

February 2020 Newsletter



Pediatric Versus Adult MS, the Same or Different?

According to the National MS Society, approximately 3 to 5 percent of individuals with MS are diagnosed before the age of 16. MS is different for each person, whatever their age. Children almost always have relapsing remitting MS and tend to have multiple symptoms at disease onset. This means the disease alternates between relapses in which symptoms flare up and remissions in which there are only mild or no symptoms. Flares can last days to weeks, and remission can last months or years. [Research](#) shows children tend to have more frequent flares than adults during the first few years after diagnosis. However, they also recover from them and go into remission more quickly than people diagnosed as adults.



The causes of MS are not well understood but are likely to be the same for adults and children. MS is not inherited however genetics appear to play a role in an individual's risk of developing the disease. Children with a first degree relative with MS (a parent or sibling) are 2 to 4 percent more likely to develop MS than the general population. Though no single gene has been identified to cause MS, many [single nucleotide polymorphisms](#)

(SNPs) have been associated with increased risk in children and adults. For example, a [2013 study](#) found 57 SNPs associated with both adult and pediatric onset MS. [Researchers](#) in Canada concluded one SNP ([HLA-DRB1](#)) is associated with increased risk of MS in children.

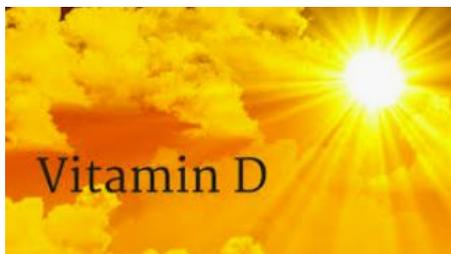
Having these alterations in the [genetic sequence](#) is not enough to cause MS on its own. Instead, a combination of genetic susceptibility and a number of environmental triggers are



generally thought to increase the risk of developing the disease. The onset of puberty increases the risk for developing MS in girls. [Research](#) shows equal numbers of boys and girls are diagnosed with MS before puberty. After puberty, 2 to 3 times more girls are diagnosed than boys which suggests that the hormonal changes that happen at puberty may affect susceptibility.

Exposure to the Epstein-Barr virus (EBV) may act as a trigger for MS in children who are susceptible to it. [Investigators](#) at the Harvard School of Public Health found the chances of developing MS is approximately 15 times higher in individuals infected with EBV in childhood and about 30 times higher among those infected with EBV in adolescence or later in life. Although the underlying mechanisms are unclear, these results provide strong evidence of an association between EBV infection and MS risk. It's important to note that many children are exposed to EBV and don't develop MS.

Low vitamin D levels may not only be a [risk factor](#) for pediatric MS, but are also linked to increased [disease activity](#). The sun is one of the best sources of vitamin D. When [UVB](#)



[light](#) from the sun strikes the skin, the body synthesizes vitamin D3 (the most natural form). MS is found more often in people from Northern climates where there's less sunshine than near the sunny equator. People in Northern climates tend to have lower vitamin D levels. This implies a link between

MS and low vitamin D. The possibility of disease prevention with vitamin D supplementation or increased sun exposure in childhood is an emerging concept that is currently under study.

A number of other environmental factors may contribute to a diagnosis of MS in children. Cigarette smoke, both first-hand use and second-hand exposure, has been [shown](#) to increase the risk of developing the disease. [Research](#) suggests changes in the gut microbiome may affect the chances of an individual developing MS at a young age. There is also [evidence](#) of a significant association between obesity and MS risk in adolescents with genetic susceptibility to the disease.

Most symptoms of MS in children are the same as in adults, including weakness, tingling and numbness, vision problems, difficulty with balance and walking, tremors, spasticity, or slurred speech. Symptoms often seen in children but not adults include seizures and lethargy. As with adults, the symptoms a child experiences depends on which nerves have been damaged.



Since demyelination can affect any part of the central nervous system, the symptoms of MS are unpredictable and vary from person to person. It is unusual for children to have significant physical impairment when they are first diagnosed. There is [evidence](#) that physical symptoms usually increase more slowly in children than in adults but, as symptoms begin at an early age, higher levels of disability are generally reached at a younger age than for people whose symptoms began in adulthood.

Mood disorders occur frequently in children with MS. Depression is the most common, occurring in about [27 percent](#). Other common conditions include anxiety, panic disorder, or bipolar depression. Approximately [30 percent](#) of children with MS have cognitive impairment or trouble with their thinking. The most frequently affected activities include memory, attention span, information processing, as well as executive functions like



planning, organization, and decision-making. [Studies](#) show these symptoms often progress over time in children and may affect their performance at school. However, a small number of subjects showed improvement in their cognitive symptoms over time, suggesting early intervention may be of benefit to address any cognitive difficulties a youth with MS may have.

A [study](#) from the University of California at San Francisco found pediatric MS subjects have more T2 and enhancing lesions than adults. Both have been associated with disability progression in adults. [Researchers](#) in Germany did a post-mortem comparison of brain tissue in pediatric and adult MS subjects. They found more extensive nerve damage in inflammatory demyelinating lesions in the pediatric brains. These data suggest that MS in children may be more inflammatory in nature.

Pediatric MS can cause emotional and social challenges for the whole family. Coping with MS may negatively affect a child's self-image, confidence, academic performance, social life, family relationships, and behavior as well as how they view the future. Watching their child endure a chronic disease like MS can leave a parent feeling helpless and frustrated. While support from caring individuals in daily life can provide some comfort (teachers, friends, family or clergy), the challenges of living with pediatric MS may still feel overwhelming at times. The National MS Society offers a number of helpful resources for all members of the household, including [brochures](#), [support groups](#) and [counseling services](#). The Society's [MS Navigator Program](#) may also provide the information, resources and support families may be looking for.

One of ACP's areas of focus in 2020 will be learning more about the needs and priorities of children and adolescents diagnosed with MS, their parents and family members. There is a robust [pediatric research network](#) in MS, funded by the National MS Society. ACP plans to engage with this existing network of pediatric centers and learn from them in the coming year. We also plan to document the unmet needs of children and adolescents living with MS through literature review, facilitated interviews and two broadly distributed surveys, one to pediatric patients and their families, and the other to health care providers. Ultimately, we plan to inform the iConquerMS program with this information and open the initiative up to pediatric patients. Integrating patient-centered data into the existing knowledge base about pediatric MS will open doors to exciting new possibilities for children living with MS and their loved ones. This is one of the many ways iConquerMS is enriching research on matters of importance to the MS community.

