

The ALL ABOARD NEWS



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

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"You want to work on all of your child's challenges."



Volume XII— Issue 7

Spring 2008

April is Autism Awareness Month!

Barnes & Noble Booksellers nationwide is promoting autism awareness. At the Barnes & Noble locations of South Hills, Monroeville, Waterfront, & Waterworks, ABOARD, along with Autism Speaks, will be offering Friday evening socials and a Saturday morning social time for siblings **free of charge**. Crystal Alexander/Freyvogel will be speaking at the South Hills, Waterfront, & Waterworks locations beginning at 8 p.m. She is a qualified therapist and educator and a protégé of Rebecca Klaw. Here is an excerpt from her presentation "Perspective of Autism from a Therapist Viewpoint".

"I want to share my perspective on working with children and their families dealing with the developmental challenges of autism. I started out many years ago teaching preschool children and found that more and more children were receiving the diagnosis of autism in their early years. I took a leave of absence and returned to the classroom myself to learn how to better serve the children I was teaching. This new understanding of what children with autism required to reach their highest potential level made me make the next move which was out of the classroom to working one-on-one in the child's setting.

As a therapist working with parents, I have found that it is stressful understanding the constant use of acronyms presented for the therapies and the disorder. For example, acronyms for therapies: (ABA, RDI, DTI), and acronyms for disorders: (PDD-NOS, CDD, ASD).

It is also stressful finding and building a good wraparound team. It is very important that the individual team members work together comfortably. Expect the beginning to be difficult until everyone gets into a routine. Parents must try to understand what a therapist should do while working with your child. My advice is to always ask your BSC (an acronym for Behavioral Specialist Consultant) and your TSS (Therapeutic Staff Support) about anything that you find confusing and always keep educating yourself. "

ABOARD CAN HELP YOU WITH ...

- Support Groups and Contacts
- Free Lending Library
- Glossary of Abbreviations and Terms
- Listing of Resources, Organization and Websites
- Office Staff to Answer Advocacy, Information, and Support Calls
- A List of Free Advocacy Publications

Meet the New Chair of ABOARD

It is a pleasure to write to you today as the new Chair of ABOARD. While I have served on the board of directors for 5 years and as treasurer, in my new capacity I find myself thinking about what the future holds for the world of autism and how far we have come. Today, we find the world of autism at the forefront of the public radar screens, with Hollywood stars lending celebrity support, big grants from NIH, World Autism Day, Autism Month, and CNN devoting a month of coverage. Pennsylvania has the Bureau of Autism Services. Cure Autism Now and NAAR, now joined with Autism Speaks, didn't exist when ABOARD was formed almost a decade ago as a group of parents searching for help and answers and support from each other.

As I lay in bed and watched the sun rise, I made an amazing connection between two very different experiences, separated by decades, in my life. I was thinking about autism being a 24 hour, 7 day a week experience. Our son is very high functioning and it isn't an issue in our home acutely every day, but you are always preparing for it during that 24/7 period. A 24 hour day- how exhausting! And then I remembered a book I read some 30 years ago called The 25 Hour Day. Only it wasn't about autism. I was reading it because it dealt with the problems of taking care of a parent with Alzheimer's Disease. It had struck my mother, and showed up shortly after my father's death. It was probably there earlier but he hadn't told us. There were little things, but I had shrugged them off. How many of us had noticed our children had quirks such as a fascination with wheels, not looking when their name was called, not relaxing when nursing? I took my mother to her doctor. He said "Everybody forgets when they get older!" How many of us were told by well meaning pediatricians "Your child will grow out of it"? I took her to a specialist (neurologist) who couldn't find anything on testing and said "she is just depressed". It took months before a diagnosis was reached—with much searching and difficulty--how familiar does that sound?

My point is not that I was failed by the medical profession. They did the best they could with the information and medical training available at the time. 30 years ago Alzheimer's was not well known to all doctors. Now it is known to all with national groups, along with families, advertising and advocating and there is extensive medical research occurring. But back then I had to deal with it and figure things out on a day to day basis with no support organization to help. Then, as now, I relied on family and friends to help me through the maze of helping a loved one with a disability.

Substitute the word autism for Alzheimer's and the situation repeated itself 10 years ago for my family. No extensive medical education for physicians, no large support or advocacy groups, no

personal knowledge of the disability---what a life-saver groups like ABOARD and similar groups in our community are!

There have been other similarities. In my mother's case, because she had been an actress and kept her union membership, she was able to go the Actor's Fund Home which provided for her dignity and well-being in those declining years of her life without leaving a terrible financial burden on my family. When the pre-school mentioned the possibility of autism, my wife was working in the rehab unit of D.T. Watson Institute; right above a school for children with autism that had existed for decades that she didn't know existed! Unlike many families, we were able to get hooked up with help in a relatively short period of time. With the loophole entitlement in PA, we were able to get the services we needed when insurance wouldn't help.

So what can I share with you from this juxtaposition of disease/disability in my life? As we have all learned, having supportive family and friends is paramount to surviving. Having a multitude of organizations that advocate and support raises the public awareness and research and treatments follow. So I am quite disturbed when I read examples of different autism organizations being slandered, researchers being maligned and attacks on government officials who have been instrumental in helping us. I don't remember this being the case with Alzheimer's. I think part of the issue is there is a difference between having an adult become a child after a full life and learning your child will have difficulties reaching a productive adulthood before they have had a chance. The losses are different. But our passions must be channeled *productively*. All of us must pledge to work for the common goal of maximizing the potentials and possibilities of our children with autism. We can't get there by bickering and being demeaning to each other. We can all take different paths, they may intersect at times, but we must respect each other's choices. So I hope we can all pledge to reach our destination of providing a positive future for our children regardless of the route we take together.

- Elliot Frank, Chair

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What is the Professional Advisory Council (PAC)?

ABOARD's Professional Advisory Council is comprised of a group of professional individuals that work in the autism community. This Council helps promote resources, information and latest technology/ trends to help those with autism while providing guidance and support to ABOARD.



Free Seminar

**45 Minutes to a
Secure Future for
Your Child**

Presented by Attorneys

James P. Shields

Thomas J. Boris

Jessica L. Crown

ABOARD is committed to helping you successfully navigate the challenges confronting you and your special needs child. We work hard researching the latest developments in medical care, social services and government programs. Estate planning is something many of you have conveyed as a top priority. We are pleased to again announce a FREE seminar hosted by Attorneys James P. Shields, Thomas J. Boris and Jessica L. Crown of the Law Offices of Shields & Boris. We offered the seminars last year and they received enthusiastic reviews. Due to popular demand, we are again offering these important seminars. Mr. Shields, Mr. Boris and Ms. Crown work closely with ACHIEVA and The Family Trust to assist special needs families plan for the future.

Your child is special, unique and the most important person in the world to you, which is why the 45 minute seminar ***What You Need to Know About Special Needs Trusts*** will be the most valuable 45 minutes you spend this year. Just for attending, you'll receive a **FREE REPORT**, entitled *The Twelve Things Every Special Needs Family Must Know About Estate Planning*.

Thursday, May 1, 2008 at 6:30 p.m.
Monroeville Holiday Inn
2750 Mossdale Blvd.
Monroeville, PA 15146
Contact: Barbara

Tuesday, May 6, 2008 at 6:30 p.m.
Washington Citizens Library
55 S. College St. Washington, PA 15301
Contact: Judy

Wednesday, May 14, 2008 at 6:30 p.m.
Crowne Plaza
164 Fort Couch Rd. Pittsburgh, PA 15241
Contact: Gina

Monday, May 19, 2008 at 6:30 p.m.
Holiday Inn North Hills
4859 McKnight Rd. Pittsburgh, PA 15237
Contact: Elizabeth

Thursday, May 29, 2008 at 6:30 p.m.
Cranberry Township Public Library
2525 Rochester Rd.
Cranberry Township, PA 16066
Contact: Pat

Tuesday, June 3, 2008 at 6:30 p.m.
Mountain View Inn
1001 Village Dr. (Rte. 30 East) Greensburgh, PA 15601
Contact: Donna Lenz

The call to reserve your space is free - the cost of not calling and planning for the future is immeasurable.

We urge you to attend this session and secure your child's future and your own piece of mind.

Planning for your child's future is a long term commitment; situations change and your plans must change along with them. Working with someone you trust is critical. **Call 800-459-1843 to make reservations. Seating is limited.**



Donte's Pizzeria, located in South Park, is having an exciting Fundraiser to benefit ABOARD Contest is May 18th, 2008

They are hosting a Fastest Pizza Eating Competition and the winner gets
FREE PIZZA FOR A YEAR! (1 small pizza per week for 52 weeks)

The Entry Fee is only \$30 and 100% of the proceeds goes to ABOARD.

Contact Donte's or ABOARD for a Registration Form for the Contest.
Submit entry by April 17th, 2008

If you need further information, please contact: Denise C. Marasco 12.977.5673
www.dontespizzeria.com

Autism Answers @ Your Fingertips

www.aboard.org/answers

What should I do if I think something is wrong?

ASK

Available 24 hours a day, ABOARD's Autism Answers empowers you with the peace of mind you need and deserve.

Get the answers to your important questions and concerns about autism by having a conversation with a peer that truly understands your situation and has walked hundreds of miles in your shoes.

**Experience the connection. Experience the support.
Experience ABOARD. We Know!**

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*Specializing in the Treatment of Children with Autism and Other
Development Disabilities*

NORTH SOUTH EAST

THERAPEUTIC AND ACADEMIC K-3 SCHOOL: Registration
is *NOW* being accepted for the 2007-2008 school year.

ACADEMIC PRESCHOOL an academic and therapeutic program
for children with autism, and their typical peers.

BHRS IN-HOME SERVICES (WRAPAROUND) using Applied
Behavioral Analysis (Verbal Behavior) and Relational Therapy for
treatment.

ON SITE THERAPEUTIC GROUPS (WONDER KIDS CLUB)
focused on social skills and communication acquisition and practice.

MUSIC THERAPY Groups, private classes and private piano
instruction for children with special needs.



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Contact Fayme Reinhart
724-443-8900 for more
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A special thank to our recent donors!

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Kenneth VanTine

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Special Thank You:

Spencer Crane for asking for
Birthday Money to be
donated to ABOARD.

Tom Franzak for proceeds
from Littleway Concerts

Jane Resh for supporting the
"Education Mentors of
Pennsylvania"

**On behalf of our Broad
of Directors and the tens
of thousand with autism
who utilize our free ser-
vices, thank you for your
support of ABOARD's
2007 Fall Annual Appeal.
As a non-profit 509(c)(3),
we are greatly dependent
on the generosity of indi-
viduals, families and or-
ganizations in supporting
our mission to maximize
the potential and possibili-
ties of Pennsylvania's chil-
dren, adolescents and
adults with autism.**

"I shall pass through this world but once. Any good thing therefore that I can do, or any kindness that I can show to any human being, let me do it now. Let me not defer it or neglect it, for I shall not pass this way again."

By Stephen Grellet

This is a wonderful quote, and one that so many people truly take to heart. We all have small talents or abilities that can make such a difference in the world. During this Autism Awareness Month, will you commit to lending a small portion of your time or talent? I believe that all of us have received a "helping hand" during certain times in our lives. Sometimes that help comes from an organization, but so often it comes directly from an individual. Did your assistance come from a teacher, public official, religious leader or friend? Was your helper anonymous? What I tend to think of and appreciate, more so than the actual help or advice received, is the fact that I was helped out of the goodness of someone's heart - out of their personal or family times. We are all so busy and our time so precious that this means a great deal.

ABOARD would love to have your help, in many different areas. If you have something to offer (and I believe we all do), we will try to match our needs with your specific talents and availability. Please help us continue to help others. We would greatly appreciate it. Take care of yourselves, and have a wonderful Spring!!

Karl W. Smelser, Executive Director



ABOARD AUTISM WALK

Advisory Board on Autism & Related Disorders
(ABOARD)
is proud to represent Autism at the
Walk for a Healthy Community
presented by Highmark Blue Cross Blue Shield



May 3, 2008 at Heinz Field
Come join us!

Register online at www.walkforahealthycommunity.org

1-800-827-9385
autismwalk@aboard.org
www.aboard.org

Maximizing potential, Maximizing possibilities

The fifth annual Highmark Blue Cross Blue Shield Walk for a Healthy Community will benefit 37 Western PA health and human services agencies. Since Highmark Blue Cross Blue Shield underwrites the cost of the walk, 100 percent of the money raised by walkers supports the 37 participating organizations, including ABOARD.

Choose either a 5K or a 1 mile fun walk route. Every registered walker will receive a t-shirt and for every \$100 donation you will receive a ticket to enter the Highmark raffle for prizes. Registration begins at 7:15am. Let's make sure Autism is well represented at this walk that benefits local agencies that deliver vital health and human service programs to the community.

Register at www.walkforahealthycommunity.org and choose ABOARD as the organization that you will be walking for!



Advisory Board on
Autism and Related
Disorders
35 Wilson Street
Suite 100
Pittsburgh, PA 15223

Toll Free : 800-827-9385
Phone: 412-781-4116
Fax: 412-781-4122
info@aboard.org:

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.

Advisory Board on Autism and Related Disorders

Yes, I want to help ABOARD!

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