Pediatric MS

December 2007
The National Pediatric MS Center at Stony Brook University Medical Center

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Advancing Research

Welcome to our Winter newsletter. Since our last edition there have been exciting advances in understanding the pathogenesis of MS and further development of new experimental therapies. The applications of current approved therapies have also been expanded.

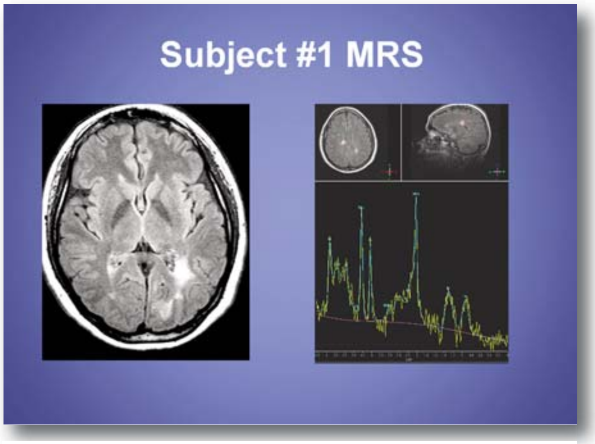

Figure 1: *Visualization of a marker of stem cells within lesions*

Recent advances in the understanding of MS include the discovery of two new genes involved in MS risk: genes coding for the IL2 receptor and IL7 receptor. These genes both encode proteins involved in the regulation of the immune response and further establish the immune mechanisms underlying the cause of MS.

New immune cells have also been identified which appear to play an early role in the development of MS lesions; these are cells which produce the cytokine IL-17. MS is usually considered a disease of the white matter of the brain. However, specialized neuroimaging studies are increasingly demonstrated involvement of the grey matter of the brain.

At the European Committee For Treatment and Research in Multiple Sclerosis (ECTRIMS) meeting in Prague last fall, new information was presented on treatments including the efficacy of plasmapheresis in individuals with severe relapses, and the relative safety of high dose oral prednisione compared to intravenous solumedrol.

Further studies showed the relative safety and efficacy of experimental oral therapies including fingolimod and fumarate. In both, phase II studies have shown benefits with relapses. At Stony Brook, these two agents are being tested in patients with relapsing remitting MS. A variety of studies showed benefits with the monoclonal antibody rituximab for the MS variant – neuromyelitis optica and for relapsing remitting MS. This medication is also being tested in individuals with primary progressive MS, and results should be available in late spring.

The National Pediatric MS Center has also been at the forefront of a variety of new discoveries in MS. We participated in two publications which came out late in 2007 showing that children with MS are more likely to show exposure to EBV virus compared to children without MS.

At the American Neurological Association, we presented work from our research involving visualization of a marker of stem cells within the lesions of individuals from both children and adults in MS. (Figure 1, above) Related to these findings, Dr. Savatic,

please turn to page 3

Center Clinical Update

WHERE OUR PATIENTS COME FROM

The National Pediatric MS Center continues to see a large number of children with MS from Long Island, areas throughout New York, and from different states all over the country. The last three months of 2007, families from Panama and Indonesia also came for consultations.

We are caring for an increasing number of children with MS and related disorders. While as many as one third of children who come to our Center are not on any treatment for MS, after our evaluation, 99% of children leave on one of the standard therapies. The children have done extremely well and we continue to find that the MS therapies commonly used in adults with MS are well tolerated and effective in children.

Overall, we have had a very productive year:

- Publication of an entire monograph devoted to pediatric MS, edited by Dr. Krupp and Deborah Hertz
- Three additional publications by Center staff
- Multiple educational presentations to pediatricians, pediatric neurologists, patients, and other physicians

Our goal is to educate the general public and medical community about MS in general and pediatric MS in particular.

To learn more, or to support our research please contact Jo Biederman at (631) 444-8096 or by email at johanna.biederman@stonybrook.edu

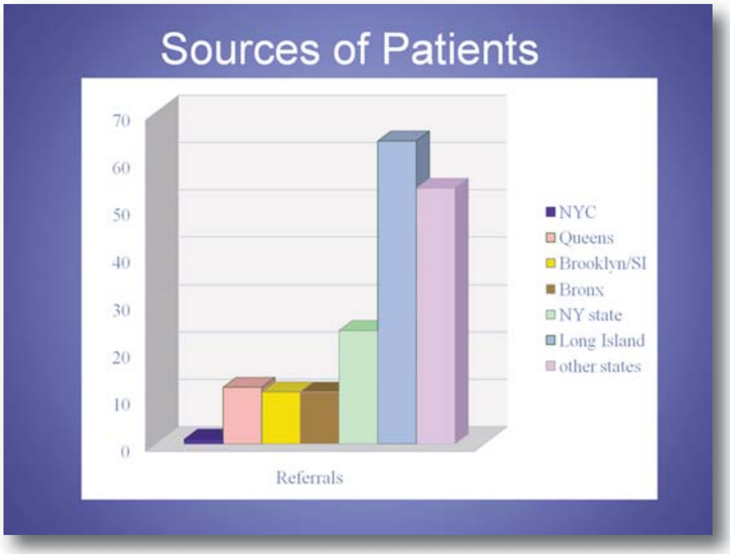

Figure 2: *Patients come to the National Pediatric MS Center from the NY Metro area, as well as other states and countries*

Figure 3: *States that have referred MS Patients to the National Pediatric MS Center*

WE ARE PLEASED TO ANNOUNCE THE LAUNCH OF OUR ALL-NEW WEBSITE:

www.pediatricmscenter.org

Please visit us often for the latest updates on Pediatric MS.

Adventure, Friendships

TEEN ADVENTURE CAMP "THE EXPERIENCE OF A LIFETIME"

At Teen Adventure Camp this summer, 39 youngsters had the experience of a lifetime, meeting new friends and greeting old ones. This interaction with other teens who live with the same disease as they do is the pivotal purpose in our partnering with Access-To-Adventure to hold summer camp sessions for teens with multiple sclerosis.

> **"EVERYONE understands me here."**

At home they may be the only person in their school or even their town who has MS, but at Camp Adventure, they feel normal.

"Everybody understands me here" says one camper who feels she is made fun of back in Texas because of the way she walks.

"Here we are not different" remarked another young man who takes pride in challenging himself on the high rope course, one of the many demanding physical exercises campers are exposed to. Camp inspires them to do what others say they cannot.

This network of support encourages teens to follow their treatment regime the support lasts all year through emails, phone calls and text messaging.

The camp is supported by the National Multiple Sclerosis Society, the Summer Soiree Fundraising Committee and other generous donors. Each year is a challenge for the Center to find sufficient funding so no camper is turned away. If you would like to help, please see the donation form in this newsletter.

MEMORIALS & HONORS

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

Simply call Jo Biederman at 631-444-8096 and she will arrange to have an acknowledgment sent.

Your donation can be made by credit card.

Advancing Research *continued from page 1*

our collaborator, published her research in the prestigious journal, *Science.* Her work received praise from around the world.

We have applied her neuroimaging and analytic methods to adults with MS, visualizing cell markers of precursors of nervous system cells (neurologic stem cells). The next phase will be to examine pediatric patients with MS and self-limited demyelinating diseases to identify what contributes to the chronic nature of MS.

At the Child Neurology Society meetings our initial observation that children with MS may show differences in the demographic profile with a greater proportion of affected minorities was supported by observations from the Pediatric MS Center in San Francisco.

Finally, Dr. Krupp participated in a widely attended educational symposium at the Child Neurology Society Meetings which taught pediatric neurologists about the importance of diagnosing and treating children with MS.

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SECOND ANNUAL SUMMER SOIREE: A HUGE SUCCESS

Above: *Dr. Krupp with Summer Soiree Honorees, Susan & Richard Fish*

Right: *Summer Soiree Committee*

Summer Chic *was the theme of the evening as honorees, Susan and Richard Fish were joined by almost 500 guests who dined and danced the evening away last summer at Carlyle on the Green in Bethpage State Park. Two teenage campers spoke to the guests about their lives with MS and how their time at camp helped them. More than $200,000 was raised to support vital medical research being conducted at the National Pediatric MS Center at Stony Brook University Medical Center.*

"Funds raised at this event will help the Pediatric MS Center advance a research program that 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 convinced this research will help to uncover the mysteries of multiple sclerosis.

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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☐ Teen adventure week

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FOR YOUR GENEROSITY.