

ASA
Chapter
of the Year
2007



Howard County Autism Society Newsletter



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May/June 2008

Festive Gala Raised \$90,000 for HCAS

By Beth Benevides Hill

With a festive spirit and much to celebrate, the Howard County Autism Society welcomed 300 guests to the Third Annual Pieces of the Puzzle Gala on April 5.

Generously cosponsored by the Hussman Foundation, the event was held at the beautiful Ten Oaks Ballroom in Clarksville. The society's largest fundraiser of the year netted \$90,000 in funds to support the newly expanded Howard County Autism Resource Center and to offer programs and services to its membership.

In years past, the gala focused on building partnerships and establishing the society as a major resource for families and individuals with autism. After its award-winning year as the national Autism Society of America's 2007 "Chapter of the Year," the society turned the corner and made the annual event an evening of celebration. Attendees remarked at the festive and relaxed feel of this year's new venue and design.

The gala, coordinated by Cindy Wright, featured an array of nearly 130 silent auction items, a live auction, Harley Davidson motorcycle raffle, 50/50 raffle, dancing, open bar, and delicious food stations, which served steak, salmon, shrimp, sushi, pasta, salads and vegetables, and assorted desserts. Hot butlered hors d'oeuvres were



Madhu Thibaudeau, Stephanie Maric and Tricia Walls enjoyed the gala.

also served as guests entered the ballroom.

Executive Director Kim Manning welcomed guests and applauded the sponsors in attendance, including the Hussman Foundation as title sponsor, and Howard County General Hospital and Ben Dorman and Catriona Johnson as gala partners.

Beth Benevides Hill and Stephanie Maric, co-presidents of the Board of Directors, presented Chief William McMahan and the Howard County Policy Department with the President's Award and Marianne Ross with the Outstanding Volunteer of the Year Award.

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Two Elementaries to Launch VB Autism Program

By Marina Shread

Howard County schools will be launching a new Verbal Behavior-based program for elementary students with autism this fall.

The new Elementary Primary Learner Pilot Program will be an extension of the Multiple Intense Needs Class-Early Learner pre-school program for children with significant special needs.

This marks the first time a program based on the Verbal Behavior teaching method has been formally offered to county elementary students. An estimated 10 students from throughout the county will be selected for the program, which will be located at Pointers Run and Waverly Elementary schools.

"The program will be designed for kindergarten- and first grade-age children who present with significant delay in functional communication, engagement and social interaction, and who have participated in the MINC-EL program," according to a Howard County Public School System (HCPSS) in-

formation sheet. "Specialists from the Department of Special Education will provide on-site support and training to classroom staff."

Verbal Behavior (VB) is a form of Applied Behavioral Analysis that uses B.F. Skinner's study of verbal behavior to teach children how to communicate.



Teachers typically use an errorless learning method in which children are guided to the correct response until they learn a new skill without prompts.

"With the outstanding success of the pilot early intervention program we look forward to seeing the results of the pilot K-1 program as we partner with HCPSS to better serve the educational needs of children on the autism spectrum," said HCAS Executive Director Kim Manning.

The program will provide a staff ratio of five adults for five children with Individualized Education Programs. Children will

receive "intensive instruction in a classroom" and in small groups. They will participate in general education classrooms and activities with non-disabled peers "as appropriate," according to HCPSS.

Staff will be trained in Verbal Behavior Analysis, behavior management, the "most to least prompting" technique, data collection, and how to help children generalize skills being taught, among other things, according to HCPSS. Training also will be offered to parents of children in the program.

Beginning in the 2009-2010 school year, the program will expand to include students through second grade.

HCPSS held a parent information session in February, the same month it announced the pilot to its Elementary Autism and Related Disabilities Workgroup. The workgroup, which includes members of the Howard County Autism Society, has been working for a year on ways to improve services for students in first through third grades.

dAp: Students Learn about Disabilities

By Catherine Blackwell

January 25 was dAp day for the students at Centennial High School in Ellicott City. DAp is a Maryland Disability Awareness Program created by teacher Anne Wade to teach students to be sensitive, caring, and respectful of peers and adults who have physical or mental disabilities.

Centennial High School piloted a new dAp Day format this year. The consensus was that parents, students, speakers and teachers all had a wonderful time and learned a lot about people in the community who live with disabilities. Students

went from classroom to classroom and listened to speakers with varied disabilities from around the country share their experiences and what they have learned about living with a disability. As a student at Centennial and a member of the Best Buddies program that facilitated the event, dAp day was a wonderful opportunity for me and my fellow students to meet some of the courageous and inspiring people with physical and mental disabilities. Many of the speakers were also inspired by the Best Buddies

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Autism Walk News

The HCAS Second Annual "One Step Closer" Autism Walk will be held at Centennial Park on September 13. Registration begins at 8 a.m., and the walk starts at 9 a.m.

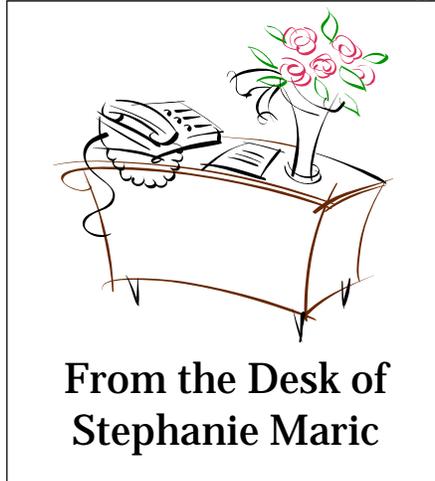
New this year! HCAS will have a website dedicated to online teambuilding and donations. Watch for announcements in June.

Want to help? Anyone interested in sponsoring the event, or serving on the Walk Planning Committee, may contact Kim Manning at 410-290-3466 or kamanning5@yahoo.com.

President's Message

As I write this President's message, we are in the midst of April – better known to our membership as Autism Awareness month. Every April we try to bring our members, and the greater Howard County community, numerous ways to learn, share and celebrate autism awareness. As we know all too well, acceptance of people living with autism starts with greater awareness.

We kicked off this year's Autism Awareness Month in elegant fashion with our Third Annual Pieces of the Puzzle Gala. If you were in attendance on April 5th at Ten Oaks Ballroom, you know what a fun and magical evening this was. We would like to extend a big thank you to those who worked tirelessly over the past several months to ensure that the gala was a success, including Auction Committee Co-Chairs Julie Foley and Madhu Thibaudeau; Director of Development Cindy Wright; Executive Director Kim Manning; Past President Debbie Clutts, who led the tickets sales for the Harley raffle; Board members Christi Hanks and Ruth Huffman, who coordinated our gala check out; and



From the Desk of Stephanie Maric

Co-President Beth Benevides Hill, who oversaw all of the printed materials for the event.

Highlights of the evening included our popular live and silent auctions featuring over 100 amazing items to bid on, a personal tribute from parent and title sponsor John Hussman (which you can read on page 6 or on our web site), and a slideshow that was compiled by Board member Ben Dorman. The slideshow featured touching photos of children and adults with autism who live in Howard County. Each face was beautiful and inspiring.

We also want to thank the hundreds of individuals and busi-

nesses who made the gala the enormous success it was by contributing auction items, monetary donations and volunteer hours. It is inspiring beyond words to see all this hard work and good will come together the night of the gala. We are truly fortunate to live where there is such a consistent and generous outpouring of support for our mission.

If you were not able to join us at the gala, we sincerely hope to see you next year! And if you haven't already, please join us at an upcoming event sponsored by the chapter (a list of which can be found on page 13 and also on our website).

Also, we want to encourage our members to consider joining one of our committees: Advocacy, Programming, Public Relations, Adult Issues and Finance. With each new member, supporter and volunteer, we grow stronger and are better able to achieve our goal of making Howard County a place where people with autism are truly accepted, supported and valued for the exceptional and unique individuals that they are.

Stephanie Maric
Co-President

From the Executive Director's Desk

Spring Greetings!

I'm writing this to you as I am basking in the afterglow of our Third Annual Pieces of the Puzzle Gala. What a lovely evening we enjoyed together as we celebrated the lives and potential of our children and families. It just thrills my heart to see the excitement and passion that is shared throughout our membership and community related to the issue of autism. As I talk with people and attend meetings I am struck with the commitment that we hold in common to provide op-

portunities for individuals with autism to realize their full potential.

John Hussman, our title sponsor for the second year in a row, gave us all food for thought regarding the assumptions that are often made about people on the autism spectrum. We must never be found guilty of assuming a lack of communication skills equals a lack of intelligence, feeling, or desire. I felt more impassioned than ever after Dr. Hussman's talk at

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Thank You For Donations to HCAS

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Thomas and Jean Brooks

From the Executive Director's Desk

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our gala to remain vigilant in advocating for opportunities and real choices for individuals with autism.

I am excited about our partnership with the Howard County Public Library that will provide some more options for young adults on the spectrum, and the openness that Howard County Parks and Recreation has to being creative and thinking 'outside the box' in providing services to families.

Let me share with you a new committee and focus that we are committed to at HCAS. It is our newly formed Adult Issues Workgroup. We have approximately 13

people serving on this committee who are doing a community assessment on a broad range of issues as they apply to adults with autism. Upon the completion of this assessment we will set our priorities and agenda for advocacy, partnerships, and support. Towson University has embarked upon a similar project so we will be joining forces with their Center to make sure that we arrive at the best possible conclusions and advocate for the most needed services.

April was Autism Awareness month and I am greatly encouraged at the public dialogue and interest that I see taking place.

There seems to be mounting interest in understanding and being responsive to the needs and issues of those with autism. Education, understanding, and openness enrich all of our lives and help us to become a community that doesn't miss out of the contributions and gifts of any of its members. I continue to be so proud of being associated with an organization that is on the cutting edge of helping these realities take place. Thank you for your support and involvement.

Together we ARE making a difference!

*Executive Director Kim Manning
kmanning@howard-autism.org*

Autism Presents Unique Challenges For Siblings

By Catherine Blackwell

There is little doubt that having a child or children with autism is stressful for most parents. Finding services, teachers, and doctors for children with autism and making sure that they have every chance to develop into healthy adults is daunting. While the specific needs of children with autism are many and often require immediate attention, the needs of typical siblings cannot be overlooked.

Autism puts a stress on the entire family, including neurotypical siblings. Siblings of people with autism have a unique position in the world of their autistic sibling—they seem to serve not only as relatives, but also as peers, mentors, models, and friends. The myriad of challenges that these siblings must face growing up often causes feelings of responsibility, embarrassment, fear, jealousy, confusion, and anger, along with guilt for feeling this way. Many



Siblings Connor and Casey

people with autism also require lifelong care and advocacy in order to ensure that they stay healthy and happy, and this challenging responsibility often falls upon the shoulders of the siblings.

My brother, Robert, is a 21-year-old adult with autism and mental retardation. He is a little more than three years older than I am. We will both be graduating

from our respective high schools this year, he from Chimes School and I from Centennial High School. I love my brother, and I know that one day it will be my role to make sure that he is well cared for. It is a burden, but one that I accept with open arms. I plan to obtain a degree in neurobiology in order to join the growing field of research of developmental disabilities in the future.

Being a sibling of someone with autism presents unique challenges. Says one sibling, "I've definitely had to learn how to get along with my brother. I've had to find different ways to communicate with him. I've learned to use sign language from my mom, and with my brother." Because autism often predominantly affects social skills, siblings, especially younger siblings, often do not understand why their autistic brother or sister is not being nice

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A Mother's Journey Through Autism

It seems like 100 years ago when my best friend Debbie visited us in Virginia with Steven, her four year old son with autism, but actually it was only 1994. Mary also had two other "normally developing" children, a boy and girl, ages 8 and 11. My two sons were 3 and 1 and autism was a condition that other people's kids had. Mary and I had known each other since we were 13. She had been the first to get married and was looking forward to raising children. Several times during the visit, Steven would show his discontent by going limp and lying on the floor. Debbie and her two other children would have to drag him to get him to a desired location. She later told me that this happened several times a day at home, the grocery store or wherever they happened to be, along with some tantrums.

On that same visit, we all went to the park across the street from our townhouse.

Steven got off the swing and began walking toward the edge of the park, seeming to have a definite destination and to be guided by some imaginary hand. However, as we watched, there really was no destination. When he got dangerously close to the road, his brother and sister again stepped in to guide him. "How overwhelming," I thought and thanked God that my children were "not like that." My biggest challenge to date was potty training and suddenly that seemed quite small. One year later, I was pregnant again, hoping for a girl, but happy for

a healthy child. The amnio showed a healthy baby boy and Nicholas was born on July 9, 1995.

Nothing indicated to me that Nicholas would be any different from my other two boys. I nursed him and he grew normally. He sat up, walked, and smiled at the designated times in the "What



Journey Through Autism First in a series By Cheryl Howard

to expect" manuals we closely followed. He received shots according to the schedule. As I had in the past, I trusted the doctors completely with his care. I often look at the photo of Nicholas at 3 months old as a smiling, happy boy and wonder when it all happened. At 18 months, we took him to my dad's 80th birthday celebration at the beach. He was quiet and well behaved. However, at age 3, he still was not talking. He did not show interest in interacting, was hard to potty train and seemed to get upset more often. The pediatrician I had come to trust reassured me that he was just being a boy and would be a late-talker as so many boys were. However discussions with my husband led me to believe that we needed to have him checked by an expert.

So, then began the visits to "Child Find," the psychologist and then the neurologist. The "Child Find" administrator reported that Nicholas had "autistic-like" tendencies. She said it without feeling—as if she were commenting on the weather. Tears came to my eyes. There

was no comfort then and there. Months later, came another diagnosis from the psychologist—PDD-NOS (pervasive developmental delay, nonspecified). It was too early to call it autism, but there was every indication that my child was not normal. One year later, the neurologist called it "moderate autism" officially changing my life and the lives of those in my family.

Suddenly, everyone seemed to now realize that something was "not quite right" with Nicholas. Dad said he had stared into space as early as 6 months of age. Grandma said he was too good, too quiet. I asked myself how blind was I? He was my son and he was perfect! Was I too busy working and being a mom to the other two? I obviously didn't expect this, as autism was of course something that happened to other people's kids.

Through these early years, Debbie was always there for me. She gave advice, told me what worked for her son and generally showed me a great strength that I aspired to have. She loved her son deeply, in spite of the hardships that autism had created. Could I also do that? Looking back, I wasn't so sure . . .

This is the first in a series about one woman's personal "Journey Through Autism."

The author and her family have been living in Columbia, Maryland, for two years, originally residing in Fredericksburg, Virginia.

She teaches English as a Second Language for Anne Arundel County public schools.

With Autism, “Think Less in Terms of Disability and More in Terms of Humanity...”

By John P. Hussman Ph.D.

One of the symbols of autism is a puzzle piece – a missing puzzle piece. It's tempting to think of that piece as some ultimate answer or cure. But if you ask people with autism who have any ability to communicate, you'll find that they're divided on whether they want a cure, but they are united in saying that what they want most is to be accepted, and valued, and seen as competent.

There's no question that we hope for discoveries that will make the lives of people with autism better. But even if we have a breakthrough tomorrow, it may still be 10 or 20 years until something is available that will significantly improve lives. So we can't give up on here and now.

And that's where the Autism Society of America stands. The Autism Society provides information, advocacy, special events, nationally known speakers, support, and community for individuals and families affected by autism right here in Howard County. All of that is part of the missing puzzle piece. So thank you for your presence here tonight, and for making a difference.

Autism is not disability.

Those aren't my own words, but those of a friend of mine named Jamie Burke. Jamie is a 20-year old young man with autism, who was without speech for much of his life, and gradually moved from assisted typing, to independent typing, and today, to speaking as he types.

That idea – autism is not disability – is warm and fuzzy enough to put on a bumper sticker. The

question is how many of us are willing to believe it. I mean, the definition of autism is loaded with words like “deficit,” “disorder,” “impaired,” and “restricted.” Can we really believe that autism is not disability? Can we offer people with autism the presumption that they are competent? The answer matters. Because the answer to that question will define the qual-

ity of people with autism are mentally retarded anyway? They gave them intelligence tests, without correcting for difficulties in speech or movement. How did they decide that people with autism have no empathy? What advanced scientific tool did researchers use to look inside of people with autism, and deny them of that large a part of their personhood? I'll tell you. They played a game with two dolls and a marble.

Let's do an experiment. Without using your mouth or your hands, I'd like you answer a question we ask people with autism all the time – What's your favorite color? (Nothing? OK, severe catatonia. And a few

bizarre, stereotyped, ritualistic motions. Wow. Sadly, you're all kind of... well, “low.” And we should probably work on your colors).

Somehow we've come to accept that if a person can't respond to a question with their body, they must not know the answer in their mind. But it's not like the brain either works or it doesn't – or that it has three speeds; high, medium and low. The brain has all kinds of structures and specialized areas. From functional MRI studies, we know that the areas that are active in speech and movement are different from the ones that are active in learning and problem solving. That specialization comes down to differences in individual nerve cells, and the variety of “buds” or “subunits” that make up receptors for neurotransmitters like GABA. I mention those because we're finding evidence from genetics and neuroanatomy that they may be



**Remarks at the 2008
Autism Society
“Pieces of the Puzzle”
Gala,
John P. Hussman
Ph.D.**

ity of life, the opportunities, and the dignity of the people we know with autism – including our own children.

The founders of our country did an amazing thing. They based our nation's entire foundation on a presumption – what they called a “proposition” – that all men are created equal. When we look back on our history, the only points of true regret are those times when we forgot – that all of us, regardless of our differences, and simply by virtue of our shared humanity, are created equal. That word “all” includes people with autism. So when Jamie says that autism is not disability, he's saying that autism does not diminish a person as a human being. And this is important – he's saying that people with autism are far more intelligent and competent than we might realize.

See, science hasn't developed the ability to read minds, or to measure empathy. How did some researchers decide that 70 percent

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2008 Gala Featured New Venue, Awards, and Inspiring Tribute

(Continued from page 1)

The police department was recognized for bringing Project Life-saver to the county. Its ongoing partnership with HCAS makes the state-of-the-art tracking system available to individuals with autism who may wander.

Ms. Ross was honored for her volunteerism. In the past year, she has developed a partnership with AMC Theatres in Columbia whereby children with special needs and their families can attend sensory-friendly movie events once a month. In addition to coordinating the program with AMC Theatre management, Ms. Ross helps advertise the events and enthusiastically greets families at the much-anticipated movie events.

Also, Ballet Royale of Maryland was recognized for hosting a beautiful production of the Nutcracker to benefit HCAS in December.

The award presentations were followed by a heartwarming photo montage of many of the membership's children and families. The video was designed by Ben Dorman. Families cheered for their loved ones as pictures flashed across the screen choreographed to Natasha Bedingfield's "Unwritten."

In his tribute speech, the Gala's title sponsor, John Hussman Ph.D., director of the Hussman Foundation, challenged the crowd to see autism in a new light. He said many of the common assumptions about autism are the result of giving tests that don't measure what they are supposed to in a person with autism.

"I'd like to suggest that autism is not a disorder of thinking or a lack of intelligence; that even people who look 'severely autistic' to the eye are thinking, feeling, people. Their senses may be overwhelmed, their bodies may be disorganized or

uncooperative, but their minds are far more competent than we previously thought. As we discover more people with autism who eventually acquire speech, or develop the ability to type – especially independently – we hear the same thing again and again: 'I'm smart. Tell people,'" said Dr. Hussman, father of a child with autism.

He encouraged people to love their children, "not for who they might have been without autism, or for who they might be if they were 'cured,' but as people who need to be nothing other than who they are, to be loved, and accepted, and seen as competent."

Then, he said, "we start seeing the gifts of people with autism, not the limitations."

After the tribute, the live auction began. It included a pearl necklace from Chip Smyth Diamonds and Fine Jewelry, a 42" plasma screen television donated by the Big Screen Store, Lasik surgery from TLC Laser Eye Centers, a Hilton Head vacation package donated by C. David and Loretta Haugh, a Bass Pro camping package, NASCAR pit passes and race tickets, a 25' sugar maple tree from Town Creek Landscaping, and the ever-popular dinner and wine tasting for ten from the Iron Bridge Wine Company.

The silent auction—coordinated by Julie Foley and Madhu Thibaudeau—featured popular vacation packages, sports tickets and memorabilia, jewelry, artwork, items for the home, spa packages, restaurant gift certifi-



John Hussman and Terri Keane attended the gala.

cates, wine, and various toys and electronics for kids. Members of Phi Sigma Sigma Sorority at the University of Maryland-Baltimore County helped with the auction.

Adding to the evening's excitement, the winning ticket of the motorcycle raffle was pulled by Tina Ice, owner of Harley Davidson of Maryland's Elkridge store. Paul Maric won the 2007 Harley-Davidson FXD™ Dyna Super-Glide® in Pacific Pearl Blue.

"It was a shock and a happy surprise," Mr. Maric said. "And it is one sweet looking bike. Or, as one friend put it, that is the Cadillac of motorcycles. I am sure the bike was impressive to everyone in the room. But equally impressive is Harley Davidson of Maryland's support for the Howard County Autism Society."

Guests also enjoyed dancing to music by DJ Chris Laich and socializing. Autism awareness puzzle piece charms and boxes of chocolates were given to each guest. HCAS is starting to plan the fourth gala for April 2009. The date and venue will be announced shortly.



Snapshots from the Gala



About 300 guests enjoyed dinner, silent and live auctions, raffles, and dancing at the Ten Oaks Ballroom.



Gala
photos by
Marina
Shread



“Our Responsibility is to Presume Competence...”

(Continued from page 6)

important in autism. The brain is very specialized. So when we give a person with autism a test that relies on their ability to speak or move accurately, we may just be testing their ability to overcome features of autism that have nothing to do with intelligence.

And that's exactly what people with autism tell us. As Jamie Burke wrote, “I understand why kids scream. It's frustrating not being able to speak. What made me feel angry was to know that I knew exactly what I was to say and my brain was retreating in defeat.” Sue Rubin (a woman with autism who also types independently) puts it this way: “Our bodies just won't do what we want them to do. We look retarded when we can't respond to commands.”

Of course, I don't want to minimize the challenges that a person with autism faces. People with autism might struggle to listen to a conversation, because they can't gate out the distracting hum of a fluorescent light. They might persevere on things that make no sense to us – like every morning when my son J.P. feels the need to organize every single item by the sink, down to the exact placement of the dental floss (and that'll test your patience if you're in a hurry). When takes a multiple-choice test, he picks “A” every time, even when he knows the material (we keep hoping his teachers will give him exams where every correct answer is, in fact, choice “A,” but we're not holding our breath).

And it's not just sight, sound, smell, taste, and touch – autism affects other senses that we parents never heard of before an autism diagnosis, like “proprioception” and “vestibular equilibrium.” The whole family learns new words like

that. Like when my daughter was little and asked, “Dad, how come when J.P. eats leaves it's called ‘pica’, but when we eat leaves it's called a salad?” Autism can make social interaction overwhelming too, even though a child desperately wants friends.

Still, I'd like to suggest that autism is not a disorder of thinking or a lack of intelligence; that



“...we sometimes find that the things we like most about ourselves – are there because a person with autism is also there.”

*John Hussman,
Ph.D.*

even people who look “severely autistic” to the eye are thinking, feeling, people. Their senses may be overwhelmed, their bodies may be disorganized or uncooperative, but their minds are far more competent than we previously thought. As we discover more people with autism who eventually acquire speech, or develop the ability to type – especially independently – we hear the same thing again and again: “I'm smart. Tell people.”

A few weeks ago, a girl with autism named Carly Fleischmann was featured on ABC news. At the age of 15, Carly, who had been immersed in 40 hours a week of tasks including words and language for years, developed the ability to type independently. That's unusual, because most people with autism who have achieved that have started with some level of hand support, typing predictable spelling words and

sentences for years before gradually becoming more independent. A parent of a child with autism wrote Carly after that story, and asked, “What would my autistic child want me to know about him?” Carly replied, “I think he would want you to know that he knows more than you think he does.”

So our responsibility is to presume competence, and then go about looking for it. If you're a parent, tell your child what's going on in the family, in the world – all the interesting stuff that you would share with another child. Hold up your end of the conversation even if they don't hold up theirs. Explain why you want them to do one thing, and not something else. Read words, spell them, type them, and sound them out. Teach them even without needing a test at the end. Their challenge is in responding, not in understanding. So assume that they understand; that they appreciate; that they love, while we keep looking for ways for their mouths or their hands to tell us.

And then love them back. Not for who they might have been without autism, or for who they might be if they were “cured,” but as people who need to be nothing other than who they are, to be loved, and accepted, and seen as competent.

Because when we do that, we open the door for them to share a meaningful life with us, without having to take an admission test. We start seeing the gifts of people with autism, not the limitations. We start to think less in terms of disability and more in terms of humanity. And not least, we sometimes find that the things we like most about ourselves – are there because a person with autism is also there.

The Hussman Foundation was title sponsor of the Gala.



National Institute of Mental Health Begins Four Major Autism Studies in Maryland

By Teresa Huggins, Ph.D.
NIMH

The National Institute of Mental Health (NIMH) has launched four major studies on autism at its campus in Bethesda, Maryland. Initial studies will define the characteristics of different subtypes of autism spectrum disorders (ASD) and explore possible new treatments.

One study will screen children to see if they qualify for other studies; it will consist of numerous cognitive and diagnostic tests.

Another study will define biological and behavioral differences in children with autism who have diverse developmental histories. This study seeks to better define the multiple subtypes within autism. It also compares children with autism who do or do not have a history of regression, with those who have other developmental disorders, as well as children with typical development. Researchers will also study a subset of the children in this study to investigate environmental factors that may trigger symptoms of autism.

In a third study, NIMH researchers are examining the use of the antibiotic minocycline to measure its usefulness in children aged 3 to 12 years with regressive autism. Past research suggests that autism may be linked with changes in the immune response that cause inflammation in the brain. Minocycline has known anti-inflammatory effects and has been shown to be helpful in other brain disorders such as Huntington's disease.

A fourth trial looks at the effect of riluzole on Obsessive-Compulsive Disorder (OCD), with or without autism. Riluzole is an

FDA-approved drug that reduces the activity of glutamate, a neurotransmitter involved in the brain circuitry affected in OCD.

Current Clinical Trials in Autism at NIMH

- Screening for Studies on Autism Spectrum Disorders
- Clinical and Immunological Investigations of Subtypes of Autism
- Minocycline to Treat Childhood Regressive Autism
- Riluzole to Treat Childhood Obsessive-Compulsive Disorder (for this study only, call 435-6652 or 496-5323)

For more information about these clinical trials, call 301-435-7962.

For a list of all clinical trials available at NIMH go to <http://patientinfo.nimh.nih.gov/>

Research News

What are Clinical Trials? Questions and Answers

Clinical trials are research studies done to answer specific health questions. Clinical studies are used to find better ways to prevent, screen for, diagnose, or treat a disease or health condition.

What are the benefits of participating in a clinical trial?

Benefits of participating in clinical trials include gaining access to new experimental research treatments before they are widely available, receiving expert medical care, and helping others by contributing to medical research. At the PDN, clinical trials also enable parents to play a more active role in the health care of their children by having access to the results of all tests, which can

be useful to serve as background information for future evaluations.

What are some potential risks or disadvantages of clinical trials?

Potential risks or disadvantages of participating in clinical trials may include side effects, no improvement in symptoms, and time and effort needed to participate. You may be in a control group and not receive benefits of a treatment.

What is a placebo?

A placebo is an inactive pill, liquid, or powder or other treatment that has no known effect. In clinical trials, experimental treatments are often compared with placebos to assess the experimental treatment's effectiveness. In some studies, the participants in the control group will receive a placebo instead of an active drug or experimental treatment.

What is a control or control group?

A control is the standard by which experimental observations are evaluated. In many clinical trials, one group of patients will be given an experimental drug or treatment, while the control group is given either a standard treatment for the illness or a placebo.

How are participants protected?

Clinical trials at the NIMH must be reviewed and approved by an IRB (Institutional Review Board). The Board, which includes doctors, researchers, community leaders, and other members of the community, reviews the protocol to make sure the study is conducted fairly and participants are not likely to be harmed. In addition, NIMH uses a Data and Safety Monitoring Board (DSMB), an independent committee made up of statisticians, physicians, and patient advocates.

(Continued on page 12)

Kennedy Krieger Recruiting Preschoolers for Autism Study

**Submitted by Kennedy
Krieger Institute**

The Center for Autism and Related Disorders at the Kennedy Krieger Institute is recruiting children with an autism spectrum disorder, who are between the ages of 36 and 54 months, to participate in a study looking at the development of memory and learning in children. The study requires two visits, each lasting approximately 2.5 hours, where the child will participate in play-based, structured activities. One additional parent visit is

needed to complete parent interviews; however, these interviews can be done over the phone. For your participation, you will receive a written report of your child's development on the standardized assessments. There is no charge to participate.

If you are interested in participating, please contact the research hotline at 1-877-850-3372. This phone number is connected to a voicemail box that is checked daily by a research staff member. Please leave a message stating that

you are interested in the "Autism and the Development of Relational Awareness" study along with your contact information and Kennedy Krieger will return your call.

NIMH Studies

(Continued from page 11)

ates. The DSMB ensures that the risks of participation are as small as possible, makes sure the data are complete, and stops a trial if safety concerns arise or when the trial's objectives have been met.

Autism Society of America Responds to Poling Autism-Vaccine Case

On March 6, 2008, the major news networks reported on a National Vaccine Injury Compensation Program case in which liability was conceded based on circumstances surrounding Dr. and Mrs. Poling's 9-year-old daughter's autism.

Medical personnel at the Division of Vaccine Injury Compensation, Department of Health and Human Services concluded that the facts of this case met the statutory criteria for demonstrating that the vaccinations Hannah Poling received on July 19, 2000, significantly aggravated an underlying mitochondrial disorder, which predisposed her to deficits in cellular en-

ergy metabolism, and manifested as a regressive encephalopathy with features of autism spectrum disorder.

Individuals living with autism need help today, and this case illustrates the need for the medical community to probe further into environmental causes of autism. The Polings, like all families affected by autism, deserve to be heard and supported in their journey raising their daughter. While we don't know the cause for autism, or its interaction with other conditions or environmental aggregators, we need to focus today on what works to maximize the potential of people with autism to

help them live meaningful, productive lives. This has always been ASA's mission and we will continue to advocate for research, family and individual support, and lifespan services for people across the autism spectrum.

ASA believes that the science of autism causes and treatments need to be more vigorously researched. We hope that primary decisions will be reached through thoughtful dialogue by parents and professionals on medical research and comprehensive treatment and services, not court rulings.

Lee Grossman
ASA President and CEO

Centennial dAp Day Features People with Disabilities from Across the Country

members who helped to host dAp Day at Centennial. Buddy pairs (one typical peer and one student with a disability) were each assigned to one or more speakers during the day, and the pairs worked together to make sure everything went over smoothly.

My buddy, Jesse Carrico, and I had a great time conversing with our guest speakers. Mark Schlossberg, one of our speakers, led an

illuminating panel for students entitled, "Are you ready to become disabled?" aimed at giving students a glimpse of what life would be like with a physical disability. Mr. Schlossberg is the Chair of the Howard County Commission on Disability Issues, and has multiple sclerosis. Other panel members included Daryl Hubbard, who became a quadriplegic after a car accident, and

Don Lanspery, who lost all of his fingers and toes after a sudden onset of blood sepsis.

In the morning, students gathered in the gymnasium to watch and participate in wheelchair basketball. That evening, dAp held a global event for Project TEAM. Paralympian skier Sandy Dukat, and Dan Keplinger, artist and star of an award-winning HBO autobiography, addressed the group.

Upcoming Events



May 2-3, 2008

Caring Communities Disability Expo at the Montgomery County Fairgrounds in Gaithersburg. Information: 866-227-4644 or www.caringcommunities.org.

May 8, 2008

Howard County Asperger's Support Group Meeting. 7:30 p.m. Faulkner Ridge Center, 10598 Marble Faun Court, Columbia. Information: 410-730-0068.

May 7, 2008

The Ellicott City SPD-Parent Support Group meeting at 7 p.m. Mary-Margaret Windsor, ScD, OTR/L, will discuss toilet training children with special needs. Location: OT Ventures. Meetings are free and open to the public. To RSVP, call 443-812-6396 or email ot_ventures@hotmail.com.

May 15, 2008

Howard County Autism Society Meeting with Dr. Janelle Love discussing "Hyperbaric Oxygen Treatment." There also will be a parent panel to discuss personal experiences with biomedical interventions and to answer questions. 7 to 9 p.m. 10280 Old Columbia Road, Suite 215, Columbia. Information: 410-290-3466 or www.howard-autism.org.

May 21, 2008

Biomedical Support Group meeting, 7 p.m., at Faulkner Ridge Center in Columbia. Information: jenn_palmer@comcast.net.

May 24, 2008

The Howard County Autism Society and AMC Columbia 14 present a sensory-friendly showing of "Chronicles of Narnia: Prince Caspian" at AMC

**HCAS Meetings Are Held in a New Location:
10280 Old Columbia Road,
Suite 215, in Columbia.**

Theatres Columbia Mall for kids with special needs. Doors open at 8:45 a.m. Movie starts at 9:30 a.m. with no trailers. Tickets are \$6 each. Information: Marianne Ross at rossfda@hotmail.com

June 12, 2008

Howard County Asperger's Support Group Meeting. 7:30 p.m. Faulkner Ridge Center, 10598 Marble Faun Court, Columbia. Information: 410-730-0068.

June 14, 2008

The Howard County Autism Society and AMC Columbia 14 present a sensory-friendly showing of "Kung Fu Panda" at AMC Theatres Columbia Mall for kids with special needs. Doors open at 8:45 a.m. Movie starts at 9:30 a.m. with no trailers. Tickets are \$6 each. Information: Marianne Ross, rossfda@hotmail.com.

On **July 12, 2008**, HCAS and AMC will sponsor a similar sensory-friendly showing of "WALL-E" at 9:30 a.m.

June 16, 2008

The Maryland Commission on Disabilities and Howard County Commission on Disability Issues host a

Listening Post, 4-6 p.m. Information: 410-313-6431.

June 19, 2008

Howard County Autism Society Meeting. 7 to 9 p.m. 10280 Old Columbia Road, Suite 215, Columbia. Information: 410-290-3466 or www.howard-autism.org

July 9-12, 2008

Autism Society of America National Conference in Orlando, Florida. See www.autism-society.org.

July 10, 2008

Howard County Asperger's Support Group Meeting. 7:30 p.m. Faulkner Ridge Center, 10598 Marble Faun Court, Columbia. Information: 410-730-0068.

August 3, 2008

Howard County Autism Society Summer Pool Party. Lifetime Fitness gym in Columbia. 6 to 9 p.m. Free. Information: 410-290-3466 or www.howard-autism.org.

September 13, 2008

HCAS Second Annual "One Step Closer" Autism Walk at Centennial Park, 8 a.m. Check our web site or call 410-290-3466.

October 23-24, 2008

Kennedy Krieger Institute's Annual Autism Conference, "Autism: Update on Diagnosis and Intervention through Adolescence," at The Conference Center at Sheppard Pratt, Baltimore. Information: 443-923-7680.

November 14-15, 2008

Wrightslaw Conference on special education law. Details to be



Take Our Recreation Survey!



The Howard County Autism Society is interested in knowing what you do for recreation and social activities with your child, or adult, on the autism spectrum. We hope to create a database so that we can share this information with others in the community. We would also like to know what you think of the opportunities that are available in Howard County and the surrounding area, and what else you would like to see made available. Please help us by completing this survey and mailing it to the office at:

HCAS, 10280 Old Columbia Road, Suite 215, Columbia, MD 21046-2378.

Or, you may fax it to the Howard County Autism Society at 410-290-5455. THANK YOU!

1. What is the gender and age of your family member(s) who is/are on the autism spectrum?
2. What recreational and/or social programs do they participate in?
3. Do you think that any of the activities that they participate in could be improved? If so, in what way?
4. What activities do you wish were available? Do you have any specific ideas with regard to an activity?

Society to Start Support Group for Siblings Affected by Autism

(Continued from page 4)

or does not want to talk to or play with them. It helps if parents sit down with younger siblings and explain why the family member with autism behaves in a certain way, and that it is not the typical sibling's fault. This should be an ongoing discussion between parents and typical children. Oftentimes parents overlook the fact that typical siblings need this type of reassurance, because typical siblings frequently internalize guilt for their autistic sibling's difficult behaviors.

Siblings have a very special bond. Many siblings of people with autism take on a parenting role for their brother or sister on the spec-

trum at a very young age, and often feel like the closest person to their sibling. One sibling says, "I treat [my brother] differently now because I know the best way to treat him, what helps him best, what makes it easier for him to understand."

Older siblings frequently state that there is one very valuable trait for siblings of people with autism—patience. Siblings must be understanding, and learn how to anticipate problems. Research has shown that siblings of people with autism tend to be wise beyond their years, more mature, more tolerant, and much more patient than their peers. They are

also frequently far more compassionate and caring than average.

It is also very important for siblings of children and adults on the autism spectrum to have a friendly environment to regularly discuss their common issues with other siblings and share ideas.

In the next few weeks, the Howard County Autism Society will be starting meetings of a Sibling Support Group to provide this setting for people of all ages with siblings on the spectrum to talk about these issues. Look for notices about this group in the mail and on the web site at <http://www.howard-autism.org>.

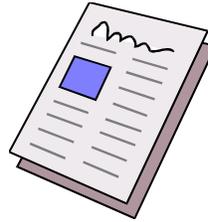
About This Newsletter

The Howard County Autism Society (HCAS) Newsletter is published five times during the school year beginning in September. No article may be reproduced without written permission from the HCAS, which copyrights this publication.

Articles in the newsletter represent the views of the authors and not necessarily those of HCAS. The publication of advertisements does not indicate any endorsement by HCAS.

How to Submit an Item for Publication

We welcome contributions from professionals, parents, siblings, and people with autism spectrum disorders. Submit your article, book review or photo by emailing it to newsletter@howard-autism.org. Submissions are due for the September/October issue by August 10, and for the November/December issue by October 10.



ASA Options Policy

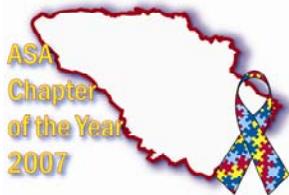
The Howard County Autism Society (HCAS) follows the national Autism Society of America's Options Policy, which reads in part: "With appropriate education, vocational training and community living options and support systems, individuals with autism can lead dignified, productive lives in their communities and strive to reach their fullest potential."

The ASA believes that all individuals with autism have the right to access appropriate services and supports based on their needs and desires." To review the entire policy, see <http://www.autism-society.org>.

All articles in this newsletter represent the views of the authors and not necessarily those of the HCAS. We recommend that you discuss any new treatment with a professional.

Newsletter Ad Rate Cards Available Online

Our advertising rates are available on the HCAS website at <http://www.howard-autism.org>. Please call 410-290-3466 or e-mail kmaning@howard-autism.org for information on how to submit classified or camera-ready ads for this newsletter. The newsletter is published five times during each school year beginning in September.



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Join us!
Parent dues are
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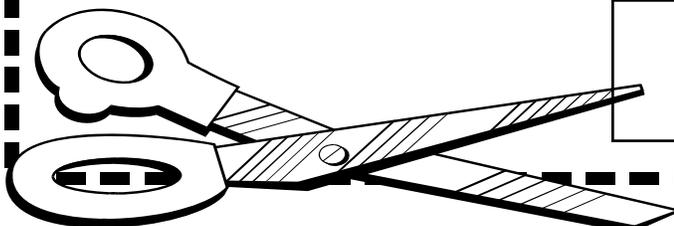
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HCAS gratefully acknowledges donors in its newsletter.
If you prefer your donation to be private, please check here. _____



Clip and return with your check payable to
"Howard County Autism Society" or join on-line at
<http://www.howard-autism.org/hccasa/membership/>

Howard County Autism Society (HCAS)

Howard County Autism Society (HCAS) is a chapter of the Autism Society of America, which was founded in 1965 to help parents, family members, professionals, and caregivers learn about autism, PDD, and related disorders, and how to effectively deal with these disabilities. We are one of about 200 chapters in 48 states across the country.

HCAS is dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families and the professionals with whom they interact. The national society and HCAS share the common goals of providing information and education, supporting research and advocating for programs and services for people with autism spectrum disorders.

HCAS works in Howard County to advance awareness of persons with autism, PDD, and related disorders. We provide:

- support for parents
- information and referral
- advocacy on behalf of persons with autism/PDD and their families
- presentations by experts on autism/

- PDD, disability rights, etc
- an active connection with the national society
 - monthly meetings
 - social activities

NEW HCAS Information and Referral Number

410-290-3466

Combined Federal Campaign #: 3038

Join the Yahoo e-Group

HCAS has an e-group where you can post questions about doctors, dentists, schools, family support services, etc. To join, go to <http://groups.yahoo.com/group/AutismSocietyHoCo/> or send an e-mail message to: AutismSocietyHoCo-subscribe@yahoogroups.com

Update Your Address

To join the mailing list or update your address, please call 410-290-3466 or email kmanning@howard-autism.org.

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