

# **New focus on pediatric MS**



## **More specialized centers, more experts and more research spark optimism for understanding and treatment.**

**by Mary E. King, PhD**

Children and adolescents with pediatric-onset multiple sclerosis and their families have new options and more reason to hope for progress in understanding and treating this form of the disease.

The Network of Pediatric MS Centers (NPMSC) recently expanded from nine to 12 locations nationwide, including new centers at the Cleveland Clinic, the University of Colorado and Washington University in St. Louis. The NPMSC was launched with National MS Society funding in 2006 to set the standard for pediatric MS care, educate the medical community about this underserved population, and create the framework to conduct critical research—both to understand childhood MS and to unlock the mysteries of MS in adults by studying MS at its earliest stages. “The network began with six centers and then grew to nine, and the expansion now to 12 centers comes with enormous outreach effort,” says Dr. Lauren Krupp, director of the Pediatric MS Center at New York University and one of the original members of the network.

The network is spearheading a range of research projects. “We help develop the science and the actual design of a study, and keep it moving forward all the way through data collection and analysis,” says T. Charles Casper, PhD, associate professor of pediatrics and director of the network’s Data Coordinating and Analysis Center at the University of Utah. The network’s

research includes investigations into the causes and symptoms of pediatric-onset MS, and studies that focus on specific questions that may help children and their families better cope with MS, Dr. Krupp says.

Dr. Casper and his cohorts also keep track of data collected from patients who visit the pediatric MS centers and agree to share their medical information. “The network’s unified approach at collecting data has provided us with [valuable] information—for example, a comparison of clinical and MRI features of pediatric-onset MS compared with related neurologic diseases, with the goal being to better distinguish the different diseases and to do so earlier in the course of the disease,” he says.

### **More participation, more information**

One reason research into pediatric-onset MS is expanding rapidly is because of the larger number of children and adolescents who are participating in the network’s data collection. Dr. Casper notes that the database now contains medical information from more than 600 children and adolescents with pediatric-onset MS, along with data from an additional 400 to 500 people with other pediatric neurologic diseases related to MS.

“This is an incredible number of individuals with pediatric-onset MS who are being evaluated across the different network locations,” says Dr. Krupp. “We are now putting together a manuscript that describes the first 490 patients. We have already learned very important things—for example, that the clinical features of children under age 12 with MS differ from teenage children with MS.”

### **A closer look at risk factors**

After years of carefully collecting data from participants in the network studies, researchers are beginning to tease out some of the factors that might affect the risk of developing pediatric-onset MS, such as diet.

“So far, we have been able to study salt, fat and fiber,” says Dr. Emmanuelle Waubant, professor of neurology and director of the Regional Pediatric MS Center at the University of California, San Francisco. “While we do not see a strong relationship between any of these factors and risk (good or bad) in our preliminary work, we are now doing more sophisticated analyses that might pick up weaker relationships. We can say that a higher salt intake was not associated with a shorter time to MS relapse,” a result that seems to differ from findings in adults. Dr. Waubant and colleagues are also studying other types of nutrients and their relationships to pediatric-onset MS, including carbohydrates, proteins and sugars. They are planning to examine vitamin D as well.

Through this work and other research, “we have learned that MS in children, as in adults, is not a ‘one size fits all’ disease,” Dr. Krupp says. “For example, we think that vitamin D levels or viral exposures may play more significant roles only in individuals with certain genetic predispositions, rather than necessarily in everyone. And that makes sense to us—that MS represents interactions between the environment, genetic predispositions and the immune

system.”

Network researchers are also evaluating other potential risk factors for pediatric-onset MS, and presented preliminary data at an international meeting last fall. This includes a study showing that boys and girls who have increased body mass index (BMI) are at higher risk for developing pediatric-onset MS. “We also have a study that is evaluating whether any of several pregnancy-related factors, such as maternal age, smoking, prenatal infections, breastfeeding or type of delivery, affect the risk of the baby going on to develop pediatric-onset MS,” Dr. Waubant says. “So far the data hasn’t shown that any of these factors definitely increase risk, but delivery by C-section appears to be linked to a lower risk of disease in our initial analyses.”

### **Support for cognitive issues**

Dr. Krupp’s special research interest is the cognitive effects of MS in children. “Studies across Europe, Canada and the United States have consistently found that about one-third of children with MS have some type of cognitive issue,” she explains. “Together with other members of the network, we are looking in more detail at what happens to these children over time. While the final story is still evolving, we can say that many children with MS will probably need a little more help, for example, in school.”

The network is undertaking a variety of initiatives to increase awareness of pediatric-onset MS in schools. “Network clinicians, social workers and nurse psychologists are communicating directly with teachers and guidance counselors about the special needs of these children,” Dr. Krupp says. “Our centers are also working hard to help guide parents to make sure children with MS obtain the support and accommodations that they need in school. In conjunction with the Society, the network has developed many written materials for parents to help with their children, as well as materials for teachers and other school personnel.”

### **Beyond the network**

The network has a close alliance with global research efforts through the International Pediatric MS Study Group, convened by the Society in 2002, and which now includes leadership from the MS International Federation, other MS societies, and medical and scientific leaders from more than 15 countries.

Along with network-sponsored research into pediatric MS, clinical studies supported by the pharmaceutical industry are also increasing. Dr. Krupp points out that for the first time, a number of multicenter clinical trials are evaluating therapies that have already been approved for adult MS but have not yet been tested in children. The goal is to determine whether these agents are safe and effective for children. For example, current industry-sponsored studies include separate investigations of fingolimod (Gilenya®), teriflunomide (Aubagio®), dimethyl fumarate (Tecfidera®), interferon beta-1b (Betaseron®) and natalizumab (Tysabri®) in preadolescent children and adolescents.

The network is not officially involved in industry clinical trials, she says. “Our primary role is testing disease-specific hypotheses and performing observational studies [rather than testing therapeutic agents]. We have reviewed a few industry trials to provide insights from our experts, but the individual centers decide whether to participate.” The network helped early on to characterize the treatment patterns in the United States for pediatric MS, has spearheaded research on genetic and environmental interactions, and played a major role in educating pediatric neurologists worldwide about pediatric MS.

“I do believe the network played a role in sparking this new research,” Dr. Krupp says, “such as utilizing uniform definitions of pediatric MS and related disorders in their database, and working toward a better understanding of how to most rapidly identify these individuals.”

Overall, Dr. Krupp is optimistic about where both network and industry research will lead. “The network expansion comes at a time when the field of pediatric MS is exploding. We are seeing new research and new insights from multiple areas of study,” she says. “We are confident that children and adolescents throughout the U.S. are getting care from clinicians at a level of expertise that was never previously possible.”

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