



SANFORD SCHOOL OF MEDICINE

The University of South Dakota
CENTER FOR DISABILITIES

NOFAS-SD News

A PUBLICATION OF THE CENTER FOR DISABILITIES
A University Center for Excellence in Developmental Disabilities Education, Research and Service



International FAS Awareness Day

On September 9th people all across the world will gather to celebrate International FAS Awareness Day. This event has been ongoing since 9/9/99 and various activities take place across the world revolving around the time of 9:09 am. The original idea was to celebrate through a moment of silence but other activities have developed over the years, such as, bell ringing. The date and time of this celebration was chosen to help remind women to abstain from alcohol usage during the nine months of pregnancy.

If you are wondering what you can do to help promote International FAS Awareness Day visit www.fasday.com for ideas on how to promote awareness in your community.

The Center for Disabilities will be celebrating International FAS Awareness Day through several awareness activities throughout the state.

FASD Resources Available through the Center for Disabilities and Recommended Reading

The Center for Disabilities has a wide array of resources about Fetal Alcohol Spectrum Disorders. The Center regularly purchases books, videotapes, DVDs, and training series as free resources for parents, professionals, and students to check out from the Wegner Health Science Center Library. The materials can be reserved or checked out via phone and shipped to people who live outside the Sioux Falls area. Some older popular resources include Michael Dorris' "The Broken Cord" in print and a videorecording of Dorris in a 1990 edition of the TV show 20/20 where he was interviewed about raising his son with Fetal Alcohol Syndrome. "Students Like Me" is a videorecording created for teachers and "Worth the Trip: Raising and Teaching Children with

Fetal Alcohol Syndrome" include both hopeful and practical suggestions for children affected by prenatal alcohol exposure by their teachers and parents. Some of the newer additions to the library include "Forgetful Frankie The World's Greatest Rock Skipper", a children's book dedicated to all those touched by FASD and "Our FAScinating Journey: The Best We Can Be - Keys to Brain Potential Along the Path of Prenatal Brain Injury". The Wegner Center Library is located at 2200 W 14th Street in Sioux Falls and can be contacted by phone at 800-658-3080, or website www.usd.edu/library/wegner.cfm

The Center for Disabilities also distributes several resources on FASD including the Fetal Alcohol Spectrum

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FASD Resources - continued

Disorders Handbook and the new Fetal Alcohol Spectrum Disorders Education Strategies: Working with Students with FASD in the Education System book. Both of these resources can be requested by calling 605-357-1439 or downloaded from our website at www.usd.edu/cd.

Recommended reading includes newly published material on FASD such as "The Long Way to Simple – 50 Years of Living, Loving, and Laughing as a Person with FASD" by Steven Neafcy; "9 Lives, I Will Survive" by Jan Crossen; and "Braided Cord: Tough Times In and Out" by Liz, Jodee, and Karl Kulp.

Notice of Availability of Larson Family Scholarship Funds

The Center for Disabilities now has Larson Family Scholarship Funds available for families meeting the eligibility criteria. These funds are made available through an award from the Larson Family Foundation and can be used to cover the costs of diagnostic evaluations and consultations for Autism or Fetal Alcohol Spectrum Disorders from the Center for Disabilities.

Scholarships awarded as funds are available.

For information about applying for these funds, contact the Center for Disabilities at 1-800-658-3080 or 605-357-1439. Completed applications for Larson Family Scholarship Funds will be reviewed by South Dakota Parent Connection to determine eligibility.

National Organization on FAS and Affiliate Network

The NOFAS Affiliate Network was officially established seven years ago to open permanent lines of communication among FASD colleagues and organizations, share resources, unify core values and messages, and turn up the volume on the appeal for attention and resources. Today the network consists of twenty-one member organizations.

The primary goal of the NOFAS Affiliate program is to unite FASD organizations into an international network for the purpose of preventing FASD and meeting the needs of people living with the disorder, while each member organization maintains its independence and identity.

Objectives

- Share information and resources
- Build the capacity of the FASD constituency and increase advocacy
- Set common goals and messages
- Seek consensus on issues within the FASD arena
- Collaborate on a range of public health and advocacy programs and services
- Leverage resources

FASD Parent Education Classes

Classes for parents or guardians of children who have a Fetal Alcohol Spectrum Disorder (FASD) will again be available from the Center for Disabilities. These classes meet once per month from November through March over the state's interactive video system (DDN). Classes follow the Triumph Through the Challenges of FAS curriculum developed by the Double Arc in Ohio and provide a good overview of FASD as well as what families can do about issues they may find challenging in raising children with FASD. For more information or to register for the upcoming trainings, contact Judy Struck at judy.struck@usd.edu or 1-800-658-3080 or (605) 357-1439.

2010 Affiliate Network Agenda

Among the current priorities are supporting the inclusion of FASD in the Diagnostic and Statistical Manual of Mental Health Disorders (DSM-V), scheduled to be published by the American Psychiatric Association in 2012. Although identifying FAS and other conditions under the FASD umbrella is primarily a medical diagnosis, long-established research confirms that mental health disorders are common among individuals with FAS. The DSM-V Task Force is examining the case for including Alcohol-Related Neurodevelopmental Disorder (ARND), or another condition under the FASD umbrella, in the revised edition. Inclusion could lead to standardized diagnosis, treatment and reimbursement for practitioners serving the mental health needs of

people with FASD, while maintaining the primary diagnosis as a medical condition.

The network also plans to explore the issue of mandatory warning posters and information advising pregnant women to abstain from alcohol in establishments selling or serving alcohol, including stores, restaurants and bars. Currently nineteen states and the District of Columbia require such advisories. The NOFAS affiliates will seek to enforce existing requirements and advocate for all states to adopt posting laws.

The Center for Disabilities became a part of the NOFAS Affiliate Network in 2004.

Center for Disabilities Collaborates with International Researchers

The Center for Disabilities Fetal Alcohol Spectrum Disorders (FASD) staff is collaborating with international researchers from the Center on Alcoholism, Substance Abuse, and Addictions (CASAA) at the University of New Mexico. Principal Investigator Philip A. May, Ph.D, along with researchers Wendy Kalberg, MA, CED and H. Eugene Hoyme, MD, have worked with the Center for Disabilities staff members to determine if "there is a unique neurobehavioral profile in children exposed to alcohol prenatally."¹ In the summer of 2009, researchers from CASAA arrived in Sioux Falls to work with individuals who may have this neurobehavioral profile. Researchers completed an in-depth assessment with a core test battery comprised of specific educational and psychological instruments to assess the theory as well as completing a genetics evaluation. In addition, individuals and their families were provided with information consisting of strengths and weaknesses

along with resources written specifically to improve educational outcomes. Education Strategists at the Center for Disabilities were able to assist local schools and individuals implement the recommendations and ideas that best worked for the individual. The research team plans to evaluate individuals in Rapid City sometime in the near future. Judy Struck, MA, Executive Director of the Center for Disabilities says "This collaboration is key to providing evidence based diagnostic evaluations in the state of South Dakota. Having our staff involved with highly regarded researchers in the area of FASD improves our ability to stay on the cutting edge of research and thereby providing our clients the best evaluations and recommendations possible." To make a referral or learn more about the Center for Disabilities FASD program, please contact 605-357-1439 or 800-658-3080 (V/TTY). For further information about CASAA research, see the website at casaa.unm.edu/fas.html.

¹ May, Philip A., Ph.D., Center on Alcoholism, Substance Abuse, and Addictions, International Neuropsychological Study of FASD and Multi-Method Intervention Study of FASD in South Africa



The Fetal Alcohol Spectrum Disorders Education Strategies Handbook

is a reference guide to be used with students suspected of having a Fetal Alcohol Spectrum Disorder (FASD) or who have been diagnosed with an FASD.

Some items included in the FASD Education Strategies Handbook -

- Overview of FASD
- Educating Students with an FASD
- Functional Assessment
- Environmental Modification
- Communication
- Executive Functions
- Brain-Based Teaching Methods
- Social Skills and Behavior



The FASD Education Strategies Handbook is free to download at www.usd.edu/cd and then by clicking on "publications". Hard copies of the FASD Education Strategies Handbook are available for free to individuals directly related to a South Dakota public school (teachers, parents, administrators, students, etc.). Hard copies of the FASD Education Strategies Handbook are available to individuals in other states or those not directly connected to a South Dakota public school for a cost of \$15.00. To request a copy of the FASD Education Strategies Handbook, contact the Center for Disabilities by phone at 1-800-658-3080 (Voice/TTY) or 605-357-1439 or via e-mail at cd@usd.edu.



Fetal Alcohol Spectrum Disorders (FASD) Education Strategies Handbook is produced by the Center for Disabilities, Department of Pediatrics, Sanford School of Medicine of The University of South Dakota and is made possible through funding from the South Dakota Department of Education, Office of Educational Services and Supports.

Congressman Don Young New Co-Chair of FASD Caucus

Alaska Congressman Don Young has joined the Congressional Caucus on Fetal Alcohol Spectrum Disorders as the Republican co-chair, succeeding retired Caucus founding member Jim Ramstad (R-MN). Congressman Young joins original Caucus co-chair Frank Pallone (D-NJ), Chairman of the Health Subcommittee of the U. S. House of Representatives Energy and Commerce Committee.

The 36-member Caucus was established in 2004 to educate Members of the U. S. House of Representatives

on issues relevant to preventing fetal alcohol spectrum disorders and increasing the quality of life for children and adults currently living with alcohol-related intellectual disabilities and birth defects.

The Caucus is planning to introduce an FASD reauthorization bill this year, a companion to S.3154, the Advancing FASD Research, Prevention and Treatment Bill, introduced in March 2010 by Senator Lisa Murkowski (R-AK) and Tim Johnson (D-SD).

Statewide FASD Prevention- WIC Project Update

The Center for Disabilities, in partnership with the SD Division of Alcohol and Drug Abuse, within the SD Department of Human Services, and a statewide project task force, is evaluating a pilot program that is intended to build the capacity of critical services to pregnant women in South Dakota who are at risk of prenatal alcohol use through the implementation of a screening for all pregnant women at identified Women, Infants, and Children (WIC) program sites. For those pregnant women who are identified as being at risk for alcohol exposure, a brief intervention plan is provided by WIC staff. Follow up with the client is provided up to and beyond the birth of the child. If needed, referral services to alcohol treatment

are provided to the client. All services provided are free of charge for participating women.

The project began with five WIC clinics across the state of South Dakota and has added five more sites during the second year of the project. The project currently screens women at 10 WIC sites; the current sites are Aberdeen, Belle Fourche, Huron, Mobridge, Pierre, Rapid City, Sioux Falls, Watertown, Winner, and Yankton. This project is funded by a contract to the Center from the Division of Alcohol and Drug Abuse. For information, contact Austin Winberg, Project Director, at austin.winberg@usd.edu or 1-800-658-3080.



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This newsletter is available in alternate format upon request by contacting the Center for Disabilities.