

Leading the fight for the  
least known MS patients...  
children.



# Advancing recognition and treatment for children with MS.

Multiple sclerosis is the most common neurological condition affecting young to middle-aged adults. What's less well known is that this chronic, often disabling disease also affects many thousands of children in the United States and beyond.

The National Pediatric Multiple Sclerosis Center was founded in 2002 to advance recognition, evaluation and treatment for this special population. It was the first multi-disciplinary program in the country dedicated exclusively to expert clinical care and scientific research of children and adolescents with MS.

Located at one of the world's leading research institutions, Stony Brook University Medical Center on the North Shore of Long Island, we have been designated as a regional Center of Excellence by the National Multiple Sclerosis Society. The National Pediatric MS Center is committed to providing state-of-the-art care and service to families affected by pediatric MS, regardless of their ability to pay.



## *Not just an adult disease.*

- **An estimated 8,000 to 10,000 children in U.S.** have been diagnosed with MS.
- Another 15,000 U.S. children suffer with MS-like symptoms such as double vision, numbness and unexplained fatigue.
- Those more severely affected by MS may have visual loss, difficulty walking or speaking. Others suffer only mild disability.
- There is no cure for MS yet; however, medications can slow its course and reduce symptoms in many patients.
- Young people with MS can grow up to lead productive and enjoyable lives.

# A unique multi-disciplinary team focused on results.



Our Center was the first in the nation to address pediatric MS by assembling a multi-disciplinary team of experts. We have brought together specialists in the disease itself, as well as in pediatric neurology, neuropsychology, pediatric nursing, child psychiatry and neuroradiology.

The team's goal is to identify the biological changes in children facing MS, to advance research that could make dramatic differences in their lives and, ultimately, to find a cure. We are today recognized as the leading program in pediatric MS and have evaluated more than 200 children at our Center.

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## MEET OUR DIRECTOR, DR. LAUREN KRUPP.

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Dr. Krupp is an internationally known expert in MS and a recognized opinion leader in clinical management of the disease. She has had an academic practice in adult MS at Stony Brook University for 20 years. In 2002, her attention was drawn to pediatric MS. Together with her gifted team, Dr. Krupp directs research at both the basic and clinical levels, working with international groups of scientists. In addition, the National MS Society has named her chair of the Steering Committee of a six-center national network that is setting the framework for pediatric MS care and research.

Dr. Anita Belman, a highly accomplished pediatric neurologist with extensive experience in inflammatory and infectious central nervous system disorders of children, has worked closely with Dr. Krupp for many years and is an integral part of the Center team.

# A Center of care and support for families of kids with MS.

An estimated five percent of individuals with multiple sclerosis have disease onset before the age of 18. Yet many pediatricians remain unaware that MS is also a disease of the young. Lack of awareness regarding pediatric MS in the medical community leaves affected children undiagnosed and untreated.

The National Pediatric MS Center is also determined to educate physicians and the general public about MS in children.

Young patients who come to our Center receive a comprehensive multi-disciplinary evaluation, conducted over one to two days.

This includes:

- Extensive neurological assessment
- Neuropsychological evaluation and psychological assessment to evaluate the effects of MS on cognition, academic performance and emotional functioning
- Ophthalmology
- Radiology
- Nursing case management
- Transition into Dr. Krupp's adult practice for continuity of care

Often children with MS and their families feel isolated, never having the opportunity to form relationships and share experiences with others affected by the disease. Our Center combats this sense of isolation by providing a support network extending well beyond medical care. The most dramatic and therapeutic aspect of our support services is our annual Teen Adventure Weekend for adolescents with MS.



# ‘At home I sit around and I’m sick... here I’m well.’

That was the reaction of one young participant to the Teen Adventure Weekend – the only camp in the U.S. specifically for adolescents between the ages of 11 and 18 who have MS.

This exciting, life-changing program is offered by our Center in partnership with the recreational therapy professionals at Access2Adventure, a non-profit organization dedicated to improving the quality of life for persons with disabilities through sports, recreation and adventure travel.

Often for the first time in their lives, these unique campers are able to join in wellness activities such as kayaking, sailing and navigating a high ropes course, while building team spirit and confidence.

Most important are the peer relationships they are able to foster with other kids experiencing the same challenges. “I never realized that there were other kids like me out there” is a common refrain heard throughout the weekend.

The program, located at Canonicus Camp in Exeter, Rhode Island, and free to all who attend, draws participants from all corners of North America – from Alaska, Hawaii and California to Florida and Texas to the New York metropolitan area.



# Working together at the forefront of research.

Our Center is among the most respected thought leaders promoting research in children with MS.

Among our research accomplishments:

- Establishing standardized definitions with international consensus to promote prospective research
- Characterization of a unique demographic pattern of children with MS
- Description of critical features that can expedite diagnosis and treatment
- Application of novel neuroimaging techniques to elucidate the biological factors which underlie the disease
- Use of sophisticated chemical analysis of blood samples to identify disease-specific markers in children with MS
- Accrual of blood samples to perform genetic and biochemical studies pertinent to understanding MS

## Expanding awareness through education.

Our extensive outreach and awareness programs are increasing the understanding of the health care community, school populations and the general public about pediatric MS.

### Strength in partnerships.

To further our research leadership, we have established relationships within our own hospital as well as with other nationally and internationally acclaimed institutions. Among our many fruitful collaborations are:

- Satellite clinics being formed at New York Presbyterian-Columbia University Hospital and Westchester Medical Center's Children's Hospital
- Immunological studies at Harvard University
- Genetic studies at the University of California at San Francisco
- International research programs on viral exposure in MS with Canada, Argentina, Germany, Russia and other countries
- An International Pediatric MS Study Group, spearheaded by Dr. Krupp, to expand collaborative research with pediatric neurologists and MS specialists from other countries
- A network of six pediatric Centers of Excellence established by the National MS Society, chaired by Dr. Krupp

# Looking to a brighter future for children with MS.

As the National Pediatric Multiple Sclerosis Center moves forward with our mission, it is our hope that . . .

- Every child and family will turn to our Center for the care and comfort they need when facing a diagnosis of MS
- Every pediatrician and neurologist will learn that MS does occur in children, and that help can be obtained from our Center
- Our research will advance our understanding of the disease for individuals of all age groups so that a cure is found

## Funding our mission.

Today the work of our Center is supported by numerous sources, including the National MS Society, Stony Brook University Medical Center, Stony Brook Foundation, Stony Brook Research Foundation and the School of Medicine.

In addition, we have benefited from generous private donations and fundraising events. These monies support research programs as well as the Teen Adventure Weekend. Our goal is to build on these initial fundraising efforts to enable our Center to become self-sustaining – thereby ensuring that all children with MS reaching out to us will receive the care they need.



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## MISSION STATEMENT

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We are committed to improving the lives of children with multiple sclerosis and advancing research that will benefit all individuals with MS.

To learn more about our programs, or ways you can help us further our mission, please contact:

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