HCAS LOOKS TO THE FUTURE ~ STRATEGIC PLAN TAKES SHAPE

Almost twenty years ago, a small group of parents came together to advocate for improved educational services for students with autism in Howard County. These parents founded the Howard County Chapter of the Autism Society of America, which today serves hundreds of individuals and families affected by autism. Whether the original founders in 1993 envisioned an award-winning chapter, or a healthy nonprofit that would open a resource center and employ staff... that’s probably unlikely. And yet, the chapter they created has become a powerful voice in the county and in Maryland for those dealing with autism. With community partnerships well beyond the school system, HCAS is trusted by families, professionals, educators, therapists, and county agencies as a reliable source of information and support.

In 2011, the Board of Directors will set out a new strategic plan for the chapter. Having accomplished every major objective on its previous five-year plan, the Board surveyed its members in 2010, studied its strengths and weaknesses, and assessed the opportunities and challenges that lie ahead. With uncommon energy for a staff of two, a Board of 17, and many volunteers, HCAS is committed to its mission of providing support to families, promoting awareness of autism, and continuing to advocate for improved services.

Results of the Assessment
In the coming months, the Board and staff will be utilizing the results of the needs assessment to evaluate, prioritize, and determine how best to meet the needs of the membership. Some of the results are presented here.

Transitioning Youth & Adult Issues
Members will notice more workshops offered dealing with the transition from high school to college, the workforce, and adulthood. Collaborations with other local agencies focused on these issues will also increase, as will advocacy for better services and options. For those interested, the “Transition & Adult Issues Committee” meets the second Wednesday of every month at the HCAS Resource Center.

After-School Programs & Autism Training
Members identified the lack of after-school programs as a major issue. HCAS will work toward identifying programs and collaborating on new offerings in the county. Routine trainings on autism are also a priority.

Autism Awareness
In addition to ongoing efforts in the schools to promote an understanding of autism, HCAS will engage employers, local colleges, faith-based communities, social service agencies, sports managers, and others in increasing awareness.

Social Opportunities
HCAS will continue to offer social events throughout the year, including Fitness First at the Columbia Gym, pool parties and picnics, potlucks, bowling, restaurant nights, and more.

Parent Wellness
All parents need a break from time to time! HCAS will offer several “mini-retreats” by certified life coaches that focus on parent wellness, setting priorities, and finding happiness in the midst of challenges.

Informational Materials and “New Member” Packets
The Resource Center will become a one-stop-shop for informational materials on autism and Asperger’s for parents, educators, newly diagnosed individuals, professionals, and employers. Packets for new members and those new to the diagnosis will also be enhanced.

There are many other objectives to be developed on the strategic plan; in order to accomplish them HCAS depends on support and participation from the membership. Please consider joining a committee: Advocacy, Asperger’s, Biomedical, Events, Program, Public Relations, Transition & Adult Issues, or Website. Please call 410-290-3466 or email info@howard-autism.org to join a committee.
Howard County Autism Society
10280 Old Columbia Rd, Suite 215
Columbia, MD 21046
410.290.3466
www.howard-autism.org

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Howard County Autism Society Presents an Amazing Evening of
Denim & Diamonds

6th Annual PIECES OF THE PUZZLE GALA
Saturday May 14, 2011
7:00pm—Midnight
The Hotel at Turf Valley

Seated Dinner * Open Bar * Dancing * Live & Silent Auction
Tickets:
$100 per person * $175 per couple * $875 per table
purchase online: www.howard-autism.org

New theme, new ticket options for couples and groups, SAME WONDERFUL EVENT! Leave the black tie and ball gown behind this year, grab your favorite pair of Armani jeans or Calvin Kleins, jazz it up with some diamonds, and come along for an amazing evening!

◊ Order your tickets SOON ~ only 300 tickets available, tables sell out quickly: www.howard-autism.org

◊ Help us make this year’s gala the most memorable celebration yet! Volunteers are needed!!

Silent Auction Committee: Jenn_Palmer@comcast.net
Planning Committee: sandra.macmahon@howard-autism.org

Perspectives: The Newsletter of the Howard County Autism Society is published quarterly. Articles represent the views of the authors and not necessarily those of the Howard County Autism Society. The publication of advertisements does not indicate any endorsement by HCAS. No article may be reproduced without written permission from HCAS, which copyrights this publication.
As we begin 2011, snowed in and cabin-feverish, I can’t help but imagine that my current frustrations with connecting to the world around me must be only a fraction of what an individual with autism lives with each and every day. I feel so trapped in my own little world! I can feel the mounting anxiety when I’m forced to stay inside when I hear the frozen rain pelting my windows and the roar of the winter wind whirling around the house. It’s only through technology, rather than face-to-face interactions, that I connect with anyone outside my home on snowy, icy days. How did people survive the winter before cell phones, ipads and Netflix?!

It’s through thinking about this comparison that I recommit to my responsibilities as Executive Director at HCAS. In my short two months here, I have been very busy identifying key areas that we wish to highlight and offer enhanced support: Aspergers, Transitioning Adults, Adults.

Autism is a vast spectrum, with a wide variety of challenges facing each and every individual with the disorder. The Asperger’s diagnosis indicates a specific grouping of abilities, as well as social deficits and ritualistic behaviors. HCAS plans to customize its supports for our Howard County families to address the unique challenges facing this subgroup within the autism diagnosis. With new research available regularly, and the current re-evaluation process for the DSMV, HCAS will continue to evaluate and create area trainings, job coaching, and community awareness opportunities to support our families.

Research outlines that supporting our youth’s transition to adulthood is the strongest resource for our maturing children. HCAS plans to be very busy this year meeting with community specialists and identifying the best strategies to offer this support in a proactive way. Beginning earlier, and offering a mixture of behavioral supports with employment coaching and opportunities certainly appears to be the best step towards a more successful transition strategy.

As much as our children need strong community support and guidance, so too do adults on the spectrum. Bringing together individuals who have grown up with support with adults who are getting diagnosed after years of struggling silently creates a quickly expanding group of individuals on the spectrum who need innovative options. HCAS will be part of the community discussions to identify what strategies and supports respond to the unique needs demanding attention. The completion of our recent Adult Issues Workshop Series, co-hosted with Pathfinders for Autism, is part of our continued commitment to provide the most current information to our families.

As a community of parents, siblings, friends and service providers, we collectively recognize that empowerment and contentment in life isn’t realized only through quality education and research-supported strategies. While important, there comes a time when we push all of the data and therapies aside, and make room to be silly, to laugh and enjoy time with each other. HCAS believes arranging a variety of social opportunities is as imperative as our speaking engagements, and sometimes even more so. Make sure to visit our website, social network or Facebook page often to find the next pool party, restaurant event, or afternoon at the park. Responding to recent requests, we are considering some unique opportunities just for adults, and planning a number of respite retreats for parents desperately in need of rejuvenating the reserves.

I’m anxious to break out of my frozen winter wonderland and get out in the Howard County community to meet more of our families, educators and specialists. I look forward to hearing your thoughts, your questions, and your concerns. It is your feedback that helps guide the direction of HCAS.

~ Mary Beth Collins
mbcollins@howard-autism.org

HCAS Gratefully Acknowledges Recent Donors

Dart Group II Foundation
Richard and Mary Anderson
Lisa Carter
Peter and Regina Ernest
Frank Feng
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Jane Plapinger
Carolyn Seaman
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Truist
United Way
John and Pamela Vogel
Pamela Wagner
Steven Wampler
The Many Faces of Autism~ Slide Show in Production
Each year at the annual Pieces of the Puzzle Gala, HCAS features a slide show presentation of the many individuals and families in Howard County affected by autism. It is a powerful visual reminder that autism knows no boundaries when it comes to race, ethnicity, age, or gender. It is also a beautiful portrait of our children, families, students, and clients whom we celebrate and honor at the annual dinner. In addition to the slide show, HCAS would like to create brochures and posters highlighting a sample of our members and their talents.

Needed:
Pictures of individuals with autism. Any age, gender, race, or ethnicity. Send photos as high resolution jpegs or tiff files.

Information to Include:
Name, Age, “Title” (such as: pianist, baseball player, musician, chess master, Lego legend, artist, painter, swimmer, equestrian . . . endless possibilities!)

Send to:
Sandra MacMahon, Resource Center and Events Coordinator:
sandra.macmahon@howard-autism.org

Deadline:
March 31, 2011

Sibling Appreciation Event Planned for April
Recognizing the all-too-often unsung heroes of our families is long overdue! HCAS is planning a special event for . . . about . . . and in honor of . . . SIBLINGS! The event will take place during the month of April. Plans are still coming together, but in addition to a social outing and/or dinner, the many special sisters and brothers to siblings with autism will be recognized for their praiseworthy patience, support, loyalty, and love. Watch for more information in the months ahead.

HCAS Welcomes Four to the Board of Directors
The annual membership vote for the 2011 Board of Directors took place on January 21 at the general membership meeting. Later than in years past, the vote was delayed due to a weather-related cancellation of the December meeting. Stephanie Maric, a long-time board member and previous president, chaired the nominating committee.

New to the Board of Directors are two parents of children with autism, Jennifer Goldszmidt and Jennifer May, and two community members, Kristin Anderson and Tom Coale.

Jennifer May, a Howard County native and CFO for a construction management and land development company in Columbia, has been active with HCAS for many years. Jennifer and her husband, Chuck, have two sons. Chase, who is on the autism spectrum, is a 6th grader at Lime Kiln Middle. Evan is in fourth grade at Fulton. Jennifer will serve on the Asperger’s and program committees.

Jenny Goldszmidt is a teacher of world languages in the Howard County Public School System. She has a daughter, Zoe, 9, with autism, who attends Waverly Elementary. Jenny will serve on the program committee and will co-chair the annual walk.

Kristin Anderson is the owner and team director of Columbia Gymnastics. Her sons Derian, 9, and Nicklas, 6, attend Linton Springs Elementary in Carroll County. Kristin and her husband, Andy, moved to Carroll County from Pittsburgh 15 years ago.

Tom Coale is an attorney with Goodell, DeVries, Leech, & Dann, LLP in Baltimore City and works in their medical malpractice litigation group. Tom is a lifelong resident of Howard County and will be working with the legislation advocacy and nomination committees.

A special note of thanks to outgoing board members Stephanie Marie and Cheri Truett for their many years of dedicated service to the autism community.
As we begin our terms as HCAS co-presidents, let us first begin by saying THANK YOU to Beth Benevides Hill for an extraordinary job as president.

During her three-year tenure, Beth put forth tremendous efforts for our members and the special needs community at large. She also took the reins in 2010 and kept the resource center open and running smoothly during our interim search for our new executive director. Beth’s accomplishments could fill up this entire newsletter, to say the least, and it is with the most sincere thanks that we bid her farewell as president and welcome her while she serves on the Board as immediate past president.

We are pleased to welcome Mary Beth Collins as executive director. Mary Beth brings a wealth of knowledge and experience. She has worked with community support organizations, such as the Special Education Citizens Advisory Committee of Harford County and CHADD. She most recently served as director of academic and community partnership for Confident Student where she helped streamline the process for families to identify and develop strategies for addressing the spectrum of learning and behavioral challenges.

We look forward to our terms as co-presidents with much excitement and anticipation. With changes to the Executive Committee, our Board of Directors, and our staff, we look forward to this opportunity for growth, partnership, prosperity, and increased awareness in the coming year.

~Marianne Ross
marianne.ross@howard-autism.org
~Sherri Braxton-Lieber
sherri.braxton-lieber@howard-autism.org

About the Co-Presidents:
Sherri Braxton-Lieber is the mother of two children, ages 4 and 8. Her eldest child is on the spectrum and attends Pointers Run Elementary School. Sherri is the director of a defense contractor and serves as a computer science and information technology adjunct faculty member at several universities, including Johns Hopkins and the University of Maryland University College.

Marianne Ross has two children, ages 9 and 11. Her eldest child is on the spectrum and attends Elkridge Landing Middle School. Marianne is a captain in the US Public Health Service where she serves as a veterinary epidemiologist at the FDA. She is also on the Board of Trustees at the Horizon Foundation and is a proud Howard Huskies hockey mom.

Splashes amid snowfalls

HCAS hosted its annual winter pool party at Lifetime Fitness on Sunday, January 23. Superbowl playoffs and snow showers did not deter the nearly 100 participants from the beautiful indoor pool, hot tub, and waterslides.

A special word of thanks to Lifetime Fitness’s Terri Short for managing the event and to the lifeguards on duty for professionally accommodating and warmly welcoming our families once again!

We look forward to our Summer Pool and Pizza Party at Lifetime on Sunday, July 17, 2011, 6:00pm.
The fourth annual “One Step Closer . . .” Autism Walk and (inaugural) 5k Run attracted 105 runners, 225 walkers, 107 volunteers/participants, and 24 vendors and exhibitors—all braving a chilly fall morning at Centennial Park in Ellicott City. The goal: to promote awareness of autism in the community and raise funds for the Howard County Autism Society Resource Center.

There are many individuals and businesses to thank—from those who sponsored the event to those who participated in the walk and 5k or donated to the cause; from those who donated food for the continental breakfast to everyone who volunteered to ensure things ran smoothly.

Attendees enjoyed a delicious breakfast, coffee, hot cocoa, moon bounces, t-shirts, race awards, popcorn, face painting, prizes, and giveaways.

Mark your calendars for the 2011 Walk/5k Run: Saturday, November 5, 2011 ~ Centennial Park

HCAS CHAMPIONS
the following teams raised $1000 or more (team captains listed)

JAKE’S JEMS
(Stephanie Carr)
$11,100

MATT’S MAVERICKS
(Debbie Clutts)
$3,280

TEAM BOXALL
(Patrick Boxall)
$2,655

RYAN’S TROOP
(Roger Thibaudeau)
$2,440

TEAM ETHAN
(Sherri Braxton-Lieber)
$2,195

KYLE’S CREW
(Beth Benevides Hill)
$1,688

ERIC’S EAGLES
(Eric Welsh)
$1,610

TAYTEN’S TEAM
(Denise Dixon)
$1,415

MALCOLM’S MOJO TEAM
(Cheri Truett)
$1,330

WOLFY’S WALKERS
(Cynthia Schwanz)
$1,255

KONSTANTAE
(Christina Konstantas)
$1,060

Annual Walk & 5K Attracts Crowd of 500 and Raises $62,000
Thank you to our sponsors

~Gold Sponsor $2,500~
Lisa Higgins Hussman Foundation

~Silver Sponsors $1,000~
COPT
The Yost Legal Group

~Bronze Sponsors $500~
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Feet First
Market Impressions
Advocacy Tips for Parents:
“What Happens When the Bus Stops Coming?”
by Kim McKay

Kim McKay and Julie Foley are parent advocates and directors of the nonprofit organization, Parents for Parents. Under the Family Advocacy and Parent Education grant awarded to HCAS, they offer free advice on education related issues.

This time of the year we, as parents of children who have IEPs, begin the process of thinking about next year. Feels like we are always thinking about what’s next—next IEP, next placement, next school, next teacher/team. . . . But do we think about those nexts without thinking about the bigger NEXT? What happens at age 18 or 21, when the bus stops coming? Is there life after HCPSS?

Rationally we know there is but thinking about that bigger NEXT makes our head (and heart) hurt. What will my child do next? Is college a possibility? What about the supports that got him/her through high school? Can he live on campus? What about the world of work? Is there an employer who will hire my child? And hire him for what? What job will he have at middle school, should you know what job your child will have at 21? No, but the sooner you start planning is tough. It’s not easy to get through today sometimes, much less plan for 4 or 8 years in the future. Our kids can change so much, it’s hard to say what they can do so far in the future. Remember this is a journey. It won’t happen overnight. Start wherever your family is, and begin there.

All this begins with a vision. Future planning is tough. It’s not easy to get through today sometimes, much less project at www.parentsforparents.org or 410-465-1193.

Plan, plan, plan. And the motto, “If you fail to plan, you plan to fail” couldn’t be more true! Here are a few tips to get you started:

- Always start with other parents. Talk to as many as you can who’ve been through it or are going through the same thing. Parents always have the best advice about what has worked and what hasn’t. As we know, there’s what should be, what’s on paper, and what really is. Parents are willing to share the ‘real deal’ and can help guide you.
- Learn as much as you can about what’s available. Do not rely on “the system” or “the experts” to know and guide you. The adult service world is incredibly complicated. Many people who work for various state agencies are not familiar with the other agencies, much less other departments within their own agency! So what’s a parent to do? Attend events and workshops. Search the internet. Read as much as you can about what agencies do what. Become an informed consumer.
- Attend the HCPSS Transition Workshop Series. Each year, the series features a wide variety of topics that help you find your way.
- Start early! Earlier than you think you should. IDEA dictates that transition planning should begin at age 14. That should be more than just a box check at your annual IEP. It’s a clue to parents to start thinking about the future. In middle school, should you know what job your child will have at 21? No, but the sooner you start the process of thinking about the future, the less daunting it is.
- Begin to think about your child in a different way. Try to think about him or her as an independent adult. What can you do now, at home and school, to foster that independence? Begin to build independence skills in everyday activities, such as chores at home, money management, talking to the doctor, and ordering from the menu. Stop thinking: “there’s no way he can make his own bed everyday!” The truth is, with some effort on our parts as parents, they will learn eventually.
- Presume competence!!! We want our teachers to presume competence, but do we always practice what we preach? Are we giving our kids time to learn new skills in the protected environments that school and home can provide? We’ve been to all the Paula Kluth workshops, and we always turn to the person next to us and say “if only the teachers could hear this message.” But we need to be reminded of it all the time, as well. Can my child come in the house from the bus without me opening the door? I didn’t know until I tried it once. After telling the bus driver what we were doing, I watched from behind a curtain to see what would happen. Funny thing, he just walked in, put his backpack away, and got a snack. All without me. A really proud moment, soon followed by the guilt of thinking about what else he can do if I let him. Had I presumed competence about him in different areas of his life? The cold hard fact was no, I hadn’t.

If you have additional questions or need free assistance with any IEP related matter, please contact the Family Advocacy and Parent Education (FAPE) project at www.parentsforparents.org or 410-465-1193.
HCPSS Offers Series of Transition Workshops

The following workshops are designed to provide families of students with disabilities, planning for the transition from school to adulthood, with valuable information and resources. Designed for families of students 14 years and older, the workshops are free and open to the public. Registration not required. For more information, contact the transition coordinator at your high school or call 410-313-5640.

March 16 (Wed) 6:30-8:00pm
“Applying for Supplemental Security Income (SSI)”
What SSI benefits are your child entitled to receive? How and where do you get Medical Assistance? What happens when your child turns 18? Are benefits available for those employed?
Presenter: Garry Levere

April 27 (Wed) 6:30-8:00pm
“Middle to High School and Beyond”
Parents of middle-schoolers . . . it’s never too early to begin planning for the transition to high school. Attend this discussion about when and how to plan and the IEP process.
Presenters: HCPSS Resource Staff

May 4 (Wed) 6:30-8:00pm
“Medical Decision Making: Guardianship and Alternatives”
Many parents feel they must establish guardianship to ensure adequate care for their children after he or she reaches adult age. Explore the pros and cons, learn the facts.
Presenters: Mindy Morrell & Beverly Rill

Funds for Low Intensity Support Services

Low Intensity Support Services (LISS), previously known as Rolling Access funds, are designed to enable families to provide for the needs of a child or an adult with developmental disabilities living in the home or to support an adult with developmental disabilities in the community. People may make multiple requests for funding through the year and across multiple years. The program provides up to $3,000 per person per year. Funds available are limited.

In Howard County, licensed providers are:

Humanim: 410-381-7171  email: info@humanim.com
Penn-Mar: 1-877-282-8202  email: LISS@penn-mar.org

To learn more, visit: www.ddamaryland.org/LISS
FACT sheet

What is the new 5 day rule and how does it affect me?

On July 1, 2010 a new law was put into place that helps parents prepare for and participate in meetings about their child. The schools must now give parents a copy of any “assessment, report, data chart, draft IEP or any other document that the team plans to discuss at least 5 business days before the scheduled meeting.”

The law also allows the school team to discuss any medical or psychological reports with the parents before the meeting. They must also give the information in writing and send it to the parents five business days before the meeting.

The law also states that parents are to receive a copy of the finalized IEP no more than 5 business days after the meeting. If for some reason the school cannot send the finalized IEP within the timeline or the IEP isn’t complete, they must at least send the draft IEP. This law applies to all children ages 3-21, who are receiving special education services.

What if I do not receive documents five business days before the meeting?
The new law allows for “extenuating circumstances” if the school cannot send the information within the timeline. The law does not explain what “extenuating circumstances” are but it says that the school staff has to tell the parent why they could not follow the new law. It also says that it cannot be considered a violation of a child’s rights or a denial of FAPE (free appropriate public education) if the school does not give the parents the documents 5 business days before a meeting.

What can I do if I do not receive the documents 5 business days before the meeting?
If you do not receive the information you have several options:
- Go to the meeting and participate as best you can. If you choose to do this, take the time to look at and try to understand the information they give you. Do not feel rushed to make decisions until you understand the information. Remember that you can stop the meeting at any time.
- Go to the meeting but ask for more time to be scheduled so you can read all information.
- Request, in writing, to reschedule the meeting until you have all of the information you need.

The new law says that the information must be given in an accessible format, what does that mean?
The law does not explain what that means but other rules say that the schools do NOT have to give the information in the family’s native language. They are required to provide translators at IEP meetings to help a family understand and participate in meetings. “Accessible formats” most likely means Braille, large print, and other options for the visually impaired. It will be important to ask for accommodations if you need supports.
Bike Camp Will Return in June

For many kids with developmental disabilities, learning to ride a bike without training wheels can be a real challenge. But thanks to the “Lose the Training Wheels” Bike Camp sponsored last June by the Howard County Autism Society and the Department of Recreation and Parks, children can learn to ride independently. The popular program returns again this summer, managed by the Department of Recreation and Parks. It will take place at the Gary J. Arthur Community Center in Glenwood. The program is one week, with one session every day, Monday through Friday. There are five sessions (each 1.15 hours) offered throughout the day.

Registration information:
Participants must be 8 years of age and have a documented disability. Participants must attend a pre-screening event at which registration will be completed. The cost is $250.

Contact:
For dates and information contact Susan Potts at Recreation & Parks at 410-313-4628 or spotts@howardcountymd.gov.

Patricia Daley, HCPSS Director of Special Education, HCAS Guest Speaker — March 17th 7:00-9:00pm

On March 17, 2011, at the monthly HCAS support group meeting, Patty Daley will update parents on recent HCPSS programs related to special education and autism, including the ongoing, countywide work of autism expert and educational consultant Dr. Paula Kluth.

Ms. Daley also will address questions and concerns from the autism community.

To ensure we cover as many topics as possible, please submit your questions in writing no later than March 10 to Beth Benevides Hill at beth.benevides-hill@howard-autism.org.
During my school years as a student, fire drills were a welcomed break from the daily routine. The surprise of the loud, unexpected noise would make us gasp, jump out of our seats, and giggle. We’d shuffle down the halls toward the exit doors, without incident. We’d wait at our assigned location in the schoolyard, and enjoy the freedom of being outside and breathing the fresh air until the ‘all clear’ bell sounded.

For most students, the high-pitched intermittent blast of the fire alarm is simply a minor, temporary irritant. But it is anything but “simple” to students who struggle with challenges like auditory sensitivity, schedule rigidity and/or anxiety, for whom this routine school safety procedure can become a complicated and, oftentimes, painful ordeal.

Auditory over-responsiveness, a subtype of Sensory Processing Disorder (SPD), presents itself as atypical sensitivity to certain sound frequencies or volume, as well as difficulty hearing auditory details, like a teacher shouting instructions while the fire alarm is sounding off. Even without the SPD diagnosis, many children with an Autism Spectrum Disorder have an over-responsive, or over-sensitive, reaction to loud and unexpected noise. There’s a host of ways these children may respond to a fire alarm: Matthew covers his ears and hides under his desk in the fetal position. Beth cries while rocking in her chair. James screams and then bolts toward the door, pushing and hurting several people in his path. Although these are typical self-protective and self-regulating behaviors, students can endanger themselves or the rest of the class.

Challenges with fire drills can escalate over time if left unattended. Once children experience the pain and fright of their first surprise fire drill, it is likely that they will develop anxieties resulting from an inability to predict when the next fire drill will take place. The ongoing fear of an impending fire drill can challenge a student’s attentiveness in class, as his/her mind is focused on the next drill rather than the lesson being taught, or the strategies needed to maintain appropriate behaviors in the classroom. When the next fire drill takes place, it could very well be that a tantrum is the explosion of the mounting stress.

An Effective Drill Prepares Everyone for a Real Occurrence

Can your child manage – or be managed – to stay safe in a true emergency? Without effective preparation, a student with autism could suffer injury or death due to elopement or tantrums in the middle of a true fire evacuation. Sensory and rigidity issues can make a fire alarm process challenging and stressful, but can make a real event tragic. Realizing the ultimate importance of a fire drill, father Derik has continued working with his child: “It is true that many autistic children have sensory issues that may be difficult to cope with. However, we have always favored a desensitizing approach in dealing with them with near perfect results. One catch… it takes time. In fact, time + consistency can overcome almost anything.”

Outbursts Sometimes Result in Academic Disciplinary Measures or Litigation

It is unfortunate to see a child struggling with auditory distress, anxiety or a disrupted routine. But when that response includes a tantrum or blatant aggression, the school must balance protection of the student with protection of the student body. Sometimes behavior will result in detention, suspension, or at times a call to police.

A recent Wrightslaw article, “When Schools Have Children Arrested for School-Related Behavior Problems,” evidences that police involvement is commonplace. Peter Wright, Esq., explains that the best thing that can be done is to use the outburst and resulting disciplinary action to bring the focus back to the quality of the IEP or 504, and improve it in the best interests of the student. “When a child with a disability is arrested for school-related behavior, this is an excellent opportunity to use the power of the juvenile court to force the school district to implement a good plan for the child - and have the Court monitor the school’s progress.”

Educators who have struggled with these challenges agree. “In order to be proactive, an IEP objective providing support during emergencies (i.e. fire alarms) is always in the best interest of the child,” says Kathleen Herron, NBCT, ECG, a teacher in Fairfax County Public Schools. “This kind of objective ensures one-on-one support as this child learns the best way to handle himself during an emergency.”

Sally Fite Stanfield, an attorney with Callegary & Steedman, encourages IEP teams to develop an effective safety plan that includes goals and supplementary aids and services. “The IEP team must consider, among many factors, the student’s cognitive ability, sensory needs, mobility, independence and ability to manage emotions and behaviors in a less structured situation when time is a factor. At least as often as we review the IEP, the safety plan can and should be revised as need be.”

Continued on next page . . .
Movie Event: “Temple Grandin”

The Autism Society congratulates Claire Danes on her Golden Globe award for her portrayal of the title character in the HBO-movie “Temple Grandin.” Danes was honored for “Best Performance by an Actress in a Mini-Series or Motion Picture Made for Television.”

Join us on World Autism Day—Saturday, April 2, at 1:00pm—at the HCAS Resource Center for a free showing of the movie and discussion.

How can we help children who experience the FIRE DRILL FREAK OUT?

Building Bridges for Autism’s Dawn Yeselavage, M.Ed., suggests:

1) Make sure your child’s teacher knows exactly when each fire drill will occur during the school year. Ask for the schedule.

2) Have your child’s teacher go over the fire drill rules with your child so he knows what is expected. A social story can be written to explain fire drill procedures to your child.

3) The day of the fire drill, make sure the rules are discussed, practice exactly what is expected, and model for the children. Have a “pretend” fire drill for the entire class. When writing the “rules,” you can write them out in a task analysis form with pictures.

4) If the child is extremely afraid of the fire drill, have the child go outside before the alarm goes off. The child can watch the other children come out of the building and see what the process is for the school building.

5) Each month, gradually increase your expectations. For the second fire drill, have the child stand by the door to go outside with headphones on his ears. Once the alarm goes off, the child can immediately exit the building. (Make sure you are discussing the fire drill on a weekly basis and role play/model if needed.)

6) The next month, the child can stand by the door to go outside without his headphones on his head.

7) Each month the child can stand a bit further from the door in hopes of getting him to the classroom and walking out with his classmates.

Lindsey Biel, MA OTR/L and co-author of Raising a Sensory Smart Child adds these two important options: noise reducing earplugs or headphones and reducing the sound of the alarm itself with egg crate foam or, if possible, simply lowering the volume.

Desensitizing the child or getting him used to the sound of a fire alarm can help reduce anxiety. School-Eaze is a CD that combines sounds that may be scary to kids, with rhythmic songs, lulling kids to a calm state with a song that explains the sound and then introduces them to it. The CD includes the sound of a school bell, changing classes, cafeteria, and fire drills. (www.route2greatness.com)

Weighted vests are also good tools to have on hand, as the deep pressure they offer is very calming to the nervous system. Alternatively, the child can wear his backpack (with books in it) for some of that deep pressure.

Many wonderful social stories created with Boardmaker® Software are available for FREE at www.boardmakershare.com.

Ida Zelaya, CHC, President of sensory street™ inc, contributed to this article. Visit her site on Facebook or at www.sensorystreet.com.
The Arc of Howard County Respite House Answers Needs of Families

The Arc of Howard County Respite House serves individuals living with developmental disabilities, including autism, from 18 months of age to adults.

The purpose of respite is to give primary caregivers a break and allow them to attend functions they would not otherwise be able to attend while caring for a dependent child or adult with special needs.

Respite services can be provided for a few hours or up to five nights at the Respite House. (In-home services are limited.) Caregivers are trained employees of the Arc.

Respite is meant to be as fun as possible, no matter the ability of the child or adult guest.

Respite Activities include:

Mom’s Day Out – services for children 18 months – 5 years

Drop Off – Sundays 11:30am-4:00pm or 1:00pm-5:30pm

Come and Go Drop In Care – 12 hours on Saturdays; families choose respite times

Ladies Night Out – A slumber party for young adult ladies with developmental disabilities

Guys Night Out – One Friday per month, 5:30pm-10:00pm, with the hopes of transitioning to an overnight activity like Ladies Night Out

School breaks, vacations, and more opportunities are available.

Additional Q&A with Angela Johnson, Respite Care Coordinator:

HCAS: Is the respite house for one person at a time, or are there several unrelated people being cared for at any given time? How many caregivers are provided?
AJ: Often, we schedule several people at one time. If a child/adult needs 1:1 supervision, then staff will be scheduled that way. Because of the size of the house and amount of staff, I can schedule up to six or seven people at one time. Typically it averages four individuals at a time on the weekends, two on weekdays.

HCAS: What is the cost to the family?
AJ: We are able to subsidize costs thanks to a grant we receive from Howard County. Our lowest rate is $3.50/hr and highest is $6.00/hr.

HCAS: Can interested families make arrangements to visit the respite house before committing to stay?
AJ: When a family applies to the program, I arrange a tour of the house. That gives me a chance to meet the family and discuss what they are looking for and the type of care their child requires. It also gives the family a chance to see where their children would be staying.

For more information:
Angela Johnson
Respite Care Coordinator
Arc of Howard County
410-730-0638, x224
ajohnson@archoward.org
Local Economist John P. Hussman, Ph.D., Revolutionizes Mapping of Genetic Pathway for Autism

A son of physicians and an economist by trade, John P. Hussman, Ph.D., may seem like an unlikely lead author on a paper identifying a new genetic pathway in autism research. But Hussman, a Howard County father to a 16-year-old son with autism, applied the same statistical tools he uses to map out complex economic relationships to produce new research findings in a paper titled “A Noise-Reduction GWAS Analysis Implicates Altered Regulation of Neurite Outgrowth and Guidance in Autism,” published in the journal Molecular Autism.

Hussman, who has been researching autism since his son was diagnosed more than a decade ago, has collaborated with Margaret Pericak-Vance, Ph.D., director of the John P. Hussman Institute for Human Genomics at the University of Miami.

“Even though John isn’t a geneticist, the type of approach he takes to integrate information and make a cohesive judgment applies to genetics,” said Dr. Pericak-Vance. “He has an ability to look at multiple sources of data and integrate and interpret them.”

“One of the challenges in human genetics today is extracting useful information from the oceans of data we can now generate,” said Dr. Jonathan Haines, director of the Center for Human Genetics Research at Vanderbilt University and a collaborator on the study. “John’s approach is a significant step forward in filtering the data so we can find genetic signals more easily.”

Dr. Hussman, whose Ph.D. is in economics from Stanford University, explained that it’s all in the numbers.

“It doesn’t matter if it’s genetics or financial data, as long as you understand how the data is structured,” Hussman said. “The genetic data we examined involves hundreds of thousands of locations across the whole genome. It’s like a huge coin-flipping experiment where the coins aren’t completely independent. You’re trying to find out which coins are tossed to people with autism more often than by chance.”

For this paper, the research team has found what they think is a significant method that can be applied not only to autism genetics, but other diseases and disorders as well.

“This research,” Hussman explained, “improves our ability to identify fairly weak genetic signals by taking account of genetic signals at nearby locations and in more than one data set. It improves our ability to find a needle in a haystack.”

In genetics, certain genes can give off strong or weak signals and be linked to a specific disorder or disease. Studies on genes involved in Alzheimer’s disease and multiple sclerosis have shown such strong signals that there is no question they are tied to those diseases. But autism is different. Most of the signals are weak and difficult to detect, making the relationship harder to identify.

Once the researchers figured out how to “reduce the noise,” the signals became easier to detect, producing a set of autism candidate genes. Further study revealed that a large number of them interact, controlling how nerve cells extend and navigate to create networks. The pathway is consistent with evidence suggesting that people with autism may have very subtle differences in how their brains are “wired.”

Dr. Pericak-Vance pointed out that while this paper’s discoveries are important, autism is still a difficult disorder to crack open.

“We do not know exactly which variants are involved and their specific role in autism, but this research gives us the pipeline to investigate more.”

“The symbol of autism is a puzzle piece,” Hussman said. “You can’t cure something unless you understand it first. This is a significant step. Once you understand the pathway that is involved, you can look for ways to rescue it.”

Dr. Pericak-Vance said that while this research is not a cure, she hopes that eventually it will lead to discoveries that will improve the quality of life for children with autism.

To read more, visit: “Mapping the Molecular Pathway of Autism” at http://www.hussmanfunds.com/wmc/wmc110131.htm

The link to the article in Molecular Autism: http://www.molecularautism.com/content/2/1/1/abstract
My Biomedical Journey through Autism

By Remy Nirschl

Six years ago, having witnessed my two-year-old son writhing in pain, with no help from mainstream pediatricians, I ventured onto a biomedical journey for my son. Richie, had exhibited many classic autism symptoms: hand flapping, toe walking, being in his own world, spinning, self-limiting his diet and consuming only milk and bread, sleeping 3 to 4 hours a night. He also exhibited some metabolic issues: monthly fevers, severe gut pain, constipation and diarrhea. I also suspected food allergies exhibited by his intense crying with bright red ears and cheeks 30 minutes after eating.

I went to several pediatricians seeking help for these symptoms. I was basically told: “it’s just autism,” “well if he cries, just let him cry it out.” Adding insult to injury, another doctor said, “you’re just finding an excuse for your son’s behavior.” Having worked with physicians as a medical social worker, I knew that orders were made for blood work and urine analysis to rule out underlying medical conditions. Yet not one of the mainstream pediatricians I went to ordered such blood work or analysis because my son had autism.

Unable to bear watching my son’s own body attack him, I searched for answers. I met some wonderful parents from Howard County doing D.A.N. protocols (Defeat Autism Now) with physicians trained under the direction of the Autism Research Institute (ARI). I decided to venture onto this path to help my son. Their mission statement, “Autism is treatable,” solidified my decision.

Several years on this journey led to important findings, treatments, and progress. After a number of blood/urine/stool tests, and other medical procedures conducted by D.A.N. physicians, some findings included: ulcerative colitis and high levels of yeast and bad gut bacteria, which made it difficult for his intestines to heal. A genetic disorder was discovered as well. Richie’s red blood cells destructed at a faster rate than other individuals’ when exposed to oxidative stress, therefore making him prone to anemia and infections.

These findings helped to shape the course of Richie’s treatments. Medications and supplements were prescribed. To heal his intestines, Richie’s diet had to change. I learned to remove offending products that contained gluten and casein proteins, which were causing inflammation in his intestines as well as causing other damage. Carbohydrates and sugars were reduced as well. I then replaced them with nourishing foods that included: fermented/cultured vegetables, grass fed organic meat, bone broth, high quality fats and oils. These steps all led to a friendly ecosystem in digestion. They are embodied in the Body Ecology philosophy: healthy digestion leads to improvement in our immune system and other systems in our body. Parents can learn about the science, special diets, and homeopathy at conferences sponsored by Autism One and ARI.

Recovered? No, but he is being treated. Neurosensory processing remains an issue and speech is emerging.

Richie, now eight years old, has made tremendous progress: he sleeps through the night, eats a variety of foods, and no longer has monthly fevers, hand flapping, or toe-walking. Red cheeks and face occur less often and we are ecstatic with the language gains he has made receptively and expressively.

As I end this article, I can hear my once nonverbal son joyfully shouting to his father “I want tickle!” And I recall that moment when I made my decision to take this biomedical journey, Robert Frost comes to mind: “Two roads diverged in a wood, and I, I took the one less traveled by, / And that has made all the difference.”

Remy Nirschl shares her personal story as part of the Biomedical Committee’s awareness efforts. Please contact a DAN! doctor to implement biomedical treatments. The committee meets bi-monthly and, with the Maryland Biomedical Group, hosts a yahoo group at md_biomed. Contact Jenn Palmer for more information: jenn_palmer@comcast.net.
Navigating the road ahead requires the right legal team.

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For more information, please contact Steven J. Lewicky
410-995-5800 • slewicky@darslaw.com
March 9, 2011 ~
Transition & Adult Issues
Committee Meeting
7:00-9:00 p.m. HCAS Resource Center.
This parent group meets regularly to
discuss issues pertaining to the transition
from high school to adulthood and
beyond.

March 9, 2010 ~
Biomedical Committee Meeting
7:00-9:00 p.m. Nourishing Journey,
10440 Shaker Drive, Suite 105, Columbia.
Contact Jenn Palmer at jenn_palmer@comcast.net.

March 10, 2011 ~
Asperger’s Committee Meeting
7:30-9:00 p.m. HCAS Resource Center.
Contact Elaine McAuliffe, 410-730-0068
or elainemcauliffe@yahoo.com.

March 12, 2011 ~
Sensory Friendly Movie
HCAS and AMC present a sensory-
friendly showing of “Mars Needs Moms”
at AMC Theatres Columbia Mall. Doors open at
9:30 a.m. Movie begins at 10 a.m. with
no trailers. Tickets $6 each. Contact
Sandra MacMahon for information at
sandra.macmahon@howard-autism.org.

March 17, 2011 ~
Howard County Autism Society
Support Group Meeting
7:00-9:00 p.m. An open forum with
Patricia Daley, HCPSS Director of Special
Education. Please submit questions in
advance to Beth Benevides Hill at
beth.benevides-hill@howard-autism.org.
HCAS Resource Center.

March 19, 2011 ~
Fitness First
7:00-9:00 p.m. Columbia Gym, River Hill.
Pre-registration in Fitness First is required.
For more information call 410-290-3466
or email info@howard-autism.org.

April 2, 2011 ~
Sensory Friendly Movie
HCAS and AMC present a sensory-
friendly showing of “Hop” at AMC
Theatres Columbia Mall. Doors open at
9:30 a.m. Movie begins at 10 a.m. with
no trailers. Tickets $6 each. Contact
Sandra MacMahon for information at
sandra.macmahon@howard-autism.org.

April 2, 2011 ~
HBO Movie Event
“Temple Grandin”
1:00 p.m. Join us on World Autism Day for a free showing of the HBO Movie “Temple Grandin,” for which Claire Danes won a Golden Globe Award for her performance as the title character. HCAS Resource Center

April 2, 2011 ~
Transition & Adult Issues
Committee Meeting
7:00-9:00 p.m. HCAS Resource Center.

April 14, 2011 ~
Asperger’s Committee Meeting
7:30-9:00 p.m. HCAS Resource Center.
Contact Elaine McAuliffe, 410-730-0068
or elainemcauliffe@yahoo.com.

April 16, 2011 ~
Fitness First
7:00-9:00 p.m. Columbia Gym, River Hill. Pre-registration in Fitness First is required. For more information call 410-290-3466 or email info@howard-autism.org.

April 21, 2011 ~
Howard County Autism Society
Support Group Meeting
Special “happy hour” in honor of
Autism Awareness Month. Place to be
determined.

May 7, 2011 ~
Sensory Friendly Movie
HCAS and AMC present a sensory-
friendly showing of “African Cats” at
AMC Theatres Columbia Mall. Doors open at 9:30 a.m. Movie begins at 10 with
no trailers. Tickets $6 each. Contact
Sandra MacMahon for information at
sandra.macmahon@howard-autism.org.

May 11, 2011 ~
Biomedical Committee Meeting
7:00-9:00 p.m. Nourishing Journey, 10440 Shaker Dr., Suite 105, Columbia. Contact: Jenn_Palmer@comcast.net.

May 11, 2011 ~
Transition & Adult Issues
Committee Meeting
7:00-9:00 p.m. HCAS Resource Center.

May 12, 2011 ~
Asperger’s Committee Meeting
7:30-9:00 p.m. HCAS Resource Center.
Contact Elaine McAuliffe, 410-730-0068
or elainemcauliffe@yahoo.com.

May 14, 2011 ~
HCAS 6th Annual “Pieces of the
Puzzle” Gala / Denim &
Diamonds Dinner
7:00pm-midnight. The Hotel at Turf
Valley, Ellicott City. For tickets and
additional information, visit

May 19, 2011 ~
Howard County Autism Society
Support Group Meeting
7:00-9:00 p.m. HCAS Resource Center.

May 21, 2011 ~
Fitness First
7:00-9:00 p.m. Columbia Gym, River Hill. Pre-registration in Fitness First is required. For more information call 410-290-3466 or email info@howard-autism.org.

Upcoming Events
For updated events information or additional information about
events listed below, visit the HCAS website at
www.howard-autism.org or call 410-290-3466
If you are not a member of the Howard County Autism Society, what are you waiting for?!

Membership has its privileges: exclusive member-only social events; receiving by mail the quarterly newsletter and the national ASA magazine, Autism Advocate; support group meetings with a phenomenal speaker lineup; and the knowledge that your support helps us continue to provide advocacy, training, and support to the families of Howard County with someone on the autism spectrum.

There are two ways you can join:

1. Join through the Autism Society of America, of which we are a local chapter. Go to their website www.autism-society.org and click on membership.

2. Designate Howard County as your local chapter. By joining the national organization is that you will receive their outstanding magazine Autism Advocate that is full of valuable articles and information. Additionally, you will add the strength of your membership to tens of thousands of families across the nation. By doing so, ASA can better advocate at the national level on issues that directly impact your family.

3. Join through our local chapter by going to our website www.howard-autism.org and clicking on membership.

If you are uncertain as to the status of your membership please send an email inquiry to info@howard-autism.org.
HCAS provides:
- support for parents
- information and referrals
- advocacy on behalf of persons with autism/PDD and their families
- presentations by experts on autism/PDD, disability rights, etc.
- monthly meetings
- social activities

Join the e-Group

The HCAS e-group connects you with other parents online where you can post questions or share information about doctors, dentists, schools, family support services, etc.

www.howardcountyautismsociety.org

Receive Weekly e-bulletin

Members receive a weekly e-news bulletin every Monday with upcoming events. Others may sign up by emailing info@howard-autism.org.