

Family Behavioral Resources Autism Services Newsletter



FBR and FBR Bridges to Hope Educate the Community about "Where It All Begins;" Rebecca Klaw, Founder of ASK!, Speaks at 5th Annual Autism Awareness Night



Family Behavioral Resources and FBR Bridges to Hope, thanks to grant funding from the DPW's Bureau of Autism Services and Autism Speaks, hosted its annual Autism Awareness Night on April 2nd, 2008 at the Radisson Hotel in Monroeville.

April 2nd not only commemorated the 5th anniversary for this yearly event at FBR, but more importantly, the 1st World Autism Awareness Day as recognized by the United Nations. This marks only the third time in history that an illness was granted an official day of recognition by the UN.

This year's keynote speaker was Ms. Rebecca Klaw, founder of Autism Services by Klaw (ASK!). Prior to working as an independent consultant, advocate and trainer, she was the Program Director for the Center for Autism at Pressley Ridge.

Rebecca's presentation, "Autism: Where It All Begins—Babies as Learners, Adults as Teachers," offered participants a greater understanding of how the characteristics of Autism impact early child development. Other topics addressed included Theory of Mind, joint attention, and social referencing. The audience learned more about how infants who are not meeting developmental milestones seem to have fixations on things as opposed to people.

As the adults participated in this informative seminar, over 50 children were treated to an evening filled with games, crafts, movies, and more in a neighboring room. We sincerely thank the FBR

Monroeville management team and the clinicians who facilitated this evening of fun!

We also thank the local organizations who provided their invaluable information to those in attendance— ABOARD, Autism Speaks, the University of Pittsburgh, Center for Excellence in Autism Research, and Autism Services by Klaw.

Rebecca has produced two DVDs: *Relationship-Based Intervention* and *Thoughtful Response to Agitation, Escalation, and Meltdowns*.

Anyone interested in either contacting Rebecca or purchasing her materials, may visit her website, www.rebeccaklaw.com.

Mark your calendars for April 2, 2009! We will be featuring Diane Williams, Assistant Professor from the University Of Pittsburgh, and Research Investigator at CeFAR!

April is Autism Awareness Month

Volume 3, Issue 2

Spring 2008

"Coming together is a beginning. Keeping together is progress. Working together is ... success."

~ Henry Ford

FBR applauds the collaborative efforts in our Autism community. Thank you for making a positive difference in the lives of families affected by Autism Spectrum Disorders!

Keep Walking for Autism! We need YOU!

There are several options for you and your family, friends and neighbors to get involved and walk in support of Autism!

Highmark Walk for a Healthy Community—Walk on behalf of ABOARD and support local support groups, advocacy, seminars, and family fun events! 5/3/08; Heinz Field; 7:15AM Registration. **100% of your donation goes to ABOARD. Thank you for your support! Visit www.aboard.org for details.**

Walk Now for Autism Events

Walk Now for Autism in Laurel Highlands! 5/18/08; Idlewild Park; 1PM Registration

Walk Now for Autism in Wheeling! 5/31/08; Warwood Trail, WV; 9AM Registration

Walk Now for Autism in Pittsburgh! Heinz Field; 8AM Registration

Walk Now for Autism in Blair County! 6/14/08; Blair County Ball Park; 9AM Registration

DID YOU KNOW?

FBR's H.O.P.E. for Tomorrow Team has raised over **\$164,000** for the Walk Now for Autism since 2004.

Last year, the Greater Pittsburgh Autism Speaks Walk Region raised over **\$1 million!** Over **\$600,000** came back to Pittsburgh for local researchers and efforts. Your dollars made a difference! Let's keep going! **Visit www.walknowforautism.org today!**

Inside this issue:

<i>A Proud Father Walks with his Son</i>	2
<i>Summer Ideas for Families</i>	3
<i>Help Save the Center for Creative Play!</i>	3
<i>Upcoming Events and Fundraisers at FBR</i>	3
<i>Support Groups</i>	4
<i>Other Local Supports for Your Family</i>	4

Stories from the Spectrum— “Walking with Kai”

By Michael Uzyak—North Hills, PA

Michael Uzyak is a very proud father from the North Hills of Pittsburgh. He shares his memories with our readers about Kai's struggles not only with Autism, but also with learning how to walk. We invite you to follow Kai's father through this touching story about his son's "steps to success."



At left:
Kai Arroyo, age 20 months, walks with his father, Michael Uzyak. Kai, now 7, walks with friends and loved ones—*unassisted*— for Autism research!

My son Kai has always loved going for walks. From the time he was an infant it's been one of his favorite things to do, and at the age of six it's certainly his preferred physical activity. For my part, I've always loved going for walks with Kai. It was a peaceful, relaxing experience, one during which Kai would leave me to my own thoughts and I would leave him to his but something shared somehow passed between us. I used to think of it as spending time “together but alone.”

“Together but alone.” It's a sad bit of irony that one of the things I enjoyed most about Kai would be my first clue that he was autistic. Of course, there were many others signs in retrospect. To begin with, my wife and I knew early on that Kai had some unspecified developmental impairment. We had started expressing concerns to his pediatrician when he was six months old, concerns which were dismissed until three months later when our suspicions were confirmed by the county's early intervention agency. That touched off a round of specialist visits and testing for some common (and some not so common) genetic disorders, all of which came back negative. Never once did any of the doctors mention autism, and if they had we wouldn't have believed them. Kai made good eye contact and was a very social baby . . . when the mood struck him, at least. He did have some repetitive behaviors – clapping and hand flapping – but those were common “autistic-like” stimulatory habits described by many of the disorders for which he was being tested. And his ability to count from one to ten and memorize at least half of the alphabet by the time he was sixteen months old? It never occurred to us that this skill was actually a form of echolalia, the repetition of verbalizations exhibited by a large percentage of persons with autism. But after watching a television news segment which described autism as always being alone

even in the midst of other people, I came to realize that Kai spent a great deal of his time around other people “together but alone.” That was the start of Kai's journey with autism.

Like most parents, I treasure just about every photograph ever taken of my children (even the bad ones). But I must confess that there is one picture of Kai that is without question my favorite. It was taken at the end of a difficult period in his development. At twenty-two months old and a year (or more) behind a number of major milestones, the hopefully ambiguous label “developmental delay” was being transformed by time and grudging acceptance into the more definite and much sharper “developmental disability” (his actual diagnosis of autism wouldn't come for several more years). In the picture he's on the street in front of our house, moving toward the camera with aid of a Kaye walker, a U-shaped frame of aluminum tubing on wheels. His lower body looks a bit like a cartoon character's, skinny little legs sticking out of a blue striped romper and ending in clodhopperish sneakers three sizes too large to accommodate the ankle braces he'd been wearing more or less every waking hour since he was a year old. I'm in the picture, too, following closely behind him with my arm outstretched to catch him if he should fall.

My wife and I both cried when we first saw the orthotic braces. Despite our attempt to disguise their true nature with a cute pattern – camouflage, appropriately enough – they were Kai's first pieces of medical equipment, the idea of his disability made tangible in plastic and metal. We had a similarly tearful reaction when his physical therapist brought over the walker, and after a few half-hearted attempts to get Kai using it we abandoned it to a corner of our foyer for weeks until the very day the photograph was taken.

So what makes me cherish above all other photos of my son one in which medical devices and adaptive mobility equipment are featured so prominently, a snapshot taken during a time when I went to sleep every night and awoke every morning struggling with the reality that his disability would be lifelong?

His smile.

It's not much of a smile – maybe more of a gentle smirk, really, a quiet

expression resplendent with enjoyment, satisfaction and accomplishment. Watching Kai trundle back and forth in front of the house in the walker I knew for the first time with absolute certainty that he would walk on his own, not because he was demonstrating the necessary physical capabilities but because that look on his face told me that he wanted to. The steps he took that afternoon, distilled perfectly in that one photo, were the most significant and inspiring I've ever witnessed.

I still turned into a blubbling mess two weeks later when Kai actually took his first independent, unsupported steps, and since taking them he hasn't stopped walking. He's logged mile after mile after mile doing a three-block route around our neighborhood (he could tell us he wanted to go for a walk long before he could communicate something as basic as hunger). He has circumnavigated every local mall too many times to count. He's strolled through six zoos and five aquariums across the country. He's hiked through dozens of parks and marched – in an unofficial capacity, I must add – in a number of holiday parades. Eight months ago he set off on a path that had terrified my wife and me more than any other – the journey up the steps of our local elementary school, out of the safe, accepting realm of our home and family and into kindergarten and the larger community. He's made that same trip practically every day since then, not to the uncertain reception which we had feared but into a wide circle of affection and support he has built himself among the staff and students.

Kai has also participated in two walks for autism research. In what I consider to be a perfect example of pulling himself up by his bootstraps, he has helped raise over \$9,000 for the cause. He'll be doing his fourth walk on June 7 in the 2008 Pittsburgh Walk Now for Autism. Kai's mother Astrid and little brother Heath will be leading the family contingent. I'll be there, too, of course – right behind him as usual but not following quite as closely as I once did. He'll also be joined by some of his classmates, teachers and other people he has met and touched along his way.

... Consider this your invitation to come along.

Fun Summer Activities for Families with ASDs



Summer is almost here and along with the long, warm days and school vacations come the inevitable drones of “I’m boooooored!” Why not try some of these simple activities that are fun for the entire family, and “Autism-friendly?”

~ Visit your local parks and recreation department for any organized group activities. Many communities have free summer programs that may include group games, sports, and arts and crafts.

~ Local libraries or bookstores often host summer reading programs for both school-age and preschool children. These may include guest speakers or story times for certain age groups.

~ If amusements or water parks are something your children enjoy often, the summer passes sold at Idlewild and

Sandcastle can be an excellent bargain. In order to make it economical, you should be someone who visits these locations multiple times over the season.

~ Many times, local churches will offer “vacation bible schools” or weeklong day camps, and often it is free to participate.

~ No time for the annual family vacation this year? Have one right at home! Buy a small tent and sleep outside. Best of all, know that the amenities of home are right there if needed! Pouring down rain? Don’t worry! Pitch the tent indoors! Don’t have a tent? You can make one out of bedsheets and hold it up with kitchen chairs!

~ Have a picnic at a local playground!

~ Older children and adolescents may enjoy having a “summer job” in the neighborhood, or even at home! They can walk the dog, clean up the yard, deliver newspapers

and more!

~ “Go fly a kite,” literally! You can make your own out of brightly colored paper or old newspapers. Fly them on a breezy afternoon!

~ If your child is learning how to label items, and they know their “ABC’s,” you can make up your own labeling game! Find foods or other household items that begin with every letter of the alphabet.

~ Does your child relate well to adults? If so, visit a local nursing home and let them spend time with a resident. Most elderly persons enjoy the company of children! Does your child love animals? Visit the local animal shelter, pet store, or zoo.

These are just a few ideas to get you started! We wish you a summer loaded with fun!

In the News: When the **Center for Creative Play** closed its doors in Regent Square on March 31st, it left a tremendous void for many families who frequented the inclusive, indoor play space. This center was utilized frequently by parents of children on the spectrum, from all over the state, and beyond. There is a grass-roots effort to reopen the Center, spearheaded by former patrons. They’ve named their group “Bring Back CFCP.” If you would like information on their efforts or would like to join the movement, you may visit www.bringbackcfc.com or send email to bringbackcfc@yahoo.com.

Upcoming 2008 FBR Events—Mark Your Calendars!

Visit www.familybehavioralresources.com, and click on the *Community* button for details.

Most flyers can be found in our *Downloadable Brochures* section.

5/1/08

FBR Family Fun Night, Southern Region. St. Benedict’s Church, McMurray, PA

5/8/08

FBR Bridges to Hope FUNdraiser at Max and Erma’s. Peters Twp., PA

5/9/08

Free Family Swim Night! The Woodlands, Cranberry, PA. Hosted in collaboration with ABOARD, Autism Speaks, and the Autism Help Network!

5/16/08

FBR Family Fun Night, Northern Region. Haine School, Cranberry, PA

5/30/08

FBR Family Fun Night, Eastern Region. Faith United Methodist Church, Delmont, PA

5/31/08

FBR Poker Run for Autism Research. Indiana, PA

7/19/08

1st Annual FBR Ride Now for Autism. Kittanning, PA

7/27/08

Autism Awareness Day at PNC Park in Pittsburgh!

Hosted in collaboration with Autism Speaks, Athletes Against Autism, ABOARD, and the Autism Society of Butler County!

8/16/08

2nd Annual FBR Golf Outing. Mt. Pleasant, PA

Camp Journey has expanded! We now offer our summer program in four areas—Beaver, Fayette, Somerset, and Westmoreland Counties! Camp Crossroads is still available in Indiana County. Visit our website for more information. Click on *Our Services* and then *Summer Camps* to learn more about how to enroll your child!

Family Behavioral Resources—Autism Services Family Support and Social Skill/Play Groups

Please call 1-866-4-FBR-ASD (432-7273) or send email to autismservices@familybehavioralresources.com with any questions or concerns. *All dates and times may be subject to change.*
Groups held at FBR BHRS locations except where noted. Please visit our website for up-to-the-minute information!

Family Support and Social Skill/Play Groups offered by FBR in partnership with ABOARD

Armstrong County

3rd Tuesday of every month @ 6:30PM

**Now located at Armstrong County Memorial Hospital; Conference Room #2, 2nd floor in Kittanning*

Beaver County

1st Tuesday of every month @ 6PM

Brentwood / Upper St. Clair

2nd Thursday of every month @ 6PM

Cranberry Township

2nd Thursday of every month @ 6PM

Gibsonia

3rd Monday of every month @ 6:30PM

Indiana County

1st Wednesday of every month @ 6PM

Mercer County

Last Monday of the month @ 6:30PM

Monroeville

2nd Monday of every month @ 6PM

Mon Valley

1st Monday of the month @ 6:30PM

**Located at the First Baptist Church, in Monongahela*

New Kensington

1st Tuesday of every month @ 6PM

N. Huntingdon

Last Monday of every month @ 6PM

Robinson Twp.

3rd Thursday of every month @ 6PM

Somerset County—FBR Somerset

2nd Thursday of every month @ 6PM

Uniontown (For Fayette and Greene Counties)—Coming Soon!

Washington County- FBR Washington

3rd Monday of every month @ 6PM

More Groups Supported by FBR:

ABOARD Bedford County Parent/Family Support Group

Social Skill/Play and Sibling Support Groups held in conjunction with this existing group for families.

1st Thursday of every month at 6:30PM

**Located at the Everett Church of God in Everett*

Deer Lakes School District

4th Wednesday of the month @ 6PM

**Located at Curtisville Primary Center, in Tarentum. Open only to families residing in the Deer Lakes School District*

McKeesport Tigers on the Spectrum

3rd Tuesday of the month @ 6PM

**Located at the MASD Administration Building in McKeesport. Open to the local community. RSVP to Patty Tkacik, Director of Special Education at 412-664-3622.*

Join one (or more) of our groups today! Groups are free to the public as part of FBR's ongoing commitment to community outreach.

Learn more about our groups for families by visiting our website. Click on the *Community Programs* page for details.

Is there a need in your area for more support?

Contact us about hosting an FBR H.O.P.E. for Tomorrow Focus Group!

GET THE LATEST NEWS FROM LOCAL AUTISM ORGANIZATIONS!

FBR is pleased to provide you with contact information for new and existing local organizations that work collaboratively to bring you conferences, seminars, and fun events for the entire family. This is just a sampling. Please see our resource guides, available for download online, for even more contacts!

ABOARD: Rebecca Williams-Thomas, Resource Coordinator. www.aboard.org; 412-781-4116

Autism Help Network: Corey Swanson, Founder. www.autismhelpforyou.org; 724-449-7072

Autism Speaks Walk Now for Autism: Lisa Maloney, Walk Manager; Greater Pittsburgh Chapter: Beth Whitehouse, Executive Director. www.autismspeaks.org; 412-367-4571

AVID Learning Center: Rebecca Moyes, President. 724-594-1092, www.avidlearning.org

Autism Society of America: www.autism-society.org. Local chapters are available in Pittsburgh, Butler County, and Westmoreland! County!

The HOPE Learning Center: Asha Persaud, Director. www.thehopelearningcenter.org

Parents in Toto: Mary Limbacher, Director. 724-473-0990, www.parentsintoto.com

The PEAL Center: Cindy Duch, Director of Parent Advising. 412-281-4404; www.pealcenter.org

www.familybehavioralresources.com—Visit us online today!