

The

ALL ABOARD NEWS



A Quarterly Publication from the Advisory Board on Autism and Related Disorders

Volume XIV— Issue I

Winter 2010

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Lookout for more details to come on

**ABOARD's
2nd Annual
Biomedical
Conference!
Spring - 2010**



ABOARD's 6th Annual All Abilities Camp Fair

**Saturday, January 30, 2010
10:00 am – 3:00 pm**

Shoppes at NORTHWAY

**Upper Level
8000 McKnight Road
Pittsburgh, PA 15237**

Come See What Your Child Can Do This Summer!

- Camps and programs for school and preschool age children with disabilities
- Inclusion friendly camps and programs
- Full and half day programs
- Information regarding extended school year (ESY)

Our Event sponsor



Shoppes at Northway (formerly Northway Mall) is located in the heart of the North Hills of Pittsburgh. Twenty minutes from downtown and is easily accessible from 279 North and the PA Turnpike.

Chairman's Message

Dear Friends of ABOARD,

As the 2009 year comes to an end, I want to take this opportunity to look back at some of our accomplishments this past year.

For ABOARD, it has been a year of renewed energy and programming. Our Saturday Seminars started again, and we had two very successful conferences: Our spring conference was Biomedical Integrative Treatment Options and our recent fall conference was the Western Pennsylvania Autism Fitness Initiative. We had a Family Swim Night with the Woodlands Foundation, a Free Family Day at PNC Park and other events throughout the year. We look forward to an invigorating and exciting 2010!

Between calls, emails, information packets and our lending libraries, we had over 5300 contacts with the autism community. And we learned, sadly, that the rate of children with ASD diagnoses is no longer 1:150 births, but 1:110 births.

ABOARD's family support groups help families meet among themselves to help find ways to support their children's

growth and development so they can maximize their own possibilities and potentials. We work with different agencies and providers to help spread information and give support to providers and families alike.

In the coming year we are looking to bring you new programs to help your children and clients and new opportunities to support ABOARD and its mission. I am also asking you, as the tax year comes to an end, to think of supporting ABOARD with a contribution to further our scope to serve families touched by the autism spectrum diagnosis. The diagnosis may be for a single child, but it affects the entire family and the community at large.

I urge all of you to take a moment to look back and celebrate the progress your child and family has made on the road with autism this past year. And I wish everyone a safe and Happy New Year!

Sincerely,

Elliot Frank
Chairman, Board of Directors

A Special Thanks to our Recent Donors!

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In Honor of David Rodes Fiftieth Birthday

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Monica Robertson

Kevin Dunn Memorial for money raised during the Golf Outing in support of ABOARD.

To Coralyn McCauley for coordinating the Jeans for Charity Fundraiser at the Career Service Dept. at Duquesne University in support of ABOARD and its participants:

Michelle Boehm
Nicole Feldhues
Linda Loewer
Charlotte Patton
Kim T. Pierce
Debra Saffer
Sandra Skriba

To St. Francis University Phi Lamboa PSI walk to benefit ABOARD.

THANK YOU !

Night at the Races



A Night at the Races fundraiser to benefit ABOARD was held on Friday, November 13, 2009, at the West View Fireman's Banquet Hall. 250 people attended the event raising \$8,800. Guests enjoyed a full dinner, beer, pop, and snacks. Along with race night fun, there was a Chinese auction, 50/50 & lottery ticket raffle, and lots of door prizes. The Emcee for the evening was Carolyn Lah who did a spectacular job keeping the event moving while being entertaining at the same time. A big thank you to the sponsors, committee, volunteers, donors, and attendees! The fundraiser wouldn't have been successful with you!!!!

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you to all and a
special thank
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wonderful
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who volun-
teered that
Night!**



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The University of Pittsburgh Medical Center (UPMC) announces

CHARTS

Children with Hyperactivity and Autism Research Treatment Study
Funded by the National Institutes of Mental Health

The UPMC Center for Autism and Developmental Disorders at the Merck



Child Outpatient Clinic is conducting a research study to examine the use of an approved ADHD medication and parent training sessions for the treatment of over-activity, inattention, and impulsivity in children diagnosed with Autism Spectrum Disorders. The parent training sessions are intended to help families manage their children's challenging behavior.

The treatment phase of the study involves 10 weekly sessions. An optional 24-week follow-up involves monthly visits to our outpatient clinic located at:

*The UPMC Center for Autism and Developmental Disorders
Merck Child Outpatient Clinic
Franklin Building, 1011 Bingham Street
in the South Side of Pittsburgh*

There are no costs to participate in this research study. Evaluations, study visits, parent training sessions, and medication are provided free of charge.

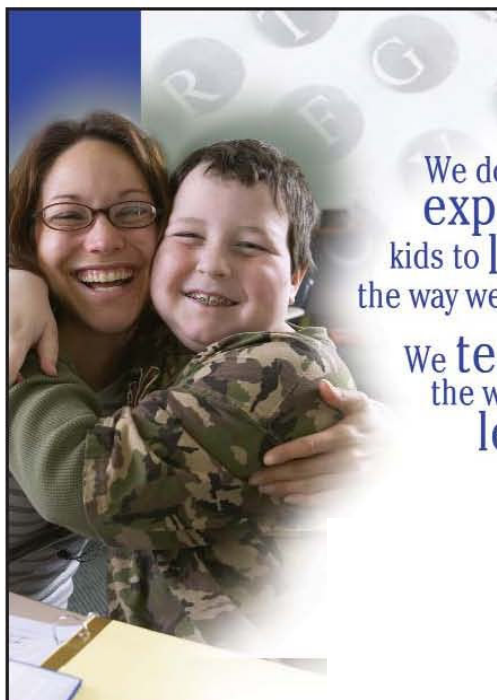
Who is Eligible to Participate?

Children who...

- Have symptoms or a diagnosis of Autistic Disorder, Asperger's Disorder or Pervasive Developmental Disorder (PDD)
- Have symptoms of ADHD: such as over-activity, inattention, and impulsivity
- Are between 5 and 13 years of age
- Are not on medication **or** are on medications that are not working well

For more information, please contact:

**Sarah McAuliffe-Bellin, M.Ed., Study Coordinator, at 412-235-5447
or mcauliffebellinsj@upmc.edu**



New Story

Formerly Milestones Community Healthcare
and Milestones Achievement Centers

We don't
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kids to learn
the way we teach.

We teach
the way kids
learn.

Every child is unique. Some children with serious and/or complex educational and behavioral challenges need a school that can implement an individualized program integrating all supports needed to attain a better life, including returning to the child's home school district. Milestones Achievement Centers are the answer.

- Pennsylvania Department of Education licensed private school for students with developmental disorders, including autism spectrum disorders
- Class size is small, with a maximum of 8 students per class.
- Classroom teachers are certified in special education and have experience with students with developmental disorders. Most paraprofessionals have a minimum of a Bachelor's Degree and experience in the field.

Supports Available:

- Applied Behavioral Analysis
- Occupational Therapy
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- Behavior Support Staff
- Nursing Services
- Physical Therapy
- Special Education

Visit our schools:

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Berwick - 570.752.5002
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Indiana - 724.463.9841
Monroeville - 412.373.5235

Reading - 610.396.3672
Wyoming - 570.714.2350
York - 717.767.8902

Pittsburgh Early Autism Study

Our Goal

Understand the earliest indicators of autism spectrum disorders (ASD)

What We Now Know

Family videotapes of children later diagnosed with ASD suggest that diagnostic signs may emerge within the first year of life

What We Will Do

Study infants who have an older brother or sister already diagnosed with ASD

Look for infant behaviors that predict a later ASD diagnosis

Benefits

Screens and assessments of autism symptoms between 18 and 48 months at no cost

How You Can Help

Participate with your infant in one or both of the projects on the reverse side. Compensation is available for participants.

1-866-647-3436 or
autismrecruiter@upmc.edu

How Babies Develop Intellectually

(directed by Dr. Mark Strauss)

Where: Infant & Toddler Development Center, University of Pittsburgh (free parking provided)

When: Infants are seen at 6, 11, 16, 24, 36 and 48 months of age

What: Babies watch pictures and movies (e.g. Mr. Rogers Neighborhood) while we record how they look at them

Infants who do not have a sibling with autism are also welcome in this research study

Website: www.pitt.edu/~infants
Email: infants@pitt.edu

How Babies Communicate

(directed by Dr. Jana Iverson)

Where: In your own home at a time convenient for you

When: Monthly while babies are between 5 and 14 months, then again at 18, 24, and 36 months

What: Trained staff visit your home for about an hour and observe infants during everyday activities and playtime with you

Website: www.pitt.edu/~icl
Email: icl@pitt.edu

Pitt Early
Autism
Study
Supported by the National
Institutes of Health



Family & Child Development Center Providing High Quality Autism Services

Our services are tailored to specific needs through a variety of community based and site based treatment programs.

BHRS (Behavioral Health Rehabilitation Services) provides services within the family, home, school and other community based settings.

Wonder Kids offers site based small therapeutic group sessions with up to 12 children/adolescents per group.

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"Growing up in a Family with Autism"

It has taken me two years to write this article. Two years ago, my family and I went through a huge transformation. Two years ago my brother--at the age of 50--received a diagnosis of High Functioning Autism (HFA). Up until his diagnosis, he had grown up with the label "learning disability." When Sam was diagnosed with HFA, I went through what I call a mini-mourning period. I had mixed feelings of shock, disbelief and sadness. My brother was no longer someone with a learning disability, but someone with Autism! I now realize that my mother was also on the Spectrum (but that is another story for another time).

As a result, I have spent the last two years revisiting my entire childhood, because the childhood I thought I had, disappeared and was replaced by a mom and a brother who were on the Spectrum. I now recognize that there are three cousins on my mom's side who are also very quirky and different, and if not actually on the Spectrum, have some of the characteristics of someone on the Spectrum. Resolving this disconnect has helped me so much in my relationship with my brother. I have always admired my brother for his quiet dignity and perseverance through the enormous challenges he has faced in his lifetime. He is intellectually my superior, and one of the most generous and thoughtful people I know. His diagnosis of HFA has allowed me to become much more accepting of his unique perspective on life. And yet, I can still become uncomfortable sometimes when he says or does something that might be construed by others as sarcastic or lacking in empathy.

Growing up, my brother had severe speech, language and communication delays. He was nonverbal for the first few years of his life, and would wander off in stores. Whenever we went shopping, my mother would put a "child leash" on my brother as he was very inconsistent in attending to his name." In fact we called him "Sammy boy," because my mom told me that this tended to help my brother "hear" his name. When Sam did begin speaking, my parents and I were the only ones who understood him. I was his

translator until he was nine. Even after that, unfamiliar adults had trouble understanding Sam much of the time. It's hard for me to know what Sam "sounded" like when he talked, because I understood everything he said, even as others couldn't. When I look back, I realize that we didn't engage in true back-and-forth conversation. We played games together that I initiated, or I would tell him stories and he passively sat and listened.

Academic learning was an absolute nightmare for my brother. His frustration and anger grew as he watched everyone else around him learn to read and socially interact so easily and effortlessly. After he was given his label of learning disability, he was placed in the one-size-fits-all special education room that existed back then. There he stayed until high school when he transferred to a vocational-technical high school and trained to become a machinist.

In retrospect, I believe not having the label of Autism as a child may actually have benefited Sam, in that, my dad had the same expectations for him as he did for me. We were both expected to clean our rooms, get up for school and do homework. The routine of homework for me was that I would go in my bedroom and close the door. Sam's homework routine was very different. Every evening my dad would say, "Sam it's time to read." Sam would begin to yell, "No, I don't want to." My dad would then have to drag my screaming and kicking brother to their reading spot, and Sam would have to read a Dr. Seuss-type book over and over again. I agree with Temple Grandin that expectations should be placed on all children. We need to assume that all children can learn and THEN see what they can do by themselves and what they need help with. My brother is a living example of this philosophy. Sam was a non-reader until middle school. My dad saw his son as a child who was capable of learning, but needed support to achieve academic success. My brother is now an avid reader who loves to read science fiction books.

I have really had to work out my emotions regarding my childhood as an adult. I remember feeling embarrassed about my brother's

not fitting in, and also very sad at watching him struggle to learn academically and to fit in socially. I was an early talker and language came very easily to me. I often felt guilty that speaking, reading and socially fitting in were so easy for me, and so hard for Sam. I used to pray for God to take away some of my reading ability and to give it to my brother. To this day, I feel very guilty about being embarrassed of my brother as a teenager, especially when I was with friends. But I also remember the moments that my parents and I were so proud and excited for Sam, e.g., when he passed his written and road driving test and got his license! This was a huge victory and celebration for Sam. Sam had wanted to take the oral test, but my dad insisted that Sam first take the written test and only if he didn't pass, would he then take the oral test. Sam was SO PROUD when he passed the written test the first time!

Sam and I had a very intense and competitive relationship with each other from about 3rd grade on. He was very volatile as a child, and could become very violent when enraged. I wasn't always safe around him. My friends never really interacted with Sam, as he was so quiet and socially awkward; conversations were usually very short and not repeated. I had to watch others, including my friends, give Sam the "what's wrong with you" look and it was so painful every time it happened. It still is.

I am fortunate in that as Sam got older, his ability to communicate with language improved. Now as an adult, he is employed full time, drives and has a social network through ABOARD. Receiving the diagnosis of HFA has boosted his self-esteem immensely. He loves meeting other adults on the Spectrum, and knows that he is indeed a very bright, intelligent person who happens to perceive life differently, and THAT'S OKAY. My brother and I are now extremely close and are both involved in the ABOARD-sponsored adult social group for adults 18 years + with HFA/Asperger's.

It's interesting how our life experiences impact our career choices. I now know

“Growing up in a Family with Autism” - Continued

that growing up watching my brother struggle to succeed academically and socially, shaped my decision to become a Speech-Language Pathologist. I never thought about it at the time: when I looked over the curriculum for Communication Sciences and Disorders, I felt like I had come home! In graduate school, I had no idea that I would end up specializing in providing language intervention for children with ASD. It just sort of happened late in my career after I moved to Pittsburgh from Arizona in 2001. I took a job at The Children's Institute, and for the first time, was seeing a significant number of children on the Spectrum. That's when everything “clicked” and I realized that this is what I was meant to be doing!

As an adult and a speech-language pathologist, I am very empathetic with the families who have children or siblings on the spectrum. I am passionate and dedicated to helping children like my brother have easier days than he did, and empower them to believe in themselves. I don't believe that I would understand children with ASD the

way that I do if I had not grown up with my brother and my mom. Although I am definitely a sister to Sam, I have also taken on a semi-parental role with him since my mom passed away. I am very fortunate that my husband is unbelievably supportive and understanding. Together we helped find a training program for Sam and got him hooked up with the Office of Vocational Rehabilitation (OVR) where he found a job through *Life's Work*. I also helped get him involved with social groups until we found the current group for adults on the Spectrum who are High Functioning or have Asperger's.

Another positive that came out of Sam being recognized as having Autism was my dad and I set up an estate trust fund for Sam. We have been able to ensure that housing, income and a caregiver will still be there for Sam, in the event we're not around. We are very lucky in that we have extended family members who are willing to take on the role of caregivers in a worst case scenario.

My brother will continue to live with my dad. For a few months after his diagnosis I

grieved over the fact that Sam probably wasn't going to move out and live on his own, get married and have a family (this is the disconnect that I spoke about earlier—because none of these things would have happened anyway, but somehow the denial allowed my dad and I not to have to deal with it). I now completely accept that my husband and I will be the caregivers for my brother when my dad is no longer around; I am now very comfortable with the reality.

I've always believed that things happen for a reason. My brother (and my mom) have given me the unbelievable gifts of compassion, tolerance, and having the luxury of being able to step out of the “box” that all of us neurotypicals live in, and to appreciate and enjoy the different world that “out of the box” thinkers like my brother live in every day of their lives.

Janice Nathan is a Speech-Language Pathologist, and is the owner of Nathan Speech Services. She lives and works in the Squirrel Hill area of Pittsburgh.

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For more information about the Autism Schools, or the entire continuum of care offered by NHS, call 724-834-2312 or visit www.nhsonline.org.

Locations in:

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Support Group Happenings

ABOARD is the largest facilitator of autism support groups in Pennsylvania. We currently have 54 groups in 46 counties. ABOARD owes a big thanks to the facilitators, who volunteer much more than the 2-3 hours at a monthly meeting. We are so grateful for their help in providing education, advocacy and support to the families and professionals in their community.

The purpose of a support group is to provide an opportunity to meet regularly for mutual support and to exchange ideas with one another. The reasons people attend support groups vary. People may come to a group to gain a better understanding of the disability, because they are in crisis, or because they have specific struggles. They may be looking for advice on a particular subject or just want to be with people who are having similar experiences.

One parent says a support group "provides information about autism and helps you realize that you are not alone - just being with others who understand my situation helps. I find it hard to discuss my concerns with those who don't have experience with autism -- other families understand." A support group can give you moral support and encouragement during a difficult time.

At a meeting, every topic imaginable to parents of kids with ASD can be discussed. Parents of children diagnosed on the autism

spectrum have a lot of questions about the services their children are eligible to receive. We could talk for hours about sensory needs, and how to work with them. Even more time is used discussing their child's language and forms of communication. Behavior modification/management is huge, both in our home and in the schools. Other important topics are respite, haircuts, dentistry, toilet-training, going to the store, siblings, friends, homework, bullying, futures, and many many more!

Being a parent of a child with a disability is a huge task. Although the nature of this disability can keep us isolated, as a community, we need to stick together and support each other.

If you are interested in attending a support group or starting a support group with ABOARD, please contact Marie Mambuca, Family Support Director at 412-781-4116

Vocational & Psychological Services

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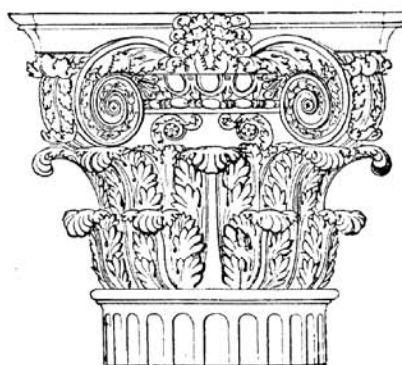
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Call 412-749-2889
or visit our websitewww.thewatsoninstitute.org

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Do you have a Letter of Intent?

A letter of intent is a document you keep in a safe place that records everything you'd want someone to know about your loved one if you should suddenly become unable to provide care.

When a family plans for their loved one's future, much thought goes into the legal and financial considerations, as well as government benefits and health care. But what is the best way to ensure that a future caretaker understands your wishes and hopes for your loved one's future? How can you assist them in stepping into your shoes and continuing the care and lifestyle that you have worked so hard to provide?

A letter of intent is a document you keep in a safe place that records everything you'd want someone to know about your loved one if you should suddenly become unable to provide care. It includes information about all of the important people that are involved in your loved one's life to provide their medical, financial and personal care. It is important when drafting your letter of intent that you understand it is not a legally binding document. It can, however, be used as a guide for the court, guardians and trustees.

The age and need for care for your loved one will dictate how long and how detailed you may make your document. In the letter of intent, you can define your loved one's condition as well as what it means specifically to them. The letter of intent is a good place to identify issues with your loved one such as ability to recognize social cues or whether they are susceptible to designing individuals who may take advantage of them. A key highlight for a family, regardless of the age of the individual, is the activities of daily life and the best routines that are followed to make an environment comfortable and engaging.

Specifically, a letter of intent includes information such as:

- **Family History**
- **Family Members and other important relationships**
- **Who you have named as guardian and trustee and why**
- **Medical History**
- **Physician history and outcome**
- **Allergies to medications**
- **Additional therapies**
- **What works well for your loved one**
- **Daily Routine and Living Skills**
- **Education and Employment**
- **Residential Options**
- **Religious Beliefs**
- **Family Traditions that you would like to see continued**

Many of the above areas include specifics that you as a family member have learned by trial and error and that knowledge may solely rest with you. The letter of intent is an excellent vehicle to transfer that knowledge. It will give a future caregiver an understanding of your family's core values and how to integrate those values into their lifestyle. This may ease any transition thereby making the individual more comfortable. It will continue the quality of life and lifestyle that you have provided.

It is crucial that you complete a letter of intent and discuss it with the other people in your life that will assist with the care of the individual. The document should be coordinated with the legal,

financial and benefit planning that you may have already completed. As with all documents that change with life events, so must the letter of intent be updated regularly to ensure that it is accurate and reflects current information.

An advisor who is certified in Special-Care™ Planning can provide you with a Letter of Intent template, help you work through the different categories as well as coordinate the document with your overall plan. This comprehensive coordination with the special care plan is an important way to accomplish goals for the future. This process ensures that you have planned and provided for the lifestyle of your love one.

By Jillian Zacks and Helen Sims, a Special care Planner, are with the firm of Guyaux Mandler Mah.

The Special Care Planner receives advanced training and information in estate and tax planning concepts, special needs trusts, government programs, and the emotional dynamics of working with people with disabilities and other special needs and their families. The certificate program is offered by The American College in Bryn Mawr, PA, exclusively for MassMutual financial professionals. The information provided is not written or intended as tax or legal advice and may not be relied on for purposes of avoiding any Federal tax penalties. MassMutual, its employees and representatives are not authorized to give tax or legal advice. Individuals are encouraged to seek advice from their own tax or legal counsel. Individuals involved in the estate planning process should work with an estate planning team, including their own personal legal or tax counsel.


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For general questions about services for persons with Autism Spectrum Disorders, please contact:

Rick J. Murray, LSW, BCBA, Chief Operating Officer
 Catherine A. Hughes, Family Support Coordinator

1-866-4-FBR-ASD; autismservices@familybehavioralresources.com

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The Advisory Board on Autism & Related Disorders (ABOARD)

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Your membership has benefits! It supports our work in meeting the needs of Pennsylvanian families challenged with autism spectrum disorders. It also keeps your organization "front and center" in the minds of those very families. Membership at the \$250 level will include acknowledgement in our quarterly newsletter for the year 2010, a link on our website to yours, and discounted exhibitor rates at our conferences.

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Advisory Board on
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We're on the web!
www.aboard.org

Our Core Principles

ABOARD believes that because there is considerable debate throughout the autism community regarding therapies, inclusion, autism cause, vaccine impact, and the potential effects of proposed legislation, our policy is to inform. We trust individuals to assimilate the information and make the best decision for their children, clients and students!

We believe that families are entitled to accurate and timely information, require emotional and practical support from other families grappling with comparable challenges, and often need advocacy assistance and training to maximize availability and utilization of treatment educational and vocational possibilities required by law.

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