



AHA/AS/PDD

On The Spectrum

The Newsletter of
The Advocates for Individuals
with High Functioning Autism, Asperger's Syndrome
and other Pervasive Developmental Disorders
www.aha-as-pdd.org

Fall 2004

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On the Spectrum

The AHA/AS/PDD Newsletter
PO Box 475

Roslyn Heights, NY 11577-0475

Bernice Polinsky, Editor
Maryann O'Shaughnessy, Assistant Editor

Dear Members & Friends,

I hope by now that you and your families have settled into the routines of school and that things are going well. We are here to support you with information, experience and sage advice at our monthly meetings in Nassau and Suffolk. The dates are listed on the back cover and directions are inside and on our website.

By now every school district on Long Island has received several copies of our fall conference brochure. They were mailed to elementary, middle and high school guidance counselors, school nurses, psychologists, social workers, special education directors, speech and language staff, and principals' offices.

It is now up to YOU to get the word out in your district. Speak up! Copy your brochures and bring them to your child's principal, teacher, and other school personnel. This is our 14th conference. Our speakers are leaders in the field and we bring them to Long Island at reasonable fees to "educate the educators". Two years ago 67 out of the 114 school districts on Long Island were represented at our conference. Last year the figure rose to 89. Good numbers, yes. But we need to reach every district's special education and regular classroom teaching staff and administrators. You can do it!

Thank you for returning your election ballots. Please join me in welcoming our new board members Bill Heslin, Joan Hourihane and our new teacher liaison and board member Lorianne Hoenninger.

Join us Sunday, October 24th for NAAR's (National Alliance for Autism Research) WALK at Jones Beach. The location has been changed in order to accommodate the over 10,000 walkers who enthusiastically joined us last year.

Our fabulous AHA/AS/PDD T-shirts are FREE to pre-signed walkers through the generosity of our friends at Lindamood Bell Learning Processes, AFC Printing, Accessible Learning, HorseAbility, Power Pals, and Pt. Jeff Bowling. Please sign up for the walk. A flyer was mailed home or go to: www.naar.org/walk/walkfiles/1059/walk.asp. Please write in our Team: AHA/AS/PDD, and Team Captain: Bernice Polinsky.

AHA/AS/PDD will again be a recipient charity from THE SHOPPING BENEFIT at BLOOMINGDALES on Tuesday, October 26th. Please see p 17 for information. You can shop beforehand and save.

And lastly, if you did something special this summer that you think other families could also enjoy, please email us so that we can tuck it away and tell others for next year. Your experiences are what makes our group so special. Your recommendations and impressions of the people and professionals in your family member's life are useful to others. Thank you for your help. We couldn't do this without you.

Take care,

Patricia R. Schissel, President

Contact Numbers

AHA/AS/PDD

PO Box 475, Roslyn Heights, NY 11577-0475

www.aha-as-pdd.org

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Bowling & Survey	Paul Konigstein
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Professional Advisor	John Pomeroy, M.D.

The search for effective treatment of Autism Spectrum Disorders (ASD) is in its infancy, and made more difficult because each individual on the autism spectrum is unique. A myriad of 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 and our newsletter, we make every effort to provide objective, up-to-date, reliable, evidence based information, and urge you to thoughtfully evaluate any proposed treatment.

Advisory Board

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Stephen Shore, M.A.

Support AHA/AS/PDD

All gifts are gratefully acknowledged and enable us to share and disseminate information about HFA/AS/PDD individuals to themselves, their families and the professionals who work with them.

Contributions can be sent to:

AHA/AS/PDD

P.O. Box 475

Roslyn Heights, NY 11577-0475

We have a 501(c)3 tax exempt status.

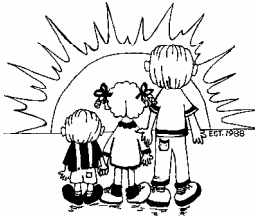
If your company participates in a **United Way** in the workplace campaign, consider designating us as your charity of choice.

Please encourage family and friends in the military, postal system and US Government to support us through the **Combined Federal Campaign**. Our CFC number is: #3096.

AHA/AS/PDD THE JOURNEY, SO FAR

by Maryann O'Shaughnessy

Our first meeting was in the spring of 1988 under the auspices of the Department of Child Psychiatry at Stony Brook and the direction of John C. Pomeroy, M.D., to whom we are most grateful. Dr. Pomeroy, at that time the Director of Child Psychiatry, O.P.D., University Hospital at Stony Brook, was doing research on high-functioning autistic-like children. As his study progressed, it became apparent to him that a number of families were in need of a support group where parents could share experiences, develop and learn about potential resources and discuss management of our children's problems.



HFA/AS/PDD

"Autistic-like" was a medical diagnosis, not an educational classification; knowledge and understanding of autism as a spectrum disorder were virtually nonexistent. No needs of individuals with higher functioning autism or pervasive developmental disorder were being met in the late 1980s. Most disheartening was the complete lack of identification of children with autism with average or above average IQ's. Instead, they were medically misdiagnosed, educationally misclassified and inappropriately served. ("He can't be autistic, he talks." "He can't be autistic, he doesn't just sit in a corner and rock." "This is a happy well adjusted, emotionally disturbed child." "Why do you want your child to be autistic?")

Our children were in schools all over Long Island, we had no way to find each other and most of us had never met other parents with children like ours. One year later, with the support of each other, continued encouragement and support from Dr. Pomeroy, and a membership of 24 parents, we began to become more autonomous. We have continued to grow in knowledge, in expansion of ways to reach our goals, and in numbers. Today we have over 700 members – parents, professionals, family members and individuals on the spectrum of autism.

Our primary purpose was, and is, to support one another as we advocate for the unique needs of children and adults with an Autism Spectrum Disorder (ASD).

Our goals are:

- To increase awareness and knowledge about ASD among the professionals who diagnose, treat, educate or provide services.

Cont'd on p 4

AHA/AS/PDD THE STORY BEHIND the LOGO

by Pat Long

In 1989 my son, Edwin, was aging out of preschool. He attended Just Kids for 2 years. I brought him there because he had language issues and severe behavioral problems. He screeched all the time, lined up his toys, his socialization skills were non-existent and he had little to no eye contact. I was told he had some autistic tendencies and a severe language delay. No one ever told me more. When it came time to prepare for kindergarten, the social worker there told me it was time for me to see his file. It was then that I found out that the diagnosis for my son was PDD. I immediately started my search for more information on this subject and found little to nothing.

One day, I was looking through a local free paper and came upon an ad. To my utter surprise, this same article described my son. To a T. Not only did I find a direction but I also found what I needed most - other parents with children like mine. I felt so alone for such a long time and now, I had hope. This small group of parents were running support meetings and providing others with answers. I went to their very next meeting and immediately knew that this was where I was meant to be.

The group was small but growing steadily. I was hooked - I found two wonderful women who have given me information, support and most treasured of all - long, lasting friendship. These women are still involved with the group and are a constant source of inspiration and comfort. Maryann O'Shaughnessy was the president at that time and her son, Michael is represented as the tallest boy in the logo. Phyllis Francois was handling membership and the newsletter at that time and her daughter, Mae, is the girl in the middle. My son Edwin is the smaller boy and they are all shown looking into the sunrise on a brighter future.

I created this logo to symbolize the mission statement of this group. My heart and soul have been invested in reaching out to as many families as we can; having a symbol that portrays a positive image is the most important thing we have in that primary step of connecting with all those families who deal with the challenges of raising a child with ASD.

My purpose in writing this article is to give you, our members, a piece of the history of this really wonderful group.

- To attain appropriate educational programs, effective social skills training, increased social and recreational activities, meaningful employment, and sufficient and satisfactory independent living accommodations for those with ASD.
- To develop a strong network of parents supporting one another through the challenges of daily life.
- To provide parents and professionals with a useful forum where they can exchange pertinent information.

In keeping with our primary purpose and the fundamental goals of educating parents and professionals, and of increasing awareness of Autism as a spectrum disorder that occurs in degrees, some of our most successful accomplishments to date are:

- * **Monthly support groups:** 6 day and evening meetings in Nassau County and Suffolk County. Four are focused on the needs of parents of school-aged children, one on the needs of parents of older teens and adults, and one in conjunction with GRASP (Global and Regional Asperger Syndrome Partnership) for individuals on the autism spectrum 18 years and up, facilitated by an adult with Asperger Syndrome.
- * **Two-day conferences,** highly successful and held annually since 1994, targeted for teachers and other professionals focusing on the educational needs of children with HFA/AS/PDD. We feature nationally known professionals such as John C. Pomeroy, Tony Attwood, V. Mark Durand, Carol Gray, Ami Klin, Linda Kunce, Catherine Lord, Brenda Smith Myles, Diane Twachtman Cullen, and our overwhelmingly popular Teen Panel.

- * **Two libraries,** one for our Suffolk members, one for our Nassau members. Both contain current and useful books, videos, and periodicals.
- * ***On The Spectrum*,** our quarterly newsletter, distributed to over 700 parents, professionals and other supportive members.
- * **Advisory Board** created and comprised of knowledgeable, well-known, well-respected professionals.
- * **www.aha-as-pdd.org,** a website created and maintained with a comprehensive reading list, support group information, links to pertinent internet sites, a mailing list to disseminate timely and useful information and articles of interest.
- * **Annual picnic** hosted since 2000, where families have bonded, young people on the spectrum have made lasting friendships, siblings have found special connections and extraordinary memories have been created.
- * **Monthly family bowling days** since 2003, held in two locations, one in Nassau County and one in Suffolk County.

1988 - *Advocates for High-Functioning Autistic-Like Children*

1993 - *Advocates for High Functioning Individuals with Autism/Pervasive Developmental Disorder*

1997 - *Advocates for Individuals with High Functioning Autism, Asperger's Syndrome and other Pervasive Developmental Disorders (AHA/AS/PDD).*

The changes in our name are due to the continuing fluctuation in diagnostic terminology, politically correct language, our efforts to be all-inclusive, and the too frequent use of euphemisms for "autism".

AUTISM SPECTRUM QUARTERLY

(formerly Carol Gray's Jenison Autism Journal)

Autism Spectrum Quarterly is a new Autism/Asperger Syndrome journal. Its premier issue was published in Summer 2004. Diane Twachtman-Cullen, Ph.D. is Editor-in-Chief with Liane Holliday Willey, Ed.D. as Senior Editor with an outstanding advisory board known worldwide. The content will be covering many areas of interest and concern.

This journal is written for professionals and everyone interested in the autism spectrum in a readable magazine style. www.asquarterly.com

Editor's Note: Liane will be our key note speaker at the AHA/AS/PDD April 2005 conference. To find out more about Liane: www.aspie.com

ADVISORY BOARD MEMBER

Martin A. Schwartzman, CFE, CIE, CPCU

Martin A. Schwartzman is a Supervising Insurance Examiner at the New York State Insurance Department. He supervises the field audit activities of the Health Bureau. Mr. Schwartzman is an Instructor for Insurance Accounting and Finance at Hofstra University, where he also earned his Bachelors degree in Business Administration.



National Board of NAAR. He and his wife Caryn, who co-chaired last year's Long Island Walk F.A.R. for NAAR, are the parents of twins, Allyson and Robby. Robby is a child with autism.

As our group has grown year after year we have often called on Marty and his fund of information to help us navigate the waters of government and science. We happily welcome him to our advisory committee and thank him for his further commitment to us.

Marty is a longtime member of AHA/AS/PDD, the President of the Long Island Chapter of NAAR (National Alliance for Autism Research) and on the

AHA/AS/PDD FAMILY BOWLING

AHA/AS/PDD members have told us that they would like more opportunities to socialize with other families like themselves. That's why we created the AHA/AS/PDD Family Bowling Program.

The second season of AHA/AS/PDD Family Bowling begins on Sunday, October 3. This program is designed for individuals on the spectrum of all ages and their families. Children, teenagers, and adults are welcome. Children bowl with bumpers while other lanes without bumpers are set aside for teens and adults. Socialization opportunities are provided both for individuals on the spectrum and for their families. Both AHA/AS/PDD members and non-members are welcome, so please invite your friends.

Our Family Bowling program has two locations: one in Suffolk at Port Jeff Bowl and one in Nassau at Syosset Lanes. The cost at both locations for this season will be only \$8 per person for two games and shoe rental. So that we can make your experience as pleasant as possible, please RSVP if you would like to attend. To bowl at Syosset Lanes, RSVP to Paul Konigstein. To bowl at Port Jeff Bowl, RSVP to Paula Beaudoin.



Dates are below and directions are on page 31.

Dates and directions are also on our web site:
www.aha-as-pdd.org

Please print out this message and paste it on your calendar for future reference. We look forward to seeing you at the alley.

Paul Konigstein, Nassau Bowling Coordinator
paulkonigstein@optonline.net
516-679-6957

Paula Beaudoin, Suffolk Bowling Coordinator
quiltingcrazy@optonline.net
631-981-4775

2004-2005 AHA/AS/PDD Family Bowling

Dates (usually, not always,
the first Sunday of the month)

12:30 - 2:30 PM

October 3

November 7

December 5

January 9

February 6

March 20

April 10

May 15

AHA/AS/PDD 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.

ONE GOOD ASPERGER MOVIE CAN MAKE A DIFFERENCE

by Jerry Newport

There have been many movies made about autism but as far as I am concerned, only "Rain Man" did us much good. It put autism on the map even if many who saw it mistakenly believe that Raymond Babbitt was a typical autistic man. Autism is part of our language today even if often misunderstood. You can't get anywhere if people don't even know you exist.

That is a good thing. People needed to know in 1988, that autism exists. I sure did. Without "Rain Man" to pique my curiosity, I could still be in obscurity, totally lost, alone or even dead. That movie inspired me to explore my own past and look for other people like me and a way for all of us to help each other. Today, just as many may need to know about Asperger Syndrome. It is hard to say just many people have Asperger's or will have it but I do know that regular Kanner autism is growing at an incredible rate. In the United States, it is found as often as one in 150 children. If that rate extends worldwide, then with over 400,000 new births a day, a new future autistic child is born every 32 seconds.

Make of the numbers what you wish but I believe that Asperger Syndrome also enters the population in larger numbers than ever. This is a big reason why Mary and I allowed our lives to be used as background information for a movie recently filmed. That movie is called "Mozart and The Whale."

The "Mozart" refers to the music talent of the female character, like my wife. If you know me, you know I am the original whale. I always liked whales because they are so big that if you are one, you don't worry about being out of step. The rest of the ocean tries to swim along with you!

"Mozart" is not our life story. Some of the movie is very close to our reality. Some is different but as Tony Attwood said, "authentic": where "Mozart" differs from our story is still in a way that one could imagine it happening with an Asperger's couple and their adult friends who have Aspergers or Autism. The movie is not a documentary either. It is a movie. It is entertaining, provocative, emotional, heartbreaking and inspiring. Asperger Syndrome can be all of those things.

The male lead, Josh Hartnett ("Pearl Harbor") doesn't look at all like me. I guess he is more like a nice, sleek,

Blue Whale where I am an Orca. But Josh is a great actor and has done a fine job of capturing the spirit of myself at a younger age. When I was twenty six, I was totally obsessed with fitting in. I was totally frustrated by this thing I couldn't name (Aspergers) that prevented me from fitting in. The female lead, Radha Mitchell, ("Man on Fire") is from Australia.

She looks a lot more like Mary did when I met her and is closer to her age back then. Radha's character, like Mary, is wiser. She accepts herself more as she is.

It is not looks that count. From what I have seen, Josh, Radha and the rest of the cast have performed a miracle in bringing to the screen what goes on inside anyone who has Asperger Syndrome or whose autism is high functioning enough for them to be part of an adult group.

After one scene, when I visited the location, I was tempted to say to the director, Petter Naess, "I think we need to adjust the cast's medication." I knew they were actors but they made me feel at home.

This movie has an interesting local connection to Long Island. The producer, Robert Lawrence, is a native of Port Washington. Robert was VP of New Projects at Universal Studios when his friend, Roger Birnbaum (recently: "Seabiscuit") bought the rights for "Rain Man."

Robert steered that project to some Oscars and promised Stephen Spielberg, who wanted to direct it, that he would let him know if he ever found another autism project. It didn't take long for Robert to introduce Mary and me to Mr. Spielberg in 1996. But life is busy for such people. When he realized he would never be able to direct our movie, Mr. Spielberg allowed another studio, Millennium Studios, to take it over.

"Mozart's" director deserves a lot of credit. Petter Naess has a lot of sensitivity. When Mary and I saw a tape of "Elling" (2001), it gave us new hope for the project. "Elling" was nominated for an Oscar for "Best Foreign Film." It is a great story about two men who move out of an institution into the apartment and have a remarkable series of misadventures, battling the system and sometimes, each other. "Mozart's" screenwriter,

Cont'd on p 21



AUTISM – A PROBLEM OF BRAIN CONNECTIONS?

by Dr. Chic Schissel

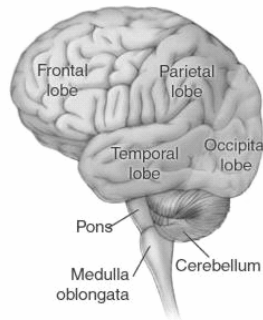
Recent magnetic resonance image research suggests that different areas of the brains of autism patients don't work with each other in the coordinated manner necessary for most high-level thinking. The individual brain areas function properly, but have trouble communicating with each other. It's sort of like a kindergarten soccer team ---- all the players run to the ball instead of playing their positions.

These early findings support a biological theory of autism called underconnectivity. A lack of connections between brain areas, or a surplus of connections that results in inefficient communication, could explain the disordered thinking of autism patients. Additional studies are needed, but these results thus far are consistent with other developments in autism research and are generating a lot of interest in the autism research community. They suggest the first plausible brain mechanism that may be able to explain all of the deficits seen in autism. The findings could lead researchers to the genes responsible for the underconnectivity. They might also guide the development of new therapies for the disorder, or perhaps lead to effective early interventions during infancy.

But, as always in Science, caution is in order. As one researcher said, "For the last 25 years, the field of autism has been filled with people who announce spectacular findings that other groups have been unable to duplicate."

Research problems are complicated because the severity and symptoms of autism can vary widely. Some recent research has focused on the size of the skull and the brain, and on the composition of the brain. Autistic children have shown abnormally accelerated growth in brain size in infancy, and abnormal increases in gray and white matter at 2 to 4 years; in certain children with autism there seems to be a defect that allows the brain to develop too

quickly. Other early-age irregularities of brain anatomy have been observed: the amygdala and the hippocampus, areas associated with emotions and memory respectively, show abnormal development in the autistic.



It is theorized that as some areas of the brain enlarge at too rapid a rate the connections that allow these areas to communicate with each other don't function properly, leading to autism. All this is early, and speculative, but could lead the way to better understanding, and, hopefully, better treatment.

The MIND Institute has been conducting early research, will continue to analyze the MRI data, and plans to launch a larger study.

Parents of autistic and normally developing children interested in participating can call the Institute at (916) 703-0320.

Editor's Note: This article was condensed from the following: STUDY: BRAIN IS ATYPICAL IN AUTISTIC BOYS by Dorsey Griffith -- Bee Medical Writer - (Published July 15, 2004) www.sacbee.com/content/news/medical/v-print/story/10002925p-10924210c.html

AUTISM SEEN AS PROBLEM OF CONNECTIONS IN BRAINS by Byron Spice, Pittsburgh Post-Gazette
www.post-gazette.com/pg/04228/361572.stm

THE AUTISTIC BRAIN: BIRTH THROUGH ADULTHOOD Courchesne E, Redcay E, Kennedy DP., Departments of Neurosciences, and Psychology, University of California, San Diego, California, USA; and Center for Autism Research, Children's Hospital Research Center, San Diego, California, USA.

www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15247547

Many thanks

to the following people who helped with editing and proofing

Eric Schissel, Chic Schissel, Ellen Bell, Jessica Rigal, Bella Freedberg, and Pat Schissel

Congratulations to The Elija Foundation on the opening of their new early intervention center, Effective Interventions, Inc., in Levittown, NY. 516-433-4202 or www.effectiveinterventions.com

Question:

What are the known medical causes of Autism Spectrum Disorder (ASD), and what medical investigations should be done (or not done) when ASD is diagnosed or recognized?

Answer:

Given the rapid increase in our awareness and knowledge of the neurobiologic abnormalities that appear to be associated with Autism, it would be understandable for parents to believe that intensive neurological and bio-medical investigation is not only indicated but will lead to an explanation of the cause their child's developmental problems. However, in clinical settings, exhaustive and even invasive medical studies are not indicated for most children diagnosed with ASD. This approach, if applied to every child with ASD, rarely yields findings that are of relevance to the diagnosis.

Although a relatively conservative approach regarding the intensity of medical work-up is justified it should be noted that medical disorders are not uncommon in Autism. The incidence of clinically relevant biologic/medical conditions that are reported in different studies of groups of children with Autism ranges from 5 to 30%. This includes not only medical disorders that might explain the cause of the ASD (probably about 5%), but also medical disorders that may be impacting on the ASD (e.g., allergies exacerbating behavioral problems), closely associated with ASD (e.g., seizure disorder) or co-occurring with the ASD (e.g., recurrent ear infections).

Genetic factors (interaction of a number of genes either independently or with environmental toxins) are considered to be the major cause of ASD. However, a number of biologic conditions have been associated with Autism - e.g., chromosomal abnormalities, exposure to viral infections in early development, severe seizure disorders, and some specific but uncommon disorders of brain development such as Tuberous Sclerosis. Children with higher functioning skills are less likely to manifest these major medical syndromes.

Testing every child with a wide range of procedures will not necessarily aid clinical opinion or determine treatment decisions. For example, abnormal EEG (brain wave testing) findings are relatively common

in random testing of very young children with ASD but the clinical relevance is uncertain and does not justify biological (e.g., anti-convulsant) treatment. Children with ASD who have true epilepsy requiring anti-convulsant therapy are typically identified by clinical recognition of seizures that is later confirmed by EEG abnormalities.

In practice, the clinician assessing the very young child with ASD will wish to firstly consider severe conditions that might present with features of Autism usually in the context of marked impairment in the child. These include rare epileptic disorders that cause regression often with loss of speech, sensory (hearing, visual) deficits, rare brain diseases and multiple handicapping conditions. Thus, the young child with severe delays in social, communication, cognitive and, often, motor skills may require fairly extensive testing of possible causes of their developmental delays. However, for most children with ASD and particularly those who have more able skills and less abnormal physical development the need for investigation is dictated by clinical judgment. Thus, blood and urine tests for abnormalities of metabolism, genetic testing, EEG (brain wave measurement) and neuro-imaging (e.g., MRI) are usually indicated by clinical signs or history (e.g., seizures, lethargy, abnormal physical features, skin lesions suggestive of neurologic disorders, family history of specific disorders).

A number of tests that are commonly requested do not yet have proven value for routine assessment of cause of ASD, but may have interest for research. These include hair analysis, allergy testing, intestinal permeability studies, stool analysis, urine screen for abnormal protein materials and testing for celiac antibodies suggesting sensitivity to gluten, blood measures for immunological or neurochemical abnormalities, and nutrient levels (e.g., vitamins). The opinions regarding the value of these measures are those of the major medical associations, but it is possible that they may be reevaluated based on replicated research findings warranting their use.

Cont'd on p 9

ACTIVITIES and PROGRAMS

GRASP

(The Global and Regional Asperger Syndrome Partnership)
Support Groups on Long Island and Manhattan
Support groups are for AS/HFA individuals, ages 18 and up.

LI GRASP/AHA/AS/PDD *meeting dates on back page.*

The Manhattan support group meets three times monthly from 6:00 PM - 8:00 PM. More information can be found at www.aha-as-pdd.org (GRASP website under construction).

Meetings are facilitated by Executive Director: Michael John Carley. For more information call 646-242-4003, or email mjcarley@aol.com

Social Language Group

Groups for Pre-Teens (10-12 years) at the Hy Weinberg Center for Communication Disorders at Adelphi University. Saturdays, from 10-11:30 am. Call: 516 - 877-4850.

Kids Saturday Play Groups

Offered by The David Center. Reservations required. Call Lorraine: 516-536-3717 or go to: www.thedavidcenter.org

Special Needs Boy Scouts Serving Autism

Special Program Division. Call Kelly: 631-924-7000 or Susan Isaacson, at 516-572-1389.

Special Needs Soccer

East End of L.I., Ages 3 - 14. Call Christine: 631-404-8813.

Friendship Connection

Activities for ages 14-18 and 18-40. Call Dr. Eliaz :516-422-4727.

Yoga

Yoga teacher and special educator experienced with students with PDD/AS/HFA. Students must be in mainstream or inclusion classes. Fall sessions and Yoga for parents. Small class sizes, boys and girls, young adults, adults. Call Terri Pakula. 516 -295-5719 or tpakula@nycboe.net

Social Skills Programs

Autism Counseling Connection: Social skills groups, parent groups, and sibling groups
Lorrie Cohen, MS. Call: 631-499-3343 or www.autismcounselingconnection.com

Christine Anselmo, E. Hampton. Call: 516-729-5564.

Jonathan Cooper, CSW, W. Hempstead/ Pt Washington. Children, adults, girls groups: 516-486-5776.

CW Post: 516-299-3211.

Staci Davis, CSW, East Meadow. Call: 516-292-1271.

Ezra Center for People With Disabilities
The Barry and Florence Friedberg JCC, Oceanside.
Mark Bernstein: 516-766-4341 x 129
or email: mbernstein@friedbergjcc.org

Family Service League
Hampton Bays, Jennifer Walsh: 631-723-2316.
East Hampton, Penny St. John: 631-324-3344.

Valerie Gaus, Ph.D., adults/groups: 631-692-9750.

Institute for Behavioral Health, Commack.
Ages 5-17. Call: 631-543-4357.

Bonnie Jan, Roslyn. Call: 516-626-2182 .

Dave Makowski, Ph.D., LIJ, New Hyde Park,
Ages 7-19. Voice mail: 718-470-3584.

Mid Island YJCC, Plainview.
Special Kids in Programs Grades K-4,
Shoshana Halbreich: 516-822-3535 ext. 346.

North Shore/LIJ Center for Autism, Bethpage
Ann Marie Werz, CSW: 516-802-8600.

SLCD (School for Language and Communication Development). Socialization program for school age children diagnosed with ADD/ADHD and/or ASD. Saturdays 9:30-2:30.
Gina LaBella: 516-609-2000.

Social Connection Center, Melville. Ages 3-12.
Catherine Maiman, M.S., Stacie Colon, M.S.:
631-696-2499 or email socialskills@optonline.net

Variety Child Learning Center, Syosset.
Willis Mawyer: 516-921-7171.

Q&A cont'd from p 8

After the initial evaluation the primary care practitioner and other physicians (e.g., pediatrician, neurologist, psychiatrist) will continue to be important sources for ongoing health care and family support. Sudden functional changes often with behavioral/emotional problems in individuals with ASD are commonly a consequence of medical factors and it is important to consider the possibility of dental pain, ear infection, new onset of seizures, G-I problems, allergies, medication effects and sleep disturbance as "cause" of the problems that are presenting.



LIBRARY NEWS

Please Return Library Items Promptly

Call Cathy: 631-331- 5114

Librarians:

Suffolk: Cathy Foy
631-331-5114

Nassau, Daytime: Martha Kovel
516-679-6957

Nassau, Evening: Joan Hourihane
516-931-8574

After a long search...
thank you and congratulations
to

Carolyn Maust

Our New Suffolk Assistant Librarian

New Materials

Congratulations It's Asperger's Syndrome! by Jen Birch.

Jarvis Clutch: Social Spy by Melvin Levine.

Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum by Ruth Elaine Joyner Hane, Kassiane Sibley, Stephen M. Shore, Roger Meyer, Phil Schwarz, Liane Holliday Willey.

Incorporating Social Goals in the Classroom: A Guide for Teachers and Parents of High Functioning Autism and Asperger Syndrome by Rebecca Moyes, Susan Moreno.

Addressing the Challenging Behavior of Children with High Functioning Autism/ Asperger Syndrome in the Classroom: A Guide for Teachers and Parents by Rebecca Moyes.

The Hidden Curriculum, by Brenda Smith Myles, Melissa Troutman, Ronda L. Schlevan.

Pathways to Play! by Glenda Fuge, Rebecca Berry.

Understanding Asperger's Syndrome: Fast Facts, by Emily Burrows and Sheila Wagner.

BOOK REVIEWS

MANNERS FOR THE REAL WORLD: BASIC SOCIAL SKILLS

by Coulter Video

reviewed by Alison Simonelli

Manners for the Real World is an informative video (to) about appropriate manners and behaviors in various social settings for upper-elementary, middle, and high-school students. Using a combination of humor and straightforward instruction, it shows teens and adults acting out situations while a narrator offers clear, concise rules pertaining to socially appropriate behaviors. This 40-minute video shows several examples of common social situations and provides clear rules for appropriate behaviors within these settings. Topics include: personal hygiene, conversations, introductions, electronic communication, table manners, and several more. Each situation is acted out using life-like role-play. In them the actors use the correct, and at times incorrect, social behaviors and manners. Natural consequences of using appropriate and inappropriate behaviors are clearly presented. At the end of each segment, a re-

cap of the rules is printed at the bottom of the screen. The video is structured in such a way that viewers can watch the entire video or only certain segments, if desired, making it ideal for teaching.

This is a must see for all students, including students with high functioning autism and Asperger Syndrome for whom social competence, including manners, are particularly challenging. This video is appropriate for pre-teens and teens "as-is"; a younger audience may need more explanation of the material covered.

This is a great teaching tool that can be used by parents and teachers. In *Manners for the Real World*, Coulter Video has created another excellent videotape that is a highly motivating instructional tool. Similar to all Coulter videos, it is a very affordable product.

THE HIDDEN CURRICULUM: PRACTICAL SOLUTIONS FOR UNDERSTANDING UNSTATED RULES IN SOCIAL SITUATIONS

by Brenda Smith Myles, Melissa L. Trautman, and Ronda L. Schelvan

reviewed by Alison Simonelli

The “hidden curriculum” refers to the set of rules or guidelines for social situations that are often not directly taught but are assumed to be known. The hidden curriculum contains items that impact social interactions, school performance, and safety, as well as idioms, metaphor, and slang. These are things most people “just pick up” or learn through observation or through subtle cues, including body language. However, many children, including those with Asperger Syndrome and autism, need explicit instructions about what is appropriate in various social situations. This is where this great reference guide comes in, based on the extensive knowledge and experience of the authors. The authors offer numerous examples of hidden curriculum items covering most aspects of human interaction, such as bathroom rules, birthday parties, clothing, eating, and many more.



As educators and parents, we sometimes forget to teach our children about the items of the hidden curriculum. Yet, lack of knowledge and understanding in this area can have a profound and often negative impact on our children when they are attempting to make friends or otherwise interact with others. This book can help prevent potentially embarrassing moments and more serious consequences, and is a great reminder of all of the things that we assume our kids will “just learn on their own.”

The book is easy to read and provides specific examples and appropriate solutions to an endless list of social situations. The section on idioms and figurative speech is a quick and straightforward guide to phrases that we use all the time. This is a great guide



ASK AND TELL: SELF-ADVOCACY AND DISCLOSURE FOR PEOPLE ON THE AUTISM SPECTRUM

by Stephen Shore

reviewed by Ronda Schelvan, M.S.Ed.

In a world where people are often misunderstood and discriminated against, knowing when, how and with whom to share a diagnosis of autism or Asperger Syndrome is an important key to self-determination. For the multitudes of people with autism spectrum disorder (ASD), this is a long-awaited book. Editor Stephen Shore, has done an amazing job of compiling six separate accounts of various aspects of self-advocacy. The author of each chapter shares a personal perspective and aspect of disclosure. The chapters give an honest, straight forward account of the significance of being self-confidante, knowing what is important to share and how to share it, plus ways to become a strong self-advocate. For example, Shore's chapter on “Using the IEP” provides effective information



on skills that all educators should encourage their students to develop. This book is unique in that it says that advocacy and disclosure should begin at a young age.

According to Kassiane Sibley, author of a chapter, “Ideally, advocacy teaching starts as soon as a family knows a child is on the spectrum” (p. 59). Easy-to-implement strategies to meet this goal are offered for individuals across the lifespan.

Ask and Tell is perhaps the best book on ASD published in 2004. It is written in an easy-to-read format which flows from topic to topic in a clear, concise manner. Also included are visual examples of work-

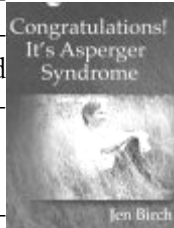
Cont'd on p 12

CONGRATULATIONS IT'S ASPERGER'S SYNDROME!

by Jen Birch

reviewed by Gissette Rivera

Over the summer, I received a diagnosis of AS through a combination of research, internal retrospection, to an official one by an MD familiar with ASD. In my mental travels I've come across some useful support systems such as friends and group support with others familiar and/or on the spectrum. If I could pinpoint any other useful support system aside from medical research and supportive friends I would say the books on personal experiences with AS too helped a lot.



One of the books I'm referring to: *Congratulations! It's Asperger's Syndrome* written by Jen Birch was a worthwhile read. The book's author is an individual with AS. The style of writing used here is a clever metaphoric representation of an individual with autism. In each chapter she talks about bits and pieces of her life not quite coinciding together except for the fact that they are all her personal experiences and/or views as a person with autism. The book isn't written in chronological order; it is just bits and pieces uniquely put together.

Her first chapter is an introduction to where she grew up in a humble family and some of her "obsessions" such as: different plants, grasses, flowers and "creepy crawlies" as a constant fascination. She mentions a secret place on her dad's farm where she spent a lot of time. This is a positive representation of a child with ASD inspired by nature. I too can relate to this spending a lot time in the grass and woods.

The next few chapters discuss her perception of the world and a new obsession with chickens. At this point she's also experienced unfortunate trauma and is lost with no support system. From my point of

view, this is where the real downfall begins. She comes across her first set of chickens through her father's laying hens. In chapter 5 she begins to realize she is "not like the other girls." She realizes that she's not interested in the mainstream girlhood full of dolls, dress up and family play. I can relate to this. As a child, I too was never interested in typical mainstream girlhood. This also makes her feel immature compared to other girls in adolescence and teen years.

The next chapter is her first introduction into the work force. Working in the library became an inspiration to play in future chapters as well. Later on in the book she mentions a struggle with sexual identity in adulthood. I can see how this is possible due to the fact that in our teens and early adulthood we all feel like there's something missing. Especially for those of us who received a late diagnosis. This leaves room for confusion on sexual identity as well. When the truth isn't that we don't easily integrate with the opposite sex but we don't integrate with other NT's who are ignorant about us.

Through this particular reading experience, I found myself there with the author through a lack of mixing well with other girls my age at the time, experiencing trauma of deep loss and not having needful support systems. However, the outcome of her struggles takes a positive turn with trial and experience. She discovers her AS in adulthood and others familiar with it. This helped her come to terms with her strengths and accepting her weaknesses as others might view them. In my opinion, this book shows a great example of what other woman on the spectrum might go through too.

Many thanks to AFC Printing at 516 997-7045

Ask & Tell cont'd from p11

sheets, letter writing samples, and reference lists.

Ask and Tell is a "must-read" book by people on the spectrum, their families, school and community pro-

fessionals and anyone seeking a better understanding of what it means to have an Autism Spectrum Disorder. *Ask and Tell* is a "must read" which leaves the reader with a feeling of empowerment.

UNDERSTANDING ASPERGER'S SYNDROME: FAST FACTS

by Emily Burrows & Sheila Wagner
reviewed by Peter F. Gerhardt, Ed.D.

Understanding Asperger's Syndrome: Fast Facts is slim volume (only 29 pages) but what space exists is reserved for a concise diagnostic overview of Asperger Syndrome and multiple brief, yet highly practical examples of instructional strategies for use in the class-

room. Although certainly not a stand alone volume in AS education, it is easy to use, accurate and affordable and so may more directly benefit all those educators, paras, SLPs and OTs who are just now beginning to work with these complex learners.

ANNUAL SPRING CONFERENCE TOPICS

Saturday, April 16, 2005

Our annual spring conference focuses on issues concerning HFA/AS older teens, adults and their families. If you have a specific topic you would like addressed at the conference, please email your suggestions to Pat Schissel (Patschiss@aol.com) or send a note to our P.O. Box (AHA/AS/PDD, PO Box 475, Roslyn Heights, NY 11577).

Childnett.tv

Dan Marino Foundation Launches Web Channel for Autism

The Dan Marino Foundation has recently launched Child Nett.tv, the first 24-hour web channel dedicated to families living with autism and other neurological disorders.

Childnett.tv is an internet access web channel that broadcasts interactive programming 24 hours a day, seven days week via the internet. The lineup includes streaming video related to autism and other neurological disorders. The mission of Childnett.tv is to reach out globally to families, clinicians and educators, connecting them through the internet, to information related to autism and other neurological disorders.

To view the program or check out the many other informative programs on Childnett.tv go to: www.Childnett.tv, register, and view the Web TV Guide.

NEW are topics such as "Early Signs of Autism" with Dr. Lonnie Zwaigenbaum, "Making & Using Visual Supports" and much more!

Coming Soon! A Live Webcast from Andy Shih,

NAAR Medical Director. You'll be able to log-on, watch his presentation on the latest research in the autism field, and even e-mail questions. Our "How To" Video Series-from potty training to creating strategies at home, experts help families tackle important daily issues More Personal Stories New Lectures from experts in the autism field (including presentations from the recent ASA National Conference)

In addition to Dr. Zwaigenbaum, Childnett.tv currently features Dr. Isabel Rapin, of Albert Einstein College of Medicine and Dr. Wendy Stone, of Vanderbilt University. Roberto Tuchman hosts a program on the web channel, as do Temple Grandin and, of course, Dan Marino. In addition, NAAR Trustee Dr. Michael Alessandri serves as clinical advisor to Childnett.tv.

On Childnett.tv, families, clinicians and educators can witness the latest therapies and treatments, seminars, as well as personal stories—all for free.

www.naar.org/news/render_pr.asp?NewsItemID=196

AWARDS FOR STUDENTS WITH DISABILITIES

The Yes I Can Awards honor children with disabilities who have made significant achievements. Each year, 27 winners are selected for their accomplishments in academics, the arts, athletics, community service, employment, extracurricular activities, inde-

pendent living skills, technology and self-advocacy. The deadline for nominations is Dec. 20, 2004.

Go to <http://yesican.cec.sped.org/awards/index.html> for more information and nomination forms.

Some Extremely Reasonable Suggestions for “Typical” Parents, Family, and Teachers on Behalf of Kids With Asperger Syndrome

by Jennifer McIlwee Myers, Aspie-at-Large

1. PLEASE don't try to make us “normal.” We'd much rather be **functional**. It's hard to be functional when you have to spend all your time and energy focusing on making eye contact and not tapping your feet.
2. PLEASE don't overprotect, indulge, or cosset us. We already have enough social problems without additionally learning to be spoiled and self-indulgent.
3. DON'T teach us social skills according to how you wish the world was, or even how you think it is. Look carefully at what is really going on and teach us **real world rules**.
4. DON'T talk and/or act as if your life would be perfect or sooooo much easier if you had a “normal” child. We don't thrive on knowing that we are the children you didn't want.
5. DON'T make the mistake of thinking that teaching us typical behaviors and successful masking means we are “cured.” Please remember that the more typical our behavior seems, the harder we are working. What is natural, simple behavior to you is a constant intense effort for us.
6. PLEASE don't punish us with rewards or reward us with punishments. For those of us who find recess to be the most stressful part of school, any action that will keep us in from recess is one we will learn to repeat ad infinitum. Getting rewarded for good behavior with fashionable but really itchy clothing will train us to NOT behave too well!
7. If you assiduously train us to imitate and conform to other children's behavior, don't be shocked if we learn to curse, whine for popular toys, dress in ways you don't like, and eventually drink, smoke, and attempt to seek out sex as teenagers. Those “nice kids” you think so highly of do a lot of things you don't know about – or don't you remember high school?
8. Please DO give us information about autism/Asperger Syndrome early on at a level we can digest. We need to know what's going on – and we will figure out that something is “wrong” with us whether you tell us or not.
9. DON'T avoid a diagnosis or help for us because you are scared of us being labeled. Without that diagnosis and appropriate support, our teachers, family, and fellow students will give us **plenty** of labels – and we might just believe them if we hear them often enough.
10. DON'T force us to do things we can't do. A forced social situation won't teach us social skills any more than dumping us in the middle of the Pacific Ocean will teach us to swim.
11. DON'T punish us for what other kids do. The fact that other kids tease and torture us for benign “autistic” behaviors doesn't mean **we** need to change, it means **they** do. Needing to bounce or swing for the whole recess is not morally wrong; tormenting someone for having a neurological disability is.
12. DON'T attempt to use humiliation or public embarrassment to “teach us a lesson.” We get way too much of that from other people, and the only lesson learned is that we can't trust you either.
13. DO punish us (or give us “consequences,” heaven help us) when it is necessary to do so – but make the connection between cause and effect very, very clear. We often need visual aids to understand how our behavior can cause an unwanted result for us!!!!
14. DON'T cut us too much slack when our behavior is potentially dangerous to us. For example, adolescent pre-stalking behavior should result in serious consequences -- because not treating such behavior seriously when we are young can lead to problems involving law enforcement when we're older!
15. DON'T trust untrained camp counselors, “typical peers,” or youth pastors to be able to deal with Asperger Syndrome. Often their answers to our problems involve highly destructive phrases like “try harder,” “you could do it if you really wanted to,” and “snap out of it.”
16. DON'T model one thing and teach another. If you yell or hit when you're mad, we will too. If you rage at us, don't be shocked at our “autistic rages.” And DON'T lecture us about our stims while you smoke, tap your foot, pick at your manicure and down your third double-latte today.
17. DON'T require us to be wildly successful at something because your ego has been wounded by having a “flawed” child. We can't all be Temple Grandin. Remember, all honest work is noble, even if you can't brag about us to your friends.
18. DO spend time with our siblings, even if you need to arrange for respite care to do so. Schedule something special for them without us along, even if it's just lunch at a fast-food joint once a week or so.
19. DO ask for help for yourself as needed. Take advantage of respite care when you can. Get cognitive-behavioral counseling and/or medication when you are depressed. Don't try to do it all alone. Remember: it is much more important that you get a nap and a nourishing meal than that we have a tidy house.
20. Most important: please, please, please DON'T wait until we're “cured” or “recovered” to love and accept us. You could miss our whole lives that way.

The author is available for presentations in Southern California (LA and Orange County); other locations sometimes negotiable. You can contact her at:

J. M. Myers, PO Box 156, Placentia, CA 92871

jenn_the_aspie@earthlink.net

EDUCATION



FEDERAL

The Education Trust has released two new briefs explaining the accountability and public reporting provisions of **No Child Left Behind (NCLB)**. The first brief "The ABC's of AYP" explains in plain language how the law works. The second brief "Questions to Ask About NCLB" lists the information the public is entitled to under NCLB. Copies of the briefs can be found at the following site:

www2.edtrust.org/EdTrust/Press+Room/new+ayp+abc.htm

NEWS FROM VESID

Vocational and Educational Services for Individuals with Disabilities of the New York State Education Department

There are a number of new announcements on the Special Education Announcement page. www.vesid.nysed.gov/specialed/timely.htm

Help VESID Design Our Future provides the opportunity for comments, suggestions and ideas regarding special education topics such as Special Education Regulatory Reform; Consequences for Performance; Rewards and Sanctions; Adequate Yearly Progress for Students with Disabilities; and the Annual Performance Report - <http://discus.nysed.gov/cgi-bin/discus-mando/discus.cgi>

The guidebook *Test Access and Accommodations for Students with Disabilities: Tools to Guide Decision-Making* has been updated to include a new section entitled Implementation Procedures. It is available to print in either word or PDF from this web site. It will not be printed in hard copy for distribution. www.vesid.nysed.gov/specialed/publications/policy/testaccess/guide.htm

Implementing **Chapter 219 of the Laws of 2003**: In relation to publishers or manufacturers of instructional materials for college students with disabilities to also make the materials available, at a comparable price to the printed version, in alternate format. www.vesid.nysed.gov/specialed/publications/persprep/chap219.htm

Amendment to Part 279 of the Regulations of the Commissioner of Education www.vesid.nysed.gov/specialed/publications/policy/part279.htm

A new memorandum has been posted to the Special Education web site related to a legislative amendment regarding the **parent member of the Committee on Special Education (CSE)**. This will only be distributed via email and Listserv. www.vesid.nysed.gov/specialed/publications/policy/parentamend.htm

has over 300 counselors in 15 district and 10 satellite offices serving over 106,000 consumers as year and spends about \$120 million a year on support services, maintenance and transportation, and case services.

Commissioner Mills' report on the audit and corrective actions and a copy of the audit are available at www.oms.nysed.gov/press/090704release.htm

NEW YORK STATE



On July 20, 2004, the Governor signed A 1892-A (Chapter 183 of the Laws of 2004) to give all school districts the authority to extend the district's compulsory school age to the end of the school year in which the student turns age 17. The law goes into effect on July 1, 2005.

<http://assembly.state.ny.us/leg/?bn=A01892>

The report entitled *The Availability and Effectiveness of Programs for Preschool Children with Autism* which was submitted to the Board of Regents, the Governor and the NYS Legislature as required under Chapter 405 of the Laws of 1999 is now available on VESID's web site. www.vesid.nysed.gov/specialed/timely.htm or www.vesid.nysed.gov/specialed/autism/preschoolstudy.htm

RESULTS OF VESID AUDIT

State Education Commissioner Richard Mills announced the results of an audit of VESID – the Office of Vocational and Educational Services for Individuals with Disabilities. The audit found that management failed to create strong financial controls and failed to provide enough oversight and monitoring of the purchase of equipment and services.

He said a small number of individuals (3) who may have broken the law have been identified and reported to the Attorney General for prosecution.

VESID provides education to adults with disabilities and helps them obtain good, productive jobs. VESID



NOTEWORTHY EVENTS

October 8 (Friday) **PDD and Anxiety**, at Meadow Club, Pt Jeff Station. Speakers: John Pomeroy, M.D., Peter Wigg, Psy.D., Sagit Vishna, Psy.D., presented by the Mental Health Association Call: 631-226-3900.

October 13 (Wednesday) 7 - 11 PM, NS-LIJ **Center for Autism Dinner Dance**, honoring Bernard Rosof, MD, MACP, Sr. V.P. Corporate Relations & Health Affairs, North Shore-Long Island Jewish Health System for his support and commitment to the autism community. Crest Hollow Country Club, Woodbury, NY. Performance by Brit-tany Maier, Miracle Child & Autistic Musical Savant. call 516-465-2527 or www.northshorelij.com/autism

OCTOBER IS DISABILITY AWARENESS MONTH

October 13 (Wednesday) 8 PM. **How to Deal With Bullies: Lessons for the Playground and Life**, speaker: Barry E McNamara, Ed.D. and **Understanding AD/HD in Adults**, speaker: Joseph Volpe, Ph.D. at the Holiday Inn, Vets Hwy, Ronkonkoma. Presented by CHADD of Suffolk County. Free to members, suggested \$5.00 donation for non members. Teachers and students are free with I.D.

October 15th and 16th (Friday and Saturday) Annual **MAAP conference, "Living Life on the Autism/Asperger Spectrum"**, in Northbrook, Illinois (a suburb of Chicago). A chance for families to learn and gather....

October 15 (Friday) **Social Skills Training** for Children and Adolescents with Asperger Syndrome & Social-Communication Disorders: A Workshop for Parents and Professionals. Presented by Social Skills Training Project. Crowne Plaza Hotel, White Plains, New York. Call 973-313-1803 or bethsklarBaker@aol.com

October 22 (Friday) **Social Disabilities: At Home and At School** in Iselin, NJ. Speakers: Ami Klin: AS Overview and Research Update; Michelle Dunn: Social Skills Curriculum to teach tolerance to all children and Dean Mooney: Nonverbal Learning Disabilities. Call: aspennj@aol.com or 732-321-0880 www.aspennj.org

October 24 (Sunday) 5th Annual **Walk F.A.R. for NAAR at Jones Beach** State Park. Join the AHA/AS/PDD Team

October 29 & 30 (Friday - Saturday) 2004 **Applied Autism Research and Intervention Conference** in Arlington, VA. Presented by OAR (Organization for Autism Research) For more about this conference: www.researchautism.org/conf.asp or contact Nicole at: nfidler@researchautism.org or 703-351-5031.

LI Family Support **Consumer Council meeting**: November 4, 2004- 7:15PM, December 2, 2004- 7:15PM. Open to anyone interested in presenting ideas (and chairing) a quarterly meeting.

November 5 (Friday) **Effective Home and School Interventions** for the Adolescent with Asperger's Syndrome with Teresa Bolick, Ph.D., author of *Asperger Syndrome and Adolescence - Helping Preteens and Teens Get Ready for the Real World..* Presented by ASCEND in PA.

January 29, 2005 (Saturday) 11 AM- 3 PM, **Special Camp Fair** presented by Resources for Children with Special Needs, Inc., at Church of St. Paul the Apostle 405 West 59th Street, Summer Programs for Children with Disabilities, Free admission. (Entrance to Fair on Columbus Avenue near West 60th Street) Manhattan. Get a free copy of the Camp Guide 2005. Call Gary at 212-677-4650.

March 4 & 5 (Friday - Saturday) **Peter and Pam Wright, Boot Camp** sponsored by LIACSN, Inc. (The Long Island Advocates for Children with Special Needs), also known as and North Shore SEPTA. At State University of New York at Stony Brook, call: Stella Tessler at 631-444-5640.



SAVE THE DATES

AHA/AS/PDD

Family Bowling ~ More information, dates and location on p.5 and our website.

Annual Fall Educationally Based Conference 2004

Monday and Tuesday, October 25 and 26, Eastern Suffolk BOCES, Holbrook, NY

First Annual NAAR Sponsored Keynote Speaker:

Michelle Dunn, Ph.D., *What's Hot and What's NOT in The Science of Autism*

Presenters: Linda Kunce, Ph.D. *The Ideal Classroom*

Michelle Garcia Winner, M.A. S.L.P.-C.C.C. *Social Thinking Across the School and Home Day Teen Panel*

For more information: www.aha-as-pdd.org for pdf of conference brochure to download.

Email: Pat at: patschiss@aol.com or Call: Bernice at 631-269-5709.

The Shopping Benefit at Bloomingdales (Whitman Mall and Roosevelt Field)

Tuesday, October 26th, 10:00 am-10:00 pm

AHA/AS/PDD will again be a recipient charity. You can shop beforehand and save.

All proceeds from our \$10.00 ticket sales will benefit AHA/AS/PDD.

Your ticket entitles you to a 15% to 20% savings on thousands of items in the store.

Tickets can be purchased at support meetings, at **OUR** Conference, support meetings or by mail.

Send a check at \$10.00 per ticket and a #10 stamped self addressed envelope, no later than **October 15**, to:

Deanna Zenn, 160 Turkey Lane, Cold Spring Harbor, NY 11724.

Questions? E-mail Deanna at: zennfam@optonline.net or call 631-692-8281.



Annual Spring Conference 2005

Co-sponsored by AHA/AS/PDD, GRASP, The Cody Center, YAI, and Gerhardt Autism/Aspergers Consultation Services

Saturday, April 16, 2005, Roslyn High School, Roslyn, NY

Key note speaker: Liane Holliday Willey, Ed.D.

Liane Holliday Willey is an author and researcher who specializes in the fields of psycholinguistics and learning style differences. Following years of improper diagnoses, she was properly diagnosed with residual Asperger Syndrome in 1999. She is the author of *Pretending to be Normal: Living with Asperger's Syndrome* and *Asperger Syndrome in the Family: Redefining Normal* as well as the editor of *Asperger Syndrome in the Adolescent Years: Living with the Ups, the Downs and Things in Between*. Liane is the Senior Editor of the new magazine, Autism Spectrum Quarterly.

Presenters:

Valerie Gaus, Ph.D., Lynda Geller, PhD, Peter Gerhardt, Ed.D., Stephen Shore, M.A. and many more.

Young Adult Panel and Adult Panel

Annual Fall Educationally Based Conference 2005

Monday and Tuesday, October 25 and 26, 2005 Eastern Suffolk BOCES, Holbrook, NY

Presenters:

Annual NAAR Sponsored Keynote Speaker: **Ami Klin, Ph.D.**, Yale Child Study Center

Paula Kluth, Ph.D., author of "You're Going To Love This Kid" a practical guide to understanding students with autism and including them fully in the classroom. **Stephen Shore, M.A.** presenting "A toolbox of skills for preparing students to lead productive and independent lives" and our outstanding **Teen Panel**.

LEGAL ISSUES IN SPECIAL EDUCATION, MEETING THE CHALLENGE

The Long Island Advocacy Center and the Nassau Coordinating Council of Special Education PTAs held a conference on March 20, 2004 entitled *Legal Issues in Special Education, Meeting the Challenge*. Several speakers divided important issues for meetings with the Committee on Special Education. Though this conference was rich with detail, we have briefly summarized some of the topics presented. It is notable that approximately half of the attendees identified themselves as having a child on the spectrum.

summarized by Joan Hourihane and Martha Kovel

The CSE: What Parents Need to Know Most Common Mistakes that Parents Make

Presentation by Marilee Shannon, paralegal

Parents/Guardians are not adequately prepared:

- ◇ Investigate and gather information about your child from various sources, the programs, and the options prior to the meeting
- ◇ Be aware of your rights
- ◇ Educate yourself on your child's disability
- ◇ You must be advised of the purpose of the CSE meeting by written notice
- ◇ Meetings must be held at a mutually convenient time and place; if you can not meet when scheduled put it in writing so the meeting isn't held in your absence
- ◇ The notice must state who will be at the meeting
- ◇ Make sure the proper people are scheduled to be there, and if not, request in writing, for their attendance
- ◇ Prepare questions for those who will be there
- ◇ If it is a CSE meeting, all the committee members must be there. If it is a subcommittee, only some may attend to work on recommendations for the full committee
- ◇ There should be no surprises
- ◇ Prior to the meeting parents have the right to obtain school records and receive the entire information packet of what will be presented at the meeting (IEP, reports, tests, evaluations). In advance of the meeting request, in writing, copies of all the reports to be referenced and upon which decisions will be based for your child
- ◇ If you have any outside reports, forward them to the school prior to meeting
- ◇ Parents need to remember that they are full

participants in the CSE.

- ◇ If you don't agree with the district's proposal, you have a right to a district paid independent evaluation (IEE). Use this right; put the request in writing
- ◇ If you don't agree with school district, you may invoke your due process rights
- ◇ Key factor to remember: Pendency (status quo) The child remains in the current placement until disagreement has been resolved, (pending the resolution) unless parent and school agree on another arrangement

Parents Use of Ineffective Strategies

- ◇ Too informal: this is a business meeting, dress in business attire - there is no need to bring cookies
- ◇ Too agreeable: the professionals don't always know or do what's best
- ◇ Too emotional
- ◇ Too aggressive and nasty
- ◇ Too personal
- ◇ Too threatening or attacking an individual teacher
- ◇ Stick to the issues at hand, what issues are worth fighting for
- ◇ Let the documents you have presented along with those presented by the district speak for themselves
- ◇ Remember the language: the district need not provide what is best for your child; avoid using the words: *better, best, beneficial*
- ◇ The district must provide a free and appropriate education for your child; use words such as: *appropriate, adequate, requires, necessary*

Cont'd on p 20

Most Common Mistakes School Districts Make

Presentation by Lewis Wasserman, Esq.

Inadequate Notice :

- ◇ Notice of meetings must be in writing
- ◇ Notice must be meaningful
- ◇ Notice must be timely
- ◇ Notice must contain purpose of the meeting, e.g., information about proposed change of placement, changes in programs
- ◇ Notice must contain a statement of Parent/Guardian rights

Inadequate Consent

- ◇ Failure to seek parental consent
- ◇ Consent must be informed and meaningful

Inappropriate Denial of Independent Educational Evaluations

- ◇ Evaluations/tests should be appropriate to measure a child's ability, including reading, memory etc.
- ◇ Parents have the right to seek independent evaluation from outside sources that do proper evaluations
- ◇ The school district can initiate an impartial hearing to demonstrate why their evaluations are appropriate.

IEP

- ◇ Absence of goals and objectives
- ◇ Failure to provide adequate program and proper changes to IEP
- ◇ Service providers must know what they are to do, (i.e., if counseling is on the IEP, then it should contain goals/objectives for counseling)
- ◇ The IEP inadequately identifies the three types of services
 - Special Education
 - Related Services
 - Supplementary aides and services
- ◇ Evaluations are insufficient
Skills cannot always be measured in standard evaluations, for example, "ability to write" is not measured
- ◇ Defective Committees
The Committee may not contain all of the required members.

Records violations

- ◇ Not allowing parents access to their child's school records
- ◇ Records of the child may be incomplete

Poor excuses for denial of service

- ◇ Cost factor - (That's too expensive to provide") cost is not a factor for the determination of services
- ◇ Rigidity factor -
"We've never done that before"
"It's against [unwritten] policy"
"This is our program and we aren't going to change it."
- ◇ Use of scheduling conflict as the explanation for failure to provide a service.
- ◇ Procrastination.

Responses by Parents/Guardians

- ◇ Ask yourself if the program at the core is adequate and is it worth fighting to change it, or if there is something else out there that has what your child needs
- ◇ Request impartial hearings
- ◇ Contact legal counsel
- ◇ Use your due process rights
- ◇ Remember that litigation takes time and be prepared to do what is necessary to expedite the process.

Reimbursement cases

- ◇ Parents have the burden to prove that the District failed to offer a free and appropriate education
- ◇ Parents must prove that the alternative is adequate
- ◇ Equitable factors are in favor of the parents

Mr. Wasserman not only discussed errors made by school districts, he also provided some practical coping skills for parents:

Litigation

- ◇ Try to resolve differences without litigation first; settlement is not a sign of defeat
- ◇ Don't prolong the process
- ◇ Control your anger

Cont'd on p 21

Failure to Follow Up

- ◇ Write a letter of understanding as to what took place, what was agreed upon
- ◇ Monitor progress both of your child (goals, objectives, test measurements) and of the service providers
- ◇ Document all contacts/ phone conversations
- ◇ If there is disagreement, put it in writing, act on it
- ◇ Seek to invoke due process rights, but if you threaten it you must follow through.

Becoming prepared for the CSE meeting:

- ◇ Be knowledgeable about your child's disability
- ◇ Join support groups (CHADD, AHA/AS/PDD, etc.)
- ◇ Join SEPTAS to find out what's going on in your district
- ◇ Check the internet
- ◇ Acquire New York State publications
 - ◇ www.vesid.nysed.gov/specialed/publications/topiclist.htm
 - ◇ Read Parts 200 and 201 Regulations of the Commissioner (Special Ed regulations)
 - ◇ Read the Transitional Planning Guide
 - ◇ VESID has NYS IEP Guidance Document, template for IEP Goals, and Test Modification Guidelines
- ◇ In writing, ask for specific tests (according to your child's disability) to be given in anticipation of the meeting (for example, diagnostic reading evaluations to determine how the child decodes, comprehends, and achieves accuracy; tests of pragmatic language or tests to evaluate written expression)
- ◇ In writing, ask to see your child's entire file
- ◇ Ask how your child's teacher is charting progress towards IEP goals and, in writing, ask to see these charts
- ◇ Have outside evaluation done. Find out if outside evaluator is willing to participate in CSE via teleconference
- ◇ Gather info and reports from outside tutors, therapists, social workers, etc.; consider having them available for telephone conference. Ask them to be available during your meeting time for 5-10 minutes.
- ◇ If you have had outside therapists or evalua-

tors, allow them to speak with *someone* at the district, and submit their reports prior to the meeting

- ◇ Ask for the same testing evaluations from year to year to "compare apples with apples"
- ◇ Compare IEP's from year to year and compare percentile ranks from year to year - look for growth or regression
- ◇ Inquire about other programs in other schools in your district, other districts and BOCES. Question your district on why they don't provide those services and request to see their written policy
- ◇ For CSE meeting, you can request (in writing) that specific people (i.e., math teacher, PE teacher) attend the meeting
- ◇ If you want to waive the committee parent member, this should also be done in writing at least 5 days prior to CSE
- ◇ Prepare an agenda for yourself – List what you are asking for, documentation support to backup your requests, write down their responses to your requests and the reasons for their refusal.
- ◇ Keep records of writings from teachers and be prepared to present such writings if necessary, at the meeting
- ◇ Understand and know about testing accommodations and modifications before the meeting, and make sure that modifications will be "adequate and appropriate" to even the playing field for the child with an ASD
- ◇ If you want to tape record your meeting, indicate this in writing before the meeting
- ◇ Anticipate their responses ahead of time
- ◇ Offer helpful solutions
- ◇ Be overly prepared !

After the Meeting:

- ◇ Write a non-adversarial letter of understanding
- ◇ In your letter, include issues discussed, what was agreed/not agreed upon and the reasons why.
- ◇ If there is disagreement, request a copy of the district's policy that stipulates their position on the particular issue, ask for them get back to you in writing.
- ◇ Log all results and participants at the meeting
- ◇ Log all telephone calls

Cont'd on p 21

- ◇ Settle as appropriate and expeditiously as possible
- ◇ Set goals and once attained get out.
- ◇ Overlook minor offences and move along

Methodology

(i.e., specific reading methods)

Remember one approach to education is not the only approach. Tremendous deference is given to the schools' approach. But what can be disputed is the appropriateness of the district's program—whether the essential components of reading are being addressed/taught to your child. Parents will lose in methodology disputes.

Pendency

If a new IEP is proposed and the parent is not in agreement and initiates due process by requesting an impartial hearing, pending the results of the process, services will remain intact. The child continues to receive existing services.

Effecting Due Process Rights

Notice needs to be served on the District clerk, Board of Education.

Marilee Shannon, cont'd from p 20

- ◇ Scrutinize the IEP (goals, measurements, evaluation criteria, teacher charting/interpretations, etc.)
- ◇ If considering exercising your due process rights, consult with an attorney who understands special education issues

Mozart, cont'd from p 6

Ron Bass, co-wrote "Rain Man."

That is the real story about "that movie" you have probably heard about. I don't know when it will be in a theater. I would love to know. I feel good about having contributed to it and would feel that way even if I hadn't been paid six figures for my rights. For me, it is a special kind of closure to how I first entered the world of autism. "Rain Man" led to seek out the truth about my own past. It led me to ASA, a support group and eventually, a life with Mary. I hope that some lucky person will see "Mozart and The Whale" and experience such a change in his fortunes.

MAY 2004 DRUG SAFETY LABELING CHANGES POSTED

Safety-related drug labeling changes for May 2004 have been posted on the FDA MedWatch website.

The May 2004 posting includes 65 drug products with safety labeling changes to the CONTRAINDICATIONS, BOXED WARNING, WARNINGS, PRECAUTIONS, or ADVERSE REACTIONS sections.

The Summary page (www.fda.gov/medwatch/SAFETY/2004/may04_quickview.htm) provides drug names and a listing of the sections changed.

2004 SAFETY ALERT: RISPERDAL (Risperdol)

Janssen Pharmaceutica, Inc. has notified health care providers of important labeling changes regarding Risperdal® (risperidone). The FDA has asked all manufacturers of atypical antipsychotic medications, including Risperdal, to add a Warnings statement describing the increased risk of hyperglycemia and diabetes in patients taking these medications, including Risperdal.

More information regarding this important safety information can be found at www.fda.gov/medwatch/SAFETY/2004/risperdal.htm. Contact your health care provider should you have any questions.



DisABILITY NEWS AND VIEWS Radio Show

with Monica Moshenko

Sundays 5-6 PM, WXRL 1300 AM, sponsored by Future Horizons, Inc. and Laureate Learning Systems.

Editor's Note: WXRL is not broadcast in our area. However, previous shows can be heard on www.disabilitynewsradio.com

Audios from our adult conferences are available to borrow at our Nassau and Suffolk support meetings

EXPANDING THE COMMUNITY

by Beth Capurso-Moldashel

We in the “autism community” are a pretty tight-knit group. By “autism community” I mean any person who has been touched by autism in one of many ways: parents, doctors, teachers, relatives, neighbors, those who are touched everyday right down to those of us who know a friend whose daughter’s child has autism. We know the lingo.....IA, PT, OT, IEP, 2G3I, ABA, ASA, PDD, CAN, NAAR, etc.; we know the tears, fears, joys, hopes, successes, failures, as well as the nuances of the slightest change in behavior. We know the behaviors. We know the symptoms.

In those initial stages of learning, right after the shock, panic and fear, as we are thirsty for knowledge, we learn what being “on the spectrum” really means. This “being on the spectrum” is what we must truly understand and accept before we can actually begin to understand our loved ones with autism. The term, “on the spectrum” gives us the “rules of the game”, so to speak. Part of the uniqueness of autism and part of what is so *damn* frustrating about it is that no two individuals are alike. No two individuals manifest symptoms in the exact same way. I once read an analogy comparing people with autism to snowflakes. They all have basic unchanging characteristics which initially identify them. From this point on many parts are different from all the rest.

The rules of the game are that there are no rules, just guidelines. Anything goes. Just as you think you’ve got it down, your whole world would change again.

This basic point, concerning variability, is what makes parent networking and support essentially crucial when dealing with autism. We must compare notes in order to stay grounded. It is a system of checks and balances....a point of reference. We help each other by discussing what we have in common and what we do *not*.

Over the years, autism has been sensationalized and given a very specific identity. I’m sure many of you, upon telling someone of your child’s diagnosis, have been frustrated when your friend asks if your child has any of those “special skills like Rainman” What about the guilt that we mothers have endured for

decades, inflicted by Dr. Bettelheim and his “refrigerator mother” theory? Have we not doubted ourselves and questioned our actions at some point even while knowing just how ridiculous his claims really were?

Once, in graduate school, I encountered an *ignorant professor*. Although this may sound like an oxymoron to some, it is a very accurate description. While discussing the topic of childhood disorders in my abnormal psychology class, I was very plainly advised that as educators we would rarely encounter children with autism. “You see”, he went on, “most of these kids are in institutions, out of regular schools because these are the kids who will be sitting in a corner, spinning a top and banging their heads on the walls.” My outrage was obvious especially to those students who knew of my personal life. They waited, looked at each other and braced themselves. I was not angry or insulted. I was exasperated and disappointed. I was disappointed that a so-called professional who was disseminating information, which should be scholarly and factual, was actually “teaching” about autism in such a damaging way.

After incidents such as this, Lifetime movies about an autistic child building a house of cards and “getting better”, and one about facilitative communication, and an autistic boy “seeing dead people” with Bruce Willis, it became apparent to me that we still, as members of “the community” had a long way to go.

It seems fundamental that we must portray autism in its full spectrum. Allow interested parties who are willing to learn, to get a full and true picture of what it can really mean to the person with autism and his or her family.

Tell them that as a mainstream teacher, you may see the child with autism invade another child’s space, or you may see another child with the same diagnosis sit in a corner and play with the same object for two hours, alone.

Tell them how one child can calculate large sums of numbers in their head while another can only count

Cont’d on page 23

WEST HILLS MONTESSORI SCHOLARSHIP CAMPER REPORT

Dear Mrs. Schissel,

I just wanted to thank you again for the opportunity to attend camp at West Hills. It was a lot of fun and I had a great time. I also got to learn about me. The staff helped me to get a lot of insight.

I went out on the boat (~ 35 ft long!), got to drive it and caught my first fish. The field trips and the work tours were informative and exciting.

I began to work with the younger campers for several weeks on site with the Long Island Summer Adventure Camp. It was a great experience and I really enjoyed the orienteering (map reading, etc.) and hiking with them.

The staff at West Hills were helpful knowledgeable and caring. They encouraged me to continue working with children.

It was a great summer.

Thank you again.
Robert Stahl



Expanding Community, *cont'd from page 22*

to ten by memory while sing-singing to the same jingle.

Tell them how one wants to eat hot dogs on toasted buns for three weeks while another will eat only beige food for two years.

Tell them how some nights are peaceful and others are horrific. Some nights you pray for it to end while other nights you hope it never does.

This is truly autism. We in "the community" see both ends of the spectrum at all different times. It is our responsibility, as those with the *inside scoop*, to educate those who do not. We must do it carefully and simply yet *completely*. They are our children. We love them, teach them, protect them, and support their world. Others will do the same if they move into "the community".

COURAGE

Words and Music by Bob Blue, Amherst, MA

A small thing once happened at school
That brought up a question for me.
And somehow, it forced me to see
The price that I pay to be cool.
Diane is a girl that I know.
She's strange, like she doesn't belong
I don't mean to say that it's wrong.
And so, when we all made a plan
To have this big party at Sue's
Most kids in the school got the news.
But no one invited Diane.

The thing about Taft Junior High,
is, secrets don't last very long.
I acted like nothing was wrong
When I saw Diane start to cry.
I know you may think that I'm cruel.
It doesn't make me very proud.
I just went along with the crowd.
It's sad, but you have to at school.
You can't pick the friends you prefer.
You fit in as well as you can.
I couldn't be friends with Diane.
'Cause then they would treat me like her.

In one class at Taft Junior High.
We study what people have done
With gas chamber, bomber, and a gun
In Auschwitz, Japan and May Lai.
I don't understand all I learn.
Sometimes I just sit there and cry.
The whole world stood idly by
To watch as the innocent burned.
Like robots obeying some rule.
Atrocities done by the mob.
All innocent, doing their job.
And what was it for? Was it cool?

The world was aware of this hell,
But how many cried out in shame?
What heroes, and who was to blame?
A story that no one dared tell.
I promise to do what I can
To not let it happen again.
To care for all women and men.
I'll start by inviting Diane.

*Reprinted with permission and thanks to the Connecticut
PDD Network.*

OUR VOICES WERE HEARD!

Fiscal year 2005 Defense Appropriations
by Ann Gibbons, NAAR Board of Trustees

On July 22, Congress passed the fiscal year 2005 Defense Appropriations bill which included money for some medical research among the over \$400 billion (!) allocated for defense. The autism community was unable to have a \$10 million line item included for autism research, but at the last minute the Conference Committee included autism in the list of diseases to benefit from the \$50 million Medical Research Program. We must share the \$50 million pot with a great many other diseases, but this is the first time autism has been included in the Defense Health Account, a small victory for our lobbying efforts, but nonetheless a beginning.

For this success, thanks are due Ed Long and his associates, our friends at ACRE, Congressional Representatives Chris Smith (NJ) and Carolyn McCarthy (NY), the Honorable Peter Kyros and all those who responded to our requests to contact their own Congressional Representatives directly. It would be great if you all could take a minute to email your own thanks to the two of them and to your representative, if they participated in this effort. Below is a list of congressional signers to the Smith/McCarthy DOD autism-funding request letter from New York and New Jersey. (Those interested in the politics of au-

tism research can notice that the signers are almost all Democrats). Their email links or phone numbers can be found at:

www.house.gov/house/MemberWWW.html

We separated NY/NJ representatives from the rest of the country to make this easier for you.

1. Carolyn McCarthy - Caroline DeRosa (D-NY)
7. Maurice Hinchey - Wendy Darwell (D-NY)
27. Jerrold Nadler - David Greengrass (D-NY)
30. Steve Israel - Deb Darcy (D-NY)
34. Carolyn Maloney - Orly Isaacson (D-NY)
39. Peter King - Kerry Ann Watkins (R-NY)
56. Tim Bishop (D-NY)
57. Eliot Engel (D-NY)
63. Gary Ackerman (D-NY)
74. Joseph Crowley (D-NY)
2. Chris Smith - Nick Manetto (R-NJ)
17. Donald Payne - Kerry McKenney (D-NJ)
21. Rush Holt - Eric Gordon (D-NJ)
22. Frank Pallone - Kathy Kulkarni (D-NJ)
35. Frank LoBiondo - Dana Richter (R-NJ)
53. Rush Holt (D-NJ)
62. Bill Pascrell (D-NJ)
66. Robert Menendez (D-NJ)



THE NATIONAL AUTISM SUMMIT CONFERENCE

The Autism Summit Conference - a national conference focusing on the Federal government's role in biomedical autism research, early screening and diagnosis, and improving access to autism services, was held November 19- 20, 2003, at the Washington Convention Center in Washington, DC. The summit provided a public forum to disseminate, evaluate, and integrate the latest practice and science-based autism information among Federal, academic, and community participants. A summary of this conference is now available and may be found at: www.nimh.nih.gov/autismiacc/summitsummary.pdf. Other information about the conference, including a link to view the videocast, may be found at: www.nimh.nih.gov/autismiacc/events.cfm.

PUBLIC ACCESS TO NIH RESEARCH

The National Institutes of Health (NIH) has posted a notice on its website to seek public comments regarding NIH's plans to facilitate enhanced public access to NIH health related research information.

They encourage that all comments be directed to the following NIH website: http://grants.nih.gov/grants/guide/public_access/add.htm

Comments must be received within 60 days of publication of this notice. (September 3, 2004)

The entire notice: <http://grants2.nih.gov/grants/guide/notice-files/NOT-OD-04-064.html>

A Washington Post Story: washingtonpost.com
Monday, September 6, 2004; Page A21

AUTISM AND SLEEP

by Dr. Chic Schissel

Are sleep deprivation and other sleep disorders factors in Autism? Sleep experts suggest that children between the ages of seven and 11 years need nine hours of sleep at night to function optimally during the day, and there is some evidence that sleep-deprived children function at an improved level when their sleep patterns improve. While there is no clear evidence that autism is specifically related to sleep disorders, it is to be expected that improved sleep will benefit all children, including those with autism.

Women are especially prone to sleep problems, confronted as they are with all the problems of child rearing. Add to that the stresses of work, household responsibilities and perhaps worry about an elderly parent. Then factor in the hormonal changes that come with being female; it should come as no surprise that many women are shortchanged on sleep. Sleep difficulties afflict women much more than they do men.



And for the parent of a child with autism the problems are heightened.

Speculation abounds, but there are no clear answers. Assistance of a sleep clinic can be helpful, and there are effective medications that are not addictive. Simply stated, efforts to improve the sleep habits of the child and the parent are worthwhile and should not be overlooked.

The full text of two sleep articles can be accessed on the following websites:

www.scienceblog.com/community/article3688.html
www.drkoop.com/template.asp?ap=93&page=newsdetail&id=514541

The third article can be purchased at:

www.eparent.com/magazine/aug03_magazine.htm
→ archived articles enter "Sleep problems in children with autism"



for the huge efforts of Paul Konigstein as coordinator - Martha Kovel, Paula Beaudoin and her son Sean Beaudoin, AND Yvonne Francis and the other 'terrific members' who make Sunday bowling the success it is! The coordinators set up for all different age groups - there is plenty of room for more people - so join us for fun!

PUBLIC BELIEVES SCIENTISTS

The public usually believes anything, no matter how foolish, that a scientist tells it, according to recent research performed by Les Marsden of the J.T. Spaulding Institute. Marsden conducted a series of tests with members of the general population. The subjects believed that they were answering an opinion survey about "recent scientific discoveries." Actually, they were responding to blatantly nonsensical "facts" that Marsden had concocted.

Among Marsden's findings:

- 78% of the subjects believed that "Venus orbits around Jupiter" after being told that "there is scientific proof." Before being told about this "scientific

proof," 42% of the subjects believed this.

- 84% of the subjects believed that "reading books causes cancer" after they were told that "there is scientific proof." Before being told about this "scientific proof," only 5% of the subjects believed this.
- 63% of the subjects believed that "Apes have evolved from trees" after they were told that "there is scientific proof." Before being told about the "scientific proof," some 9% of the subjects believed this.

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<http://paul.merton.ox.ac.uk/science/gullibility.html>

THE MATT AND DEBRA CODY CENTER FOR AUTISM AND DEVELOPMENTAL DISABILITIES

631-632-3070 or www.codycenter.org

With new staffing and status as a satellite clinic of the Stony Brook University Hospital and the Department of Pediatrics, the center is now able to offer a range of new or enhanced services at the Port Jefferson Station site. These include

- primary care and pediatric consulting services through Dr. Anne Hansen, our new clinic medical director;
- more extensive psychiatric services with the appointment of Dr. Joseph Gartner, previously the director of the child psychiatric inpatient service at Stony Brook;
- an on-site genetics clinic with Dr. David Tegay;
- as well as maintaining child neurology and developmental pediatrics clinics with Dr.'s Savatic and Soares respectively.

Partially through grant support, training of fellows in child psychiatry and residents in pediatrics and family practice will be an important component of the center's efforts to educate physicians to understand and treat individuals with developmental disabilities. In the next year they will be seeking families who would be willing to allow residents to learn from them what the impact and demands are like for families coping with a family member who has a developmental disorder. The parent educational program, which has been very popular over the last couple of years, will continue. The present, but not complete, schedule is below. To keep informed about activities check the web site (www.codycenter.org) regularly or call 631-632-3070 to learn more.

The Cody Center has also created an extensive research program in collaboration with scientists from Stony Brook, and the laboratories at Brookhaven and Cold Spring Harbor. Perhaps, of most importance to the community has been a significant broadening of the clinic structure.

WORKSHOP SERIES FOR FAMILIES

Although there is no fee, a donation of \$10.00 per workshop is suggested. To register for workshops, please call the Cody Center at (631) 632-3070 at least one week before each workshop to ensure admission. Workshops will be held from 7:00 PM TO 9:00 PM at Endeavor Hall on the Stony Brook University campus. Additional information and directions to Endeavor Hall are on the Cody Center web site, www.codycenter.org.

TUESDAY, OCTOBER 5 *Early Intervention to Preschool Services: Everything You Need to Know*

Presenter: Chris McCauley, Early Childhood Direction Center

This workshop is designed to help families of young children with autism or other developmental disabilities understand the differences between Early Intervention and the Preschool Special Education system.

*No donation or fees requested

TUESDAY, OCTOBER 19 *Neuropsychological Testing for Children with Autism Spectrum Disorders: Understanding Social, Cognitive and Learning Problems*

Presenter: Katherine Delaney, Ph.D., Cody Center

This workshop will help parents understand how and when neuropsychological testing would be valuable to their child.

TUESDAY, OCTOBER 26 *From Preschool to Kindergarten: Information for Families of Children with Special Needs*

Presenter: Chris McCauley, Early Childhood Direction Center

This workshop is designed to help families understand the special education system for children from five to twenty-one, including the decision making process through the district CSE, the services available to children, and the rights and responsibilities of parents.

TUESDAY, NOVEMBER 9 *Writing Social Stories*

Presenter: Peter Wigg, Psy.D.

Social stories, a technique developed by Carol Grey, are one method for helping a person understand the unwritten aspects of the social environment. This workshop will review the research related to social stories, teach the participants how to write and utilize a social story, as well as provide additional resources. Participants are invited to bring an example of a situation where it was difficult for them to help a child understand an event/interaction/rules. Each participant will write a social story during the workshop.

TUESDAY, DECEMBER 7 *A Comprehensive Social Skills Program for Young People with ASD: It Really Does Take a Community to Raise a Child*, Presenter: Linda Schreiber, Ph.D.

THE NORTH SHORE/LIJ CENTER FOR AUTISM

516-802-8600 or www.northshorelij.com/autism

DOES YOUR CHILD HAVE AUTISM, PDD-NOS, OR ASPERGER'S SYNDROME?

DOES YOUR CHILD HAVE REPETITIVE BEHAVIORS?

- Get upset when interrupted from the usual routine
- Repeat the same activities or movements again and again
- Have intense preoccupations with certain topics or activities

If you answered "YES" to both questions, your child may be eligible to participate in research being conducted at the North Shore-LIJ Center for Autism. This multi-site study is co-sponsored by the National Institute of Child Health and Human Development (NICHD) and the National Institute of Mental Health (NIMH). The purpose of the study is to determine if treatment with the study medication is effective in improving children's functioning and decreasing their repetitive behaviors.

Participation in this study involves: A comprehensive diagnostic evaluation, cognitive assessment, frequent visits with study psychiatrists and research staff to closely monitor participants and assess change, taking study medication for 12 weeks, with the option of continuing for 16 weeks if significant improvement is noted.

All of the above is provided at no charge.

For more information contact May-Lynn Andresen, at 516-802-8603 or mandrese@nshs.edu.

BOOKLET: YOUR NEXT PATIENT HAS AUTISM

"Your Next Patient Has Autism" was developed as a collaborative effort by the Education Subcommittee of the Autism Steering Committee which was established by the Center for Autism and the North Shore LIJ Health System. The brochure can be found in its entirety on our website: www.northshorelij.com/body.cfm?id=159

The brochure will be distributed to Health System personnel who may encounter a patient with autism including: physicians, nurses, emergency dept. staff, phlebotomists, EKG and EEG technicians, nursing assistants, etc. Please help in the health systems efforts to educate the health care community by printing out your own copy and offering it to your family member's care providers, and don't forget the dentists! They encourage you to let them know what response you receive (mandrese@nshs.edu). Be sure to watch their website for other educational tools that may be useful to you as well as the professionals that serve you and your family.



2004 NEWSLETTER SURVEY RESULTS

Newsletter readers ranked the importance of various newsletter features as follows:

1. Service provider information
2. Calendar of events
3. Conference summaries
4. Legislative/government information
5. Human interest stories
6. Book reviews

The scores were all relatively close together and many respondents volunteered that they had difficulty ranking these choices or considered them all important.

Newsletter readers ranked the importance of various newsletter topics as follows:

1. School issues
2. Home and family issues
3. Medical research
4. Medication
5. Financial issues

School issues and home and family issues were similarly ranked as a number one topic. Medical research and medication had comparable scores but were clearly less of a concern than school and family issues. Financial issues were clearly the lowest ranked topic.

PEOPLE WHO MAKE A DIFFERENCE

PICNIC PALS

This month's "People Who Make a Difference" tribute is for everyone who helped make our annual picnic a great day. In honor of our long standing and hard working board member who recently passed away, our annual picnic is now called the Annual AHA/AS/PDD Abby Irwin Family Picnic. We wish to thank the following people, organizations and companies whose generosity helped make this year's picnic a success.

Lynn and Bill Levine organized and ran the whole event!

Cathy and Tom Foy took phone reservations, helped set up and helped with the cooking and serving.

Eileen Gruber for the use of her van, volunteering to come very early and stay very late to help pack and unpack all the supplies.

Kevin Gersh, President of West Hills Montessori for supplying the serving tables and grills, and for doing all the cooking.

The staff of West Hills Montessori, Kevin Gersh &

Dawn, Rob, Dan, Megan, Debra, and Maria, for bringing all the toys and keeping the kids occupied all afternoon.

Cliff Elkins who led the hike up to the highest point on Long Island.

The people from Michael Carley's adult group who helped set up, serve and clean up.

Trader Joes for donating the basket of goodies that was raffled off to help defer the costs of the picnic.

The Grenadier Corporation for supplying the large insulated drink dispensers.

All of our members and guests for attending and making the day a great success,

And last but not least, Mother Nature for supplying the absolutely terrific weather.

We hope that the 120 people who attended the picnic had a great time, and we hope that next year we will have even more families networking, socializing, and just plain having a good time



When Someone Makes a Difference

"People Who Make a Difference" is an ongoing feature in this newsletter. If someone extraordinary has touched your child in some special way, please send a short paragraph to Bernice: bernicep@optonline.net or fax: 631-269-5709

Please include:

- 1. The person's name;*
- 2. Whether the relationship is a connection with an agency or school, and if so which agency or school;*
- 3. How and what the person does or did to make a difference.*

Don't forget to sign up for the Yahoo email list for AHA/AS/PDD mailings. Go to page 30 to learn how to sign up.



FROM THE INTERNET

Archive of DisABILITY News & Views Radio show out of Buffalo, Monica Moshenko moderator.
www.Disabilitynewsradio.com

Teaching Children with ADHD - Instructional Strategies and Practices. (2003) (Guidebook)

Produced by the U.S. Office of Special Education Programs, this new guide, designed for teachers, other school staff, and families, focuses three main components for successfully educating children with ADHD: academic instructions, behavioral interventions, and classroom accommodations.

www.ed.gov/about/reports/annual/osep/index.html#adhd-res

Getting Organized and Having Good Work Habits
Managing time and effort, organizing materials and workspace, study skills, additional reading about organization and good work habits

www.allkindsofminds.org

→ Library → The Learning Base → Getting Organized and Having Good Work Habits

Special Ed Advocacy: Mistakes People Make, by Robert K. Crabtree

Several common errors which can undermine parents' ability to obtain appropriate services.

<http://familyeducation.com/article/0,1120,23-8163,00.html>

Tools to Start the year off in a professional way!!!

The IEP Letter Writer is a simple tool that helps anyone quickly write a professional letter to a school to request information, request action, or follow up from a conversation or meeting.

www.fapesolutions.com/Letters/Default.asp

New brain protein regulates sleep and anxiety Science Blog.com - USA Researchers have found how a recently discovered brain protein plays a major role regulating sleep and stress -- a discovery that can lead to a new class of ...
www.scienceblog.com/community/article3688.html

Special Ed Advocacy - **Advocating for Your Child-Getting Started**, Asking the Right Questions, Game Plan for New Parents, etc. www.wrightslaw.com

Grants for individuals - The Disabled

www.lib.msu.edu/harris23/grants/3disable.htm

Waiver Services

You can get limited waiver information at:

www.omr.state.ny.us/index.jsp

Summaries of the research into a few of the most common **treatment modalities**. Go into their web site and then click on "autism information.":

www.asatonline.org

Of interest: in New Scientist: **Einstein & Newton showed signs** of Autism (ASD).

www.newscientist.com/news/news.jsp?id=ns99993676

Wrightslaw - **How to Use a Parent IEP Attachment** by Judy Bonnell.

www.wrightslaw.com/advoc/tips/bonnell.iep.attach.pf.htm

Speech Language Development and Speech language Disorders on ASHA site.

www.asha.org/public/speech/

Items of interest and "speech language therapy materials."

www.mnsu.edu/comdis/kuster2/welcome.html

Handbook on Services to Pupils Attending Non - Public Schools from the NYS Dept. of Education.

www.emsc.nysed.gov/nonpub/HANDBOOK%20on%20Services%20to%20Pupils%20Attending%20Nonpublic%20Schools/Handbook%20page.htm

Souls: Beneath & Beyond Autism 2005 Calendar, Starfish Specialty Press.

www.starfishpress.com/products/souls-cal.html

Autism Watch, aims to provide a scientific perspective on the many aspects of autism. www.autism-watch.org

Getting Started, Advocacy 101, Tactics and Strategies, Special Education Laws, etc.

www.fetaweb.com

The National Children's Study, from a broad range of sources. www.nationalchildrensstudy.gov

GASAK (Grandparent Advocates Supporting Autistic Kids) Monthly Meetings

Nassau, Thursdays at North Shore Child & Family Guidance. Call Liz Goulding Tag: 516-484-3174.

Suffolk, Wednesdays at Cody Center Pt Jeff Station. Call Ellen Woodward 631-632-3127

October 20, Speaker Carla DeVincent, Coordinator of Research, Cody Center

AHA/AS/PDD Membership Application

Name: _____

Address: _____

_____ Zip _____

Phone No.: (_____) _____

E-Mail: _____@_____

Parent _____ Teacher _____ Other _____

Professional (Please state 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 _____

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

Other _____

I give my permission for my name and phone number to be shared with other parents who may have similar concerns.

Signature _____ **Date** _____

Yearly dues are \$20.00 Please mail this application with your check, payable to AHA/AS/PDD, to:

AHA/AS/PDD
P.O. Box 475
Roslyn Heights, NY 11577

AHA/AS/PDD is a not-for profit 501c (3) organization.
Your membership dues are tax-deductible.
We gratefully accept tax-deductible donations.

Any questions?
e-mail Pat Schissel at : patschiss@aol.com

For further information, please call:
516-484-8404
631-269-5709
631-363-6033
www.aha-as-pdd.org

AHA/AS/PDD

Yearly Dues

**All memberships run from
January to December each year.**

Our \$20 dues entitles you to:

- receive our quarterly newsletter;
- borrow books from our library at support meetings;
- receive discounts at our conferences.

AHA/AS/PDD notifies members of relevant articles, events and date changes or cancellations. If you wish to be on this list join by going to our webpage and clicking on the Yahoo groups button at the top left (www.aha-as-pdd.org). Postings are sent in blind copy to respect your privacy.

AHA Yahoo Mailing Group

On our web page: www.aha-as-pdd.org click on the Yahoo Groups button at the top left of the page (that will take you to the "Welcome to Yahoo Groups" page).

If you do not already have a Yahoo ID, create a name and password, and then follow the directions below. If you already have a Yahoo ID and password, sign in.

On the next page click on "Groups Home" (top right of page.); next page go to the "Search" window under "Join a Group". Type in AHA-AS-PDD; next page click on "Join this group" and fill in the application form.

The application form: Before you signed on to Yahoo Groups you already had an email address. By creating a Yahoo ID, Yahoo automatically gives you another email address, a Yahoo email address. At the "Alternate email address" question, enter your original email address, not the one Yahoo gives you. (Example: patschiss@aol.com, NOT @yahoo.com). Your original email address is what Yahoo considers your alternate email address and is the address the mass emails will go to.

FYI:
Previous emails can be accessed on our messages page.



DIRECTIONS



DDI (DEVELOPMENTAL DISABILITIES INSTITUTE), Smithtown

From Eastern L.I.:

LIE (Long Island Expressway/495) to Exit 55. First right at Motor Parkway; immediate right onto Old Willets Path. Cross over 454/Veterans Highway and Jericho Turnpike (approx. two miles). Old Willets Path becomes Plymouth Blvd. Left at the first stop sign onto Parnell Drive. First left onto Hollywood Drive. DDI campus is at the top of the hill.

From NYC or Nassau County:

Northern State Parkway to the end. Left at the second traffic light onto Old Willets Path. Cross over Jericho Turnpike (approx. one mile) and follow as above.

ROSLYN HIGH SCHOOL, Roslyn

From the West:

Expressway under construction. Look for exit 37 carefully after Searingtown Rd.

LIE (Long Island Expressway/495) to exit 37 (Willis Ave/Roslyn Road). Remain on the service road to the second light. Left onto Roslyn Road. First right onto Round Hill Road. First left into High School entrance.

From the East:

LIE (Long Island Expressway/495) to exit 39 (Glen Cove Road) Remain on the Service Road to the third light (Roslyn Rd). Right on Roslyn Rd. First right onto Round Hill Road. First left into High School entrance.

Northern State Parkway (either direction) to exit 29 (Roslyn Road). Right turn onto Roslyn Road, continue past LIE, First right turn onto Round Hill Road. First left into High School entrance.

THE CODY CENTER - CLINICAL DIVISION, 5 Medical Drive, Port Jefferson Station, NY 11776

LIE (Long Island Expressway/495) Take exit 64 north (Route 112)

Turn right on Nesconset Highway (route 347) Go 3/10 mile to left turn lane (see Health South on left)

Turn left onto side road, and immediately turn left into the Health South parking lot. (At the end of the Health South parking lot, go to the right to reach the other buildings). The Cody Center is building #5.

JAMES E ALLEN ELEMENTARY SCHOOL, Deer Park Road, Dix Hills, 600 Wing.

LIE (Long Island Expressway/495 - either direction) Exit 51 S. (Deer Park Road /Route 231) Proceed South on Deer Park Road for approximately 1 and 1/2 miles. As soon as you pass the Upper Room Tabernacle Church, make a left turn at the traffic light which will bring you into the parking lot of the school. Park in the front and enter the main entrance. Once inside the building go right to the Staff Lounge in the 600 wing.

Northern State: Exit 42 S. Proceed S. for approximately 2 and 1/2 miles and follow as above.

SYOSSET LANES, Robbins Lane, Syosset is located on Route 25 (Jericho Turnpike) in Syosset at Robbins Lane. Take the Long Island Expressway (Exit 41 North) or the Northern Parkway (Exit 35 North) to Route 106/107 North. At the Milleridge Inn, take the ramp to Route 25 East. The alley is 1/2 mile ahead on the right.

PORT JEFFERSON BOWL, Chereb Lane, Port Jefferson Station

LIE (Long Island Expressway/495) to exit 64 (Rte 112). Go North about 7 miles, go over Rte 347, continue for about 3/4 mile. Turn left onto Chereb Lane. (Rite Aide Shopping Center and 7-11 store on corner of Chereb and Rte112).

Northern State East turns into Rte 347. Take Rte 347 to Rte 112 North. Turn left onto Rte 112 North and follow as above.

Support Groups

Parent Support Groups and Support for Individuals on the Spectrum

Directions to all support meetings can be found inside this edition

Daytime	Evenings	
<p>Nassau County <i>Pat S. 516-484-8404</i> Roslyn High School, Roslyn Thursdays 10:00 am - 12 noon</p> <p>October 7 November 4 December 2</p>	<p>Nassau County <i>Pat S. 516-484-8404</i> Roslyn High School, Roslyn Wednesdays 7:30 - 9:30 pm</p> <p>October 6 November 10 December 1</p>	<p>Parents of Older Teens & Adult Children <i>Bernice 631-269-5709</i> James E Allen Elementary School, Dix Hills Thursdays 7:00 - 9:00 pm</p> <p>October 14 November 18 December 9</p>
<p>Suffolk County <i>Pat L. 631-363-6033</i> The Cody Center, Pt. Jeff. Sta. Wednesdays 10:00 am - 12 noon</p> <p>October 6 November 10 December 15</p>	<p>Suffolk County <i>Pat L. 631-363-6033</i> DDI, Hollywood Dr., Smithtown Wednesdays 7:30 - 9:30 pm</p> <p>October 20 November 24 December 15</p>	<p>Individuals with ASD 18 and Up <i>Michael J. Carley 646-242-4003</i> Roslyn High School, Roslyn Saturdays 4:00 - 6:00 pm</p> <p><i>New Time</i> October 2 November 13 December 11</p>

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