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The New Face of Multiple Sclerosis

Doctors Increasingly Detect
 The Disorder in Children;
 Recognizing Early Signs

By **AMY DOCKSER MARCUS**
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Multiple sclerosis, a potentially devastating disease that affects the central nervous system, has long been considered an adult condition. But doctors are increasingly diagnosing the disease in children and teens -- and they believe that thousands more young people may have symptoms that are going undetected.

As a result, medical researchers are beginning to study MS specifically in young people. The hope is that a better understanding of pediatric MS will not only help children -- for whom the disease poses a number of unique issues -- but also yield insights into the causes of multiple sclerosis generally. Some research indicates that MS may be related to an environmental trigger early in life, so researchers are looking for clues in children that could lead to better diagnosis and treatment for everyone.



Darren McColleston/Getty Images

Amanda Driscoll was diagnosed with multiple sclerosis at age 13.

A diagnosis of MS in kids is rare: Most of the approximately 400,000 patients in the U.S. are adults, usually diagnosed between the ages of 20 and 50. Just 10,000 children, mostly age 10 to 17, are believed to have MS. But doctors also say that as many as 15,000 more kids may experience signs of the disease, such as blurry vision, numbness and fatigue, that go unrecognized. Because the disease is largely found in adults and symptoms can come and go, doctors typically don't suspect MS.

Doctors have known for many years that the disease can occur in children, but diagnosis was rare. Now, improvements in diagnostic imaging tests, a broader array of drugs available to slow the disease, and growing anecdotal evidence that many adult patients had symptoms when they were younger are all helping fuel a drive to diagnose the condition early.

There is no cure for MS, an autoimmune disorder in which immune cells enter the central nervous system, causing inflammation that damages myelin, the protective coating around nerve cells. The disease isn't usually fatal, except in rare cases. But it can scar the brain, spinal cord and optic nerves with lesions that leave people with varying degrees of physical and cognitive problems. Some patients become disabled and wind up in a wheelchair. To help slow the progression of the disease, patients are usually on medication for the rest of their lives.

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To further understanding and awareness of pediatric MS, the National Multiple Sclerosis Society is providing \$13.5 million over the next five years to six regional pediatric MS centers that will focus on treatment and research. The centers, at the University of Alabama in Birmingham, State University of New York at Buffalo, the Mayo Clinic in Rochester, Minn., Stony Brook University Hospital in Long Island, the Massachusetts General Hospital for Children in Boston, and the University of California in San Francisco, will pool their data in an effort to establish the first national database of pediatric MS cases. Researchers say the database will lead to more clinical trials involving children, who are often treated for multiple sclerosis with medicines that are approved for use in adults but haven't been rigorously studied in children.

Medications to treat MS include the injectable drugs Avonex, Betaseron, Copaxone and Rebif, as well as Novantrone, which is given intravenously. The drugs can cause flulike symptoms, and are usually given to children in smaller doses than for adults. Another promising treatment, Tysabri, was pulled from the market last year over safety concerns, but it is now going back into clinical trials.

FOCUS ON KIDS

Some resources for families of children with multiple sclerosis

Young Persons With MS referral network

Run by the National Multiple Sclerosis Society, with the Multiple Sclerosis Society of Canada, operates a support network and referral service for families with a child or teen diagnosed with MS. 1-866-KIDS-W-MS,

www.nationalmssociety.org¹

Teen InsideMS

Online publication from the National MS Society for teens, including material written by and for teens with MS.

www.nationalmssociety.org/Teen%20InsideMS.asp²

National MS Society Scholarship program

For people and families living with MS who need financial assistance for higher education.

www.nationalmssociety.org/scholarship_menu.asp³

Teen Adventure Weekend

A camp for teens with MS, sponsored by the National Pediatric MS Center at Stony Brook University Hospital in Long Island. www.pediatricmscenter.org⁴

Source: National MS Society

No one knows the exact cause of multiple sclerosis, but it is believed that a combination of genetic factors and environmental triggers are at the root. Narrowing down what those triggers might be is a huge challenge. By the time patients are diagnosed as adults, "people have been exposed to hundreds of thousands of infectious agents, viruses, bacteria, allergens, you name it," says John Richert, vice president for research and clinical programs for the National Multiple Sclerosis Society in New York. Finding the environmental trigger "is virtually impossible at that point."

Looking for Triggers

In pediatric MS, however, the amount of time between the environmental trigger and the onset of disease may be much shorter. Studying children with MS "will give us a

clearer view of what the likely important exposures have been that trigger the disease," says Dr. Richert. A better understanding of the causes of pediatric MS might also offer insights into other autoimmune diseases, such as lupus or rheumatoid arthritis, adds Lauren Krupp, director of the National Pediatric Multiple Sclerosis Center at Stony Brook University Hospital.

Studies so far of children with multiple sclerosis have generally been small, making it difficult to draw broad conclusions. But pediatric MS appears to differ from the adult disease in some respects. Just like in the adult population, more females than males get pediatric MS. But while adults with the disease tend to be Caucasian women, in children doctors are seeing greater numbers of patients from minority populations, such as African-American, Latino, Asian and Middle Eastern.

Cognitive Problems

Doctors believe that hormones in growing children may make them more prone to relapses than adults. Cognitive problems in children, such as memory lapses or reading difficulty, may have a profound impact because children are still learning and developing, researchers say. No one knows yet whether children may experience permanent cognitive damage.

It also takes children longer to reach a stage of the disease where they start experiencing disabilities, such as needing a cane or other assistance to walk. But because they get the disease at an earlier age, they can also become disabled at a much younger age than adults. This is one of the reasons why doctors say it is critical to identify MS in kids as early as possible and begin treating it.

It isn't easy to diagnose multiple sclerosis because there is no single test yet for the disease. Instead, doctors rely mainly on imaging tests taken over time and observed for growing numbers of lesions. In children, it is even more difficult because there are no published guidelines on what constitutes pediatric MS. In addition, there are other more-common conditions in children that doctors are likely to think of first when presented with MS-like symptoms. For instance, acute disseminated encephalomyelitis, which can occur after a virus, can produce vision, balance or strength problems.

Getting the Diagnosis

For children who are diagnosed with MS, suffering from the disease is often a lonely and isolating experience. Unlike other chronic conditions that affect children, such as diabetes, children with MS usually don't know anyone else with the condition. At the age of 13, Amanda Driscoll, now a high-school freshman in Tewksbury, Mass., came downstairs before school complaining that her vision was blurry and she felt dizzy. The school nurse told Amanda's mother to take her to the doctor for an eye exam. This led to further tests, including an MRI, which turned up lesions on Amanda's brain. Eventually, she was diagnosed with MS, the only one in her school with the condition.

Sitting in her doctor's office one day in February for a regular check-up, Amanda, now age 15, explained that she tries not to think about having MS because "I've heard that people with MS are in wheelchairs, and I don't want to think about that happening to me."

Tanuja Chitnis, director of the Partners Pediatric Multiple Sclerosis Center at Massachusetts General Hospital for Children in Boston, told Amanda that medications like the one she is taking are able to slow down the course of the disease, and that fewer people end up with severe disabilities.

Educating Others

At school, Amanda said that her friends don't really understand MS. "One guy asked me if he kissed me, can he get MS," she recounted. (She told him no.) One time during a mile run in gym class, Amanda felt weak and tired. The gym teacher accused her of not trying hard enough. Dr. Chitnis sent a note into school explaining the disease and its symptoms. If Amanda feels numbness or tingling in her feet or arms during school, she said, "I brush over it and keep going until the symptom passes. I want to stand out at school, but not because I have MS."

Amanda has already had to make some difficult decisions. Her doctor reviewed the medications that she could take. One, Avonex, required an injection once a week, but often made people feel like they have the flu, the doctor told her. The other, Copaxone, involved Amanda giving herself a shot every day, but that drug has fewer side effects. Amanda's mother thought she should choose the once-a-week medicine to minimize the distress of frequent shots. But Amanda went with the daily drug.

"The other medicine needs a bigger needle," she said. "I'd rather do a little bit every night than one

huge needle." She also wanted the drug with the least amount of side effects, she said, because, "I've got people to see and things to do."

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