2022 Highlights from iConquerMS

People living with MS are the heart and soul of iConquerMS. A primary objective of the initiative is to enable all people living with MS to drive, shape, and accelerate research. Network members are able to not only contribute data about their MS experience, but also steer the direction of research by contributing their ideas. Ideally, tens of thousands of people from all parts of the country, from all backgrounds and ethnic groups, and of all ages and stages of living with MS will participate. This diversity will create a rich, interactive resource for MS research. This innovative program has made significant progress toward realizing this vision. In 2022, the network has grown to over 8,500 adults living with both relapsing remitting and progressive forms of MS. Here’s a look at some of the other milestones we’ve reached in the past year:

Expanding and Enriching the Network

♦ Welcoming children, adolescents and their family members to iConquerMS! Support for pediatric MS within the network is being designed and implemented based on input from individuals in this very important age group and their loved ones. We look forward to partnering with pediatric MS researchers and healthcare providers to support their work!
Supporting MS caregivers - Care partners are the backbone of many families. We have a few initiatives underway to support those in this important role. With help and feedback from MS caregivers, we are expanding iConquerMS to include MS caregivers in the network (stay tuned for the launch!). We are also working to develop a “toolkit” to provide access to resources to address many of the situations caregivers face. Are you an MS caregiver that wants to share your insights? Take a short survey here!

Investigating Topics That Matter to the MS Community

Working together to defeat COVID-19! The COVER-MS study, conducted via iConquerMS, provided important information about the safety of COVID-19 vaccination in people with MS. The study is still open and we are now exploring vaccination efficacy by measuring antibody response. You can learn more about this sub-study here. Interested to learn more? Email us at info@iConquerMS.org.

Helping people with MS succeed in the workplace - Our newest research survey gathered information about work-related challenges and resources for people with MS. The results will be used to develop personalized tools to help them make employment decisions and access resources to stay employed.

Advancing Participant-Driven Research

Our Questions Have Power! iConquerMS members not only help conquer MS by confidentially sharing their health information, they can also power MS research with their questions and priorities. The Our Questions Have Power program was launched in 2021 with an initial focus on COVID-19. Earlier this year, we
extended it to include a second topic: MS symptoms and their management and treatment. iConquerMS participants are invited to share the questions on this topic they think should be studied and to vote on questions submitted by others. These questions will be shared with people affected by MS, researchers, healthcare professionals, advocates, and funders — and, together, we’ll work to launch research studies to answer them.

Disseminating Research Results

♦ Check out a new iConquerMS website feature! The iConquerMS community has made many studies possible over the years. Our new Research Projects page is a convenient place to track their status, see summaries of the work being done and review research results!

♦ Want a chance to connect with MS researchers? New this year, the Chat with Chat webinar series enlightens us about the researchers working with iConquerMS, what they study and how their work will benefit people with MS. Ten episodes have aired to date. We thank Chat Ngorsuraches for hosting this exciting program and look forward to what he has in store for us in 2023!

iConquerMS members are part of a community that is making a difference! Not already an iConquerMS member? Please consider joining today. Together, we can make an even greater impact advancing relevant, participant-driven MS research in 2023!