

Kids Get MS Too

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Multiple sclerosis (MS) is an autoimmune disease affecting the central nervous system (CNS) that involves demyelination, inflammation and axonal destruction. MS is typically diagnosed in individuals between 20 and 50 years of age. While we can't quantify an exact number of children and adolescents with MS, we estimate there to be 8,000 – 10,000 children nationally and another 10,000 – 15,000 children and teenagers experiencing MS-like symptoms.

Many pediatricians, neurologists and nurses have not had much experience with MS in children, due to the low prevalence. The diagnosis of MS in childhood can be challenging and complicated by other more common childhood disorders such as (but not limited to) acute disseminated encephalomyelitis, inherited leucodystrophies, and inborn errors of metabolism. Beyond the challenges of diagnosis, knowledge about optimal treatment for children is unclear, since there is no data on the efficacy and long term impact of treatments on children. The currently used disease modifying therapies for MS are only FDA approved for use in individuals over the age of 18. These treatments are being used off-label, but clearly research studies are necessary.

To address unmet needs of children with MS and their families, the National MS Society is currently funding a network of six Pediatric MS Centers of Excellence in the United States.

The sites see children with MS and related disorders including optic neuritis, acute disseminated encephalomyelitis, transverse myelitis and neuromyelitis optica. Each site involves teams of specialists including adult and child neurologists, a pediatric nurse, pediatric social worker, pediatric neuropsychologist and school liaison.

Multiple sclerosis can affect a child's ability to perform academically. Children with MS, like adults, can face cognitive impairment, severe fatigue, bowel and bladder dysfunction and depression. These symptoms can impact the child's ability to learn and socialize, and have been misinterpreted as behavioral problems.¹ Due to the unpredictability of the disease, symptoms may come and go, which can also be misinterpreted by teachers and families. What complicates the situation further, is the isolation these children and adolescents may experience, not knowing anyone else their age with MS. It is the goal of the network of pediatric MS centers to develop resources for families as well as for schools. Each site has a school liaison prepared to work individually with the affected families and with schools. Additionally, the sites have funds available to financially assist families with travel expenses and care, when necessary.

For more information about pediatric MS or available resources and services please visit the National MS Society website at www.nationalMSSociety.org or call 1-800-344-4867. Contact information for the Pediatric MS Centers of Excellence sites can be found this site.

Editor's note: A more comprehensive article as well as other materials will be available at their booth at the FASN State Conference, February 8 & 9, 2008.

Reference:

1. MacAllister, WS, Boyd, JR, Holland, NJ, et al., for the International Pediatric MS Study Group. The psychosocial consequences of pediatric multiple sclerosis. *Neurology*, 2007, 68:s66-s69.