

PROMISE 2010

FUNDING VITAL MS RESEARCH

National MS Society • Summer 2008



THE FOUR PROMISE: 2010 INITIATIVES

Nervous System Repair and Protection. Four international teams, with more than 50 investigators, are making great progress in collaborative efforts to lay the groundwork for clinical trials to repair and protect the nervous system in people with MS.

Pediatric MS Centers of Excellence. Six centers, launched nationwide in January 2006 are in full operation offering diagnosis and comprehensive care and treatment for children with MS, and providing information and support to families.

The Sonya Slifka Longitudinal MS Study. The team recently published data on health-related quality of life for people with MS versus those of the general population and those with other diseases. An additional group of 2500 MS patients is being sought to enhance the existing patient database. Additional information on the recruitment is available at nationalMSSociety.com.

The MS Lesion Project. The possibility that MS has multiple causes is the focus of this path-breaking international collaboration that is mapping out patterns of MS damage to develop better treatments. The team has been working to find a way to detect lesion patterns non-invasively by using MRI (magnetic resonance imaging) scans or blood work to determine whether patterns predict different disease course or response to specific therapies.

A Big Commitment to the Smallest MS Patients

Children with MS and their families have traditionally been underserved. While research continues on the cause of MS in adults, less is known about pediatric MS. This is dramatically changing with six Pediatric MS Centers of Excellence in full operation with funding from the MS Society's Promise: 2010 campaign.

The centers are a first-of-its-kind effort to bring world-class care to children with MS and related disorders. There is a huge need for: accurate diagnosis of children with MS, development of treatment protocols for kids with MS, determination of triggers of pediatric MS, and the ability to provide resources and support for children and families to help them move their lives forward.

While the needs are great, the opportunities are vast as well. We're confident that the partnerships formed with topnotch professionals at the Pediatric MS Centers of Excellence are going to help meet the special needs of children with MS. And it's all made possible by contributions supporting the Promise: 2010 campaign.

This update will introduce you to clinicians who say the Society's emphasis on collaboration has drastically improved the quality of care they provide and to a family that turned to the network to help make the best of a heartrending situation.

▶ THE PEDIATRIC MS CENTERS OF EXCELLENCE NETWORK

An estimated 25,000 children in this country have MS or related disorders. With the help of the Society's pioneering network of Pediatric MS Centers of Excellence, that's 25,000 families who now have the option of getting the help they've always needed.

"The pediatric centers offer a unique opportunity for families," said Deborah Hertz, associate vice president of medical programs at the Society. "They diagnose MS and other central nervous system demyelinating disorders; provide quality, comprehensive care; and offer financial assistance including travel and accommodations to families who could not otherwise access these services."

Until recently, MS research and treatment generally overlooked kids with MS. With one exception, there were no existing facilities in the U.S. offering the kind of comprehensive care and support that the six new centers provide.

Teams of experts, including pediatric and adult neurologists, nurses, neuropsychologists and school liaisons, provide comprehensive treatment and care for children — all in one place. Plus, they teach families how to cope with the effects of MS on their child's educational, physical and social development.

"The pediatric MS centers welcome children with any central nervous system demyelinating disorder, not just MS. We are developing national resources that will bring us closer to revealing what causes MS in adults and children," Hertz said. Only two years after formally opening in January 2006, the centers collectively had seen more than 600 children.



Paige, diagnosed in 2006

▶ A FAMILY LEARNS ABOUT MS

"People were shocked when we told them our daughter had MS," said Janine Maklary, mother of 15-year-old Paige, diagnosed with MS at 12. "They were sure that someone had made a mistake."

It all started when Paige began to have trouble with her eyesight. She could only see out of the corners of her eyes. "Her teacher kept telling her to turn around in class," Richard Maklary said. "She thought Paige was sitting sideways because she wasn't paying attention."

Janine and Richard took Paige to an eye doctor, who found nothing wrong with her eyes. They took his suggestion to have Paige get an MRI. On their way home after the MRI the doctor called telling them to go right back to Stony Brook, one of the six Pediatric MS Centers of Excellence. There the doctor said those fateful words: "Your child has MS."

At first they felt devastated. Today they feel very fortunate to have received a diagnosis so quickly. "We've heard stories from other families about their children with MS being misdiagnosed," Janine said. "Many doctors know a lot about adult MS, but aren't knowledgeable of condition in children."

The Maklarys want to help the world better understand pediatric MS. "The Society needs to get into the schools and educate the staff," Janine said. One of the goals of the Pediatric MS Centers of Excellence, according to Society's Deborah Hertz is educating educators about pediatric MS.

Once, Paige got a 30 on a test and her mother requested a re-test. On the do-over, Paige got 97 — tops in the class. "Maybe the first time the room was too hot," Janine said.

▶ TEAMWORK BENEFITS MS PATIENTS

Marianne Doyle, MSW, has a system for helping families whose routines have been shattered. As the social worker for the University of California San Francisco, Regional Pediatric Center she is a family's first contact at the center. Doyle recognizes the tension people have about coming to the clinic so her goals are to "clarify how their day is going to go and make sure we meet their needs."

Families travel from as far as Hawaii, Alaska and the Rocky Mountains to visit the Pediatric MS Center of Excellence, UCSF because it offers a full team dedicated to pediatric MS and related disorders. The team includes two adult neurologists, a pediatric neurologist, two neuropsychologists, a neuro-ophthalmologist, a full-time clinical coordinator, one or two doctors in training and a social worker.

"We do a battery of neuropsychology tests. The neuropsychologists follow up with a child's school with recommendations and advocacy," Doyle said. "Those services are exceptionally expensive, are not a normal part of care; families have to seek them out. And they aren't typically covered by insurance." They are however services the Pediatric MS Centers of Excellence provide to meet the diverse needs of children living with the unpredictability of MS.

"The way the National MS Society designed and funded the centers definitely had an impact," Doyle said. "Social



workers talk on the phone quarterly and share resources. The teamwork that is taking place within the Pediatric MS Centers and the degree of coordination and collaboration is very unique."

Clinicians at other centers agreed that the multidisciplinary nature of the centers is a boon for patients and their families. Before the centers launched, "there would be a breakdown in communication between the physicians treating a child, their understanding of all the neurological and psychological ramifications of that condition, and their ability to get that information back to the child's community," said Joe Ackerson, PhD, the neuropsychologist at the Center for Pediatric Onset Demyelinating Disease at Children's Hospital of Alabama in Birmingham.

"Ours is really a team approach. I had a case where a child was experiencing difficulties with concentration, memory, and fatigue related to their medical condition. We had to educate the school that the child did not become lazy and unmotivated, but an underlying condition that makes it harder to do the things kids normally do in school simply looks like laziness."

The existence of the network of Pediatric MS Center of Excellence clinics with common goals and methods means patients as well as clinicians are forging a national network to compare notes with, said Maria Milazzo, pediatric nurse practitioner with the Stony Brook clinic. "The National MS Society continues to play a leadership role in establishing those relationships and helping them grow."

The team at UCSF Regional Pediatric MS Center. Front row: Janace Hart, clinic coordinator; Dorothee Chabas, MD, PhD; Sunny Im-Wang, PsyD; Emmanuelle Waubant, MD, PhD. Back row: Kimberly Ehrlich, RN, MSN, MPH, CPNP; Laura Julian, PhD; Jonathan Strober, MD; Marianne Doyle, MSW; Sara Teasdale, neuro-ophthalmology research assistant. Not pictured: Ari Green, MD.



▶ **SIX MS CENTERS
MOVE US CLOSER
TO A WORLD FREE
OF MS**

The Promise: 2010 campaign is committed to raising more than \$35 million in support of the four campaign initiatives. A minimum of \$13 million of the campaign is committed to creating the network of six Pediatric MS Centers of Excellence providing dedicated treatment that children with MS need. Funding from the Promise: 2010 campaign has established the following pediatric treatment centers.

- ▶ **Center for Pediatric Onset Demyelinating Disease** at Children's Hospital of Alabama, University of Alabama at Birmingham, Birmingham, AL.
- ▶ **UCSF Regional Pediatric MS Center**, University of California, San Francisco, CA.
- ▶ **Pediatric MS Center of the Jacobs Neurological Institute** of the University at Buffalo, Buffalo, NY.
- ▶ **Partners Pediatric MS Center** at the Massachusetts General Hospital for Children, Boston, MA.
- ▶ **Mayo Clinic Pediatric MS Clinic**, Rochester, MN.
- ▶ **National Pediatric MS Center** at Stony Brook University Hospital, Stony Brook, NY.

To learn more, visit nationalMSSociety.org/pediatricMS.



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▶ **CONTACT US**

If you would like to learn more about Promise 2010 or how you can further your involvement, contact Mary Milgrom at 1.303.813.6619 or mary.milgrom@nmss.org.