

A warm welcome to all iConquerMS™ participants and friends!

iConquerMS™ is off to an amazing start in 2015, buoyed by positive responses from throughout the community to the launch of our www.iConquerMS.org portal.

We cherish the way our community has come together. In December, iConquerMS™ hosted a Leadership Summit in Boston for our entire Governing Board and Committees, to set the strategic course for what we hope will be a ground-breaking patient-powered research endeavor. There, participants paired up and interviewed each other to elicit thoughts and feelings about MS and about the potential for research that truly involves patients as partners. Watch the video at <http://youtu.be/jpNEbvyWIBw>. Want to participate? We urge everyone to pick up a camera and engage their friends and loved ones in similar interviews!

This month, we are kicking off a national awareness and recruitment campaign to alert all individuals living with MS around the country. Each day, we add new participants to the hundreds, who have already registered from almost every state. A groundswell of interest continues to build from the coordinated outreach to members by our collaborating organizations, including the National Multiple Sclerosis Society, the Multiple Sclerosis Association of America, the Multiple Sclerosis Foundation, and Can Do MS. We could surely not undertake this ambitious initiative without their support!

iConquerMS™ is often described as a '21st century research movement' because it is so dynamic. We continuously register participants online. We use state of the art digital tools to collect/aggregate/analyze the data. We store data 'in the cloud'. And, we're a part of a digitally inter-connected national research network called PCORnet that is expected to process data from tens of millions of Americans to fuel research studies.

There is no better symbol of modern community-building than empowered patients communicating through social media. Below are excerpts of just a few of the blogs and postings that have appeared to date. They are honest, heartfelt, and at times heart-breaking reminders of the challenges before us. Most of all, they reflect the enthusiasm, dedication and determination that are hallmarks of this pioneering initiative, driving us forward to the goal of 20,000 registered participants.

We invite everyone to be part of our local and national dialogue in coming days. Stay tuned for updates on recruitment, upcoming events such as webinars, and research insights.

Sincerely,



Robert McBurney, Ph.D.

Principal Investigator, MS Patient-Powered Research Network (iConquerMS™)

President & CEO, Accelerated Cure Project for MS

"How would you like to take the multiple sclerosis research world by storm? Get prepared, because the time has come for you and me, along with our many MS friends and acquaintances throughout the country, to do just that. No longer are we merely clinical guinea pigs or the subjects of market research, we are the leaders and partners in research that may lead to discoveries that improve numerous lives, identify more effective therapies, and ultimately fill in the missing puzzle pieces needed to cure MS."

Lisa Emrich, iConquerMS™ Communications Committee Chair, iConquerMS™
<http://www.healthcentral.com/multiple-sclerosis/c/19065/172963/accelerated-cure/>

"From time to time groundbreaking stuff happens on the planet that gets us really jazzed up and the launch of iConquerMS.org is no exception. As someone who lives with Multiple Sclerosis, this project is so very near and dear to my heart and I am super proud to be part of the iConquerMS™ team and watch this go live."

Christie Germans, iConquerMS™ Membership Committee, iConquerMS™
<http://thelesionjournals.blogspot.com/2014/12/im-conquering-ms-wanna-join-me.html>

"Okay, my fellow MSers, are you sick of sitting on the sidelines like powerless spectators observing a do or die contest that will determine your very own fate, waiting anxiously for neurologists, researchers, and pharmaceutical companies to ride to the rescue? Are you, like me, sick and tired of being sick and tired, weary of having very little ability to do anything about the situation except listen to the same old same old, held hostage by a status quo that offers more questions than answers? Enter iConquerMS™, a new patient driven research initiative that allows those living with MS to participate in a groundbreaking research effort aimed at amassing the most comprehensive database about MS patients and the manifestations of their disease ever created."

Marc Stecker, iConquerMS™ Communications Committee, iConquerMS™
<http://www.wheelchairkamikaze.com/2014/11/iconquerms-your-chance-to-help-bloody.html>

"How many times have you said If they would just ask me? Or lamented that your questions about MS go unanswered because researchers have not talked to you? I am excited to tell you that this is about to change – and a real opportunity for people living with Multiple Sclerosis to help shape information about our disease is here. Now."

Laura Kolaczowski, Lead Patient Representative, iConquerMS™
<http://multiplesclerosis.net/living-with-ms/will-mean-iconquerms/>

"The patient perspective is often sought only on the periphery of MS research or as part of federally funded research, which often requires patient advocate input. iConquerMS™ will allow more of us to be a part of research direction, decisions, and outcomes."

Trevis Gleason, MS Blogger
<http://www.everydayhealth.com/columns/trevis-gleason-life-with-multiple-sclerosis/patient-driven-research-idea-we-should-all-get-behind/>