



Holiday Greetings!

At this special time of year more than ever, our thoughts turn gratefully to those who have made our progress possible.

We thank you and wish you a joyous holiday season and a new year of peace and happiness.

National Pediatric MS Center Staff

We need your email address!
The Center is collecting email addresses to enhance our communication capabilities.

Please forward your email address to:
johanna.biederman@stonybrook.edu



Progress Report: News in Research

The landscape of MS therapies and approaches to care is rapidly changing. An emphasis on symptomatic relief, as well as controlling disease progression are two major growths in MS research.

Improved insights in MS pathogenesis are leading to new hypotheses and scientific studies.

The European Committee of Research In Multiple Sclerosis meeting in September was attended by thousands of physicians and scientists devoted to the understanding and care of MS. Many of the presentations involved novel research developments and advances in MS therapy. Here are some of the meeting's highlights:



Dr. Lauren Krupp

Update on therapy

A new oral medication called **Fampridine**, which is designed to improve walking and strength, is a novel approach to the management of MS and has been recommended for approval to the Food and Drug Administration (FDA). Fampridine is designed to improve nerve conduction by blocking potassium channels on the membrane of myelinated axons. In doing so, the electrical impulses can travel more efficiently to their targets. In two different studies, approximately one third of individuals taking the medication had a consistent improvement on 3 of 4 tests of walking speed. This "responder" group also had improved strength and felt better overall. Responders included people who had more advanced MS, but were still able to ambulate, albeit in some cases with assistance. It is estimated that this medication will become available in early 2010.

More options are now available to treat individuals with their first attack of MS. The PreCise study, comparing Copaxone versus placebo for individuals with their first MS attack, showed that for the Copaxone-treated group, the risk of developing clinically definite MS (i.e. having the second MS defining attack) was reduced by 45% compared to placebo, and the time to having a second attack was delayed by 386 days more than in the placebo group.

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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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Research *continued from page 1*

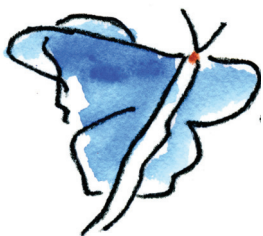
In a post-study analysis based on all patients who completed two years of the study without developing MS, there was a significant reduction in new "T2" lesions (43% during the first year and 52% over the entire two years) in those who took Copaxone versus those who took placebo.

Based on these results, the FDA has now added Copaxone to Avonex and Betaseron as medications approved for individuals with Clinically Isolated Syndrome (the first MS attack).

Positive data continues to accumulate on new oral therapies. The medications fingolimod and cladribine have beneficial effects on relapse rate and MRI burden. More information is leading to a better understanding of their safety.

Other new findings may point to novel pathogenic mechanisms in MS. In a recent study examining the blood outflow from major veins draining from the brain to the heart, clinical researchers detected abnormalities of vein drainage. The investigators found significant evidence of slowed and obstructed drainage in the veins draining the brain in many of those with MS. The investigators called this venous obstruction "chronic cerebrospinal venous insufficiency." They speculate that the reverse flow of blood into the brain might set off the inflammation and immune-mediated damage that has been well described in MS. If confirmed, these findings may open up new research avenues into the underlying pathology of MS. Many questions remain about how and when this phenomenon might play a role in nervous system damage seen in MS, and at the present time there is insufficient evidence to suggest this phenomenon is the cause of MS.

Summer Soiree Exceeds Goal and Raises \$190,000



What a night to remember! Gaily dressed revelers in "denim chic" filled the ballroom at the

Crest Hollow Country Club once again and helped raise funds to sup-



port the Center's research efforts and Teen Adventure Camp.

Feet were stompin' and dancers were swinging to the fabulous music of Big Shot, a Billy Joel tribute band that was the hit of the evening.

But it was the night's honorees, **Cynthia and George Marks**, who put it in proper perspective by reminding us all of the special reason to support this event:

"Children get MS too, and we need to do all we can to help," Cynthia said as she accepted the Philanthropist Award from Dr. Lauren Krupp.



Above: Hospital President Dr. Steven Strongwater (in back) stops to chat with honoree, Cynthia Marks (seated center) and Merry Slone & guests at the Soiree

Left: The fabulous Summer Soiree Committee

Updates in Pediatric MS Research

Many research studies focused on children with MS are underway. Children, in general, have a greater relapse rate early in their disease course. As part of a network of six Pediatric MS Centers of Excellence, we found that most of the disease modifying therapies in adults can be used in children.

However, about one-third of patients continue to have relapses despite treatment and go on to second-line therapies including Tysabri.

We have been part of another study that found that the youngest children (under 12) show marked differences in their clinical presentation on MRI and CSF findings relative to teenagers. Whether this younger group will provide the most information regarding the causes of MS remains a distinct research goal for our Pediatric MS Center and others.

As part of the network of Pediatric MS Centers, we are currently seeking NIH funding to better understand the environmental and genetic interactions that lead to MS, including certain HLA genetic markers and Vitamin D levels, an environmental factor which is increasing in importance

Since our last newsletter, two papers from our group have been published on the children we have evaluated and another paper has just been accepted for publication. One of our collaborators, a group to which we send blood samples from the children, has identified an antibody in the blood of children directed against one of the components of myelin, myelin oligodendrocyte glycoprotein. This antibody is specific to this protein and binds to brain glial cells which include oligodendrocytes, the cells that make myelin within the central nervous system. Remarkably, this antibody was most often present in the very youngest children with MS (those less than 10 years of age).

This finding might explain in part why the youngest children with MS have clinical presentations that differ most from adults. Identifying antibody proteins which could be integral to the pathogenesis of the disease is one step towards identifying interventions which could halt MS.

Almost all of the children we have evaluated for MS have continued to participate in our research studies and donate blood for various studies. It is the courage of both these children and their parents which underlies all our efforts to change for the better the course of all individuals with MS. **We thank them and all the friends for support in the crusade against MS.**

FAQ

Pediatric MS

What are the types of MS in children?

Virtually all children start with a relapsing-remitting course, characterized by clearly defined attacks (relapses) of symptoms that subside (remit) on their own or with treatment. During the periods of remission, there are no new symptoms or progression of the disease. Other forms of MS are rarely seen in children.

Is MS in children different than MS in adults? How?

The symptoms of MS are similar in both children and adults. However, some young persons with MS have symptoms which adults rarely experience. In a rare number of cases, these symptoms may include irritability and altered mental status. It is not yet known what the impact of the disease is on the developing central nervous system of a young person with MS. The early onset of MS may have an impact on learning ability. Children with MS may experience difficulty with school performance, particularly with respect to concentration and short-term memory.

Taken in part from *KIDS GET MS TOO: Questions and Answers* – a publication of the MS Society of Canada and the National MS Society.

Have a question? Please submit to: johanna.biederman@stonybrook.edu

new ways to
GIVE

Make your donations to the NPMS Center **online via credit card**, by simply going to Stonybrook.edu/pediatricmsgiving

We also offer memorial and honor donation envelopes; for extras contact **631-444-8096** or johanna.biederman@stonybrook.edu

New Model for Camp MORE INTERNATIONAL CAMPERS JOIN THE FUN

Our sixth year of summer camp brought a new model, with two overlapping sessions.

Forty campers quickly got caught up in the excitement of the Teen Adventure Program. First time campers settled in and by the time returning campers arrived two days later, camp was running at full swing.



This year's camp also included four Peer Mentors, camp alumni who

are now in college and bring life experience to the group.

This year's campers included teens from Jordan and Panama, as well as a group from California, and our alumnus from Alaska. Staff included the team from the National Pediatric MS Center at Stony Brook University, a staff member from the LI chapter of the NMSS, as well as a number of volunteers.

Access-to-Adventure once again organized the activities for the camp, including the high ropes course, kayaking, and a day sailing in Newport Harbor.

To close the session, Campers showed off their music, dance and artwork skills in an innovative performance of "Where the Wild Things Are".



The Campers are planning a mid-winter reunion. For more information, contact Maria Milazzo at Maria.milazzo@stonybrook.edu.



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