



## From ME but about YOU: iConquerMS™ People Power Grows!

I'm overwhelmed by everything that iConquerMS™ has achieved since its national launch in February 2015. Just over 18 months since the launch of this very active engaged network of people with MS whose goal is to accelerate research on topics that matter most to them, **YOU** have contributed to the following achievements.

- Over 3,100 people (YOU) have joined the movement, from all parts of the world and all walks of life, with a majority of YOU filling in the questionnaires that form our growing database of MS disease experience.
- Hundreds of YOU have provided online input on research projects, expressing YOUR preferences for what questions should be studied and how studies should be conducted. YOUR input guides iConquerMS™ like a North Star.
- We launched our signature research project, REAL MS™, in August this year. This long-term study will collect information over many years from YOU and people like YOU, to help YOU and researchers learn about factors that affect YOUR health and quality of life (see story on page 2).
- All of the major MS patient advocacy organizations, including the National MS Society, Multiple Sclerosis Foundation, MS Association of America and CanDo MS, are supporters of iConquerMS™, encouraging people like YOU to register and get involved.
- Our lead funding organization PCORI recognized the value of YOUR participation and our work together by providing an additional \$1.35 million in funding for a three-year period, running from September 2015 to September 2018.
- PCORI also awarded Accelerated Cure Project for MS a \$250,000 Engagement Award, to support development of the *Multiple Sclerosis Minority Research Engagement Partnership Network*, an inclusive outreach program that leverages synergies with iConquerMS™ to get a greater diversity of people with MS involved in research (see story on page 5). Can YOU help with this initiative?
- iConquerMS™ will participate in a \$4 million research study called *Healthy Mind, Healthy You*, comparing stress management approaches, following input from YOU that stress and mood disorders associated with MS are high-priority concerns.
- YOU have been invited to participate in our first two collaborative studies, one conducted by the Westat research company, to assess the benefits of MS adult day programs, and the other led by Dr. Deborah Miller at Cleveland Clinic to learn about insurance access and concerns among people like YOU.
- The iConquerMS™ Research Committee, comprised largely of people like YOU who are living with MS and who have research experience, has developed research policies to guide all our networks research endeavors.
- YOUR network received unrestricted (no strings attached) contributions from two major biopharmaceutical companies, Biogen and Genentech, supporting iConquerMS™ leadership meetings and a series of meetings, called Research Studios, connecting people with MS to researchers in collaborative discussion. Some of YOU participated in these meetings that were filled with enthusiasm for the initiative's mission.

## Where do we go from here?

As iConquerMS™ grows with help from YOU spreading the word, so does the extensive national network of networks that iConquerMS™ is linked with. PCORnet, comprised of 20 People-Powered Research Networks and 13 Clinical Data Research Networks now encompasses an estimated 145 million Americans, almost half the US population!! That means PCORnet, as a whole, likely includes over 200,000 people with MS. What a tremendous resource for asking and answering questions about MS that matter to YOU. YOU and researchers working together must find creative ways to liberate the power in the super-network that we have created together with people like YOU who have other medical conditions. Together with YOU, researcher and other people with a variety of medical conditions are on the verge of posing personal, scientific and clinical research questions through PCORnet, thereby building out an unprecedented digital resource for research into hundreds of diseases, including MS.

YOU are probably excited by what we've accomplished together so far. But YOU should be far from satisfied. In coming months, we will continue our efforts – led by, informed by, and driven by YOU. Everyone like YOU who has pioneered and participated in this initiative to date deserves to take a bow and receive a round of applause.

ONWARD!!!

Best wishes to all,



**Robert McBurney,**  
Co-Principal Investigator, iConquerMS™  
CEO, Accelerated Cure Project for MS

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## REAL MS™: Based on Real Outcomes that Lead to Real Knowledge

Have you ever wondered:

- How well do the available MS treatments affect health, symptoms, and quality of life for different people?
- How helpful is exercising, in terms of short-term and long-term benefits?
- What can people living with MS expect to happen over time?

So have we! And now there's a way that **every person with MS** can help answer these questions.

iConquerMS™ recently launched REAL MS™, an on-going study of multiple sclerosis intended to answer important questions about the effects of MS across all people living with the disease, and identify factors and strategies that affect MS outcomes. REAL MS™ (Research Engagement About Life with Multiple Sclerosis) includes a diverse population of thousands of individuals living with MS (YOU!), who participate by answering online questionnaires about health, activities, employment, and other topics. In the future participants will also have the option of providing biosamples for scientific analysis.

REAL MS™ is modeled on the Framingham Heart Study, a community-based research study that has had a profound impact on the understanding of the causes of heart disease and how to treat and prevent it. REAL MS™ has the potential to help answer many important questions that people with MS seek answers to. For instance, in the future, REAL MS™ could provide information about which drugs and supplements work best for which people, which symptoms have the biggest impact on quality of life, or what people can expect from lifestyle changes such as diets and exercise programs. All REAL MS™ research findings will be openly and promptly shared with the MS community.

The current set of questionnaires included in REAL MS™ cover topics such as MS status, demographics, quality of life, overall health, other health conditions, and physical activity. The choice of topics was guided by the input of people with MS, and REAL MS™ participants are asked to suggest additional topics for inclusion in future REAL MS™ surveys.

"Those of us living with multiple sclerosis are very excited by the launch of the REAL MS™ study," noted Laura Kolaczowski, Lead Patient Representative and Co-Principal Investigator of iConquerMS™. "We see it as the first-ever opportunity for active involvement of participants in determining which research questions will be studied and how research protocols are designed. Those of us who live with MS now have a voice in research, and if as a result, new knowledge emerges to guide our treatment choices based on individual characteristics, the impact will be tremendous."

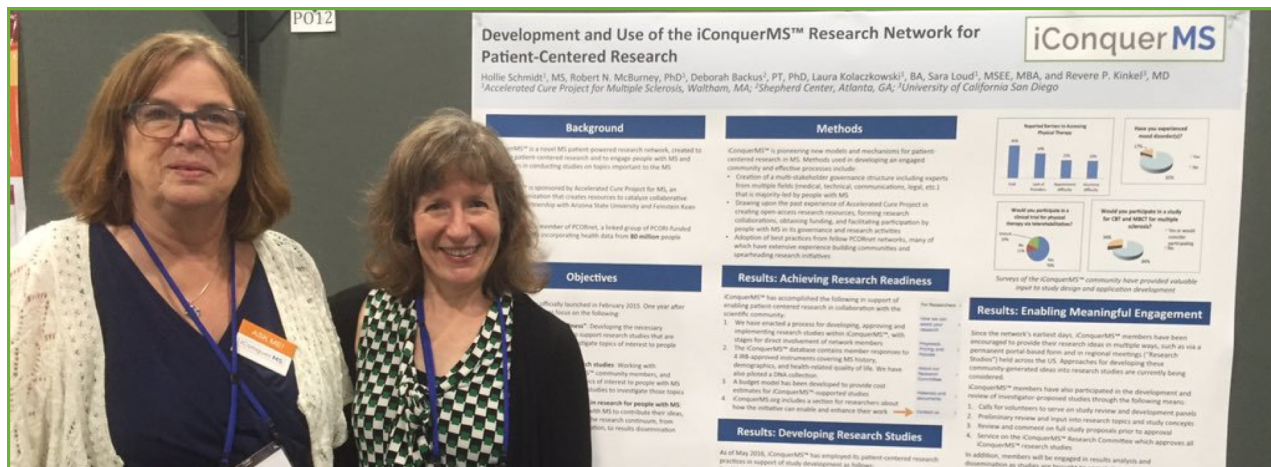
Becoming part of REAL MS™ is easy. If you are a registered participant of iConquerMS™, just log onto [www.iconquerms.org](http://www.iconquerms.org) and complete the surveys on your dashboard. If you are not yet officially registered for iConquerMS™, just visit <http://www.iConquerMS.org/join> to get started!

## Did you know?

When you participate in REAL MS™, the information you provide helps us invite you to events, opportunities, and studies that are available to you. For instance, we recently invited REAL MS™ participants with primary-progressive MS to join an expert panel for an experimental drug.

**Don't miss out – take a few minutes to participate in REAL MS™!**

## iConquerMS™ Presents at CMSC Meeting



iConquerMS™ believes in community – and that includes caregivers, physicians, nurses, and all those who care for and about people living with MS.

As a result, each year representatives of iConquerMS™ attend the annual meeting of the Consortium of MS Centers (CMSC), which seeks to provide MS healthcare professionals with the most up-to-date information to improve both clinical practice and research.

The comprehensive care model that CMSC supports is focused on a wide variety of approaches and activities including, among others, basic and translational research, disease modifying treatments and new and emerging therapies, disease management, symptomatic care, MS collaborative care, advocacy issues, and quality of life strategies. Since the research capabilities of iConquerMS™ could touch on and be of help in all of these areas, CMSC annual meeting attendees found our initiative (presented in a poster session by Hollie Schmidt) to be of great interest.

There was also an iConquerMS™ booth in the CMSC exhibit hall which was staffed by representatives of the iConquerMS™ leadership including Karen Jackson, Cheri Binns, Lisa Emrich and Laura Kolaczowski. We had many enthusiastic discussions with healthcare providers, researchers, and people with MS that stopped by to learn about iConquerMS™.

Attending meetings like CMSC is an important way that iConquerMS™ connects those living with the disease to the health care and research communities!



## iConquerMS™ Now Easy to Enroll Via Mobile Devices

Visitors to the iConquerMS™ portal commented that when they are on the go, it would be great to log onto the site via their iPhone or other mobile device.

In September, we launched a new site design at iConquerMS.org with a mobile-friendly display. Take a look and let us know what you think!

To fill in iConquerMS™ surveys and questionnaires, please use your PC or desktop computer to log into iConquerMS.org as these pages are not yet mobile-friendly.

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## PCORI Engagement Award to Help Increase MS Research Participation by Underrepresented Communities

A team led by the Accelerated Cure Project for Multiple Sclerosis (ACP) has been approved for a Eugene Washington PCORI Engagement Award by the Patient-Centered Outcomes Research Institute (PCORI) to support development of the *Multiple Sclerosis (MS) Minority Research Engagement Partnership Network*, a collaboration designed to identify and address disparities and increase participation by underrepresented communities in MS medical research.

Although MS has traditionally been thought of as a Caucasian disease, recent studies show that African Americans may have the highest risk of MS, and experience more aggressive forms of the disease. African Americans and Latinos are less likely to receive certain health services and treatments, and minorities also have lower participation rates in medical research for many diseases, including MS.

"There is a tremendous need to involve minority communities in the design and development of research, and to engage researchers in increasing their representation in clinical studies," said Robert McBurney, Ph.D., President and CEO of ACP. "This award will allow ACP to better understand minority engagement for our MS research projects. We are pleased that PCORI has recognized the potential this program has to make important inroads in building minority participation, not only in MS research, but in all kinds of medical research."

Focusing primarily on African-American and Hispanic-American communities, the Partnership Network will develop a strategy and toolkit to support a variety of outreach activities, based on the analysis of barriers conducted by the network and the resulting strategies that are developed by the network in the first two years. "

This project was selected for Engagement Award funding not only for its commitment to engaging patients and other stakeholders, but also for its potential to increase the usefulness and trustworthiness of the information we produce and facilitate its dissemination and uptake," said Jean Slutsky, PCORI's Chief Engagement and Dissemination Officer. "We believe the results of this project may have potential to improve outreach among different underrepresented populations and other disease states, and we look forward to following its progress and working with ACP to share the results."