iConquerMS™ -- Research Driven by You!

Have you ever wanted to tell MS researchers what topics you thought they should study? Or wished you had more opportunities to participate in MS research? Or felt that your knowledge as a person with MS could help in designing clinical trials or new products for MS?

If you have, we have an online community for people like you who want to engage in, learn about, and influence MS research. This community is called iConquerMS™, and its members participate in many kinds of activities, from joining research studies, to helping design studies and products, to sending in suggestions about the research they’d like to see performed.

We wanted to share a few of the many research activities that have happened recently in iConquerMS. If you’re an iConquerMS member, you may have been involved in some of these activities. And if you’re not already a member, we hope you’ll sign up to contribute your ideas, information and experience going forward! Just go to iConquerMS.org to learn more and enroll.
For the American Committee on Treatment and Research in MS (ACTRIMS) meeting in February, we showed the general characteristics of our members and highlighted the effects of MS that appear to affect people the most, such as fatigue and sleep disturbance. (Download this poster here.)

In May for the Consortium of MS Centers (CMSC) meeting, we presented insights about our members’ perception of stigma and their satisfaction with their social roles and activities. (Download this poster here.)

REAL MS: REAL MS™, aka Research Engagement about Life with MS, is the flagship research project of iConquerMS. REAL MS is what is called a prospective survey: we collect information from our members when they join iConquerMS, and then ask for updated information every 6 months thereafter.

We’ve conducted two updates so far and are starting to build a detailed picture of our members’ health and quality of life over time. With data from over 2,200 iConquerMS members in hand, we’ve begun analyzing the responses to learn about life with MS and are sharing our findings at conferences:
Later this summer we’ll be releasing the 3rd round of surveys, which will include improvements and new topics and questions suggested by our members. We look forward to a great response and the ability to answer many more questions about life with MS, thanks to the help of the iConquerMS community!

**Other Studies:** Last year, iConquerMS members were invited to be part of a study led by Dr. Deborah Miller of the Cleveland Clinic on the topic of **insurance coverage and concerns**. This May, Dr. Miller and her colleagues presented two posters at the CMSC meeting with a variety of findings. For instance, most of the study participants reporting having health insurance, but over half of them were concerned about losing this insurance if their employment situation changed. Also, fewer than half of the participants had disability or long-term care insurance that would provide support if they became disabled. You can see the abstracts for these posters [here](#) and [here](#).

The study team is now working on additional analyses and publications, and the National MS Society will be using the results in its public policy and educational efforts.

In May, ACP invited iConquerMS members and others to take a survey on **research participation and perceptions** among people with MS. We noticed that racial and ethnic minority groups were not fully represented in iConquerMS or the ACP Repository, or in clinical trials and studies performed elsewhere. So we applied for funding from the Patient-Centered Outcomes Research Institute to study the reasons behind this imbalance. This survey will help us understand which factors are most important to focus on in research-related outreach efforts. We’ll share the findings of the survey and will ask for ideas for follow-up activities that might help encourage research participation in a wider group of people.
Coming up next: a study to learn about the most valuable characteristics of MS medicines for people with MS. Lots of conversations are taking place among health care leaders, politicians, and organizations about the price and value of drugs. But the voice of people living with MS hasn’t been included as much as it should be. Working with Dr. Surachat Ngorsuraches from South Dakota State University, we’ll be sending a group of iConquerMS members a survey that asks them to compare and choose between pairs of hypothetical MS therapies. The results of this study will contribute to efforts to ensure that people can get access to their therapy of choice.

Research Input Opportunities: People with MS are experts about living with and managing the disease, and each individual with MS has a unique and valuable set of insights. Researchers are increasingly recognizing how useful those insights could be when planning their studies, and are coming to iConquerMS for help connecting with this expertise.

Recently we helped a biotech company invite people with MS to a one-day patient advisory board. They were designing a clinical trial for a new MS drug and wanted to make sure it was designed and communicated as effectively as possible. The input from our members will help ensure that the trial can be completed successfully.

We also helped a team of engineering students from Arizona State University who were developing an auto-injector support device and needed input on their design. Many iConquerMS members viewed the team’s video online and provided constructive feedback. The students have all graduated, but one of them is pursuing further development of the device and hopes to bring it to market!

Over the next few weeks, we’ll be inviting iConquerMS members to talk with the founders of a start-up company. They’re developing products to support people with MS and their doctors in making healthcare decisions, and want to know more about the experience of being an MS patient. One-on-one interviews will help them create products that meet the needs of people with MS.

Do you want to share your expertise as a person with MS? Join iConquerMS, and be sure to complete your REAL MS surveys so we can match you up with the right opportunities!