



www.northshorelij.com/autism

Spring/Summer 2004

We are pleased to bring you the first issue of *Focus on Autism*. We hope this newsletter will serve as a resource for parents, practitioners and school personnel who are all working to create the most productive environment for children with autism. For more information about our services or to make an appointment, please feel free to give us a call at 516-802-8600.

Center for Autism Assessment Model Offers Coordinated Response

Autism Center's Medical Director Stresses Cooperation, Integration



One of the fundamental principles of the Center for Autism is to provide a team approach to patients and their families. Joel Bregman, MD, the Center's medical director, is dedicated to seeing this mission fulfilled.



Joel Bregman, MD

Dr. Bregman's professional history makes him the right person for the job. Along with his work at the Center, he is an assistant clinical professor of child psychiatry and pediatrics at the Child Study Center at Yale University, where he continues to collaborate on clinical research. A graduate of Yale and, later, an associate professor at Emory University, Dr. Bregman helped to establish the Emory Autism Resource Center (EARC), serving as its first medical director.

During his tenure, the EARC was awarded a Certificate of Significant Achievement from the American Psychiatric Association.

In the following interview, Dr. Bregman highlights his goals for the Center for Autism.

Q: What makes the Center for Autism unique?

A: I think we are unique in several respects, including our programs and clinical services, as well as our participation in research. What makes us truly unique is our interdisciplinary team. We try to draw upon all of our knowledge and experience – we work together on assessments to

arrive at a unified diagnostic formulation and develop an integrated treatment plan. Unfortunately, this approach is quite rare these days in the treatment of autism.

We also offer school and home assessments in order to get a good sense of the children's life experience, another rather unique aspect of the Center.

Q: What are some of your goals for the Center?

A: One service that we would really like to see grow and expand is our school consultation program. The most recent addition to the Center's staff is a psychologist/board-certified behavior analyst, who will be taking a lead role in this effort. It is very difficult for children with autism to generalize – to take one behavior they have learned in a particular situation and apply it in

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Families who are dealing with an autism diagnosis know that a complex web of specialists is necessary to establish the best course of treatment and services for each child. However, all too often these specialists are not part of a coordinated team, and it becomes nearly impossible to create an integrated care plan.

At the Center for Autism, specialists work together to create individualized treatment approaches that are geared toward creating the continuity that is so important to this population. Child and adolescent psychiatry, psychology, speech and language pathology, clinical social work and, when indicated, pediatric neurology specialists all directly participate in the assessment of each child.

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CENTER FOR
AUTISM



NORTH SHORE - LONG ISLAND JEWISH HEALTH SYSTEM

Setting New Standards In Healthcare

More Than Words

A Hanen Program for Parents of Children with Autism Spectrum Disorders

Research has shown that children who present with developmental delays in speech and language resulting from a primary diagnosis of autism spectrum disorder (including the subtype of pervasive developmental disorder) benefit greatly from the introduction to therapeutic services (e.g., applied behavioral analysis, speech and language therapy, social skills training, etc.), especially at an early age.

To generalize therapy treatments and newly learned or developing communicative skills, parental involvement is necessary. Parents have proven to be the clinician's best resource for pertinent information, as primary advocates for their child's needs and excellent record keepers of their child's development and progress. For these reasons, among countless others, parents should play an active role in their child's attainment of communication goals.

The Hanen program for parents of children with autism spectrum disorders, "More Than Words," was designed to:

- Empower parents and caregivers
- Provide parents with specific strategies on how to bolster language comprehension
- Improve the expressive skills of their child (non-verbal and verbal)
- Incorporate predictability and repetition in combination with pictures and written words in their child's play and activities of daily living

The program also targets the development of appropriate play skills, and explains the purpose of non-preferred behaviors and subsequent replacement with desirable behaviors.

This program is intended for parents of children with autism who are under the age of 6 years and are experiencing difficulties with social interaction and communication.

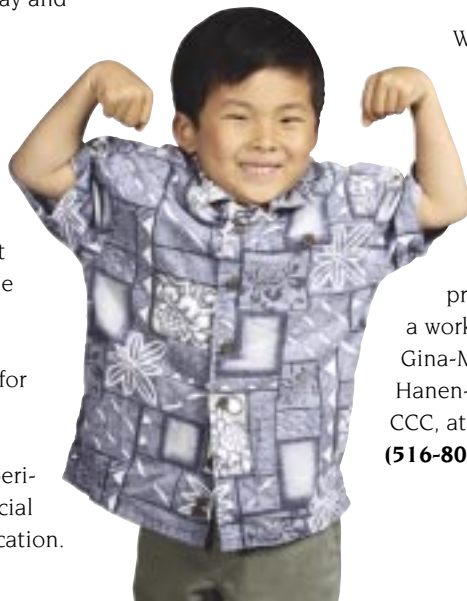
The program can be readily combined with other forms of direct therapy.

The Hanen Center requires that a Hanen-certified speech language pathologist, who has completed the necessary requirements and training programs, present and lead this 11-week program. Currently, there are four speech/language pathologists certified to present this workshop in the state of New York.

Through weekly, two-hour training sessions (includes 11 sessions), led by a certified Hanen speech language pathologist, the parent participants will:

- Learn specific strategies to help facilitate communication between themselves and their children during weekly training, through participation in activities, discussions, exercises and videotaped feedback
- Learn to create language plans or goals customized to the stage of communication their child is currently in, thereby creating language learning experiences throughout the day during daily activities such as mealtime, bedtime and playtime
- Share experiences and successful techniques with other parents in the group
- Develop long-lasting friendships with other group members, which in turn may lead to possible play-dates for their children, friendships and parties

Workshops will begin early summer 2004 at the North Shore-LIJ Center for Autism, located in Bethpage, New York. If you are interested in learning more about this program and/or attending a workshop, please call Gina-Marie Muscillo, Hanen-certified MA, SLP-CCC, at the Center for Autism (516-802-8600) to enroll.



New Resource Guide to Provide Support and Information for Parents

Since opening our doors in March 2002, we have received hundreds of calls and requests for information about services, recreational programs, camps, respite and many other types of programs for individuals with autism spectrum disorders (ASDs) across Long Island. Because of the overwhelming task of coping with the diagnosis, many parents do not know what to do first or where to look for information, help and support. Lack of a coordinated initiative to inform parents and professionals about available services and how to access them exacerbates parental and caregiving difficulties. It quickly became apparent that this concern is not unique to us, but one that is commonplace in autism.

The North Shore-LIJ Center for Autism is collaborating with The Cody Center for Autism and the Advocates for Individuals with High Functioning Autism, Asperger's Syndrome, and other Pervasive Developmental Disabilities (AHA/AS/PDD) on the development of the *Long Island Autism Resource Guide*, which will be a coordinated, inclusive resource document that offers families, physicians and providers a comprehensive guide to the services that are available across Long Island.

When complete, it will be located on each of our Web sites as well as in a printed version. We are seeking funding for its completion and are looking forward to offering this valuable resource to the autism community.

Meeting the Social Skills Training Needs of Children with Autism Spectrum Disorders

The North Shore-LIJ Center for Autism has developed a unique and comprehensive approach to social skills programming to meet the needs of children with autism. The program uses a continuum approach from intensive needs to center-based learning through community-practice approaches.

The process begins with an initial screening visit for appropriate group assignment. The youngsters are placed according to their functional, developmental and social abilities. The plan and techniques are designed to match the specific needs of each child within each group.

autism but also neurotypical students, who are learning about autism as well as becoming sensitized to people with differences through training provided by Center staff.

Our community-based social skills program is designed to ensure a person-centered approach to teaching a range of functional social skills. Each group consists of up to 10 special needs children, two group leaders (social worker, special educator) and a peer mentor. The individuals in the group meet at the Center and together choose and plan their own community program/activities that they would like to experience.

Our social skills programs are designed to ensure a person-centered approach to teaching a range of functional social skills.



Offerings include: intensive needs programming, developed for the child who may initially require some one-to-one training; dyads; center-based groups; and community programming. The long-term goal for each student is to eventually progress to a community-based learning environment, where the individual will become better equipped to function within a community setting, each according to his or her individual potential. As each child progresses, he or she is re-evaluated, as are the group dynamics, allowing the individual to move forward on the continuum at his or her individual pace.

Each group is paired with a “neurotypical peer” to teach the youngsters modeling techniques, a skill set that is needed in this population. This model has been quite beneficial to not just the youngsters with

As they plan their outings, they discuss and form strategies about the potential difficulties they may encounter. Some of the learning environments that the group has chosen include: bowling, dinners at restaurants, movies, trips to Jillian’s and Adventureland, shopping and attending local fairs. Targeted skills have included: travel training, money skills, crossing streets, conversational skills, decision-making, negotiating with peers and appropriate interaction with strangers.

We are very grateful to the David Center, which recently provided a donation to subsidize the costs of our Community Social Skills Program.

The North Shore-LIJ Health System Walks F.A.R. for NAAR

The National Alliance for Autism Research (NAAR) is a grassroots organization with a mission to fund, promote and accelerate biomedical research and science-based approaches to revealing the causes, prevention, effective treatments and, ultimately, a cure for autism spectrum disorders.

To date, NAAR has committed \$14.9 million to fund 169 biomedical research projects and fellowships worldwide. Many of these funds have been raised through their signature autism walkathons, which also spread critically needed autism awareness in communities across the country.

The Center for Autism, the systemwide Autism Steering Committee and the entire North Shore-LIJ Health System displayed tremendous support for the mission and service of this effort through leadership in the Long Island Walk F.A.R. for NAAR walkathon, held on Oct. 26.

Approximately 150 Health System employees served as Walk captains, recruiting 1,000 walkers from the Health System alone, who together raised more than \$100,000! Through the efforts of the entire Walk leadership, which included Walk Co-Chair May-Lynn Andresen and Corporate Chair Dr. Bernard Rosof, the 2003 Long Island event became the world’s largest single-day autism walk event, raising nearly \$1.2 million.



Small Miracles

A Friendship for the Future

Two 13-year-old boys joined our community skills group in search of a friend. One was not attending school at all. In fact, his mother was home-schooling him as a direct result of the severe teasing that he had endured in mainstream. The second boy was experiencing great difficulty in getting along with his peers.

Prior to joining our group, both boys were depressed and isolated from virtually all peer-related social experiences. However, after only a few short weeks in the group, these two boys connected with each other and formed a friendship! They began calling each other and making plans to “hang out” on the weekends, together practicing the skills they learned while at group. For



the first time in many, many years, they had someone other than a family member with whom to spend time.

The impact for them is clearly much broader. They have begun taking a lead and helping the other youngsters in the group with their social issues. There is nothing more joyful than seeing kids who previously had no healthy peer relationships fill the room with conversation and laughter.

A Halloween Party

Despite the rapidly growing numbers of children being diagnosed with autism, many of their parents describe themselves as feeling very alone and isolated.

During a recent support group meeting, the issue of Halloween trick-or-treating arose. As a tear rolled down her face, one parent described her feelings of isolation about spending another Halloween alone with



her child. Sadly she recounted the memories from previous years, passing other parents and children who strolled through the neighborhood, laughing together and sharing their experience in groups.

As the parents discussed the various ways of coping with loneliness, they realized they had each other. The conversation quickly escalated with excitement as they made plans to meet and trick-or-treat together. Before long, the plans grew into a fun-filled afternoon that would include sharing lunch, snacks and friendship.

There is nothing more joyful than seeing kids who previously had no healthy peer relationships fill the room with conversation and laughter.

Autism Center’s Medical Director... *continued from page 1*

another setting. That is why it is so important to work with them in their natural environment.

For these children, social interactions and relationships can be very perplexing and challenging. That is also why another one of our goals is to maintain a family- and community-based treatment approach. We can help to simplify their environment, work closely with their families to establish successful home programs, and provide them with social skills training within their community. It takes a great deal of strategic planning and training, along with a daily commitment to behavioral treatment approaches, to make a lasting impact on the lives of children with autism and their families.

Q: What are your research goals for the Center?

A: We hope to establish a clinically meaningful research program at the Center in order to better understand the causes, varied presentations and effective treatments for autism spectrum disorders. Clinical research should enhance clinical practice and clinical experience should inform clinical research. In order to promote this effort, as well as to support the research efforts of our colleagues, we have established a research sub-committee with representation from key programs across the North Shore-Long Island Jewish Health System. The breadth of expertise within the Health

System should enable us to contribute to knowledge in the field and successfully apply scientific findings in our assessment and treatment programs.



We are also very excited to be a part of The Greater New York Autism Research Center of Excellence, an NIH-funded project designed to promote clinical research and best practices within major centers across the country. We welcome the opportunity to collaborate with the Seaver Center of Mt. Sinai Medical Center and Columbia University on several research projects, including medication and genetics studies.

New York Mets to Celebrate Autism Awareness Month

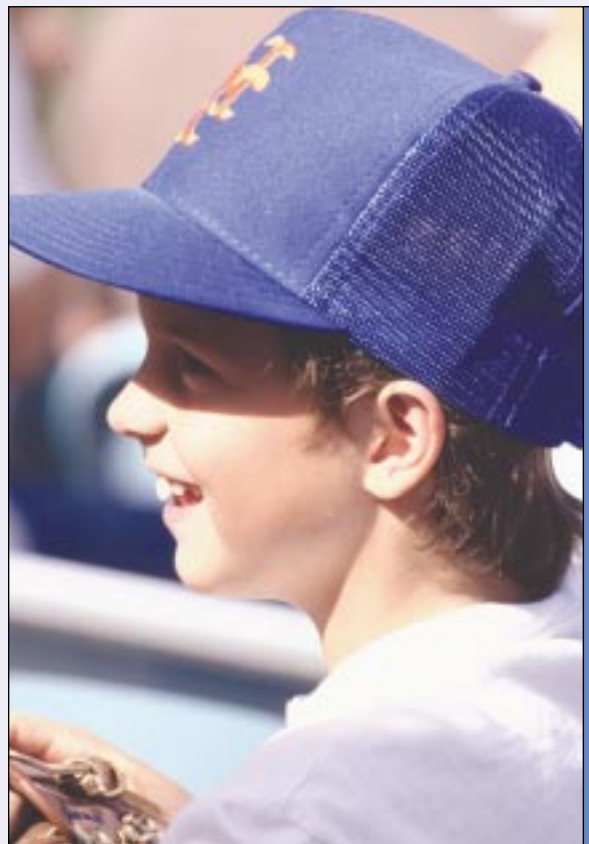
On Sunday, April 18, 2004, the New York Mets will join the National Alliance for Autism Research (NAAR) and the Center for Autism to promote National Autism Awareness Month.

Autism Awareness Day at Shea Stadium is an opportunity for families and friends to raise the public's knowledge of autism spectrum disorders. Several thousand people are expected to attend the event, which features the New York Mets vs. the Pittsburgh Pirates.

Volunteers will staff information tables at the stadium, answer questions related to autism and describe available services. As part of Kids' Opening Weekend at Shea, entertainment will be aimed at kids and families. All attendees are encouraged to wear orange to the game in support of autism awareness.

The New York Mets will donate a portion of the proceeds to the sponsoring autism organizations, including the Center for Autism.

To reserve tickets or for more information, visit www.northshorelij.com/autism or call 516-802-8600.



Defining the Boundaries of the Autism Spectrum

The Center for Autism Offers Education to the Professional Community

The Center for Autism recently hosted a groundbreaking educational conference for the professional community, which brought world-renowned experts to Long Island to assist in the clarification of important autism issues.

The conference focused on several topics, including the core impairments in autism spectrum disorders, the process of diagnostic classification and the clarification of the distinctions that exist between autism and non-autistic conditions with similar behavioral presentations.

The goal of the conference was to improve understanding of the underlying nature of autism, especially in the realm of differential diagnosis of related and co-morbid conditions, such that more informed and targeted educational and treatment programming can be achieved for our autism community here on Long Island. The distinguished speakers included representatives from Yale, McMaster University and the National Institutes of Health.

They lectured to a sold-out crowd of professionals, which included general and developmental pediatricians, primary care physicians, psychiatrists, neurologists, psychologists, nurses, speech and language pathologists, social workers, school professionals and parents.

In addition to the National Alliance for Autism Research, we are also grateful to the Pfizer Corporation for their unrestricted educational grant, which helped make this program possible for the Long Island community.



Conference participants included, from left: Alice Kau, PhD, health scientist administrator, National Institutes of Health; Lonnie Zwaigenbaum, MD, associate professor, department of pediatrics, McMaster University; Peter Szatmari, MD, professor and vice chair, research head, division of child psychiatry, department of psychiatry and behavioral neurosciences, McMaster University; Joel Bregman, MD, medical director, North Shore-LIJ Center for Autism; Rhea Paul, PhD, professor of communication disorders, Southern Connecticut State University Lecturer, Yale Child Study Center; and Bernard Rosof, MD, senior vice president, corporate relations and health affairs, North Shore-LIJ Health System. Not pictured: Kenneth Towbin, MD, chief, clinical child and adolescent psychiatry, National Institutes of Health.

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Assessment Model... continued from page 1

The team meets prior to the day of the assessment to review the child's history and plan an individualized, effective assessment strategy, including:

- Diagnostic assessment that includes specialized instruments
- Psychological or neuropsychological testing including intelligence testing, achievement testing, specific neuropsychological testing and assessment of adaptive functioning
- Speech and language assessment that includes measures of basic receptive and expressive languages, specific measures of language pragmatics and semantics and articulation testing
- Specialized assessments of related conditions such as tic and movement disorders or attention deficit hyperactivity disorder (ADHD)

- A neurological examination and/or functional analysis of behavior when indicated

Two or three members of the team are present at each evaluation, providing a common set of observations while simultaneously facilitating the consistency and cohesiveness in the diagnostic formulation and treatment recommendations.

After a feedback and treatment planning session with the parents or caregivers, a single report is generated that contains a comprehensive formulation and an extensive set of treatment recommendations.

This collaborative method of conducting an assessment has proven highly effective for the children and families that have been working with the Center for Autism.

For more information about this assessment model, please call **516-802-8600**.

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