



The FEN Pen

Volume 12 Issue 1

Spring 2009

Great Lakes FASD Regional Training Center Launched with Training of Trainers Certificate Program

Georgiana Wilton, PhD



March 2-6th 2009 marked the University of Wisconsin's first certificate program for fetal alcohol spectrum disorders (FASD) educators. This week-long intensive training was conducted by the Great Lakes FASD Regional Training Center and the Wisconsin FASD Treatment Outreach Project. Sponsors included the State of Wisconsin Bureau of Prevention, Treatment and Recovery and the University of Wisconsin departments of Pediatrics, Family Medicine, and Professional Development and Applied Studies. Thirty participants from seven states participated.

This training showcased the new ***FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice*** developed by the Centers for Disease Control and Prevention (CDC) and kicked off activities of the Great Lakes FASD Regional Training Center.

See page 5 for a photo of the FASD TOT graduates!

Participants earned 30 continuing education units from the University of Wisconsin, and upon completing two individual training activities will earn their trainer "certificate." Many medical and allied health disciplines were represented including nursing, medical genetics, social work, counseling, nutrition, and health education.

To inquire about training in your area or for more information on the Great Lakes FASD Regional Training Center, please contact us:

Great Lakes FASD Regional Training Center
University of Wisconsin
Department of Family Medicine
777 S. Mills Street
Madison, WI 53715
Phone: 608-263-5613
Fax: 608-263-5813
Email: fasd.trainingcenter@fammed.wisc.edu
Web: www.fasdeducation.org



Family Empowerment Network

University of Wisconsin
School of Medicine
and Public Health
Department of Family Medicine
777 South Mills Street
Madison, WI 53715

Telephone

608-262-6590
800-462-5254

Email

fen@fammed.wisc.edu

Website

pregnancyandalcohol.org

FEN Team

Georgiana Wilton, PhD
Patricia Cameron, MS
Kristi Obmascher, BS
Lyric Dold, MA, MS, LPC

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.

© 2009 The FEN Pen

*Funded by the State of Wisconsin
Department of Health Services
Bureau of Prevention, Treatment and
Recovery*

Upcoming Wisconsin FASD Trainings:

Monday, June 22nd
St. Mary's Hospital
Minocqua, WI
For medical, public health,
AODA & human service providers
Contact: Kari or Jackie
715-358-6224
877-801-3485

Wednesday, June 24th
Women's Way
Eau Claire, WI
For AODA, health, & human
services providers
Contact: Lynda Olson
715-855-6181

Sharing your Success Stories with FASD

Kristi Obmascher

The Centers for Disease Control and Prevention (CDC) recently released a booklet with guidelines for writing and sharing “success stories.” Those of us involved with FASD-related programming are often frustrated with the things that don’t go right; and forget to share with one-another, potential funders, the general public, and others all of our amazing stories of success.

Do you have an FASD success story to share? Has your child, student, client, or someone else you know with an FASD accomplished a goal? Has your project, agency, or community had a successful outcome related to FASD? If so, please consider sharing your story! Beginning in June of 2009 the Great Lakes FASD Regional Training Center (GLFRTC) will showcase a range of FASD success stories on our website: fasdeducation.org



The guidelines for submitting a success story include the following:

1. Email a short (one page or less) description of your story to:
fasd.trainingcenter@fammed.wisc.edu
2. Clearly define the success! Identify who, where, what, and when.
3. Share specifics about the impact/outcome of your success (what happened, why is it significant).
4. Ask permission from everyone who is listed or cited in the story.
5. Include one contact person including name, email address, phone number.

The CDC booklet “Impact and Value: Telling Your Program’s Story” includes more details on creating an effective success story.

Check out the “Awareness and Education” page of our website: www.pregnancyandalcohol.org to download a copy of the booklet.

Contact Kristi Obmascher for more information, or to share a success story (Kristi.obmascher@fammed.wisc.edu).

Summer Camps

Easter Seals Camps 2009

Contact: 1-800-422-2324

www.eastersealswisconsin.com

Email: camp@wi.easterseals.com

Wisconsin Dells, WI

Camp Kee-B-Waw

Ages 6-13 (for kids with and without a disability)

Weekly Day Camp

Cost: \$150/weekly

Camp Wawbek:

Trailblazers Camp

Ages 7-18 (for kids with mild to moderate disabilities)

June 28-July 3rd overnight: \$695

June 28-July 9 overnight: \$1,390

Ages 19-40

July 12-19 overnight/ \$695

Transition Camp

Ages 16-25

August 16-21 overnight: \$695

Wisconsin Elks/Easter Seals Respite Camp

Ages 3 and up (for individuals with cognitive delays or multiple delays)

Other Camps 2009

Camp Pow Wow

Menomonee Falls, WI

ARCh- Assoc for Rights of Citizens with handicaps

Ages 5-99

Day and residential camps

throughout the summer

262-542-9811

(continued on p. 4)

FASD AND THE POSITIVE PUBLIC SCHOOL EXPERIENCE

By: **Kim Bahr**

“He’s just lazy”, “She just doesn’t listen”, “He can’t sit still”, “We don’t have the services for her”, “He knew these math problems yesterday”. Do these phrases sound familiar? If your child with an FASD is going to a public school you may have heard one or more of these statements before. Many school personnel and numerous professionals do not understand FASD, let alone know how to deal with a child who has one. In my job as a special needs adoption social worker, I have worked with several different school districts and have not found any that knew much, if anything, about children with an FASD. That is until now.

My husband and I moved almost seven years ago to a country home just outside of Edgerton, WI. We adopted two boys who were 2 ½ and 1 ½ at their respective adoptions. In 2005, approximately 2 years after the adoptions, we realized that our older son Jason, who was four years old at the time, was displaying behaviors that were unusual for a typically developing four year old. To make a long story short, we found out through birth/medical records and testing that Jason has Fetal Alcohol Effect (FAE), or what is currently called Alcohol Related Neurodevelopmental Disorder (ARND).

Jason was in Early Childhood at Edgerton at the time and we took the report with his diagnosis on it to the school and tried to explain what ARND is. We found that most of the staff did not know about ARND but were very willing to read information that we had given them. My husband and I were both surprised and elated that teachers and other staff were open to learning about a new disorder. We made sure to give out metered doses of information so as to respect their schedules and not inundate them with the massive amounts of data out there on ARND. In fact, we found that staff who worked with Jason, even his regular education teachers, wanted to learn as much as they could about ARND and how best to help him be successful in school. Every time a new behavior surfaced, they would ask us how we handled those situations so that they could do the same and provide consistency for Jason. As we all know, consistency is very important for children with an FASD.

Over the last four years, Edgerton School District has helped Jason be more successful in several ways, but for brevity, I’ll only give three examples.

1) Jason’s case manager has totally accepted Jason for who he is and has taken the time to really get to know him and ask us questions. During IEP meetings and parent teacher conferences, others would bring up Jason’s behaviors that are typical of children with an FASD (poor boundaries, not sitting still, blurting out in class) and his case manager would say, “That’s just who Jason is.” We also learned that Jason was not eating much, if anything, at lunch because the cafeteria was just too chaotic and Jason was too distracted to be able to eat. His case manager offered to let Jason come to her room and eat lunch; she was giving up her lunch hour and downtime for this. She has now let us bring a variety of food that Jason can choose from each day providing him with opportunities to start working on life skills with him such as putting food on plates, getting napkins, opening different containers, etc.

2) Jason’s regular education teacher has also read a lot of information about children with an FASD. She has learned that Jason needs several sensory breaks throughout the day and has set up a certain area in her room where Jason can go to look at books and be away from the rest of the group for a few minutes. She also realizes that when Jason gets hungry, his behavior gets out of control. She has allowed us to bring in different snacks for Jason and will give them to him even at times when it’s not “snack time”.

(continued on page 6)

WI Summer Camps (continued)

Challenge Camp
Oconomowoc, WI
Rogers Memorial Hospital
Ages 5-18 with ADHD
Day camps throughout July and August

2 week session: \$840
Contact: Karen Beal
1-800-767-4411 ext 293

YMCA Camp Timbertop
Stevens Point, WI
Ages 8-13 (for kids with learning disabilities)

Overnight Camp
July 19-25 \$390-\$520
Contact: Pete Mathai
715-342-2980 ext:308

Adventures in Independent Living
Campbellsport, WI
Ages 8-18 (for kids with all disabilities)
August 3-8th Call for cost
Contact: Kathy Mohar 414-291-7520 ext. 215

Adventures for L.I.F.E. Camp
Ages 12 and up (for individuals w/ disabilities)

Resident Camps: Friendship Center near Dodgeville, WI & at Ross Lodge at Greendale, WI Whitnall Park

Day Camps: held at Blue Lotus Farm and Retreat Center near Newburg, WI

Offer pickup points in the Milwaukee area. Contact: Nancy Pickett 414-937-2098

For information about more camps please go to the website:

www.wisconline.com/attractions/camps/

A Visit to our State Capitol

By: Marilyn Holschuh, Vice President
 ORCHIDS FASD WI

My name is Marilyn Holschuh and I am the Vice President of Orchids FASD Services in Wisconsin. Orchids is a group of concerned parents and professionals living in Wisconsin who want to provide safe, structured, appropriate housing for adults with an FASD. Most of our adult children currently live at home and this puts an immense burden on us as parents/caregivers to keep them safe and out of harms way.

Another goal of Orchids is to develop programs where adults with an FASD can continue to develop good social and vocational skills so that they can become productive, contributing members of a community.

On March 16th several of us from Orchids visited the State Capitol in Madison to talk to our legislators about FASD. We shared our personal experiences with them and talked about our concern over the lack of services for adults with an FASD. We felt the legislative aids that we spoke with were very interested in what we had to say and even helped us to understand the complex process of introducing a bill in either the state assembly or senate.

We also visited with a representative of the Governor's office who also spent at least a ½ hour with us listening to our concerns. He explained to us what happens when a concern is brought to the attention of the Governor's Office and suggested that we get in touch with additional political forces to help us get the word out about FASD awareness. He stressed the importance of talking to the legislators who are the chairpersons and members of the Health and Human Services Committees and the Ways and Means Committees.

All in all, we felt that this was a very good experience. We exercised our right as citizens of a democracy and felt that our elected officials are willing to hear our stories and work with us to create a better solution to the problems we expressed.

We hope to do this again around September 9, 2010, which is FASD Awareness Day and we hope that more of you can join us!



FASTeN: Fetal Alcohol Syndrome Telephone Network & Listserv

FASTeN is a telephone & Listserv support network for families affected by Fetal Alcohol Spectrum Disorders (FASD). On selected Thursday evenings, you can participate in a teleconference with other parents or caregivers to share ideas, receive (and give) support, or listen to people who will share valuable resources for families. The Listserv is open to a registered group of families to allow them to pursue topics from the teleconferences or other issues related to FASD.

April 23rd (Adults) May 14th (Children)

Times:

Adults: 7:00—8:00 pm Central Time

School-Age: 2:00—3:00 pm Central Time

If you would like to register, please call or email FEN for the dial up instructions.

1-800-462-5254 608-262-6590

2009 Graduates of the FASD Training of Trainers Certificate Program in Madison, WI



Wisconsin FACETS Free Telephone Workshops

To register call: 1-877-374-0511
(please register 1 week in advance. Workshop materials are mailed to you)

WI FACETS offers information, referrals, individual assistance, advocacy supports, workshops and support groups for families of children with disabilities at no cost to Wisconsin residents.

May

11th 7-8 pm No Child Left Behind Workshop series
19th 7-8 pm IEPs Part I
28th 7-8 pm IEPs Part II

June

4th 12-1 pm Initial Evaluation & Reevaluation
8th 7-8 pm IEP Content & Planning Tool
22nd 7-8 pm Early Intervening Services and Rtl

July

9th 12-1 pm Dispute Resolution Options
30th 12-1 pm Communication Strategies

August

3rd 12-1 pm Bullying and Harassing
11th 7-8 pm Self Advocacy
27th 7-8 pm Pre-school Transitions and Options

September

1st 12-1 pm Least Restrictive Environment Decisions

October

1st 7-8 pm Functional Behavior Assessments
8th 12-1 pm Dispute Resolution Options
15th 7-8 pm Self Advocacy
28th 12-1 pm Positive Beginnings Supporting Young Children with Challenging Behaviors

Wisconsin Diagnostic Centers

UW-Madison, Clinical Genetics Center

Diagnosticians: David Wargowski, MD
Greg Rice, MD
Phillip Giampietro, MD, PhD
Address: 335 Waisman Center
1500 Highland Ave
Madison, WI 53705
Telephone: 608-262-2507

Outreach Sites: Appleton, Rhinelander, Ashland
Telephone: 608-263-2510

Children's Hospital of Wisconsin, Genetics Center

Diagnosticians: William Rhead, MD, PhD
David Bick, MD
Address: P.O. Box 1997
Mainstation 716
Milwaukee, WI 53201
Telephone: 414-266-3347
Scheduling 414-607-5280

Marshfield Clinic, Genetic and Birth Defects Clinic

Diagnostician: Elizabeth McPherson, MD
Address: 1000 North Oak St
Marshfield, WI 54449
Telephone: Toll Free: 877-216-8535
Direct: 715-221-7401

Gunderson Lutheran Medical Center

Diagnostician: Kerry Baldwin Jedele, MD
1900 South Avenue
Address: LaCrosse, WI 54601
Telephone: 800-362-9567

MaMaaawi (Together for Children)

Red Cliff Developmental Assessment Clinic

Diagnostician: Grace Heitsch, MD
Address: 88455 Pike Road
Bayfield, WI 54814
Telephone: 715-779-3707

SAVE THE DATE

FASD Training of Trainers Certificate Program

March 1-5, 2010

St. Mary's Hospital Madison, WI

Contact: Kristi Obmascher

608-261-1418 or 800-752-3157

(continued from page 3)

As consistency is very important for children with an FASD, the staff realized that Jason would do much better in a multi-age classroom.

He is in a 1st/2nd grade classroom and this is his second year in the same room with the same teacher. She understands about “routine” for Jason and gave him the same locker, the same desk and the same place in the classroom this year. As a result, Jason had a very smooth transition from summer into the school year.

3) Jason has Sensory Integration Disorder that can go along with having an FASD. His occupational therapist understands these sensory issues and took it upon herself to do joint compressions, brushing, etc. right away in the morning in order to help “ground” him for the day. She consistently communicates with Jason’s regular education teacher to find out if what she did that morning worked or not. If not, she tries something else the next day until she finds a routine that works for him.

There are other accommodations that staff in the Edgerton School District have made to help Jason be more successful at school, but none are more important than providing and having open communication between them and us on a daily basis. My husband and I wanted to move closer to Madison in order to have a more diverse school for our children. However, in talking to other parents of children with an FASD and learning how much they need to “fight” for services and accommodations for their child in school we have decided that Edgerton is the best place for us. A huge “thank you” to all the staff at Edgerton Community Elementary School for your understanding, compassion and patience when working with Jason!



Kim Bahr is a mom of 2 boys with an FASD and an adoption social worker with Lutheran Social Services of Wisconsin. She recently completed the FASD Training of Trainers that took place in Madison, Wisconsin. She resides in Edgerton with husband Paul and their two sons.



A Psalm of Life

BY HENRY WADSWORTH LONGFELLOW

Tell me not in mournful numbers,
Life is but an empty dream;
For the soul is dead that slumbers,
And things are not what they seem.

Life is real! Life is earnest!
And the grave is not its goal;
Dust thou art, to dust returnest,
Was not spoken of the soul.

Not enjoyment, and not sorrow,
Is our destined end or way;
But to act, that each to-morrow
Find us farther than to-day.

Art is long, and Time is fleeting,
And our hearts, though stout and brave,
Still, like muffled drums, are beating
Funeral marches to the grave.

In the world’s broad field of battle,
In the bivouac of Life,
Be not like dumb, driven cattle!
Be a hero in the strife!

Trust no Future, howe’er pleasant!
Let the dead Past bury its dead!
Act,— act in the living Present!
Heart within, and God o’rhead!

Lives of great men all remind us
We can make our lives sublime,
And, departing, leave behind us
Footprints on the sands of time;

Footprints, that perhaps another,
Sailing o’er life’s solemn main,
A forlorn and shipwrecked brother,
Seeing, shall take heart again

Let us, then, be up and doing,
With a heart for any fate;
Still achieving, still pursuing,
Learn to labor and to wait.

...UPCOMING EVENTS...

<p>May 1-2, 2009 [SCHOLARSHIPS AVAIL] National FASD Conference: Addressing Social and Behavioral Issues Across the Lifespan American Center—Madison, WI 1-800-752-3157 kobmascher@dcs.wisc.edu www.pregnancyandalcohol.org</p>	<p>May 18-20, 2009 Wisconsin Assoc of Alcohol and Other Drug Abuse (WAAODA) Spring Con- ference Olympia Resort Oconomowoc, WI 608-829-1032 waaoda@tds.net</p>	<p>May 29-30, 2009 NAMI-Wisconsin (Natl Assoc on Men- tal Illness) Annual Conference Madison Marriot West Middleton, WI 800-236-2988 namiwisconsin.org/conference</p>
<p>May 31-June 4, 2009 25th Annual National Rural Inst of Alco- hol and Drug Abuse Conference University of Wisconsin—Stout Menomonie, WI 715-532-9030 www.uwstout.edu/outreach/conf/nri</p>	<p>June 1, 2009 Sex, Drugs & Rock n' Roll: Addiction, Compulsion and Craving— David Mays, M.D., PhD Plaza Hotel & Suites Wausau, WI UW Extension 800-725-9692 www.dcs.wisc.edu/pda/aoda</p>	<p>June 2, 2009 Growing Up the Hard Way: Mental Ill- ness & Children at Risk David Mays, M.D., PhD Plaza Hotel & Suites Wausau, WI UW Extension 800-725-9692 www.dcs.wisc.edu/pda/mental-health</p>
<p>June 17-20, 2009 The American Professional Society on the Abuse of Children (APSAC) 17th Annual Colloquium Omni Hotel—Atlanta, GA 630-359-4274 dbandy@apsac.org</p>	<p>October 7-9, 2009 FASD Across the Lifespan: Institute of Health Economics The Westin Edmonton Alberta, Canada www.buksa.com</p>	<p>October 19-22, 2009 Midwest Conference on Child Sexual Abuse Bruce Perry, M.D., PhD Madison Marriott West/Middleton, WI 608-263-5130 or 800-442-7107 www.dcs.wisc.edu/pda/midwest</p>

The FEN Pen

**University of Wisconsin-Madison
Department of Family Medicine
777 South Mills Street
Madison, WI 53715**

Visit us on the web!
www.pregnancyandalcohol.org
