# FASD: Changing the Conversation

6th National Biennial Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorder

# APRIL 9 to 12, 2014

Hyatt Regency Hotel | Vancouver, BC

"Rise above principle and do what is right"

- Walter Heller, American economist

a place of mind THE UNIVERSITY OF BRITISH COLUMBIA Interprofessional Continuing Education

in collaboration with



Conference Information Online: www.interprofessional.ubc.ca

# **General Information**

Description	It is imperative to a just society to acknowledge, address and support adolescents and adults with fetal alcohol spectrum disorder within the context of ethical service provision. Now is the time for the exploration, examination and deliberation of what we do, how we do it and how we might change. The conference will bring together a diverse group of professionals, families and individuals with FASD to discuss research, evidence, model practice and ideas to expand how we sustain and enhance the lives of individuals with FASD. Participants will consider and debate how we continue to build on strengths and modify existing programs, services and systems to address barriers to ethical practice in healthcare, housing, social services, mental health, criminal and civil justice, employment and education. Participants will explore ideas for the creation and provision of integrated and collaborative approaches across systems with an emphasis on inclusion, creating a good life, social justice and practicality.			
Goals and Objectives	<ul> <li>Discuss projects, programs and practices and new research findings including the ethical implications for improving the lives of adolescents and adults with FASD</li> <li>Explore and examine ethical issues within service delivery and support for adolescents and adults with FASD and their families</li> <li>Consider and explore new ideas and possibilities for the development of promising practices</li> <li>Directly hear and learn from individuals with FASD</li> <li>Please note: 25% of the program will be interactive.</li> </ul>			
Audience	The conference will be essential for those living or FASD and planning for their futures. It will be of pa to have individuals with FASD as our guests.	-		
	Administrators/Managers	Government Officials		Policymakers
	Administrators/Managers     Alcohol & Drug Workers	Housing Officials/Provider	~c	Private/Public Funders
	Corrections Workers	Individuals with FASD	3	Program Providers
	Counsellors	Judges		Psychiatrists
	Educators/Administrators	Lawyers		Psychologists
	Elected Officials/Hereditary Officials	Members of Faith Commu	nities	Researchers
	Employment Services	Mental Health Specialists		Social Service Providers
	• Ethicists	Nurses		Social Workers
	Family Members	<ul> <li>Occupational Therapists</li> </ul>		<ul> <li>Speech Language Pathologists</li> <li>Spouses/Partners</li> </ul>
	Financial Planners	<ul> <li>Physicians</li> </ul>		Vocational Rehab Service Providers
	First Nations, Metis and Inuit Communities	Police Officers		
Exhibiting	Exhibit space is available for community and heal Melissa by phone at 1-604-822-7708 or by email: n		mited and is provided or	n a first-come, first-served basis. Please contact
Professional Credits	A certificate of attendance will be prepared for all registrants including pre-approved continuing education credits where appropriate. This program meets the accreditation criteria of the Canadian Counselling and Psychotherapy Association (CCPA), and has been accredited for up to 22 CEU hours.			
Location	The Hyatt Regency Hotel, 655 Burrard Street, Vancouver, BC. A special rate of \$159 plus applicable taxes until Thursday, February 6, 2014 is available for conference delegates. After this date, the price will increase to \$167 plus applicable taxes. The rooms can be shared at only \$83.50 per person; however it is your responsibility to find a roommate. Please specify that you are booking under the Adults w/ FASD 2014 conference room block. Reserve your accommodation today by contacting the hotel toll-free: 1-888-421-1442 or local number: 604-683-1234.			
Public Transportation	The Hyatt Regency is conveniently located a couple of blocks from the "Vancouver City Center" Canada Line Skytrain stop. The Canada Line travels directly			
Parking	Parking We encourage you to take easy and affordable public transportation, as parking rates at the hotel are very expensive. Below a Hyatt (all rates are subject to change):		expensive. Below are the parking fees for the	
	Weekday Rate	We	ekend / Holiday Rate	
	Each 20 minutes or potion thereof: \$3.00		urly or potion thereof: \$2	2.00
	Hourly Rate: \$9.00	Dai	ly Rate: \$8.00 maximum	between 6.00 am and 6.00 pm
	Daily Rate: \$25.00 maximum between 6.00 am and 6.00 pmEvening Rate: \$4.00 maximum between 6.00 pm and 6.00 am (next day)Evening Rate: \$11.00 maximum between 6.00 pm and 6.00 am (next day)			
Registration	Pre-registration prior to March 12, 2014 is strongly recommended to ensure you receive all conference materials. Please see registration form (on back of brochure) for details.			
	<b>Online</b> / *The most secure method*. Secure, fast, online registration is available for Visa and MasterCard hold-ers at the conference organizer's website: interprofessional.ubc.ca			
	Phone / Register and pay over the phone: Local/International: 1-604-827-3112 or toll-free within Canada/USA: 1-855-827-3112			
	<b>Fax</b> / Fax the registration form to 1- 604-822-4835 and indicate that you would like to pay with VISA or MasterCard. We will send you the secure on-line link to enter your credit card information.			
	Mail / Send the registration form with cheque to: IN 9546 REGISTRATION, Interprofessional Continuing Education, The University of British Columbia, Rm.105 – 2194, Health Sciences Mall, Vancouver, BC, Canada V6T 1Z3			
	Refund / Transfer and Cancellation Policy			
	Refunds will be made (less a \$50 processing fee) if written notice of withdrawal is received by March 12, 2014. No refunds will be granted for withdrawal after that date. There is a \$25 replacement charge in case of a registration transfer. Please contact us prior to March 12, 2014 if you cannot attend and would like another person to come in your place. Interprofessional Continuing Education reserves the right to cancel or move this program if registration is insufficient. In the event of cancellation, a refund will be issued.			

# General Information, cont.

#### **Payment by Credit Card** Methods of 1. Complete the full registration online at interprofessional.ubc.ca with your Visa or MasterCard **Payment** 2. Fax the registration form to 1-604-822-4835 and indicate that you would like to pay with Visa or MasterCard. We will send you the secure on-line link to enter your credit card information \*PLEASE DO NOT FAX CREDIT CARD INFORMATION\* 3. Register and pay over the phone: Local/International: 1-604-827-3112 or toll free within Canada/USA: 1-855-827-3112 (VISA or MasterCard) Participants paying by credit card outside of North America: Please inform your credit card company of the transaction as some banks put a block on credit card payments made outside your country. **Payment by Cheque** Please make your cheque payable to the University of British Columbia and send it along with complete registration form to: IN 9546 REGISTRATION, Interprofessional Continuing Education, The University of British Columbia, Rm.105 – 2194, Health Sciences Mall, Vancouver, BC, Canada V6T 1Z3 **Alternative Payment Methods** Mail or fax complete registration form along with one of the following: 1. Signed purchase order (PO) 2. Letter of Authorization (LOA) from the manager on the organization's letterhead stating that they will be paying the registration fees.

The letter should include the amount of registration fees, name and contact information of the manager

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3. Signed cheque requisition form (ChReq)

# **Program-at-a-Glance**

## Wednesday, April 9, 2014

8:00 - 8:30	Registration Open	
8:30-10:00	Welcoming Remarks	
	Morning Keynote	
10:00 - 10:30	Break: Exhibits & Posters	
10:30 – 11:45	Remarks	
	Plenary	
11:45 – 1:00	Lunch (provided) & Exhibits	
1:00 – 2:30	Concurrent Session A	
2:30 - 3:00	Break: Exhibits & Posters	
3:00 - 4:30	Concurrent Session B	

# Friday, April 11, 2014

8:00 - 8:30	Registration Open
8:30 – 10:10	Remarks & Plenary
10:10 – 10:40	Break: Exhibits & Posters
10:40 – 12:10	Concurrent Session D
12:10 – 1:30	Lunch (on your own) & Exhibits
1:30 – 3:00	Concurrent Breakout session E
3:00 – 3:30	Break: Exhibits & Posters
3:30 – 5:00	Plenary Panel

#### Thursday, April 10, 2014

8:00 - 8:30	Registration Open
8:30 - 9:40	Remarks & Plenary
9:40 - 10:10	Break: Exhibits & Posters
10:10 - 11:40	Plenary Panel
11:40 – 1:10	Lunch (on your own) & Exhibits
1:10 – 2:40	Concurrent Session C
2:40 - 3:10	Break: Exhibits & Posters
3:10 – 4:40	Plenary Panel

## Saturday, April 12, 2014

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8:30 – 9:00	Registration Open
9:00 – 10:30	Concurrent Session F
10:30 - 11:00	Break: Exhibits & Posters
11:00 – 12:30	Concurrent Session G
12:30 – 1:30	Lunch (provided) & Exhibits
12:45 – 1:30	Poster Session
1:30 – 2:30	Closing Keynote
2:30 – 3:15	Presentation of Starfish Awards & Closing Ceremonies Closing Remarks

# **Planning Committee**

Jan Lutke, Conference Chair, Manager Research and Community Engagement, Canada FASD Research Network, Vancouver, BC, Canada

**Tina Antrobus,** MA, RCC, Registered Clinical Counsellor, Private Practice, Coquitlam, BC, Canada

**Dorothy Badry,** PhD, RSW, Assistant Professor, Faculty of Social Work, University of Calgary, Calgary, AB, Canada

**Odette Dantzer,** Policy Director, Disability Services Branch, Ministry of Social Development and Social Innovation, Victoria, BC, Canada **Anne Fuller,** RN, MSN, Provincial FASD Consultant, Children and Youth with Special Needs Policy, Ministry of Children and Family Development, Government of British Columbia, Victoria, BC, Canada

Kristina Hiemstra, Director, Interprofessional Continuing Education, University of British Columbia, Vancouver, BC, Canada

**Brenda M. Knight**, Registered Psychologist, Private Practice, Vancouver, BC, Canada

**Corey La Berge**, MA, LLB, Deputy Children's Advocate, Manitoba, MB, Canada

**Christine Loock,** MD, FRCP(C), Associate Professor, Department of Pediatrics, University of British Columbia; Responsive Intersectoral Community Health, Education, and Research (RICHER) Initiative, BC Children's Hospital & Sunny Hill Health Centre for Children, Vancouver, BC

Michelle Sherbuck, Technical Communications, Alpha Technologies, Surrey, BC

Marsha Wilson, MA, Leadership, Faculty Member, Douglas College, New Westminster, BC, Canada

**Kee Warner**, Executive Director, Whitecrow Village FASD Society, Nanaimo, BC, Canada

# **Advisory Committee**

Sally M. Anderson, Ph.D., ICCFASD Coordinator and Executive Secretary; Office of the Director, National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, Bethesda, MD, USA

**Ilona Autti-Rämö**, MD, Research Professor, Head of Health Research, Research Department, The Social Insurance Institution, Helsinki, Finland and Adjunct Professor at the Child Neurology Department, Helsinki University Hospital, Finland

**Dorothy Badry,** PhD, RSW, Assistant Professor, Faculty of Social Work, University of Calgary, Calgary, AB, Canada

Tatiana Balachova, PhD, Associate Professor, Co-Director, Interdisciplinary Training Program in Child Abuse and Neglect (ITP), Department of Pediatrics, The University of Oklahoma Health Sciences Center, Oklahoma City, Oklahoma, USA

**Diane Black,** PhD, FAS Foundation of the Netherlands, Uithuizen, the Netherlands; and Chair, European FASD Alliance

Paul D.Connor, PhD, Neuropsychologist, Private Practice and Courtesy Clinical Assistant Professor, Fetal Alcohol and Drug Unit, University of Washington, Seattle, WA, USA

Lori Vitale Cox, PhD, Clinical Coordinator, Eastern Door Diagnostic Team for FASD and Related Conditions; Director, Nogemag Healing Lodge for Youth, Rexton, NB, Canada

**Dan Dubovsky,** MSW, FASD Specialist, SAMHSA FASD Center for Excellence, Rockville, MD, USA **Elizabeth Elliott,** MD, MPhil, FRACP, FRCPCH, FRCP, Paediatrics & Child Health, Sydney University and The Children's, Hospital Westmead, Sydney, Australia

Ronald G Friesen, Chief Executive Officer, The Continuing Legal Education Society of BC, Vancouver, BC, Canada

Lorian Hayes, Director of National Indigenous Australian Fetal Alcohol Syndrome Education Network, Bundaberg Queensland Australia; Enrolled PhD School of Medicine University of Queensland, Herston, Queensland, Australia

**Kimberly A Kerns**, PhD, Associate Professor, Department of Psychology, University of Victoria, Victoria, BC, Canada

**Denis Lamblin,** MD, Developmental Pediatrician, SAF FRANCE President, REUNISAF Founder, Medical director of the CAMSP (Fondation du Père FAVRON) Reunion Island, Saint Louis, France

Christine Loock, MD, FRCP(C), Associate Professor, Department of Pediatrics, University of British Columbia; Responsive Intersectoral Community Health, Education, and Research (RICHER) Initiative, BC Children's Hospital & Sunny Hill Health Centre for Children, Vancouver, BC, Canada

**Rebecca Martell,** Clinical Associate, Occupational Performance Analysis Unit (OPAU), Department of Occupational Therapy, University of Alberta, Edmonton, AB, Canada

**Philip A May**, PhD, Research Professor, University of North Carolina at Chapel Hill-Nutrition Research Institute, Kannapolis, NC, USA Raja A.S. Mukherjee, Consultant Psychiatrist, Honorary Senior Lecturer, Surrey and Borders, Partnership NHS Foundation NHS Trust; St George's University of London, UK FASD Specialist, London, UK

Kieran D O'Malley, MB BAO BCh DABPN, Child and Adolescent Psychiatrist, Charlemont Clinic, Dublin, Ireland

**Moira Plant,** PhD, Professor of Alcohol Studies Alcohol & Health Research Unit, University of the West of England, Bristol, UK

**Edward Riley,** PhD, Director, Center for Behavioral Teratology, Distinguished Professor, Department of Psychology, San Diego State University, San Diego, CA, USA

**Christine Rogan,** BA, Health Promotion Advisor, Alcohol Healthwatch Trust and National Coordinator, Fetal Alcohol Network New Zealand

Hans-Ludwig Spohr, Department of Pediatrics, DRK-Kliniken Westend and head of FASD-Counseling Center, Charité, Humboldt-University, Berlin, Germany

Maggie Watts, Consultant in Public Health Medicine, NHS Ayrshire & Arran, Ayr, Scotland

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

# Acknowledgements

 $We would \ like to \ acknowledge \ with \ great \ appreciation \ the \ financial \ support \ from \ the \ following \ organization:$ 



# Wednesday, April 9

	"Conviction is worthloss unloss it is converted into conduct". The mas Carbula Scottich historian
	<i>"Conviction is worthless unless it is converted into conduct"</i> – Thomas Carlyle, Scottish historian
8:00 – 8:30 am	Registration Open
8:30 – 10:00 am	<b>Welcoming Remarks</b> Jan Lutke, Conference Chair, Manager Research and Community Engagement, Canada FASD Research Network, Vancouver, BC
	Morning Keynote: Changing the Conversation: Ethical Perspectives on FASD (Includes Q&A) Arthur Schafer, B. Litt (Oxford), Ethicist Professor, Director of the Centre for Professional and Applied Ethics, University of Manitoba, Winnipeg, MB
	Learning Objectives • Identify a range of ethical issues raised by FASD • Become acquainted with the strengths and weaknesses of some key ethical arguments
10:00 – 10:30 am	Break: Exhibits & Posters
10:30 – 11:45 am	Remarks: Changing the Conversation: Something I want to talk about, Presented by an Adult with FASD
	Plenary: Changing the Conversation: The Ethics of Child Protection Interventions with Parents Who Have FASD (Includes Q & A) Peter W. Choate, Ph.D, Assistant Professor, Social Work, Mount Royal University, Calgary, AB
	<ul> <li>Learning Objectives</li> <li>Challenge the notions of FASD as a debilitating condition that necessarily warrants child protection involvement</li> <li>Question the often seen approach of interventions that place the parent as being either good enough or not as the only dynamic option</li> <li>Consider that the presumptive bias of incapacity acts as a social process of disempowering a specific group of people – parents</li> </ul>
	who have FASD * A continuation of this session will take place in Session A2
11 45	
11:45 am – 1:00 pm	Lunch (provided) & Exhibits

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Concurrent Session A: 90 minutes (all concurrent sessions include 25 minutes of interaction and/or Q&A)

## A1 – Oral Session 1

#### A1a Mapping FASD: the Invisible "Work" of Caregivers/ Parents and Connected Institutions

#### 15min+Q&A

Melody Morton-Ninomiya, BA, B.Ed., M.Ed., PhD(c), Researcher, Faculty of Medicine, Memorial University, St. John's, NL

#### A1b Using Web Tools to Provide Global FASD Education for Parents

#### 15min+Q&A

David Gerry, By Example Education Inc., Victoria, BC Cheryl Sivertson, By Example Education Inc., Victoria, BC

# A1c FASD and Homelessness: Having the Conversation 20min+O&A

Dorothy E Badry, Ph.D, MSW, RSW, Faculty of Social Work, University of Calgary, Calgary, AB Meaghan Bell, MA, Social Worker, Calgary Homeless Foundation, Calgary, AB

#### A2 The Ethics of Child Protection and the Parent with FASD\* Intermediate/Advanced

Peter W Choate, Ph.D, Assistant Professor, Social Work, Mount Royal University, Calgary, AB

\* Continuation of the Plenary Session – digging deeper

Parents identified with an FASD diagnosis have a high probability of involvement with child protection systems. They are often met with a presumptive bias that they will be unable to parent. This session explores that process and the ethical quandaries associated with it. This will be an interactive session with case studies to inform the issues and discussions and to provide a basis for further advocacy approaches.

- Be able to articulate the major ethical challenges arising from a child protection system working with parents with FASD
- Be able to consider how those dilemmas might be resolved, improving the capacity to advocate for and work with these parents

## A3 Mindfulness Training: A Novel Approach to Intervention in Adolescents and Adults with FASD

Intermediate Colette Smart, Ph.D, Assistant Professor of Psychology, Department of Psychology, University of Victoria, Victoria, BC Kimberly Kerns, Ph.D, Associate Professor of Psychology, Department of Psychology, University of Victoria, Victoria, BC

As registered psychologists, it was incumbent upon the researchers to make every effort to attend to relevant ethical principles in design and delivery of the intervention as well as dissemination of the results. First and foremost, we obtained formal ethical approval through our institution's ethical review board. Attention to certain ethical issues became particularly salient in the adult intervention program. An important aspect of this was minimizing discrimination in recruitment and participation. Being mindful of this, we opted to modify the program into a residential format as opposed to the typical weekly format, which otherwise would have precluded participation of individuals (1) without reliable transportation, and (2) those outside of the immediate geographical area. All participation costs were covered (e.g., transportation, housing, materials) in order to not discriminate against those with limited financial means. In addition, every effort was made to attend to issues of cultural sensitivity, given that many of the adult participants happened to be from the First Nations community. Although not part of the standard program, we invited local Elders to open our program and formally welcome us to the land on which it was being hosted. As a result of being attentive to these issues, we believe that we were able to mount a program that was most inclusive to the largest number of individuals within the FASD community.

Learning Objectives

- Gain an appreciation of the cognitive, behavioral, and social challenges faced by persons with FASD
- Gain an understanding of mindfulness training (MT), its impact on brain and behavior, and how it has been applied in clinical research
- Gain introduction to the application of MT in adolescents and adults with FASD, including specific modifications made to apply such training in each of these groups
- Gain an appreciation of the challenges of recruiting for and conducting group interventions with persons with FASD

## A4 Managing Mentally Disordered Offenders with FASD in the Community: What Works and What Should Work Better?

Advanced

Mansfield Mela, MBBS, FWACP, MRC (Psych), Forensic Psychiatrist and Researcher, Department of Psychiatry, University of Saskatchewan, Saskatoon, SK

**Caroline Tait,** *PhD, Department of Psychiatry, University of Saskatchewan, Saskatoon, SK* 

The presentation will address the ethical challenges in working with a particularly vulnerable population (offenders, those with mental illness, and those with mental illness and FASD). Consent becomes a substantial issue, as many individuals have a serious disability, and discriminating assent/consent factors can be difficult. These issues are worthy of further discussion and exploration in the future, especially with populations with multiple vulnerabilities.

Learning Objectives

Learn about the different steps that have been shown to be useful interventions in MDOs with FASD

- Be aware of the link between FASD and mental disorders, as well as effective approaches that can be used to intervene with MDOs with FASD
- Relay the relevance of legal, collaborative, psychotherapeutic, diagnostic, and pharmacological interventions

#### A5 Pragmatic and Ethical Reasons Why a Person Would or Would Not Want to Keep Their FASD Diagnosis Private Intermediate

Jonathan Rudin, Program Director, Aboriginal Legal Services of Toronto, Chair, FASD Justice Committee, Toronto, ON

Given the challenges of obtaining an FASD diagnosis, discussion has often focused on how such information can be maintained and provided to a range of service providers. What is not often discussed is the politics of diagnosis and relationships between marginalized populations and those who exercise state power. This session will focus on the ethical considerations around the sharing of information, why people may legitimately not want such information shared and the importance of personal autonomy in deciding how personal information is disseminated.

Learning Objectives

- Learn about the social construction of disabilities in general and FASD in particular
- Learn how information is obtained and used by police, prosecutors, courts, corrections and child welfare authorities and both the positive and negative uses that can be made of an FASD diagnosis
- Learn about the ethical issues that arise when considering the dissemination of information regarding an individual's FASD diagnosis
- Learn why it may be important for individuals with FASD to keep their diagnosis private even though the release of that information may be of immediate benefit to them

#### A6 Breakthrough! – A Model for Improving Capacity of School Districts to Work Effectively with Students Living with FASD

#### Intermediate to Advanced

**Deb Evensen,** MA, Educator & Behavioural Specialist, Fetal Alcohol Consultation and Training Services (FACTS), Homer, AK, USA

Two Alaskan school districts took bold steps to increase capacity to deal with the challenges of FASD. Starting in 2008, empowered teachers "doing what it takes" and emergent ideas from an ongoing "think tank" resulted in impressive outcomes. A combination of in-classroom assistance, deep learning about FASD, and creative/tailored application of methods soon led – through grade levels – to the model's early success (and to new hope).

- Explore the current misfit between learning, social and behavioural needs of students with FASD and expectations of the school system
- Learn about the social and behavioural challenges faced by students with FASD as they progress through the school system
- Learn about a model that guides students with FASD toward more positive outcomes within the school system

# **3-hour session**

#### A7 Windows of Vulnerability Across Development:

#### & B7 Insight from an Animal Model of FASD

#### Intermediate/Advanced

**Facilitator: Joanne Weinberg**, PhD, Professor and Distinguished University Scholar, Department of Cellular & Physiological Sciences, University of British Columbia, Vancouver, BC

Wendy Comeau, PhD, Research Associate, Department of

Cellular and Physiological Sciences, University of British Columbia, Vancouver, BC **Parker J Holman**, MSc, MSEd, PhD Student, Department of Cellular and

Physiological Sciences, University of British Columbia, Vancouver, BC Vivian Lam, BSc, PhD Student, Department of Cellular and Physiological Sciences, University of British Columbia, Vancouver, BC

Ni Lan, PhD, Research Associate, Department of Cellular and Physiological Sciences, University of British Columbia, Vancouver, BC

**Alexandre Lussier,** MSc, Student, Department of Medical Genetics, University of British Columbia, Vancouver, BC

**Charlis Raineki,** Research Associate, Department of Cellular and Physiological Sciences, University of British Columbia, Vancouver, BC

This advanced workshop will provide an overview of potential windows of vulnerability in relation to individual assessment of cognitive and emotional well-being, later mental health, as well as vulnerability to immune disorders/dysfunction and potential genetic modifications that may be present in different stages of development and may be predictive of individual outcomes.

This workshop will attempt to address how we might incorporate timing of exposure and developmental stage into our assessment of particular deficits in FASD. In addition, our presentation will offer insight into how intervention strategies may take development into account, with focused interventions designed and targeted based on the expectations of behaviour at each milestone throughout development.

Learning Objectives

- Discuss how system dysregulations associated with prenatal alcohol exposure may be differentially expressed over the life course
- Gain an understanding of how animal research may inform the molecular and neurobiological basis of functional dysregulation observed in individuals with FASD.
- Discuss the importance of establishing a neurobehavioural profile that is specific to individuals prenatally exposed to alcohol

# **A8** Session Only for Adults with FASD

#### Making Life Work

**Tina Antrobus,** *MA RCC, Registered Clinical Counsellor, Private Practice, Coquitlam, BC* 

Marsha Wilson, MA, Leadership, Faculty Member, Douglas College, New Westminster, BC

Participants in this session will learn about support and strategies that work best to help with daily life challenges. You will:

- · Learn about different ways to make life work
- Talk about ways to make sure that important dates, appointments and things you have to do are not forgotten
- · Learn about how to manage sleep and stress

2:30 – 3:00 pm	Break: Exhibits & Posters
3·00 – 4·30 pm	Concurrent Session B

# **Concurrent Session B: 90 minutes**

(all concurrent sessions include 25 minutes of interaction and/or Q&A)

# B1 – Oral Session 2

#### **B1a** Reflections on DSM5: How the Term Neurodevelopmental Disorder Can be Used in Diagnosis and Advocacy 30min+O&A

**Christine Lilley,** *Ph.D, Registered Psychologist, Sunny Hill Health Centre for Children, Vancouver, BC* 

#### B1b Fetal Alcohol Syndrome: A Long Term Follow up of 100 Patients

#### 15min+Q&A

Luther K Robinson, MD, Professor of Pediatrics, Dysmorphologist, Department of Pediatrics State University of New York at Buffalo School of Medicine and Biomedical Sciences, Buffalo, NY, USA

#### B1c FASD Diagnosis and the Study of Prevalence – So What? Now What?

#### 15min+Q&A

**Bob Walker**, FASD Project Manager, Yukon Department of Health and Social Services, Whitehorse, YT

Kailey LeMoel, FASD Prevalence Study Manager, Policy and Communications, Yukon Department of Justice, Whitehorse, YT

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# **B2** Changing the Conversation in the Courts; The Ethics of Access to Justice for Those With FASD

#### Intermediate

Kathryn A Kelly, BA, Project Director, FASD Legal Issues Resource Center, University of Washington, Fetal Alcohol and Drug Unit, Seattle, WA Karen E Ruddy, LLB, Judge, Territorial Court of Yukon, Whitehorse, YT Michael Jeffery, JD, Superior Court Judge, Alaska Court System, Barrow, AK, USA

Rodney Snow, BA, LLB, LLM, Partner, Davis LLP, Whitehorse, YT

Lawyers, judges and other court professionals involved in the legal system have an ethical obligation to assure that all who are served by the courts have equal access to justice. Without recognition of the brain impairment of those with FASD and modifications of the system to accommodate their disability, the justice system is neither fair nor just.

- Examine the past profound disservice to those with FASD by the justice system and prepare you to become instruments for change on behalf of those with FASD for whom you advocate within the justice system
- Describe how organizations and courts themselves are working to transform the justice system into a provider of supports and services rather than an institution that imposes sanctions on disabled and vulnerable children and adults. The hope is that, with your help, these reforms of the system can be replicated widely

#### **B3** A New Conversation: Canadian Guidelines for Adult Diagnosis of FASD

#### Intermediate

Jocelynn Cook, Ph.D, Executive Director, Canada FASD Research Network, Vancouver, BC

**Christine Loock,** *MD*, *FRCP(C)*, *Associate Professor, Department* of Pediatrics, University of British Columbia; Responsive Intersectoral Community *Health, Education, and Research (RICHER) Initiative, BC Children's Hospital & Sunny Hill Health Centre for Children, Vancouver, BC* 

Is it ethically sound to ignore the need for diagnoses based on age? During the recent update and revision of the Canadian diagnostic guidelines for FASD, a particular focus was on creating sound, evidence-based diagnostic recommendations that are specific for the adult population. Adults with FASD experience unique challenges that should also be recognized and addressed.

Learning Objectives

- Identify the key diagnostic features associated with adult diagnosis
- Understand the specific diagnostic criteria for each FASD subtype
- Recognize the assessment criteria for adults with FASD (especially related to obtaining confirmation for prenatal alcohol exposure)

## **B4** Challenging Conversations for Transition: Better Training and Access in All Systems of Care Informed with Ethical Principles

#### Intermediate

Gail Andrew, BSc, MDCM, FRCP(C), Developmental Pediatrics, Medical Director, Glenrose Rehabilitation Hospital, FASD Clinical and Research Services, Alberta Health Services, Edmonton, AB

This presentation will explore the interactions between the individual living with the impairment of FASD, caregiver advocacy and knowledge and current systems of support and gaps. Successful transition requires the systems of care to understand the challenges of FASD across the lifespan while respecting that individual's right to safe participation in life. Training of all professionals is a major component. System navigators including mentorship models are essential to provide connections to services that are evolving to close gaps.

Learning Objectives

- Identify current needs at transition to adult life for persons living with FASD
- Review current national discussions on transition principals, policy and solutions
- Discuss ethical and policy implications

#### B5 Changing the Conversation: Adapting Therapeutic Communication for Individuals with FASD Intermediate/Advanced

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

Approaches to communicating within intervention and treatment settings need to be tailored to the meet complex needs of individuals with FASD. This session will focus on reviewing common differences and suggest communication approaches within the therapeutic setting that will enhance the creation of an environment for an increase in resilience, connection, personal growth and healing within an ethical context. Learning Objectives:

- · Identify components for effective communication
- Maximize the capacity for the individual to self-report
- Modify our current approaches to communicating
- Develop realistic goals for our interactions
- Reflect on our current practices

## **B6** The Ethical Imperative to Provide Education on Fetal Alcohol Spectrum Disorder in Social Work and Allied Health Professions

Intermediate

Dorothy Badry, PhD, MSW, RSW, Faculty of Social Work, University of Calgary, Calgary, AB

This presentation will provide an overview of the need for education on FASD to be embedded into post- secondary curriculum and the need for specialized practice within human service and health-based professions. A dialogue on professional responsibility to become FASD informed and knowledgeable in theory, practice and prevention across the lifespan is critical to effectively support individuals with FASD and to advance an ethical framework for practice.

Learning Objectives

- Understand what FASD informed practice means
- Offer a roadmap for engagement in FASD education and training for professionals and caregivers

#### A7 3 HR Session Cont'd

#### & B7 Windows of Vulnerability Across Development: Insight from an Animal Model of FASD Presenters: Wendy Comeau, Parker J Holman, Vivian Lam, Ni Lan,

Presenters: Wendy Comeau, Parker J Holman, Vivian Lam, Ni Lan, Alexandre Lussier, Charlis Raineki

4:30 pm Adjourn

# Thursday, April 10

<i>"The world o</i> – Albert Eins	<b>as we have created it is a process of our thinking. It cannot be changed without changing our thinking."</b> Stein		
8:00 – 8:30 am	Registration Open		
8:30 – 9:40 am	Remarks: Changing the Conversation: Something I want to talk about, Presented by an Adult with FASD		
	Plenary: Starting the Conversation: Do We <i>Really</i> Know What Happens When Children with FASD Become Adults? Some Speculations and Food for Thought (Includes Q&A) Edward Riley, PhD, Director, Center for Behavioral Teratology, Distinguished Professor, Department of Psychology, San Diego State University, San Diego, CA, USA		
	Learning Objectives		
	• Start a dialogue about the long term consequences of prenatal alcohol exposure and the implications for health and behavior.		
	Does prenatal alcohol exposure impact physical and health consequences later in life?		
	How does maturation impact behavioral outcomes?		
9:40 – 10:10 am	Break – Exhibits & Posters		
10:10 – 11:40 am	Plenary Panel: Ethically Building Safety Nets for Vulnerable Young Adults: Changing the Conversation When No One's Listening (Includes Q&A) Facilitator: Alan Markwart, BA, BEd, MA, Former Assistant Deputy Minister, BC Ministry of Children and Family Development; Adjunct Professor, School of Criminology, Simon Fraser University; Consultant, Victoria, BC Melanie Mark, Associate Deputy Representative, Advocacy, Aboriginal and Community Relations, Representative for Children and Youth, BC Irwin Elman, Provincial Advocate for Children and Youth, ON Corey La Berge, Deputy Children's Advocate, MB		
	Learning Objectives		
	Lessons from the Youth Leaving Care Hearings in Ontario		
	<ul> <li>Learn about the expanded mandate of British Columbia's Representative for Children and Youth to include advocacy on behalf of British Columbians from their 19th to their 24th birthdays who are eligible to receive services from Community Living BC (CLBC)</li> </ul>		
	• Learn about successes and challenges advocating on behalf of Manitoba youth living with FASD as they transition to adulthood		
11:40 – 1:10 pm	Lunch (on your own) & Exhibits		
1:10 – 2:40 pm	Concurrent Session C		

# **Concurrent Session C: 90 minutes**

(all concurrent sessions include 25 minutes of interaction and/or Q&A)

# C1 – Oral Session 3

Cla Why FASD Is So Scary and What Can We Do About it? – A Judge's Perspective

15min+Q&A

Michael I Jeffery, JD, Superior Court Judge, Alaska Court System, Barrow, AK, USA

(1) The Great Divide: Adult FASD in Alberta and British Columbia

#### 25min+Q&A

Kathy Horne, Ph.D, Psychologist, Queen Alexandra Centre for Children's Health, Victoria, BC

David Gerry, BSc, By Example Education, Victoria, BC

C1C Adults with FAS: Neurological Alterations, Friendship, Victimization 15min+Q&A

Reinhold Feldmann, MD, Developmental Psychology, Department of Pediatrics University Hospital, Muenster, Germany

#### C2 Microboards as Social Networks and Support Beginner

Linda M Perry, B.Ed., Executive Director, Vela Microboard Association, Surrey, BC

Individuals with FASD are often extremely vulnerable to those they interact with. If the network is made up of sound, supportive people, the person can often realize many of their dreams and goals. However, without this kind of support many people with FASD experience isolation and can find they are involved in a social milieu that can lead to negative outcomes.

This workshop will demonstrate the positive results that can be realized when a network comprised of family and friends, formalize their commitment by incorporating an individualized non-profit (Microboard). The individual for whom the Microboard is created receives positive support and friendship within the context of a group focused on maximizing the person's potential. This process can also provide additional support to family members that have also experienced isolation in their efforts to assist their children with FASD. This workshop leads to more exploration of how natural supports can be utilized in ways that can maximize the potential for community connections, reduce social isolation and result in a more positive outcome for individuals with FASD and their families.

# Thursday, April 10

Learning Objectives

- Come away with an understanding of how a formalized personal support network (Microboard) can assist a person with FASD to increase positive experiences of community inclusion and to realize personal goals in a customized and empowering way
- Have an understanding of the steps involved in creating a Microboard and how to get assistance to explore and/or develop one

#### **C3** FASD Counts! The Challenges of Counting Youth Affected by FASD Transitioning out of Care (aka Prevalence): Results of a Tri-Provincial Study

#### Beginner

**Don Fuchs,** Ph.D, Professor, Faculty of Social Work, University of Manitoba, Winnipeg, MB

Linda Burnside, Ph.D, Researcher/Practitioner, Avocation Counselling, Consulting, Research and Training, Winnipeg, MB

Those who provide services and supports to individuals with FASD (for example, parents and other caregivers, teachers, social workers, etc.) need to understand the impact of FASD, as youth with FASD often require adaptations to how services are providing additional supports, or different approaches or perspectives in interpreting and understanding their behaviour. This presentation will provide participants with up-to-date knowledge based on current research that can assist parents, caregivers, teachers and social workers in development of effective prevention strategies.

Learning Objectives

- Provide participants current data on the prevalence of adolescents in care and aging out of three major child care welfare jurisdictions
- Increase participants' awareness of the importance and benefits of studying the prevalence of FASD in adolescents in care
- Familiarize participants with the implications and social and economic impact of current rates of youth with FASD in child welfare care

# **(4** Promising Practices in Substance Abuse Treatment for Justice-Involved Youth with FASD

#### Intermediate

Kaitlyn McLachlan, Ph.D, Psychology, University of Alberta, Edmonton, AB Katherine Wyper, M.Ed., Educational Psychology, University of Alberta, Edmonton, AB

Allison Pooley, B.Ed., B.A., Program Director, Asante Centre, Maple Ridge, BC

Understanding the rate and impact of FASD on the lives of adolescents in care and transitioning out of care is essential for child welfare agencies. More importantly, prevalence rates for youth in care help sensitize child welfare agencies to the critical role they play as the guardians of children with FASD in ensuring that their care is suited to their high needs and their transitioning out care does not put the youth at risk. This presentation will present the results of a recent tri-provincial study which looks at the prevalence of youth in care with FASD in the provinces of Alberta, Manitoba and Ontario. In addition it will discuss the implications of these findings for child welfare practice with youth and young adults with FASD. Knowing how many individuals are affected by FASD allows child welfare service providers to determine: how many youth and care givers need specialized supports; what kinds of services youth may need as they prepare to, and then transition out of care; how many staff are required to deliver specialized services and how many staff ned training; what kinds of policies are needed

to guide specialized services; what kind of funding is required to meet the needs of the population; and what additional resources are needed due to the size of the population in need.

Learning Objectives

- Provide an overview of the complex factors underlying substance abuse among justice-involved youth with FASD
- Review findings from two novel studies evaluating relevant practice knowledge
- Identify evidence-based barriers and promising practices to inform future service delivery

# C5 The Wisdom of Experience: The Dual Roles of International Mothers Who Make a Difference

Michelle Sherbuck, Technical Communications, Alpha Technologies, Surrey, BC

Janet Christie, Executive Director, ARCC Society, Victoria, BC Kathleen Mitchell, MHS, LCADC, National Organization on Fetal Alcohol Syndrome (NOFAS), Washington, DC, USA

This session will provide information on what has made it challenging, and what has been helpful when advocating for their family members. It will cover areas such as health, addiction, mental health, employment, housing, social services, and issues encountered due to stigma, and misconception – for them as birth mothers and for their adult children, as individuals with FASD.

Learning Objectives

- How to better advocate for and support adults with FASD
- Understand how issues stigma impact advocacy efforts as experienced by birth mothers and their families
- Recognize the importance of including birth mothers in FASD initiatives and the importance of supporting women to prevent alcohol and drug exposed pregnancies

#### C6 Challenging Conversations – A Basic Human Right – Access to Health and Community Supports Intermediate

**E. Sharon Brintnell**, M.Sc, Occupational Therapy, Department of Occupational Therapy, University of Alberta, Edmonton, AB

Martha Roxburgh, BScOT, Occupational Therapy, Occupational Performance Analysis Unit, University of Alberta, Edmonton, AB

Anjili Sawhney, RN HSA, Nursing, Occupational Performance Analysis Unit, University of Alberta, Edmonton, AB

The presentation's content identifies changes needed in the organization of community supports for offenders and challenges the limited options now being offered within a disability and human rights perspective

- Explore the interrelationships of social determinants of health and FASD
- Identify characteristics of holistic residential supported living models for persons with complex needs
- Describe environmental supports to sustain community living for adults with FASD
- Describe approaches being introduced in corrections sites to address offenders' functional needs for successful return to community living

# Changing the Conversation

# Thursday, April 10

C7 Session Only for Adults with FASD What I Need to Know About My Brain and How it Works Edward Riley, PhD, Director, Center for Behavioral Teratology, Distinguished Professor, Department of Psychology, San Diego State University, San Diego, CA, USA This small group session will address questions like "How is my brain different and why does it do what it does?". Adults with FASD are encouraged to bring questions.		<i>"I alone cannot change the world but I can cast a</i>		
2:40 – 3:10 pm	Break: Exhibits & Posters	stone across the waters		
3:10 – 4:40 pm	Plenary Panel: Changing the Conversation: What Does It Mean to <i>Really</i> be an Adult? (Includes Q & A) Facilitator: Brenda M. Knight, <i>Registered Psychologist</i> , <i>Private</i> <i>Practice</i> , <i>Vancouver</i> , <i>BC</i> Matthew, Erin, Ashley, Justin, Tori	<i>and create many ripples"</i> – Mother Teresa		
	Learning Objectives			
	Understand how panel members have faced their challenges			
	Gain perspective on the potential for positive outcomes			
	leflect on the role of support			
		Illustrate hope for individuals with FASD		
4:40 pm		Friday, April 11		
	• Illustrate hope for individuals with FASD Adjourn	Friday, April 11		
4:40 pm 	Illustrate hope for individuals with FASD			
8:00 – 8:30 am	• Illustrate hope for individuals with FASD Adjourn Registration Open	talk about, Presented by an Adult with FASD cess to Diagnoses (Includes Q&A) Clinical Assistant Professor, Fetal Alcohol and Drug Unit, University of Dogtog First Nation, NB Dartment, The Social Insurance Institution, Helsinki, Finland and Adjunct exandra Centre for Children's Health, Island Health, Victoria, BC ting Communities about FASD, Roswell, GA, USA ccess to adult FASD diagnostic services wledging and sorting through the many potential competing as the client ages		
3:00 – 8:30 am	<ul> <li>Illustrate hope for individuals with FASD</li> <li>Adjourn</li> <li>Registration Open</li> <li>Remarks: Changing the Conversation: Something I want to represent the conversation of the conversation</li></ul>	talk about, Presented by an Adult with FASD cess to Diagnoses (Includes Q&A) Clinical Assistant Professor, Fetal Alcohol and Drug Unit, University of Dogtog First Nation, NB Dartment, The Social Insurance Institution, Helsinki, Finland and Adjunct exandra Centre for Children's Health, Island Health, Victoria, BC ting Communities about FASD, Roswell, GA, USA ccess to adult FASD diagnostic services wledging and sorting through the many potential competing as the client ages		
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# "Change is the end result of all true learning." - Leo Buscaglia

APRIL 9 TO 12, 2014 | Vancouver, Canada

# **Concurrent Session D: 90 minutes**

#### (all concurrent sessions include 25 minutes of interaction and/or Q & A)

#### D1 Why Ask Why? Ethics and Logic in the Diagnosis of FASD Advanced

**Kelly Price**, Ph.D., R.Psych, Child Psychology Leader/Neuropsychologist, Queen Alexandra Centre for Children's Health, Island Health, Victoria, BC

One of the primary principles of medical ethics is veracity, or 'truth telling'. Veracity cannot co-exist with errors in logic. Content of the presentation will reflect upon logical errors and subtle nuances in what we communicate to our clients about the role of alcohol in their symptoms, the role of other causative agents, and the role of alcohol in subclinical cases of FASD. We will also address blame and responsibility in FASD and the way that systems sometimes treat mothers.

Learning Objective

• Encourage audience members to reflect upon the basis of our knowledge and to elucidate ethical issues faced by diagnosticians in the FASD field. These issues are vital in making informed choices in advocating for FASD

#### D2 How to Grow Your FASD Program & Diagnostic Clinic, from the Ground Up and on a Shoestring Intermediate

Tannice Fletcher-Stackhouse, NP-PHC, Nurse Practitioner, Primary Health Care, NorWest Community Health Centres, Thunder Bay, ON Maureen Parkes, FASD Coordinator, NorWest Community Health Centres,

Maureen Parkes, FASD Coordinator, NorWest Community Health Cen Thunder Bay, ON

As we gain experience working with clients living with FASD and their families, we are gaining a very distinct experience unique to this client group. We learn to understand how these clients function. We learn to adjust our expectations accordingly. We become very clear in our therapeutic intent. We have formed strong partnerships with organizations serving the same population to ensure knowledge transfer.

Learning Objectives

- Share our experience to illustrate the development of an FASD program from the ground up
- · Learn how to expand with little additional funding
- · Learn how to develop programs and services by layers
- Learn about building in community engagement to enhance
   partnerships and awareness

#### **D3** Translating the Conversion into Action

#### Intermediate

Karen A Steele, J.D, Attorney, Karen A Steele, Esq., Salem, OR, USA Ricky Lee Dunitz, Advocate, Amity, OR, USA

Life changes can be positive or negative. Involvement in justice is, by its nature, life-changing, either for positive or negative, for client and community. Natural and systemic tendencies are to want quick and easy, "one size fits all," solutions that don't necessarily reflect current research and understanding regarding FASD, or etiology. Succumbing to those tendencies puts at risk and even works contrary to the interests of clients involved in justice system and the community at large. Instead, ethical practice should be grounded in a framework reflecting current research and understanding, girded with sincere relationship strengthened by understanding behaviors from neurobehavioral perspective, and generate solutions dovetailing brain function and client and community goals. To do otherwise ignores reality and sacrifices lives at the expense of systemic comfort.

Learning Objectives

- Define justice as it relates to those exposed to alcohol in utero, and describe how that definition interrelates with the goals of the Justice system and the community at large
- List ways in which failure to assess from a standpoint of brain function can lead to negative results for the person with FASD, for Justice and for the community
- List three neuro-behaviorally informed accommodations relevant to practice in justice

#### D4 "HANDLE WITH CARE" – The Ethical Implication of Labels and Diagnoses for FASD-affected Individuals, Their Caregivers and Our Culture Beginner

Donnie Kanter Winokur, B.A., Speaker, Author, Trainer, FASD Empowered -Educating Communities about FASD, Roswell, GA, USA

Evidence-based interventions and global literature proposes that a diagnosis anytime across the lifespan offers improved outcomes for individuals living with FASD. Yet providers and caregivers struggle to "label" these individuals. An ethically based conversation will address the potential benefits to the affected persons and the ability to educate others.

Learning Objectives

- Explore the ethical ramifications of physicians deliberately choosing to misdiagnose or undiagnose FAS in favor of providing a "label" that may procure more available services
- Recognize the consequences of unrecognized and untreated individuals with FASD as they grow into adolescence and adulthood
- Examine the benefits and disadvantages around acceptance using a "label" of FASD for individuals living with the hidden disability of FASD

#### D5 Innovative Outcome Evaluation and Social Return on Investment Analysis of an FASD Mentorship Program. The Experience of the McMan Mentorship Program in Southern Alberta Intermediate

Hélène Wirzba, MD, Consultant, Wirzba Consulting Inc, Lethbridge, AB

A sound evaluation methodology and well documented outcomes are essential in order for emerging practices to become promising practices. This presentation will discuss how one organization was successful in building its evaluation capacity, and is using outcomes to inform practice.

- Present an innovative evaluation initiative of an FASD mentorship program, using a standardized assessment tool and a Social Return On Investment (SROI) analysis
- Review the outcomes and SROI finding, looking at 85 unique clients having received support services for up to 3 years
- Discuss how the findings were used to assist in case management, and in documenting and improving the practice
- Discuss how other organizations may learn from McMan's findings and evaluation expertise

#### D6 Changing the Conversation: Sometimes We Just Don't Want to Go There

#### All levels

Facilitators: Ann Dowsett Johnson, Author, Journalist and Co-founder of the National Roundtable on Girls, Women and Alcohol, Toronto, ON, and Brenda M. Knight, Registered Psychologist, Private Practice, Vancouver, BC

Presenters: Michelle Sherbuck, Technical Communications, Alpha Technologies, Surrey, BC

Janet Christie, Executive Director, ARCC Society, Victoria, BC Kathleen Mitchell, MHS, LCADC, National Organization on Fetal Alcohol Syndrome (NOFAS), Washington, DC, USA

This session will cover how stigma impacts individuals with FASD and their respective families. It is designed as an interactive roundtable sessions. Facilitated by award-winning journalist and author Ann Dowsett Johnston and psychologist Brenda M. Knight, and will provide new understanding in helping those living with, and advocating for, individuals with FASD. The presenters have over 50-years combined experience working in the field of FASD and FASD prevention, and have an innate understanding of the familial and systemic issues and dilemmas experienced by both professionals and families.

Learning Objectives

- Describe some of the issues of stigma and shame experienced by individuals with FASD
- Describe some of the issues of being both a birth mother, as well as an advocate for your family member with FASD
- Discuss some of the shared experience between birth, foster and adoptive families
- Articulate ethical issues related to FASD diagnosis and conversations about FASD diagnosis with adults and adolescents
- Review how stigma impacts the all family members

# **3-hour session**

# **D7** Medication for Chronic Sleep Problems in Adolescents & E7 and Adults with FASD

Intermediate

Osman S Ipsiroglu, MD (FRCPC), PhD, Paediatrician, Sleep Research Lab, Sunny Hill Health Center for Children, BC Children's Hospital, Vancouver, BC Jennifer Garden, B.H.K., MCI.Sc. (OT), MSc. Registered Occupational Therapist, Sleep Research Lab, Sunny Hill Health Center for Children, Vancouver, BC Dean Elbe, BSc(Pharm), PhD, Clinical Pharmacy Specialist, Child and Adolescent Mental Health, BC Children's Hospital, Vancouver, BC

In this workshop, we will provide (mental) health care professionals, teachers and social workers with a practical clinical summary of the different guidelines for treatment and prevention of discomfort, pain, disruptive and challenging sleep wake behaviours, due to Restless Legs Syndrome. Special emphasis will be given on adolescence and pregnancy, as well as hands-on assessment of RLS in the community.

We see recognizing and understanding sleep deprivation and its connections to "challenging disruptive daytime/night time behaviours" as a new clinical approach; missed sleep problems become subject to inappropriate medication trials and even poly-pharmacy.

Learning Objectives

• Discuss commonly reported symptoms for sleep wake behaviours in adolescents and adults with FASD utilizing the Vancouver-Polar-BEARS-app©

- Identify commonly reported sleep problems in adolescents and adults with FASD
- Discuss management of anemia during pregnancy to prevent sleep wake disruption, but also potentially mitigate contributing factors for alcohol abuse
- Highlight commonly used medications in adolescents and adults with FASD for treatment of sleep wake behaviours

12:10 – 1:30 pm	Lunch (on your own) & Exhibits
1:30 – 3:00 pm	Concurrent Session E

# **Concurrent Session E: 90 minutes**

(all concurrent sessions include 25 minutes of interaction and/or Q&A)

# E1 – Oral Session

#### E1a Maternal Drinking and Adverse Life Outcomes Linked to FASD Among Young Adults

#### 15min+Q&A

Philip A. May, PhD, Research Professor, University of North Carolina at Chapel Hill-Nutrition Research Institute, Kannapolis, NC, USA

## E1b Collaboration for Development of Health and Social Care Service System for the People with FASD and their Families in Russia

#### 15min+Q&A

Elena A. Varavikova, MD, PhD, MPH, Leading Researcher, Federal Health Research for Information and Organization Institute CNIIOIZ, Moscow, Russia

#### E1C The Complexities of Caring for Individuals with FASD: The Perspective of Mothers 15min+O&A

**Debbie Michaud,** MSW, RSW, Child Welfare Supervisor, Kenora Rainy River Districts Child & Family Services, Sioux Lookout, ON

#### E1d Using Web Tools to Provide Global FASD Education for Parents (Repeated)

15min+Q&A

David Gerry, By Example Education Inc, Victoria, BC Cheryl Sivertson, By Example Education Inc, Victoria, BC

#### E2 Starting a Conversation: Bringing Together What We Know About the Sexual and Reproductive Health Issues for Women with FASD Intermediate

**Deborah Rutman,** Ph.D, Research Psychologist, School of Social Work, University of Victoria, Victoria, BC

**Yvonne Inguz,** RM RN BA MPH, Sexual Health Nurse, Department of Medical Science, Flinders University South Australia, Adelaide, South Australia

In this session, we will engage participants in discussion about issues relating to sexual and reproductive health, including ethical issues such as ensuring access to care; FASD-informed sexual health care; and promising practices in sexual/reproductive health care services.

Learning Objectives

Enhance their knowledge about sexual and reproductive

health of women with FASD, based on the most recent literature and interactive discussion

 Participate in a facilitated discussion about these issues and contribute to putting the sexual and reproductive health issues of women with FASD "on the map" in our conversations about how to enhance the lives of adults and adolescents living with FASD

## E3 From DSM-4 to DSM-5: What Does the Future Hold for FASD and ID in the Forensic Context?

#### Intermediate

Anthony P Wartnik, JD, Retired Judge and Lawyer, APW Consultants, Mercer Island, WA, USA

**Paul D Connor**, PhD, Neuropsychologist, Private Practice and Courtesy, Clinical Assistant Professor, Fetal Alcohol and Drug Unit, University of Washington, Seattle, WA, USA

The presentation will address how and why the DSM-5 will require public agencies such as child welfare, developmental disabilities, and school districts together with other social services, health care providers and the justice systems will have to truly begin meeting their responsibilities regarding screening, assessment, diagnosis and provision of appropriate and adequate services for persons with FASD and ID/MR arising from FASD/ND-FAE.

Learning Objectives

- Understand the differences in and significance of the changes from DSM-4 to DSM-5 and their potential impacts regarding definition of ID/MR and ND-PAE
- Explore the deficits presented by ID and their likely impacts on the justice system regarding mitigation and death penalty issues
- Gain insight into reasons and processes of screening, assessment, and forensic diagnosis including useful diagnostic tools
- Study the relevance of prenatal alcohol exposure on cognition across the criminal justice spectrum

#### E4 Five Aboriginal Maternal Mothers in One Community Who Challenged and Changed the Conversation Beginner

**Lisa Lawley,** Circle of Life Manager/Maternal Mother, Kermode Friendship Society, Terrace, BC

**Louisa Gray,** *BA, AIDP/AECD Manager/Maternal Mother, Kermode Friendship Society, Terrace, BC* 

Wanda Quock, Maternal Mother/grandmother, Kermode Friendship Society, Terrace, BC

Jeri-Lynn Olson, Aboriginal Infant Development /Maternal Mother, Kermode Friendship Society, Terrace, BC

Myrna Stephens, Maternal Mother, Kermode Friendship Society, Terrace, BC

This presentation will explore how imperative it is to educate service providers about historical and Intergenerational Trauma and how it has affected Aboriginal adults and adolescents with FASD. We will demonstrate how intergenerational trauma has affected Aboriginal people to the present day. We will share the strategies that we implemented in our lives to be the change we wanted to see.

Learning Objectives

- Describe how intergenerational trauma and historical trauma has affected Aboriginal adolescents and adults living with FASD today
- Learn how western practices and traditional practices combined can create a better outcome for Aboriginal adolescents and adults living with FASD

Learn about utilizing the medicine wheel to support people living with FASD

#### E5 D2 Re-balancing the Wheel – the TES, Two Eyed Seeing Diagnostic Wheel for FASD and Related Conditions Advanced

Lori Vitale Cox, Ph.D, Educational Psychology, Eastern Door Diagnostic Team, Elsipogtog First Nation, NB

This presentation will cover ethical considerations such as: 1. Is it ethical to diagnose FASD without formally considering such issues as mental health, and other 'secondary disabilities' when these may in fact be primary to the way the condition unfolds over time when not properly 'treated' or supported? This is especially true for adolescents and adults; 2. Is it ethical to diagnose FASD without considering the intergenerational context of the individual when research indicates that there are genetic and epigenetic factors involved?; 3. Is it ethical to diagnose FASD without providing 'treatment' through the life span? These should be considered in the formal diagnosis of secondary disabilities and the supportive and targeted interventions through the lifespan that could ameliorate them; 4. Is it ethical from a public health prevention perspective to ignore family based or generational approach to diagnosis and treatment (support) when evidence indicates that families are often affected generationally?

Learning Objectives

- Promote awareness of: 1. the limitations of present diagnostic systems in terms of social and intergenerational contexts as well as secondary disabilities and 2. the adverse effect on adults and adolescents in terms of diagnosis, intervention and prevention of FASD
- Present an in-depth look at the revised TES Diagnostic Wheel for FASD and related neurobehavioral conditions and consider how it offers multi-dimensional approach to diagnosis
- Invite discussion of: 1. how to use the TES Diagnostic Wheel to drive subsequent 'treatment' through provision of appropriate intervention and support and 2. the ethics of FASD diagnosis without corresponding treatment throughout the life-span

#### E6 Session Only for Adults with FASD Let's Talk...What Do You Really Want to Ask Us?

Panelists: Matthew, Erin, Ashley, Justin, Tori

A private small session for adults with FASD. Think of the questions that you want to ask the panel of adults and then ask them. Jan and Brenda will be there to help.

## E7 3 HR Session Cont'd Medication for Chronic Sleep Problems in Adolescents and Adults with FASD

Osman S. Ipsiroglu, Dean Elbe, Jennifer Garden

3:00 – 3:30 pm	Break – Exhibits & Posters	
3:30 – 5:00 pm	Remarks: Changing the Conversation: Something I want ot talk about, Presented by an Adult with FASD	
	<ul> <li>Plenary Panel: Starting the Conversation: Human Rights, Self Determination &amp; the Law - What About FASD?</li> <li>(Includes Q&amp;A)</li> <li>Facilitator: Alan Markwart, BA, BEd, MA, Former Assistant Deputy Minister, BC Ministry of Children and Family Development; Adjunct Professor, School of Criminology, Simon Fraser University; Consultant, Victoria, BC</li> <li>Beverly Froese, LL.B., LL.M., Attorney, Public Interest Law Centre, Winnipeg, MB</li> <li>Fiona Gow, Barrister and Solicitor, Health &amp; Social Services Group, Legal Services Branch, Ministry of Justice, Victoria, BC</li> <li>Honourable Mary Kate Harvie, Judge, Provincial Court of Manitoba, Winnipeg, MB</li> <li>Jan Lutke, Conference Chair, Manager Research and Community Engagement, Canada FASD Research Network, Vancouver, BC</li> <li>Jonathan Rudin, Program Director, Aboriginal Legal Services of Toronto, Chair, FASD Justice Committee, Toronto, ON</li> </ul>	
	Learning Objectives	
	<ul> <li>Explore the ethics of competency and capacity for individuals with FASD</li> </ul>	
	<ul> <li>Understand the ethical issues in defining and implementing the rights of individuals with FASD in regards to balancing liberty and personal autonomy with the right to be safe, healthy and to thrive.</li> </ul>	
	<ul> <li>Provide an overview of the complex factors underlying decision making for Adolescents and Adults with FASD, including individuals with an IQ over 70</li> </ul>	
	<ul> <li>Review existing mechanisms that might allow someone to support an individual with FASD without a legal finding of incompetence</li> </ul>	
	Be able to consider challenges and potential suggestions of changes	
5:00pm	Adjourn	
	Saturday, April 12	
	<b>"Act as if what you do makes a difference. It does."</b> – William James	
8:30 – 9:00 am	Registration Open	
9:00 – 10:30 am	Concurrent Session F	

## **Concurrent Session F: 90 minutes**

(all concurrent sessions include 25 minutes of interaction and/or Q&A)

#### F1 Building Connections for Success with Adolescents and Their Families

#### Intermediate

**Sandra McNeill,** *BA*, *Program Counsellor, New Directions: FASD Family Support, Education and Counselling Program, Winnipeg, MB* 

This presentation will equip the audience with tools to engage adolescents with FASD and their families, through establishing connections and utilizing individual and family strengths, while exploring and challenging our own expectations of "normative behavior", self-determination and how to safely express personal choice and individuality for youth.

Learning Objectives

- Describe a model of service delivery proven to be effective in working with families and adolescents with FASD
- Utilize methods/tools used to build relationship and connection while addressing at risk behavior
- Compare stories from participants, caregiver's and other service providers regarding the difference this type of involvement has made in their lives
- Discuss how these ideas could be put into practice

#### F2 The Wellness, Resiliency and Partnerships Coaching Project – Improving the Sustainability of Practice and Building System Capacity in Supporting Students with FASD

#### Intermediate

**Tracy Mastrangelo,** SW, Regional Consultant, Edmonton Public Schools, Edmonton, AB

The Wellness, Resiliency and Partnerships (WRaP) project has gathered evidence and data to suggest that the Success Coach model is an effective, sustainable support for students with FASD.

Using a strength-based approach, Success Coaches provide a wraparound model to support students in 3 main areas; academic success, student engagement and social, emotional and physical well-being. Now in the 5th year the project will explore expansion of the model and future partnerships.

- · Learn about history of the development of the WRaP project
- Learn the results of the data collected to assess the efficacy and sustainability of the intervention
- Learn about capacity building within a system to support students

#### F3 Front-line Perspectives of Professionals Working with Individuals with FASD in the Justice System Intermediate

Katherine Wyper, M.Ed., Doctoral Student, University of Alberta, Edmonton, AB

Sandra Potts, Community Liaison Worker, Northwest Central Alberta FASD Services, Barrhead, AB

**Michelle Stewart,** *PhD, Assistant Professor, Department of Justice Studies, University of Regina, Regina, SK* 

Donna Hassman, Sergeant, Regina Police Service, Regina, SK

The goal of this session is to highlight the collaborations and innovations that are taking place at the front-line of justice services in Alberta and Saskatchewan. By bringing together researchers and practitioners, we hope to illustrate how two active research projects are working in collaboration with community members, and we believe this panel offers new insight into the ways in which research can be socially-accountable and culturally respectful while remaining academically rigorous. We also hope to demonstrate that FASD research and service delivery is more effective and ethical when conducted in a collaborative manner, as opposed to through isolated silos. Whether studying FASD as a researcher, or working with FASD as a front-line practitioner, it is imperative that we are collaborative and ethically responsible; how that responsibility is framed is its own challenge. In this panel we hope to discuss these and other challenges.

Learning Objectives

- Provide insight about how FASD is understood by front-line workers across various sectors (policing, social services, and community-based organizations) and how this understanding impacts their work
- Illustrate novel programs or practices that better serve individuals with FASD
- Explore the successes and challenges of implementing programs or policies intended to better serve individuals with FASD
- Facilitate a space in which front-line workers, researchers, and community members can network and share their practices and findings; to highlight these forms of collaboration

#### F4 Integrating Knowledge, Experience and Treatment Approaches for Mental Health Care Intermediate / Advanced

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

It is an opportune time in the field of mental health as professionals integrate their experience, techniques, intuition and treatment preferences with our more advanced understanding of the uniqueness of individuals with FASD.

The intent of this workshop is to stimulate confidence and competence within supportive environments so that clinicians can review their skill development and create a more effective approach to ethical mental health care for individuals and families living with FASD.

Learning Objectives

- To stimulate a review of our current practices
- To consider adaptations to our treatment approaches
- To foster mutual respect and collaboration amongst professionals

## F5 When FASD is FASD and Not Something Else Intermediate

**Ilona Autti-Rämö,** *MD*, *Research Professor*, *Head of Health Research*, *Research Department*, *The Social Insurance Institution*, *Helsinki*, *Finland and Adjunct Professor at the Child Neurology Department*, *Helsinki University Hospital*, *Finland* 

Much effort has been given to identify a neuropsychological profile specific to prenatal alcohol exposure as such or to exposure pattern or amount of doses. Also screening tools to identify those persons that should undergo a diagnostic procedure for FASD are currently being tested and in use. Less emphasis has been focused on the hereditary and other pre- and postnatal risk and protecting factors that may play a larger role in the phenotype after prenatal alcohol exposure.

Learning objectives

- Prenatal alcohol exposure as such doesn't determine the outcome of the fetus
- Raise awareness of the protective and risk factors during life course
- Raise awareness on the possibilities to improve the outcome of the child with prenatal alcohol exposure

# **3-hour sessions**

#### F6 3 Hour Session

#### & G6 Closed session to primary health providers Care of Adults with FASD: a Toolkit for Primary Health

#### Care Providers Intermediate

**Christine Loock,** MD, FRCP(C), Associate Professor, Department of Pediatrics, University of British Columbia; Responsive Intersectoral Community Health, Education, and Research (RICHER) Initiative, BC Children's Hospital & Sunny Hill Health Centre for Children, Vancouver, BC

Rod Densmore, MD, Interior Health, Salmon Arm, BC

Sandra Witherspoon, Physician, Research Education & Action for Community Health (REACH), Vancouver, BC

Health care providers feel that they are not well prepared to care for patients who have FASD even though clinics have been providing primary care for patients with FASD for years. This presentation will describe the specific health needs. By reviewing case histories of complex patients who have FASD, attendees will learn how health care providers can help mental and physical health concerns. Attendees will leave this session with a toolkit of ideas, resources and references.

- Understand practical tools for screening PTSD, sensory processing problems, traumatic brain injuries, visual processing impairments and functional limitations in adults with FASD
- Gain familiarity of resources that clinicians can use to successfully advocate on behalf of their patients who have FASD with other professionals such as psychiatrists, social workers, educators, and legal system employees
- Discuss how to approach the most common medical conditions that we've seen in patients who have FASD

#### F7 The Benefits of FASD Advocacy as Seen Through the & G7 Lens of Interfacing Intervention and Ethics Intermediate

#### Susan L Doctor, PhD, FASD Specialist, University of Nevada, Reno, NV, USA

In order to provide a comprehensive recipe of advocacy for those with FASD this workshop will take participants on a journey that enfolds the fields of intervention and ethics within the FASD domain. This presentation is constructed to address the interface of two disciplines that have previously most often been seen through separate, unrelated lenses. Professionals working within the FASD field are often guided by ethics perceived under a professional domain other than the FASD. This workshop attempts to braid the two concepts together, thus changing the conversation to speak directly to the ethical issues relative to the provision of services to those with FASD.

Learning Objectives

- Gain perspective on global and comprehensive FASD interventions
- Gain perspective on Kirchener's ethical principles and the relationship to FASD
- Gain perspective on the interface of intervention, and ethics that forms a comprehensive approach to advocacy for those with FASD

10:30 – 11:00 am	Break – Exhibits & Posters
11:00 – 12:30 pm	Concurrent Session G

"The universe is so well balanced that the mere fact that you have a problem also serves as a sign that there is a solution."

 Steve Maraboli, Life, the Truth, and Being Free

## **Concurrent Session G: 90 minutes**

(all concurrent sessions include 25 minutes of interaction and/or Q&A)

# G1 – Oral Session 4

#### **G1a** Life Consequences of Youth and Young Adults with Fetal Alcohol Spectrum Disorders

#### 15min+Q&A

Leigh E Tenkku, Ph.D, Professor, School of Social Work, University of Missouri, Columbia, MO, USA

#### G1b Forest and the Femme: Empowering Women Through Access to Nature

#### 15min+Q&A

Jamie Adams, Program Coordinator/Founder, Forest and the Femme Society, Vancouver, BC

**Leslie P Germain**, M.C, Mental Health and Addictions Counsellor, Forest and the Femme Society, Vancouver, BC

#### G1C Online Mindfulness Training for Adolescents with Fetal Alcohol Spectrum Disorder 15min+O&A

Alison E Parker, Ph.D, Research Scientist, Innovation Research & Training, Durham, NC, USA

#### **G2** FASD, Attachment Trauma, and Open Adoption: Balancing the Potential Benefits with the Risks of Adolescent Contact with the Birth Family Intermediate

Serena Patterson, Ph.D, Psychologist, Private Practice, Comox, BC

The practice of open adoption with ongoing contact between birth family and adolescents with a history of fetal alcohol exposure and early trauma is examined critically. Specific recommendations are made regarding how the best interests of the child may be better assessed and protected in older child adoptions.

#### Learning Objectives

- · Understand that adoption openness carries risks and benefits
- Identify possible risk factors that should raise caution in open adoption arrangements involving ongoing contact
- Identify special considerations regarding birth family contact when the child has a history of trauma, the family has active addictions, or the child has FASD

# **G3** Navigating Trauma and FASD: Ethics, Practice and Perspective

#### Intermediate

**Tina Antrobus,** *MA*, *RCC*, *Registered Clinical Counsellor*, *PLEA Community* Services, Coquitlam, BC

**Britta West,** *MA*, *RCC*, *TITC-CT*, *Clinical Traumatologist, Family & Individual Counsellor, PLEA Community Services, Coquitlam, BC* 

The co-occurrence of FASD and trauma creates complexities with respect to mental health and therapeutic intervention and support for both individuals and families. This session will provide participants with a greater understanding of complex developmental trauma among those living with FASD. A neurodevelopmental and family systems framework for therapeutic intervention will allow for an exploration of common challenges for current therapeutic practice and build a rationale

#### "If not us, then who? If not now, then when?" - John Lewis

for adapted trauma-informed strategies for supporting individuals and families impacted by FASD and trauma.

Learning Objectives

- Learn how trauma and FASD impacts individual neurological/ social/emotional development and implications for therapeutic intervention and support
- Gain a greater understanding of how families are impacted by FASD and complex trauma, experienced in children, parents, and among family members across generations
- Learn how to incorporate trauma-informed strategies for therapeutic intervention, at the individual, familial, and systemic level to improve practice

# **G4** Best Practices for Supporting High-Risk Youth with FASD in a Secondary School Setting

#### Intermediate

**Cliff Whitford**, Counsellor, Boyle Street Education Centre, Edmonton, AB **Neda Mitchell**, B, Mus., B Phys. Ed, Work Experience Coordinator, Boyle Street Education Centre, Edmonton, AB

**Carmen Rasmussen,** PhD, Assistant Professor, University of Alberta, Edmonton, AB

This session will address the need for and, potentially, an avenue for change in the way youth with FASD are supported into adulthood. We will discuss results from a collaborative project between staff at Boyle Street Education Centre (BSEC) and researchers from the University of Alberta. BSEC is an inner city charter school developed to support the educational success and social development of high-risk youth (some of which have FASD). The purpose of this project is to investigate the process of supporting high-risk youth and youth with FASD at BSEC in their transition to adulthood. We will present information on current data collected at BSEC to inform best practices for teaching highrisk youth and identify strategies employed by BSEC that are linked to successful transitions. This information will be compared to existing research available on best practices for supporting high-risk youth as well as individuals with FASD. This research will fill an important gap by building our knowledge of best practices for supporting youth with FASD and how practices may be changed to support a successful transition to adulthood.

Learning Objectives

- Learn how to deal with high risk youth affected by FASD utilizing a multi-disciplinary approach in an educational setting
- Learn how to deal effectively with behaviours associated with FASD
- Learn how to downplay the stigma of FASD in an educational setting

#### G5 Making it Work: Meeting the Vocational Needs of Adolescents and Adults with FASD Intermediate

FASD Treatment Outreach Project, Madison, WI, USA

Georgiana Wilton, Ph.D, Senior Scientist, Department of Family Medicine, University of Wisconsin, Madison, WI, USA Angelica Salinas, MS, Outreach Specialist–Project Coordinator, Wisconsin

In an era of challenging economic times, vocational opportunities for individuals with FASD become even more competitive and limited. A clear understanding of the vocational system is necessary along with appropriate assessment options, creative accommodations and innovative 'marketing.' This workshop will provide a practical model and tools to address these challenges.

Learning Objectives

- · Describe the value of work in a diverse cultural context
- Identify common barriers to employment experienced by adolescents and adults with FASD
- Identify limitations of the functional assessment and strategies to improve on the concept
- Summarize the evidence base of adaptations to accommodate workers with FASD

#### G6 3 HR Session Cont'd

#### Care of Adults with FASD: a Toolkit for Primary Health Care Providers

Presenters: Rod Densmore, Christine Loock, Sandra Witherspoon

- **G7** 3 HR Session Cont'd **The Benefits of FASD Advocacy as Seen Through the Lens of Interfacing Intervention, and Ethics** Susan Doctor
- 12:30 1:30 pm Lunch (provided) & Exhibits
- 12:45 pm Poster Session: Poster presenters will be at their posters to answer questions

#### 1:30 – 2:30 pm Remarks: FASD: A Guided Conversation About What It Means To Be Human (Includes O&A)

**Corey La Berge**, *MA*, *LLB*, *Deputy Children's Advocate*, *Manitoba*, *MB* 

Learning Objectives

- Think about what FASD teaches us
- Think about experiencing FASD, witnessing FASD, and caring and their significance to healing and social justice
- Think about the significance of conversation as a means for cultural change

#### 2:30 – 3:15 pm Clos

#### **Closing Remarks**

Jan Lutke, Conference Chair, Manager Research and Community Engagement, Canada FASD Research Network, Vancouver, BC

#### Presentation of Starfish Awards & Closing Ceremonies

"The secret of change is to focus all of your energy, not on fighting the old, but on building the new." – Socrates "You cannot change your destination overnight. You can change your direction." - Jim Rohn

# **Poster presentations**

All poster presenters will be available at their posters for Q&A during the following poster session time: Saturday, April 12, 2014, 12:45 pm – 1:30 pm (Lunch)

#### Surrey School District # 36 – The FASTRACK Program

Bilal Bhamjee, BA, BEd, MEd, Teacher, Surrey School District #36, Surrey, BC Linda V Young, CYCW, Child and Youth Care Worker, Surrey School District #36, Surrey, BC

Gemino Silva, EA, Educational Assistant, Surrey School District #36, Surrey, BC James R McCue, EA, Educational Assistant, Surrey School District #36, Surrey, BC

#### FASD The Prevention Conversation: A Shared Responsibility

**Hazel Mitchell**, PHEc, Prevention Conversation Project Manager, South Alberta FASD Service Network/ grant from FASD-CMC (Ministry of Human Services) Lethbridge, AB

**Theresa Bosko,** Project Officer, Fetal Alcohol Spectrum Disorder Initiatives, Human Services, Government of Alberta, Edmonton, Alberta

# Alberta FASD 10-Year Strategic Plan: A Policy Framework for a Collaborative and Coordinated Response

Theresa Bosko, Project Officer, Fetal Alcohol Spectrum Disorder Initiatives, Human Services, Government of Alberta, Edmonton, Alberta Shelley Birchard, MSW, Administration – Policy and Program Development, Health Services, Edmonton, AB

#### Speech Language Findings In Children Seen in an FASD Diagnostic Clinic

Hasmukhlal Rajani, MBBS; FRCP(C), Pediatrician, University of Alberta, Edmonton, AB

Karen Nolan, M.Sc., R.SLP, S-LP(C), Speech Language Pathologist, Northwest Central FASD Network, Edmonton, AB

Brent Symes, B.A., M.Ed., Ph.D, Psychologist, University of Alberta, Edmonton, AB

#### "A Funny Thing Happened When the Money Ran Out..... We Kept Going!"

Marsha Wilson, MA, College Instructor, Douglas College, New Westminster, BC Kim Hetherington, Social Worker, Consultant - Guardianship & Children & Youth with Special Needs, Coast Fraser Region East & SouthMinistry of Child and Family Development, Abbotsford, BC

#### Improving Alberta's FASD Programs and Services Evaluation Practices

**Hélène Wirzba**, MD, Consultant, Wirzba Consulting Inc, Lethbridge, AB **Christopher Cameron,** MA, CE, Consultant, Objective Research and Evaluation Inc, Calgary, AB

# **Registration and Tuition Fees**

# Registration

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PLEASE WRITE IN BLOCK LETT One registration form per person	ERS: 1. Please photocopy if more are needed.	TUITION FEES		
Mrs. Mrs. Miss	Mr. Dr.      First Name Initials	Pre-registration prior to March 12, 2014 is strongly recommended to en- sure you receive all conference materials. All rates are quoted in CAD and the tuition fee includes GST. Please use one registration form per per- son. The main registration fee includes conference material, Wednesday and Saturday lunches, refreshment breaks, and a certificate of attendance.		
Organization Name/Mailing Addre	255	-		
		*EARLY BIRD RATE, BEFORE/ON MARCH 12, 2014		
Mailing Address City	Prov/State Postal Code	<b>Conference - Full Program (Wednesday - Saturday)</b> *The Early Bird Rate is available for the full program and not available for individual rates.	□ \$650 (\$619.05 + tax)	
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Daytime Telephone Number / Loc	al	RATE AFTER MARCH 12, 2014		
E-Mail		Conference - Full Program (Wednesday - Saturday)	□ \$750 (714.28 + tax)	
		<b>Conference - Individual Day Rates</b>		
Please inform us of any dietary rec	quirements	Wednesday, April 9, 2014 only	□ \$224 (\$213.33 + tax)	
		Thursday, April 10, 2014 only	□ \$224 (\$213.33 + tax)	
AFFILIATION/PROFES		Friday, April 11, 2014 only	□ \$224 (\$213.33 + tax)	
Please indicate which Affiliation/Pr	ofession best describes you:	Saturday, April 12, 2014 only	□ \$224 (\$213.33 + tax)	
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Corrections Worker	Physician	Paper copy <u>or</u>		
Educator (Adult)	Policymaker	<ul> <li>Electronic (a memory stick with the presentation materials will be give to you on-site at the conference)</li> </ul>		
□ Individual with FASD	Psychiatrist			
	Psychologist	<b>Full-Time Student Rate (Before March 28, 2014)</b> \$300 (\$285.71 + tax) *A letter from your supervisor/department head stating that you are a full time		
Law Enforcement Officer	Social Worker	student along with a valid student photo ID must be s		
Lawyer	Vocational Rehab Service Worker	tions. Please fax a copy if you register online.		
Mental Health Counsellor	□ Other:	Total Payment	=\$	
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Session C: Session D:		PO/LOA/ChReq: Purchase order/letter of au requisition form is enclosed with faxed/mail		
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Session G:				