

# Raising awareness of fetal alcohol spectrum disorder

By Kathy Yanchus  
Special to the Champion

The devastating consequences of consuming alcohol while pregnant are well known, yet its effects can be misdiagnosed, and community resources and support systems for children and adults affected are often inadequate.

Halton is no exception when it comes to a lack of proper support for people living with fetal alcohol spectrum disorder (FASD), and the reasons why are many, beginning with a lack of awareness and proper diagnosis, unless a mother readily admits she drank while pregnant, agree members of the recently-formed Halton FASD committee.

Exposure to alcohol interferes with brain development and can cause mild to severe physical, brain and central nervous system disabilities, as well as cognitive, behavioural and emotional issues. The effects of FASD are lifelong and affect not just the child, but the family and society.

"What's happening is it's not being identified as a brain disorder and kids and adults are obviously ending up in the justice system, when it's actually a medical disorder that's probably never really been either readily identified or treated in any way," said Halton police Inspector Jackie Gordon, a member of the committee.

In fact, it was the findings of the Halton Hu-

man Service and Justice Coordinating Committee (HHSJCC) in 2010, that prompted an urgent response by Halton community leaders. It found that those suffering from FASD are over-represented in the justice system.

In June of 2011, HHSJCC held a FASD conference to raise awareness among community and medical-based organizations representing mental health, child and youth, addiction services, public health, schoolboards, developmental services and parents of children with FASD.

This was followed by the creation of A Vision for Addressing FASD in Halton and subsequently a dedicated Halton FASD leadership group, which now meets monthly.

"At the end of the day we're all dealing with folks who have been affected by FASD in our services and it's not something we immediately go to, probably just because of lack of awareness," said Cheryl Gustafson, RN, BScN, MN, CPMHN(C) and Halton FASD committee chair. "They are often in our criminal justice system where they shouldn't be, so we have



Cheryl Gustafson

to develop better strategies and supports and resources to address the needs of these folks. There is a fair bit of work yet to be done in a lot of communities, but lots of communities have made great gains in addressing the needs of those with FASD. There are many who have gone before us, so the road's already been well paved in terms of successes. We really drew on how some of those communities developed strategies.

"To be honest I have been a nurse for almost 25 years in mental health and I

knew very little. We don't always have that information. If it looks like someone is affected by FASD it should be part of our thinking and this wasn't even on my radar as a clinician.

"In the last couple of years a fair bit of groundwork has been done, just increasing the awareness in Halton of the issue. We're all caring for these folks and probably not in the best way that they need. We all need to know more and do more," said Gustafson, patient care manager for the inpatient mental health service at Oakville-Trafalgar Memorial

Hospital.

Down the road, Gordon would like to see Halton police officers trained in identifying FASD.

"That's what we're going to work towards, prevention, training and then services to deal with it once it's identified," said Gordon. "Our biggest challenge is to bring awareness to the issue, there are a lot of people who just don't know much about it, other things have taken higher priority."

There's some shame associated with women admitting to drinking during pregnancy, so statistics may not be a true reflection of the scope of the problem, added Gordon. It's currently estimated that one in 100 Canadians have FASD.

Halton parents of children with FASD must go out of catchment area to access services, diagnosis and appropriate treatments for their kids, said Gustafson.

"They're the ones who have to educate our educators," she added. "It's a gap that probably needed to be addressed a long time ago. We have come a long way in two years. We have some very influential people at the table in terms of making change happen and moving it forward and being committed to seeing the vision become reality."

As the parent of an adopted child with FASD, Burlington's Jennifer McKee has lived a nightmare over the past decade.



## Nightmare experience with FASD

“For birth moms, I want them to know it has a lifetime effect on not only the child but the families and the community. It’s going to be never ending unless we get the awareness out there, things are not going to get better.”

As a Halton FASD committee member, McKee comes away from meetings “so hyped, so pumped, there’s so much I want to do and say.”

Within hours of adopting their son at the age of 26 months, the family knew something was “horribly wrong,” said McKee.

“He was very violent with my daughter. He would hit other kids with toys, show aggression. When it would be time to leave (play sessions), he would be quite belligerent with me, screaming. He would bite, spit, hit.”

In an effort to increase his socialization, McKee twice registered her son in daycare part-time, both efforts being short-lived, shocking and frightening experiences.

When he finally started SK, her son was “unbelievably belligerent” and his physical aggression escalated, his violence targeting both her and her daughter.

Today, McKee’s 12-year-old son resides in a “wonderful” private Oakville facility, and receives a combination of collaborative problem-solving and Applied Behavioural Analysis (ABA) treatment, typically used for autistic children and it seems to be working very well, said McKee. He attends a behaviour resource class in Burlington. “That’s all that’s available.”

“My son comes home on weekends with a goal to hopefully be home within next few months. It’s been an incredible journey. I feel angry that we didn’t have the information going into this. It’s been a struggle to find resources because there’s nothing in our community. I’m cautiously optimistic right now. My husband and I have been very firm that we are not prepared to have him back and relive that life until we are absolutely certain he can manage because I’m not a professional, I have another child to think of here. There’s nothing out there, no one knows about FASD.

“I think I know what’s to come and some things will just be a constant challenge. I feel my husband and I are different parents, my daughter is different, we’ve all learned. We know enough now, we seem to approach things differently, we react differently. His rage can go from 0 to 60 in a heartbeat which scares me.”