

December 2020 Newsletter



An Encouraging Look Back – 2020 Newsletter Highlights

The ACP newsletter is one of the ways in which you can learn about MS related topics, new findings in MS research, the latest news from ACP, and our volunteers' contributions. We've covered a wealth of information over the last 12 months. As the year draws to a close, we'd like to review some of our newsletter themes from 2020. For those who would like to revisit any of them, they are just a click away!

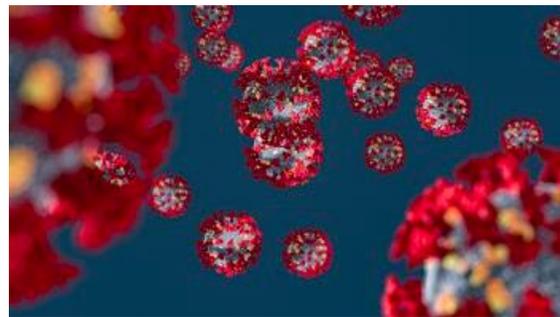


- **Looking for a boost during the pandemic?** There are a number of ways people with MS can [decrease the likelihood and severity](#) of COVID-19 infection. iConquerMS members are participating in research toward finding the [best solutions and outcomes](#) for all affected by MS. [Meet](#) some people with MS that are reaching out and making a difference in their communities during this uncertain time.
- **Thinking about New Year's resolutions?** Some of the smallest [positive changes](#) in behavior can help, for example [quitting smoking](#) and [watching what you eat](#).
- **Curious about aging with MS?** Learn more about the [process of aging](#), including [cognitive changes](#) that may occur, and how [menopause](#) affects women with MS. Read

about whether MS [changes or weakens](#) as an individual gets older and if it is safe to [stop disease modifying therapy](#) (DMT) at a certain age. Check out a number of [helpful therapies](#) that may make life a little easier for MSers of all ages.

- **Frustrated by the [rising cost](#) of MS medications?** [Here](#) are some resources that can help!
- **Does MS affect children, too?** Discover the [causes and symptoms](#) of pediatric MS, as well as how the disease is [diagnosed and treated](#) in youth.
- **How can I help find a cure?** [Join](#) iConquerMS! Network members have played an [instrumental role](#) in advancing [people-centered MS research](#), including contributing to the [development](#) of new MS treatments and the National MS Society's [Pathways to Cures](#) research plan.
- **We are grateful!** Many individuals give of their time and talents to help us in our work. Whether they are assisting with [administrative tasks and other projects](#), [fundraising](#), or serving as a [board member](#), we are grateful to all who contribute to our effort to accelerate MS research and move us closer to a cure!

The coronavirus disease 2019 (COVID-19) is a potentially serious respiratory disease that was first reported last December in China. Since then, the virus has spread to nearly every continent and case numbers continue to rise. The pandemic is a concern for people with MS and other autoimmune neurological conditions



who are receiving DMTs that act on the immune system. These treatments could potentially increase susceptibility to and severity of COVID-19 infection. In May, we discussed a number of ways people with MS can [decrease this risk](#). The unprecedented impact of coronavirus around the world has sparked the need for powerful partnerships to work together to fully understand the impact of COVID-19 on people living with MS, and in general, as well as determine the most effective ways to prevent, treat and ultimately cure this illness. ACP has been a [leader](#) in these research efforts by being the first to collect valuable patient-reported outcome data from iConquerMS network members relating to their experience with COVID-19 and sharing this information with other MS organizations and researchers who are working toward this goal. Collaborations such as these will significantly contribute to finding viable solutions and the best outcomes for all. In May

we also introduced you to [6 individuals](#) who are reaching out and spreading a little cheer in the MS community during the pandemic.



Making resolutions for the New Year is as traditional as making a champagne toast at midnight. MS can put many obstacles in the way of a person's resolve to make healthy lifestyle choices. For some, looking ahead may be uncertain and scary. In other cases, motivation may collapse when symptoms flare. However, in January we covered how some of the smallest [positive changes](#) in behavior can be the biggest spark leading to significant benefit in people with MS. Quitting smoking is one of the most popular resolutions. We also reviewed what researchers are discovering about the [detrimental effects](#) of this habit. Another popular promise for the New Year is to eat a healthier diet. It's important for people with MS to watch what they eat. A food allergy occurs when the body's immune system sees a certain food as harmful. In March we looked at how diet, food and other types of [allergy](#) may, or may not, play a role in MS disease activity.

Over the summer we featured a three-part series on aging and MS. In June we focused on the [process of aging](#) and things people with MS can do to make the most of their elder years. There is evidence that the risk-benefit ratio of DMTs shifts with aging. We also explored the controversial subject of whether or not it is safe to [stop](#) these medications at a certain age. The MS disease process is a complicated one and it evolves over time. An immune response occurs in which the body's own white blood cells attack the nerves in the



brain and spinal cord, causing inflammation. This, in turn, damages the protective covering surrounding the nerves (demyelination). The immune system functions less effectively as a person gets older. In July we investigated the question of whether MS [changes or weakens](#) as an individual gets older. Menopause is a natural part of aging that occurs when the ovaries stop producing hormones called estrogens. In July we also investigated the question of whether menopause may be a [turning point](#) for MS symptom severity and disease progression in women living with the disease. For most people, difficulty with thinking and memory are a natural part of growing older. For those living

with MS, cognitive changes may also occur as a direct symptom of the disease due to the loss of myelin surrounding nerve fibers in the brain. In August we looked at the [difficulties with thinking and memory](#) that may occur as people with MS get older and detailed a wide range of [helpful therapies](#) that may make life a little easier for MSers of all ages.

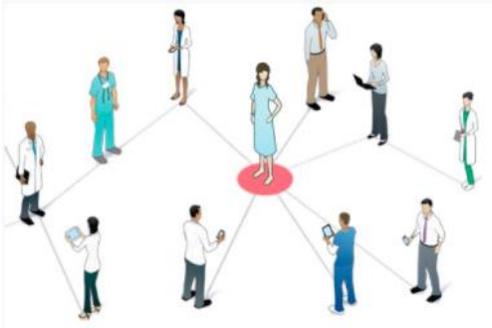


In September we explored the financial side of living with MS. DMTs are treatments that can reduce the activity and progression of MS. Unfortunately, continually [escalating prices](#) have created a significant barrier to obtaining these important medications for many individuals with MS. Having an unpredictable progressive disease like MS is stressful on its own. For those living with the disease, the impact of cost on access to treatments only adds to an already challenging situation. Thankfully, there are a number of [financial assistance programs](#) available to help. In September we offered some suggestions for accessing these resources that may help make the process easier.

According to the National MS Society, approximately 3 to 5 percent of individuals with MS are diagnosed before the age of 16. In February, we explored the topic of pediatric MS, including its [causes and symptoms](#), as well as how MS is [diagnosed and treated](#) in youth. Looking to the future, One of ACP's areas of focus will be learning more about the needs and priorities of children and adolescents diagnosed with MS, their parents and family members. iConquerMS will expand its scope to include pediatric participants in the coming months. Stay tuned!



There is a growing recognition of the importance of incorporating the patient perspective into clinical decision making and research. We explored this [people-centered approach](#) in October. People with MS and their caregivers have a wealth of information to contribute to MS research, gained from their experience living with the disease. This wisdom can be used to deepen the understanding of living with such conditions and help develop sustainable, high quality and efficient care. It can also inform research priorities and mold decisions and policies that shape the way medical products are developed and brought to the marketplace. ACP and iConquerMS are leading the way in the movement to put



people living with MS at the forefront of MS research. In April, we highlighted our collaboration with the National MS Society to ensure the [Pathways to Cures](#) research plan is informed and influenced by the perspectives of people affected by MS. We also featured the key role iConquerMS members have played in [patient-focused drug development](#). In October, we covered [other ways](#) iConquerMS members have helped to advance people-centered MS research and the initiative's exciting plans for the future!

Working with our partners, we've made significant progress in our mission in the last year. iConquerMS has grown and its members have engaged in and helped change the future course of MS research. We are grateful to the many individuals and organizations who support us in so many ways to make our work and progress possible. In the spirit of the holidays, our November newsletter gave thanks for all who contribute to our effort to accelerate MS research and highlighted a few individuals who serve behind the scenes at ACP, including those that have organized [fundraisers](#) on ACP's behalf, our [volunteers](#), and [board members](#). Together, we are working with the research community to improve the quality of care for people with MS and move us closer to finding a cure. We look forward to new possibilities in the upcoming year. Stay tuned and look for updates in future newsletters! Have a suggestion for a topic to be covered? We value your input! Let us know by completing [this survey](#)!

