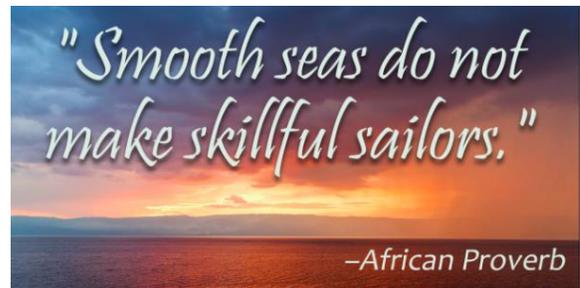


December 2020 Newsletter



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!

