



Pediatric MS

June 2007

The National Pediatric MS Center at Stony Brook University Medical Center

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 STONY BROOK
UNIVERSITY
MEDICAL CENTER

Experts predict a cure for MS “within 10 years”

It is with great pleasure that I can provide a summary of recent advances in adult and pediatric MS which were presented in May at the Academy of Neurology meeting in Boston. There, clinical researchers presented exciting developments in MS therapies that dramatically halt relapses and decrease MRI lesions. While the treatments have been studied in adults, once proven safe, they can be considered for children.



Dr. Lauren Krupp

Several of these therapies (rituximab, alemtuzumab, and daclizumab) are all based on the principle that certain molecules on T cells are responsible in part for MS and need to be blocked. The treatments are antibodies directed against molecules that cause T cells to be activated and cause the damage associated with the disease.

Other advances are in oral treatments such as laquinimod which is a safer version of a treatment which had been shown to decrease relapses in patients with MS. The possibility of an effective oral therapy would be a major breakthrough in the treatment of MS

There were exciting developments in pediatric MS as well. Centers which are networked with us presented findings from California and Boston. There were also important findings from pediatric MS Centers in Europe on the clinical features including effects on cognition in children. Investigators from all over the world are collaborating in pediatric MS. Recently, I was invited to represent the United States in an International Pediatric MS Group which is composed of a steering committee in which Argentina, Australia, Canada, France, Italy, the United States, and Russia are all sharing their clinical experience. This group is determined to perform collaborative research to understand what causes MS in children.

One of the leading experts involved in MS since the 1970s noted that it is realistic to assume we will have a cure for MS within the next 10 years. By cure, we mean we can halt disease progression, reverse neurological deficits, and have a preventative vaccine. With the support we have received from the National Multiple Sclerosis Society, the National Institutes of Health and pharmaceutical industry, we will continue to participate in searching for an MS cure.

Camp Program Reaches New Heights

While our Teen Adventure Weekend campers strive to reach new heights by taking on the rope climbing challenge, the program itself has reached new heights by doubling in size each year.

This year is no different. For our 4th Annual Teen Weekend Retreat, we are expanding our program to add an additional day and will again run two camp sessions. This will allow more adolescents with multiple sclerosis the opportunity to meet others facing the same problems they do, and challenge themselves beyond their wildest dreams.

New Adventures

The staff is planning new adventures as well as organizing old favorites such as the high ropes course and drumming circle. More time will be spent cooling down at the on-site lakefront, splashing



around in kayaks and canoes. A kayak harbor tour is one of the new activities planned for this year.

Facilitated discussions among the campers about topics such as life and career planning, life as a teen with MS, and healthy living strategies while away from home are also new on the agenda.

And, for the first time we will host a session for parents to meet, share, and learn from others with the same experiences.

Staff from the National Pediatric MS Center will be joined by staff from National MS Society, as well as volunteers from the local MS society chapters. Access-2-Adventure will be handling the programming.

Applications flying in

Once again, response to the camp invitations has been overwhelming, with kids from as far as Alaska and Canada sending in applications. Returning campers are eagerly planning reunions with friends and new campers have learned about the program from other kids on the on-line support group.

Be assured that as the kids are packing their bags, and anticipating fun filled days at the National Pediatric MS Center Teen Adventure Weekends, the staff is just as busy...and just as excited!

The Weekends are offered free of charge, thanks to the generosity of donors. To sponsor a kid at camp, please contact Jo Biederman at 631-444-8096.

2nd Annual Summer Soiree

Mark Your Calendar NOW!



Join us for a summer evening of fun, food and dancing at Carlyle on the Green Thursday, August 9, 2007. This fabulous event will honor Susan and Richard Fish of Port Jefferson and will feature a video presentation on Teen Adventure Weekend as well as our world-class raffles!

The event raises funds to benefit research at the National Pediatric MS Center. Tickets are \$130 per person.

For information on sponsorship or how you can help make this event a success, contact Jo Biederman at 631-444-8096 or jbiederman@stonybrook.edu.



**National
Multiple Sclerosis
Society**

The National Pediatric MS Center is supported by a generous grant from the National Multiple Sclerosis Society.

Attention Senior Readers

ARE YOU (OR DO YOU KNOW SOMEONE) OVER 70½?



If so, you have a unique opportunity to benefit both yourself and the National Pediatric Multiple Sclerosis Center.

Last August, the federal government signed into law a tax incentive for donors age 70 ½ or older to contribute IRA (individual retirement account) assets to a qualified charitable organization. This provision allows qualified donors to exclude up to \$100,000 per year of “qualified charitable distributions” from adjusted gross income, if paid directly from a regular or Roth IRA.

The provision is scheduled to expire on December 31, 2007 so don't delay! Please note that the current legislation **excludes** funding of charitable remainder trusts, charitable gift annuities or similar life income plans.

We hope you will take prompt advantage of this limited time opportunity to help the NPMS Center. To obtain additional information, please contact Jo Biederman at 631-444-8096 or jbiederman@stonybrook.edu.

Contact 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.

The National Pediatric MS Center 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 Campers, Cecilia Calderon and Lee Goncalves along with Dr. Lauren Krupp and Nurse Practitioner, Maria Milazzo recently appeared on Bonnie Graham's **Something To Talk About** show on Channel 10 Public Access PATV.*

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SPECIAL DONORS: SPECIAL THANKS



Jo Biederman gratefully accepts a \$10,000 check from Jerry DiCecco at the Bartender's Ball

Thanks to the following donors whose generosity helps our Center to provide care to every child with MS who reaches out to us, as well as helping our team of scientists continue their research to find the answers to MS.

- ◆ Jerry DiCecco of the Bartender's Ball
- ◆ Lisa and Robert Lourie
- ◆ Declan Blackmore of Summerhill Landscapes, Inc.
- ◆ Americana Manhasset Champions for Charity
- ◆ Student OT Association of Stony Brook
- ◆ Michael A. Maffetone Community Service Grant
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- ◆ Milton Luxenberg
- ◆ Maria Perna
- ◆ Gary & Corky Paston for designating our charity in honor of their 50th Wedding Anniversary

And for Teen Adventure Weekend

- ◆ National Multiple Sclerosis Society – Teen Adventure Weekend
- ◆ Mary Fuller Leykom – Teen Adventure Weekend
- ◆ Joel Simon, JSM Music – Teen Adventure Weekend

Want to put your name on the list? Fill out the form below and send it to us with your donation. Every dollar makes a difference!

YES, I WANT TO FIND A CURE FOR PEDIATRIC MS.

- I would like to make a donation of \$_____ to be used for:
- Research Clinic Teen adventure sponsorship (\$2000)



STONY BROOK UNIVERSITY MEDICAL CENTER

Name: _____ Phone: _____

Address: _____ City: _____ State: _____ Zip: _____

E-mail address: _____

Please make checks payable to **SBF-NATIONAL PEDIATRIC MS CENTER**

Please charge my \$_____ donation to (circle one) **Mastercard Visa Amex Discover**

Card Number: _____ Expiration Date: _____

Signature: _____

THANK YOU FOR YOUR GENEROSITY. PLEASE RETURN TO:

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