Fetal Alcohol Spectrum Disorder: Diagnosis & Adoption (Part 1)

Minnesota has the tenth highest alcohol use rate in the nation. Consumption of alcohol during pregnancy is the number one cause of preventable mental disabilities. Alcohol consumption during pregnancy does far more damage to the unborn child than any other drug.

- Children diagnosed with Fetal Alcohol Syndrome (FAS) have abnormal facial features, slow growth both before and after birth, and brain injury.
- Children diagnosed with Fetal Alcohol Effects (FAE) may lack the outward physical appearance of alcohol damage and have some of the above characteristics. Or they may demonstrate all of the characteristics but still not have proof that the birth mother drank.

Together FAS and FAE are classified as Fetal Alcohol Spectrum Disorder (FASD), a lifetime disability that is not curable. Early diagnosis and intensive, appropriate intervention can make an enormous difference in the prognosis for the child, preventing secondary disabilities that result from primary disabilities related to FASD. Because of the brain injuries associated with FASD, individuals often have attention deficit and hyperactivity disorder (ADHD), learning disabilities, problems with daily living including poor impulse control, memory problems, sensory integration issues, relationship difficulties, an inability to understand cause/effect and thus to generalize. They also demonstrate a tendency towards high risk behaviors. Considered “soft signs,” these symptoms are not behavioral problems but rather show the permanent, unchanging damage to the brain that is out of the child’s control.

Adoptive parents need to be aware of FASD because: Alcohol consumption during pregnancy may not appear in adoption paperwork.

- Women who use drugs during pregnancy are very likely to be using alcohol as well.
- During pregnancy, a woman may not know that she is pregnant until several months into the pregnancy. Her pre-pregnancy pattern of drinking many continue into the early stages of pregnancy when the effects of consumption are most dangerous to the fetus.
- Medical history of siblings can help determine a diagnosis of an adopted child. A woman who has delivered a child with FASD is at 70 percent greater risk of delivering additional affected children. Often younger siblings have a higher incidence rate than older brothers and sisters.
- Children with FASD are over-represented in foster care and adoption. So prevalent is the diagnosis among older “special needs” children that some adoption workers tell potential parents to assume prenatal exposure to alcohol unless there is clear proof otherwise.
- Among the 2 million adults in the U.S. with suspected FAS disorders, the combination of the primary brain dysfunction (poor judgment, lack of impulse control) and the secondary disability of alcoholism results in another risk that is not always recognized, that these individuals are very likely to have unprotected sex that results in pregnancy, and another generation of babies are at risk of damage from prenatal alcohol exposure.

The diagnosis process for FASD includes:

- A complete medical examination
- Psychological, occupational therapy and speech/language evaluations

To learn more about MN ADOPT and our efforts to ensure each child will have a permanent family, call 612-861-7115 or visit www.mnadopt.org
- Evaluation of the prenatal, birth and previous medical history
- Measurement of head size and facial features
- Occupational therapy evaluation to determine motor functions and adaptive abilities.
- Speech and language evaluation to determine abilities to understand and communicate.
- Adoptive parents can prepare for a diagnostic procedure by gathering all they know about their child’s health and family history. They can bring photos of the child, preferably at a young age. Photos should be straight on, not smiling and without glasses.

**DIAGNOSIS**

Regional FASD clinics offer team evaluations for children with significant behavior, learning or physical problems that may be related to the disorder. A treatment plan will be developed based upon the recommendations of the team. Minnesota clinics that specialize in FASD diagnosis include:

**Minnesota Children with Special Health Needs**
**Division of Family Health**
**Minnesota Department of Health**
85 East Seventh Place, Suite 400
PO Box 64882
St. Paul, MN 55164
651-215-8956
800-728-5420
mn-cshn@health.state.mn.us
www.health.state.mn.us/divs/fh/mcshn/directory0102.htm

**University of Minnesota FAS/E Diagnostic Clinic**
Pi-Nian Chang, Ph.D.
University Gateway Center
200 Oak Street SE (Oak and University Avenue SE)
Suite 160, KDWB Variety Center
Minneapolis, MN 55455
612-624-9134 or 800-688-5252

**University of Minnesota International Adoption Clinic**
Counsels international adopters (after viewing videos of children being considered), screens adopted children after arrival, providing follow-up and referral to specialists.
Dr. Dana Johnson
Box 211, 420 Delaware Street SE
Minneapolis, MN 55455
612-624-1164 or 612-626-2928

**Health Partners Ramsey Clinic -- Child and Adolescent Psychiatry**
Elizabeth Reeve, MD
640 Jackson Street
St. Paul, MN 55101-2595
651-221-3061

**Mayo Clinic - Department of Medical Genetics**
Pamela Carnes, M.D
200 First Street S W
Rochester, MN 55905
507-284-8208 Fax: 507-284-1067

**Minnesota Indian Women’s Resource Center**
2300 5th Ave. S
Minneapolis, MN 55404
612-728-2018
Hennepin County Medical Center - Department of Pediatrics
Linda Thompson, M.D.
701 Park Avenue South
Minneapolis, MN 55415
612-347-2617
Works particularly with infants.

Hennepin County Medical Center
Child Behavior Learning Clinic
Rachel Trockman, M.D., Pediatric Neurologist
701 Park Avenue
Minneapolis, MN 55415
612-347-2675
Fax: 612-904-4227

Cass Lake Indian Hospital
Diane Pittman, M.D., Pediatrician
RR 3, Box 211
Cass Lake, MN 56633
218-335-2293
Fax: 218-335-2601

Abbot Northwestern Hospital - Perinatal Center
Shari Baldinger, M.S., Geneticist
800 E 28th Street
Minneapolis, MN 55407
612-863-3536
Fax: 612-863-5692

— CONTINUED PAGE 4 —
What to Tell My Child Once I Have the FASD Diagnosis

Some adoptive parents are reluctant to discuss the FASD diagnosis with their child. A solid diagnosis can be a relief for the child who can be helped to understand that many of their difficulties have a solid medical reason. Parents can begin to help the child see that their birth mother did not intentionally hurt them by drinking during pregnancy. Not all children with FASD are alike, with some displaying more of the reasoning and behavioral problems than the physical features. Each child will have individual special needs and may display varying degrees of symptoms:

**FETAL ALCOHOL SPECTRUM DISORDER SYMPTOMS**

<table>
<thead>
<tr>
<th>Attention and Focus</th>
<th>Education</th>
<th>Social</th>
<th>Sensitivity</th>
<th>Physical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agitated, unable to sit down</td>
<td>Requires constant reminders; cannot understand abstracts</td>
<td>Has difficulty keeping of making friends; misses social cues</td>
<td>Resists change in any form</td>
<td>Has problems going to sleep; often smaller in stature</td>
</tr>
<tr>
<td>Difficulty playing independently</td>
<td>Must re-learn previously learned skills</td>
<td>Doesn’t understand social expectations</td>
<td>Has low frustration level</td>
<td>Exhibits unusual physical characteristics</td>
</tr>
<tr>
<td>Talks incessantly</td>
<td>Lacks motivation to learn; does not generalize</td>
<td>Requires constant supervision; developmental delays; plays with younger kids</td>
<td>Over stimulated by public areas such as shopping centers</td>
<td>Experiences eating difficulties</td>
</tr>
<tr>
<td>Acts without thinking</td>
<td>Labeled “slow learner”</td>
<td>Alienates loved ones</td>
<td>Overly sensitive to touch, movement, sights, smells, or sounds</td>
<td>Over reacts or under reacts to pain</td>
</tr>
<tr>
<td>Easily distracted</td>
<td>Has academic delays</td>
<td>Doesn’t learn from mistakes</td>
<td>Over reactive to touch, movements, sights, smells, or sounds</td>
<td>Inability to make sense of a situation can lead to FAS shutdown</td>
</tr>
<tr>
<td>Unable to sit still or to calm self</td>
<td>Unable to understand time or money</td>
<td>Often aggressive and physical; exhibits rage</td>
<td>Has difficulty in regulating emotion</td>
<td>Exaggerated feelings with roller coaster emotions</td>
</tr>
</tbody>
</table>

Many people with FAS/FAE have strengths that mask their cognitive challenges:

- Highly verbal
- Bright in some areas
- Artistic, musical, mechanical
- Athletic
- Friendly, outgoing, affectionate
- Determined, persistent
- Willing
- Helpful
- Generous
- Good with younger children
RESOURCES

**Minnesota Organization on Fetal Alcohol Syndrome (MOFAS)**
MOFAS offers Project Seeds of Success (SOS), an education and outreach program designed for individuals who have been diagnosed with FAS/FAE and their families. Project SOS is a parent-driven, child-centered program that is designed to strengthen relationships between families and schools by building partnerships, providing resources, and improving the education system for children with FASD.
1821 University Avenue N-185 St. Paul, MN 55104
651-917-2370
Fax: 651-917-2405
www.mofas.org

**Thunder Spirit Lodge**
A resource center that strives to improve the wellbeing of individuals, families, and communities affected by alcohol and drug-related birth defects. Provides family support, research and training, crime prevention, advocacy, education and intervention.
4026 Central Avenue NE
Columbia Hts MN 55421
763-789-6385
TSL1234@aol.com

**National Organization of Fetal Alcohol Syndrome (NOFAS)**
Comprehensive resources with bookstore, legislative updates, articles of interest to families living with FASD.
www.nofas.org

WEB SITES

**FAS Alaska**
Comprehensive website includes numerous links to resources around the world, training and consultations, research, connections to families, articles, homeschool resources. Focuses on intervention techniques for educators.
www.fascets.org

**FASCETS- Fetal Alcohol Syndrome Consultation, Education and Training Services Inc.**
Non-profit organization that provides direct services for individuals, family systems and professionals affected by Fetal Alcohol Spectrum Disorder including information, training, consultation and resources.
www.fascets.org

**FAS Characteristics**
Log on to view facial characteristics and a list of symptoms associated with FASD.
www.come-over.to/FAS/faschar

**FAS Community Resource Center**
Resources include articles of interest to parents ("When the Teen with FASD Drinks," "Teaching Kids about FASD."), research, fact sheets, web links, products, camps, lending library and homeschooling help.
www.come-over.to

**Advanced Communications and Business Resources**
Designed by Canadian businessman, this site offers a FASlink Archives with over 70,000 FAS related letters and articles. FASlink is a free Internet listserv that includes biological, foster and adoptive parents and caregivers as well as a wide range of professionals including those in medicine, social work, education and justice. Participants also include individuals who have FAS or FAE.
www.acbr.com/fas

**ARC of Hennepin and Carver Counties**
Resources for families of children with developmental disabilities include future planning, family support, respite care, assisted technology and managed care. ARC successfully connects families to the wisdom and know-how of other parents, family members and professionals understanding and living the experience throughout their entire lives.
www.archennepincarver.org