CanFASD
CANADA FASD RESEARCH NETWORK

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FASD Basic Information

The first published literature that linked alcohol use with birth defects was in France, in 1968, by Dr. Paul Lemoine. In 1973, researchers at the University of Washington published their findings regarding a group of children who shared uncommon physical features and developmental delay. These children all had mothers who had consumed alcohol pregnancy. The term “Fetal Alcohol Syndrome (FAS) was created to describe the patterns observed in these children.

Today, Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges. Depending on the amount and the timing of alcohol exposure, a minority of infants exposed will also develop a characteristic pattern of facial features, and some will have a growth deficiency. However, those effects are relatively rare and have little impact on day-to-day function. Decades ago, the facial features of FASD received a lot of attention in the press. The presence or absence of facial features depends on whether alcohol was consumed in a very narrow window of time during pregnancy. It does NOT reflect the degree of brain disorder. The vast majority of people with FASD are not visibly different; you cannot see FASD. Although in a very small percentage of people the face may look different, the important fact is that in all individuals with FASD, the function of the brain is permanently affected.

Alcohol exposure during pregnancy results in changes to the developing brain at neurochemical and structural levels. Often, these changes are not detected until a child reaches early or middle school-age when difficulties at school and at home become increasingly problematic. These challenges can include problems in social communication and attention, motor and sensory problems, memory, and difficulty learning from consequences. As an individual grows, they are also at increased risk for depression, anxiety, and other mental health conditions. Scientific evidence has conclusively shown that alcohol consumption during pregnancy can cause fetal harm. There is insufficient scientific evidence to define any threshold for safe low-level drinking during pregnancy or when planning to become pregnant. The life-long damage to the brain is the most common and serious result from prenatal exposure to alcohol and can occur at any time during a pregnancy. The safest choice for a woman who is pregnant or planning to become pregnant is not to drink alcohol.

A common misconception is that FASD is associated with social, ethnic, or cultural backgrounds. However, the majority of Canadian women drink alcohol. In a 2012 Canadian Alcohol and Drug Use Monitoring Survey, 70% of females aged 15-24 used reported drinking alcohol in the last 12 months while 80% of females over the age of 25 reported using alcohol in the past 12 months. Approximately one half of all pregnancies are unintended, and women often continue their usual pattern of alcohol consumption into the early weeks of an unplanned pregnancy. The highest rates of unintended pregnancy occur in women aged 15-19 years of age, which is also a population at increased risk for binge drinking.

FASD is often an invisible disability and prevalence research faces considerable limitation, yet, prenatal alcohol exposure is considered the most common known cause of developmental disability in the western world. Previous estimates claimed that one in every one-hundred Canadians have this disability. Current studies suggest that closer to four percent of individuals in Canada have FASD, around 1.4 million people. However, as FASD is considered an "invisible disability" it is likely that these numbers do not represent the true prevalence rates. Despite 40 years of public health campaigns warning against the risks associated with alcohol use in pregnancy, prevalence does not appear to be decreasing. The indirect and direct costs for supportive needs in health, mental health, social services, and education, as well as the negative costs through criminality and criminal justice system involvement, are estimated to be almost $10B/year.

Unlike most other birth defects, the diagnosis of FASD is not straightforward. Medical signs are difficult to recognize in newborns, infants, and young children. Diagnosis can be delated or missed entirely, as most of the damage caused by alcohol use during pregnancy cannot be easily quantified until problems arise. Problems caused by prenatal alcohol exposure may not be noticed until children are in school or until the teenage years because this is when those impacted by FASD often have significant difficulty meeting societal expectations. FASD is challenging to detect and the diagnostic process relies on an inter-disciplinary team approach. Diagnostic services are not widely available across Canada, especially in rural and remote areas. Many families are reluctant to seek a differential diagnosis because of the stigma associated with addiction and substance use.

No two people with FASD will have the same challenges due to the wide variation of alcohol effects on brain development. Individuals with FASD are at increased risk for mental health issues, school difficulty, addictions, trouble with the law, and difficulties maintaining employment. Some of the more commonly seen challenges include:

- Executive functioning – difficulty with judging, planning, delaying gratification, consequences, organization, impulsivity, memory
- Communication – can be highly verbal, but lack comprehension skills both written and verbal
- Neuromotor defects – impaired balance and coordination

If the above are not appropriately understood and addressed, individuals with FASD are at increased risk for early school failure, involvement with the law, family disruption, and homelessness.

Our understanding of FASD is in a period of rapid expansion and change. We are beginning to understand the extent of the global impact of this lifelong disability. Research, and the answers it may provide, is critical for moving this field forward, changing the way we view this brain based disability and lessening its impact on individuals, families, and society.

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