, Sydney Medical School, University of Sydney; and The Sydney Children's, Hospitals Network, Westmead, Sydney, Australia

Claire Coles, Ph.D., Professor, Department of Psychiatry and Behavioral Sciences; Director, Maternal Substance Abuse and Child Development Program (MSACD), Emory University, Atlanta, GA

Christine Looock, MD, FRCPC, FAAP, Developmental and Social Pediatrician, Associate Professor, Department of Pediatrics, University of British Columbia, BC Children's Hospital & Sunny Hill Health Centre for Children, Vancouver, BC

The session will include information about FASD from national databases, on adult outcomes, on FASD in racialized and other equity seeking populations, on the challenges we encounter in addressing FASD, and on innovations developed to facilitate the diagnosis of FASD and support for individuals and their families.

- Overall objective: To provide updated information on prevalence, contexts, and current state of play regarding FASD in Australia, Canada and USA, the challenges we face in each country, and solutions that have been developed to address these challenges.



3:30 - 3:40 Remarks: Nothing About Us Without Us - Life with FASD in the Rest of the World
Nury van Beers, ALC FASD Changemaker, Netherlands

3:40 - 4:40

AFTERNOON PLENARY

FACILITATOR:

LIFE EXPERIENCE OF INDIVIDUALS WITH FASD IN A RURAL SOUTH AFRICAN CONTEXT



LEANA OLIVIER

Ph.D., Chief Executive Officer, Foundation for Alcohol Related Research (FARR), Cape Town, South Africa



CHRISTINE LOCK

MD, FRCPC, FAAP, Developmental and Social Pediatrician, Associate Professor, Department of Pediatrics, University of British Columbia, BC Children's Hospital & Sunny Hill Health Centre for Children, Vancouver, BC

- Review results from follow-up on a cohort of South African individuals diagnosed with FASD and matched controls 16 years after diagnosis
- Reflect on professionals' perceptions about the life outcomes of people living with FASD in developed versus developing countries
- Consider the implication of the difference in perceived independence between individuals with FASD and that reported by their parents/caregivers

4:40 - 5:00

AFTERNOON PLENARY

THE RESEARCH LEGACY OF DR. ANN STREISSGUTH: PIONEERING STUDIES OF FASD IN MIDDLE AGE AND BEYOND



SUSAN STONER

Ph.D., Research Associate Professor, Ann Streissguth Ph.D. Professor of Fetal Alcohol Spectrum Disorders; Addictions, Drug & Alcohol Institute; Department of Psychiatry & Behavioral Sciences; University of Washington School of Medicine, Seattle, WA

- Provide an overview of studies of FASD by Dr. Streissguth from 1974-2004
- Recognize the significance of Dr. Streissguth's work
- Describe emergent findings from longitudinal studies with the Streissguth research cohort

5:00 Adjourn

“RESEARCH serves to make BUILDING STONES out of STUMBLING BLOCKS.”

ARTHUR D. LITTLE —”



- 8:00 - 8:30 Registration
- 8:30 - 8:40 Remarks: Nothing About Us Without Us - Epigenetics in FASD: What We Want to Know; What We Need to Know
Shannon Butt, ALC FASD Changemaker
- 8:40 - 9:40

MORNING PLENARY

THE CHANGING WORLD OF EPIGENETICS: EXPERIENCE IS WRITTEN IN OUR GENES, BUT DOES IT HAVE TO STAY THERE?

FACILITATOR:



JOANNE WEINBERG

Ph.D., Professor and Distinguished University Scholar, Emerita, Department of Cellular & Physiological Sciences, University of British Columbia, Vancouver, BC

Epigenetic Signatures of Developmental Adversity: Implications for Risk and Resilience in FASD



ALEXANDRE LUSSIER

Ph.D., Instructor in Psychology, Harvard Medical School, Massachusetts General Hospital, Boston, MA

- Discuss the epigenetic mechanisms that might underlie the effects of early life adversity during sensitive periods
- Compare and contrast findings from animal models and human epigenetic studies of prenatal alcohol exposure and FASD
- Assess evidence of epigenetics as a mechanism for risk and resilience for physical and mental health outcomes

Early Life Experience and Developmental Vulnerability: Adversity, Outcomes, and Intervention



JAMES REYNOLDS

Ph.D., Chief Scientific Officer, Kids Brain Health Network; Professor, Department of Biomedical and Molecular Sciences, Queen's University, Kingston, ON

- Describe the impact of early life adversity on brain development and long-term health outcomes
- Recommend tools for assessing child development and developmental support planning to improve long-term outcomes

9:40 - 10:10 Break, exhibits, posters

10:10 - 11:40 BREAKOUT SESSION E

Each session will have a 25% interactive component.

E1

90-minute session

E2

90-minute session

My Health Coach: A community-engaged partnership to develop a scalable mobile health tool for adults to aid with FASD self-management

Christie Petrenko, Ph.D., Research Associate Professor, Mt. Hope Family Center, University of Rochester, New York, NY
Christiano Tapparelo, Research Associate Professor, Department of Electrical and Computer Engineering, University of Rochester, New York, NY
Emily Speybroeck, Graduate Student, Clinical Psychology, University of Rochester, New York, NY
 & available members of the ALC who contributed to this project (Myles Himmelreich, CJ Lutke, Anique Lutke, Katrina Griffin, Maggie May, and Emily Hargrove)

- Describe the user-centered design approach used in initial development and evaluation of the My Health Coach app for adults with FASD
- Describe feasibility trial results including user acceptability, recommendations for future refinements, and lessons learned

Capacity to Stand Trial Issues and Ensuring Effective Participation for Defendants with FASD in Canada and New Zealand

Mansfield Mela, MBBS, FWACP, FRC Psych, MSc, FRCPC, Professor and Forensic Psychiatrist, Department of Psychiatry, University of Saskatchewan, Saskatoon, SK

- Identify factors that impact on capacity to stand trial in defendants with FASD
- Consider how to respond to these identified factors at all stages of the legal process to ensure a fair process



E3

90-minute session

The SAFTHON, an International Movement

Denis Lamblin, MD, *Developmental Pediatrician, President SAF FRANCE; President and Delegate Director, Local & Regional Networks, International SAFTHON (FASTHON); National & International Relations, FASD Resource Center, Père Favron Foundation, Reunion Island, France*
Sarah Lamblin, MA, *Communication Consultant, SAF FRANCE; SAFTHON, Paris, France*
Joëlle Balanche, *International Relations Coordinator, FAS FRANCE; Psychomotrician, CAMSP, Père Favron Foundation, Reunion Island, France*

- Recognize the importance of a global advocacy strategy for a better recognition of FASD by public health actors, institutions and systems in their own countries
- Exemplify or consider SAFTHON as a cost effective strategy and communication support that builds on the combined commitment of many countries in the prevention of FASD
- Initiate a SAFTHON awareness campaign in your own country to influence stakeholders utilizing tools and strategies provided by SAF France professionals

E5

90-minute session

Closing the FASD Health Service Gap in the Eastern Doorway—Taking Action on the Truth and Reconciliation Commission (TRC)'s Calls to Action— Participant Action Research in Wabanaki

Lori Vitale Cox, Ph.D., *Director Elsipogtog Eastern Door Centre; Adjunct Professor UBC Faculty of Medicine, Department of Pediatrics, Elsipogtog FN, NB Canada*

- Discuss FASD in relation to generational trauma and the colonial process
- Discuss Two Eyed Seeing approach to FASD service delivery and the Eastern Door Centre model and its challenges and successes
- Discuss the findings of Indigenous Community Based Participant Action Research regarding FASD health service delivery in the Eastern Doorway (Atlantic Canada)
- Engage session participants in a discussion regarding both successes and gaps in delivering culturally safe FASD services in other communities and regions of Turtle Island

E4

90-minute session

Using Community Outreach and Organizational Partnerships to Make Change for Those Living with FASD: FASDNow!, a California Alliance

Annette Kunzman, MBA, *Treasurer and Acting Executive Director, FASD Network of Southern California, Manhattan Beach, CA*
Shannon Lacobacci, BS, *Certified FASCETS Facilitator, FASD Network of Southern California, Manhattan Beach, CA*

- Identify 2-4 ways that a) children and adults with FASD as potential consumers of services of care systems, and b) caregivers and (c) service providers can influence and drive the delivery of these services by working together
- Identify 4-6 strategies for connecting with an audience that wants or needs to become more knowledgeable about FASD and can apply that knowledge to their family, agency, or professional setting
- Discuss three practical challenges to implementing the strategies available as identified in the first two objectives
- Specify 3-5 action items for developing an effective grassroots effort in your environment

E6

90-minute session

CDC - Jo meeting with Tom Donaldson and/or Elizabeth Dang TBD

11:40 - 12:40 Lunch (provided), exhibits, posters



12:40 - 12:50

Remarks: Nothing About Us Without Us - Our "Human Rights ARE Our Best Interests" Whose Best Interests? Whose Rights? Yours? Ours? Adult Leadership Committee

12:50 - 1:50

CLOSING PLENARY

FETAL ALCOHOL SPECTRUM DISORDERS: A RIGHTS PERSPECTIVE VERSUS BEST INTEREST

FACILITATOR:



PETER W. CHOATE

RCSW, Ph.D., Clinical Social Worker Professor, Social Work Mount Royal University, Calgary AB



TERRI PELTON

BSW, RSW, Executive Director, Child and Youth Advocate of Alberta, Calgary, AB



MOIRA PLANT

Professor Emeritus Alcohol & Health Research Unit, University of the West of England, Bristol, UK; Adjunct Professor, Curtin University, Edinburgh, UK

- Integrate an understanding of human rights as having a higher importance in the lives of people with FASD as opposed to best interest
- Assess and utilize human rights in program development, case planning and service delivery
- Acquire knowledge for the application of human rights advocacy

1:50 - 2:30

CLOSING CEREMONY

STARFISH AWARD PRESENTATIONS & CLOSING CEREMONY: WE ARE THE FUTURE

2:30

Adjourn. Have a safe journey home!

