

October 2020 Newsletter



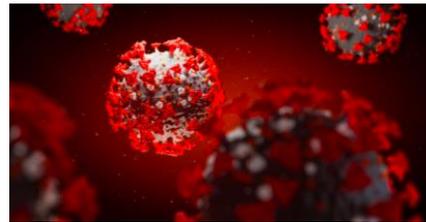
Transforming MS Research and Improving MS Care



iConquerMS is a people-powered research network developed to advance and accelerate people-powered research in MS. This initiative was co-designed with people affected by MS and all research done through the initiative is done in close collaboration with its members. Network members participate in many kinds of activities, such as participating in research, helping design studies and products, and making suggestions about future research they'd like to see performed. In addition, iConquerMS participants provide data about their first-hand experience living with MS by completing their REAL MSTM surveys and through other means. These data are made available to investigators, and also to help inform the healthcare decisions of others living with the disease. This collaboration between people affected by MS and the research community is part of an effort to transform MS research, improve the quality of care for MS patients and may one day play a significant role in finding a cure. iConquerMS leads the way in bringing the patient voice front and center in MS research.

The initiative has played a significant role in responding to the COVID-19 crisis and its impact on people with MS. As the pandemic unfolds across the globe, the demand for data on the impact of the virus on the MS community grows rapidly. This information is

crucial for those living with the disease and their healthcare providers to make evidence-based decisions on how to manage their condition during the pandemic or in case of a COVID-19 infection. ACP joined an [international data collection](#) created by the [MS Data Alliance](#) and the [MS International Federation](#). As part of this effort, a survey was launched on iConquerMS to learn more about how network members are dealing with the pandemic and what their personal experience has been with the new coronavirus. These data may help researchers gain insight into such important questions as whether or not the risk factors for COVID-19, or the proportions of severe coronavirus outcomes in people with MS differ from those seen in the general population. In addition, does the type of MS treatment an individual may be taking have an effect on COVID-19 outcome? This powerful international collaboration aims to act as a stimulus to steer ongoing and future scientific research.



The COVID-19 pandemic has caused many MS healthcare visits to be conducted over phone or video. ACP is working with researchers from the Veterans Administration to learn more about telehealth during this uncertain time. 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 be used to advocate for healthcare options that are the most helpful for people with MS.

Each autumn, the iConquerMS governance and other stakeholders in the MS community gather at the initiative's [Leadership Summit](#) to discuss the future direction of iConquerMS. iConquerMS has made significant progress in many areas of focus discussed at recent meetings. For example, to learn more about the unmet needs of caregivers, ACP partnered with a sister organization supporting families coping with Alzheimer's disease on a survey about the challenges and concerns of providing care to a loved one with MS.



Network members who are caregivers and partners to those members living with MS, provided input on how caregiving affects their health and quality of life, as well as how they feel about interactions with healthcare providers. Data collected from the survey will be used to create educational materials for caregivers and healthcare providers alike. Ageism in MS

research and care was another area of focus suggested at a previous Leadership Summit. Historically, MS clinical trials have had age restrictions that have limited the participation of people with MS over the age of 55 (resulting in missing important data). To fill in these gaps and to determine a pathway forward, network members of all ages have provided information about the care they receive and researchers have ready access to these data.

iConquerMS participants are able to suggest research topics or questions for future study. To shed light on the subject of MS, reproduction and parenthood, EMD Serono, in collaboration with ACP, recently released a 5-part educational podcast series, called “Uncovering Sex in MS: A Dialogue About Sex, Parenthood and Hormones.” A number of network members participated in this opportunity. The podcast series, hosted by Jon Strum of [RealTalk MS](#), offers practical perspectives from clinicians on their experiences with female and male preconception counseling, postpartum planning, sexual dysfunction, and the potential impact of aging-associated hormonal changes on MS disease course.



The iConquerMS network has also been instrumental in investigating alternative approaches to MS disease management. [Research](#) shows that exercise is good for people with MS and may decrease symptoms and improve health and

walking ability. STEP for MS is a clinical study comparing the outcomes of a 16-week exercise program conducted at home to a program conducted in a gym. 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. [Qigong](#) is a Chinese exercise technique that involves controlled movements, breathing and meditation. Researchers at [TheSwitchVR](#) and Virginia Tech are developing a study to understand how people with MS think and feel about practicing Qigong using an online library of videos. Not only will input from the iConquerMS community play an instrumental role in improving and finalizing the study design, but researchers hope to use the iConquerMS portal for data collection and invite network members to participate in the study.

iConquerMS is working with [Icometrix](#), a company that has developed software and services that help healthcare providers view, store, and analyze medical images. Network members



have provided information regarding whether people with MS have access to their own MRI files and if they're interested in viewing, understanding, and/or sharing their MRIs. These data will be used to determine if it is feasible to conduct future research studies that involve MRIs.



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. iConquerMS members have been invited to participate in several different focus groups and advisory boards organized by non-profit organizations and pharmaceutical companies. These activities are aimed at better understanding what people with MS are looking for in terms of the benefits provided by 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. At the end of 2019, EMD Serono initiated a clinical trial ([EVOLUTION RMS 1](#)) studying the efficacy and safety of evobrutinib. Prior to the initiation of the trial, ACP entered into a year-long partnership with EMD Serono to ensure the patients' complete MS experience was captured and meaningfully incorporated into the design and implementation of this trial. As part of this collaboration, eight members of the iConquerMS community were invited to participate in a PFDD Council. The Council worked closely with the iConquerMS project team and team members from EMD Serono. The collaboration between iConquerMS and EMD Serono is the first of its kind in MS drug development research. Feedback from the Council has had a lasting effect in the whole spectrum of what is important in drug development throughout the industry.

iConquerMS has a number of ongoing initiatives which continue to advance patient-centered MS research. REAL MS™ (Research Engagement About Life with MS) is a longitudinal study of MS. 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. In addition, ACP and the National MS Society are working in partnership on the Society's [Pathways to Cures](#) research plan. Data collected from iConquerMS members is being used to inform Pathways to Cures activities by providing both quantitative and qualitative feedback from the iConquerMS community, representing the broad perspective of those affected by MS.

My Research Surveys

New | In Progress | Completed

- REAL MS - Demographics >
- REAL MS - MS History >
- REAL MS - Overall Health >
- REAL MS - Quality of Life >
- REAL MS - Other Conditions >
- REAL MS - Physical Activity >
- REAL MS - Demographics - Summer 2016 >
- REAL MS - MS History - Summer 2016 >
- REAL MS - Overall Health - Summer 2016 >

Looking to the future, iConquerMS will continue to focus on the needs and priorities of the MS community. The initiative's diversity, equity and inclusion task force will continue to work to expand outreach channels to reach minority communities, as well as methods to evaluate the success of these efforts. For example, iConquerMS is conducting a special outreach to communities of color to tell them about the initiative and their ability to influence COVID-19 research in MS. iConquerMS also hopes to expand its scope to include pediatric participants. The initiative will continue to work to further PFDD and address the unmet needs of caregivers. Want to be a part of the movement to put patients at the center of MS research? If you haven't already done so, please consider [joining](#) the iConquerMS community today and add your voice to the thousands already driving people-centered MS research forward!

