

On The Spectrum



In This Issue:

Temple Grandin Joins AHA Advisory Board p.3

Our Busy Fall Activities p.4

How To Be Your Child's Best Advocate p.6

AHA is a New York non-profit organization providing information and support for families, individuals and professionals affected by Asperger Syndrome, High Functioning Autism and other Pervasive Developmental Disorders. www.ahaNY.org

AHA Board of Directors

President
Pat Schissel, LMSW

Vice President
Michael A. Buffa, Esq.

Recording Secretary
Susan Deedy, Esq.

Treasurer
Lynn Levine

Membership
Rosalie Edelson

Past President
Pat Long

Newsletter Editor
Bernice Polinsky

Board Member
Bea Gravino

Public Relations
Bill Heslin

Information Technology
Carole Kalvar

Development
Dan Rotella

Board Member
Bill Braun

Education Liaison TBA

Professional Advisory Board

John C. Pomeroy, M.D., Chair

Diane Adreon, M.S.

May-Lynn Andresen, R.N.

Tony Attwood, Ph.D.

Michael J. Carley, M.F.A.

Michelle Dunn, Ph.D.

V. Mark Durand, Ph.D.

Valerie Gaus, Ph.D.

Lynda Geller, Ph.D.

Peter F. Gerhardt, Ed.D.

Temple Grandin, Ph.D.

Ami Klin, Ph.D.

Brenda Smith Myles, Ph.D.

Jerry Newport, B.A.

Martin Schwartzman, CFE, CIE, CPCU

Stephen Shore, Ed.D.

On The Spectrum

The AHA Newsletter

PO Box 916, Bethpage, NY 11714-0916
www.ahaNY.org, info@ahaNY.org
p.516-470-0360 f.516-470-0362

Editors: Bernice Polinsky, Joan Hourihane
Art Director: Donna Levantini

Assistant Editors: Emily Raphael,
Stuart Cohen, Rosalie Edelson,
Chic Schissel, Pat Schissel

Contents

Featured Articles:

AHA's Initiative JUMP	p 3
Wrapping It Up-AHA's 20th Anniversary Year	p 4
Roadmap to An Excellent Doctor	p 5
Developing Talents	p 8
From the Trenches	P 8

Departments:

AHA Information	P 2	Book Reviews	p 10
Ask the Expert	P 6	Autism Centers	p 13
Support Dates	P 9	Directions	p 14
Achieving a Milestone	p 10	Save the Dates	Back cover

Contact Information

AHA Association

PO Box 916, Bethpage, NY 11714-0916
www.ahaNY.org p. 516-470-0360 f. 516-470-0362 info@ahaNY.org
Administrative Staff: Maureen Holohan, Joan Hourihane

Adult Issues:

Bernice Polinsky 631-269-5709

Nassau

Alisa Minkin 516-539-1651

East End:

Susan Bachemin 631-680-8894

Susan Kinsey 631-734-8156

Suffolk:

Stacy Rebello

StacyR@ahaNY.org

Queens:

Donna Benkert

DonnaB@ahaNY.org

Dear Members and Friends,

I hope that you have had a good start to the fall. AHA has been busy as usual. Many thanks to everyone who has joined in our activities. Among the events was a successful first golf outing spear-headed by board members Bill Heslin and Dan Rotella with the capable assistance and energy of Maureen and Jim Holohan and many others, all who deserve a giant thank you! We joined with our friends at Elija for one rainy and then one perfect fun-filled evening at Teddy Roosevelt Park for the Sunset Festival; hopefully the first of many recreational activities we will co-present. Our 18th annual fall conference included amazing speakers, especially our stupendous teens! An update on JUMP, the job initiative, is reported on in this issue. Watch for news of another fabulous spring conference scheduled for May 9th. In this issue we report about the FUNdraiser given on Nov 5th for AHA by our generous angels from the Long Island Way David Gussin and Lloyd Gutin .

As the year gets underway, if you are preparing for your school-age child or as in my case, getting papers in order for *another* professional entering our son's life, the phrase "if its not written down it didn't happen" comes to mind. Nothing fancy - a note faxed or a short typewritten sheet to make sure that a meeting you were at is remembered as you heard it. Months and years later you will be glad to have these reminders stored away. Pat Schissel, President



Dr. Temple Grandin was diagnosed with autism at age two and went on to become the world's foremost expert on livestock handling. Dr. Grandin is an Associate Professor of Animal Sciences at Colorado State University. She has designed one-third of all the livestock-handling facilities in the

United States and is the author of many books: *Emergence: Labeled Autistic*, *Thinking in Pictures*, *The Unwritten Rules of Social Relationships: Decoding Social Mysteries Through the Unique Perspectives of Autism (with Sean Barron)*, *Animals in Translation: Using the Mysteries of Autism to Decode Animal Behavior*, *Developing Talents: Careers for Individuals with*

Asperger Syndrome and High Functioning Autism and *The Way I See It: A Personal Look at Autism and Asperger's*. She lectures internationally on the subject of autism spectrum disorders. Dr. Grandin received a B.A. in Psychology from Franklin Pierce College, an M.A. from Arizona State and a Ph.D. from the University of Illinois

Dr. Grandin is a fabulous speaker and has tremendous insight into the way individuals on the spectrum experience the world around them. We are proud to welcome Dr. Grandin to the AHA advisory board and hope that she continues to enlighten us with her insights. She has presented on Long Island through AHA on many occasions and we are so fortunate to have her as part of our team.

JUMP Jobs For Us Mentoring Program

by Cheryl Couch

JUMP is making strides. The initiative is currently recruiting employee candidates. Each JUMP candidate is asked to complete an employee profile which will aid in making effective job matches. Profile data will also be used, anonymously, to reflect the immense need for this program and aid in gaining grant funding. Once additional grant funding is secured, anticipated for early 2009, each of the elements of the program will be developed. The most critical elements entail, employer/mentor training, alignment of job coaches and training for coaches on how to support individuals with autism spectrum disorders. As the program awaits potential grant funding it moves forward on recruiting potential employers. For this the program will rely

heavily on friends and family in the autism community. A formal presentation and brochure have been created to support advocates of the program in recruiting employers. Education on how to use these support resources will be provided at an upcoming JUMP committee meeting early in 2009. The aspiration of the 2009 JUMP pilot is to have six successful placements. These successes will aid in strengthening the pilot approach and gaining additional grant funding.

*If you are interested in being a JUMP advocate please send an email to JUMP@ahaNY.org and plan on participating in the next meeting. If you are interested in gaining employment through JUMP, please request an **Employee Profile**.*

Another Successful Fall Education Conference!

by Pat Schissel

AHA successfully presented its 18th annual educational conference Monday and Tuesday, October 27-28 in Holbrook, NY to an enthusiastic audience of educators and other professionals in the field and family members.

A big **THANK YOU** to:

Everyone who attended and participated!

Our speakers – Brenda Myles, Michelle Winner, Barry Grossman and Ruth Aspy who provided valuable understanding and practical strategies, and our Teen Panelists who shared their experiences and insights with everyone.

Our sponsors – **The Laurence Polatsch Memorial Fund** www.larrypolatsch.com/index.php for their generous support of AHA's conference. We feel privileged to have been chosen as a grant recipient honoring Laurence Polatsch's memory. **OAR, the Organization for Autism**

Research www.researchautism.org for donating their outstanding guidebook on Asperger Syndrome to each participant. Funding like this helps AHA continue to bring nationally known speakers to Long Island— as we have been doing for 18 years, long before anyone had even heard terms like higher functioning autism (HFA) – or Asperger Syndrome (AS) - or considered these students able to succeed in the classroom. Our conferences remain one of the only ways to receive information on the ways students with HFA or AS learn and process information.

Our staff and volunteers - AHA is run with the passion and support of a predominantly volunteer army of dedicated workers – many who attended and worked at the conference. They put their knowledge to use for the *hot-line* calls they answer, *support groups* they run and *networking* they do on behalf of AHA.

Wrapping It Up - AHA's 20th Anniversary Celebration Year



AHA's 20th Anniversary Golf Classic

Tuesday, September 2, 2008. A spectacular day and a huge success. There was an impressive turnout for AHA's inaugural fundraising event. Many people contributed to its success. Thanks especially to Dan Rotella and Bill Heslin, who ably chaired our wonderful committee; Maureen and Jim Holohan, who worked tirelessly; and our enthusiastic supporters. Emcee Ed Nitkewicz was outstanding.

Annual Abby Irwin Family Picnic

Sunday, June 8, 2008. AHA, together with the Cody Center, joined in celebrating our 20th anniversary at West Hills County Park. Thanks to all the volunteers who helped with the smorgasbord of activities including balloons, pony rides, bubbles, parachute, softball, tug-of-war, relay races and so much more. Good food and fun were provided in sun and shade for all the families and individuals on the spectrum - a great day!

Thank you for Supporting AHA

Thank you for Supporting AHA

Thank you for Supporting AHA



FUNdraiser at Savannah's

November 5, 2008. Our thanks to Amazing Angels for Autism, **David Gussin**, publisher of 516.Ads.com, and **Lloyd Gutin** of 1-800-GOT-JUNK?, of the Long Island Way. This fundraiser was another way that the "for profits" in the Long Island Way have gone above and beyond to help the non-profits. The event was held at Savannah's in East Meadow. In addition to raising funds for AHA, it raised awareness of autism to the over 250 people in attendance. Pictured above: Lloyd Gutin, Donna Cariello (L.I. Way), Pat Schissel, David Gussin, Bernice Polinsky, Mike Buffa and the Lindner Center's Social Worker, Halley Ceglia.



Sunset Festival

September 19, 2008. Theodore Roosevelt Memorial Park, Oyster Bay. It was a pleasure teaming up with Nicole Dibra and Deb Harris of the Elija Foundation, and sponsors, Thivierge and Rothberg P.C. and Nassau Suffolk chapter of the Autism Society of America. This waterside sunset event honored organizations, families, friends and neighbors; celebrated the collective efforts of our local organizations; and honored the successes of individuals with autism. There were food, fun, and games for all ages. Highlights were the balloon maker's amazing creations, cotton candy, a horse exhibit, bounce houses, and a dunking booth, thanks to Dr. Bobby Newman, who was a good sport and took a few dips in the tank.

A very special thank you to everyone who goes the extra mile to make AHA a successful organization for everyone who accesses our services.



Roadmap to an Excellent Doctor - How to Find (and keep) an Excellent Doctor

by Mary Meyer Inspired by a lecture given by Peter Della Bella MD at our Spring Conference 2008

Introduction: When we decide we need a new doctor, it often is not a tranquil time. The opportunity for thoughtful analysis and careful evaluation isn't there. On the contrary, it may be an emotional or frustrating time. But why do we need or want a change? The current situation is not working. This roadmap was created to help you find that excellent doctor for yourself or a loved one, and a professional environment that does work.

The goal of our search is a positive doctor-patient working relationship. Achieving that goal requires an effort for both the patient (or the patient's parent) and the doctor. The payback: less stress, fewer misunderstandings, better results. Studies have shown that the best predictor of success in treatment is a positive doctor-patient relationship.

The good news is that we are living in an age in which such a relationship is definitely possible. The internet enables patients to gather a great deal of information. It also facilitates accurate health records and email communication. Many doctors welcome a patient who wants to be involved in the treatment process.

The Process: The process of finding and keeping a good doctor requires diligence. It is not necessarily difficult, but it requires preparation. The first step is to list your needs – what do you expect/need the doctor to do? This will be critical as you begin your screening process.

Screening: Make a list of potential doctors. Review your insurer's list of doctors. Some doctors provide results of customer surveys with questions such as "does your doctor listen and explain things to you?" Network with anyone you believe has good information, especially advocacy organizations like AHA Association (www.ahaNY.org). Contact potential doctors with your prepared list of questions and information. Doctors value time, information and relationships. Your list should include:

- Who referred you
- Your needs – be clear and concise
- The physician's experience with this population
- If the parent of an adult, how communication with the parent is handled
- How sessions are managed and payment method

Develop a list of alternatives and evaluate your options, using the information you have gathered, plus important factors like how quickly your initial phone call was returned, and do you like and feel comfortable with the doctor.

Initial Session(s): Bring copies of old evaluations. Bring your medicine bottles or a current list. Teach your doctor (family history, drug reactions, intervention record, traumatic incidents).

Bring a master list of key providers, with contact information.

Bring *questions* into visit time:

Ask about alternatives. Is there anything that doesn't fit in the diagnosis? Is there anything else it could be? Could there be *more than one* problem? Do not leave without a clear understanding of what is wrong, the treatment plan, why, and the specifics.

Your contribution to the process: A good doctor patient relationship is *not* a spectator sport. You and your child, whether adult or school age, are a vital part of that relationship.

The first step is to list your needs - what do you expect/need the doctor to do?

This will be critical as you begin your screening process.

Be informed. Especially if you are the parent of an adult child, you must be aware of the HIPAA Privacy Rule. By law, the doctor cannot disclose information about your adult child without his or her permission. However, a savvy practitioner can convey vital information to you without breaking the privacy and trust of the patient. (You should be aware of the doctor's approach from your initial visit.)

Be respectful of the doctor's time. Don't be late. If you have a question or need a letter, bring it up at the beginning of the session.

Keep good records. Create a medication/intervention record with dates, interventions, doses, and results. Record if stopped and why.

Communicate. If you make changes to your medication, let the doctor know what you did, why, and the result. Provide feedback: send a complimentary letter when you are pleased.

When it's just not working: If you decide after a reasonable amount of time that things are just not working for you or your child, you may want to revisit some of the questions you initially asked, i.e., "Is there anything that doesn't fit? Is there anything else it could be? Could it be more than one thing?" Provide feedback by telling your doctor what you need. Ask what you can do. Ask for help in finding another doctor if you believe that is best for you. Don't be afraid to change doctors. You learn from each relationship, and change is one step closer to success.

Summary: Finding a good doctor can be a challenge. Changing the emphasis from simply finding a "good doctor" to developing a positive doctor-patient working relationship can alter your search, and hopefully provide a satisfactory long-term result.

Additional reading: *How Doctors Think* by Jerome Groopman, MD, Houghton Mifflin 2007

How to be your child's best advocate and play nice with others

Recommendations from AHA's support group facilitators

Sue Bachemin, Donna Benkert, Mike Buffa, Joan Hourihane, Sue Kinsey, Amy Perri, and Joan Trojak
edited by Emily Raphael

Sitting at the long table during CSEs (Committee on Special Education) and annual reviews can be unnerving. Even the savviest advocates can become anxious and unfocused during meetings. As CSE and annual review season approaches, we decided to ask some of our most experienced members to share their knowledge: AHA facilitators Amy Perri, Joan Trojak, Donna Benkert, Sue Bachemin, Sue Kinsey, Mike Buffa, and Joan Hourihane contributed their thoughts. There were commonalities in their responses: most notably, the real work should be done before the meeting. There are some excellent suggestions below on organization, making contacts, and preparation. If you're well prepared you'll be more confident and have a clearer idea of your child's needs and what your focus should be during the meeting.

Preparation

When you receive an important document (e.g., evaluation, report card) write the receipt date in pencil and put it in one Master file or binder. Take time to organize your paperwork and the main goals for your child. As you move into the meeting, stay focused on those goals. Before the CSE, make certain you meet with the teachers and therapists, etc., to find out your child's present levels of performance. An IEP is only good if it has helped your child make progress during the year, so find out exactly how much progress your child really has made. Get into the school and meet the staff to create a good working relationship before there are any problems, and get involved in the school (PTA, class parent).

You also need to understand how progress has been monitored. Though parents often think they must wait three years, the triennial is actually the minimum frequency: Parents are allowed to ask for standardized evaluations once a year. Yearly testing will give you a clearer picture of whether the IEP needs to be revised to help your child progress.

If you get a sense that your child's services may be in jeopardy, obtain a reputable private evaluation well before your meeting (note that there are often long waiting lists for good evaluators) and give the reports to the Committee before the meeting.

A week or so before the CSE, prepare an agenda. Read relevant reports in the master file - evals and home/school communication notes. Make a general list of problems and potential solutions: put some thought into

what you'd like to see for your child in terms of six months, a year, and future success as an independent adult with Aspergers. Make a **list of goals**, services, manpower **supports** (O/T, P/T, speech, one-to-one aide, peer sensitivity training, etc.) and important **modifications** to your child's school day (e.g., extra time between classes, extra time for test-taking, specific peer support like Best Buddies or other club, safe place or designated personnel like a counselor who can aid if things reach critical mass).

Before the meeting, create from this list a clear, one-page, bullet-point **PARENT AGENDA** for the IEP with three columns: 1st column "**what we're asking for,**" 2nd column "**schools response, yes or no,**" 3rd column "**if yes, when and how and who, if no, reason why not.**" Fill in empty columns 2 and 3 at the CSE. This is the *only* piece of paper you need in front of you at meetings: **it will help you stay on track under pressure.** (See the *Wrightslaw* article "How to Use a Parent IEP Attachment," by Judy Bonnell, www.wrightslaw.com)

Make sure you have all the information you need to make informed decisions. If possible, get a rough draft of the proposed IEP. Let staff know it's nearly impossible to digest all the information in the meeting without advance preparation. If the district typically does not furnish reports ahead of time, request in writing that you receive copies of reports for review so that you can participate as a full member of the CSE. You have a right to all information that the rest of the team will have. Also put in writing any additional people you want at the meeting (e.g., the gym teacher if adaptive PE is being discussed, etc.).

Advance information should also include the proposed goals from each provider. If the needs are complex in certain areas, a separate goal review meeting with the provider may be warranted. If you're frustrated with lack of progress, check the goals: are they clearly stated and measurable, and is the method of measurement indicated? It also helps to put time into communicating with providers when things have gone right throughout the school year.

During The Meeting - Interpersonal

This is often an emotionally fraught time, so it helps to approach the professionals at the meeting as if you are on the same side - with the common goal of

Cont'd on p 7

Present yourself to the team

helping your child. Before and during the meeting, take time for some deep breaths, and center yourself. Give yourself the time you need to digest the information before making a decision; there is no law stating how long a CSE should last. Honestly state your concerns and ideas in a candid, non-confrontational way. Be ready to let go of some of the minor details in order to focus on the bigger picture for your child's success. Be flexible where it is warranted and don't budge when you absolutely know what your child's needs are and can prove it.

Make sure that you're really listening: you may gain valuable insights from other members of the committee, and it helps to understand the group's dynamic. Agree to whatever you CAN agree to; ask that unresolved issues be tabled for a future date. At least then there will be a new IEP that includes the things you think will help your child and those things can be implemented without a wait. You may have to agree to disagree. Sometimes it's worth agreeing to the recommendation to see if it works. But ask for measures that will ensure that, if the recommendation does not work, the Committee will reconvene soon to adjust the IEP. You can ask that a date to reconvene be written into the notes on the IEP. But decide NOW how progress will be determined.

Bring someone with you: if the mother typically goes alone, remember that we're not in a post-feminist world, and sometimes "the man with the tie" can give your side more authority. And as with important medical appointments, it helps to have another set of ears and someone to take notes - it's hard to do so when you're involved in the discussion. You can also rehearse before the meeting to simulate key arguments or concerns. You can ask your child's doctor to be present in person or by telephone. Their influential title and lack of emotional investment may make your argument for the needs of your child more persuasive. Pay attention to your own presentation: this is a professional meeting, so act and dress accordingly.

You may be listened to more seriously if you check your frustration or anxiety at the door. The same "takes 20 positives to neutralize a negative and 100 to reverse it" rule that works for teachers, will likely work on teachers. But along with being professional towards the teachers comes the responsibility to be true to your child's needs by sticking to your guns on the essentials. Know when enough is enough.

During The Meeting - Getting What's Needed

Make sure that you have your organized binder with you at the meeting: if any questions arise, you will have the information at your fingertips. If you are requesting new

services, particularly OT or PT, have a doctor's prescription ready.

If you don't understand what the testing means, ask until you do. Ideally, do this prior to the meeting, but if not, ask during the meeting until you understand. Have everyone identify themselves and their title/position; take notes. In some circumstances, it may be prudent to record the meeting; you will most likely need prior approval from the district.

The name of the game is not how MUCH you can get on your child's IEP but whether the supports really support him or her and enable progress. It will do your child no good, for example, to enforce the "daily speech therapy" provisions of the Part 200.13 if your child's REAL communication issues have much more to do with social skills deficits than with frank speech issues. Sometimes it's better to have the Committee come up with a creative solution than to invoke the letter of the law.

Don't say that what you want is the "best" for your child. Couch your requests in language from IDEA: that you want an "appropriate" public education that meets the "unique" needs of your child and "prepares" the child for further education, employment and independent living. A school district is not legally obligated to provide the "best" education.

If it becomes clear during the meeting that you will need additional documentation or information before making a decision, request to adjourn the meeting. You do not have to sign off on anything.

After The Meeting

You may want to write a letter to the CSE Chair thanking the Committee members for their time and effort. In that letter, summarize what was agreed to and anything that was denied (over your objections). Ask that the Chair respond in writing if there is a misunderstanding. **KEEP THAT LETTER IN YOUR FILE.** Keep in mind, you can always call another CSE at any time if the decisions made at this meeting don't seem to be working. And remember, if it was not written down, it didn't happen.

Attending support groups is a critically important way to network and get input from other parents who have "been there, done that." The support group facilitators have done a terrific job of guiding you through this complex process. We realize that there is a lot of information to absorb. Support group meetings are about bringing your notebook, not just your tissues. Facilitators have shared similar experiences, can empathize with your emotional responses, and will help you brainstorm solutions to your specific issues.

Developing Talents

by Michael Alan Baldasare

Having an ASD sometimes makes it difficult for me to communicate ideas, concentrate on tasks and control my emotions. Creating helps me to communicate thoughts and ideas. Since I have to concentrate when I write and draw, I keep up my good feelings and am able to stay on task.

When I was younger, my special interest was "Sesame Street". Despite my disability, I kept my interest in "Sesame Street," but have branched out in different ways. I still watch certain episodes, but I also draw cartoons, create animations and write new "Sesame Street" scripts, skits and parodies.

In tenth grade, a "Muppet Central Forum" friend sent me classic "Sesame Street" episodes. They motivated me to come up with my own cartoon ideas relating to the alphabet never before used by the show. I draw my cartoons using Prisma-Color markers, pencils and pens usually on 8.5x11 paper.

When I was seventeen, I started Computer Animation classes at Hofstra University. Flash MX and Photoshop facilitated my learning experience, and my cartoons came to life! I learned more about art, especially different techniques, and about my own talents. I also learned about Web Design while in high school. Now I have my own website called "The Muppets' Ultimate Picture Gallery," which features characters from "The Muppet Show" and "Sesame Street". I am currently majoring in Commercial Art at Nassau Community College and working in the Admissions Office as well.



An obstacle I sometimes face is understanding others and having them understand me. In my art classes, however, even though the techniques are tricky, my professors and I understand each other perfectly. I just completed a class in 2D Drawing and got an A! This semester I am taking two Art classes, Drawing 1 and Micro-computer Graphics. I'm enjoying both of them.

A recent experience in which the arts played an important part in my life was when my "P for Pants" cartoon was exhibited at the Jewish Community Center of Manhattan. This is the first time my art work was on exhibit for others to enjoy. An unexpected surprise was that my work was purchased by a true art lover!

Since I am a high achiever, The Michael Alan Baldasare Achievement Award has been founded in my school district. Recipients are students with disabilities who are hard-working, respectful of others, consistently working towards self-improvement and have a good attitude toward learning. I personally present this scholarship annually.

Many things are still difficult for me, but I continue to move forward. Overcoming obstacles is not easy, but I do it! I have my artwork and a job, and I made it to college! My "Green Light" is: LEARNING NEVER ENDS!

Editor's Note: We are happy to read that Michael is succeeding in a strong area of interest and talent.



Helpful Hints from the Trenches

Using theatre activities to teach your child social understanding at home

by Joan Hourihane

Role-playing works! When my sons were younger, I frequently used their stuffed animals to role-play or demonstrate social situations with them. I used this opportunity for teaching a social story (via plush animals). When the boys did or said something that could be considered offensive or hurtful to others, I would make their teddy bears act out that inappropriate social behavior, then my kids would tell the bears what they did

wrong and what the bears could have done differently so as not to hurt or offend someone (I usually played the victim). The kids got a real kick out of it and learned something all at the same time while having fun. To this day, there are times when the bears resurface for more mischief and fun!

*Send your **Helpful Hints** to: newsletter@ahaNY.org*

The language of this newsletter is the property of the AHA Association.

Reproduction of this material, whether all or any part, is strictly prohibited without permission: info@ahaNY.org

This newsletter is protected by the United States Copyright Act of 1976. All rights reserved.

2009 AHA Support Group and Networking Meetings *

For parents, family members of individuals with HFA/AS/PDD

<p style="text-align: center;">NASSAU</p> <p>Daytime..... 516-470-0360 Tuesdays, 10:00 am – 12 noon AHA's Office, Bethpage January 6, February 3, March 3, April 7, May 5</p> <p>Evening..... 516-470-0360 Thursdays, 7:30 pm – 9:30 pm AHA's Office, Bethpage January 8, February 5, March 5, April 2, May 7</p>	<p style="text-align: center;">SUFFOLK</p> <p>Daytime.....516-470-0360 Wednesdays, 10:00 am – 12 noon Putnam Hall, Stony Brook University January 14, February 11, March 11, April 15, May 13</p> <p>Evening.....516-470-0360 Wednesdays, 7:00 pm – 9:00 pm Putnam Hall, Stony Brook University January 14, February 11, March 11, April 15, May 13</p>
<p style="text-align: center;">QUEENS</p> <p>Daytime.....DonnaB@ahaNY.org Wednesdays, 10 am – 12:00 noon YAI/Bayside 211-11 Northern Blvd. January 14, February 11, March 4, April 8, May 13</p>	<p style="text-align: center;">EAST END</p> <p>Evening.....Susan K. 631-734-8156 Thursdays, 6:00 pm - 8:00 pm John Jermain Library, 201 Main Street, Sag Harbor January 8, February 5, March 5, April 2, May 7</p>
<p style="text-align: center;">MANHATTAN</p> <p>Evening.....631-269-5709 or 516-470-0360 Wednesdays, 7:00 pm – 9:00 pm Lighthouse Int'l, 111 E 59th Street, NYC December 3, January 28, February 25, March 25, April 29, May 27</p> <p><i>Partnered with The Asperger Institute at NYU's Child Study Center</i></p>	<p style="text-align: center;">PARENTS OF OLDER TEENS & ADULTS</p> <p>Evening.....Bernice 631-269-5709 Thursdays, 7:00 pm - 9:00 pm cell 516-383-4488 YAI/NIPD, 656 Commack Rd, Commack January 8, February 5, March 5, April 2, May 7</p>

AHA Partnered with GRASP - www.grasp.com Support for individuals with HFA, AS, PDD

TEENS (ages 13 - 19) Saturdays 12:30 pm – 2:30 pm December 13, January 10, February 7, March 14, April 4, May 16 AHA's Office, 4300 Hempstead Turnpike, Bethpage, NY	ADULTS (ages 19+) Saturdays 4:00 pm – 6:00 pm AHA's Office, 4300 Hempstead Turnpike, Bethpage, NY
--	--

*Directions to meetings: www.ahaNY.org, email info@ahaNY.org; call 516.470.0360

PLEASE NOTE: Our meetings are for adults. The presence of children is distracting and disruptive to participants. We regret any inconvenience, however, children will not be admitted to meetings.

AHA Board Meeting Dates

**AHA's Office: 4300 Hempstead Turnpike, Bethpage, NY, 8:00 pm:
 Wednesday, December 10, January 14, February 11, March 11, May 6**

Sunday Family Bowling - Please RSVP

Nassau: AMF East Meadow Lanes: (Rte. 102, corner of Front St. & East Meadow Ave., across from Public Library)
 Dec. 14, Jan. 25, Feb. 22, Mar. 22, Apr. 26, May 17
 Time: 11:30 am – 1:30 pm

Contact: Adriana McCrindle at 516-783-0917
Email: NassauBowling@ahaNY.org

Suffolk: Port Jeff Bowl, 31 Chereb Lane, Pt. Jefferson (Rite Aid Shopping Center & 7/11 Store on corner)
 Dec. 7, Jan. 11, Feb. 8, Mar. 8, Apr. 5, May 3
 Time: 12:30 pm – 2:00 pm

Contact: Joe Kraker at 516-382-0492
Email: SuffolkBowling@ahaNY.org

Cost is \$10 for two games; shoe rental included.

Achieving a Milestone

by Mitchell Hammer

Joy. Pride. Relief. All those emotions and more ran through Barbara and me as we watched our son Michael successfully navigate his Bar Mitzvah. He chanted, in Hebrew, that week's portion from the Torah scrolls and recited prayers, led the congregation and offered two speeches. He didn't make any major mistakes. He also didn't toe walk, rock back and forth or jump out of his seat. When the rabbi placed his hands on his shoulders for his benediction, he looked him in the eyes and stood perfectly still. Michael has autism, and he is fairly high functioning; but the path to his Bar Mitzvah success was just as complicated as most other parts of his life.

A special needs child can have a successful Bar/Bat Mitzvah experience but it requires the same type of education, advocacy and creativity you should be using in other parts of your child's life.

- Choose a temple that is understanding and supportive of special needs children and is willing to be flexible. Ours was at first, but then changed personnel to folks who had no training with special needs children. We had to hire a tutor at our own expense and their personnel ended up supplementing ours.
- Remember that you don't have to have the "usual" service with your child performing the "usual" tasks of a Bar/Bat Mitzvah. Think outside the box.
- Be flexible. Modify according to your child's circumstances. Our son handled paragraphs 1-6 beautifully (after nine months of tutoring and practice). Mastering paragraph 7 would have been too much so it was dropped. He read his Haftarah portion in English rather than Hebrew. Do you think anyone made a big deal over

this? Of course not.

- Identify your key people and develop a rapport and understanding with them.
- Practice EVERY day...you can change the material or routine, but you must practice daily.
- Push, prod, poke and challenge your child...he/she will accomplish more than you imagined. This was our tutor's secret. She



would never let Mike settle for less which, because things are difficult for him, is the route he usually wants to take. She was so successful that we are now retaining her to tutor him for his regular school-work. And we have made a good friend.

Our son was not ready to do this when he turned thirteen, so we did it when he was fourteen. And that is the key: remember, that this is your special child's experience, not everyone else's....be flexible and creative and find those same qualities in those you need to work with to make this happen. Hopefully it will lead you to one of the more rewarding experiences of your and your child's lives.

AHA congratulates Michael Hammer for successfully completing his Bar Mitzvah. Enormous effort and lots of preparation enabled him to achieve this major milestone with skill, poise and charm. BRAVO Michael! Mitch and his wife Barbara are AHA members. Mitch co- led the early Long Island NAAR WALKs.

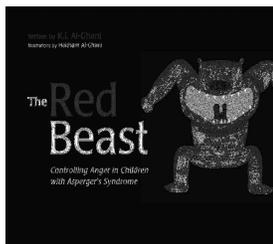
Send your **special achievements** to: newsletter@ahaNY.org

Book Reviews

The Red Beast

by K.I. Al-Ghani

reviewed by Samara Tetenbaum, M.A.



Regardless of how one chooses to label it, anger (emotional outbursts, meltdowns, tantrums, rage) is frequently expressed by children with Asperger's (AS) and high functioning autism (HFA). Though the reasons for the anger vary from child to child, anger is often

linked to frustration due to communication deficits, an inability to identify and appropriately express one's emotions, anxiety, sensory issues, or an insistence on sameness and routine. *The Red Beast*, by K.I. Al-Ghani, is one of the few books on anger management specifically cre-

ated for children with AS/HFA. The red beast is described as the anger that is located inside everyone. The story puts the reader into a day with Rufus and walks us through his experience of what happens when he loses control to the red beast. The reader is then shown how Rufus is able to calm down and regain control of the red beast and in doing so, work on controlling his anger.

Anger and emotional control are highly abstract concepts. One of the greatest strengths of *The Red Beast*, is the use of interesting visual supports to make the experience of losing control of one's anger more concrete. For example, people often have difficulty hearing and seeing the world around them when they are

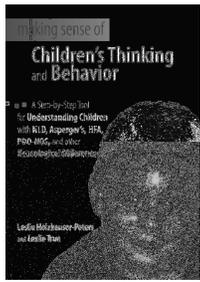
Cont'd on p 11

Making Sense of Children's Thinking and Behavior:

A Step-by-Step Tool for Understanding Children with NLD, Asperger's, HFA, PDD-NOS, and Other Neurological Differences

by Leslie Holzhauser-Peters and Leslie True

reviewed by Julie Ivans, M.S. and Shana Nichols, Ph.D.



Making Sense of Children's Thinking and Behavior represents a joint effort between a mother of a child diagnosed with NLD (*Non Verbal Learning Disabilities*) and the speech therapist who worked with them. This book provides a comprehensive guide for developing a better understanding of how children with neurological differences think and

why they do what they do.

In the first chapter of the book, the authors describe their Systematic Tool to Analyze Thinking (STAT). This clear, step-by-step approach provides parents, teachers, and professionals with a mechanism for understanding the behavior of children with neurological differences by illuminating the thoughts that occur along with behavior. The authors describe the components of STAT, which include assessing the situation, developing a hypothesis, asking questions to obtain a step-by-step account, and actions to consider. As professionals, what we love about this approach is that it is *systematic* - there is no room for immediate, reactive emotional responses. It teaches adults to stop and think about the meaning of children's behavior *before* responding - a great skill for us all to develop. As a systematic step-by-step approach, STAT is also wonderful for family members and new professionals who might be struggling with making sense of a child's behavior. Knowing that a child is not following instructions because changes in routine are difficult, reduces the likelihood that "defiant" and "oppositional"

will be identified as the cause of a behavior. The subsequent chapters in the book describe each of the 12 different areas of weakness for these children and provide engaging and thought-provoking case stories of children diagnosed with neurological differences, including Ms. True's son. The case studies presented in the book are at times touching and humorous, and clearly demonstrate the often misunderstood deficits of these children, such as social communication and thinking about other's thinking. The authors talk about "ah ha" moments that people experience when they finally understand why a child acted the way he/she did. Through these stories, the authors clearly demonstrate how to better understand children's thinking and resulting behavior by using the STAT.

Throughout the book, Ms. Holzhauser-Peters and Ms. True also describe common misperceptions of children and parents of children with neurological impairments. In a thoughtful manner, the authors explain the harm that can be caused by these misperceptions, and how to use the STAT to view everyday situations from the unique perspective of the child. *Making Sense of Children's Thinking and Behavior* is a practical guide that would greatly benefit parents, families, teachers, and other professionals working with children with NLD, Asperger's, HFA, and PDD-NOS. The next time someone says to you, "she just doesn't want to listen," consider suggesting a great book for them to read. We have already begun recommending it in our work!

Jessica Kingsley 2008

Red Beast Cont'd angry. Al-Ghani, therefore, describes the beast as having tiny ears and eyes with illustrations to match this description. The bold illustrations, drawn by a 22 year old with an autism spectrum disorder, provide a stunning background for the story.

Another wonderful strength of *The Red Beast* is the inclusion of numerous suggestions for ways to control anger (or tame the beast). Al-Ghani lists many suggestions for parents at the end of the book in addition to including techniques Rufus uses to tame his beast in the story itself. Taming techniques include going to a quiet room, counting, squeezing a stress ball, and popping bubble wrap. *The Red Beast* presents a difficult topic to children in a friendly and engaging manner. Elementary and younger middle school aged children will find the story appealing and the illustrations entertaining. Parents will find this book a useful tool in helping teach their children to better manage their anger.

I recently used this book with a group of 11-12 year old girls with HFA. The girls related to the story and enjoyed seeing Rufus control his anger. The girls did find one illustration alarming, however. When Rufus loses control to the red beast he is taken to the safe room. The corresponding illustration is of the beast being carried away in a net. One group member did not like the idea of being treated like an animal when she is angry. If a child reacts this way to the story it is a good opportunity to discuss how they would like others to respond to their anger and what others can do to help them control their anger. Overall, the book was successful in explaining anger to the group. The book also provided a wonderful follow up activity. All of the group members will be creating their own anger boxes to fill with tools to help them control their anger. This is an excellent way to extend the story and help the lesson regarding anger generalize across settings.

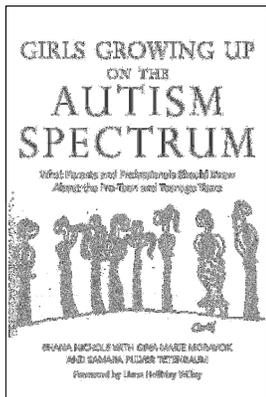
Jessica Kingsley 2008

Girls Growing Up on the Autism Spectrum:

What Parents and Professionals Should Know About the Pre-Teen and Teenage Years

by Shana Nichols with Gina Marie Moravcik and Samara Pulver Tetenbaum

reviewed by Stuart Cohen, Ph.D.



Girls Growing Up on the Autism Spectrum is a clearly written presentation of the significant challenges faced by girls on the autism spectrum as they make the transition to adolescence and adulthood. The book is an important addition to the autism literature: gender issues related to females on the spectrum have often received less attention than have issues related to males. While the book

is primarily designed to serve as a practical guide for the caregivers of girls on the spectrum, teachers and other professionals who support the girls and their families will also find its focused literature reviews, detailed interventions, and extensive use of case material helpful. The authors cover managing the physical, social, and emotional challenges faced by girls during this transitional period.

The authors have a rich clinical experience dealing with individuals with developmental disorders and conduct a “Girls Growing up on the Autism Spectrum” group at the Fay J. Lindner Center for Autism and Developmental Disorders on Long Island. One fundamental principle is the importance of being proactive, not reactive when dealing with the girls’ transition from childhood to adolescence, especially given the deficits in self-awareness, heightened sensory sensitivities, and emotional and social

vulnerability faced by this population. The authors provide detailed and practical action plans that families can use and emphasize a flexible problem-solving approach. The liberal inclusion of case study material from girls on the spectrum and their mothers is a very valuable feature. The authors emphasize the central role of family values in deciding upon a course of action and present a wide range of options.

The material is helpfully presented:

- The regular use of sub-headings within chapters alerts the reader to the important issues covered and divides material covered into shorter and more manageable chunks
- Information and recommendations for approaching problems are presented in bullet format, which helps to highlight the significant points
- Practical action plans presented are based on a detailed analysis of the task with all steps clearly specified
- Action plans address problems at all functional levels
- The authors provide an extensive list of resources at the end of each chapter

Girls Growing Up on the Autism Spectrum is a book that I recommend most enthusiastically. It is a valuable addition to the autism spectrum literature as it addresses the unique problems faced by girls on the spectrum, a population that is often unrecognized and underserved.

Jessica Kingsley 2008

Autistic Planet

by Jennifer Elder

reviewed by Gage



The children's book, *Autistic Planet*, written by Jennifer Elder, is an excellent way to inform neurotypical individuals just a little bit about how people on the Autistic Spectrum interpret the craziness of the world

around them. The ideal place for this book would most likely be in an elementary school library, or on the book-

shelf of a parent of someone on the spectrum. Not only would *Autistic Planet* shed some light on the subject say, for example, a second grade class, but perhaps for the teacher as well. Given the age group, the writer did an exceptional job explaining echolalia and a heightened sensory sensitivity, as well as a devoted passion in one's core interests, all the while in a song-like rhyme which was short and to the point.

Jessica Kingsley 2008

The search for effective treatment of Autism Spectrum Disorders (ASD) is in its infancy and is made more difficult because each individual on the autism spectrum is unique. Myriad interventions are being offered, including a wide variety of medications, therapies, educational methodologies and nutritional approaches. While many of these methods reflect sound current practice, many of them do not. A parent's urgency to take action may be exploited by unsound practices that can be costly, time-consuming and physically demanding. Through our support programs, website, mailing list and our newsletter, On The Spectrum, we make every effort to provide objective, up-to-date, reliable, evidence-based information, and we urge you to thoughtfully evaluate any proposed treatment.

AUTISM CENTERS

Fay J Lindner Center for Autism and Developmental Disabilities

North Shore-LIJ Health System, Bethpage, NY - 516-802-8600 www.northshorelij.com/autism

Services Offered:

- Transdisciplinary Comprehensive Diagnostic Assessment
- Specialty Evaluation; Counseling; Treatment: Psychiatry, Psychology, Speech & Language; Communication & Social Skills; Adaptive Function; Medication Management; Behavior
- A Variety of Individual & Group Offerings: Social Skills; Sexuality Education; Cognitive Behavioral Therapy; Girls Growing Up on the Spectrum; Money Management; Transition
- Family Support & Education, Service Coordination
- Professional & School Training, Consultation, Supports
- Clinical Research Opportunities

The Matt and Debra Cody Center for Autism and Developmental Disabilities

Port Jeff Station, NY & Hampton Bays, NY - 631-632-3070 www.codycenter.org

Clinical Services:

Evaluation of children/adults for ASDs, Developmental Disabilities
Psychiatric treatment, medication management
Individual, group, family counseling
Neuropsychological testing
Sexuality education & reproductive health care
Primary care
Specialty consultation: child neurology, developmental pediatrics, genetics
Social skills training groups, Behavioral clinic

Resource Center and Family Support Services:

Non-Medicaid service coordination incl. high school to adult transition
Respite, recreation programs
Information and referral services
Family and community workshops
Transition support services: workshops, transition Consultation, eligibility evaluations and testing

Educational Programs:

Autism consultation services: schools, agencies

The Asperger Institute at NYU Child Study Center

New York, NY - 212-263-8916

Lynda Geller, Ph.D., Clinical Director

Clinical Services for children, adolescents, and adults on the autism spectrum

- Diagnostic evaluation, including the Autism Observation Schedule (ADOS) and the Autism Diagnostic Interview (ADI-R)
- Psychiatric assessment and treatment
- Individual cognitive behavior therapy (CBT)
- Consultation about Asperger Syndrome to schools
- Transitional life planning and support
- College support and preparation for college
- Specialized neuropsychological evaluation
- Interdisciplinary diagnostic evaluation
- Social skills groups
- Facilitated social recreation
- Family support and education
- Intellectual and adaptive assessment

Montefiore Autism Center

Yonkers, NY - 914-375-4880

Michelle A Dunn, Ph.D., Director of Clinical Services

- Diagnostic services/Evaluations
- Cognitive/language intervention for children age 4 to young adults with ASD
- CBT for individuals on the spectrum, parents, siblings, and entire families
- Consultation services to establish the **SOS**: Social skills in Our Schools Program in public schools
- Clinical Research opportunities

DIRECTIONS

Nassau Daytime/Evening Support/Information Series/AHA Board Meetings

GRASP Teen & Adult Groups

AHA OFFICE, 4300 Hempstead Turnpike, (Fay J. Lindner **CENTER FOR AUTISM**), Bethpage.

Southern State to the Seaford Oyster Bay Expressway (Exit 28A N) to Route 135 North - Syosset. To Exit 7 W - Hempstead. You are now on Hempstead Tpke (Route 24). * Make a U-turn at the second left - Seitz Dr (7-Eleven on the left). After the first traffic light, make the first right after the Embassy Diner into the parking lot of the Center for Autism. Go to the back entrance.

LIE Exit 44 or **Northern State** Exit 36A: to Seaford Oyster Bay Expressway - (Rte 135 S – Seaford). Continue to Exit 7 W - Hempstead. You are now on Hempstead Tpke (Route 24); follow as above.*

Suffolk Daytime/Evening Support - PUTNAM HALL - Conference Room, S Campus, Stony Brook University

From the LIE: Exit 62 N (Nicolls Rd./Rt. 97). Go 7 miles, cross Rt. 347, continue another 1.5 miles. Turn left into the South University Entrance (South Dr.). Go past the Dental Center and turn right at traffic light (Marburger Drive). On the right side of the road is a bus stop. Turn right after this bus stop and immediately bear left toward Campus Police. Follow curved road to the parking lot - Putnam Hall is on the right.

From Rt. 347: proceed north on Nicolls Rd. 1.5 miles. Turn left into the South University Entrance (South Dr.) and proceed as above.

From Route 25 A: head south on Nicolls Rd/Rt. 97. Pass the first two entrances to the university (North Entrance and Main Entrance). Turn right into the third entrance, South University Entrance (South Dr.) and proceed as above.

East End Support - JOHN JERMAIN LIBRARY, 201 Main Street, Sag Harbor

Directions from the west: take Route 27 east into Bridgehampton, look for monument and take slight left onto Bridgehampton / Sag Harbor Turnpike CR-79. Continue approx. 4 miles, straight through at traffic signal (becomes Main Street) look for library on right across from Whaling Museum on left.

Parents of Older Teens/Adults - YAI/NIPD - 656 Commack Rd, Commack

LIE Exit 52. (Commack Rd). Proceed 1/4 mile north. YAI is on the right hand side immediately past a diner and a small strip shopping center.

Queens Support - YAI/Bayside - 211-11 Northern Blvd., Bayside, Queens, (NYL Conference Room - 2nd Floor)

From Queens: Grand Central Parkway East to Exit 21 - Clearview Expressway, North to Exit 5 - Northern Blvd (Rt. 25-A). Right turn onto Northern Blvd. Less than 1/2 mile to 211th St. Building on left, YAI logo at the top, across the street from a KIA car dealership. Street parking only.

From Long Island: Cross Island Parkway North to Northern Boulevard West (Exit 31 W). Appr. 1/2 mile to 211th St. Building on right. As above.

Manhattan Support - Lighthouse International, 111 East 59th Street, NYC (Park/Lex), Subway (4,5,6 or N,R,W).

The AHA Electronic Listserv informs over 1400 people worldwide

Sign up for the listserv at www.ahany.org

AHA's 2009 Evening Information Series

- Positive Behavioral Strategies for Home and School: When Yelling Isn't Working
- How to Plan for an Effective IEP Meeting - Bring Your Questions
- What are the Components of a Quality Comprehensive Evaluation? Why It's So Important to Get A Private Sector Evaluation
- Life Skills for the Higher-Functioning Child: He Can Do Calculus But Can't Tie His Shoes
- Life After High School . . . Now What Do We Do???

Be sure to check our website for date, time and location

For further information: www.ahaNY.org Join our E-list 516-470-0360

AHA Mission Statement

To increase awareness and knowledge about higher functioning autism among the professionals who diagnose, treat, educate or provide services. (Autism is a spectrum disorder that varies in degree from mild to severe with a wide range of needs.)

To develop a strong network of parents supporting one another through the challenges of daily life.

To attain appropriate educational programs, effective social skills training, increased social and recreational opportunities, meaningful employment, and sufficient and satisfactory independent living accommodations for those with High Functioning Autism (HFA).

To provide parents and professionals with a useful forum where they can exchange pertinent information.

AHA does not endorse any products, services, establishment, individual, program or treatment represented on these pages. Individuals should educate themselves and make their own decisions concerning their particular needs. Authors' opinions expressed in this newsletter are not necessarily those of AHA.

Lending Library

AHA's Library List is on our website. Members may borrow books and other media materials at support meetings OR you may purchase the items directly through our website at either Amazon.com or AAPC Publishing. AHA receives a small commission for purchases through these sites and you receive your standard discount and ease of internet buying. Want to help during the year? Email Joan: joanh@ahany.org

Support AHA

All donations are appreciated, acknowledged, and enable us to share and disseminate information about HFA/AS/PDD.

We are a 501(c)(3) not-for-profit organization.

Contributions can be sent to:

AHA Association
PO Box 916, Bethpage, NY 11714-0916

If your company participates in a **United Way In The Workplace** campaign, consider designating us as your charity of choice.

Please encourage family and friends in the military, postal system and US Government to support us through the **Combined Federal Campaign**.

Our NYC CFC number is 6044.

Our LI CFC number is 3096.

Donate online via the **American Express Just Giving**:
www.americanexpress.com/give and receive bonus points in your American Express Program.

AHA Membership Application 2009

Last Name: _____

First Name: _____

Address: _____
_____ Zip _____

Phone No.: (____) _____

E-Mail: _____@_____

Parent _____ Teacher _____ Other _____

Professional (Please note area of expertise)

Name of Individual with ASD:

D.O.B.: _____

If a child:

School District: _____

School Placement (if out of district): _____

If an adult:

Living: with parent (s) _____ group residence _____
independent _____ other _____

Work: full time _____ part time _____
independent _____ job coach _____

Other _____

I would like to volunteer my time (please check) _____

I give permission for my name/phone number to be shared with families with similar concerns.

Signature _____ Date _____

Yearly dues (2008):

__ (1) year \$40.00 through 12/31/09
__ (2) year \$70.00 through 12/31/10
__ Lifetime \$400.00 \$_____ Donation to AHA

Please mail this application with your check or credit card info payable to AHA Association, to:

AHA Association

PO Box 916

Bethpage, NY 11714-0916

AHA is a 501(c)(3) not-for-profit organization. We gratefully accept (tax-deductible) donations.

Any questions? e-mail AHA President Pat Schissel at: PatS@ahaNY.org

or call one of the numbers on this brochure

Payment Type (circle one):

Check • Money Order • Master • VISA • Discover

Card # _____

Exp (Mo/Yr) ___/___ Total Amt Enclosed \$ _____

Signature _____

1208

AHA Yearly Dues Entitle You To:

- receive our newsletter;
- borrow books from our libraries at support meetings;
- receive reduced rates at AHA conferences and events.

Yearly memberships run from January 1 to December 31.



SAVE THE DATE FOR THIS EXCITING AHA EVENT

- Saturday, May 9, 2009 - AHA Spring Conference at Adelphi University
Keynote Temple Grandin, Ph.D.
 - Workshops
 - Employment
 - Post High-School Options
 - Effective Pharmacotherapy, Being an Active Consumer
 - Legal Issues
 - College Coaching Training
 - Panels
 - Art Exhibit
 - Resources
 - Books and Authors

Questions? Email: info@ahaNY.org

www.ahaNY.org



Asperger Syndrome and High
Functioning Autism Association (AHA)
PO Box 916
Bethpage, NY 11714
www.ahaNY.org
info@ahaNY.org
516.470.0360