



# Pediatric MS

May 2006

The National Pediatric MS Center at Stony Brook University Hospital

## Mission

*We are committed to improving the lives of children and adolescents with multiple sclerosis by providing a center of excellence for comprehensive treatment and by advancing a research program that will benefit all individuals with MS.*

## Stony Brook Center Chosen as "Center of Excellence"

The National Pediatric Multiple Sclerosis Center at Stony Brook Hospital has been designated as one of six centers nationwide as a "Center of Excellence" by the National Multiple Sclerosis Society. Over the next five years, the National MS Society will invest \$13.5 million to launch and fund these centers to support targeted areas of research and patient care that hold great potential in the fight to end the devastating effects of MS.



The National Pediatric MS Center, under the direction of Dr. Lauren Krupp, was a pioneer in starting the first center to treat children and adolescents with MS in the United States. Her work was quickly recognized nationally and other centers have since followed her lead in developing specialty centers for children. Dr. Krupp has been chosen to chair the Steering Committee of these six Centers of Excellence.

*Dr. Lauren Krupp, front L, with National Pediatric Center staff members*

The centers, established in geographically diverse regions throughout the United States, will treat as many children as possible and will set the standard for comprehensive care for pediatric MS, including medical diagnosis and treatment, rehabilitation, psychosocial issues and educational components. Dr. Krupp will also lead the centers in creating a framework to conduct critical research—both to understand childhood MS and to unlock the mysteries of MS in adults.

"One of the many challenges with pediatric MS is that because the disease typically strikes adults, it may not be on the pediatrician's or even a pediatric neurologist's radar screen as a possible diagnosis when a child is experiencing MS-like symptoms," said Dr. John Richert, Vice President, Research and Clinical Programs for the National MS Society. "By establishing a network of Pediatric MS Centers of Excellence, our plan is to give the medical community the tools they need to help identify and treat MS early on. We also want to give families a range of resources that have not been available previously to help them cope with the daily impact that MS has on their lives."

To read more about the "Centers of Excellence" and their locations, log on to our website [www.pediatricmscenter.org](http://www.pediatricmscenter.org).

*Smart Medicine*

**STONY  
BROOK**  
UNIVERSITY HOSPITAL

*Expert Care*

# Everyone Needs a Friend

Being a teenager is hard enough--but for teens with MS, an additional set of challenges awaits. At the Teen Adventure Weekend, an innovative program designed specifically for teens with MS, participants build confidence, friendships, and more.

For some, it will be the first time they have ever interacted with another kid that shares a common diagnosis and life challenges. We need your help to make this experience happen for all who want to attend.



*Building confidence on the ropes*

This summer, to accommodate as many teens as possible, our Teen Adventure Weekend will be expanded to include two separate camp sessions. Word of its success and importance in helping teens cope with their illness is spreading, so requests for spots are piling up.

At the Teen Adventure Weekend, teens between the ages of 11 and 18 who have multiple sclerosis participate in recreational and team building activities designed to enhance their self confidence and help them to build lasting peer relationships.

Participants from the four corners of the continent (Alaska, California, Florida, Texas, Canada as well as the tri-state New York area), travel to Exeter, Rhode Island. There they meet up with the wonderful staff of the National Pediatric MS Center who partner with

Access2Adventure, a non-profit organization dedicated to improving the quality of life for persons with physical disabilities through sports, recreation and adventure travel. An incredible four days follow.

The response has been extremely positive. Last year, Alex's mother wrote to tell us of her son's experience at the Teen Adventure Weekend. "That camp was the best thing that happened to Alex in a long time. He says he sometimes feels like a freak and I think some kids in his school may have called him that. Being with

---

*"That camp was the best thing that happened to Alex in a long time. He says he sometimes feels like a freak and I think some kids in his school may have called him that. Being with a cool group of teenagers where having MS is the 'regular' condition was a great normalizer for him."*

---

*Next page, please*

## UPCOMING EVENTS

### SUMMER SOIREE

Join us for a summer evening of fun, eclectic dining and dancing on Thursday, July 27, 2006 at the Crest Hollow Country Club. A fabulous silent and live auction will round out the evening, all to raise funds for the National Pediatric MS Center.

For information on how you can help make this event a fabulous success, contact Jo Biederman at (631) 444-8096 or you may email her at [johanna.biederman@sunysb.edu](mailto:johanna.biederman@sunysb.edu).

Mark your calendar now!

*The National Pediatric MS Center is a unique multi-disciplinary clinical and research program located within Stony Brook University Hospital, 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.*

Newsletter concept/design by:

**SCARLET**  
communications inc.

[www.scarletcommunications.com](http://www.scarletcommunications.com)

From page 2

a cool group of teenagers where having MS is the 'regular' condition was a great normalizer for him." Alex found several friends last year at camp.

"I never realized there were other kids like me out there" is a common refrain heard throughout the weekend. Another youngster says "at home I sit around and I'm sick...here I'm well."



*Drumming around the campfire*

You can help a teen develop a sense of belonging and find a friend. It costs \$2,000 to change each kid's life. Please consider sponsoring a teen or just be as generous as you can. In return, you will receive a personal note from the participant you are sponsoring, letting you know what this experience has meant to them. Please contact Jo Biederman at (631) 444-8096 or by email at [johanna.biederman@sunysb.edu](mailto:johanna.biederman@sunysb.edu) for additional information.

## With Your Help, We Have:

- ◆ Evaluated more than 160 children and adolescents with MS
- ◆ Initiated a collaboration with Dr. Mirjana Savatic, noted pediatric neurologist, who has done extensive research identifying biomarkers in pediatric neurological diseases including visualization on MRI of stem cell activity in children with MS and related diseases
- ◆ Explored new treatments for demyelinating disorders that mimic MS
- ◆ Increased the 2006 Teen Adventure Weekend to TWO four-day sessions enabling 40 (twice as many as last year) youngsters to share this wonderful camp experience

## Contact the National Pediatric MS Center

**Phone:** (631) 444-8096  
**Web:** [www.pediatricmscenter.org](http://www.pediatricmscenter.org)  
**Mail:** Stony Brook University Hospital  
HSC T12-020  
Stony Brook, NY 11794

### Staff

Lauren Krupp, M.D., Director  
Anita Belman, M.D., Pediatric Neurologist  
William MacAllister, Ph.D., Pediatric Neuropsychologist  
Maria Milazzo, R.N. CPNP  
Dawn Madigan, B.S. R.N.  
Jo Biederman, Director of Development

### Board of Advisors

Lauren Krupp, Director  
Randall Heyler, Chairman  
Anne Dunne, M.S. R.N.  
Deborah Hertz  
Richard Press  
Mim Olsten  
Dr. John Peabody  
Lillian Pardo, M.D.  
Madeline Raylman  
Merry Slone

## Research News

These are exciting times at the National Pediatric MS Center at Stony Brook as our center continues to grow and reaffirms its commitment to a research program that will help individuals with MS! A major research endeavor for our center is to study the impact of MS on cognitive functioning in children and adolescents. We have shown that about a third of children with MS will show some cognitive changes, and unfortunately, some show further changes over time. However, armed with this knowledge we can seek out appropriate academic interventions and possibly medications that can improve memory and attention in these individuals.

More recently, we have established a collaboration with the pharmacology department within our own Stony Brook School of Medicine. Through this partnership, we plan to study the protein signatures of MS and related demyelinating diseases with a novel spectral analysis approach. It is our hope that this will eventually lead to diagnostic tests to make the diagnosis earlier, thus enabling more rapid initiation of treatment and better clinical outcomes.

Furthermore, the National MS Society's recent creation of a regional network of collaborating pediatric MS centers across the United States provides an unprecedented opportunity to help our cause. For the first time, we will be available to address the genetic causes of MS in children, an undertaking that will require large number of participants only available through a nationwide collaboration.



# CHANGE A LIFE. CHANGE THE WORLD. GIVE TODAY.

Please support the work of the National Pediatric MS Center. Complete the form below and return with your donation, or contact us at (631) 444-8096 to learn more about helping children and teens with multiple sclerosis. Thank you!

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

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_ **Phone:** \_\_\_\_\_

**City:** \_\_\_\_\_ **State:** \_\_\_\_\_ **Zip:** \_\_\_\_\_

**E-mail address:** \_\_\_\_\_

**My donation of \$** \_\_\_\_\_ **is enclosed.**

**Please use for (circle one):**      **research**      **clinic**      **sponsor a teen (\$2000)**

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

**Card Number:** \_\_\_\_\_ **Expiration Date:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

**THANK YOU FOR YOUR GENEROSITY. PLEASE RETURN TO:**

Johanna Biederman, Director of Development  
National Pediatric MS Center  
Stony Brook University Hospital  
HSC T12-020  
Stony Brook, NY 11794

