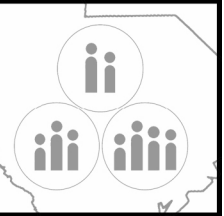


FEDERATION OF FAMILIES OF SOUTH CAROLINA
SUPPORTMATTERS



A Mother's Story on Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder, (FASD) is a term used to describe a range of syndromes and disorders that can occur in a child whose mother consumed alcohol during pregnancy. The effects and symptoms vary in severity. Many children share the common effects which include emotional, physical and learning difficulties. The common physical characteristics that can be associated with FASD are facial deformities, growth deficits, heart, liver, kidney defects, vision and hearing problems as well as permanent brain damage. FASD is the only 100% preventable cause of mental retardation and birth defects in the United States. It is estimated that FASD affects 40,000 infants each year. This is more than Spina Bifida, Down Syndrome and Muscular Dystrophy combined.

Alcohol damages the parts of the brain that gives us memory, self control, coordinator and judgment. Children with FASD often have difficulties with learning, attention, memory, central nervous system, and problem solving skills that may have lifelong implications. FASD is a permanent condition and affects every aspect of the child's life and the life of their family.

The emotional toll on families can not be underestimated. For birth parents, acknowledging that their child's mental retardation, birth defects, and/or neurodevelopment disorders are a result of maternal prenatal alcohol consumption is very difficult to face. For adoptive or foster parents, discovering that their child suffers from FASD

after years of trying to understand his cognitive and behavioral problems results in feelings of frustration and isolation.

As an adoptive mom, I can tell you raising a child with FASD is the hardest but the most rewarding thing I have ever done. Andrew is now 7 years old and is in the first grade. He is sweet, generous, loving and very naive. He also has exhibited many of the symptoms associated with FASD since the day we brought him home at 1 week old. He cried all the time! Until he was 3 years old and on medication he never slept for more than 30 minutes at a time, day or night. To say life seemed impossible is actually an understatement. He required constant attention and if I let him out of my sight in another room for one minute he would destroy it. If I was not right beside him when he had a bowel movement in his diaper he would take it off and smear feces all over the walls, carpets and bed. We had to put a lock on our refrigerator because he would climb out of his crib in the middle of the night and dump everything out of the refrigerator smearing it in the carpet, walls, and beds. We went years knowing that there were serious problems, but no one could help us. All of the professionals said that his behaviors were out of their expertise. We went from Doctor to Doctor, counselor to counselor and searched everywhere for answers for him and our family. By the age of three, he was thrown out of every daycare in our area, went through at least 30 babysitters, and could not stay in the nursery at Church. He was very violent toward everyone; however, most of his rages were taken out on me. He would bite me, hit me and throw things at me. He would put holes in the wall, windows, threw rocks at us, as well as the cars and was basically never happy. When he started school a whole new nightmare started. The fourth day of school he had thrown toys, supplies and destroyed the classroom then ran out of the room causing the teacher to have to leave other students to chase my 4 year old. He was moved

Contact Us

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Federation of Families of South Carolina

Youth Council In Action

The Federation of Families of South Carolina (FFSC), Youth Council In Action (YCIA), was organized and named by nine youth in 2007. The youth organizers have parents involved with FFSC. The group was organized at the request of FFSC Board of Directors as an advisory of youth who could express the needs of children and adolescents with mental health needs. The YCIA has developed guidelines for new members. Youth should be between the ages of 12 and 21 and either be identified with a mental health disorder or be the sibling or friend of a youth who is identified. New members will be added to the advisory council from each area of the state that develops a youth network. Currently Anderson, York and Williamsburg counties are working to develop youth networks. The YCIA have developed interview questions to determine the level of interest of new members to participate on the advisory council. Any youth interested in participating on the YCIA and helping develop a youth network in their community should call the FFSC office.

Richland and Lexington Counties Youth Network

Youth from Richland and Lexington Counties have formed an education and support network. The youth network will meet December 11, 2007 at 7:00pm at Three Rivers Behavioral Health Center in West Columbia. There will be a presentation on adolescent self-injury. The January 8, 2008 topic will be youth transition beyond high school. These meetings are open to youth, ages 12-21 with mental health and/or co-occurring drug and alcohol problems, their siblings and friends.

The family support network, for parents and other caregivers, meets at the same location and time in the private dining room. For more information about either group, call Crystal Bivens at 803-799-0402.

The New Epidemic Adolescent Self-Injury

Self-injury has become epidemic-like with approximately one out of every 200 girls between the ages of 13 and 19 practicing self-injury. Girls tend to be more prone to self-injurious behaviors but an estimated 11,000 American boys are also affected each year.

The actual definition of self-injury, also called self-mutilation, is deliberate injury inflicted by a person upon his or her own body without suicidal intent. Self-injury can take many forms, the most common are: cutting, burning, scratching, pulling out hair, carving, stabbing with a sharp object or constant picking at the body.

There are no set rules or reasons that someone would self-injure but the most common reason is to release stress and tension or bad feelings. To make emotional pain more real, to take away a feeling of numbness or to express feelings that cannot be expressed. The intention of committing suicide is not why most self-injurers harm themselves. They see self-injury as a way of keeping themselves alive and of coping with emotional stress. People who attempt suicide want to die. Those who self-injure want to feel better. They are attempting to survive the only way they know how. The truth is they have stumbled across an unusual but effective way to relieve their deep emotional pain. They have discovered that physically stimulating a specific part of the body can reduce emotional pain. This is called the body-mind connection.

Self-injury is treated with medication (medication prescribed such as anti-depressants are used to treat the underlying feelings) and counseling to help the person cope and deal with the causes and problems that result in self-injury.

Treating the self-injury behavior is very important but parents need to realize that treating the underlying cause of the behavior is equally important.

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Congratulations Poster Contest Winners!

Thank you!! If you participated in voting for the artwork that will be featured on the 2008 Children's Mental Health Week poster.

The third annual poster contest took place in October and was our most successful to date. This year we far exceeded past years with thirteen entries and over 30,000 votes. Fantastic! The winning artwork is from William S. Hall Psychiatrist Institute Unit 256.

Last year a number of Federation of Families state organizations in other states used the poster designed for South Carolina. Children's Mental Health week is observed each year the first week of May. Stay tuned for the unveiling of the 2008 Children's Mental Health Week poster.



Federation of Families of South Carolina

JOB OPPORTUNITIES

OASIS Project Family Coordinator

The Federation of Families of SC will be working with the SC Department of Mental Health, OASIS project to increase family involvement in targeted communities statewide. Job duties will include family outreach, training, and assisting with a community needs assessment. Preference in hiring will be given to a parent or primary caregiver of a child or adolescent with an emotional disorder or mental health needs. Must have reliable transportation and be able to work a flexible schedule to meet the needs of families.

Project Focused Agenda Outreach Coordinator

The Focused Agenda partners include the SC Department of Education, Office of Exceptional Children, SC Department of Mental Health, Child, Adolescent and Family Division, SC Department of Juvenile Justice and the Federation of Families of South Carolina. The Federation is seeking three part time family outreach coordinators and one part time statewide youth coordinator to work on this project. These positions will work in the targeted areas of the state that have been identified in promoting Positive Behavior Interventions and School Based Mental Health Services as part of the Focused Agenda. Outreach coordinators will provide information, training and support to family members in these communities as well as work to increase family involvement. The statewide youth coordinator will work with the outreach coordinators to identify and engage youth to become involved and develop youth networks in these targeted areas.

For more information on any of these positions go to www.fedfamsc.org or contact the Federation of

GoodSearch

Next time you need to do a search make sure to go to GoodSearch and enter the Federation of Families of South Carolina as your organization. GoodSearch makes donations to registered organizations each time you use their service and enter an organization name. Use GoodSearch today!!



Thanks to the following Donors

Dr. & Mrs. Peter Neil Barry
Anonymous thru Allstate The Giving Campaign
Memorial—In Memory of Leroy Robinson Sr. by faculty and staff of Southeast Middle School

The Federation of Families of South Carolina will keep you up to date on current issues and provide direction on who to contact to effect policy change. Emails are sent on state and national issues related to children's mental health. Topics may include IDEA reauthorization, Medicaid funding, children's services, and respite care. If you are interested in joining the Action Alert Team, or if your e-mail address has changed, email crystal.bivens@fedfamsc.org. In the subject area please type "add me to the Action Alert Team email list".



Federation of Families of South Carolina

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to an emotionally disabled class where they had experience with other children like him.

By the time he was 5, he had so many diagnoses I lost count, but none of them actually explained the severity of his behaviors. We had tried 21 different medications and tried at least 4 different kinds of therapy. We started researching the internet and found a few sites about FASD and found that there were several places in the US that specialized in FASD.

Andrew and I packed up, leaving my husband and other two children at home and went in search of a diagnosis. We went to Baltimore, MD and saw a FASD specialist that finally gave him an accurate diagnosis of Fetal Alcohol Syndrome. While we finally had a diagnosis, nobody seemed able to help us get his behavior under control and his behavior was getting worse. At that time, he was on 7 medications, however none were effective. We went back on the internet searching and learning about FASD and found a "severe" behavior clinic, The Marcus Institute, in Atlanta GA. They observed his behaviors and they immediately asked if we would be open to coming to Atlanta to live for a couple of months so he could attend the clinic. It was their observation that his behaviors were something that would not ever get better without extreme intervention. At this point we had no choice; he was getting bigger, stronger and more destructive everyday. After fighting insurance complications, Andrew and I went to Atlanta where he underwent treatment, testing and training for eight weeks.

After two months of hard work the severe behavior clinic was able to decrease his problem behaviors by 96.6% from when we first started the program. The skills we learned are skills we are still using to keep his behavior under control. While we still have bad days, we also now have good days. He is able to stay at school all day now, with the help of a shadow, and he is able to play baseball and football with other kids his age and he is happy.

Andrew, as well as most children with FASD, will never be what others feel is "normal" and that is okay with us because he is now a happy little boy. He is learning to read, and is slowly learning social skills. We had to adjust our expectations as well as learn to think "outside of the box" when we are dealing with him and his problems. We are living a fairly normal life,

whatever that is. We are not healed in the traditional sense, but we are functioning and making progress. He is now off of 5 of the 7 medications and has really grown physically and emotionally.

Most children with FASD have many issues to face their entire lives. FASD is not a treatable or curable condition that can be fixed with therapy or medication. There are some children who benefit from certain types of medication, but the medications only address some of the symptoms. Creative behavior management works well most of the time. Children with FASD have processing problems and can not understand cause, effect, or consequences. One of the most important things I have learned from my son is to keep an open mind, a sense of humor, and my faith in God.

Many thanks to Kerry Johnson of Newberry for contributing her story.



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When a parent learns that their child is self-injuring they fear what it means for their child and they are hurt. It is very difficult for parents to understand why their child would hurt themselves to try to feel better.

Adolescents may react in a number of ways if confronted by their parent about self-injury. They may deny it, make excuses, get angry or apologize and promise never to do it again. But, it is rare that even if they could explain why they are doing it that they would discuss the underlying problem with a parent. Once discovered the youth may appear to have changed their attitude and to have stopped the behavior but may just be doing a better job of hiding it or has found other ways of dealing with the stress. Seeking professional help is very important.

To adolescents they tend not to see this behavior as a big deal and believe that if it makes them feel better they have taken care of the problem. To the parent it should be viewed as a cry for help.

For more information on self-injury see our website at www.fedfamsc.org, for support and referral to help contact the Federation office. Call Toll-Free 866-779-0402.



Family Support Networks

If you are the parent of a child or adolescent who has been identified with a mental health disorder or is having emotional or behavior problems, join other families in your community who will understand.

If there is not a group listed in your community, please call our office toll free at 1-866-779-0402. We may be able to connect you with other parents in your community.

Anderson County

Phone Support Only
Jimmie Craig (864) 338-0227

Barnwell County

WINGS
Call for day and time
Macedonia Elementary School
Jones Bridge Road, Blackville
Catherine Mack (803) 284-1026
Eartha Peeples (803) 284-3136

Beaufort County

Call for day, time and location
Rita Jaklitsch (843) 706-2395
Sharon Brown (843) 757-7107

Beaufort County

Phone Support Only
Melina Lee (843) 379-4411

Charleston County

Phone Support Only
Kristin Jacksa (843) 881-7277

Chester County

Chester
4th Tuesday
Call for time
Chester Public Library
Katherine Caldwell (803) 581-7672
Susan Stack (803) 581-5365

Dillon County

Call for day, time and location
Laurie Caulder (843) 752-1610

Fairfield County

Phone Support Only
Shirley Green (803) 635-6086

Florence County

Florence/Darlington
2nd Saturday 8:00-9:00am
Pamplico Highway across from
Carolina Hospital
2nd Wednesday 9:30-10:30am
Carolina Hospital—2nd floor South
Tower Conference Room
Call (866) 779-0402 for more info

Greenville County

Greenville
Call for day, time and location
Maria Atkinson (864) 884-7460

Greenville County – Greer

Greer/Greenville/Spartanburg
1st Thursday 10-11am
(parents of 12-up)
2nd Wednesday 10:30-11:30
(parents of 5-12)
NAMI Greenville Office
2320 East North St Suite L
Kelly Troyer (864) 346-7446

Greenwood

Parents United
Every Monday 5:00-6:30
Greenwood Children's Center
113 Liner Dr.
Tara Cothran (864) 941-8196

Hampton County

Hampton
Call for day, time and location
Mary Morris (803) 943-9191

Horry County

Phone Support Only
Melanie Alcock (843) 564-0040

Lancaster County

3rd Sunday
Lancaster Public Library
Bridgett Reeves (803) 273-9133

Newberry County

3rd Monday 6:00-7:00pm
Call for location
Kerry Johnson (803) 940-1383
Ryan Kinard (803) 276-3541

Richland/Lexington County

Lexington/West Columbia
1st Tuesday 7:00-8:00 pm
Three Rivers Hospital – Hwy.378
(private dining room)
Crystal Bivens (803) 794-9796

Richland County

Phone Support Only
Pheobe Malloy (803)695-5700(w)
(803)776-4105 (h)
Lillie Griffin (803) 731-7643(h)

Spartanburg County

Phone Support Only
Patti Smith (864) 591-0453

Sumter County

Sumter—Phone Support Only
Maureen Fitzgerald (803) 469-9729

Williamsburg County

Hemingway/Andrews/Kingtree
Call for day, time, and location
Glander Pressley (843) 382-8685

York County

Rock Hill
2nd Tuesday
Oakland Ave. Presbyterian Church
Judy Rauppis (803) 324-1439
Carol Mapp (803) 324-0780

York County

Rock Hill
Sibling Support Group (Ages 8-13)
One Saturday per month
Call for time
YouthNet Building
Christine Wilson (704) 634-8298

York County

Rock Hill—Phone Support Only
Catawba Nation—Peer-to-Peer
Sherri Smith (803) 324-8936

York County

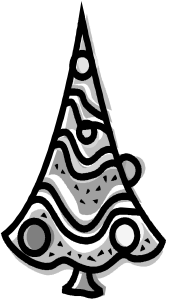
Fort Hill
2nd or 3rd Monday
St. Philip Neri Church
Betsy O'Brien (803) 802-4484



Updated 12/5/07



It's the season of giving!



Help the Federation of Families of South Carolina continue its mission in 2008.

In 2007 the Federation provided:

- *one-on-one assistance to over 800 family contacts
- *developed a website that has averaged over 900 visitors a month
- *distributed over 14,000 pieces of information regarding children's mental health
- *provided technical assistance to 25 family volunteers who facilitate family support networks
- *represented families on over 47 committees
and many other services.

No donation is too small! Please complete the information below and return it in the en-

Please accept my tax deductible donation to the Federation of Families of South Carolina.....

Name _____

Address _____

_____ **Zip** _____

Telephone _____ **E-mail** _____

I am enclosing \$ _____ to help the

Federation continue its mission in 2008.

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