



# The FEN Pen



Volume 9 Issue 2

Family Empowerment Network

Fall 2004

## A Note From the Director...



Georgiana Wilton, PhD

### What's in a name?

For 31 years now we have had clinical evidence of a condition called Fetal Alcohol Syndrome (FAS). From this diagnostic label, many other diagnostic and expressive terms have been used to describe the continuum of effects associated with prenatal alcohol exposure. Our bowl of alphabet soup has become thick with all of the acronyms: FAS, FAE (fetal alcohol effects), ARND (alcohol-related neurodevelopmental disorder), ARBD (alcohol-related birth defects), pFAS (partial FAS), PAE (prenatal alcohol exposure), PEA (prenatal exposure to alcohol), and SE-AE (static encephalopathy-alcohol exposed).

Most recently, FASD (fetal alcohol spectrum disorders) has become widely used—and in most cases incorrectly. FASD was originally used to describe the continuum of effects that can occur in a child when a mother drank alcohol during her pregnancy. Unlike Autistic Spectrum Disorders, it was not meant to be a diagnostic term.

Over the months (perhaps years) the term took on a life of its own. I began hearing, “My child has FASD” and “Will you help us develop an IEP for a student who is diagnosed with FASD.” Once I was even informed that FASD is a new diagnosis that can be made by non-medical personnel (like a school psychologist).

continued on page 4.....

## FEN Coordinator...



Patricia Cameron

With the hard work and strong commitment of our staff, the Treatment Outreach Project (TOP) and the Family Empowerment Network (FEN) have had another productive year.

These two programs delivered needed information and services in Wisconsin and across the country to individuals seeking help for family members who have been prenatally exposed to alcohol. Our associations with the Waisman Center, the state of Wisconsin's Division of Public Health and Bureau of Mental Health and Substance Abuse Services have been invaluable for our program's effectiveness and success.

This year we have concentrated our efforts in educating public health nurses and administrators about Fetal Alcohol Spectrum Disorders (FASD) to facilitate a broader understanding of the issues surrounding prenatal alcohol exposure and the services that are available to better serve their families' needs. Trainings on FASD were presented to regional prenatal care coordinators and other health providers in various locations around Wisconsin. This year an additional 138 health service providers now have a working knowledge of FASD resources for additional information and services. It is very exciting to see the network of FAS service providers in Wisconsin grow!

In June, we conducted the second annual Training of Trainers on Fetal Alcohol Spectrum Disorders in Minocqua. Eleven professionals from Wisconsin took time out of their busy schedules to participate in this intensive training and become local trainers and contact persons on FASD. We had another great group of participants that represented the diversity of services offered to families who are affected by prenatal alcohol exposure.

continued on page 4.....

### Inside This Issue:

A Note From the Director .....	1
A Summary of 2004 .....	1
FASD Training of Trainers.....	2
FASD Trainers .....	3
FASTeN .....	5
A Parent Making a Difference.....	6 & 7

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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, Department of Family Medicine

*See a listing of Wisconsin contacts who were trained at the FASD Training of Trainers on page 3.*

*If you are interested in becoming a local FASD contact person/trainer, contact the FEN office.*

## **FASD Training of Trainers**

Minocqua, Wisconsin



*The 2004 FASD Training of Trainers was held at The Waters of Minocqua in June. Eleven individuals from various professions, including AODA counselors, public health nurses, and Birth to Three service professionals attended the 4 day training.*

*On the 5th day, last year's participants joined the group to report how they used the material in their daily work for prevention and intervention of FASD. We are very proud to have such a committed group of professionals join us in our efforts to create a better awareness of FASD in Wisconsin*

## **FASD Listservs**

### ***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 a past FEN Retreat and the other is for the families who participate 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. If you are interested in being a part of FASTeN, please see the form included in this month's FEN Pen.

## Wisconsin's FASD Trainers

The individuals below completed a comprehensive course on Fetal Alcohol Spectrum Disorders over the past two years in Minocqua, Wisconsin and have committed to being an FASD contact person in their area. If you would like more information about FASD, please check with a contact from the list below or the Family Empowerment Network (FEN).



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continued from page 1,  
What's in A Name?

Needless to say I was *thrilled* when a definition of FASD was agreed upon in April 2004 by a group of experts representing the National Institute on Alcohol Abuse and Alcoholism (NIAAA) the Substance Abuse and Mental Health Services Administration (SAMHSA), the Centers for Disease Control and Prevention (CDC), and other research and service professionals. The FASD Center for Excellence ([www.fascenter.samhsa.gov](http://www.fascenter.samhsa.gov)) defined FASD to be an umbrella term used to describe the range of effects that can occur in an individual whose mother drank during pregnancy. FASD is *not* intended to represent or replace a clinical diagnosis.

Unfortunately, at the current time there is no strict consensus on what specific diagnostic terms to use. But, as we all know, the actual diagnosis isn't as important as our realization that it is accompanied by lifelong physical, cognitive, and/or behavioral challenges...

...so, what's in a name?



continued from page 1,  
Patti Cameron

These individuals will be added to the list of 17 others who participated in the training last year. We now have FASD contacts in most areas of Wisconsin who can support the programs offered through FEN and TOP at the local level. Find the complete list of contacts on page 3.

The FAS Outreach Clinics have had a strong response and have reached capacity. They are offered no charge-no hassle without getting approval from insurance companies and HMOs.

Parents and professionals call or email FEN daily with new and challenging issues. One such issue that seems to be recurring is transition planning for older students. Many parents believe that once the school has listened, evaluated, observed, and granted their child an IEP, their worries are over, but find themselves panicking when their child turns 18 and is set to graduate without a transition plan.

Schools are required by law to begin the process of developing a transition plan for all students with an IEP at the time the student turns 14 and the plan must be in place by 16 yrs. This transition plan should include vocational and life skills training. If the student has not met his/her requirements for graduation, the school is obliged to continue the student's programming through the year the student turns 21. This can include technical school training paid by the local school district.

Another big concern that parents face once their child graduates from high school is lack of appropriate housing and employment. In many cases, a supported living and working environment is necessary for young adults with FAS/ARND to find success in life. In this issue, we feature an interview with Walt Teichen, a father of a young adult son with FAE who is creatively trying to address this issue. His efforts will pave the way for others to develop supportive environments in their area where adults with FASD can live and work successfully.

FASTeN, FEN's FAS telephone network connected parents via a conference call on July 21st. Dr. Ed Riley, a psychologist doing functional brain MRI research on individuals with FAS was the guest speaker. The ease with which he talked to parents about the neurological behaviors associated with FASD made the conversation flow as if we were all sitting around a kitchen table drinking coffee, finding answers to our children's unconventional behaviors.

continued on page 5.....





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We are doing our best to educate, nurture parents and help service professionals understand the world of FASD. They in turn become strong and can nurture and educate others. Through our efforts this year, I believe we have established a working network of professionals/service providers in Wisconsin who can assist families with children prenatally exposed to alcohol. And if some days it feels like you are alone or the task at hand seems overwhelming, try to remember the words of humanitarian/anthropologist, Margaret Mead.

*“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it’s the only thing that ever does”*

*-Margaret Mead*



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## **FASTeN:**

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# **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). On selected evenings, 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! Call or email the FEN office to register.



Time: 7-8 pm Central Time

Dates: October 21, 2004  
November 18, 2004  
January 20, 2005  
February 17, 2005  
April 21, 2004  
May 19, 2005  
July 21, 2005  
August 18, 2005

### **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](mailto:fen@fammed.wisc.edu)



## **New Residential Facility in Development**

The following is an email interview with Walt Teichen, a father of an adult son with Fetal Alcohol Effects (FAE). He is developing a residential facility for adult men with in the Chicago area. Please feel free to contact Mr. Teichen with any questions (contact info below).

***Q. Why do you think this type of home is important or necessary?***

A. This type of home is important for many reasons. Most importantly is the fact that most of these men, if left unsupervised will get into trouble. Statistics and research have shown that. The real trouble does not start until after the child gets out of school and loses the structure that the school day provided. Another reason is that other programs do NOT work. A person with FAE/ARND cannot fit into a program for the Developmentally Disabled (DD), or a Mental Health program, even if they qualify for the program. Most states do not classify these men as DD. As far as I know Minnesota is the main one, and there could be a couple of others. I am only speaking about the individual who is a little higher functioning, and has all of the decision-making problems associated with FAE.



***Q. So the men who would qualify for this residence do not fit the criteria for DD or MH diagnoses in most states? Where is your son living now?***

A. If they are a little higher functioning they do not qualify for DD, as far as I know in almost every state except MN. Thankfully, Kevin does not have a Mental Health Diagnosis. Kevin is currently living in the DuPage County Jail, until we get another short term option set up.



***Q. Describe the structure of the residence.***

A. Originally it was one big dorm type building, but one of our board members has been doing research and we have not yet determined exactly what the residence is going to look like. The same would apply to the vocational training space. We might have to build a separate building for that depending on state licensing issues. There will also be a barn to raise the pigs, cattle, and chickens. In the near future we would like to have our own Chapel and Gym.

The men are going to be busy most of the day. They will have a full day; which will range from doing barn chores, to religious activities, to vocational and behavioral training. The busier they are the better.



***Q. How will you fund this project?***

A. We are hoping to have very unique funding for the program. We have received a commitment from a church that has a group called Construction for Christ. They are a group of 40 contractors who have agreed to work on the project. We have other verbal commitments from other contractors. We hope to

get many of the building products donated by the building supply companies.

The land is going to be donated by a Christian woman. And an architect has agreed to do all of the drawings for free. We have also started conversations with some local civic groups that might be willing to pay for the construction of some of the other buildings that will be needed. We do not have any commitment yet. That is the building portion.

Funding could take several different forms. If the land, labor, and most construction products are donated, that cost will be minimal. If we can get missionaries, the labor costs will be minor also. But any additional funding is going to be through grants, donations, and fund raising.



***Q. Who will be eligible?***

A. The eligibility is going to be for men initially with Fetal Alcohol Syndrome and Effects. We will be training the staff specifically for FAS/E and it is going to be quite extensive. As we know, these men have unique behavioral characteristics. We have not established any eligibility criteria yet. But the response from being on WGN TV has been greater than we anticipated



***Q. Since the funding will be coming from Christian churches/missionaries, will individuals have to be Christian to be eligible?***

A. They do not have to be, but they do need to commit to try to make a change in their life, have God become a bigger part of their life, and becoming a Christian and doing Christian studies.



***Q. How many individuals will it accommodate?***

A. Since there is only one program in the US currently for these men, we anticipate the demand for the program is going to be greater than we can accommodate. We are going to start small so that we do not make any mistakes and provide a high quality of service. We need to make sure that these men succeed. It is going to be better in the long run to take it slow and get all of the wrinkles out before there are too many men in the program. We will probably start with 3 – 4. We hope to keep expanding the program. It is going to be very difficult to determine how many men we might be able to accommodate in the future. There are too many factors to take into consideration



***Q. How will you screen applicants?***

A. The board has not set the guidelines yet. This is a very tough position to be in. Just from the news piece on WGN TV we have had over a dozen requests to find out more. Once we get more exposure I expect to have well over 20 – 25 families that will want their son in the program. So, I imagine we will be very selective in the initial group of men.



***Q. How will you staff it?***

A. As mentioned above we hope to have most of the staff as missionaries from churches. We will have to have some paid staff. We will also have to hire outside consultants to work with the men on vocational training. We will be holding a brunch and silent auction in November and hopefully a motorcycle ride next year. In addition we will be looking into family foundations and grants. The staff is going to go through extensive training by different groups that have trained many individuals in the behavior characteristics of Fetal Alcohol Spectrum Disorders.



***Q. How have the plans progressed so far?***

A. We are moving along slowly, but have started to gain momentum. There are many battles to overcome. The biggest battle is the lack of awareness of the disability. Once we start getting more publicity we feel like we will move quickly. We have assembled a very dedicated and caring board, which we are looking to expand. Much of our progress has been described above. We are trying to get out into the community and do more speaking to church and civic groups. Those are going to be our best area of support.



We wish you well in this very exciting and needed project, Walt. You have already done a remarkable amount of work and I believe your vision will be realized in the future. It is amazing what one committed person can do. Thank you for sharing this worthwhile enterprise with FEN. Your story will be an inspiration and guide for others to follow. Step by step, we all are trying to create a better understanding of FASD in the world so that those who are affected will be able to reach their highest potential in life, allowing them to become valued and contributing members of a community.

For more information, email Walt at: [walt@knowhimministry.org](mailto:walt@knowhimministry.org)

## Upcoming Conferences

### **Behavioral Challenges: Balancing Quality Care, Client Rights and Restrictive Measures**

November 12, 2004  
The American Family Resource Center  
Madison, Wisconsin

For more information call:  
Linda Draayers at 414-543-3004 ext 101

### **On the FASTrack to Understanding: A National Conference on Fetal Alcohol Spectrum Disorder and related Neurobehavioral Disorders**

October 28th and 29th, 2004 in  
Riverside, California at the Riverside  
Convention Center, sponsored by Arc  
Riverside, CalFAS and Arc California

For more information please call  
1-888-818-6298 or email

### **FASD International Francophone Conference: Take Action Now for a better Future!**

December 9th and 10th, 2004 at  
Centre des Congres de Quebec et  
Hilton Quebec, Canada, presented  
by SAFERA, in collaboration with  
the First Nation of Quebec and  
Labrador Health and Social Service  
Commission (FNQLHSSC)

For more information please  
contact:  
SAFERA  
(418)-882-2488  
Toll-Free: 1-866-ASAFERA  
(272-3372)

### **The 2005 FASD National Conference: Fetal Alcohol Spectrum Disorder, Equality of Access: Rights and the Right Thing to Do**

February 24-26, 2005 at Victoria  
Conference Centre at 720 Douglas Street  
in Victoria, British Columbia, Canada.  
Sponsored by Interprofessional  
Continuing Education, The University  
of British Columbia. In cooperation  
with: Connections: Serving Adolescents  
and Adults with FASD, Sunny Hill,  
Health Centre for Children, and The  
Asante Centre for Fetal Alcohol  
Syndrome.

Online Registration:  
[www.interprofessional.ubc.ca](http://www.interprofessional.ubc.ca)

For more information please contact:  
1-604-822-6156

## *Web Resources for Transitioning Young Adults*

### **National Center on Secondary Education and Transition**

[www.ncset.org](http://www.ncset.org)

### **Opening Doors to Post-Secondary Education and Training**

[www.dpi.state.wi.us/dpi/dlsea/een/pdf/tranopndrs.pdf](http://www.dpi.state.wi.us/dpi/dlsea/een/pdf/tranopndrs.pdf)

### **The Parents' Place of Maryland**

[www.ppmmd.org](http://www.ppmmd.org)

### **Transition Coalition**

[www.transitioncoalition.org](http://www.transitioncoalition.org)

### **Transition Planning for Adolescents with Special Health Care Needs and Disabilities: Information for Families and Teens**

[www.communityinclusion.org/transition/familyguide.html](http://www.communityinclusion.org/transition/familyguide.html)

