# The

# ALL ABOARD NEWS



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

Volume XIII— Issue 3

Summer2009

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# SAVE THE DATE ABOARD presents

### Western Pennsylvania Autism Fitness Initiative

Featuring: Eric Chessen, MD, YCS and Founder of Autism Fitness

Friday, November 20, 2009 8:30 a.m. – 4:00 p.m. Regional Learning Alliance, Cranberry PA

ABOARD's Fall conference, "Western Pennsylvania's Autism Fitness Initiative", will be presented by Eric Chessen, M.S., YCS. Eric is the founder of Autism Fitness and works exclusively with young individuals (ages 5-21) with autism, developing and implementing fitness programs for both individuals and groups. In addition to working with his athletes, Eric provides lectures, hands-on workshops, and his Autism Fitness Initiative seminars around the country for parents, educators, and fitness professionals. Eric is a contributing columnist to numerous autism and fitness publications including Spectrum Magazine and the Autism @ Home Series.

The Western Pennsylvania Autism Fitness Initiative (AFI) will be a full-day event that focuses on providing both conceptual and practical information on developing and implementing fitness programs for young individuals (ages 5-21) with autism and related disorders. The AFI seminar will involve both lecture and hands-on instruction to address:

- Overview of fitness and applied physiology
- \* How exercise benefits young individuals with ASD
- Why fitness is crucial for optimal development in other areas (cognition, self-regulation, socialization)
- \* Common physical deficits in children and young adults with autism
- \* Autism Fitness theory and application of exercise
- \* The 5 essential movement patterns and how to teach them
- \* Using ABA methods for integrating fitness programs
- Developing and implementing your own fitness program with any individual or group in multiple environments

Registration Details Coming Soon!

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#### Chairman's Message

Dear Friends,

Summer is here! Another school year is over, and we all get a break from school projects and IEP's. I hope we can relax a bit from our 24/7 lives on the spectrum and enjoy the summer with our families. As I write this, I recall a postcard my aunt received long ago from her son in the National Guard which read: "Sleep Well Tonight; Your National Guard is Awake!" It's like that for ABOARD! While we all enjoy the summer, Jen, Marie, Rebecca and the board of directors are "awake", working hard on plans for the rest of the year.

Our Fall Saturday Seminars are back by popular demand. They will cover Autism and Seizure Disorders, Behaviors and Occupational Therapy and how OT relates to biomedical. See page 15 for additional information.

The ever popular Night at the Races event is going to be held Friday, November 13th at the Westview Fireman's Hall. Sincerely, Proceed's from this fundraiser will benefit ABOARD. It's a fun night with food, drink and prizes.

Our next fall conference will be one week later, Friday November 20<sup>th</sup>. This unique conference will emphasize physical fitness for those on the spectrum and the special issues surrounding it, featuring Eric Chessen. For more information, visit: www.autismfitness.com.

Our GALA fundraiser will be held January 23, 2010 at the J. Verno Studios where we had our event last year. More information on awards and the theme will be coming in the next few weeks.

All these conferences and events need volunteers to help them be the most successful they can be. Their success ensures ABOARD can be there for you when you need us. Maybe you can only spare a day, or perhaps there is a particular event you would be excited to be a part of. If you can help ABOARD continue its amazing work by giving of your time and skills, please call the office at 412-781-4116.

Elliot Frank, Chairman, Board of Directors

# ecial Thanks to our Recent Donors!

#### \$1,000-\$2,499

Stephen and Mary Jo Crane W.H.A.T. Woodland Hills Aquatic Team Swim-A-Thon, swimmers, their families and sponsors.

#### \$250-\$500

Funding for General Operating Expense was provided by Geraldine Kennedy Cooper Fund of The Pittsburgh Foundation **Dorothy Brailer** 

#### \$100-\$249

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#### \$50-\$99

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#### In Memory Of

Adelaide and Jay C. Steele By Robert and Valerie Swaskoski

**Bryan Downey** By Melissa Hill

#### Special Thank you:

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

Pennsylvania School Counselors Association Members

> Celeste L. Alfieri Stephen & Judith **S**chmitz Phillip and Colleen Heckman Kathryn Zboyovski Gary and Emilia Peiffer

Kappa Delta Rho's National Fraternity at the University of Pittsburgh at Johnstown for hosting the Autism Walk on April 18, 2009 and for all the participants and donors.

#### 2008 CFC Campaign

**Junemarie Brandt Curtis Meeder** Robert Murdock

#### **CALL TO GET MORE INVOLVED!**

ABOARD was started as and is a parent run organization! Although we collaborate with all agencies and organizations involved with autism spectrum disorder, we are run by parents. We are for parents, and we are all parents. Being a parent is hard work... adding autism just makes it more interesting! The office staff strives to help parents accept their child's diagnosis, get the resources that are available to them, and connect with other families. It is a difficult process to accept things we cannot change, so we talk about changing the things we can. We encourage families to help the child or adult develop their full potential.

ABOARD has been providing education, advocacy and support since 1996. We've come a long way but as you know, there is still a long way to go. Autism is talked about a lot now, but the families and professionals working with people with ASD know that it is not enough. ABOARD is there for parents and professionals to:

- \* Talk directly with other parents of children with autism
- \* Receive our free information packet
- Learn about your rights and resources
- \* Receive educational assistance from diagnosis through adulthood
- Find a local support group
- \* Borrow from our free lending library
- \* Learn about area events
- Join our weekly email list full of valuable information
- \* Attend our informative and education seminars and conferences

In 2008 ABOARD responded to over 3,700 information requests for guidance and support, had 53 family support groups in the support group network, distributioned 1400 information packets and 750 publications from our lending library, and provided trainings to parents, paraprofessionals, and educators. It's a massive task made possible only by the considerable help of our donors and volunteers.

With the incidence of autism on the rise, ABOARD's goal of meeting the needs of families affected by ASD becomes even more vital. We have already seen what a group of parents can accomplish when they created ABOARD and now we need volunteers even more to help us continue to help families affected by Autism. We are a small office that does the work of many worker bees, maybe there has been a time you wondered how could you give back to the cause of Autism. Yes there is always the monetary donation you could give which ABOARD greatly depends on: however, maybe you have a skill or talent that could help us! It could be a one time thing for a couple hours or a longer commitment to join a committee, chair an event, or support the office. Below is just a summary of areas we could use your help. If you just took one piece, you would be making a big difference!

- \* Office Administrative Help (Receptionist, Data Entry, Mailings, Database Management, Mailings, Library)
- \* Support Group Coordination
- \* Marketing/Information Coordination (Eblast, Newsletter, Event Advertising)
- \* Event Coordination (Table Exhibitor, Assist at Conference, Events for Families, Joint Ventures)
- Fundraiser Coordination (Community Support and Outreach, Solicitations,)
- \* Grant Coordinator (Writers, Follow-up, Research)

Join with the other parents at ABOARD to help continue the mission that was created by parents and will continue to serve parents! Contact Rebecca Williams-Thomas at 412-449-0165 or rwthomas@aboard.org if you would like to help!

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### Thanks to our United Way Fall 2008 Campaign Donors

#### \$5,000 or more

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#### \$1,000 or more

Richard J. Foukes Anonymous Donor from PNC Financial Services Group, Inc.

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Kathy P. Tosh Anonymous Donor from University of Pittsburgh

# ABOARD'S 2009 Organization/Corporate Partners

Please visit our website www.ABOARD.org for a link to all our of Organization/Corporate Partners websites!

**Achievement Center** 

Alliance for Infants & Toddlers
Alliance Health Wraparound

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**Program** 

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# **Nathan Speech Services**

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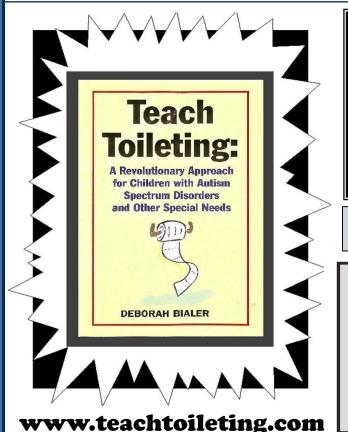
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### CHARTS

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



The CHARTS study examines the use of an approved ADHD medication and parent training sessions for the treatment of over-activity and inattention in children diagnosed with Autism Spectrum Disorders. Parent training sessions are intended to help families manage their children's challenging behavior.

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

Merck Child Outpatient Clinic Franklin Building, 1011 Bingham Street in the South Side of Pittsburgh

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

#### Who is Eligible to Participate?

#### Children must...

- Have symptoms or a diagnosis of Autistic Disorder, Asperger's Disorder or Pervasive Developmental Disorder (PDD)
- Have symptoms such as overactivity, inattention, and impulsivity
- Be between 5 and 13 years of
- Not be on medication or be on medications that are <u>not</u> working well

For more information, please contact:

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

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# What a Great Day for a Walk!

If you walked with ABOARD at the Highmark Walk for a Healthy Community event at Heinz Field on May 30 you know what I mean! The weather was perfect, the music was great and the kids had a blast at the inflatable play area and the DDR station. Thanks so much to those of you who came to Heinz Field and walked with coworkers, family or friends. We really appreciate your time and efforts and hope that you had a great morning.

In 2004 Highmark chose ABOARD as a representative of autism at the Walk for a

Healthy Community. That year 12 organizations were represented and the walk was held at Station Square. Every year a few more local non-profits joined and by 2007 this walk had outgrown Station Square and was moved to Heinz Field. This year 44 health and human services organizations joined together for this great Pittsburgh event. At least 7,500 people from Western PA came to show their dedication to those organizations. Highmark underwrites the cost of the walk so 100% of what is donated goes to the organization that walkers choose to support. ABOARD is proud to be a part of this important event and thank all of you that supported us there.



That encouragement is what motivates us to help the autism community. We are dedicated to helping families navigate the different systems and services so their family member can achieve their maximum potential. And we are equally dedicated to helping the professionals who work with them.



# A SPECIAL THANK YOU TO THE FOLLOWING:



Thank you Donna Enzerra & Diane Catterall for obtaining the donation of 300 free salad coupons from McDonald's Corporate that was used for an incentive prize for all ABOARD walkers at the 2009 Highmark Walk for a Healthy Community!



Thank you to Chroma Graphics in Oakdale, PA for the discount on the ABOARD hats used for an incentive prize for all the ABOARD walkers that raised \$ 50.00 or more at the 2009 Highmark Walk for a Healthy Community!



Thank you to Heather Harbert and Heather Plassio of NHS for their volunteer time at the ABOARD table for the 2009 Highmark Walk for a Healthy Community!

### Thank you to all those who showed up to support ABOARD!

#### **TEAMS and TEAM CAPTAINS**

A BROTHER'S LOVE...K.J. & P.J. - Lenore Wossidlo
ABOARD Adult Social Group - Janice Nathan
Becca Boo - Jen and Del Suppo
Daily Family - Anne Daily
Dudash Family - Michael Dudash
EBII Rocks - Jennifer Do and Karleen K. Preator
Guthrie Family - Brian Guthrie
Loving Care Agency of Pitts - Jan Gazza
Mattozzi Family - Judy Mattozzi
Milestones Achievement Center- Elizabeth Wistuk
PFQ - Tammy O'Brien
Pitt El Students- Hallie Foster

Simonetti Family - Larry Simonetti Team Crane - Steve Crane Team CTR - Beth Rom
Team Daniel - Serina Burkhart
Team Kennedy - Jennifer Straskulic
Team LEE - Rebecca Williams-Thomas
Team Meditch - Christina & James Meditch
Timberland - Melissa Painter



#### **WALKERS**

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#### Thank you to all our donors for making this year's walk such a success!

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## **Movement for Children with Autism**

For many adults, exercise is a luxury. For typically developing children, physical activity is easy and fun. Our kids with autism need encouragement to move. Why? Because for them, movement can be frustrating and difficult.

# Motor Skills Lay the Foundation for Cognition:

Crawling, pulling up, walking, climbing, skipping, running, jumping, throwing and catching are key building blocks for cognitive and academic development, as well as for a life of health and fitness. Movement increases respiration abilities, improves digestion and balances out our moods.

Crawling, pulling up, walking, climbing, skipping, running, jumping, throwing and catching are key building blocks for cognitive and academic development, as well as for a life of health and fitness.

Physical activity helps children gain foundational motor skills. At the play-ground, children experiment with ways to use their bodies and perfect emerging skills. Swimming, biking, skiing, skating all aid in learning where the body is in space and how to use each part as a team.

At best they may acquire "splinter skills," or out-of-sequence abilities. Because skills develop, splinter skills rarely become fully integrated into a child's skill set. Long-term effects may become obvious only when a child is expected to do such complex motor and cognitive activities as reading and writing.

Instead of working on the end product, try some simple activities that strengthen the foundation. Use wide boards for balancing, scarves, balloons and big balls for throwing and catching, and small towers for climbing.

#### **Encourage Your Child to Move:**

Sedentary activities, like watching TV and playing video games compete for our children's attention. Although entertaining, they are not helpful in building the strong motor skill foundations we desire.

Movement is food for a child's nervous system. Make daily physical activity a priority. Like air, food and water it is a necessity of life!

#### Begin Where They Are:

Motor development follows a distinct sequence during the years when skill acquisition is most rapid, from birth through age six. Many children with autism did not follow this sequence. Some never crawled; others walked early. Many are fearful of heights, escalators, playing ball or riding bikes. Yet we try to teach them these activities so that they can enjoy these seemingly pleasurable activities. At best they may acquire "splinter skills," or out-ofsequence abilities. Because skills develop, splinter skills rarely become fully integrated into a child's skill set. Longterm effects may become obvious only when a child is expected to do such complex motor and cognitive activities as reading and writing.

Crawling, pulling up, walking, climbing, skipping, running, jumping, throwing and catching are key building blocks for cognitive and academic development, as well as for a life of health and fitness.

Patricia S. Lemer, M.Ed., NCC, Executive Director, Developmental Delay Resources <a href="https://www.devdelay.org">www.devdelay.org</a> and email at devde-

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# Do you have a Life Care Plan?

With so much information and days consisting of work, family, care for your children, healthcare, education, and benefit programs, when it comes time to make the tough decisions about your child's future, you're overwhelmed. When you're ready to sit down and make these decisions you sometimes need to involve the state, federal government, attorneys, investment advisors and the questions becomes where to begin?

Because of this overwhelming complexity, most families take one of two paths. Either they choose to address issues as they arise or attempt to piece it together, due to time constraints and not knowing where to turn. Or they have established a Special or Supplemental Needs Trust for their child. While this is an important step, it is only the beginning and does not address the issues of living (i.e. Has a letter of intent been completed?). And for the majority of you, you will live well beyond the age of 65. That is a much more complex thing to plan for than a premature death.

There are many considerations that must not only be addressed, but must also be coordinated. Your plan for your child needs to include educational, social, and medical implications with financial strategy, estate planning, legal considerations, and government programs. You will need to work with a team of advisors to help you create a coordinated life care plan for your child.

A life care plan addresses where you are currently, and what your child's future entails. A life care plan balances the need to provide for your loved one with special needs, with the need to

provide for other family members and yourself personally. Families feel that they must choose between providing for their loved one, or providing for their retirement and are unsure if both can be accomplished. But a well thought out life care plan can potentially help you accomplish several of these goals together.

# I 0 major areas of concern with life planning:

- 1. Address Primary Issues
- 2. Create a Special Care Vision
- Choose a Guardian(s) & Truste(es)
- 4. Identify Financial Resources
- Determine Plan and Care Costs
- 6. Prepare Letter of Intent
- 7. Prepare a Will
- 8. Establish a Supplemental Needs Trust
- 9. Hold a Family Meeting
- 10. Review your plan annually

The specific details of each one of these steps are beyond the scope of this article. But all are vital in addressing the current situation as well the future obligations to you and your loved ones. The most critical of these steps is the final step, and that is the review of your plan on an annual basis, and at each key trigger point of your and your child's future (i.e. age of majority)

A plan must be reviewed for many reasons, some being the extension of look back periods, changes in waiver funding, and the constant change in tax and estate laws. These factors can put pressure on your plan and require that families plans be flexible to accommo-

date these changes.

You need to make sure that your team of advisors is proactive in keeping you informed of the ever changing world and how it impacts you and your plan personally. Ideally you work with one resource that can help you piece all of these parts together so that your plan can be proactive and help you to accomplish your goals for your child's future.

Helen Sims is a Special Care Planner with the firm of Guyaux Mandler Mah. She can be reached at 412.562.4439 or

hsims@finsvcs.com

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.

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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
- Speech Therapy
- Behavior Support Staff
- Nursing Services
- Physical Therapy
- Special Education

Visit our schools:

Allentown - 610.973.0970 Berwick - 570.752.5002 Dubois - 814.37.5387 Harrisburg - 717.901.9906 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

#### 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





# 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.

Creative Arts Program includes music, movement and art groups, instrument instruction, digital storytelling and a focus on expressive arts.



North Hills • South Hills Penn Hills • Butler County

For referrals/inquiries: 724-443-4888 or email: FCDC.Referral@wesleyspectrum.org

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Do you have questions or concerns about the way your child plays, moves or talks?

#### We Can:

- Complete an assessment of your child's skills
- Coordinate appropriate services or supports
- Monitor your child's developmental progress

#### Services Are:

- Provided in the home or other community settings
- Offered at no cost to the family

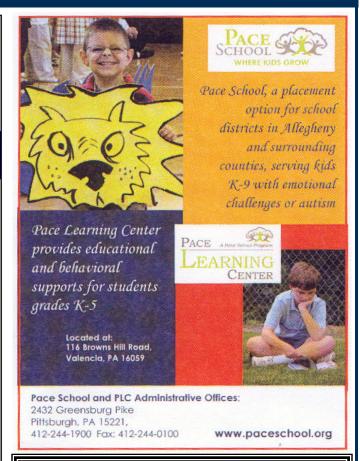
#### Our Program:

- Is open to Allegheny County children ages birth to 3 years
- Actively involves parents and other caregivers
- Is confidential

Early Intervention in Pennsylvania is a system of services & supports designed to help families with children who have or who are at risk of developmental delays. In Allegheny County, coordination of services for children between ages birth to 3 years is provided by The Alliance for Infants and Toddlers, Inc.

Contact The Alliance to make an appointment:

412.885.6000



#### Save the Date!

Night at the Races Friday, November 13, 2009 West View Fire Hall

Proceeds benefit:
Advisory Board on Autism & Related
Disorders (ABOARD)





### **SAVE THE DATES**

# for these upcoming events with ABOARD in FALL 2009



### **Saturday Seminar Fall Line Up**

"Free Special Care Planning Workshop"
Helen Sims and Clint Guyaux, Special Care Planners from Guyaux Mandler Mah
ABOARD Office
September 26, 2009
9:30 a.m. – Noon

"Autism and Seizures"

Shannon Bursick and Jane Boyd from Emma Bursick Memorial Fund and Additional Speakers (TBA)

ABOARD Office

October 3, 2009

9:00 a.m. – 3:00 p.m.

"Positive, Powerful and Practical Strategies for Behavior Support"

Bonnie V. Jamieson M. ED. and Marcia Laus M. Ed., Educational Consultants from The Watson Institute

ABOARD Office

October 10, 2009

9:00 a.m. – 3:00 p.m.

"Sensory Integration and its Emerging Biomedical Theories"
Ronna Hochbein, OTR/L Private Practitioner and Author
ABOARD Office
October 17, 2009
9:00 a.m. – 3:00 p.m.

## **Fall Conference**

"Western Pennsylvania Autism Fitness Initiative"
Featuring: Eric Chessen, MD, YCS and Founder of Autism Fitness
Regional Learning Alliance, Cranberry PA
Friday, November 20, 2009
8:30 a.m. – 4:00 p.m.

For more information please visit



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

> 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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Yes, I want to help ABOARD!
Name:
Address:
Email:
Phone (in case of questions):
Gift Amount & Payment Method
□ \$50 □ \$100 □ \$250 □ \$500 Other \$
☐ Check Enclosed
☐ MasterCard #
□ Visa #
Expires Signature



United Way of Allegheny County Contributor Choice Agency Number 9817

#### Sign up for Facebook Causes to help ABOARD

If you are a member of Facebook and a supporter of ABOARD, then join our cause! By joining the ABOARD cause and inviting your Facebook friends, you are raising awareness about autism and all the things ABOARD does!

http://apps.facebook.com/ causes/228832/49465600? m=16ba113e



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GOODSEARCH.COM Select "ABOARD"

#### ABOARD is an IRS-Approved 501 (c)3 organization.

Your donation qualifies as a charitable deduction. ABOARD is registered with the Pennsylvania Department of State Bureau of Charitable Organizations. To receive a copy of the official registration and financial information, please call 800-732-0990 within Pennsylvania or visit www.dos.state.pa.us.

Are you receiving ABOARD Alerts? If not, send us your email address!