

## **Chatham psychologist launches group to help families living with FASD**

*UNC researcher says up to 1 in 20 people may have a developmental disability caused by prenatal alcohol exposure (JAMA, Online, February 6, 2018)*

*The New York Times* reported February 6 that a new research study found up to one in 20 first graders are suspected of having a Fetal Alcohol Spectrum Disorder (FASD). The study, led by UNC researcher, Philip May, PhD, was published in this week's *Journal of the American Medical Association (JAMA)*.

“The JAMA study reinforces that prenatal alcohol exposure is a significant public health issue that cannot be dismissed,” says Kathy Hotelling, PhD, executive director of newly formed nonprofit, NCFASD Informed, Inc. and longtime resident of Chatham County.

Dr. Hotelling continued, “People suffer more significantly from the lifelong effects from prenatal exposure to alcohol than drugs or other toxins. Unfortunately, the level of awareness of this fact is very low in North Carolina and around the United States. For those with exposure to alcohol *in utero*, proper diagnosis and appropriate interventions are essential for the best quality of life. Those who live with an FASD face extraordinary challenges throughout their lifespan. This is exacerbated by estimates that about 90 percent of those with this disability are not properly diagnosed.”

“We want to improve the quality of life for families suffering from an FASD in North Carolina. We are driven to instill hope and showcase the strengths of our

children, teens and adults. It is no longer acceptable for people with developmental disabilities to barely survive -- we want them to thrive.”

The inspiration for Hotelling to launch NCFASD Informed, Inc. came after many years of struggling to get her own daughter diagnosed.

Hotelling took her daughter from specialist to specialist at leading hospitals around the country. She knew her daughter had delays in cognitive, social, and adaptive function. She said the same thing to each specialist consulted (four neurologists, three psychiatrists, a developmental pediatrician, a geneticist, two gastroenterologists, a cardiologist, a dietician, a neuropsychologist, as well as those in the allied health field such as physical therapy, speech therapy, and occupational therapy): “I think she was exposed to alcohol *in utero*”. No one believed her. What Hotelling realized later is that they were looking for the “face” of FASD. Hotelling was a trained psychologist and knew in her gut they were incorrect. Her daughter was living with the effects of prenatal exposure to alcohol.

The fact is, only 10 percent of who have been impacted by alcohol *in utero* have facial characteristics known as the “face” of exposure. The reality is, however, that exposure to alcohol is a spectrum disorder, thus the phrase Fetal Alcohol Spectrum Disorder (FASD), the term used for the various diagnostic terms that have been used for the last 50 years. Individuals are affected in different ways in part based on when during pregnancy and how much alcohol a mother consumed, including whether she binge drank. The mother does not have to be an alcoholic to expose her fetus to alcohol. Fifty percent of women who become pregnant were not trying to get pregnant and about the same number do not know until about week 8 of pregnancy that they are pregnant; thus, for a woman who drinks, there is plenty of opportunity to unwittingly expose her child to alcohol *in utero*.

Hotelling finally prevailed when her daughter was 10 years old. After ten years, during which at least eight diagnoses had been accrued, her daughter was diagnosed with an FASD. Previous diagnoses had described pieces of her daughter's symptoms, but they did not address the underlying cause. Fortunately, her daughter was in early intervention programs such as speech, physical, and occupational therapy, and had an Individualized Education Program (IEP) throughout her schooling to accommodate her behaviors and academic challenges. Research shows early intervention enhances positive outcomes for all with a developmental disability. Early diagnosis and intervention enhances positive outcomes.

In an effort to support families with those with an FASD, since 2010, Hotelling has led the only FASD parent support group in the state. Every week, she hears from at least one family in crisis, trying desperately to help a child, teen or adult, but too often struggling with either a lack of diagnosis or misdiagnosis, usually ADHD.

To more rapidly meet the needs of an underserved population, early in January 2018, Hotelling and another parent joined forces to launch NCFASD Informed. Hotelling hopes to receive 501(c)(3) tax exempt status by the end of the year. She, her business partner, and other parents with children with an FASD, are working on a model of FASD informed communities. They will start their awareness program focusing on interventions parents can implement immediately. In time, outreach will include educators and health professionals around the Triangle area, and eventually all of North Carolina.

### **About NCFASD Informed, Inc.**

NCFASD Informed was formed by two parents who have struggled with getting others to focus on what their children can do, rather than what they can't. The

mission of the all-volunteer, grassroots, nonprofit organization is to create FASD informed communities to empower individuals impacted by prenatal exposure to alcohol. It's vision: a world where individuals with development disabilities, including FASD, can thrive.