

# November 2021 Newsletter



## Collaboration – We’re Better Together

According to [dictionary.com](https://www.dictionary.com), “Collaboration is the act of working together, especially on a goal or shared project.” Since its inception, collaboration has been at the heart of ACP’s work and mission. The [ACP Repository](#) was established in 2006 as a source of high-quality samples and associated data that is readily available for MS research studies. If samples are used, researchers must return their results to the Repository database, so they can be shared with others (thus fostering collaboration within the research community). [iConquerMS™](#) was launched in 2014 as the only people-powered research network in MS. This powerful initiative brings together and enables people with MS, their care partners, researchers, healthcare providers and others to work together to help drive MS research forward. According to ACP’s CEO Sara Loud, “To me, the collaborative nature of our work is most exciting... A complex disease like MS is unlikely to be cured in a fragmented research environment. There is a tremendous need for collaboration in order to accelerate MS research toward better ways to diagnose, treat, and eventually cure the disease.”



ACP and iConquerMS are changing the landscape of MS research by increasing the awareness of and engagement in [participant-powered research](#) (PPR). We are grateful for all that have partnered with us to make this movement possible. Over the past seven years, iConquerMS leaders, network members, researchers, healthcare providers and other advocacy organizations (among others) have joined in an ongoing collaboration to determine ways to successfully drive PPR forward. The group has worked to engage researchers and inform them of the potential iConquerMS holds as a powerful resource for their studies. They've helped investigators better understand the patient perspective and create research plans collaboratively to ensure they are "doable" for intended participants. Facilitating funding for PPR has also been a main area of focus. This cooperative effort has been and will continue to be an activity that brings together all of the major stakeholder groups in MS research.



[iConquerMS](#) has partnered with a number of investigators on studies looking at a wide variety of subjects related to living with MS. For example, [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 compares the outcomes of a 16-week exercise program conducted either at home, or in an exercise facility. 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. iConquerMS has also been a key resource for exploring the COVID-19 crisis and its impact on people with MS. As part of an [international data collection](#), network members were polled in April 2020 to learn more about how they were dealing with the pandemic and what their personal experience had been with the (then) new coronavirus. Data collected through this effort is acting as a stimulus to steer ongoing and future scientific research. In collaboration with researchers at Case Western Reserve University and Massachusetts General Hospital, the iConquerMS research team is conducting the [COVER-MS study](#) ([C](#)OVID-19 [V](#)accinE [R](#)esponse in [M](#)S) to collect information from iConquerMS members related to their experiences with COVID-19 vaccines. These real-world results provide a better understanding of the effects of these vaccines in the MS population. We look forward to more exciting research collaborations in the future!



ACP remains committed to overcoming the barriers to participation in MS research for all living with the disease, regardless of age, race, ethnicity, orientation, abilities, or location. In order to diversify its membership, iConquerMS is forming a RIDE Council (Research, Inclusion, Diversity and Equity) that will come together with people in the MS community who belong to underrepresented groups, invite them to join the iConquerMS network, and brainstorm ideas on how to better serve their community. The [MS Minority Research Engagement Partnership Network](#) (MREPN) is a multi-stakeholder network, founded and led by ACP, that has come together to define and address the issue of racial/ethnic minority underrepresentation in MS research. The group has designed and implemented important resources for [community partners](#), [healthcare](#) and [research professionals](#) aimed at increasing the participation of minorities in MS research so that it reflects the needs and priorities of all living with MS and all can receive the best care.



Care partners play an essential role in the lives of people with MS. They are also a valuable resource of information for MS research. Unfortunately, the health and well-being of care partners are often compromised by the demanding and relentless role they hold. ACP has a new initiative to intentionally expand iConquerMS enrollment to include care

givers as research partners. Through this effort, caregivers will be able to participate in iConquerMS in two dimensions – both as an observer and partner to the person living with MS, and as a person with their own needs and priorities. Input and data from this often-overlooked group has the potential to improve healthcare and outcomes not only for people affected by MS, but for the general population. ACP’s work with caregivers has benefitted greatly from the guidance and insights shared by members of its Care Partner Advisory Board (CPAB), a dedicated group representing a wide variety of care partner roles and experiences. A newly formed iConquerMS Care Partner Engagement steering committee will include some members of the CPAB, working in collaboration with researchers, healthcare providers, and funders to guide the work ACP is doing to expand iConquerMS.

Over the past year, iConquerMS has been laying the groundwork to expand its scope to include the MS pediatric population and will be able to begin enrolling iConquerMS participants under the age of 21 and their loved ones in the coming year. This will be accomplished alongside and

in a way that is similar to the care partner expansion of the network. This effort is being overseen by a steering committee comprised of youth and parents living with MS, and is co-led by [Emily Blosberg](#), founder of [Mr. Oscar Monkey](#). Through this powerful collaboration, families will be able to contribute valuable data to shed light on many aspects of living with pediatric MS, help steer the future direction of MS research, and may one day play a role in unlocking the answer to a cure.

Samples from the ACP Repository have played an instrumental role in understanding the genetic underpinnings of MS. The [International MS Genetics Consortium](#) (IMSGC) is an international cooperative, composed of members from academic institutions all over the world, founded on the principle that collaboration will lead to more rapid progress than can be achieved individually. In 2019, the IMSGC published the largest MS genetics [study](#) to date. As part of this research, DNA samples from the ACP Repository helped to confirm 233 variations in the human genome that contribute to the risk of developing MS. The variations were found to influence many different types of immune cells and tissues, indicating that general dysfunction in the immune system underlies the onset of MS. The study also identified a genetic variant for MS on the [X chromosome](#), which could be an interesting lead to investigate why women are more likely to develop MS than men (women have two X chromosomes while men have one). The IMSGC is a prime example of the collective power of patients, researchers, and funders coming together to accelerate important research into the genetic markers that are associated with MS. In 2018, the entire [exome region](#) of the more than 3,200 DNA samples in the ACP Repository was sequenced as part of a [collaboration](#) with Regeneron Genetics Center. Combining this new genetic information with the extensive participant and clinical information collected for each ACP Repository participant will lead to new insights into the causes and mechanisms of MS. Threads from this research are generating additional collaborations, which will expand the pool of returned data that researchers can draw from as they work to understand the mechanisms of MS. All ACP Repository participants have contributed to this unprecedented combined data set. Thank you!





ACP's partnerships with [RealTalk MS](#) and [Smart Patients](#) help people with MS learn about, talk about and engage with research and with each other. As a member of the [MS Coalition](#), ACP is able to come together with other MS nonprofit organizations and leverage its resources for the benefit of the entire MS community.

According to Sara Loud, "None of our work would be possible without our partners. I am grateful for the collaboration of our iConquerMS members and our Repository participants, for the researchers who engage with us to advance their work and the funders who make that work possible, for the leaders in other nonprofit organizations and throughout industry who share our desire for better outcomes for those impacted by MS, for the donors who support ACP in recognition of the importance and value of our contributions to accelerating research and innovation to improve the lives of those affected by MS, and to all of you who guide us with your insights and feedback. The list of those who make our work possible is long... We are guided by the needs and priorities of those affected by MS and can only do our best work when you are part of it. I am looking forward to all we will accomplish together in 2022 and beyond."

