

The ALL ABOARD NEWS



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

Volume XIV— Issue 2

Spring 2010

Inside this issue:

Chairman's Message/ Donors	2
Grandin Award Winner	3
Why Families Should Consider Participating in Research	6
Camp Fair 2010	8
Support Group Happenings	9
Beyond Individualization: Building IEPs on Individual Strengths, Needs, and Wants	11
A Special Care Plan. . . Where do you begin?	16
Organization membership form for 2010	19



COME WALK WITH ABOARD !

The 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 22, 2010 at Schenley Park
Register online at

www.walkforahealthycommunity.org

Save the Date!

ABOARD is participating in the eighth annual Walk for a Healthy Community presented by Highmark Blue Cross Blue Shield on Saturday, May 22, 2010 at Flagstaff Hill in Schenley Park, Pittsburgh.

The Walk for a Healthy Community is a fundraiser that benefits local health and human service agencies in Southwestern Pennsylvania. Since Highmark Blue Cross Blue Shield underwrites the cost of the walk, **100% of the money raised by walkers goes directly to support ABOARD's mission of maximizing the potential and possibilities of those with an Autism Spectrum Disorder.**

Start gathering friends, family members, neighbors, and co-workers to join you at this important local event. There will be incentive prizes, games, and entertainment too.

Highmark's new website makes supporting ABOARD even easier. You can register your team and set team and individual goals. Supporters of your team can use the site to make pledges via credit cards. For more information, visit www.walkforahealthycommunity.org.

Chairman's Message

Dear Friends of ABOARD,

We made it through another winter! Though it seemed long and never-ending, we can sense spring is upon us! Sometimes I think raising some of our children on the spectrum is like that too. Often we get so caught up in the difficulty of the current day and constant challenge of autism that sometimes we lose the perspective of accomplishments made or ground gained. Always remember to take a deep breath and look how far you have come.

This past January, ABOARD held its 10th Annual Gala. It was one of our most successful to date and was attended by over 200 guests. Held at the J. Verno Studio on the South Side, there was food, music and much camaraderie among all the guests. The annual Grandin Award was also presented at the gala. Read about the finalists on page three of this newsletter.

April is Autism Awareness Month. You will receive ABOARD's email blasts about all the different events that are occurring. And when the weather is finally sunny and warm on a regular basis, don't forget to contact the ABOARD office to get your discounted tickets to Kennywood, Idlewild and Sandcastle Amusement Parks. This year we have tickets for all three parks available to you!

In lieu of a Spring Conference this year, ABOARD will be working with AHEADD on their Adult Autism Awareness Day on April 16th. More attention is being paid to our much underserved Adult Autism/Asperger's community. The 2nd Annual Adult Autism Awareness Day is geared toward professionals, parents and adults with autism and Asperger's. The focus this year is on employment.

Professionals who are working directly with Adults with Autism and Asperger's will be provided with practical steps toward effectively preparing for and obtaining competitive employment. For Adults with Autism/Asperger's, there will be opportunity to participate in mock interviews and receive sensitive, constructive feedback.

And don't forget Sunday, April 18th is Autism Awareness Day at PNC Park! Enjoy a day of sun and baseball with your family. If you come with a group of 20 or more, your name will go up on the big board! You can call the ABOARD office for more information.

Enjoy the spring!

Elliot Frank, Chairman of Board of Directors

A Special Thanks to our Supporters!

A Special Thank You to our Gala 2010 Sponsors!

Diamond Sponsor
PNC Bank, NA

Gold Sponsor
L.B. Foster Company

Silver Sponsor
Community Care Behavioral Health

FBR Autism Services
FHL Bank of Pittsburgh
Mine Safety Appliances Company
Pressley Ridge
WABTEC Corporation
The Watson Institute

Bronze Sponsor
Portec Rail Products, Inc.

UPMC Presbyterian
Shadyside
Western Psychiatric
Institute & Clinic

Bar Sponsor
Alliance Health Wraparound
Allegheny
Tangent Rail
Value Behavioral Health
Phillip H. And Betty L.
Wimmer Foundation

Patron Sponsors
Steve and MJ Crane
Jason and Carolyn Hare
Dave and Lori McMaster
Bob and Cyndi Murphy
John and Patricia Rodella
Wesley Spectrum Services

Thank you to all the donors and attendees of the Gala that help make this such a wonderful night and large success!

Thank you to our General Donors!

Lawrence C. Deihle
Edward Dzenis
Jim Hinton
Emily A. Lippert
Theresa Jamison
Margaret and Gary Miller
Majorie McMaster
Linda Lee Sanders

\$100.00 Donation
Del and Jennifer Suppo

In Memory Of Milton Strahl
From Lester Jay Hadburg

In Honor of Jeff Toner
From Marilyn Dibernardo

In recognition of Dr. Lynne Porterfield retirement.
From Michelle Lubetsky

Special Thank you to Freeport High School and Carolyn Lah for the English Department book fair. The fair took place in October in conjunction with Barnes and Noble Cranberry with the donation of a portion of the proceeds from the books the students purchased.

ABOARD Honors Three Nominees and Presents the Annual Grandin Award for Service to the Autism Community

ABOARD recently awarded its annual Grandin Award to **Gerard Stropnick**y at their January 2010 Gala. The Grandin Award is given by ABOARD to acknowledge one individual who most clearly contributes to ABOARD's mission of "maximizing the potential and possibilities of children, adolescents and adults in Pennsylvania."

Gerard Stropnick was honored for his years of service to the autism community in the Danville, PA area. As a parent of a child with autism, Jerry and his wife joined their local ABOARD support group. Soon, Jerry became the facilitator of this group. In this role, he has helped many families struggling to cope with the autism diagnosis and make decisions about therapies.

Over the years, Jerry observed that many families felt isolated and did not take their children with autism or their siblings to public places. These families needed a safe place to share some fun time with all of their children and to be with others affected by autism. In 1999, with the help of volunteers and the families in his support group, Jerry founded Camp Emerge. That year 33 campers and volunteers attended the weekend camp. Jerry has worked to secure funding so that camp is affordable for all and more weekend camps have been added as the need has increased. Attendance has steadily grown and in 2009 over 350 individuals attended camp.

Bonnie Jamieson was recognized for her dedication to the autism community. She has devoted much of her career to autism which includes her work with the Regional Intervention Program (RIP) in Harrisburg, LEAP Preschool, and as a trainer for project STEEM, a federally funded in-service training grant. More recently, Bonnie has been an autism consultant with the Watson Institute, and has advised and provided support to numerous school districts throughout western PA.

Judy Lee worked in the social work and mental health field during the early years of her career. In 2002 she accepted a position as a Behavior Specialist Consultant (BSC) for Wesley Spectrum. Two years ago, Judy became the school based mental health consultant for Bethel Park High School. She was to work with one student, whose needs were so great that he was being considered for placement outside the school district. Through her efforts, not only was this one student helped, but that one student case load has now increased to over 40 students being helped by Judy.



ABOARD is pleased to honor these outstanding individuals and to congratulate Gerard Stropnick as the winner of this award. The autism community is fortunate to have these individuals dedicated to those affected by autism spectrum disorders.

Left to Right: Gerard Stropnick, Judy Lee and Bonnie Jamieson



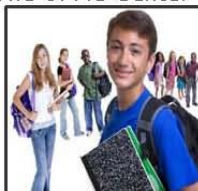
UPMC | University of Pittsburgh
Medical Center

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**

creating new stories for children, families and ourselves



New Story schools and services help children with the most serious and complex educational and behavioral challenges.

It's a place where children and their families feel safe, find hope and have the opportunity to live a good life.

In addition to its schools located throughout PA, New Story offers a number of services including:

- ★ Behavioral Health Rehabilitation Services
- ★ Intensive Case Management / Resource Coordination
- ★ Social Skills Intervention Group
- ★ Family-Based Services
- ★ Applied Behavioral Analysis
- ★ Extra Miles for Families
- ★ Therapeutic Camp

NewStory

To learn more visit www.newstory.com
or call 1-877-622-7245

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 from 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



Does your child need an educational and social learning program?

Pace Programs blend social learning, with a strong academic curriculum

and connect students to the full range of services they need to thrive.



PACE A Pace School Program
LEARNING CENTER
724-903-0083

PACE SCHOOL WHERE KIDS GROW
412-244-1900

Learn more, visit www.paceschool.org

Why Families Should Consider Participating in Research

Western Pennsylvania is home to a significant number of important research efforts in the field of autism spectrum disorders (ASD). Many opportunities are available to families who wish to participate in research studies, from improving early diagnosis, increasing our knowledge about learning and brain functioning in autism, to assessing the effectiveness of novel treatments. Research has already had a significant impact on ASD services both locally and across the country. For example, researchers have developed tools that allow pediatricians to conduct early screening for autism in toddlers and preschoolers. Research on intensive services provided during the preschool years has demonstrated our ability to obtain impressive gains for many children in the spectrum. Recent large-scale drug studies have resulted in FDA (Food and Drug Administration) approval of medications to treat agitation and aggression in autism.

There are a number of reasons why families might consider participating in a research study. First, there may be direct benefits to the child and family if the study involves assessing a treatment intervention. Second, the research may have indirect benefits, such as helping clinicians learn more about brain functioning or early diagnosis. While not necessarily benefiting the participating child and family, the study findings may help other families in the future. Finally, most research efforts provide services at no cost to families as well as offer access to ex-

pertise that might not otherwise be available.

The first step in looking into the possibility of participating in a study is to contact the study's coordinator. This typically involves a 5-10 minute telephone screen during which time you will be provided with specific information about the study. If it sounds like something that would be of interest, the coordinator will then request more specific information about your family and child. At the conclusion of the telephone screen and a determination that your child may be eligible to participate in the study, a screening visit is scheduled. During this visit, the study consent is reviewed. The consent provides a clear description of the study procedures, the risks and benefits, and your rights as a study participant (including your right to change your mind and withdraw from the study at any time). Once the consent is signed, screening assessments can begin to determine if your child can participate in the study itself. Some studies involve a single visit, while others require repeated sessions (such as when assessing the effectiveness of a treatment).

Families who are interested in participating in research studies can seek out a number of local and national resources. For example, the ABOARD newsletter and website contain information on various research efforts. The CeFAR website (www.pittautismresearch.org) and CHP website (www.chp.edu/CHP/Child+Development+Clinical+Trials) also contain information on local re-

search efforts. Families can also log onto Clinicaltrials.gov to learn about studies being conducted across the country. Below is a partial list studies currently being conducted through the University of Pittsburgh (including Children's Hospital of Pittsburgh and Western Psychiatric Institute and Clinic). We hope that you and your family will consider participating.

-Treatment of Sleep Disturbances in Young Children with Autism (412-692-8404): The purpose of this study is to determine if a parent training or parent education program will be helpful to families of young children with ASD who have significant sleep problems (ages 2-6).

-Treatment of Disruptive Behaviors in Young Children with Autism (412-692-8404): This study is designed to reduce behavior problems in young children with ASD (ages 3-7). It will compare the effectiveness of a parent training program versus a parent education program.

-Autism Treatment Network (ATN)(412-692-8404; 412-235-5512): The ATN was formed to create guidelines for the medical problems that can accompany ASD. The main goal of the ATN is to improve the treatment, care and quality of life for children with this disorder (ages 2-17).

-Nutrition and Autism (412-692-8404): This study is part of the ATN and examines the nutritional deficits and needs of children with ASD (ages 2-11).

Why Families Should Consider Participating in Research—Continue

-Treating ADHD symptoms in Children with Autism (412-235-5447): This is a 10-week study examining parent training and an approved ADHD medication to treat symptoms of over activity and inattention in children with ASD (ages 5-13).

-Autism Adult Sleep Survey (j.taylor.pitt@gmail.com): This is a one page, anonymous survey inquiring about sleep trends in adults with ASD.

-Treatment of Anxiety with Biofeedback (412-235-5445): This study involves 10-14 weekly visits involving the use of biofeedback to treat symptoms of anxiety in 9-17 year-olds with ASD.

-Autism Center of Excellence: Neurocognitive Basis of Autism (autismrecruiter@upmc.edu or 1-866-647-3436): This study focuses on how individuals think and process information as well as obtaining information on brain structure and function. The program includes children and adults with ASD.

-Pitt Early Autism Study (PEAS) (autismrecruiter@upmc.edu or 1-866-647-3436): This study seeks to understand the earliest indicators of autism by studying infants who have an older sibling with ASD.

-Cognitive Enhancement Therapy Intervention for adults with ASD (autismrecruiter@upmc.edu or 1-866-

647-3436): This study examines a non-drug treatment approach designed to help improve attention, memory and problem-solving skills for individuals with ASD (ages 16-40). Participants meet weekly with a therapist.

-Facial Recognition Intervention Study for Children with Autism (autismrecruiter@upmc.edu or 1-866-647-3436): This is an intervention program designed to help children with ASD (ages 10-15) improve their ability to recognize faces. Participants are trained to use computer software and given a laptop computer to take home to complete practice sessions.

Benjamin Handen, PhD, BCBA-D and Cynthia Johnson, PhD, BCBA

PRESSLEY RIDGE AUTISM AND DEVELOPMENTAL DISABILITIES PROGRAM



Children receive intense educational and therapeutic services while improving their behavioral, social, communication and life skills.

- * Day School for Autism
- * Therapeutic Social groups
- * Behavioral Health Rehabilitation Services
- * Extended School Year Summer Programs

Extended School Year—Open for Enrollment

Pressley Ridge

Serving Children and Families Since 1832

For more information: 412-322-9533 or www.pressleyridge.org



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

www.afit.org

Camp Fair 2010



ABOARD had over 350 people attend its 6th Annual All Abilities Camp Fair! The event was held on Saturday, January 30, 2010, at the Shoppes at Northway (formerly Northway Mall). Families and professionals were able to stop by and obtain information from area agencies as to the programs they were offering this summer. The following agencies exhibited their therapeutic, recreational and educational programs geared for individuals with an autism spectrum disorder or special ability at the event:

AHEAD
AIU3
Baierl Family YMCA
Computing Workshop
Conductive Education
Developmental Delay Resources
Family Behavioral Resources
Familylinks
Glade Run Lutheran Services
Miracle League of Southwestern PA
New Story
Pressley Ridge
Sharp Visions
SPEAK Program
Total Learning Center
The Watson Institute
Wesley Spectrum Services
Western Psychiatric Institute
The Woodlands

Thank you to all the camp fair exhibitors and the event sponsor:



Support Group Happenings

Families and caregivers of children and adults with autism spectrum disorders need to meet and share their struggles and successes. I constantly say "I've learned a lot from parents" because that's true. ABOARD is able to help people connect by providing support groups throughout the commonwealth of Pennsylvania. And if you have or attend a support group, give us a call, we can talk about adding it to the directory.

This last quarter brought many stories. It's spring and many parents are working on their child's Extended School Year program. Surprisingly, some counties don't have many options for summer planning for kids with ASD. There is a lot of concern for those families and their children to ensure they can achieve a free, appropriate public education. According to The Right to Special Education, A Guide for Parents, 2009 Edition (found at www.elc-pa.org), *The IEP Team must meet by February 28th of each school year to determine a child's need for Extended School Year (ESY) services over the summer months or at other times when school would not usually be in session for children with severe disabilities (such as children with autism, serious emotional disturbance, severe mental retardation, and severe multiple disabilities.* Most children on the ASD spectrum need a continuance of their school year so they can make progress on their goals academically, behaviorally and socially. Fortunately, many parents have learned to be very creative in planning their child's summer.

School placement can be a common topic for many families. Sometimes it's hard to make a choice, there are so many factors involved. Inclusion, behaviors, academic ability, bullying, the list seems endless. Many kids successfully attend the public school in their neighborhood. "The true essence of inclusion is based on the premise that all individuals with disabilities have

a right to be included in naturally occurring settings and activities with their neighborhood peers, siblings, and friends" (Erwin, 1993, p.1). Our federal and state laws really help enforce inclusion, but for many kids with ASD this could be too challenging. Fortunately, in western PA there are many wonderful choices for kids on the spectrum. Families who live in rural areas may not have enough appropriate approved private schools for those students who can not make progress in a typical environment. Home schooling is a wonderful option for many families too. The direct support from cyber schools can be wonderful and there is a network support group to learn more!

Early intervention is another topic discussed at meetings. What is an appropriate placement for their small children just diagnosed on the spectrum? Many of us remember the fear in making the wrong decisions as far as placement. Thanks to the many 'veterans' at our support group meetings, the families worries are eased as they discover the importance of working with their school team as well as the power in their own decisions as the best advocates for their children. Thanks to the many wonderful services Pennsylvania government allows children with behavioral disorders, families can schedule intensive treatment for their children, for example, one-on-one behavioral intervention, pre-school, social skill groups, speech, occupational and physical therapy and a plethora of small groups of typical activities our children can do with wraparound employees. As always, no system is perfect but Pennsylvania offers such services where other states don't have to... we often have families moving in from other states to get these services and resources.

Unfortunately, bullying is a huge topic for discussion and concern not just for children on the spectrum but for all. It is a

very 'pervasive' problem in the entire world. But children on the spectrum can be particularly damaged and singled out. According to www.safeyouth.org, *"Children and youth who are bullied are typically anxious, insecure, and cautious and suffer from low self-esteem, rarely defending themselves or retaliating when confronted by students who bully them. They are often socially isolated and lack social skills. One study found that the most frequent reason cited by youth for persons being bullied is that they didn't fit in."* Parents must work closely with their IEP team and school personnel if there are problems. For more information, GoodSearch (with ABOARD as your cause of course) the Pennsylvania Department of Education or Education Law Center websites.

Obviously there are many more conversations going on at support groups and other events when parents get together. But there is some fun!! Many groups meet at restaurants, have parties or go to kid-friendly places. With spring finally here, the groups will have more opportunities for outside activities. Call ABOARD for our list of groups, or if you would like to chat.

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

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.

REHABILITATION SPECIALISTS, INC.

Speech and Language Therapy

Kathleen R. Helfrich-Miller, Ph.D., CCC

BELLEVUE | ALLISON PARK

Ph 412.761.6062 (*all appointments*)

Fx 412.761.7336

www.rehabspecialists.net

Accepting all insurance plans.



PEDIATRIC THERAPY SPECIALISTS, INC.

Robinson Township and Wexford locations

412-787-1180

OT PT Speech

call NOW to schedule your appointments
- summer schedules now forming!

Sensory Integration, Oral motor therapy,
Therapeutic Listening, Core strengthening

Your AD here call **ABOARD** at 412-449-0165

COSTA Law Offices

Estate Planning and Administration, Special
Needs Planning, Guardianship and Elder Law

We will come to you! In-home consultations.
(724) 318-8155 www.costalawoffices.com

Because... finding the right attorney makes all the
difference!

Monaca, PA Beaver County-
Serving SW Pennsylvania



*"I wish that
my allergies
would
go away."*

Children & Allergy Statistics

- In 2007, approximately 3,000,000 children under 18 were reported to suffer from 1 or more allergies.
- Of all the chronic diseases that affect children under 18 years old, Allergies are the 3rd most common.
- Allergic Dermatitis (itchy rash) and Eczema affects almost 9,000,000 children younger than 11 years of age.
- Roughly 27% of children with food allergies also suffer from eczema or another skin reaction and are 4X more likely to develop asthma.
- Allergic Rhinitis affects as many as 40% of all children.
- The prevalence of food allergies among children under 18 increased nearly 30% from 1997 to 2007.

****Laser Allergy Relief Center****

724-387-1014

www.LZR7.com

www.pantherchiro.com

Dr. Danielle Marra, DC

**FREE! LZR7 LASER
ALLERGY ASSESSMENT**

Experienced treating kids on the spectrum
DAN protocols
Nutrition store on site
Cranial Adjusting

Beyond Individualization: Building IEPs on Individual Strengths, Needs, and Wants

Out of a total education enrollment – 1,787,351 – in the Commonwealth of Pennsylvania for the 2009-2010 school year, 15 percent of these students are enrolled in special education.

Everyone in special education knows that IEPs must be individualized. In fact, individualization of each child's special education plan is built into educational law and reflected in the first letter of the ubiquitous acronym "IEP". Individualization is great, but still not optimal. To be maximally effective, each IEP must be built around the individual child's strengths, needs, and wants.

Too often, individual educational plans focus on remediating what is wrong. Noting the many failings of a special child in an IEP guarantees that it will be individualized, but this surely is not positive. Developing goals to reduce the number of times that a child fails may be a step in the right direction, but less frequent failures is not the same thing as more frequent successes! When we focus on a child's strengths and make sure that more opportunities are presented to use those strengths in positive ways, we increase successes. More successes equate to fewer failures and fewer behavioral complications associated with those failures. A great IEP must include goals that build on the child's strengths to increase the child's successes.

Focusing on the child's strengths to

increase successes is also not enough.

Repeating the same successes over and over may give us many opportunities to reinforce the child, but will not lead to growth and development in new areas. We must include goals in the IEP that help the child acquire the knowledge and skills that are needed for maximum growth and development. Still, we must remember that not everything that is different than what we ideally want must be changed. We can learn to tolerate individual differences. This involves changing who we are more than changing who the child is. Allowing a child to be different reflects positively on us as educators provided that this does not interfere with the child's overall needs being met. Meeting critical individual needs is not the same thing as changing behaviors that annoy us. It involves changing behaviors so that the child can grow and develop in an optimal manner, not so that we can feel more comfortable around the child.

Even as we focus on meeting the child's needs, we must not ignore what the child wants. The child may not absolutely need what the child wants, but success that is defined totally based on our standards and ignores the child's choices, is clearly not the highest form of success. What a child wants may be different than what we want for the child, but helping the child achieve what the child wants to achieve in a way that is significant to the child is indispensable

for developing the child's feeling of competence and self-worth.

We must help the child achieve what is needed to be achieved. We must also enable the child to "win" some of the conflicts that the child has with others. Balancing the child's needs with the child's wants enables the child to achieve positive outcomes by our definition as well as by the child's definition. Both are critical to achieving the optimal outcome for the child.

Dr. Paul Volosov is the founder and president of New Story – a group of schools and services located throughout Pennsylvania, which help children with severe and complex emotional and behavioral disorders live good lives. Dr. Volosov received his master's degree in human development and his Ph.D. in school psychology. As a certified school psychologist and a licensed psychologist, Dr. Volosov has founded a number of organizations including Growth Horizons, Inc., Salisbury Behavioral Health, Inc., and New Story (formerly Milestones Achievement Centers). Each of these companies supports people with serious and complex challenges and helps them take responsibility for themselves and others so that all can live satisfying and contributing lives. For more information visit: www.newstory.com.

RIDE^{TO} THE RIVER

FOR AUTISM POKER RUN



To Benefit ABOARD
(The Advisory Board on Autism and Related Disorders)

ABOARD



Ride starts and ends at
Three Rivers Harley-Davidson
1463 Glenn Avenue, Glenshaw, PA 15116



AUGUST 8, 2010 • 11AM



www.aboard.org

autismnews@aboard.org • 412.449.0165

Visit the website or call for your raffle ticket and a chance
to win a 2011 Harley-Davidson FATBOY Motorcycle!



Trailblazing for Autism

Come ride with us! Enjoy two hours of marked trails with hills, valleys, and creeks in the Pennsylvania woodlands. Rest and relax after your ride and end your day with a hearty meal and Chinese Auction.

Where: Victory Bible Chapel and Stables
1135 Camp Nancy Road
Apollo, Pa 15613

When: Saturday, June 5, 2010
12:00 p.m. to 7:00 p.m.

Cost: \$65.00 per person includes trail ride and dinner
\$30.00 per person includes dinner

Please visit www.aboard.org or call 412-449-0165 for more information and to register for this event.
Rain or Shine.

Proceeds benefit the Advisory Board on Autism and Related Disorders (ABOARD) and Eminent Horsemanship




2010 Park Ticket Sale

Take advantage of the discounted rate while supporting ABOARD!



Idlewild Tickets - \$18.00 (100 Tickets Available)

The gate price at Idlewild this year is \$29.95. Children 2 and under are free. Tickets are valid **WEEKDAYS** only any time **May 31, June 4 – August 12 and September 6**. Tickets cannot be upgraded to weekend usage and are VOID after September 7, 2010



Sandcastle Tickets - \$18.00 (500 Tickets Available)

The gate price at Sandcastle this year is \$29.99. Children 3 and under are free. Tickets are valid any day. Open Daily: **June 12 - August 22, August 28 & 29, September 5 – 7.**



Kennywood Tickets - \$25.00 (500 Tickets Available)

The gate price at Kennywood this year is \$35.99. Children 2 and under are free. Tickets are valid for any day in **May, June and September**. Tickets valid **WEEKDAY** only for July and August but can be upgraded to weekend usage at gate.

Visit www.ABOARD.org to purchase tickets



Presents:

TEACHING CHILDREN TO BE THE BOSS OF THEIR BRAIN

**Helping Children with Autism Spectrum Disorders
Achieve Academic & Social Success**

Presented by: Janice Nathan, M.S., CCC-SLP

Saturday, May 8, 2010; 9 a.m. – 3 p.m.

The ABOARD Office, 35 Wilson Street, Suite 100, Pgh, PA 15223

This session will emphasize how to help children with Autism Spectrum Disorder become independent learners in unstructured and structured settings. Participants will understand how the brain acquires and uses knowledge, and armed with this knowledge, learn effective, easy-to-use and brain-logical strategies to help children with ASD succeed in academic and social settings.

You will learn to understand differences in language development in typical children vs. children with ASD. You will also learn to describe the prerequisite skills needed for social communication, and the importance of social communication for learning in academic settings. Last, you will learn strategies designed to develop language for reasoning and problem solving in academic and social setting.

Register at www.aboard.org or call for detail



COMMUNITY PARTNERS CONCERT FEATURING
GLORIA GAYNOR
PARTNER/CODE for
 tickets to benefit
ABOARD is 18183
 TICKETS ON SALE MARCH 1ST AT 9 AM
 JUNE 24, 2010 • 7:30 PM • HEINZ HALL
 CALL 412.392.4900 • 800.743.8560
PROCEEDS BENEFIT THE PARTICIPATING NONPROFIT PARTNER OF YOUR CHOICE



911-Medical ID PLUSTM Family
 This Card Contains
 My Emergency Medical Information

2GB USB

To access my information push tab out (contact up). Plug into USB Port on any WindowsTM computer.

www.911medicalid.com U.S. Patent 7,136,288 B2 - Powered by Freecom

*Protect yourself and your loved ones
 by caring your medical records with
 you wherever you go!*

Size of a credit card ! Software included!

order on line:
911medicalidPittsburgh.com

Receive \$5.00 off -use promo code :
ABOARD

Plus a 5% donation will be given to ABOARD
 Rose Scheyer, Maika Sales LLC
Allegheny County's Licensed Distributor

Vocational & Psychological Services

Martin Meyer, Ph.D. - Psychologist
Julie Uran, Ph.D. - Psychologist

Child & Adult Mental Health Services
Wraparound and Autism Services
Evaluations ~ Counseling
Social Skills Groups
Tutoring and Educational Support

Board Certified Behavior Analysts
Specializing in Autism Services
Individual, Group & Family Therapy

New Castle 724-656-6866 Butler 724-287-5604
Slippery Rock 724-794-1954 Sharon 724-982-4790



Helping children and adolescents reach their optimal potential

Monongahela Valley Hospital's Center for Children's Rehabilitation Services provides specialized services to meet the rehabilitation needs of children and adolescents.

SERVICES

Physical Therapy
Speech Therapy
Occupational Therapy

Please call 724-258-2971 to make an appointment or for more information.

Center for Children's Rehabilitation
MYH HEALTH CARE

1029 Country Club Road Suite 202
Monongahela, PA 15063



Creative Discovery for Children in the Autism Spectrum

Drama is a powerful tool for teaching social skills, body language and the mechanics of social interactions. The CLO Academy's New Horizons Program is proud to offer performing arts classes for children in the Autism Spectrum.



Experienced Teachers

Classroom Support

Free Parking

Parents' Lounge

Safe and Accessible Professional Facilities

"I love CLO. Singing songs and dancing on the stage. The teachers make it like a game."

*-Trevor, age 12
2009 Student*

**Call 412-281-2234 for more information.
Register online! pittsburghCLO.org**

A Special Care Plan... where do you begin?

Designing a special care plan, the mere thought can be overwhelming. Especially in light of all the planning you do to get from day to day. When you think about a special care plan you may be unsure where to begin or what decision needs to be made first. You may feel that you do not have the time or you need to wait until everything is more settled. For most of us that never happens. One solution is to start now to coordinate a plan that is consistent with your family's vision and values and build over time. That coordination includes bringing a team of advisors together to determine the most appropriate special care strategies and harmonizing it with your overall plan.

So what is that first step in the planning process? **Goals!** Start by identifying your primary concerns and separate them into short and long term goals. These may be tasks that have either been on the "to do list" for far too long or things that you know are fast approaching.

Examples of long term goals may include:

- * **Determine eligibility for government benefits**
- * **Seek vocational training and support**
- * **Plan for college**
- * **Get other children and relatives involved in the plan**

Next is to think long term and what those more broad goals may be. Although you may not be sure of the outcome it is still important to identify these long terms goals based on your current experiences as well as your hopes for the future of your loved one. These goals may relate to your loved one's ability to live independently and make decisions regarding their own care and finances as well as what employment opportunities may be an option. The importance is not on knowing the outcome but rather on identifying the issues so that you can plan i.e. Will your child attend college? Can they live independently? By indentifying the issues you are better able to put contingencies in place today that are flexible enough to address many potential outcomes.

Some examples may be:

- * **Join a support group**
- * **Complete our will and estate planning**
- * **Address concerns in our child's IEP**
- * **Decide who you will name as a Guardian**
- * **Complete a Letter of Intent**
- * **Maximize Government Benefits**

As life changes , so will your plan change from year to year but addressing your goals as the first step will enable you to tackle the different areas

as they arise. So, as you begin the process of setting your goals, remember that it is essential to coordinate your team of advisors so that you can focus on the resources necessary in the process as well as the network of providers that play an integral role in the lifestyle of your loved one. Sitting down and setting your goals is the important step and is the basis for your special care plan. This foundation will allow you to move forward with a greater understanding of the needs and values of your family.

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.



Watson
INSTITUTE

Summer 2010 Programs

Therapeutic summer camps for teens with autism ages 13-21 at our sites in Sewickley, Upper St. Clair, Sharpsburg and the East End.

Inclusive camp experiences for children with autism ages 3-15 at various summer camps in western PA.

ACCLAIM summer program for high school juniors and seniors who plan to attend college.

Call 412-749-2889 or visit www.thewatsoninstitute.org

Nathan Speech Services

Janice Nathan, M.S., CCC-SLP

Licensed Speech-Language Pathologist

**ASD
Specialist**

**Speech
Therapy**

Advocacy

IEP Support

*Specializing in Individual and
Social Group Therapy for
Children Ages 3-14*



412-363-8388

nathanspeech@aol.com

www.nathanspeech.com



FAMILY BEHAVIORAL RESOURCES

FAMILY FOCUSED THERAPY



Family Behavioral Resources offers **BHRS/Wraparound Services** for children and adolescents with behavioral health needs. FBR is also proud to offer a **specialized program** and **Autism Team**, led by a **Board Certified Behavior Analyst** to treat children with **Autism Spectrum Disorders** in across Pennsylvania. FBR also offers:

- Psychological Evaluations
- Outpatient Therapy
- Social Skill/Play Groups
- Parent/Professional Workshops

- Medication Management
- Family Support Groups
- Focus Groups
- Resource Packages for Families

- Family-Based Services
- Sibling Support Groups
- Trainings for School Districts
- Summer Camps (STAPs)

FBR is now an approved provider of services under the PA Adult Autism Waiver.
In need of services? Contact us at adultasd@familybehavioralresources.com!

FBR offers Family Support Groups, Social Skill/Play Groups, and Sibling Support Groups in areas where needs have been identified. All support groups at FBR are proudly hosted in collaboration with and support from ABOARD.

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



A CARF Three-Year Accreditation has been awarded to Family Behavioral Resources for its Intensive Family-Based Services - Mental Health (Children and Adolescents), Outpatient Treatment - Mental Health (Adults), and Outpatient Treatment - Mental Health (Children and Adolescents). *BHRS is accredited under Outpatient Treatment. Ask us about CARF today!

The Advisory Board on Autism & Related Disorders (ABOARD)

2010 ABOARD Membership Form

YOUR MEMBERSHIP is CRUCIAL

Committed to *NO LESS* than the maximum potential of every
Pennsylvania child, adolescent and adult with ASD

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.

Organization/Corporate membership dues: \$250

Organization _____
 Primary Contact Name _____
 Address _____
 Phone # _____ Fax # _____
 E-mail _____ Website _____

Mail form with your check made payable to ABOARD or credit card info. to:
ABOARD, 35 Wilson St., Suite 100, Pittsburgh, PA 15223

Credit Card (VISA, Master Card) _____ Card # _____
 Name as it Appears on Card _____
 Statement Billing Address _____
 Ex. Date _____ CCID # _____ Authorized Signature _____

phone: 412.781.4116 or 800.827.9385/Fax: 412.781.4122

ABOARD'S 2010 Organization/Corporate Partners

ACHIEVA

AHEAD

Alliance for Infants & Toddlers

Alliance Health Wraparound

AVID Learning Center

Barber National Institute

Children's Institute of Pittsburgh

Community Care Behavioral Health

Comprehensive Children

& Family Services

Costa Law Offices

Diversified Human Services, Inc.

Dynavox

Easter Seals Western PA

Emmaus Community of Pittsburgh

Family Behavioral Resources

Fayette County MH/MR Program

Glade Run Lutheran Services

Integrated Care Corporation

Midwestern Intermediate Unit 4

Nathan Speech Services

New Story

NHS Human Services

PACE School

Pediatric Therapy Professionals, Inc.

Pediatric Therapy Specialists

PLEA

Rehabilitation Specialists, Inc.

River Speech & Educational Svcs. Inc.

Ron Dunn Agency

Shamrock Solutions Inc.

Southwestern Human Services

Step by Step, Inc.

Stern Center for Developmental

& Behavioral Health

Value Behavioral Health of PA

Watson Institute

Western Psychiatric Institute and Clinic

Westmoreland Case Management

& Supports, Inc.

Westmoreland County MH/MR Program

WJS Psychological Services, Inc.

Youth Advocate Programs, Inc.



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.

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



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!