

# Rajani FASD Assessment & Diagnostic Clinic Training Services

LINKS: A Newsletter for Alberta FASD Diagnostic Clinics

# Success through Collaboration and Engagement

Experience has shown us that the power of being able to connect with one another is key to achieving great things. Collaboration, relationship building and co-operation are some of the most powerful and cost-effective tools available for clinics to realize and attain their goals. Each time we reach out or engage with others, whether another clinic coordinator, a community stakeholder or partner, or families we work with, there are opportunities to both learn and inform through that connection.

Each September, the Annual FASD Clinic Coordinator takes place in either Calgary or Edmonton. This year, we saw almost 30 attendees at this meeting in Edmonton. Fine tuning, clinic surveys, receiving feedback, and reviewing best practices ensures the topics and events planned are relevant and inspired by the wisdom and experience of the group attending.

The meeting included highlights of the Telehealth Pilot Program, which will provide clinics with options in delivering assessment and diagnostic services, especially those in rural or remote communities. This project is being evaluated by an external evaluator and we will share the results when completed in 2020. Amber Bell gave an update on the University of Washington's Facial Recognition Software program, which has been a frustrating program for some clinics to use in the past. It is helpful to have someone dedicate targeted time to overcome barriers and questions in use of this software. The use of the program could be useful for future Telehealth diagnosis.

The National Testing Tool survey that was completed by so many clinicians across Canada (completed after the Alberta Testing Tool survey and subsequent paper was published) is now in the writing stage and should be published over the next few months. Links will keep you updated. Research or surveys that clinics have participated in can be time consuming; however, the information shared and subsequent results assist us with current knowledge and education in the field. Thank you for all who took the time to attend the coordinator meeting and your continued contribution to useful information for projects.



# Ask A Clinician?

Role of the Physician on the Multidisciplinary FASD Assessment and Diagnosis Team Dr. Gail Andrew, Pediatrician, Glenrose Rehabilitation Hospital

The Physician must be trained on the 2015 Canadian Guidelines for FASD Diagnosis as a member of the multi/interdisciplinary team for FASD diagnosis and understand the 10 brain domains that are assessed. To participate in the discussion on the evidence for significant brain impairment in at least 3 domains, the Physician needs to have knowledge about the roles of the other team members and what functions of the brain they are assessing. Analysis for the facial dysmorphology of full or partial Fetal Alcohol Syndrome has been the responsibility of the Physician who has clinical experience in facial measurements. However, with the current software for facial analysis from Dr. Astley at the University of Washington, there is the potential to do digital photographs of the individual being assessed even at a remote site by a trained person and obtain the scoring of the Physician is much more than "facial analysis". The Physician needs to be knowledgeable in the medical fields of Neurology, Genetics, Psychiatry and General Pediatric health, as the diagnosis of FASD is a differential diagnosis or "what else could explain the findings" and also to consider comorbidities or "what else is co-occurring".

Although in most clinics the search for PAE is the role of the clinic coordinator, the Physician may be part of the decision on the strength of the evidence for prenatal alcohol exposure at a level 3 or 4 for the individual to be assessed in the clinic. The Physician needs to know about other risk factors that can affect the outcome of the pregnancy including other teratogens and the roles of maternal trauma and stress on the developing fetus. The Physician needs to be able to do a developmental history from birth, looking at the timing of emerging milestones for delays, early signs of disruptive behavior and difficulties in social emotional development and behavioral regulation, patterns of learning difficulties. The history needs to include environmental factors that can be supportive or adversive, such as neglect, lack of opportunities for attachment, multiple moves in the Caregiving situation. Interpreting a three generation family history is important to look for familial/genetic conditions or evidence for multigenerational trauma.

Knowledge about Neurology is important to clinically identify other conditions with differences in tone, coordination and movement patterns, for example Cerebral Palsy, Myopathies, Developmental Coordination Disorder. There needs to be consideration of factors of premature birth or birth asphyxia that can also lead to brain damage with a similar clinical presentation as FASD. Acquired brain damage after birth such as Shaken Baby Syndrome or from accidents or meningitis is another factor. In the domain of Neurophysiology and Neuroanatomy, the Physician needs to be aware that there is a 7% increase for seizures in FASD compared to the general population. If there is microcephaly or structural abnormalities on an MRI, other causes need to be evaluated and not to assume that it is part of FASD. There are several Genetic Syndromes that have a similar face to FAS, such as Williams, 22q11 Deletion, etc but they have other characteristics and known genetic markers. With the recent availability to do more detailed chromosome analysis using a chromosomal micro array in those individual with significant intellectual disability (IQ less than 70), more deletions or duplications and copy number variants are being identified. The Physician on the FASD team needs to have that awareness and be able to order the test or recommend that the referring physician consider doing it. In young children, metabolic causes for intellectual disability need to be considered as there may be a treatable condition such as PKU. In some cases, a dual diagnosis may be considered by the team Physician resulting in FASD and the genetic condition both diagnosed.

The Physician needs to know how to evaluate for mental health conditions using criteria in the DSM 5. This is very important in FASD as 65 to 90 percent of individuals living with FASD will have a comorbid diagnosable mental health condition. The most common is ADHD (over 60%) but Anxiety and Depression increase with age. Mood Disorders are considered in the Domain of Affect Regulation in the Canadian Guidelines, with the provision that the mood disorder is not related solely to postnatal trauma.

*Our Vision~ We envision a region with no new FASD births and where currently affected individuals are well supported.* 

### Ask A Clinician?

Role of the Physician on the Multidisciplinary FASD Assessment and Diagnosis Team (Continued)

The Physician needs to be very well informed about trauma as many of our children, youth and adults coming for an FASD assessment have experienced many adverse life experiences in their early years (referred to as Adverse Childhood Experiences or ACEs). The ACEs include neglect, abuse, domestic violence, parental substance use or incarceration, multiple moves in caregiving. The risk for prenatal alcohol exposure and for ACEs are both rooted in the social determinants of health and these factors are often multigenerational so it is not surprising that an FASD assessment needs to consider these factors. With multiple moves in the foster care system, the Physician needs to be aware of Attachment disorders and advocate for prevention. Trauma itself can lead to alterations in the hypothalamic pituitary axis and change the diurnal cortisol levels contributing to "fight or flight" response to environmental factors that may underlie the dysregulated behaviors that the individual presents with. It is difficult to tease out how much PAE or trauma is contributing to the presenting brain dysfunction. The Physician needs to know the local resources for targeted therapy for trauma, attachment and mental health conditions to make recommendations for that individual and their caregivers.

The Physician needs to take a detailed health history from birth. Some infants, especially those with drug as well as alcohol exposure may experience a withdrawal period after birth called Neonatal Abstinence Syndrome needing urgent medical care. Poor coordination of suck and swallow, gastroesophageal reflux and poor nutrition provision can lead to failure to thrive, further compromising the infant's brain development. These infants can be very irritable and difficult to care for putting placements at risk and impacting bonding and attachment. Prenatal Alcohol Exposure can affect all developing fetal organ systems and lead to malformations referred to as Alcohol Related Birth Defects (ARBD). The most important are cardiac anomalies, vision and hearing problems. These may have been missed at younger ages and need to be checked at the FASD clinic. It is becoming increasingly aware that individuals with FASD have alterations in their immune systems and can have onset of many conditions at younger ages such as arthritis and digestive conditions. Sleep disorders are very common in FASD either from airway obstruction or from dysregulation of the circadian sleep rhythm. Doing a thorough sleep history is very important as inadequate sleep impacts attention, concentration, mood regulation and day time function. Sleep needs to be an early target in interventions. The Physician in making recommendations as part of the FASD assessment may prescribe medications to address ADHD, mood Disorders or provide suggestions to the referring community Physician using appropriate guidelines. The Physician should be aware of community resources such as access to mental health services or a sleep clinic for further management.

As FASD is a lifespan condition, the Physician on the FASD team is in a position to provide anticipatory guidance to the caregivers and community physicians. Every person with FASD should be connected to a primary health care provider who is knowledgeable about FASD. Sexual health and risk for addictions may also fall under the responsibility of the team Physician directly or in referral to community resources. The greatest challenge that the Physician may face is debriefing the youth or young adult who is receiving the FASD diagnosis. This needs to consider the communication, cognitive and emotional stability level of the person as well as the availability of a healthy support team for them to move forward and access supports and services. It needs to be done without blaming mothers. The information needs to be strength based but also realistic. The youth/ young adult needs to be offered hope for the future through access to mentors, system navigation and natural or paid supports. These roles on the FASD team may be shared with the team social worker depending on the team structure or with a community support service such as Coaching Families. They need to be connected to supports across multiple systems. This role can be shared by various team members but the Physician has the responsibility to insure that it is provided. This is a medical diagnosis. The Physician signs off the report and take responsibility, according to the guidelines of the College of Physicians and Surgeons of that province.

## Clinic Highlight: Mustard Seed FASD Clinic

The Mustard Seed is a Christian non-profit organization that has been caring for individuals experiencing extreme poverty and homelessness since 1984. The Mustard Seed provides a safe haven where we can support the whole person through basic services, housing, wellness services, employment programs, and partners within the community to address the root causes of poverty. In 2018, The Mustard Seed helped to support 5,227 individuals experiencing poverty and homelessness in Calgary, Edmonton, Red Deer, and our newest location in Kamloops, BC.

The Mustard Seed in Calgary has a fully functioning Wellness Centre that includes Advocacy supports that help clients connect with over 150 different agencies within the city, medical care including doctors and nurses, mental health supports including counselling and addictions counselling, and most recently, an FASD Assessment and Diagnostic Clinic that opened in September 2018, specializing in the adult populations they serve.

The FASD Clinic at The Mustard Seed is unlike any other clinic of its kind. The kind of clients that the clinic sees are often in active alcohol and drug addictions, and frequently have mental health complications. Assessments for these individuals are completely free for the client, and run on the generous support of grants and donors. Our FASD Clinic has been able to "catch" those individuals who have fallen through the cracks of society - those who have never had the means to be diagnosed before now, and give them the



hope that they can get out of addictions and off of the street, and live normal, healthy lives when they have the right tools to help them along the way.

The Mustard Seed FASD Clinic team consists of the Clinic Coordinator, an Occupational Therapist, a Psychologist, an Advocate to provide wrap-around services following the client diagnosis (such as assistance applying for AISH and PDD), and an FASD trained medical doctor from CUPS Health Clinic.

Boris Lesar, Reg. Psychologist Samantha Lowe, OT, Health and Wellness Manager Dr. J. Marlinga, Physician Erin Bareham, LPN, FASD clinic coordinator Missing: Donna Ryder, RN, Wellness Advocate

#### The "Hold" List

This is a unique way that the Mustard Seed FASD clinic handles "no shows". Understanding the minds of those with FASD, you can imagine how they struggle with getting clients to show up for their assessments; now add addictions and mental health on top of it, and it's almost impossible to get those clients assessed. The "Hold" list is a way to combat this common problem. The clinic schedules clients with appointments as usual, but makes those spots available to clients who may be waiting for future appointments to come in and wait for the chance to be assessed sooner. If the client that was booked in with an appointment does not show, the client waiting on "Hold" will then be seen in their place. This method has been hugely successful, and the clinic is seeing an increase in clients who are getting assessed sooner, and virtually eliminating the need for a waitlist.

The FASD clinic at The Mustard Seed Wellness Centre is ahead of their goal of 25 assessments for the year, and is looking forward to continuing to serve the most vulnerable and at-risk populations in Calgary.

## International FASD Awareness Day-Events throughout Alberta



Candy was delivered to all grade 9 students in the Foothills service area for the "Be a sweetie" Campaign.



A BBQ and a mocktail challenge at Tri-City Mall in Cold Lake.



Community teams took part in an office relay and a BBQ in High River.



Timbits were delivered to RCMP, Firefighters and FCSS offices in the Foothills service area.



A free BBQ with information at town hall in Bonnyville.



FASD trivia and lunch at the Youth & Senior Community Centre at Kikino Métis Settlement.

### Annual Co-ordinator's Meeting



This year's Annual Clinic Coordinator meeting had 28 people attending from all regions of Alberta, as well as cross-ministry committee (CMC) members. As always, the day was busy and not all agenda items could be discussed in the time we scheduled. Clinics will continue to be updated on the telehealth pilot project and use of the University of Washington Facial Analysis Software proaram. Additional information will be circulated for Pediatric FASD clinics using the Affect Regulation check list and screening tools that were

discussed at the meeting. Coordinators also shared strategies, questions and comments about wait lists, and recommendations that could assist with tracking and managing these lists. Much appreciation to all who took the time and effort to attend this meeting; your feedback is important to the work we do and provides valuable input to future training requests, as well as identifying areas that need



#### Suzanne Johnson-Thanks and Appreciation!

Medigene Services in Calgary will be "retiring" in the Spring of 2020. Suzanne Johnson has been "at the helm" of Medigene since 1999 and is looking forward to new ventures in her RV and enjoying her 5-month granddaughter, Katrina. Since 1999, Medigene has completed over 1800 assessments, provided mentorship and services to agencies and stakeholders in the Calgary (and beyond) region and participated in projects, surveys and trainings with the Rajani Clinic Training Program. She will be missed, but will still find time for mentoring and education.

Thank

You!

# Crystal's Miracle Minute Tips

#### <u>Clean Up Your Inbox in One Click</u>

Taking time off is wonderful until the moment you open your email after returning to work. If you work in an email-heavy company, you may have received hundreds of emails while you were out of the office, and now you're faced with the difficult task of sorting through each one.

With Outlook's clean-up function (introduced in Outlook 2010), you can drastically reduce the number of emails you have to deal with in just a few clicks—whether you're coming back from vacation or you just have too many emails piled up. The clean-up function removes all email replies that are duplicated in a later thread, allowing you to read a single thread instead of dozens of individual emails. To clean up your inbox quickly:

While viewing your inbox, click the "Clean Up" button, and select "Clean Up Folder."



Click the "Clean Up Folder" button in the popup to confirm the action.

Clean U	lp Folder	It there are pro	blems with how this n
	the Deleter	nt messages in the current fo d Items" folder. ow this message again	lder will be moved to
	Settings	Clean Up Folder	Cancel

Outlook will automatically remove all duplicate emails, leaving you with significantly fewer emails to sort through.



The clean-up tool removed 29 duplicate emails from the inbox. If needed, those emails can be accessed in the trash folder.

The clean-up function can be a little disconcerting to use initially. What if it deletes something important like a reply that contained an attachment that was removed in a later thread?

Rest assured: the tool is sophisticated and will not delete any emails with attachments or text that aren't exactly duplicated in later threads, and you can always review deleted items in the trash folder if needed.

# Links & Such

#### https://canfasd.ca/media/media-resources/

This tool kit is intended for health care professionals, service providers, journalists, or anyone who might speak to the media about FASD. Use this resource to help guide you on how to speak to the media about FASD, or how to run your own media campaign on FASD/alcohol and pregnancy, ensuring that the language you use is informed, inclusive, and non-stigmatizing.

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#### https://estore.canfasd.ca/fasd-for-school-staff-level-ii

FASD for School Staff Level II is an advanced training course intended for all educators working with students with FASD including all administrators, teachers, educational assistants, ECE's, office admin, Board personnel and bus drivers. This Level 2 training course, **building on the Level 1 Foundations in FASD course**, provides the perspective of individuals who have FASD and their caregivers, is evidence-based and current, employs a culturally sensitive approach, and is presented in a way that is responsive to educators.

#### https://conference.alignab.ca/

ALIGN's annual conference is Jan. 29, 30, 2020 in Edmonton. This conference would be of interest across different sectors who support the wellness of children and families.

Louisa Clapper (coordinator with Bridges Family Programs, Medicine Hat) and husband Craig welcomed Freddie (Winifred), aka, her Chinese name Won-Yin on April 28th, 2019. Freddie arrived during a snow storm and loves to rock her Red Shoes!







FASD Assessment & Diagnostic Clinic Contact List Updated: September 2019

C | Child Clinic A | Adult Clinic

#### Cumulative Risk Diagnostic Clinic [C]

Child Development Centre Alberta Children's Hospital 2888 Shaganappi Trail NW, Calgary, AB T3B 6A8 [P] 403.955.5878 Coordinator: Bernadette Jesse Bernadette.Jesse@ahs.ca

#### MediGene Services, FAS Diagnostic Clinic C | A

Foothills Professional Building Suite 110, 1620-29<sup>th</sup> Street NW, Calgary, AB T2N 4L7 [P] 403.571.0450 Program Manager: Suzanne Johnson <u>medigen@telus.net</u>

#### Central Alberta OBD Triage Clinic C | A

#206-33 McKenzie Crescent Red Deer County, AB T4S 2H4 [P] 403.342.7499, ext. 2 Contact: Allyssa deHeer <u>adeheer@fasdca.ca</u>

#### Lakeland Centre for FASD C | A

P.O. Box 479, Cold Lake, AB T9M 1P3 [P] 780.594.9905 Diagnostic Services Manager: Tia Luedee <u>tluedee@lcfasd.com</u>

#### Pediatric FASD Clinical Services [C]

Glenrose Rehabilitation Hospital 10230-111 Avenue, Edmonton, AB T5G 0B7 [P] 780.735.8278 Coordinator: Diane Plouffe <u>Diane.plouffe@ahs.ca</u>

#### Glenrose Adult FASD Assessment Clinic [A]

Glenrose Rehabilitation Hospital 10230-111 Avenue, Edmonton, AB T5G 0B7 [P] 780.735.6166 Coordinator: Bernadene Mallon Bernie.Mallon@ahs.ca

#### Canadian FASD Diagnostic & Training Centre C | A

316 Kingsway Garden Mall NW Edmonton, AB T5G 3A6 [P] 780.471.1860 Coordinator: Morgan Dumville info@dvmassey.com

#### Centrepoint Young Offender Program [C]

Suite 701, 10242-105 Street, Edmonton, AB T5J 3L5 [P] 780.428.4524 ext. 227 Social Worker: Roxanne Pereira <u>Roxanne.Pereira@ahs.ca</u>

#### Northwest Primary Care Network [C]

Children and Youth FASD Diagnostic Clinic Northwest Primary Care Network 11202-100 Avenue, High Level, AB TOH 1Z0 [P] 780.841.3253 Social Worker/Coordinator: Cheryl Cunningham-Burns <u>Cheryl.Cunningham-Burns@ahs.ca</u>

#### Northwest Regional FASD Society

Mackenzie Network [A] Box 3668 \_ High Level, AB TOH 1Z0 [P] 780.926.3375 Contact: Kimber Lepensee <u>clinic.fasdsociety@telus.net</u>

#### Alberta Health Services/NEAFAN C | A

600 Signal Road, Fort McMurray, AB T9H 3Z4 [P] 780.750.6678 Diagnostic Assessment and Clinic Lead: Kerri Power <u>kerri.power@ahs.ca</u>

#### NW Peace FASD Diagnostic Clinic C | A

#204, 9805-97 Street, Grande Prairie, AB T8V 8B9 [P] 780.533.5444 Clinic Coordinator: Jen Duperron-Trydal Jen@nwfasd.ca



FASD Assessment & Diagnostic Clinic Contact List Updated: September 2019 C| Child Clinic A| Adult Clinic

#### Northern Association for FASD C | A

P.O. Box 3334 4826-51 Ave, High Prairie, AB TOG 1E0 [P] 780.523.3699 Coordinator: Charlene McLay <u>nafasd@telus.net</u>

#### North West Central FASD C | A Assessment & Diagnostic Team

Box 5389, Westlock, AB T7P 2P5 [P] 780.284.3415 Coordinator: Sharon Pearcey <u>sharonp@nwcfasd.ca</u>

#### Pediatric Specialty Clinic [C]

Children's Rehabilitation Services-Central Zone #300 Professional Centre 5015-50 Avenue, Camrose, AB T4V 3P7 [P] 780.608.8622 Coordinator: Lorraine McPhee Lorraine.McPhee@ahs.ca

#### Siksika FASD Clinic [C]

Box 1130 Siksika, AB TOJ 3W0 [P] 403.734.5687 Coordinator: Vanessa Buckskin vanessab@siksikahealth.com

#### Prairie Central FASD Clinical Services [A] 4838-49<sup>th</sup> Street, Camrose, AB T4V 1N2

[P] 587.386.0186 Amanda Lindholm a.lindholm@prairiecentralfasd.ca

#### Complex Needs Diagnostic Clinic [C]

Wapski Mahikan Society, Alexander First Nation Box 3479, Morinville, AB T8R 1S3 [P] 780.853.7723 Diagnostic Coordinator: Amber Bell adbell@ualberta.ca

#### FASD Assessment and Support Services C|A

Bridges Family Programs 477 Third Street SE, Medicine Hat, AB T1A 0G8 [P] 403.526.7473 Contact: Melissa Linkson <u>mlinkson@memlane.com</u>

#### Lethbridge Family Services-DaCapo Services C | A

FASD Assessment & Diagnostic Clinic 1107-2<sup>nd</sup> "A" Ave. N., Lethbridge, AB T1H 0E6 [P] 403.320.9119 Children Coordinator: Jennifer Vanderkooij, <u>ivanderkooij@lfsfamily.ca</u> Adult Coordinator: Krista Tittlemier <u>Ktittlemier@lfsfamily.ca</u>

#### Alberta Hospital Edmonton [12-21yrs] Turning Point Program

17480 Fort Road, Box 307, Edmonton, AB T5J 2J7 [P] 780.342.5002 Sherry Muscat, Registered Psychologist <u>sherry.muscat@ahs.ca</u>

#### Foothills FASD Assessment & Diagnostic Clinic C | A Box 5146

101, 520 Macleod Trail, High River, AB T1V 1M3 [P] 403.652.4776 Contact: Kathy Lambourn Kathy.lambourn@foothillsfas.com

#### Enviros FASD Assessment & Diagnostic Clinic C | A

#220, 3115-12th Street NE, Calgary, AlbertaT2E 7J2 [P]403.219.3499 Contact: Rita Spark ndc@enviros.org

#### **Mustard Seed FASD Clinic**

1010 Centre St. SE, Calgary, AB T2G 0V8 Phone: 587-393-4021 Contact: Erin Bareham erinbareham@theseed.ca

Our strength will grow through community