

Effects linger for children of women who drink during pregnancy

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FETAL ALCOHOL SEPCTRUM DISORDER

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ST. LOUIS -- When Ellen Corona adopted her now 16-year-old son [Scott](#), he was a perfectly healthy baby. But in the third grade, he started to have problems.

He was treated for ADHD and bipolar disorder. Four years later while seeing a specialist in Tourette Syndrome, he was finally diagnosed with fetal alcohol spectrum disorder. But the diagnosis didn't provide answers.

"There's a lot of gray areas, areas they don't understand," said Corona, 53, of Wildwood, Mo. "There's no specific line of treatment."

Fetal alcohol spectrum disorder is a group of mild to severe physical, neurological and behavioral conditions caused by a mother drinking alcohol during pregnancy. The term "fetal," however, can be misleading. The disorder is often diagnosed during late childhood, and the symptoms are life-long.

Despite the need, no social services programs in the U.S. are geared to treat the specific symptoms of youth and young adults with FASD, said Leigh Tenkku, assistant professor of family and community medicine at [St. Louis University](#). Instead, those suffering with the disorder are treated with a hodgepodge of programs for other developmental disabilities. Interventions are often nonspecific and lack scientific evaluation.

"The brains of individuals with FASD are not fully developed, which affects their ability to handle emotions, problem solve and pick up on social cues," Tenkku said. "As they get older, these problems affect their ability to maintain a job, their relationships and their parenting abilities."

Researchers at SLU are trying to change the course for youth struggling with the disorder. The university is conducting one of two research projects funded by the [Centers for Disease Control and Prevention](#) to develop evidence-based treatment targeting older youth and young adults. The other is at the University of California, Los Angeles.

SLU's research project, called Partners for Success, combines a personal mentor with biweekly therapeutic home visits for the family. The mentor will model appropriate behavior and help those with the disorder to integrate techniques taught during home visits into their daily lives. Researchers are trying to recruit 100 study participants ages 16 to 25.

"This is a totally new approach to mentoring older children and adults with FASD, but it's built on well-established research in the field," Tenkku said. "This program is very promising, and we're hopeful that it will revolutionize the way we support these individuals."

Corona recalls how the medication for ADHD left her son without an appetite and sleepless. Middle school was the hardest time, she said. He struggled to fit in, was angry and impulsive. She's tried everything from chiropractic care to massage therapy to help, even buying punching bags for him to help let off steam.

"We just gritted our teeth and got through," she said. "Every day was so sad and so depressing."

There is no known safe amount of alcohol to drink while pregnant, health experts say. Because about 60 percent of women do not know they are pregnant at four weeks' gestation, a critical period in organ development, the CDC warns women to not drink alcohol if they are sexually active and do not use birth control.

Fetal alcohol syndrome was first labeled in 1973 and represents the severe end of the FASD spectrum. People with FAS have abnormal facial features and growth problems along with a mix of other physical and behavioral problems. Scientists have and are still learning about different levels of neurological damage caused by alcohol use during pregnancy. The CDC and other experts have developed guidelines for diagnosing FAS, but the diagnostic criteria for FASD is still in the works.

"This is still a very new field, and we are still learning about this," Tenkku said.

Studies have shown that one or two cases of FAS occur for every 1,000 live births in the U.S. The CDC estimates that at least three times more suffer from FASD. The estimated cost for FAS alone is more than \$4 billion annually. Early intervention, however, can improve symptoms and prevent costly outcomes.

"Many go undiagnosed as having FASD, and they end up in our mental health treatment centers. They end up in our substance abuse centers, and they end up in our jails," Tenkku said.

Corona said a mix of medications is helping her son sleep and ease his mood swings. He is doing well in school thanks to a special education plan addressing his needs. But, she said, he still doesn't grasp cause and effect. He melts down when things don't go his way. She wonders if he will be able to go college, hold a job.

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Children with fetal alcohol spectrum disorder may have these traits, according to the U.S Centers for Disease Control and Prevention:

_Abnormal facial features, such as a smooth ridge between the nose and upper lip

_Small head size

_Shorter than average height

_Low body weight

_Poor coordination

_Hyperactive behavior

_Difficulty paying attention

_Poor memory

_Difficulty in school, especially with math

_Learning disabilities

_Speech and language delays

_Intellectual disability or low IQ

_Poor reasoning and judgment skills

_Sleep and sucking problems as a baby

_Vision or hearing problems

_Problems with the heart, kidneys or bones

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