



# The FEN Pen

Volume 11 Issue 1

Summer 2007

## Family Empowerment Network Celebrates 15 Years!

Georgiana Wilton, PhD

I can hardly believe that FEN is reaching its 15<sup>th</sup> birthday. Back in the 1992-1993 fiscal year (working at a University, one learns to think either in terms of academic or fiscal calendars), an idea was born. It seemed simple: to provide support and resources to families affected by fetal alcohol syndrome. Although the idea itself seemed to suggest one easy goal, as we know all too well, addressing issues related to prenatal alcohol exposure are complicated indeed. At 15, FEN has taken on the personality of a teenager. It requires a lot of time, careful supervision, late hours, and we are never sure what lies around the next bend. And, lest I forget, it takes money!

If we believe that it takes a village to raise a child, it certainly can be said that it took a team to raise FEN. Over the past 15 years, FEN has benefited from the energies and talents of three coordinators. In addition to myself, Kristi Obmascher (formerly Swendrzynski) and Patricia Cameron have nurtured its growth. It is really their energy and talents to which I am referring. Their dedication to the project is evident from the fact that we all remain friends and colleagues...continuing to work to raise awareness about the effects of alcohol use during pregnancy, prevent FASD, and provide inter-

vention, support, and advocacy to families affected.

We have seen a lot of changes over the past 15 years. Diagnostic criteria have been refined (and new categories added), information—of varying degrees of accuracy—is readily accessible on the internet, increased funding opportunities are available, specialized diagnostic centers are available in many states, and there are more State-level FASD coordinators than ever before!

Although FEN itself does not receive dedicated funding, it subsists through pieces of other projects. In each funding proposal that is written by our team, we include targeted funds to provide family support and educational activities. Families continue to set our priorities, lead us in a direction that is meaningful, and evaluate our success.

We are looking forward to our 15<sup>th</sup> birthday, and hope you can join us for our celebration April 3-4, 2008 in conjunction with our 6<sup>th</sup> national FASD conference.

We look forward to another 15 years and hope you will continue to be a part of it.



### *Family Empowerment Network*

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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.

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*Funded by the State of Wisconsin  
Division of Mental Health and  
Substance Abuse Services*

## Healthy Choices: Personal Steps to a Healthier Lifestyle

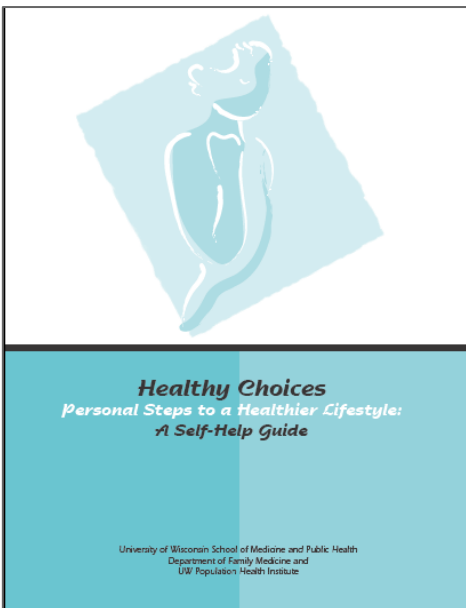
### Women Ages 18 – 44

- Do you have questions about your health habits?
- Do you use even a small amount of alcohol?
- Would you like additional information?
- Would you like strategies to help you assess your health habits?

To request your own self-help guide, please call the:

**Healthy Choices Line**  
800.752.3157

*This line is staffed from 4:00 – 10:00 p.m. Monday – Thursday.*



3rd National—Sponsored by Speckhard-Knight Charitable Foundation

## Teen Adult FASD Conference

**August 3-6, 2007**

Confidence Learning Center—  
Brainerd, Minnesota

A Conference Camp by and for individuals with FASD/ARND and their support person(s) age 15 through adult  
**Limit 50 Teams**

**50 Participants & 50 Support People**

**IF YOU HAVE AN FASD, COME AND JOIN IN THE FUN TO BUILD A NATIONAL VOICE TO DEVELOP HEALTHY & EFFECTIVE SUPPORTS**

Want to learn more—Visit:  
[www.betterendings.org/fasdcamp2007/](http://www.betterendings.org/fasdcamp2007/)



### Inviting . . . you! Life Experts on Fetal Alcohol

“I don’t want to go home because this is the one place where everyone understands me.”

2002 Participant

**For more information,**  
**651.917.2370 (MOFAS)**  
Conference Coordinator:  
Cathy Callaway  
952.431.6839  
cathycallaway@yahoo.com

#### Friends, Fun, Learning

#### Challenges

- Smitty’s Revenge
- Confidence Course
- Slipper Slide

#### Crafts

- Sand Candles
- Leathercraft
- Looms
- Scrapbooking
- Poster Contest
- T-Shirt Surprise

#### Sports

- Boating
- Fishing
- Archery
- Broomball

#### Fun

- Bingo
- Campfire
- Swimming
- Sandcastles
- Meet/Feed Animals
- Hayride
- Hiking

[www.betterendings.org/fasdcamp2007/](http://www.betterendings.org/fasdcamp2007/)

## A Model Program for Supporting Families Affected by Fetal Alcohol Spectrum Disorders: "Families Achieving Success"

Lyric Dold, MA, MS, LPC

How would you go about trying to improve family experiences and increase successes for a child with fetal alcohol spectrum disorders? How would you effect a positive change in all members of that child's family given the myriad stresses and trying events? Since one affects the other, where do you start?

These are interesting questions which are difficult to answer. Currently, the attempt to answer this is in a family intervention being designed and piloted through the Department of Family Medicine at the University of Wisconsin, Madison. The intervention is based upon three theoretical frameworks: Motivational Interviewing, Dialectical Behavior Therapy, and Family Systems Theory. The model is in-home therapy conducted by a counselor with follow-up evaluation at three, six and twelve-months.

The overall goal of the intervention is to improve adaptive functioning in children who receive a diagnosis of FASD at the University of Wisconsin. Objectives of the counseling will be to show improvement in the functioning of families as measured by the Feetham Family Function Scale. Another objective is to improve the mean levels of the Vineland Adaptive Behavior Scales (VABS) measure in the children.

Specifically, the intervention will provide education about FASD and what constitutes a

healthy family, exercises to improve communication among family members, ways to solve problems that arise for the child and family members, and ways to relieve stress. Participants will have five in-home family counseling sessions with child care provided, if necessary. The family will be paid \$200 if they complete the program. Resources include a workbook for the parents, meditation CDs, booklets specifically designed to give to siblings, teachers, and job supervisors, and helpful books geared toward increasing understanding of the cognitive and affective aspects of FASD.

Several sources were used to design the program. A 2005 study polling parents of children with Downs Syndrome found that their most frequently valued coping mechanisms were: attributing a cause for the event, establishing a sense of mastery or control over the event and over one's life, and enhancing one's self esteem. Another study involving parents of critically ill children called, "Creating Opportunities for Parent Empowerment (COPE)" provided audiotapes and written information and a parent-child activity workbook in order to increase parent's knowledge and understanding and direct participa-

tion in the child's emotional and physical care. This project found that there was less maternal-reported anxiety and negative mood states (depression) and more nurse reports of maternal involvement in the child's care after participation in the program.

The most valuable source of information for designing the program came from selected parents of children with fetal alcohol spectrum disorders. Their expert suggestions became the foundation of the program and each activity tries to reflect specific ideas which came from in-person personal interviews of these parents.

What appears at first as a daunting and impossible task has become an interesting and exciting adventure. Hopefully, the results of the intervention prove to be the answer to the questions, or at least a good start.

For additional information, contact Lyric Dold at [lyric.dold@fammed.wisc.edu](mailto:lyric.dold@fammed.wisc.edu) or 608.263.0452.



## FASTeN Teleconferences Connect Wisconsin Families

Patricia Cameron, MS

In an effort to connect families around the state for support and encouragement, FEN offers teleconferences eight times a year for parents to share ideas, experiences and strategies related to issues around raising children with FASD. The teleconferences alternate their focus between school-age children and adult children.

Some of the topics discussed in the past year for parents of school-age children included transition planning as part of the Individualized Education Plan (IEP), partnering with your child's school to create an effective IEP, the Katie Beckett Benefit program, neurobiofeedback, and social language development.

Topics for parents of adult children with FASD included transition planning out of high school, the Comprehensive Community Services program, humane housing for individuals with FASD, guardianship, and the new Sommerville Transitional Learning Center in Texas.

IDEA, the Individual Disability Education Act requires that public schools develop transition plans for students in special education. The transition planning process should begin by the age of 16. In Wisconsin, transition plans can begin for students in special education as early as 14 years of age. The development of the transition plan depends on the needs of the student, the parents' wishes, and school/community resources.

Students with FASD, who have a cognitive disability, will likely transition into the adult developmental disability system. However, many individuals with FASD who qualify for special education, do not have a low enough IQ to qualify for the adult developmental disability system. Transition plans for individuals with FASD need to identify the abilities and interests of the student and incorporate these into community experiences, along with teaching daily living skills and academics. There have been cases where schools neglect to develop transition plans for high functioning students in special education. Parents need to take a proactive approach by contacting the school to set up an appointment to begin the transition process and inviting their child to participate in the transition planning.

Another teleconference discussed the new county-funded Comprehensive Community Services (CCS) program, which may be a means for individuals with FASD to get support services as adults. In order for individuals to qualify for CCS, they must fit the criteria for a mental illness or drug/alcohol dependency. The



CCS program does not provide housing, but provides supports to individuals so that they can live interdependently in "humane housing." Many parents felt that a group home was not a good fit for their adult children, preferring an apartment with one other roommate. The CCS program would provide the supports for individuals to live in an apartment, without the feeling of confinement that is common with group homes.

Guardianship is another concern for parents of individuals with FASD. Guardianship for the estate involves control over financial activities such as checking accounts, savings accounts and trusts. Guardianship for the person includes personal and home care, medical care and social services. One concerning issue about guardianship is that the guardian could be financially responsible if the adult son/daughter was sued for damages due to vandalism or burglary.

Besides guardianship, another way to establish financial security for an individual with a disability is a special needs trust. Special needs trusts are intended to pool the funds of the individual with a disability for management purposes, and still maintain the individuals' eligibility for public benefits such as Medicaid. There are lawyers who specialize in guardianship and special needs trusts and it is recommended that families work with one when beginning either process. Some helpful websites are listed at the end of this article.

Sommerville Transitional

Learning Center is defined as a young adult community where individuals can learn life skills in a campus setting. This living & learning community, an 86-acre ranch, was born from the intuitiveness and experience of a community developer and the dream of a parent of an adult son with FASD. They joined the teleconference to explain how this idea is being developed in a small community in Texas and to answer specific questions from parents about the programming.

Sommerville provides three different tiers of structure and training, with each level customized to the needs of each community member. It sounded like a dream come true, but the cost of up to \$4,000 per month may be prohibitive for many families. While many families participating in the teleconference could not afford this, the discussion propelled them to investigate the concept in Wisconsin and to find possible sources of funding and support within the state legislature.

FASTeN teleconferences offer a unique venue for families to network and discuss pertinent issues specific to FASD. Please consider taking advantage of this supportive resource. The 2007-2008 teleconference dates are published for your reference.

Guardianship/Trust Websites:

<http://dhfs.wisconsin.gov/aging/guardianship>

<http://cwag.org>

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

## FASTeN

### Fetal Alcohol Syndrome Telephone Network & Listserv



FASTeN is a telephone and Listserv support network for families affected by Fetal Alcohol Spectrum Disorders (FASD). On selected Thursday evenings, and an occasional Tuesday, you can participate in a family teleconference to share ideas, receive (and give) support, or listen to a guest who works in the field of FASD. The Listserv is open to a registered group of Wisconsin families to allow them to pursue topics from the teleconferences or other related issues.

#### Dates 2007-2008

|                           |                          |
|---------------------------|--------------------------|
| September 13 (school-age) | February 21 (school-age) |
| October 11 (adults)       | April 17 (adults)        |
| November 15 (school-age)  | May 15 (school-age)      |
| January 24 (adults)       | July 17 (adults)         |

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

**Contact FEN For The  
Call-In Number & Access Code**

For more information, please contact:  
Family Empowerment Network (FEN)  
800.462.5254  
[fen@famned.wisc.edu](mailto:fen@famned.wisc.edu)

**Toll-Free Number  
No Cost to Families**

## Child Care Resource & Referral

Amy Irwin, BA

Child Care Resource and Referral (CCR&R) agencies are community based experts who make child care work for families by: developing professionals who care for children; connecting families with child care services; and, collecting data that impacts communities. There are 16 community based CCR&R agencies serving the entire state of Wisconsin.

Each CCR&R manages a database, which is updated continuously, of local regulated child care. Thousands of changes are made each year as programs open and close, or change their services. The database allows CCR&Rs to provide parents with the most up-to-date information

possible. CCR&Rs refer equally to all regulated child care programs and serve families from all income groups. In Wisconsin, regulated child care means the program has been either certified by the county or licensed by the state.

### Regulated Child Care

Certified family child care providers may care for up to three children, in addition to their own, for a total group of six children under seven years of age (providers' own children over seven years of age do not count toward the group total of six children). Among other criteria, certified family providers must have a criminal background check, 15-20 hours of early childhood education and a home

safety inspection. Visit Wisconsin Department of Workforce Development at [www.dwd.state.wi.us/dws/programs/childcare/certification/](http://www.dwd.state.wi.us/dws/programs/childcare/certification/) for more information.

Licensed family child care providers may care for four to eight children, including their own children under seven years of age, in their home (providers' own children over seven years of age do not count toward the group total of eight children). Licensed family providers must have 40 hours of early childhood education, current CPR certification, 10 hours of training in infant/toddler care if providing care for children under the age of two, and 15 hours of continuing education each year. They also must have written policies and procedures, and are sub-

## National Conference on Fetal Alcohol Spectrum Disorders (FASD)

Evidence-Based Strategies to Support Individuals, Families,  
and Communities Affected by FASD

**SAVE THE DATE**



**APRIL 3 - 4, 2008**

Space is limited for this two day conference offering state-of-the-art information and strategies for providers, families, and communities affected by FASD. Participants may pre-register online at [www.fammed.wisc.edu/fen/training.html](http://www.fammed.wisc.edu/fen/training.html) or request a pre-registration form by contacting the Healthy Choices Project.

**The Healthy Choices Project**  
**Toll-Free: 800.752.3157**  
**Email: [healthy.choices@fammed.wisc.edu](mailto:healthy.choices@fammed.wisc.edu)**

*Conference Location — American Family Insurance National Headquarters in Madison, Wisconsin*

ject to site inspections.

Licensed group child care centers are for nine or more children in an out-of-home setting. The staff to child ratio varies depending on the age group. For example, children birth through two years of age require at least one caregiver for every four children; with a maximum group size of eight children. Four and five year olds require one caregiver for every 13 children and a maximum group size of 24. Group centers are subject to many rules concerning staffing, building/equipment, programming and operation.

The Wisconsin Department of Health & Family Services is responsible for the licensing of family and group programs. For additional information, visit [www.dhfs.state.wi.us/rl\\_dcfs/ABOUT.htm](http://www.dhfs.state.wi.us/rl_dcfs/ABOUT.htm).

Beginning in 2007, anyone working with children under age five in a regulated child care setting must also complete training in Shaken Baby Syndrome Prevention.

### Child Care Referral

Looking for child care can be a daunting task and many families do not know where to start. Contacting a local CCR&R can be a good first step. Families discuss child care needs with a referral specialist. A computerized search for regulated programs that best meet those needs is conducted and an objective summary of regulated programs, along with quality child care information, is provided. Families then compare and evaluate a variety of programs to find one that works best for them; CCR&R agencies provide referrals, not recommendations. Visit



[www.wisconsincrr.org/](http://www.wisconsincrr.org/) to find a local CCR&R.

### Quality Child Care

Quality should be foremost in families' minds when choosing child care. What does a quality learning environment look like?

- Providers understand how children develop and receive regular training to improve their skills.
- Children have lots of opportunities to choose their own play activities.
- Providers seek out resources or specialists when there are developmental concerns.
- Parents are invited to participate often.
- Providers plan activities and experiences that are right for each child's age and level of development.
- Children read (or are read to) daily and talk about the material that has been read.
- Providers are respectful of children, answer their questions and help them solve problems.
- Parents feel they are important partners in their child's learning environment.

### Inclusive Child Care

When children with special needs are in quality care environments with typically develop-

ing children, everyone benefits. When individual differences are celebrated, children become adults who are able to look beyond disability to value ability.

What should parents know about inclusive child care?

- You are the expert where your child is concerned.
- You are a key member of the team and your ideas are valuable when it comes to planning the support your child needs to be successful.
- Federal and state laws give children with developmental delays or disabilities specific rights and protections in child care settings.

Visit the U.S. Department of Justice at [www.usdoj.gov/crt/ada/childq%26a.htm](http://www.usdoj.gov/crt/ada/childq%26a.htm) for more information concerning child care and the Americans with Disabilities Act (ADA).

What should child care providers know about including children with special needs?

- Each child is an individual; look for strategies that build on unique strengths and encourage full participation.
- Children with special needs often have many different providers in their lives. It is critical that everyone work together as a team!

There is **NO Known Safe Amount, Safe Kind, or Safe Time** to Drink Alcohol During Pregnancy



Call the Healthy Choices project for information or help at 800.752.3157

*Adapted from information provided by CCR&R of Central Wisconsin, Inc. and Think Big. Start Small.™ Reprinted with Permission.*

## **...UPCOMING EVENTS...**

|  |  |   |
|--|--|---|
| <p><b>Teen Adult FASD Conference</b><br/>           Date: August 3-6, 2007<br/>           Location: Brainerd, MN<br/>           Contact: Cathy Callaway<br/>           Phone: 952.431.6839<br/>           cathyallaway@yahoo.com</p>                         | <p><b>Nine Zero Conference</b><br/>           Date: September 7, 2007<br/>           Location: Santa Clara, CA<br/>           Contact: Nancy Bain<br/>           Phone: 408.272.6565<br/>           Nancy.Bain@hhs.co.santa-clara.ca.us</p>      | <p><b>International FASD Awareness Day</b><br/>           Date: September 9, 2007<br/>           Location: Worldwide<br/>           Contact: FASworld Canada<br/>           Phone: 416.264.8000<br/>           info@fasworld.com</p>                        |
| <p><b>FASD: Young Children with FASD</b><br/>           Date: September 21, 2007<br/>           Location: Madison, WI<br/>           Contact: Kristi Obmascher<br/>           Phone: 608.262.8971 or 800.442.4617<br/>           kobmascher@dcs.wisc.edu</p> | <p><b>FASD: Into Action</b><br/>           Date: October 4-6, 2007<br/>           Location: Portland, OR<br/>           Contact: Wendy Temko<br/>           Phone: 503.621.1271<br/>           wtemko@fascets.org</p>                            | <p><b>FASD: Model Prevention Programs</b><br/>           Date: October 26, 2007<br/>           Location: Madison, WI<br/>           Contact: Kristi Obmascher<br/>           Phone: 608.262.8971 or 800.442.4617<br/>           kobmascher@dcs.wisc.edu</p> |
| <p><b>FASD: Effective Treatment</b><br/>           Date: November 9, 2007<br/>           Location: Madison, WI<br/>           Contact: Kristi Obmascher<br/>           Phone: 608.262.8971 or 800.442.4617<br/>           kobmascher@dcs.wisc.edu</p>        | <p><b>Alcohol Exposed Pregnancy</b><br/>           Date: November 12-13, 2007<br/>           Location: Austin, TX<br/>           Contact: Office for Prevention of DD<br/>           Phone: 512.206.4544<br/>           top@hhsc.state.tx.us</p> | <p><b>6th National Conference on FASD</b><br/>           Date: April 3-4, 2008<br/>           Location: Madison, WI<br/>           Contact: Healthy Choices Project<br/>           Phone: 800.752.3157<br/>           healthy.choices@fammed.wisc.edu</p>   |

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*Visit us on the web!*

[www.fammed.wisc.edu/fen](http://www.fammed.wisc.edu/fen)