

# NEWSLETTER



*Winter Newsletter | March 3, 2018*

## WHY COLLECT DATA?

- Results provide real-time information on the difficulties, challenges and needs of those who present for an FASD diagnosis
- The database captures type of diagnosis, recommendations for interventions, specifics of assessments and demographics
- Many questions can be asked of the data to help us to better understand FASD in Canada
- To date we have 725 records from 28 participating clinics!

## QUESTIONS OF THE QUARTER

**Should we enter information for families who had an assessment, but for whom we do not have confirmation of prenatal alcohol exposure?**

- Yes! If they have the 3 facial features they can still receive a diagnosis without confirmation of prenatal alcohol exposure. It is also useful to see who comes for an assessment and where referrals are from.

**Should we enter information for individuals who are assessed, but who do not receive an FASD diagnosis or an At-Risk designation?**

- Yes please! It will be interesting to compare those with FASD and those without.

**What does Dataform mean by trauma and post-natal trauma?**

- We are working to better define these terms and others to ensure consistency with data entry across clinics.

## DATA HIGHLIGHTS

- 433 individuals diagnosed with FASD
- On average, they waited 11.63 months between the time of referral and assessment
- Most referrals were from Social Services Agencies (46%) and family members (26%)
- They were 15.75 years old, on average, at the time of diagnosis
- 77% of individuals were being assessed for the first time, 8% were being re-assessed and 2% follow-up
- Over half of those with FASD in the database are adults (57.89%); 21.53% are adolescents (12-17) and 20.57% are children (0-11)
- PAE was confirmed in 86% of the cases
- Poly-substance exposure was common

## CLINIC SUPPORT!

A number of tools for clinics are under development - COMING SOON....

- Video on how to fill out Dataform
- Frequently Asked Questions list
- Written guide to filling out Dataform, including definitions

*Does your clinic need support entering data?*

**Please let us know- WE CAN HELP!**

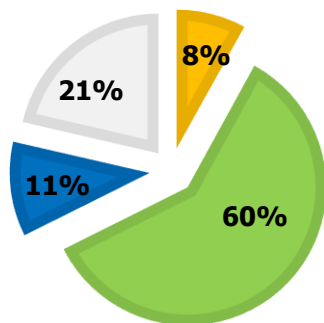
# NEWSLETTER



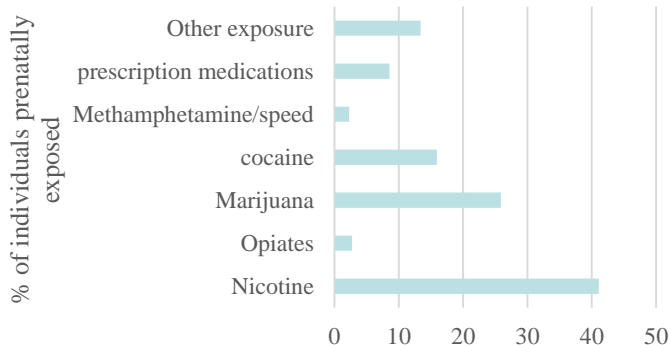
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## DATA UPDATE

- FASD With Sentinel Facial Features
- FASD W/O Sentinel Facial Features
- At Risk
- No FASD Diagnosis



### Other Prenatal Exposures

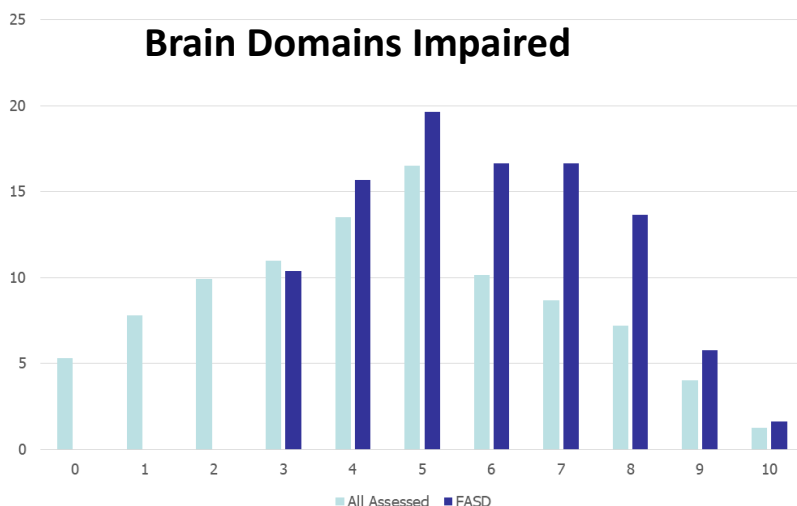


Only 4% of individuals assessed for an FASD diagnosis were confirmed to only be exposed to alcohol prenatally.

### Issues Being Experienced by those with FASD

Issues Being Experienced by those with FASD	%
Employment problems	42
Teachers assistants	40
Needs help living on own	29
Offender	20
Needs assisted or sheltered housing	15
School expulsion/suspension	12
Victim	8
Custody issues/family court	6
Incarcerated	6

### Brain Domains Impaired



## UPCOMING PRESENTATIONS

- [8<sup>th</sup> International Research Conference on Adolescents and Adults with FASD - April 18 to 21, 2018 \(Vancouver, Canada\)](#)
- [European Conference on FASD 2018 - September 24 to 26, 2018 \(Berlin, Germany\)](#)