

When Children Get MS

BY DEBORAH HERTZ, MPH

Pediatric MS is not common: An estimated 8,000–10,000 children and adolescents in the United States have the disease. Because of this relatively low incidence, pediatricians and most neurologists are not prepared for the specific challenges in the diagnosis and management of the disease in people under 18. Other childhood disorders with similar symptoms can make diagnosis of MS in children particularly challenging. By some estimates, there are another 10,000–15,000 children who have what may or may not be the first symptoms of the disease.

The National MS Society has launched two ground-breaking initiatives—an international study group and a series of regional pediatric MS care centers across the U.S., in 2001 and 2006, respectively—to improve the quality of care for children with MS and to spark international collaborative research that will increase the body of knowledge about pediatric MS and the disease in general.

These initiatives are designated for Promise: 2010 funding. The pediatric programs are especially grateful to the James Cantalupo Memorial Fund for important support.

International Pediatric MS Study Group

The study group, which includes pediatric and adult MS experts, was established to improve communication and collaboration among a broad spectrum of researchers and clinicians. The group currently involves researchers from more than 10 countries, and MS Societies from the USA, Canada, France, Germany, and Italy, as well as the MS International Federation.

Neurology, the official journal of the American Academy of Neurology, published a special supplement on pediatric MS by the study group in 2007, which addressed consensus definitions to describe pediatric MS and similar disorders, the diagnostic considerations, psychosocial issues, treatments, and clinical features.

For more information on the study group and its recommendations, visit nationalmssociety.org/PedStudyGroup.

Network of Pediatric MS Centers of Excellence

In 2006, the Society established six geographically dispersed Pediatric MS Centers of Excellence. A rigorous peer review process selected sites that had both adult



and pediatric expert teams, including a close tie to an adult MS center for teens and young adults over 18, the ability to collaborate in a network, and the ability to become self-sufficient after the five-year funding from the Society.

The goals are:

- To offer the best medical care and psychosocial support to children and adolescents with MS and related conditions;

- To educate families, health-care professionals and the public about pediatric MS; and

- To create a framework for future research.

An integrated network means the teams can share difficult cases, develop stan-

dards of care, and—most important for research—collect data in a uniform manner. This past year, the network agreed on what data to collect on all children. With parental consent, this information will be entered into a communal data coordinating center, to be established later this year.

Questions to be answered by studying pediatric MS

Because there are now disease-modifying therapies available to treat adults with MS, there is a heightened sense of urgency to conduct clinical trials to understand the effectiveness of these therapies in children, what doses are appropriate for them, when to initiate treatment, long-

term effects, and how treatment impacts disease progression. Studying children will also help scientists understand:

■ **Environmental trigger(s).** The shortened interval between exposure to some environmental factor and disease manifestation offers opportunities to study the influences of infectious diseases, vaccinations and other potential environmental triggers.

■ **Hormonal influences.** Before age 10, the ratio of boys to girls with MS is close to 1:1, but after 10, there are more girls than boys, a trend that continues in

adult MS. Further investigation may shed light on the role of hormones in the development of the disease.

■ **Demographics.** In both the U.S. and Canada, a higher than expected number of African-American and Hispanic children have been diagnosed with MS. Research may reveal clues to the genetics of the disease.

■ **Pathophysiology.** By studying the earliest stages of MS, scientists will learn more about the disease process and what causes it to occur so early in some people.



Genetic Research at Home:

Will Your Baby Develop MS? BY MARCELLA DURAND

Dr. A. Dessa Sadovnick is a medical geneticist at the University of British Columbia. In 1993, she and Dr. George Ebers, who was then at the University of Western Ontario, began the Canadian Collaborative Project on Genetic Susceptibility to MS. Dr. Ebers, who is currently at Oxford University, first had the idea of Canadian collaborative research while studying HLA in 1980. (HLA refers to a group of genes that encode antigen-presenting proteins.)



The Genetic Susceptibility study, funded by the MS Society of Canada Scientific Research Foundation, collects DNA samples and data including family histories, health information, and demographics, from more than 29,000 families registered at MS clinics across Canada. Drs. Sadovnick and Ebers teamed up to study the information in this database.

What are the odds?

“We’ve learned that if only one parent has MS, the lifetime risk of the child develop-



The Society is optimistic that research in pediatric MS will not only answer critical clinical issues for children about diagnosis, treatment, impact on learning, and long-term outlooks, but it will also provide insights into MS more generally. For more information about pediatric MS or the Pediatric MS Centers of Excellence, visit nationalmssociety.org/PediatricMS. ■

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ing the disease is between 3% and 5%," Dr. Sadovnick said. "These odds are higher than for a person with no MS in the immediate family—which is about 0.2%—but it is still relatively low."

In families with more than one person with MS, however, the risk is somewhat greater. "If there are two or more people with MS in the family," Dr. Sadovnick explained, "including aunts, uncles, nieces, nephews, and first cousins—the lifetime risk may approach 10 to 15%."

The roles of gender, race, race and ethnicity

A study at the Mayo Clinic in Rochester, Minnesota, found that in a group of 441 children with one parent with MS, fathers were more than twice as likely to have a child who develops MS. Dr. Orhun H. Kantarci reported on his team's findings in the July 25, 2006, issue of *Neurology*. Drs. Sadovnick's and Ebers' group, how-

ever, studying Canadian families, did not confirm these findings.

Drs. Sadovnick and Ebers are also looking at families with one or both parents of color. "MS is comparatively rare in African-Americans and even rarer in Africans living in Africa," Dr. Sadovnick said. But recent research at the University of California, San Francisco has uncovered an African allele, or DNA code, that affects susceptibility to MS.

Should you have kids?

"There is no rule," Dr. Sadovnick said. "Each couple must consider their own situation in deciding what's best for them."

It may be useful for potential parents to discuss the issues with a genetics counselor. Most Society chapters can provide a list of area experts. However, there is no way yet for anyone to predict the outcome of a specific birth. Ultimately, the decision is up to the parents. ■