



Summer 2008

The National Pediatric MS Center at Stony Brook University Medical Center

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Promising MS Research

Multiple sclerosis (MS) is a challenging disease that requires multiple approaches from multiple investigators. Our growth in the understanding of the basic science and clinical aspects of the disease has led to better therapies and more treatment options.

Some of the many discoveries in basic scientific research, clinical treatment, and pediatric MS are reviewed below. They represent only a snapshot of ongoing research devoted to MS.

Basic Science

A new model of how the immune system directs its attack against the nervous system has been developed and it centers on a particular class of immune cells – TH 17 positive cells. In the animal model of MS, blocking these cells improves the disease course. Hopefully, identifying this fundamental abnormality in MS of the immune response against the brain and spinal cord will lead to innovative and improved MS therapy.

Last year, two new genes were identified which contribute to MS risk and code for the proteins on two different immune cells. Studies are now being done which are improving our understanding of what these proteins do and how they contribute to increased autoimmune inflammation.

Clinical Treatment

Most of the new therapies being tested aim to decrease MS relapses. Of these, one published this year found that Rituximab, a therapy which blocks B cells, reduced relapses and improved MRIs in MS. This treatment is given intravenously only two times per year, each one week apart. This finding suggests great promise for a therapy that would involve much fewer treatments per year than those currently available. Unfortunately, in a separate study, Rituximab was not helpful to patients with primary progressive MS. Aside from reducing future relapses, treatment of MS also should focus on improving the daily symptoms from the disease. A very exciting clinical trial with Fampridine-SR improved walking speed in both relapsing and progressive forms of MS. This medication has effects on potassium channels which may improve conduction of demyelinated nerves.

Attention Physicians

Dr. Lauren Krupp will be conducting several special talks on Pediatric MS for the medical community. Please join us at one of the following venues:

- 9/8/08 **Pediatric MS**
Weill Cornell Medical Center
New York City
- 9/18/08 **Hot Topics Session on Pediatric MS**
World Congress on Treatment and Research in MS
Montreal, Quebec, Canada
- 9/25/08 **Pediatric MS**
Sponsored by the Greater North Jersey Chapter
National MS Society
West Orange, NJ.

For information on any of the above programs, please contact Jo Biederman at (631) 444-8096.

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A New Beginning: Alumni Camp

MAKING THE TRANSITION TO ADULTHOOD

The transition to adulthood can be difficult for teens, but a group of Teen Adventure Camp alumni recently got a head start on the process when they met in rural Rhode Island for the first Teen Adventure Alumni Camp.

Whether they're off to college or joining the workforce, most of the teens will soon be on their own for the first time, managing their MS without their parents.

"You understand me like no one else."

Instant bonds were formed as the alumni moved in to "Tent City" for four days. The kids were eager to talk with those who had already taken their first steps to independence, as well as old friends from past camp sessions.



Figure 3: Welcome to Tent City!



Figure 2: Teen Alumni Campers enjoy an immediate bond in a Rhode Island woods.

One camper said, "It is so nice to find someone who is just like me, I've found my best friend."

The young adults enjoyed kayaking and all the usual activities, and took on new challenges like rock climbing before digging into a Rhode Island style clam bake. Evening campfires facilitated discussions about struggles and accomplishments. As one camper said, "you understand me like no one else."

The successful alumni camp session reminded us that those with pediatric MS are not alone.

This year's regular camp sessions are scheduled for July 20-25 and August 13-17. Camp sessions remain popular for the 11-18 year olds with MS. We are very grateful to the National MS Society and all the chapters who contributed funds to help to make this experience so meaningful for the kids.

MEMORIALS & HONORS

Please remember the Pediatric MS Center when you want to send a memorial or honor a loved one on a birthday or anniversary.

Simply contact Jo Biederman at (631) 444.8096 and she will notify your friends or family of your thoughtfulness along with your personal message.

Donations can be made by credit card

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Clinical Care at the Center

A COMPREHENSIVE, CARING APPROACH

The National Pediatric MS Center's comprehensive team approach to the treatment of pediatric MS is receiving positive feedback from families reaching out for help. Recently, one mom emailed us, "Your explanations, patience and warmth made our initial fears and concerns regarding MS much less intense. We came back home with a completely different perspective although we still recognize the seriousness of our daughter's condition. We now have a plan to follow as well as hope and determination."

Our team now includes pediatric and adult neurologists specializing in MS, neuro-ophthalmology, child psychiatry, neuropsychology, neuroradiology, physical and occupational therapy, anthropology and nursing.

"We now have a plan to follow as well as hope and determination."

To make the young patient's first visit worthwhile and productive, we begin gathering information even before he or she arrives. We look at health records and test results; speak with the referring physician, and talk with a family member, too.

A team evaluation usually takes two days and includes investigation, information and a caring approach to the



Figure 4: (L to R) Dr. Mirjana Savatic, Jo Biederman, Regina Troxell, Dr. Lauren Krupp, Dawn Madigan, Elayne Feld and Maria Milazzo, NP

development of a treatment plan. It's just the start of our relationship with the patient, the family and the local physician.

Nurse Practitioner Maria Milazzo coordinates this important relationship. She provides nursing care, support and a wealth of information including local organizations that can help, such as the National Multiple Sclerosis Society.

For further information or answers to your questions, call Maria at 631-444-7802.

3rd Annual Summer Soiree Set for August 7

2008 EVENT TO HONOR DR. NORMAN CHERNIK AND ANNE DUNNE

A delightful evening of dining and dancing is planned for this year's Summer Soiree on August 7 at Crest Hollow Country Club in Woodbury.

Guests will enjoy The Jumpers Orchestra and their outstanding horns at this must-attend event, which raises funds to help the National Pediatric MS Center's research program.

At this year's event, we will proudly honor Dr. Norman Chernik and Anne Dunne of South Shore Neurologic Associates for their years of service to people with MS.

"This research has the potential to make a huge difference in the lives of all individuals with MS," said Dr. Lauren Krupp, Director of the Pediatric MS Center. She is con-

vinced this research will help to uncover the mysteries of multiple sclerosis.

The festivities start at 6:45 pm. To reserve your tickets or to purchase a table, please call Jo Biederman at (631) 444-8096, or e-mail her at johanna.biederman@stonybrook.edu.
See you at the Soiree!



Promising MS Research *continued from page 1*

Of the 240 individuals studied with the drug (the MS Comprehensive Care Center at Stony Brook was a participating site) 49% actively treated vs. 9% of controls improved walking speed. The treatment was also associated with improved strength. This represents a major step forward in the symptomatic management of MS.

Another promising drug is naltrexone. It provided symptomatic improvement for individuals with MS by improving measures of quality of life. The treatment appears to increase circulating endorphin levels. More research is needed to confirm its benefit and mechanism of action.

Pediatric MS

To date, the National Pediatric MS Center has evaluated 235 children. We have participated in a network of six pediatric MS Centers funded by the National MS Society. As of May 2008, 600 children/teens have been evaluated through the network—and the number continues to grow.

Recently, there has been an explosion of research devoted to pediatric MS. Over 16 studies from the United States, Canada, Italy, Turkey and Argentina described the ethnic, neuroradiological, cognitive and other clinical features of children with MS from around the world. An Italian study confirmed our Center's experience that many children with MS suffer mild to more pronounced chal-

lenges with cognitive functioning. Our Center presented information on a set of potential biomarkers in the blood of children with MS that might be able to speed up diagnosis.

Taken together, since our last update there has been a steady increase in basic and applied scientific knowledge which is a positive sign that we our expanding our ability to help children and adults with MS. Halting the disease process remains the goal.

CHECK OUT OUR WEBSITE
www.pediatricmscenter.org

WE APPRECIATE YOUR RESPONSE TO EACH ISSUE. YOUR COMMENTS AND KIND WORDS HELP US IMPROVE.

thank you

About the National Pediatric MS Center

*The National Pediatric MS Center is a unique multidisciplinary clinical and research program located within Stony Brook University Medical Center, one of the world's leading research institutions. The Center was the first of its kind in the United States exclusively committed to the care of children and adolescents with MS. It is a designated **Center of Excellence** by the National Multiple Sclerosis Society.*

Our mission: *We are committed to improving the lives of children with multiple sclerosis and advancing a research program that will benefit all individuals with MS.*

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For more info, contact Jo Biederman at
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FOR YOUR GENEROSITY.**