

Taking off the kid gloves



Clues about what triggers MS early in life may help investigators understand the causes of MS.

by Mary E. King, PhD

Just a decade ago, many clinicians did not realize that multiple sclerosis could occur in children. Now we know that 2 to 5 percent of people with MS begin to have symptoms before age 18. Understanding the development of pediatric MS may provide vital information about MS in people of all ages.

“Very good data suggest that MS is the result of both environmental and genetic factors that affect the immune system,” explains Dr. Lauren Krupp, director of the [Lourie Center for Pediatric MS](#) at Stony Brook Children’s Hospital in Stony Brook, N.Y. “Many of the environmental exposures occur during childhood. It is much easier to track those down in a 7-year-old with only seven years of environmental exposures than in an adult,” she says.

“Children with MS may have a form of the disease in which symptoms become apparent very shortly after the exposure period” to as-yet-unknown environmental factors, adds Dr. Tanuja Chitnis, director at Partners Pediatric MS Center at Harvard’s Brigham and Women’s Hospital in Boston. People with adult-onset MS may also have been exposed in childhood or late adolescence to the same environmental factors. However, this exposure is usually followed by a long silent period, with the disease only becoming apparent later, in adulthood, Dr. Chitnis says.

“Understanding the interaction of these early exposures and their effects on the immune system may help us understand adult MS,” Dr. Chitnis emphasizes.

Consequently, pediatric MS is the focus of numerous ongoing studies, exploring the effects of environment, diet and genetics in risk for MS.

The starting point

Conducting pediatric research is fraught with logistical challenges, however. “Because pediatric MS is less common, we need to have large, extensive network studies to get meaningful data to help us understand the disease,” says T. Charles Casper, PhD, principal investigator for the Data Coordinating and Analysis Center (DCAC) for the [National MS Society’s Network of Pediatric MS Centers](#) (NPMSC) at the University of Utah School of Medicine in Salt Lake City.

The difficulty of finding enough children with the disease to study is compounded by the fact that pediatric MS also is more challenging to diagnose than adult MS because other childhood disorders have similar symptoms and characteristics.

To begin to address these hurdles, in 2006 the National MS Society’s “Promise: 2010” initiative established a first-of-its-kind network of six pediatric MS centers across the U.S. to provide comprehensive evaluation and care to children with MS.

Building on that groundwork, the Society recently committed \$2.5 million to support the infrastructure, study design, and data collection and analysis for an expanded network, now composed of nine centers, to conduct this vital research. The DCAC also maintains a pediatric patient registry, another first.

“By pooling information across the network we are able to build a critical mass of information that can be mined for insights into the disease,” says Nicholas LaRocca, PhD, vice president of Health Care Delivery and Policy for the Society. “Moreover, in the course of developing the registry, the network established procedures for the collection of standardized data, which can now be used to speed research of all kinds.”

One current NPMSC project is comparing hundreds of children with MS to children without the disease, looking at differences in many environmental factors, including diet, birth order, number of siblings and more. Another project, which began at the Stony Brook center but will expand into the other network centers, is identifying the cognitive, social and behavioral changes that occur in children with MS.

“The beauty of the range of studies being pursued is that they will not only contribute to an understanding of the underlying causes of MS but also will address the day-to-day issues faced by youngsters affected by the disease,” says Dr. LaRocca.

Global reach

Pediatric clinical trials

More information about the pediatric fingolimod (Gilenya®) clinical trial (see information at left), including eligibility requirements and current locations, can be found on clinicaltrials.gov.

Additional medical centers within the Network of Pediatric MS Centers still may choose to participate in this trial, so you may wish to call the closest one to you to see if it will be participating, if it's not listed at the link above.

Researchers understand the importance of looking beyond their borders. The Society convened an International Pediatric MS Study Group (IPMSSG) in 2002, which has evolved into a network of more than 150 medical and scientific leaders from more than 40 countries. The organization has developed and published standardized criteria for diagnosing childhood MS and encourages research into pediatric MS, as well as other childhood diseases that have similarities to MS. The IPMSSG also fosters collaboration that leads to international clinical trials, says Dr. Chitnis, chair of the IPMSSG.

The first international clinical trial of MS treatments in pediatric patients has already begun, and the National MS Society helped bring together the key stakeholders and define the protocols to get it underway.

The trial compares interferon beta-1a injections with fingolimod (Gilenya®), an oral drug approved for use in adult MS.

“The collaborative efforts of the international MS community are opening exciting new frontiers,” says Dr. La Rocca. “Coordinated pediatric research may unlock some of the long-held mysteries about how and why MS develops.”

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