



Home  
Newsletters  
Events  
Resources  
Sign-Up  
Donations  
About Us  
Search

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Newsletter

April 2008

- [FASD Leadership Conference on the Next Challenge: Intervention and Treatment for Alcohol-Affected Individuals](#)
- [From Tragedy to Triumph](#)
- [Thinking of Kirt](#)
- [FASD Conference, in Seattle](#)
- [Submit an article to Iceberg](#)

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## FASD Leadership Conference on the Next Challenge: Intervention and Treatment for Alcohol-Affected Individuals

*By Heather Carmichael Olson, Ph.D.*

In October of 2007, another positive step was taken to advance the field of fetal alcohol spectrum disorders (FASD), by highlighting progress in intervention and treatment. The FASD Fall Leadership Conference, titled "Intervention and Treatment for Alcohol-Affected Individuals: The Next Challenge," was sponsored by the FAS Center of the Marcus Institute in Atlanta. A university center for Excellence in Developmental Disabilities, affiliated with the Kennedy Krieger Institute, the Marcus Institute is a charitable non-profit organization with a mission of "turning disabilities into possibilities."

That positive outlook was the foundation of the conference, and intervention and treatment remain important themes to families and treating professionals. Intervention and treatment methods are also gaining increased attention in research, public policy and publications. There is mounting community awareness of the need for (and possibilities of) treatment for those with FASD.

### Conference participants:

Attending this well-run conference were leaders in FASD intervention: parents, clinicians, researchers, policymakers, judges, representatives of family and professional organizations— and experts in other fields who could prompt creative and productive new directions. Participants came from all over the U.S., and from locations as far away as Canada and South Africa. Dr. Claire Coles, Director of the Marcus Institute FAS Center and Professor of Psychiatry and Behavioral Sciences at Emory University School of Medicine, and her remarkable team of colleagues were the energizing force behind this effort. The conference was designed to bring together individuals who could discuss what has been done so far in FASD intervention, brainstorm what is needed to move the field forward, and create informed recommendations. Peer-reviewed publications were sent out in advance to create common ground among participants.

### Conference goals and expert opinion survey:

The morning of October 21st began with Dr. Coles laying out conference goals and information from an opinion survey sent to attendees prior to the conference. A significant highlight of survey results showed that all respondents firmly believe in the possibility (and reality) of improved outcomes for individuals with FASD. Participants gave many reasons, such as what we now know scientifically about brain plasticity, and what we know about the effectiveness and positive outcome of early intervention in other contexts. Other reasons included promising results of current systematic research on tailored FASD intervention studies, and "protective factors" that have been identified related to positive outcomes in naturalistic, retrospective research. Respondents indicated there was also reason to believe in improved outcomes based on reports by parents of children with FASD. These parents gave examples of significant improvement in their children arising from learning and behavior interventions.

The opinion survey also outlined the next steps (and most important areas) for intervention and treatment for individuals with an FASD. These were in the areas of advocacy, research, clinical applications, education, care giving/family education and support, professional/community outreach, and public policy. Early intervention was often cited, as were behavioral interventions, social skills/friendship groups, alcohol and substance abuse education, and medical treatments. Responders also emphasized the great need for individualized programming for affected individuals and their caregivers. Survey results gave many other ideas about treatments, limitations in knowledge, and challenges between or within systems of care. Survey results also noted recommendations made in 1996 by the Institute of Medicine Report on FASD that still need action.

*At the Leadership Conference, there was a clear sense that sustained effort, and building on what has been done so far, were important in responding to the needs of individuals affected by prenatal alcohol exposure.*

### **Maintaining momentum and mapping the future of FASD intervention:**

Callie Gass, who has played a central role in the Substance Abuse and Mental Health Services Administration (SAMSHA) FASD Center for Excellence, gave a talk entitled, "Continuing the Conversation: Town Hall Meetings Four Years After." Fifteen town hall meetings held in different states across the U.S. were convened in 2002 and 2003. Their findings were published in a report called: "*Starting the Conversation: Town Hall Meetings on Fetal Alcohol Spectrum Disorders*," available through the SAMSHA FASD Center for Excellence. The town hall meetings allowed various FASD constituency groups to identify areas of need and share information on available services for preventing and treating FASD. Participants ranged from persons with an FASD to families, providers, community leaders, researchers and policymakers, while testimony addressed needs and best practices. The meetings raised awareness of FASD and increased support for states' efforts. Ms. Gass noted that the FASD Center for Excellence has been working to meet identified needs, and to catalogue efforts toward prevention, diagnosis and treatment of FASD on an impressive Web site. She pointed out what has been done to prepare useful publications, sponsor community-based research, and conduct a widespread campaign of public and professional education. [See [fascenter.samhsa.gov](http://fascenter.samhsa.gov) for more information].

Dr. Heather Carmichael Olson of the University of Washington gave a talk entitled, "A Call to Action: Mapping the Future of FASD Intervention." Dr. Olson covered the history of FASD intervention efforts. And she sounded a call to action to maintain progress and map the future of this important effort. Dr. Olson noted that the July 2007 annual meeting of the FASD Study Group, an international research-gathering panel, was focused on intervention research. She also spoke about the efforts of the [National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect](#), a Congressionally mandated committee that operated from 2000 to 2007 and was coordinated by the U.S. Centers for Disease Control (CDC). This task force included researchers, clinicians, policymakers, family advocates, and liaison representatives of important professional organizations. Dr. Olson reviewed the 10 specific recommendations of a new Brief Research and Policy Report, written by task force members, titled, "A Call to Action: Advancing Essential Services and Research on Fetal Alcohol Spectrum Disorders." (See sidebar)

**The  
National  
Task Force  
on FAS and  
FAE is  
about to  
issue a  
Brief  
Research  
and Policy  
Report  
titled: "Call**

Dr. Olson suggested strongly that advocates (and others who care about FASD) obtain and disseminate copies of the report to stimulate progress on intervention.

Dr. Olson also discussed the “essential ingredients” in intervention for FASD and the need for a continuum of services, emphasizing that FASD affect individuals of all ages and families across generations. Dr. Olson shared ideas for leveraging research to make faster progress on FASD intervention, including mention of current systematic CDC-funded treatment research. Ending her talk, Dr. Olson shared her views on why FASD intervention is very worthwhile. Current research suggests the promise of intervention... but so does the commitment, courage and progress made by affected individuals and their families, and caring providers. These are human resources with great power for change.

### **The possibilities of early intervention for FASD:**

Early intervention was a clear focus in the conference, and is likely to be a major focal point in treatment for FASD. Early intervention holds promise, but research and community efforts need to be mobilized. Shahirose Premji, R.N., N.P., of the University of Calgary in Alberta, Canada, spoke about “Early Intervention for Children and Youth with an FASD: Is There a Sufficient Research Base?” Her published research, in which she reviewed existing literature, emphasized the need for building a foundation of scientific evidence upon which to draw recommendations about efficacious interventions for children and youth with an FASD. This was another call to action for the field.

Dr. Sharon Landesman Ramey, of Georgetown University Center on Health and Education in Washington DC, gave a talk based on her wealth of experience, extensive publication and public policy leadership in the field of early intervention. Dr. Ramey conducted some of the very earliest research on the impact of prenatal alcohol exposure on human infants. At the conference, Dr. Ramey spoke about “Tailoring Early Interventions to Maximize Child Benefits and Feasible Service Delivery.” Among other topics, Dr. Ramey presented principles of effective early intervention, and suggested strategies for how early intervention for FASD could be approached. She acknowledged the utility of family support services. But essential points made by Dr. Ramey were that the most effective early intervention lies in direct treatment of the child, and that more intensive early intervention has been found to be most effective over time.

### **Assisting the educational system in responding to FASD:**

Assisting the educational system in responding to school-aged children with FASD was another major conference focus. Dr. Anne Smith, of the U.S. Department of Education, and Dr. Sally Anderson, of the National Institute on Alcohol Abuse and Alcoholism (NIAAA), spoke about this topic. They gave an overview of themes from a recent symposium called, “Improving Educational Outcomes for Students with Intellectual and Behavioral Disabilities due to Prenatal Alcohol Exposure.”

This symposium was sponsored by the [Interagency Coordinating Committee on Fetal Alcohol Syndrome \(ICCFAS\)](#), which works to guide collaborative efforts of service systems relevant to disorders caused by prenatal alcohol exposure. The recent symposium showcased growing research on how to improve outcomes for school-aged children with FASD, and the need for data to guide educational efforts. At the conference, this presentation emphasized a commitment to implementing evidence-based educational practice for FASD.

### **Brainstorming recommendations for intervention and treatment for FASD:**

The afternoon of October 22nd and morning of October 23rd were spent in targeted and productive group discussion. Groups were focused on: (1) Education/Early Intervention, (2) Medical/Diagnostic Issues, (3) Social Policy/Justice Issues, and (4) Behavior/Mental Health Issues. Groups were set up to include a wide variety of perspectives and practical experience pertinent to

*to Action:  
Advancing  
Essential  
Services  
and  
Research  
on Fetal  
Alcohol  
Spectrum  
Disorders.”*

**This report  
can be used  
by  
advocates,  
and by  
those who  
want to  
learn about  
FASD  
intervention  
and  
research.**

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the specific discussion topic.

Throughout the conference, formal and informal discussion was wide-ranging. Only a few discussion topics are mentioned here. Dr. Colleen Adnams, from the University of Cape Town in South Africa, discussed intervention and prevention efforts in an area of the world where the public health problems of FASD is especially prevalent and troubling. Dr. Barbara Morse, of the Fetal Alcohol Education Program in Boston, Massachusetts, talked about the need for pulling together standards of care, educating physicians and medical students about FASD, and creating a "better public face for FAS." The activities of the CDC-funded [Regional Training Centers](#) for professional education on FASD were mentioned. Participants noted the importance of "service to science" data gathering, and also highlighted the importance of supporting families, and the continuing and pressing need to train professionals in many disciplines about FASD. Groups generated creative ideas for education and for raising community awareness through the Web. There was also speculation about needed directions for future research, and lively networking to create ideas for future projects.

The final hour of the conference brought together the "sense" of the conference, the output of group discussion, and concrete recommendations. These are to be disseminated by conference organizers in future publications.

### **Coming together with hope for the future:**

This conference was a wonderful intersection of families, professionals and policymakers. Representatives of the NIAAAA, CDC, SAMHSA, Center for Substance Abuse Prevention (CSAP), and the U.S. Department of Education were all there. Academic institutions, hospitals, state and judicial agencies, developmental disability organizations, consultants from other fields, and FASD family advocacy organizations, such as NOFAS, were represented. Pioneers and leaders in the field came together with a new and growing generation of those interested in FASD. This Leadership Conference was creative and energizing—accomplishing its aim to build momentum and a strong sense of purpose to help individuals with FASD and those who care for them.

**This article can present only conference highlights. Additional detail on conference content may be available directly from the FAS Center at the Marcus Institute at: <http://www.psychiatry.emory.edu/PROGRAMS/GADrug/>**

*Heather Carmichael Olson, Ph.D., is a licensed psychologist in the University of Washington FAS Diagnostic Clinic. She is also a faculty member in the Division of Child Psychiatry with the University of Washington School of Medicine, and a clinical researcher with the Seattle Children's Hospital Research Institute. Over the years, she has worked directly with many families raising children with fetal alcohol spectrum disorders. She is currently the intervention developer of the Families Moving Forward Program (FMF), a tailored intervention for families raising children with FASD. At present, she is principal investigator of a research study transitioning the FMF Program into the community. She also directs the Early Childhood Mental Health Clinic at Children's Hospital and Regional Medical Center.*

[return to top](#)

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Briana, age 17 and a high school senior, won an award at her school in March 2008 for "Every Student Succeeding." Below is the essay she wrote about her struggles and triumphs in overcoming adversity.

### **From Tragedy to Triumph**

*By Brianna Koepp*

I came into this world April 13th, 1990 at Long Beach Memorial Hospital to a crack addict and alcoholic. My birthmother, I am told held a bottle of Jack Daniels Whiskey firmly to her chest and the emergency room personnel were unable to pry it from her grip until I was born. Then my first fragile minutes of life kept them otherwise occupied. I was suffering intrauterine growth retardation, holes in my heart, cerebral palsy, as well as withdrawal.

My prognosis was bleak. Children born with Fetal Alcohol Effects and Crack Cocaine addiction were expected to have a poor future. After a stint in neonatal intensive care I was whisked up by the Department of Children and Family Services and placed in a foster home.

My initial placement was in the home of a kind Jehovah Witness family that went on a vacation and left me for respite care in what became my permanent home. While in respite with the Koepppe family, the foster mother noticed I kept turning blue and I was very unresponsive and weak. She took me to a cardiologist and found I had several holes in my heart. I also went to a neurologist who discovered I had cerebral palsy. The first foster family had assumed that because I was a drug baby I could be over-stimulated so they kept me in a box in a darkened room all the time. This made my cerebral palsy worse and I became very withdrawn, and failed to thrive. I was six weeks old when the Koepppe Family got me. They had an adult daughter who was a nurse and she immediately began physical therapy. They held me constantly and played with me to stimulate my brain.

Initially, I was assessed as possibly being autistic and mentally retarded. My foster parent's days were filled with taking me to from one specialist to the next; a neurologist, a developmental pediatrician, a geneticist, and a cardiologist. I suffered global delays which meant I was not able to communicate, walk, or play like other children my age. My lower legs suffered from hypertonia and my upper body suffered from hypotonia, or weak muscles. My foster parents brought up the topic of adoption to my social worker, but she shot it down stating I was damaged goods and considered unadoptable because of my multiple problems.

The most important thing I have learned from my adopted family is to never give up. They did not accept that I was damaged goods and that there was no future for me. They also did not accept that I was unadoptable. The woman, who became my mom, didn't go to my social worker's supervisor, nor did she go to her supervisor. Instead she contacted the director of adoptions and made her listen to her desire to adopt me, and also told her that she felt I could be anything I wanted to be as long as I had a loving safe family behind me, and that they were that family.

It took fifteen court appearances for my adoptive parents to fight for the termination of my birthmother's parental rights, and for me to be referred to adoptions. I was three when my adoption was finalized. My parents told the judge they would love me no matter what my future held, but they were determined I would make it. They did everything they could to help me reach my potential. Their determination became my own motto.

The Journey of my short life has not been easy. I went through years of physical, occupational, and speech therapy. Initially I went to Buena Park Speech and Language Center, a non-public school for special children. There I first learned sign language to communicate. Then, I was transferred to my own school district where I received intensive speech therapy. During this time my family also worked with me. They patiently and repetitively went over academic milestones so when I entered kindergarten I could already read. My health problems continued. I still suffered failure to thrive and was chronically ill. I tired out easily from muscle fatigued. I also had to have three surgeries. Eventually, I did learn how to walk. First, on my toes at two, then my parents put me in dance class to help my muscle coordination. I watched the advanced senior dancers in awe and told myself someday that was going to be me. I had to work ten times harder than everyone because of the holes in my heart and my hypertonia, but the girl who was not supposed to learn to walk continued to dance. I have been dancing now for fourteen years. Last year I performed at Disneyland, on a cruise ship to Mexico, and for the Sante Fe Springs Parade with the Broadway cast of Grease as well as took high first awards in several dance competitions.

When I was in third grade my class was able to attend an honor roll assembly for the upper graders. I watched the smartest kids of my school take Presidential Honor Awards and make honor roll. I knew that school came hard for me but I was determined that when I was graduated from fifth grade, I would be walking off the stage with those awards too. Teachers informed me it would be very difficult to receive those awards, but my family supported me and in fifth grade, I took home every award, but the Daughters of the American Revolution (DAR).

I have continued to struggle throughout my school years, yet I have remained an honor student both in middle and high school. Today, I am a senior taking Calculus, and at this time I have a B. I am very proud of myself. Through my personal struggles, I have learned invaluable life lessons. I have learned that anything is possible when a person believes in themselves, establishes personal goals, and is willing to work hard enough to attain their dreams. I look at how my life was supposed to have been a tragedy, but instead through faith and hard work became a personal triumph. I know I will continue to succeed.

## Reader submission

### Thinking of Kirt

My name is Aaron and I am 17 years old. I am adopted. My birthmother abused drugs and alcohol and I have had to work hard in school. My family has adopted a lot of kids who have been hurt by drugs and alcohol. My sister adopted Kirt and he has Fetal Alcohol Syndrome. At school I hear about kids who get drunk all the time and are partying. A lot of these girls end up pregnant. My teacher asked us to write a poem about the dangers of alcohol so I wrote about Kirt. He is mentally retarded. It is so sad he could have been normal if his mom hadn't drank during her pregnancy. These girls could have a baby like Kirt. My sister liked the poem I wrote and told me to share it with you. Maybe you should talk to teenagers more they aren't hearing enough about FAS.

--Aaron Koeppe, December 2007



Kirt  
Now... 7 years old  
Birthmother ignored  
What she was told.

She took a little Heroin  
She took a little speed,  
A dime a day...  
Didn't take care of her need.

An innocent babe, Kirt  
Grew in her womb  
Every sip of alcohol was  
Leading to his doom.

Born too tiny  
With a small head  
The doctors figured  
He was better off dead.

"Why?" They cried,  
"We told you pregnancy  
And alcohol doesn't mix!"

You've brain damaged your baby!  
This is not something we can fix!"

Fetal Alcohol Syndrome is Kirt's illness's name  
Drink any alcohol while pregnant,  
And your child will be lame.

Some young girls they party,  
...have sex, do drugs and are wild...  
Never knowing they are growing a child.

By the time you find out your baby could be hurt  
Before you think of partying  
Please think of Kirt!

[return to top](#)

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## FASD Conference, in Seattle

The Center on Human Development and Disability (CHDD), at the University of Washington, is hosting an FASD conference showcasing FASD efforts at the CHDD and sister institutions. The event is sponsored by CHDD Director, Michael Guralnick, Ph.D.

A distinguished researcher in the field of FASD, Claire Coles, Ph.D., will be a featured speaker. Dr. Coles is Director of the Fetal Alcohol Center at the Marcus Institute, a university-based child development center in Atlanta, Georgia, She is also Professor of Psychiatry and Behavioral Sciences at Emory University School of Medicine in Atlanta.

The key event will be a 3-hour conference.

Place: Experimental Education Unit at the University of Washington (CD 150 auditorium)

**Date:** April 3, 2008

**Time:** 9-noon

Topic: FASD: How Do We Meet the Challenge?

Speakers:

Susan Astley: Strides in FASD Diagnosis and Prevention in Washington State

Therese Grant: Preventing FASD: Successful Strategies and Lessons Learned from the Parent-Child Assistance Program

Heather Carmichael Olson: A Call to Action: Current Research on FASD Intervention (and Contributions from Washington State)

Claire Coles: FASD: New Directions for Research and Practice

Refreshments will be served.

All are welcome to attend.

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Thank you.

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[return to top](#)

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