

Hawaii Mothers Speak Out About Fetal Alcohol Spectrum Disorders (FASD)

There have been recent national news articles about Fetal Alcohol Spectrum Disorders (FASD) and parents who could no longer control the behavior of their adopted children. FASD is 100% preventable if a woman does not drink while she is pregnant, however, we continue to see children born with FASD, a condition where there is damage to the physical, mental/emotion, learning, and/or central nervous system as a result of mothers drinking alcohol during pregnancy. Under the umbrella of FASD there are: 1) Children with Fetal Alcohol Syndrome (FAS) that meet all three criteria [facial features, growth deficits, and central nervous system (CNS) impairment; 2) Alcohol-related Neurodevelopmental Disorder (ARND); and 3) Birth defects, Alcohol-Related Birth Defects (ARBD), as a result of alcohol exposure during mother's pregnancy. ARND and ARBD (or Fetal Alcohol Effects/FAE) requires documentation in the child's records that mother drank alcohol during pregnancy to meet diagnostic criteria.

Ginny Wright, a former Hawaii foster parent, is a mother of five adopted children, two of whom have been diagnosed with Fetal Alcohol Spectrum Disorders (FASD). Ginny has been a pioneer in bringing awareness to parents and professionals in the field of FASD. After unsuccessfully searching for FASD experts in Hawaii to address the needs of her 4th adopted child, Ginny finally initiated a trip to Cedar Sinai Medical Center where her child was diagnosed with Fetal Alcohol Syndrome (FAS). Her 5th adopted child was later diagnosed when she was 9 years old. Since then, the 5th adopted child's two younger siblings who are in foster care and living with another family have recently been diagnosed with FASD—all from the same mother. Ginny's girls live in a stable, loving environment. The girls have parents who were able to get documentation, diagnosis and services, and have long-term commitment to learn techniques in raising children with FASD in a nurturing home. All of this has made a significant difference for these girls' happiness and well being, and increasing the chances of them integrating successfully into society as adults.

Two other Hawaii adoptive mothers adopted their children—one from Russia in 1992 at three years old and the other from the Republic of Georgia as an infant is now in her teens with self-destructive behaviors. Both children displayed concerns from infancy and experienced greater difficulties adjusting in school. These mothers attended FASD trainings from Dan Dubovsky, FASD Specialist from Substance Abuse and Mental Health Services Administration (SAMHSA) and Dr. Ira Chasnoff, Children's Research Triangle, both experts in the field of FASD, and learned that children exposed to alcohol during birth mother's pregnancy may appear capable of completing tasks. However, because of the damage to their brain from alcohol, these children may be unable to complete tasks presented to them and are often mislabeled or have secondary diagnosis such as attention deficit disorder with hyperactivity (ADHD), other psychiatric disorders with behavioral problems. These mothers felt their child may be displaying symptoms of FASD, but couldn't find Hawaii providers trained to diagnose a child with FASD. One of the children received a diagnosis after 14 years. The other mother recently took her daughter to doctors on the mainland. She soon received validation from the mainland doctor that her daughter had symptoms related to FASD, however, diagnosis is pending because documentation that the mother drank alcohol during pregnancy is required if the child does not have FASD facial features. This family encountered extensive family financial expenses and problems with medical/insurance system to get evaluations. Both adoptive mothers feel that if their child had been identified with the primary disability (FASD) and received timely, appropriate services at an earlier age, their children would not have had to experience years of being labeled as lazy and unmotivated, failing continuously to meet unreasonable expectations, being bullied, receiving social and emotional rejections by peers and professionals, and eventually these life events eroding and lowering their child's self-esteem and mental well being to the extent it has.

In a study conducted by the University of Washington, 415 patients with a primary disability of FAS or Fetal Alcohol Effects (FAE) of children, the majority of these individuals experienced secondary disabilities (disability not present at birth but occur as a result of the primary disability). Six main categories were identified:

- Mental Health Problems - 60% of children with FASD have ADHD and most individuals have clinical depression as adults; 23% of the adults had attempted suicide, and 43% had threatened to commit suicide.
- Disrupted School Experience - 43% experienced suspension or expulsion or drop out;
- Trouble with the Law - 42% had involvement with police, charged or convicted of crime;
- Confinement – 60% of these children age 12 and over experienced inpatient treatment for mental health, alcohol/drug problems, or incarceration for crime.
- Inappropriate Sexual Behavior – Reported in 45% of those age 12 and over, and 65% of adult males with FAE.
- Alcohol/Drug Problems – Of the adults with FAE, 53% of males and 70% of females experienced substance abuse problems.

The odds of escaping these adverse life outcomes are increased 2- to 4-fold by receiving the diagnosis of FAS or FAE and intervention at an earlier age and by being reared in good stable environments.¹

¹ Streissguth, A.P., Barr, H.M., Kogan, J. & Brookstein, F.L., "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)." Final Report to the Centers of Disease Control and Prevention (CDC), August, 1996. Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06, (1996)

When a woman has an unplanned pregnancy, the risk of consuming alcohol during the early stages of pregnancy is high. Therefore, women of child-bearing age should consult their physician and abstain from drinking alcohol if they are contemplating pregnancy, are sexually active and not using contraceptives or are pregnant. There are 23,016 pregnancies annually and 247,259 women of reproductive age (15-44 years of age) in Hawai'i (2006 Data from FHSD Profiles, 2009). In Hawai'i, 45.3% of pregnancies are unintended. These women may not be aware that they are pregnant until the later stages of pregnancy and may unintentionally drink alcohol during pregnancy. Among the unintended pregnancies, the majority were classified as mistimed (32.3%), with the remainder being unwanted (13%). Approximately 6.3% of women (1,167) reported using alcohol during their pregnancy in 2008. This is almost a two-fold increase from 2002, when only 3.6% of women reported using alcohol during their pregnancy. Other data from PRAMS show that from 2005-2008, the rate of alcohol use prior to pregnancy increased from 42.1% in 2004 to 49.2% in 2008,²

These three Hawaii adoptive mothers hope that through public awareness, collaboration among the community, federal, state, city, and non-profit agencies, Hawaii will be able to provide the support and services needed to first prevent more children from being born exposed to alcohol during mother's pregnancy by screening women within the childbearing age, and for children born with FASD to be identified, and provided appropriate and timely services so these children may grow to their full potential in the near future.

For more information about FASD or if you would like to share your story, please contact:

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Additional Resources:

Healthy Mothers, Healthy Babies Coalition of Hawaii Mothers Care www.hmhb-hawaii.org	FASD Center For Excellence: http://www.fasdcenter.samhsa.gov/	Centers for Disease Control and Prevention (CDC) – FASD http://www.cdc.gov/ncbddd/fasd/index.html	National Organization for FASD http://www.nofas.org/
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² Kazi M, Shor R, Hayes D, Fuddy L. "Preconception Alcohol Use Fact Sheet." Honolulu, HI: Hawai'i Department of Health, Family Health Services Division; August 2010.