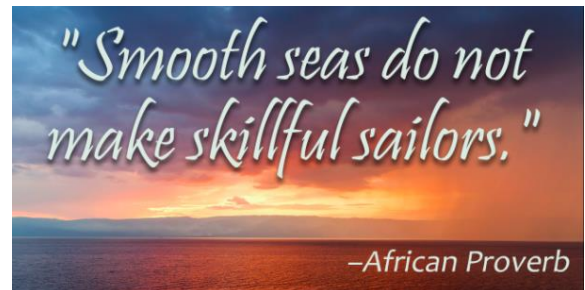


December 2020 Newsletter



A Lot Can Happen in a Year

According to an African Proverb, “Smooth seas do not make skillful sailors.” The events of 2020 have been a challenge for everyone. People’s lives have been turned upside down as activities and livelihoods have been disrupted. Many are struggling with feelings of isolation as gatherings with friends and loved ones needed to be held from a distance, if at all. Despite these hardships, and in partnership with so many committed to accelerating MS research, at ACP we have not only persevered, but rallied in our work toward faster diagnosis, better treatments, and a cure. To wrap up the year on an uplifting note, we bring you the highlights of 2020.



At ACP, collaboration is at the heart of all we do. [iConquerMS](#) has partnered with a number of investigators in the recent past on studies looking at a wide variety of subjects related to living with MS. Network members have contributed valuable data for this research by completing surveys, offered through the iConquerMS portal. It is our pleasure

to share the following study results from the past year and we'd like to thank the participants who made these insights possible.

2020 iConquerMS Research Results and Publications

One of the first research collaborations for iConquerMS looked at the effects of MS adult day programs on health-related quality of life (HRQOL) and health care utilization of people with MS, and HRQOL and wellbeing of caregivers. These programs offer medical care, rehabilitation therapies, nutrition therapy, cognitive training, tailored education, exercise programs, and social interaction. [Results](#), published earlier this year, showed these services had a positive effect for people with MS and their caregivers, although it was not clinically meaningful or sustained. However, another part of the study reported on the [qualitative benefits](#) of these programs. Almost universally, participants felt receiving and giving social support were the most important benefits. Other positive effects included increased emotional well-being, better understanding and acceptance of MS, practical know-how for accomplishing ordinary tasks, increased mobility and improved motor functioning. Participants reported that MS adult day programs have a profound influence on their mental health, much of which they attribute to membership in a socially connected community.

iConquerMS has been a key resource for exploring the COVID-19 crisis and its impact on people with MS. As part of an [international data collection](#), a survey was offered to network members in early April to learn more about how they are dealing with the pandemic and what their personal experience has been with the new coronavirus. Data collected through this effort aims to act as a stimulus to steer ongoing and future scientific research. Over one thousand people from 24 countries have completed the COVID-19 survey to date, the vast majority of whom have been diagnosed with MS and live in the United States. Preliminary results from earlier this year show only 47 individuals were tested for the new coronavirus (9 tested positive) and 145 wanted to be tested but weren't because the test was either not available, not offered by the individual's doctor, or they didn't meet the criteria for testing. Those completing the survey reported difficulties or delays in accessing their healthcare. Many had medical visits or tests postponed or cancelled due to COVID-19. One third of respondents had healthcare visits performed via telehealth as a result of the pandemic. Data revealed the coronavirus and public health response have moderately impacted people's ability to exercise, their financial situation

and their diet/access to food. Responses also revealed that people are experiencing stress, anxiety, boredom, and isolation during the current pandemic. We've recently launched a follow-on survey to see how responses have changed over time. Already a member of iConquerMS? [Log in](#) to respond to the new survey! Not yet a member? [Join now!](#)

iConquerMS recently collaborated with [Icometrix](#) on a survey investigating magnetic resonance imaging (MRI) in people with MS. These data will be used to determine if it is feasible to conduct future research studies that involve this type of scanning. 876 network members completed the survey. Half reported having an MRI for the purpose of diagnosing or treating MS every year. Approximately a quarter said they have an MRI every 2 years and almost 20% indicated they get one less often than every 2 years. Almost a quarter of respondents reported never receiving an electronic version of their MRI, almost 90% of whom said they would like to have received one. Of those that received a copy, almost half received it upon request, 27% got one without requesting it and 3% obtained a copy by participating in a research study. Most subjects (80%) received an electronic version of their MRI on a CD disk, 16% accessed their images through their clinic's patient portal, 4% through a direct download into their computer/device and less than 1% received their scans on a USB-drive. More than 70% of subjects indicated they look at their MRI images on their own, but only 14% reported to completely understand them. The most popular reasons for not looking at MRI images were not being sure how to view the images, not having a software program for viewing the files and not knowing how to interpret the images. Most participants were interested in knowing whether their MRI was performed according to current clinical guidelines for MS and almost all were interested in knowing whether there were any changes between one MRI and the next. The vast majority of respondents were interested in sharing their electronic MRI with a researcher, if asked.



iConquerMS has played an instrumental role in other studies over the past 12 months, many of which are either ongoing or results are still pending. [Research](#) shows that exercise is good for people with MS and may decrease symptoms and improve health and walking ability. [STEP for MS](#) (Supervised versus Telerehab Exercise Program for People with Multiple Sclerosis) is a collaborative effort between seven research sites in the U.S. and iConquerMS. This four-year study is comparing the outcomes of a 16-week exercise program conducted either at home, or in

an exercise facility. The iConquerMS portal is being used for data collection, and to communicate with participants. The researchers conducting the study hope that the findings will make exercise and its benefits more available to people with MS who have problems walking. For another study, ACP is working with researchers from the Veterans Administration to learn more about [telehealth](#) during this uncertain time. This study is particularly timely as the COVID-19 pandemic has caused many MS healthcare visits to be conducted over phone or video. The iConquerMS community was surveyed just before the start of the pandemic and again more recently to determine how many people with MS had a telehealth visit in recent months and what they thought of their remote visit. Their responses will help us better understand the types of people who use or would like to use this new technology and may one day help revolutionize MS care!



[REAL MS™](#) (Research Engagement About Life with MS) is an ongoing study which continues to advance [patient-centered MS research](#). Participants complete detailed questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. A ninth round of REAL MS surveys was recently released through the [iConquerMS portal](#). The information collected through these surveys will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. If you are a member of iConquerMS, please [log in](#) to submit this important information!

iConquerMS is expanding its research collaborations to include caregivers to those living with MS, charting a course toward easing their burdens and improving MS research in the process. ACP has developed an 8-member Care Partner Advisory Board (CPAB) to better



understand the needs and priorities of care partners to those living with MS. The CPAB is just one of the initiatives ACP will undertake to address the considerable burdens of care partners, in an effort to alleviate the substantial impact on the health and quality of life of both

the person providing the support, and the person with MS receiving it. The CPAB members represent a wide variety of care partner roles including spouses to those living with MS, a parent with a young adult daughter who was diagnosed with MS in her teens, and a woman who has provided the primary caregiving for her mother since childhood. The CPAB has met virtually throughout 2020 to identify the challenges faced by care partners, identify resources that currently exist to address those challenges, and to chart out the development of new resources where none exist. The CPAB is working to develop the “Care Partner Protocol,” a living set of recommendations to be provided by health care providers at the time of diagnosis and throughout the MS journey, and it will also be available online. The Care Partner Protocol was conceived by Jon Strum, founder and host of [RealTalk MS](#), and CPAB member. The CPAB work is also guided by Rosalind Kalb, a clinical psychologist and consultant, and Deborah Miller, a director at the Mellen Center for MS Treatment and Research at Cleveland Clinic. Drs. Kalb and Miller each have significant experience in working with and providing support to people living with MS, care partners, and families. ACP is thrilled to be working with the CPAB team and members to advance and accelerate the development of the Care Partner Protocol and to identify and address the substantial needs of MS care partners. Interested in staying in touch about ACP’s activities related to care partners? Please fill out the brief form [here](#).

ACP and iConquerMS are leaders in the growing patient-focused drug development (PFDD) movement. PFDD is a systematic approach to ensure that patients’ experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and evaluation. In 2020, iConquerMS members have participated in focus groups and advisory boards organized by non-profit organizations and pharmaceutical companies. These activities are aimed at better understanding the benefits people with MS are looking for from future MS drugs and obtaining their input on clinical trial design elements such as study activities and outcome measures. This type of input has great potential to influence the therapies that become available for people with MS in the future and the ways in which they are studied. Interested in contributing your experiences and insights to MS research and development? We look for participants among iConquerMS members. If you haven’t already, please consider [joining](#)!

ACP remains committed to overcoming the barriers to participation in MS research for all, creating an inclusive initiative regardless of age, race, orientation, abilities, or location. The iConquerMS diversity, equity and inclusion task force will continue to work to

expand outreach channels to reach minority communities until this goal is achieved and MS research reflects the needs and priorities of all living with MS. iConquerMS has been laying the groundwork to expand its scope to include pediatric participants over the past year and hopes to begin enrolling subjects under the age of 18 in the coming months.



According to Sara Loud, Chief Executive Officer, “We, at ACP, believe accelerating MS research can, and will, result in faster diagnosis, better treatments, and a cure. It is the only way to answer the questions of today, and find solutions in the future to benefit those affected by MS. 2021 will bring new questions about COVID-19 and MS, including how potential vaccines may impact ongoing MS treatments, and how COVID-19 infections will impact the health and well-being of those presently living with MS, and those who will be diagnosed with MS in the future. iConquerMS is the world’s first and only MS people-powered research network. The initiative will be a critical resource in answering these questions and more.” We look forward to an exciting and productive New Year in partnership with all of you! Stay tuned!



An Encouraging Look Back – 2020 Newsletter Highlights

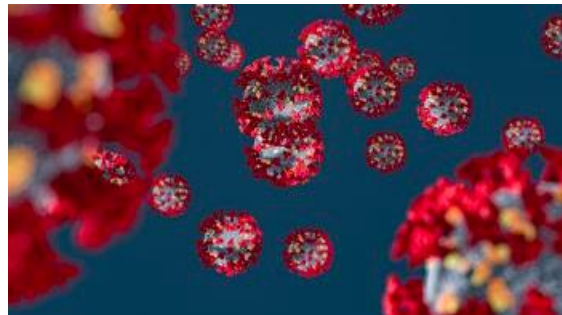
The ACP newsletter is one of the ways in which you can learn about MS related topics, new findings in MS research, the latest news from ACP, and our volunteers' contributions. We've covered a wealth of information over the last 12 months. As the year draws to a close, we'd like to review some of our 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.

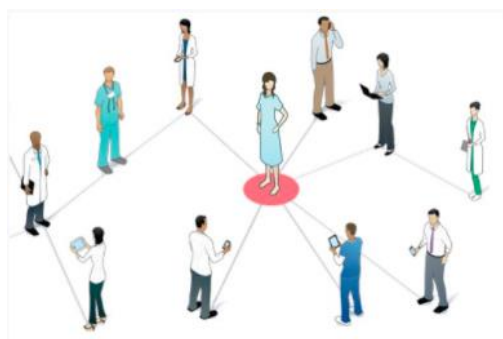
Over the summer we featured a three-part series on aging and MS. In June we focused on the [process of aging](#) and things people with MS can do to make the most of their elder years. There is evidence that the risk-benefit ratio of DMTs shifts with aging. We also explored the controversial subject 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.

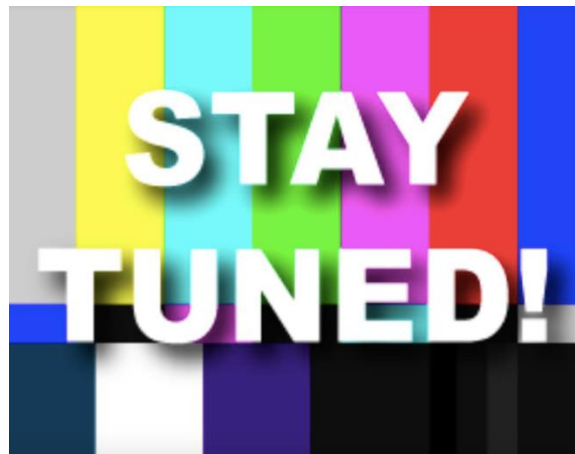
According to the National MS Society, approximately 3 to 5 percent of individuals with MS are diagnosed before the age of 16. In February, we explored the topic of pediatric MS, including its [causes and symptoms](#), as well as how MS is [diagnosed and treated](#) in youth. Looking to the future, One 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](#)!



December 2020 Research Spotlight

RESEARCH OPPORTUNITIES



Coming Soon! Share your experiences with COVID-19 vaccines.

ACP, through its people-powered research network [iConquerMS](#), will soon begin collecting information from people affected by MS related to their experiences with COVID-19 vaccines. The data collected will be securely shared with researchers studying the effects of COVID-19 vaccination on people affected by MS. Already a member of iConquerMS? You'll be the first to know when the survey is launched! Not yet a member? Please [join](#) iConquerMS now and stay tuned! In the meantime, please share your experiences related to the pandemic through the newly launched *COVID-19 Recent Experiences* survey now available on iConquerMS!



What kind of psychological support would you like for living with MS?

Please read on for an invitation from investigators at the University of Reading to participate in one of their studies.

Psychological and medical literature suggests that people with MS are more prone to mental health problems which highlights the need for such services to be made available for this population. There are different types of support available to people with MS, however not all are accessible or suitable to match the varying needs of people living with the disease.

Over the next 18 months our research aims to develop a psychological intervention that is tailored for people with MS. We are inviting you to help us in this endeavor by completing a survey. We are asking individuals living with MS about their experiences of accessing support (positive and negative), and their opinions about what kind of support would be useful. We will use this information to design a psychological intervention that will reflect the views of the MS community.

To read more about this research and take part in the survey, please go to the [University of Reading website](#) and click the 'start' button at the bottom of the page. Or you can go directly to the survey by clicking [here](#).



Real MSTM (Research Engagement About Life with MS)

In the summer of 2016, the iConquerMS initiative launched REAL MS, a longitudinal study of MS. REAL MS participants complete questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. A **ninth round** of REAL MS surveys are now available through the [iConquerMS portal](#). Completing these surveys is one of the simplest ways you can accelerate MS research. The information collected will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. REAL MS is just one of the many ways iConquerMS is facilitating research on topics of importance to people affected by the disease. If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS. Already a member? Please [log in](#) to your account and complete your open surveys!



New Year, New You

Study Title: Step for MS (Supervised versus Telerehab Exercise Program for People with Multiple Sclerosis)

Study Purpose:

New research shows that exercise is good for people with MS and may decrease symptoms and improve health and walking ability. An exercise study called *STEP for MS* will compare the outcomes of a 16-week exercise program conducted at home to a program conducted in a gym. The researchers conducting the study hope that the findings will make exercise and its benefits more available to people with MS who have problems walking.

This Study Involves:

Participants will exercise two times per week for about one hour each session for 16 weeks. A trained “coach” will help participants learn how to exercise and will provide encouragement throughout the program. Participants will take assessments before starting the program, two months into the program, at 16-weeks when the program ends, and at 6 and 12 months after starting the program.

Eligibility:

If you are between the ages of 18 and 65 years and you have Multiple Sclerosis you may qualify if you:

- Can **walk** but you have **some difficulty**, with or without a device
- **Do not exercise** regularly
- Have not had a **relapse** in the past month
- Can commit to **train 2 times a week for 16 weeks**
- Can **drive to study site** for assessments and potentially for exercise training
- Have reliable **internet access**

Participating Locations:

- Massachusetts General Hospital, Boston, MA (**new site now open!**)
Contact: Dr. Plumer 617-724-3103/ PPlummer@MGHIHP.EDU
- Shepherd Center, Atlanta, GA
Contact: Erica Sutton at 404-367-1305
- Cleveland Clinic, Mellen Center, Cleveland, OH
Contact: Darlene Stough at 216-445-5877/ stoughd@ccf.org
- University of Colorado, Denver
Contact: Alexa Vareldzis: neurologyresearchpartners@cuanschutz.edu / 303-724-4644
- University of Alabama, Birmingham
Contact: Petra Silic at 205-975-1306/ petra09@uab.edu
- University of Georgia, Athens
Contact: Megan Ware at 423-260-5045/ megan.ware20@uga.edu
- Marquette University, Milwaukee, WI
Contact: Heidi Feuling at 414-288-6209/ Heidi.feuling@marquette.edu
- University of North Carolina, Chapel Hill
Contact: Rachel Keen at 704-877-5636/ rayray@live.unc.edu

For more information, please visit our

website: <https://www.iconquerms.org/welcome-step-ms>