

# Chicago Tribune

## Families battle an ‘invisible disability’



By [Bonnie Miller Rubin](#)  
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For a decade now, the call has gone out every year on the ninth day of the ninth month warning women about the dangers of drinking while pregnant, yet Fetal Alcohol Syndrome remains stubbornly below the national radar, some health officials say.

At precisely 9:09 a.m. Wednesday, carillon bells will ring out from Austin, Texas to Auckland, New Zealand to observe Fetal Alcohol Spectrum Disorders Awareness Day, another chance to spread the word about the disorder.

In New York, women—and even some men sporting pregnant bellies—will “freeze” in front of “Today Show” studios to emphasize the importance of taking a 9-month pause from drinking alcohol during pregnancy.

And in the Chicago area, some 300 public health professionals, teachers and parents will convene at an all-day forum at Prairie State College, to raise awareness about birth defects that experts say are preventable.

Yet, almost 30 years after the U.S. Surgeon General began warning women about alcohol-related brain damage, and a decade after the first international observance, the disorder is still not as widely recognized as autism, epilepsy or other developmental disorders.

“It’s frustrating,” said Kathy Mitchell, of the National Organization on Fetal Alcohol

Syndrome (NOFAS). “Many physicians and health clinics still do not screen women for alcohol use, do not educate them on the hazards of drinking while pregnant and do not even recognize FASD in their patients.”

The reasons why the disease does not have a higher profile are complex, ranging from the lack of a celebrity spokesman, to Americans’ complicated relationship with liquor, say experts.

In the United States, 40,000 children are born each year with FASD—more than spina bifida, Down Syndrome and muscular dystrophy combined, according to the National Organization on Fetal Alcohol Syndrome. Children exposed to alcohol in utero are prone to poor judgment, impulsivity and are often unable to grasp cause and effect. Lifetime costs for one individual with FAS in 2002 were estimated to be \$2 million, according to the CDC.

So why no telethons? Ribbons? Marches in Washington?

“There’s a lot of stigma associated with alcohol abuse and this spills over into FASD,” said Edward Riley, of San Diego State University, and one of the nation’s leading researchers on the condition. “For biological parents, it is difficult ... it means they have to be willing to admit that they were a contributor. And for adoptive parents, it means that the perfect family they were looking for might not become a reality.”

According to the CDC and virtually every other mainstream public health organization, there is no known safe amount or safe kind of alcohol, or safe time to drink alcohol, while pregnant.

But convincing moms that even a few beers or an occasional martini can do irreparable damage continues to be a muddled message. Last year, on “Good Morning America” an obstetrician told a woman in her eighth month who enjoyed a glass of wine with dinner most evenings not to worry. “You’re not going to do harm to that baby,” he said.

Shortly after the segment aired, the American College of Obstetricians and Gynecologists fired back with its own response, calling the information “potentially dangerous” and reiterating its “long-standing position that no amount of alcohol consumption can be considered safe during pregnancy.”

For Mitchell, educating the public is not only professional, but personal. She openly confesses to her drinking and the havoc it wreaked on the developing fetus. Her now 36-year-old daughter still lives at home, “playing with her collection of sticker books and baby dolls. She will be forever impaired because of my drinking.”

While experts say positive strides have been made, Mitchell claims there are only “a small handful” of medical schools teaching physicians to recognize the range of birth defects. Too many clinicians still define the condition by its the most severe manifestation—marked by facial deformities and stunted growth. “Unless a child has

profound features or adopted from Russia, the possibility of FASD is never even thought of.”

Lori Gertz of Long Grove said she visited 38 health care providers before getting a diagnosis for her now 6-year-old daughter, adopted at birth in the Midwest. The little girl’s rages were blamed on everything from colic to bad parenting. “Because I also have two biological children, one doctor suggested that I couldn’t love a baby that wasn’t my own,” said Gertz, who blogs about her experiences.

But even when kids do fit a predictable profile, finding help can be a challenge, due to a lack of clear diagnostic criteria. Nancy Petersen of Roselle adopted two kids—a son and a daughter—from Russia in 1997. Victor, who was almost 5 years old at the time, started showing behavioral symptoms almost immediately. “You could tell him the waffle iron was hot, but he still had to touch it.”

Armed with documentation of Victor’s birth mother’s chronic alcoholism, it still took Petersen five years to get help because he’s a good-looking kid with no outward signs that his capabilities lag far below his chronological age. “It’s an invisible disability,” said the mother, whose son, now 16, attends a therapeutic school in Bartlett.

Both Gertz and Petersen will be at the forum at Prairie State College in Chicago Heights on Wednesday, sponsored by the Illinois affiliate of the National Organization on Fetal Alcohol Syndrome and Trinity Services.

The first FASD Awareness Day was held in 1999, conceived by two mothers—one in Tucson, the other in Toronto—struggling or support and answers.

Looking back on the past decade, Ed Riley, the researcher, said, “We have a much better understanding of the mechanisms ... and have started to look at interventions in much more rigorous fashion ... However, I think we have a long way to go ... I am often discouraged, but for the most part, I remain optimistic that we’re finally on the right track.”