



The FEN Pen



Volume 8 Issue 1

Family Empowerment Network

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Michael Fleming, MD, MPH

On behalf of the Department of Family Medicine, I would like to welcome the Family Empowerment Network into the University of Wisconsin Medical School!

We expect to develop a number of programs and initiatives to expand and further support the mission of FEN. We will continue to serve families by providing information, referrals, training, and support. In addition, we hope to develop a research initiative in order to learn more about how to help families with children who were prenatally exposed to alcohol.

I have had an ongoing interest in the prevention of FAS and all adverse effects of prenatal alcohol exposure. In one of the largest trials conducted, I demonstrated that brief physician counseling reduces alcohol use in women of childbearing age. A new ongoing study, *The Healthy Moms Project*, is testing the efficacy of brief clinician counseling with postpartum women to reduce the adverse health effects of alcohol use—including preventing alcohol exposure in future pregnancies.

Here at FEN, we are working to continue and build on these research efforts, and combine them with Dr. Wilton's research focused on resilience in families raising children with FAS or other alcohol-related effects. We will work to identify a cohort of children with alcohol exposure to increase our

understanding of how alcohol consumption affects not only families, but entire family systems.

With that goal in mind, it is my pleasure to welcome FEN aboard. I look forward to a long and productive collaboration.

Dr. Fleming is the Principal Investigator of the Family Empowerment Network (FEN).

A Note From the Director...



Georgiana Wilton, PhD

The field of FAS seems to be in a transition period...changing from a strict focus on diagnosis and understanding the mechanisms of how alcohol affects the human body to include a focus on families. How families function when raising a child with FAS or any of the conditions associated with prenatal alcohol exposure has been an interest of mine since FEN's inception.

At the federal level, the CDC's FAS Task Force has been traveling the country hosting Town Hall meetings to hear from families. FEN had the privilege of hosting the meeting that took place in Chicago in August 2002.

In this issue we'll share testimony from families. What follows is my testimony and my reflections on working with FEN as we celebrated our 10th anniversary in 2002.

I've had the privilege of talking to families via our advocacy line, conferences and retreats about their son or daughter, grandchild, sibling, parent, or extended family member who was affected by prenatal alcohol exposure for over 10 years. Instead of telling you what I want in terms of services, advocacy, etc. I want to tell you what I don't want.

I don't want to take another phone call where a mother tells me that at her first prenatal visit-very excited to be pregnant after years of infertility-she confessed to her physician that she had several glasses of champagne at her sister's wedding several weeks before. Her physician informed her the "it was too late...the damage was already done...her child would have Fetal Alcohol Syndrome!" She decided to have an abortion after reading all about FAS, and was calling me to ask if her past alcohol use (at her sister's wedding) could also affect future pregnancies.

I don't want to be told by another psychiatrist to reassure the mother whose child has FAS and had begun systematically killing family pets that "experimentation with death is normal for an 8 year old, and his mother should just relax."

I don't want to sit through another criminal trial where a judge says, "FAS is

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just an excuse for bad parenting. This time I'm going to throw the book at him."

I don't want to be told by one more lawyer that since FAS can not be cured, "these people" should not be given leniency".

I don't want to experience the desperation of an adoptive parent-one who had tried unsuccessfully to get information and services in her county-that she was planning on buying a one-way ticket back to his native country and putting her child on the plane.

I don't want another birth parent to face the stigma that currently exists surrounding FAS. Being a woman who is an alcoholic in our society carries with it a "shame, or dishonor" that is neither warranted nor productive. We don't view a women with epilepsy who gives birth to a child with Fetal Hydantoin Syndrome in the same way. I have worked with many birth parents who are in recovery, and maintaining healthy homes for their families - and whose children, both with and without FAS, are thriving.

I don't want any family raising a child with FAS to have their child needlessly taken away from them for "failure to thrive" because they aren't growing quickly enough according to "standardized scales".

These are just a sampling of the struggles we have become involved with over the past 10 years.

I don't want the level of misinformation that exists surrounding FAS in most fields (including health care, social service, education, criminal justice just to name a few). I don't want physicians entering practice having never heard about FAS.

So, what do I want?

I want increased education for all professions by people who have accurate, up-to-date information about FAS - and what raising a child can really mean. I want parents voices heard - and not dismissed. I want the so-called "experts" to put their trust in families and actively listen and learn. I want more family research - and

more answers to the questions families have - in addition to the questions scientists have.

My challenge to the FAS Task Force is simple: to put families on the top of your agenda - and to keep them there.

Patricia Cameron....

FAS Training Coordinator



It has been a long time since our last issue was printed and a lot has happened. FEN was given new life with a grant from the Wisconsin Bureau of Substance Abuse Services and a new home at the University of Wisconsin, Department of Family Medicine. Dr. Michael Fleming will be guiding FEN in its new course. Georgiana will continue to be the director of FEN, but her recently awarded PhD will give her the liberty to conduct the research related to FAS/E that she has been waiting to develop since her association with FEN and with the families who have contacted us through the years. I will be coordinating a program called the Treatment Outreach Project (TOP) in Wisconsin.

One of the goals we will concentrate on this year is to develop more FAS Family Support Groups.

Through the TOP project we will be conducting FAS presentations to women in treatment or recovery at various sites around the state, impressing upon them the importance of early identification of alcohol exposed children.

At these trainings, we will offer the services of two geneticists from the

Waisman Center at the University of Wisconsin (one of 14 Developmental Disabilities Centers nationwide) to assess children who were exposed to alcohol during gestation. FEN will then offer follow-up services for those who were identified as FAS/FAE.

We have high expectations for this project and look forward to the associations we will make around the state with those who want to give FAS/E the attention it deserves. FEN continues to get calls from professionals and parents raising children with FAS/E requesting information through our 800 line (the number has not changed) and also requests to speak to professionals and parent groups.

One of the goals we will concentrate on this year is to develop more FAS Family Support Groups. As we get calls from parents around the country who need to connect with others who are experiencing the same challenges of raising children with FAS/E, we hope to put those names in a data base and organize FEN's very own parent support network. There is much work to be done but I think we are off to a good start. Thank you again for being patient with us during this transition. Our new home at Family Medicine is a place where FEN will blossom to serve more families with a growing body of expertise developed through research.

FASD = Fetal Alcohol Spectrum Disorder. A term used to describe the full range of effects associated with fetal alcohol exposure. It replaces FAS, FAE, ARND, and ARBD.

FASD refers to a range of birth defects, which can include:

- Distinctive facial features
- Growth deficits
- Brain damage
- Physical problems, such as heart, lung, and kidney defects
- People with FASD often have behavior and learning problems and may lack social skills

Below are two parent testimonies submitted as part of the report to congress from the FAS Town Hall Meeting in Chicago on August 2, 2002

Parent Testimony I

Bobbi Cain Hershey Freeport, Illinois

As a parent of two sons with FASD, I would love to be part of today's Town Hall Meeting on the subject of Fetal Alcohol Spectrum Disorders. However, the fact that I am a parent of children with FASD is precisely why I am unable to attend this worthwhile meeting.

Why can't I attend? Because finding a responsible baby-sitter who can handle the demands and frustrations of two boys whose need an external brain to think for them, watch out for them, protect them and constantly chase after them has been virtually impossible. In addition to being responsible, a sitter would have to be medically trained to deal with the asthma attacks and chronic health problems that have been a daily part of our lives for nine years. Of course, a sitter needs a driver's license to transport the children to the Emergency Room if necessary, as we have made that trip before and need to be prepared for it to happen again. Family members are unable to meet the demands of our children, and friends choose not to. As a parent of FASD children, we are heavily invested in our children. We have learned that we have to be—they need a committed and dedicated caregiver to make sense out of a chaotic and frustrating world of FASD and as a mother, I am that person. And I am tied down to my role as their caregiver and external brain—and I am tired. I need respite care but there is no agency in our town of 28,000 people to provide it. And, there is no money to pay for a professional who may come along. That is just one of



the issues we face as parents of children with FASD.

A second issue that needs to be addressed is the total lack of interest and knowledge of caseworkers with the Illinois Department of Children and Family Services (DCFS). Both my boys came to us through the foster care system. As foster parents for 15 years, the DCFS Office claims they have never had a child with FASD except for the two we adopted. Obviously, that is not accurate, but no one person in DCFS has been trained to learn what FASD is or tried to learn the needs of FASD children. If I told them my sons had a diagnosis of autism or ADHD, DCFS would have at least heard of the "problem", although they probably would not provide services to help accommodate those diagnoses either. As it is, DCFS continues to place FASD children into foster families who are clueless about FASD and the children go undiagnosed for years—bouncing in and out of foster homes their entire childhood. I sought diagnosis and intervention immediately for our boys, but instead of being praised, I was considered "a thorn in my side" by caseworkers who thought I was looking for problems.

Cooperation and support from DCFS would have made our FASD path much more productive and more bearable in trying to help our sons when they first were placed with us. Fortunately, we were assertive enough to take this journey without DCFS. Foster parents who do not have the energy, resources or assertiveness to carry on, let go of their foster children and put them back into the broken system. FASD within DCFS is not identified, supported or believed in northern Illinois. It's time that DCFS be mandated to be trained in FASD and related support services are arranged for foster parents to tap into.

The FAS Townhall Meeting Chicago, Illinois, August 2, 2002

On August 2, 2002 FEN members headed for Chicago by bus to participate in one of 12 FAS Town Hall Meetings in the country. A panel of experts established by three Federal agencies, The FAS Center for Excellence, Center for Substance Abuse Prevention (CSAP) and Substance Abuse Mental Health Services Administration (SAMHSA) listened to over 50 testimonies prepared by family members and professionals who work with children and adults who have Fetal Alcohol Syndrome/Effects. These testimonies will be summarized and included in a report to Congress who will then recommend a national strategy to address Fetal Alcohol Syndrome. A national strategy is long over due. By establishing a common foundation, we can all work toward a cooperative goal of improving the outcomes of those affected by giving them the structure and tools they need to live productive, fulfilling lives. Included in this issue are two testimonies submitted to the committee by FEN members; one from a mother raising two young sons and the other from a mother of a grown son. Both speak of the frustration of encountering professionals who lack knowledge about FAS and policies that impede the process of getting them the services they need. We have high hopes that the committee will address these concerns and make recommendations and policies that will be a guiding light for those of us who live, love and work with those who have FAS/E.



Georgiana Wilton is shown displaying the FEN 10th Anniversary cake along with Patricia Cameron, parents and other professionals who came to Chicago to testify at the FAS Town Hall Meeting.



From right: Ken Hobbs, Director of ARC in Wisconsin, Nancy Kathmann, hearing specialist and parents, Nanette and Chris Scudder, parents from Sturgeon Bay, Wisconsin enjoy visiting during the FEN 10th Anniversary Luncheon.

Families from Wisconsin and Illinois visit and share stories of their children during the FEN 10th Anniversary Luncheon held before the FAS Town Hall Meeting in Chicago on August 2nd.



A sample of the professionals and parents who testified at the Town Hall Meeting.

I would not trade my sons for anything in this world. But I would not ask for this journey. Two issues I leave with you tonight: First, help in finding capable respite help, along with the funding to pay these people necessary for parents of FASD children. Second, training for DCFS workers would be an incredible step in the right direction to diagnosis and intervention for FASD children and their families.



Parent Testimony II



Doris Newmeyer Chilton, Wisconsin

My name is Doris, and I adopted my son, Tony, from Mexico when he was 9 years old, 18 years ago. I was told little of his past, but I learned later that his mother would leave him with people to care for him, and seldom returned for him. Soon he was living on the streets or, if he was fortunate enough, living with just anybody. As a result, he was sometimes abused, and he would return to the streets. At 9, he had never gone to school.

I could tell that Tony had something wrong during those first few weeks here. Tony's memory was very short; he had temper tantrums such as a 2 year old would have, banging his head on the living room carpet. He often could not follow the rules even when explained in Spanish by our local doctor and the Spanish teacher. A Spanish student baby sitter took care of him until I came home from work, sometimes finding Tony hiding in a tree. We acquired a support family who had a son Tony's age, and who tried to help Tony fit in



with children his age. I thought his problems were because of the language barrier, but his Spanish was limited and he could not read in Spanish. It took Tony 3 years to learn minimal English.

The teachers here in the U.S. decided to put him in 3rd grade. The Spanish high school teacher and her students worked with him for several weeks. His first teachers were very giving, but within a year he was placed in a Learning Disabilities Program. Later he was made to skip 6th grade and was placed in an older children' LD program, with some already on alcohol and drugs. Things just fell apart.

I took Tony to many doctors. A psychiatrist and psychologist team recommended to help Tony get rid of his negative past. Lithium and Nortriptyline did not help. When he was 13, and in a drug and alcohol program, the doctors diagnosed Tony with Fetal Alcohol Effects, a disease I had never heard of, and because they didn't know Tony's biological mother, they would not put the diagnosis on paper. He still had some of the features of FAS children have when young. I was told there was no help, and that Tony would have the disease forever.

Tony has struggled in and out of drug and alcohol programs, and jail and prison for taking things, always returning them when caught. In December 2000, through the help of

the Family Empowerment Network and Georgiana Wilton, Tony was allowed to see Dr. Wargowski at the University of Wisconsin in Madison. With the help of Tony's background and photos when he was young, Dr. Wargowski gave Tony the diagnosis of Fetal Alcohol Syndrome on paper. We were told there was help now, but medicine would have to wait until Tony got out of jail or prison. We owe so much to the Family Empowerment Network, Dr. Wilton and Dr. Wargowski who have been such support.

1. I would like to stress that all children, who are adopted, should be checked for FAS. Perhaps this is in place with domestic adoptions, but what about foreign adoptions? The earlier one finds out about the disease, the quicker one can get help.

2. For those with FAS, there should be special learning disability classes where teachers can adjust what is expected of them so that students do not lose their self esteem and hope of getting through the course. In the Emotionally Disturbed Program Tony was placed in, in high school, the classes met in the same building with regular high school students. At time when I picked him up from school, I could hear him and others from his class addressed as "stupid" and other similar names by regular students. Could classes be held in a vocational tech school, where most students are more mature? Tony said

he would like to have someone who has FAS and who has learned to attain goals successfully, to act as a role model to him, showing positive help instead of all the negative feedback he encountered.

3. These Town Hall Meetings are important. As I recall, meetings such as this one, helped some of the western states to pass laws making FAS acknowledged by judges, lawyers and psychiatrists so that just sentences can be given to those suffering from FAS. Can states in the Midwest also seek such laws for those with FAS?

4. I am tired of hearing that FAS is an “excuse” for Tony’s behavior and impulsivity, and not the reason. With Dr. Wilton’s suggestion for his sentencing last year, Tony was succeeding this time in Huber. However, not all the necessary suggestions were followed, such as rides to and from work, attending AA meetings and getting AODA counseling. Now Tony is in prison for 2 years for picking up 1.2 grams of marijuana on his way to work.

I love my son, and now he needs help to keep him away from alcohol and drugs and out of prison. It is not his fault that he has such to struggle with FAS.

FAS students should be able to attend elementary and high school classes specialized for them as well as summer camps where they can interact with those with the same problems. Effective medications that are strictly monitored should be administered. Teachers and county health care counselors should be required to take a course on FAS and how to help those with it and their families. In my county, counselors told me they only read several paragraphs on FAS, and had not heard of Michael Dorris’ book. “The Broken Cord”. How can they be effective counselors to those with FAS and their families? Professionals in the courtroom should also be schooled in the limitations those with FAS have, and sentence them accordingly.

Please, what can we do to help those with FAS to become productive citizens?



Did you know.....

- Alcohol causes more damage to the fetus than any other substance.
- Caring for someone with FASD can cost as much as \$5,000.
- FASD occurs in about 12 per 1,000 births
- 40,000 babies are born each year with FASD

FASD Fact Sheet
SAMHSA, DHHS



Check it out!!

This story is posted on Theresa Kellerman's website: www.FASSTAR.com
It is a treasure chest of user friendly information and resources on FASD.



The Plant Lady

A true story, simple in its telling, profound in its lesson —by “Mary”

Sometimes God works in funny ways. I was feeling worried about my FAS daughter and went into a greenhouse to buy myself a plant (healthier than eating chocolates). The MANAGER, a nice chatty lady, helped me choose a plant and I asked her how one got a job in a greenhouse. (Did you have to attend college? How did you learn all about plants?) She told me that she had learning difficulties because her mom was an alcoholic, had left her in bars continually as a young child and had died of alcoholism. (At this point I realized she had FAS facial features and was very short.) Through perservation she found a job where she could work outside, so she could talk a lot to herself, and not have to spell or do mathematics. She stated she learned the plants’ requirements like she was learning gossip about them....not through boring memorization. Her plants also like the fact that she talks a lot. She tells the owner how many plants they sell each week and he helps her order more. She said she learned to drive at an older age and was married. She appeared to be around 30, and seemed to be quite happy.

Now every time I tend to my special plant, I think of the Plant Lady, and I am reminded that maybe there is hope that maybe my daughter will also someday find a place to bloom.

UPCOMING CONFERENCES

The 1st International Conference on Family-Centered Care: Advancing the Quality of Health Care in the 21st Century

Dates: September 4-6, 2003

Location: Sheraton Boston Hotel

Boston, Massachusetts

Contact: Institute for Family-Centered Care,

7900 Wisconsin Ave., Suite 405,

Bethesda, Maryland, 20814,

www.familycenteredcare.org;

301-652-0281

Truth & Consequences of Fetal Alcohol Syndrome

Dates: October 27-28, 2003

Location: Atlantic City Convention Center

Atlantic City, NJ

For additional information contact:

jbing@arcnj.org or

hilda.mitchell@dhs.stat.nj.us

Brochures will be available on-line after May 1 at:

<http://www.arcnj.org> and

<http://www.state.nj.us/humanservices/OPMRDD/ofp.html>

Several on-line courses on topics related to FASD area available through the University of Wisconsin Medical School' Continuing Medical Education program. If you are not a medical professional needing CME credits, the courses are free.

Simply log on to: <http://cme.uwisc.org>. Then click on "Substance Abuse: Tobacco, Alcohol, Drugs". There are several options that might be of interest to you.

Fetal Alcohol/Women

Fetal Alcohol/Children's Treatment

Attention Deficit/ Hyperactivity Disorder

Depression in Primary Care Treatment

Post-Traumatic Stress Disorder

If you have questions, please call (608) 263-2850

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We are now on the Web...check us out at
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