

For Parents Of Children With Autism & Developmental Disabilities

Spectrum

UNITED June/July 2005

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MUSICAL SAVANT
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**BREAKING
DOWN
IDEA**

ISSUE #8

\$5.99US \$7.99CAN



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Under One Roof

ATN centralizes treatment and research information to aid parents and doctors

By Kimberly Acevedo

Eva Woodsmall can't remember how many hours or weeks she has spent visiting doctors with her son Andrew. Andrew was diagnosed with autism when he was 2 years old and the following year and a half was filled with doctor's appointments. At a minimum, his mom recalled, they visited one doctor each week. While Andrew ended up seeing several doctors in one month, it didn't mean that he was getting the best care and the most understanding.

"I think that there is definitely a case that pediatricians are not equipped with the knowledge and handling of autism and I think we see that across the board in general," says Woodsmall, who lives in Los Angeles. "A lot of

doctors have says to me that they never studied autism in medical school. It's really rather remarkable that there is no standard of care."

Woodsmall realized she was facing a problem after she visited general pediatricians and was often referred to a neurologist. While Andrew, now 5 years old, doesn't have any major health issues, Woodsmall says, any parent would want to make sure their child is healthy and pain free. But finding proper health care from a doctor who understands autism is difficult.

"It's a huge stress on him and the family," she says. "When you have a child with autism waiting in the office for two to three hours it really is taxing on a family.

Autistic children are in a world that is really unprepared for them.”

Woodsmall isn't the only one who has recognized that there is a need for greater medical attention within the autism community. Dr. Margaret Bauman, who is a pediatric neurologist and learning specialist at Massachusetts General Hospital, had one west coast parent called saying her child was exerting 133 aggressions everyday and suffering from sleeplessness. Bauman believe the aggressions were a sign that something was terribly wrong. She immediately recommended that the child be taken to a gastroenterologist. After a series of tests, the child was diagnosed and treated for esophagitis. Now, the child's aggressions have been reduced to one aggression for every three days. Dr. Bauman, along with health care practitioners from six medical centers across the United States, saw a desperate need to improve the quality and effectiveness of the medical treatment that the autistic population had been receiving. The Autism Treatment Network (ATN), a national non-profit organization, became the long deserved answer to a problem that has been long ignored.

“These kids are non-verbal and they don't have anyway to tell us that they hurt,” Dr. Bauman says. “What they do is act out or they have behavioral issues in various forms. If you identify, within the health care system, what the problem is and you treat that then guess what? Their behavior improves or goes away.”

While there is no cure for autism, the ATN has been established to evaluate medical conditions associated with autism, diagnose the problem and then determine the most effective method, through research, for the treatment of young people. The ATN intends to formulate a national autism database that would give physicians, parents, researchers and others who treat autism access to guidelines on the most effective method of treatment for medical issues faced within the autism community. The ATN will promote research for improving the treatment of autism. The six medical centers that are involved with the ATN are the Massachusetts General Hospital, University of Washington Autism Center, Baylor College of Medicine, The Cleveland Clinic, Oregon Health and Science University and the Columbia University Medical Center.

Several medical centers have expressed interest in joining the ATN, but, for now at least, the prospect of adding any other centers seems bleak. Since the ATN is exclusively funded by private donations, the financial constraint wouldn't allow for the additional medical centers to join.

“The only thing that is limiting us at this time is funding, and we would hope that in the future that this is a network that everyone wants to be a part of and everyone wants to contribute to and that literally every person who has autism in the United States is able to receive good quality care from someone who understands how to treat autism,” says Cure Autism Now (CAN) CEO Peter Bell, who has a child diagnosed with autism.

Currently, a center can only join the ATN if it could financially support itself, which Bauman believes, is very unlikely. Bauman operates a multi-disciplinary clinic in Boston and while they do the best that can be done, each year the clinic faces a \$250,000 deficit. It's almost impossible to close the deficit, she says. And even with the deficit, a year waiting list and an under paid staff, Bauman says she would never consider closing the clinic doors because receiving medical care by staff who understand autism is extremely important.

“We have about 4,000 patient visits a year in this clinic,” she says. “It would be very hard to turn our backs on these kids and families. I couldn't do it. Where are they going to go?”

Within the next two or three years and with ample funding, Richard Fade, one of the co-founders of the ATN, says he would like to see the ATN expand their network to about 20 centers into what he called the “NFL cities” across the country, referring to the population centers in which the National Football League licenses teams. During the researching phase, the ATN is operating on private donations. However, eventually the ATN will seek financial support from outside sources.

“We haven't gone to the federal government to ask for money directly, although the government is very aware of what's going on,” says Bauman, who sits on the ATN board. “I think part of the plan is that we would apply for a grant to support some of the research.”

While the financial constraint puts a temporary hold

“Cure Autism Now has made significant contributions in our clinical practice, database and ongoing development efforts and we look forward to working together with CAN to be our principle vehicle for outreach and fundraising. We believe the ATN is one of the best ways you can put a dollar to work for your family in the field of autism.”

- Richard Fade, Co-Founder, Autism Treatment Network

on the expansion of the ATN, that doesn't stop it from searching for prospective centers. The ATN is looking at centers that use a multi-disciplinary approach when treating autistic patients. That means, if an autistic patient is suspected of having a gastric abnormality or an irritation, that patient can either be immediately examined or referred to an expert who can evaluate the patient. The center should concentrate on the whole child rather than just treating the autism, Bauman says.

Running the ATN is going to cost an estimated \$10 million for the first three years, Fade says. That figure is only for the "core network" of 6 to 8 participating centers. Also, the ATN will hold an annual consensus conference that will share its findings with physicians in September in Chicago.

"It is our goal that physicians and institutions which participate and study this information should be able to track a great deal of the work we are doing within the ATN," Fade says.

It's no secret that autism is on the rise with every 1 in 166 children being diagnosed and the ATN saw the need to create guidelines that would ensure effective medical treatment. Before the ATN, guidelines to treat autism were unheard of and rarely thought of. Misperceptions about the disease were running rampant.

"The medical establishment has long subscribed to the notion that autism is not treatable and that just isn't true," Bell says. "We know that there are a lot of medical treatments that are available today that can significantly improve the quality of life for these kids. The reality is if you catch it early and particularly if you look at children, or people who have autism and some of the underlying medical conditions that they have, if you treat those you can really produce some significant outcomes and improvements."

Originally, the medical community believed that parents were the cause of autism. So the belief began that if you fixed the parents, you fixed the problem. Doctors eventually began considering the possibility that autism was a neurological or developmental problem. Therapies and interventions were used to treat autism.

With inconsistent treatment methods for autism and the lack of accessible information proved that guidelines desperately needed to be developed. While one doctor's method of treatment in autistic patients may be better than another, patients and doctors would never know. Without guidelines, patients would have to rely on the doctor's experience with autism or lack thereof.

The accessibility of "appropriate measurement tools to determine whether or not an individual with autism does improve with a certain treatment or therapy has been lacking," Bell says. "There are a lot of other disorders like

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- Dr. Margaret Bauman, Pediatric Neurologist,
Massachusetts General Hospital.

ADHD or Alzheimer's or schizophrenia that have fairly crude measurement tools that are currently available."

Since there are several common medical issues an autistic patient faces, the six medical centers will begin their research focusing on three problems that they feel largely affect the autism population. Among those are gastrointestinal problems and metabolic and sleep disorders.

"We tried to take the things we thought were most significant for the families and kids directly," Bauman adds. "There are certainly a myriad of multiple of issues that need to be addressed but you can't do it all at the beginning."

Gastrointestinal issues were among the first areas chosen to study along with several based on the belief that families would benefit from validating existing practices, negative and positive, Fade says.

The ATN's research will be conducted throughout the year. But, Bell noted, not every child who is brought into the center will participate in the study. Patients must meet specific criteria to be a part of the study. The ATN's research will focus on learning and understanding how to treat autistic children.

Each medical center will recruit 100 patients with ages from 6- to 12-year-olds. The patients would fill out a lengthy questionnaire including questions about gastrointestinal symptoms, behaviors and sleep disorders. The first 100 patients—regardless of race—will be subjected to a number of tests that correlate with their symptoms for a diagnosis. From this, doctors can document what percentage of patients are afflicted with what problems including

esophagitis, gastritis, ulcers or colitis. Doctors then can determine how they were treated and which method was the most effective.

Bell announced the initial developing plans for the ATN during a leadership conference. The ATN was modeled after the Cystic Fibrosis and childhood leukemia networks, both of which have had great success in developing treatment guidelines and research. Both networks have well over 100 centers across the nation. The response for the plan was overwhelmingly positive.

"A lot of people asked 'where can I go? Where can I make an appointment?' " says Bell, who is also an ATN board member. "Our ultimate goal is to have good quality effective care within driving distance of everyone."

CAN and the ATN have partnered to accelerate ATN's research. Doing so, allows the ATN to utilize CAN's research for the past ten years. CAN is one of the leading fundraisers for autism research within the United States.

"Cure Autism Now has made significant contributions in our clinical practice, database and ongoing development efforts and we look forward to working together with CAN to be our principle vehicle for outreach and fundraising," Fade says. "We believe the ATN is one of the best ways you can put a dollar to work for your family in the field of autism."

While the treatment centers are already in operation, the ATN will release practice guidelines to treat conditions related to autism as research develops.

"We have already issued an initial memo on the nature of the multidisciplinary practice we are requiring to be created at each participating center," he says. "We anticipate further detail on the common practice guidelines to be published this summer."

Bauman believes the ATN will shed some light on an area that really hasn't been addressed to its full potential. Bauman says "We've had a lot of assumptions here that probably, in many cases, were wrong and my hope is that the ATN will draw attention to some of these medical issues and I think it already has."

For Woodsmall, who is expecting a daughter, the initial beginning of the ATN gives her hope. While she's unsure if the ATN will play a role in early diagnosis, Woodsmall says she will be contacting the ATN shortly after her daughter is born to be on the cautionary side. In the meantime, keeping her son Andrew pain free and healthy is priority one.

"I think that it will give us the opportunity for our son to get the proper care and doing it under one roof is so much better," she says. "It's amazing and it's really a great opportunity. There is so much more that we haven't covered [with Andrew] and if anything comes up, then they will be able to treat it accordingly."

Gastrointestinal Disorders

By Olufemi Leverett

Gastrointestinal (GI) Disorders affect millions of people of all ages. These symptoms can cause varying degrees of results. Symptoms can cause excruciating discomfort or can be just a mere inconvenience. Some of the common GI disorders include infant regurgitation, irritable bowel syndrome, constipation and recurring abdominal pain which each affects about ten percent of the pediatric population, according to the International Foundation for Functional Gastrointestinal Disorders (IFFGD). Early interventions in children can prevent or reduce the chance of them developing GI disorders as an adult, according to IFFGD.

A metabolic disorder is a problem in the body that interferes with how food is digested in the body to keep it healthy. Because patients with metabolic disorders vary in their physical symptoms, treatment of these disorders must be individualized.

"This is a broad mission," ATN co-founder Richard Fade says. "To be successful and obviously in hopes of providing 'more value sooner' we need to focus on what we suspect to be high potential areas for treatment. There is a tremendous amount of activity in the area of GI issues and autism-diet, gut flora, inflammation and more; we have credible physicians within our organization who reference impressive outcomes in treating some of their patients with autism."

For more information
on the ATN visit
www.autismtreatmentnetwork.org
To make a donation visit
www.cureautismnow.org.