



The FEN Pen



Volume 9 Issue 1

Family Empowerment Network

Winter 2004

A Note From the Director...



Georgiana Wilton, PhD



It has been over a year since we've moved into our new home at the University of Wisconsin's Department of Family Medicine. In that time we have experienced tremendous growth...not just in our funding, but in the types and quality of programming that we are able to conduct.

Patti's column will share information on our new grant for the *Treatment Outreach Project* and our new initiatives. For my part, I am pleased to announce the opening of the Fetal Alcohol Spectrum Disorders Clinic at the University of Wisconsin's Waisman Center.

This clinic is a cooperative effort between the University of Wisconsin Medical School's Department of Family Medicine, Wisconsin's Clinical Genetics Program, UW Waisman Center, and UW Children's Hospital. It is designed as a research, training, and service clinic and is staffed by a dedicated team of clinicians. We are currently seeing patients one day per month, and offer a multi-disciplinary clinic that not only includes a physical exam to

diagnose FAS, but assessments in the following areas: psychology, occupational therapy, speech/language, audiology, nutrition, and family support.

The clinic day is intensive to be sure, lasting anywhere between 4 and 7 hours, but hopefully provides a family with answers to questions, resources and recommendations for follow-up, and long-term support through FEN.

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Treatment Outreach Project Coordinator.....Patricia Cameron



We finally had our first real snowfall of the year. The crystal white snow and cold days invigorate me and I find myself reflecting back on the previous 12 months, on what we accomplished in our efforts to create a better understanding of FAS in our corner of the world and to assist and empower families who found themselves in the midst of turmoil and didn't know where to turn but managed to contact us through referrals from the TOP project, our 800 number, website and email.

The starting the new FAS Clinic at the UW's Waisman Center with a team of committed clinicians has given me hope that FEN is not

alone in its efforts to improve the understanding of what it means to have FAS.

I can't help but also include the Treatment Outreach Project (TOP) in this reflection as it completed its first year on September 30th. We had an ambitious agenda for the first year of TOP and it kept the FEN staff hopping. We learned, listened, created and adapted the program as we went along to better serve families who are raising children with prenatal alcohol exposure in Wisconsin.

Ten FAS presentations were conducted for clients and staff at women's treatment centers around the state with the intent of identifying children and adults who would benefit from an FASD assessment offered at their center. The questions asked by participants and their evaluations of the presentations indicated their willingness to learn about FASD and an acceptance of the potential effects of their alcohol consumption on their children. Treatment center staff were attentive to the emotional needs of

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The articles, responses and opinions in the FEN Pen are for general information and resource only. They are not intended to provide specific advice or recommendations, but rather opinions and information for general situations. The opinions expressed here do not necessarily represent those of FEN staff, its advisors, or the University of Wisconsin - Madison, Department of Family Medicine

See a listing of Wisconsin FAS contacts who were trained at the FAS Training of Trainers last June. on page 8.

If you are interested in becoming a local FASD contact person/trainer, contact the FEN office either by email or phone.

FEN Training of Trainers

Minocqua Wisconsin



The 2003 FAS Training of Trainers participants



Many of the participants were women's treatment providers who will use this information to educate women in treatment, showing their commitment to raising awareness of FASD and preventing prenatal alcohol exposure among women at risk.

The FAS Training of Trainers was held at The Waters of Minocqua in June. Eighteen professionals from around the state attended the 4 day training, committing to serve as FASD liaisons in their communities. Georgiana Wilton, PhD, is shown at left presenting at one of the training workshops.



FASD Listserves

New services for FEN Families:

FEN now supports two listservs for families raising children with FASD. One listserv is offered to the families who attended the FEN Retreat last August and the other is for the families who participated in FASTeN, FEN's new family telephone support network. We believe that communicating through email is a valuable tool for parents to stay connected with other parents who share the same concerns about their children in between the FEN sponsored family programs. The next FASTeN support group is scheduled for April 22nd. If you are interested in being a part of FASTeN, please see the form included in this month's FEN Pen.

FASTeN

Fetal Alcohol Syndrome Telephone Network



The Family Empowerment Network (FEN) is sponsoring a telephone support network for families affected by Fetal Alcohol Spectrum Disorders (FASD). Four times each year, you may dial in from anywhere in the U.S. (using a toll-free number) to share ideas, receive (and give) support, or just hear that you are not alone!

DATES:

January 20, 2004

April 22, 2004

July 21, 2004

TIME: 7:00 - 8:00 p.m. Central Time

Participation is limited to 16 callers for each meeting. *You must pre-register to receive the Wisline number and access code.* For more information, please contact:

Family Empowerment Network
1-800-462-5254
(608) 262-6590
fen@fammed.wisc.edu

**Toll-Free Number—in the US
No Cost to Families**

*University of Wisconsin Medical School
Continuing Medical Education
announces*

Online CME Courses

Several on-line courses on FASD and related topics are available for free to service professionals through the University of Wisconsin Medical School Continuing Medical Education program. Log on to: <http://cme.uwisc.org>. Then click on "Substance Abuse: Tobacco, Alcohol, Drugs". Please call (608) 263-2850 for more information.

Upcoming Programs/Conferences:

Treatment Outreach Project 2004 (TOP)
FASD trainings and FAS outreach clinics offered at the following locations in Wisconsin:
Madison, Milwaukee, Green Bay, Eau Claire and Rhinelander
Contact: 1-800-462-5254

March 25-27, 2004
Adults with FASD: Swimming Upstream, A Reality Check
Coast Plaza Hotel and Suites at Stanley Park
Vancouver, BC
Contact: 1-800-663-1144

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Georgiana Wilton.....

I think the clinic offers some unique features: a nutrition assessment, and long-term follow-up. As we all know, nutritional concerns are common in individuals with FASD. Concerns include failure to thrive, food sensitivities (e.g., textures, taste), food allergies, and quantity regulation. By including this component as part of a multidisciplinary assessment, dietitians can collaborate with the other clinicians to determine what—if any—difficulties exist (e.g., structural issues, physiological issues, taste/texture issues) and suggest alternate strategies.

One final feature is the family support component. Because FEN staff members are an integral part of the clinic, we develop a *Family Services Plan* specific to the needs and desires of the family. This follow-up plan outlines the type of assistance FEN will provide and can range from consultation with schools for IEP development to participation in one of FEN's listserves for family support.

While we recognize that no clinic can offer everything to everybody, we strive to meet the needs of families—even if for some issues that means tracking down the most appropriate referral.

We hope, with additional funding, to build the clinic to include more staff and more clinic days. Until then, we will continue to revise our protocol based on family and clinician feedback. For more information on the clinic, please contact FEN.



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women who chose to have themselves or their children assessed.

Two Geneticists from the University of Wisconsin's Waisman Center assessed thirty-nine children and adults at the outreach clinics, with several receiving a diagnosis of FAS, partial FAS or ARND. FEN developed a multi-disciplined services plan for each family receiving a diagnosis, incorporating formal and informal supports to ensure the well being of the child and family.

Along with the FASD presentations and outreach clinics, TOP also conducted a one week FASD Training of Trainers. A variety of service professionals (i.e.: social workers, public health nurses, addiction counselors and educators) from all over Wisconsin convened for a weeklong intensive training on Fetal Alcohol Spectrum Disorder. These individuals have become local resources on FASD in their communities, offering trainings and information.

Consistent with its mission, FEN has also been instrumental in connecting families in Wisconsin and northern Illinois through the annual FEN Family Retreat weekend, which took place in Madison, Wisconsin last August. Just recently, we have incorporated a FEN Retreat listserv so that these families can communicate with each other as a group during the year. We hope to offer more listservs as the need arises, connecting families that are facing similar situations into the same listserv.

FASTeN (Fetal Alcohol Syndrome Telephone Network) is another family support service that

FEN is offering. Parents/caregivers can call into a teleconference facilitated by a licensed family counselor to discuss pressing issues that they face with their children. FASTeN is offered four times a year. For more details, look for the flyer in this issue.

As you can see, FEN staff have been very busy this past year with many rewarding and valuable projects, but the most exciting project is the new FASD Clinic at the University of Wisconsin's Waisman Center. FEN is very pleased to be helping with Wisconsin's first FASD multidisciplinary clinic. Read Georgiana's column for more information.

So the season of reflection has almost come to an end and we will all get back to business as usual. But before we get too wrapped up into our work of taking care of business, I hope you can all take time to reflect on the fruits of your efforts this past year. I believe this prepares us and gives us strength for what lies ahead. I look forward to the collaborations and projects that will bring us together to improve peoples' understanding of FASD in the coming year. Don't hesitate to call or email us with your good news or needs that you may have. We at FEN want to share in your celebrations and to assist and empower you to handle the challenges. Peace and goodwill to all.





Fetal Alcohol Syndrome Websites

<http://www.fammed.wisc.edu/fen>

Family Empowerment Network

<http://www.fascets.org>

**Fetal Alcohol Syndrome Consultation,
Education and Training Services, Inc.**

<http://groups.yahoo.com/group/post-adopt>

Post Adopt Online Support Group

<http://mofas.org>

Minnesota Organization for FAS

<http://www.acbr.com/fas/faslink.htm>

FASlink

<http://www.betterendings.org>

Better Endings New Beginnings

<http://come-over.to/FASCRC>

FAS Community Resource Center

www.fascenter.samhsa.gov

FAS Center for Excellence

<http://health.hss.state.ak.us/fas>

State of Alaska, Office of FAS

<http://www.nofas.org>

**National Organization on Fetal Alcohol
Syndrome**

<http://fetalalcoholsyndrome.org>

Family Resource Institute

<http://www.fetalalcohol.com/frame-home.htm>

**FAS/E Support Network of British
Columbia**

<http://depts.washington.edu/fadu>

**Fetal Alcohol and Drug Unit, University of
Washington**

<http://www.cdc.gov/ncbddd/fas>

**Centers for Disease Control and
Prevention**

<http://www.thearc.org/misc/faslist>

The Arc, FAS Resource Guide

<http://www.fasbookshelf.com>

FAS Bookshelf, Inc.

<http://www.fasworld.com/home.ihtml>

FAS World

Waisman Center FASD Clinic

A collaboration among the the University of Wisconsin Medical School's Department of Family Medicine, Wisconsin's Clinical Genetics Program, UW Waisman Center and UW Children's Hospital the Waisman Center FASD Clinic brings a new service to Wisconsin residents. This clinic is designed as a 5-hour multidisciplinary assessment of prenatal alcohol exposure of children between the ages 3-12 by a team of clinicians. It is offered one day a month. If you know of someone who would benefit from an FASD assessment, please contact FEN at 1-800-462-5254 or email: fen@fammed.wisc.edu

New Bill To Help Families

Legislation to Help Avert Custody Relinquishment Needs Cosponsors and Personal Stories

On October 2, 2003, a bipartisan group of legislators introduced a bill called the **Keeping Families Together Act** (S. 1704/H.R. 3243), to help end the practice of parents giving up legal custody of children who have serious emotional disturbances to state agencies as a way to ensure that the youngsters receive mental health services their parents cannot afford.

The widespread use of custody relinquishment to secure treatment for children with mental disorders is one of the most tragic consequences of the inadequate access to children's mental health services parents in this country face today. According to a recent report by the General Accounting Office (GAO), in 2001 alone, approximately 12,700 children in 30 counties across 19 states were placed into the child welfare and juvenile justice systems, solely as a way of providing them needed mental health services. Unfortunately, this finding grossly understates the magnitude of this problem because, as the GAO learned, many states do not collect data on such placements.

Enactment of the **Keeping Families Together Act** would help end custody relinquishment by funding state interagency systems of care to serve children more efficiently while keeping them with their families. The bill would also set up a federal interagency task force to examine mental health issues in the child welfare and juvenile justice systems, and would enable states to provide Medicaid coverage for home and community-based care for children who would otherwise be placed in residential treatment centers.

How You Can Help:

Personal Stories

The sponsors of this legislation are collecting stories from families who have been faced with and/or undergone custody relinquishment to demonstrate the need for this bill. If you or someone you know can help with this effort please forward a description of your experience with custody relinquishment to Kirsten Beronio at: kberonio@nmha.org.

Co-sponsors Needed

In addition, please contact your senators and representatives and urge them to co-sponsor **the Keeping Families Together Act** (S. 1704/H.R. 3243).

- a. Call: Call the U.S Capitol Switchboard at 202-224-3121 and ask for your senator's office telephone number.
- b. Fax: Call your senators' offices to request their fax numbers or visit their Web sites, where a fax number is usually listed.
- c. E-mail: Visit www.congress.org, enter your ZIP code, select the appropriate senator and click on the e-mail address. A message form will appear that you can fill out and e-mail to your senators' and representative's offices.

Message points

- "I am calling/writing to urge Senator/Representative ____ to co-sponsor S.1704/H.R. 3243, **the Keeping Families Together Act.**"
- "Each year, tens of thousands of parents are forced to relinquish custody of their children to the state solely to secure desperately needed mental health services. The heartbreaking choice these families face results from the widespread lack of mental health services for children across this nation."
- "**The Keeping Families Together Act** offers far less drastic ways for parents to secure needed mental health care for their children."
- "Co-sponsorship of this bill by Senator/Representative ____ would help improve access to community-based care for these children and protect them from being separated from their families."

An open letter to educators from a parent of a child with special needs.

Look Through the Windows of My World

By Pat Linkhorn

This "open letter" is, of course, not representative of all parents of children with disabilities, but I've tried to make it a fair sampling of the views I've heard expressed from other parents. I know I won't live to see Utopia and my children probably won't either; but the laws that are being passed today providing inclusion of children with handicaps into public schools give educators the opportunity to make this a generation of better people. And that's one step closer!

You can't walk a mile in my shoes, but take a short journey with me and I can show you scenes from my life. You're the person responsible for my child's education - a superintendent, a principal, a teacher, a guidance counselor or a special education director. The object of this is not to make you feel sorry for me. It's to try to help you understand me and my child. If you can understand something about the places I've been, you may be able to understand where I'm coming from today.

The first window shows me after I've learned to accept my child for who he is. I've learned to take all the backward glances and tasteless remarks in stride. I've seen ignorance from some people I used to think were intelligent and I've met some really wonderful people who I never would have known, had my child been normal. I've had to learn how to make people understand that my child is a child first and handicapped second.

I've seen miracles too. I've seen the first step the doctors said would never happen and I've seen the light of recognition in my child's eyes when he finally grasped the "meaning of something". And I've seen sunsets you wouldn't believe once I had to really look at them and explain them to my blind child. What may seem ordinary to you has taken on a whole new significance for me.

I've learned a whole new language too. It's called "medicalese". Doctors tend to speak in words you don't hear every day. At first, I thought I'd never

be able to keep all the terms and "isms" straight, but I speak it fairly fluently now. I'm beginning to learn "teacherese" now. You use a lot of abbreviations and numbers, but I know I can learn your language too.

Even though I've accepted my child, I have many fears for my child's future. I realize it's going to take a lot more effort if my child is to lead a fulfilling life. Learning is difficult for him and in some cases, impossible, but I've been trying to make his life as normal as possible. I try to focus on the abilities he has and I try to make him feel worthwhile. I realize there are some things that my child can't do yet and some he will never be able to do. Sometimes I tend to focus too much on what he can do and not what he can't do, but it helps me and my family. Some days I seem to be taking three steps backward for every one forward.

You may only see the bad things about my child. It may not seem fair to you to spend more time with him when you have a classroom full of children who learn things in standard ways. My child may disrupt your class. He may not seem to be learning much. I don't expect you to ignore other students for his sake. I don't want him forgotten in a back class room with all the other "different" kids either, although he may have to spend some time in a smaller class room with more individual attention. My goal is to make his life as normal as I can, and being around regular kids helps. It will take some understanding on both our parts to work this out. Perhaps some of your brighter students could help my child in some areas. You'll be teaching them about responsibility and they'll learn acceptance. They may view handicapped children as children first and handicapped second.

As a parent, I know I'm not perfect. I make mistakes every day. I realize teachers are only human too. I also remember the time when some of my teachers were up there with God, in my estimation. They had such an impact on my life! Your lives aren't as worry free or stress free as I used to think and my child only adds to a day that's too full and too underpaid. If you at least make the effort to try to treat my child as a person, I know how he will view you. Sit next to God for a while.

My attitude may not be the best you've seen lately. I may already have had some run ins with the "system" before I ever talk to you. I may come on too forcefully and seem too demanding. Maybe I've had to be to get services for my child. Maybe my sister-in-law has excluded my child and I from every family get together

she's had since I've had a "disabled" child. Maybe my husband isn't supportive. Or maybe the professionals I've dealt with before have done everything they could to help me. Maybe I'll assume that you will too, and I won't remember all the hard lessons I've learned along the way. Or I may remember each one too vividly. I may be a combination of all these feelings. Whatever the case, I am just a normal person who wants the best for my child.

I know that my son won't grow up to be the captain of the foot ball team and my daughter won't be a Homecoming queen, but that doesn't mean that I don't have dreams for them. I've just substituted other dreams for those I've lost. We all harbor some pretty unrealistic expectations for our children and I'm no different than any other parent.

I seem to want too much from you, I don't mean to. I have a lot on my mind. I may not have totally accepted the direction my life has taken; it sometimes takes years for a parent to get to that point of acceptance. That's really not too hard to understand when you realize that I lived with that dream for most of my life, whereas I've lived with my "reality" for a lot shorter period. I may be feeling cheated because my life seems so different from yours. There may be a lot of resentment in me. Or I could just be tired of fight-ing the battle. It may be that you have a better education and you may feel more qualified to make decisions about how and what my child will learn.

In most cases, you are the expert. But if you feel I'm realistic and I've accepted my child's limitations, there will be instances when I will know what will work best. In that case, I am the expert. I've learned some things that you should be thankful you've never had to learn.

If you take all the things you've seen through my windows into consideration, you may understand me and my child better. If we work together, maybe we can do what I pray for each night. That is to give my child as many opportunities as possible to lead a normal life, in a world that isn't fair.

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Pat Linkhorn is the Editor of Special Education at About.com and a professional advocate for families with children who have special needs. She is also an experienced parent and has two girls with special needs - autism and blindness due to prematurity.
<http://thelinkto.com/linkhome>

Wisconsin's FASD Training of Trainers 2003

The individuals below attended a comprehensive course on Fetal Alcohol Spectrum Disorder last June in Minocqua, Wisconsin and have committed to being an FAS contact person in their area. If you would like more information about FASD, please check with your local FAS contact from the list below or the Family Empowerment Network (FEN).

Eau Claire

Cindi Pope
email: cindipope@yahoo.com
(715) 456-2631 or 855-6181

Fond du Lac

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e-mail: arcfdlaoda@dotnet.com
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