

News from the Circle



CIRCLE OF HOPE: *A Birth Mother's Network*

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As part of the **Circle of Hope** – a network of birth mothers with children affected by prenatal alcohol exposure - I am honored to share a little of my story. Being one of the founders of the network has enabled me to fulfill a dream of carrying the message of recovery and hope to all women who are struggling with this issue.

Please Save The Date! Let Your Voice Be Heard!



May 17th and 18th - NOFAS is gearing up for our annual Hill Day and Leadership Awards Benefit.

This is a wonderful opportunity for your voice to be heard by your United States Representative and Senator.

May 17th: Workshops will provide Hill Day attendees with tips on how to present information to state representatives. An expert from the field will also be present for the latest on FASD.

May 18th: Attendees will spend the day on Capitol Hill letting their voices be heard. After a successful day on the hill, NOFAS will host their annual NOFAS Leadership Awards Benefit at The National Guard Association, Hall of States at One Massachusetts Ave., NW.

The 2005 NOFAS Leadership Awards Benefit will be hosted by The Honorable Tom and Linda Daschle.

A STORY OF RECOVERY

Twenty five years ago, I was hospitalized and in a coma, with cirrhosis of the liver. We even had the "death bed" scene, and I can remember the nurses saying, "I hope her husband gets here quickly, she is dying so fast!" I also remember thinking, "I'm not dying, and I'm getting better!" I did get better, slowly, and after being prevented from getting any treatment for alcoholism, a year later I drank again when my husband said, "I want a divorce. You are no fun because you can't drink anymore!" After a week of drinking, I made it into inpatient treatment, and have been sober since. My recovery program has included a twelve-step program that has helped me start and sustain a whole new life.

While I was drinking, I was a Girl Scout executive. My husband was a special agent for federal law enforcement agencies. We looked like a wonderful family, so wonderful we were approved to adopt a 7 year old boy. We adopted Jimmy when I was already in late stages of alcoholism, and my husband not far behind. When I was pregnant with my oldest daughter, Stefin, there was concern that I might miscarry. At that time (1970) women who were having this problem were prescribed alcohol to relax the uterus. My physician suggested I have a cocktail each evening to relax. As you can imagine, the amount of alcohol I consumed each evening amounted to more than one cocktail. I did the same thing when I was pregnant with my daughter Sidney, born in 1975. Stefin weighed 3 lbs. 14 ounces at birth, almost full term. They could never figure out why she was so small. Sidney was very premature, and weighed 2 lbs. 8 oz. at birth.

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While I was in treatment for alcoholism, my husband served me with divorce papers and began the process to get custody of our children. I was devastated. Not only did I need to work through the guilt and shame of being an alcoholic, I was labeled a “bad mother”. After six months, he decided he didn’t want custody of our youngest, (then 2 years old), because she was too “active”, so he and his new wife returned her to me. He took the older two children to Guam to his next duty station and I did not see them for 2 years. My older daughter joined me when she was 13 years old, my son when he was finished with high school. I am so grateful for these three wonderful children, now ages 35, 34 and 29.

I learned about FAS in 1982 when I was taking classes to become a drug and alcoholism counselor. I thought, “Not my kids, they look normal”. But, a heavy weight deposited itself in my stomach and whenever the girls had troubles at school or elsewhere, the weight got heavier. When Sidney was 14 years old, her teacher suggested she be tested for learning disabilities. Because the schools would not test her, (she was not two years behind), I called the research program at the University of Washington. I thought because I was drinking while I was pregnant, she might qualify to be part of their research studies and get tested. Part of the procedure included being examined by a doctor. I cannot describe how I felt when he told me she had FAS. The labels guilt, shame, and “bad mom” decked me. I promptly went into denial and didn’t believe she really had FAS. I slowly began to learn how to parent her as if she did. After I had

healed enough to face the diagnosis of FAS without falling apart, I let go of the denial and became an advocate for moms and children impacted by FASD, telling my story whenever.

Sidney is now 29 years old, and although there were some difficult times, especially during adolescence, she is now happily married to a wonderful young man who is in the U.S. Navy. She is also in recovery for addiction. We didn’t understand that Stefin had FASD until she was in her early 20’s. She was misdiagnosed as bipolar during high school, along with other labels, none of which reflected her organic brain injury. When we discovered the real damage, I was then able to begin parenting her appropriately. It is never too late to make changes. She is now a single mom, raising a 10 year old son on her own. She is struggling financially, but making it.

By being willing to stand up and say, “I am an alcoholic, and I drank while I was pregnant...” telling my daughters’ and my story to whoever would listen, I continue healing my grief, shame and guilt. My daughters tell their stories too, and they tell me it helps them be good advocates for themselves. We all want to reach as many women as possible to help them make the decision not to drink while pregnant. And, if they have an addiction and could not stop drinking during a pregnancy we want to help them deal with the stigmas and pain and to go on to be the best person and mom they can be.

Marceil Ten Eyck

MAKING PROGRESS: A GLANCE AT 2004 WORLDWIDE

Hope for Women in Recovery Summit in Phoenix is a Huge Success!



Last June NOFAS and the FASD Center for Excellence held their second *Hope for Women in Recovery Summit* in Arizona. There were over nine American Indian tribes that participated in the *Summit*. Attendee’s included Tribal Leaders, addiction treatment providers, community leaders and policy makers, and women in treatment.

The primary goal of the *Summit* was to reach women who are at the highest risk for exposing their unborn children to alcohol and to reach the state policy makers who serve them. The *Summit* educated attendees on fetal development and the affects of fetal alcohol exposure and provided strategies for women who may have discovered that they already have a child with pre-natal alcohol exposure. There was also a panel of birth mothers in recovery and living with their children with Fetal Alcohol Spectrum Disorder (FASD) to educate and provide support to women currently in recovery.

Congratulations CALFAS

CALFAS, the California affiliate of NOFAS had a huge success this past October with the "On the FAS Track to Understanding" conference. Around 200 attendees participated from all across the country and Canada, gathering many professionals from the FASD arena along with public school educators from southern California. We are very proud of CALFAS for continuing to make such huge strides for the FASD community.

NOFAS is Growing!

Four new affiliates have joined the NOFAS Affiliation Program. Washington state, headed up by COH founder, Julie Gelo. FASCETS, founded by COH founder, Diane Malbin, has become our Oregon affiliate. Deb Evensen-Hill, a long time FASD educator and advocate, along with her husband, Wes Hill, will be heading up NOFAS Alaska. And Ann Cady from Connecticut is leading the NOFAS affiliate in Connecticut. These new affiliates join Minnesota, South Dakota, California, and NOFAS United Kingdom. This round of new affiliates is just the beginning, and NOFAS will continue to grow its Affiliate Program throughout the country in years to come. Contact NOFAS to learn more information about starting an affiliate in your state.

Thanks Everyone!



MAKING STRIDES WORLDWIDE

Awesome Work NOFAS – UK!

Susan Fleisher, founder of NOFAS-UK accomplished a great deed! She educated Lord Mitchell of the House of the Lords on FASD and the devastation it brings to individuals and their families. In May 2004, he addressed the House and explained FASD and why it is a medical issue that needs immediate attention. He suggested that warning labels need to be printed on alcoholic beverages. He also stated that the Ministry of Health knows the risk, but is doing nothing just like the tobacco companies did in the 1950's. For the full text of Lord Mitchell's speech go to <http://www.nofas.org/resource/nofasuk.aspx>

NOFAS - UK Releases New Videos

A Child for Life:

NOFAS UK recently completed two excellent 22 minute educational films on FASD. One was created to target young people about the dangers of alcohol use during pregnancy, and will be shown to over 5000 students in the UK. The second film was designed for communities and allied health professionals. Several birth families who deal with the effects of FASD on a daily basis are highlighted allowing the viewer to have a better understanding of the astonishing lifelong affects that FASD can bring. This is a great film and is very useful for training materials.

If you are interested in purchasing this film call NOFAS.

Price: \$35 each; bulk orders and prices can be arranged. Be sure to specify youth or community. To order contact Julio Varillas at 1-800-66-NOFAS, varillas@nofas.org , or go to www.nofas.org.

Wonderful JOB SUSAN!

SAMHSA Releases New Video

Recovering Hope -- Mothers Speak Out About Fetal Alcohol Spectrum Disorders: A one hour of inspiration and information created for women in treatment. All of the founders of the COH participated in the creation of this wonderful film. Marceil Ten Eyck, Julie Gelo, and Kathy Mitchell's stories are all featured in the video, along with many other compelling families who share their experiences of living with the lifelong effects of FASD. The video is narrated by Dr. Ann Streissguth.

Copies are available for pre-order at http://store.health.org/catalog/SC_Itemlist.aspx?ID=qf.ordr%20 through the National Clearinghouse for Alcohol and Drug Information.

What's Ahead...

February 24-26, 2005

Victoria, British Columbia

Victoria Conference Center

Fetal Alcohol Spectrum Disorder Equality of Access: Rights and the Right Thing To Do

For registration information go to:

www.interprofessional.ubc.ca

April 13th, 2005

Chapel Hill, North Carolina

The William & Ida Friday Center for Continuing Education

"Working with Substance Using Pregnant Women and Mothers – the Why's and the How's"

For registration information contact **Lisa Bennett at (919) 966-9803.**

April 20th and 21st, 2005

Sponsored by *Mohawk Valley Perinatal Network and Family Ties Network*

April 20th – Utica, NY – Radisson

For more information regarding the Utica location contact **Diana Haldenwang at (315) 732-4657.**

April 21st – Liverpool, NY – LeMoyné Manor Inn

For information regarding the Liverpool location contact **Kathleen Hayden at (315) 424-0009.**

May 13th and 14th, 2005

Lexington, Kentucky

Lexington Convention Center

"FASD Forward: Innovative Approaches to Fetal Alcohol Spectrum Disorders in our Families and Communities"

Conference brochure and registration forms can be obtained by phoning **Kelly at (859) 225-3296** or e-mailing her at kmoore@bluegrass.org

A D V O C A C Y

Go to the NOFAS Advocacy Site and Help Reintroduce Vital Legislation!

Please use our Capwiz monitored Advocacy Site to help reintroduce *The Advancing FASD Research, Prevention and Support Bill*. This bill is the most important legislation on FASD to come before Congress in the past five years. It is a comprehensive bill including FASD prevention, identification, treatment and care that has been vetted by major FASD advocacy organizations as well as relevant federal agencies. It identifies specific roles for various federal agencies such as the NIAAA, NIMH, NCBDDD, CDC and SAMHSA, as well as the Departments of Education and Justice that have never focused on FASD in the past. This bill will be of special interest to individuals and local organizations because one of the focus areas of the bill is promoting community partnerships.

The link to our advocacy page is <http://capwiz.com/nofas/home/>. It is user friendly and has simple directions for you to use your zip code to locate your representatives. Using Capwiz to write to your Senators and Congress Representatives would help us track the exact number of offices that would have been contacted.



The National Organization on Fetal Alcohol Syndrome (NOFAS) is a nonprofit organization dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and improving the quality of life for individuals and families living with Fetal Alcohol Spectrum Disorders.

NOFAS and the **Circle of Hope** are bringing families together to help prevent and treat fetal alcohol spectrum disorders. For more information, contact **NOFAS** at 1-800-66NOFAS ♦ (202) 785-4585 ♦ Fax (202) 466-6456 ♦ Email COH@nofas.org ♦ 900 17th Street, NW, Suite 910, Washington, DC 20006 ♦ www.nofas.org

We would like to hear from you. Submit your story or article that addresses birth issues. Submit any FASD or addiction happenings in your area to be included in the COH calendar to Kelly Raiser at raiser@nofas.org. Or you can write to us at NOFAS, 900 17th St., NW, Suite 910, Washington, DC 20006, Attn. Kelly.

**THE CIRCLE OF HOPE IS BROUGHT TO YOU BY
A GROWING GROUP OF DEDICATED WOMEN
AND THE NATIONAL ORGANIZATION ON
FETAL ALCOHOL SYNDROME**