



iConquerMS™ reports Phase I progress – gains PCORI Phase II award!

We are delighted to tell you that iConquerMS™ will continue on from its first phase, thanks to the Phase II award to the program recently announced by the Patient-Centered Outcomes Research Institute (PCORI), for an estimated \$1.3 million over three years. This gratifying news resulted from our application submitted in the spring, that included 37 letters of support from the iConquerMS™ governance members, MS clinics, MS advocacy organizations, pharmaceutical companies, partners and collaborators.

During Phase II, Laura Kolaczowski (the Lead Patient Representative for the iConquerMS™ initiative) and I will serve as co-Principal Investigators. While it is a PCORI requirement to have one professional researcher and one person from the community, it is also our preference: this approach reflects the patient-centeredness of iConquerMS™, and as a researcher with 30+ years of scientific study experience, I'm delighted to see this long-overdue change in the culture of medical science.

Our progress in Phase I of this initiative should not be overlooked, as we approach the end of the initial funding period this month. During our first 18-month award period, we created a patient-driven Governance structure; launched the data collection and patient engagement portal; recruited more than 2300 individuals living with MS to participate; collected health data from 70% of the registrants; branded and publicized our program in traditional and social media; and built collaborative relationships with all the major MS advocacy organizations around iConquerMS™. We view these milestones as both a strong foundation and a platform for outreach to an ever-widening community of participants in this novel research endeavor.

iConquerMS™ is increasingly well prepared for an ambitious research agenda. Hand in hand with the Research Committee, the Project Team is developing the necessary research policies and procedures to guide the creation, development and execution of research projects employing data collected by iConquerMS™. We are committed to community review of research proposals, to ensure that any research conducted with iConquerMS™ data resources is of interest and value to our community. In addition, we are planning "research studios" in four cities this fall, where small numbers of people with MS will come together with researchers to brainstorm about research projects. Our research pipeline is starting to fill in, with proposals in process around mood disorders and comparative effectiveness of disease-modifying agents. When our new Research section is launched at the iConquerMS.org portal in coming weeks, we expect to hear from researchers in the U.S. and internationally about additional opportunities.

Meanwhile, day by day, our numbers increase. New registrants come on board, and we now have plans to ask participants to reply to surveys again, so that we can truly document the experience of those living with MS over time.

As always, we welcome your input and ideas as we enter this exciting new phase of the program, and appreciate all your dedication, hard work and support.

Sincerely,



Robert McBurney,

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

President & CEO, Accelerated Cure Project for MS

Call to Action: We need your help!

Our enrollment goal this month is 300 new participants!

One by one by one...
if you tell your friends and colleagues who live with MS
about iConquerMS™ ...
we can reach the target levels needed for robust research.

Please ask them to JOIN NOW.



Spotlight on your Governance Board: Doug Franklin

Q: Why did you decide to join the iConquerMS™ Governing Board?

Doug: iConquerMS™ is really a unique initiative that has come at a perfect time. I see it as providing patients with what's probably their first chance ever to have a hand in research design and implementation.

Q: What trends have you observed in MS care and research over the years that you have been in the field?

Doug: Years ago, there were so few treatments available that physicians would diagnose a patient with MS and send them off after just a brief consultation. In essence, there seemed to be very little to talk about. Nowadays, it's totally different, because we have a 'shared management' of the disease between physicians and patients. There are many more drugs available to treat the disease, and the MS Coalition has developed "Disease Modifying Therapies Best Practices Guidelines" with consensus from the experts. And, of course, in our digital age, there are tools to help patients to manage their disease: the Multiple Sclerosis Association of America (MSAA) has developed the "MyMSManager" app and made it available to all MS patients, as well as an MS Search communications vehicle to help patients and providers focus their interactive discussions.

Q: What do you believe is novel or most important about iConquerMS™?

Doug: iConquerMS™ is special because of the idea of involving patients in the design of research. I remember attending the PCORI launch meeting in 2013, and thinking that this concept was so powerful that it could really put a national spotlight on MS as a disease worthy of public attention and increased funding. People don't think about this disease as much as they do about cancer or heart disease or diabetes, but there are hundreds of thousands of patients with MS, and we need to change perceptions to make progress.

Q: What are the two most pressing needs that you see in the field?

Doug: First, the need for improved access to care for MS patients; and second, the need for more research.

Q: How can iConquerMS™ enhance the work of the MS Association of America, and vice versa?

Doug: iConquerMS™ is already making an important contribution to MSAA by helping us to help patients feel that they are not alone, and of course by arming patients with information and the ability to really drive the research agenda. MSAA, in turn, is committed to being supportive of iConquerMS™, not only through my participation in the Governance Board but by promoting iConquerMS™ to our constituency, and sharing knowledge and resources wherever possible.

Q: What are you most looking forward to in coming years from the iConquerMS™ initiative?

Doug: I believe that iConquerMS™ has a major opportunity to “shine a light” on this disease; to promote more and more data sharing globally among the biomedical community; and to fuel more research collaborations across the traditional silos. iConquerMS™ can be seen as a catalyst for breaking down outmoded barriers, and as a linchpin in the MS Coalition for the common good. I’m very proud to be part of iConquerMS™.

Doug Franklin is a founding member of the iConquerMS™ Governance Board. He has served as the President and CEO of the Multiple Sclerosis Association of America (MSAA) for 17 years, and has a long and distinguished career in nonprofit leadership. A published international expert in social marketing and corporate social investment, he is a graduate of four universities and holds dual certifications in two professional associations. He also served 9 years as President of the Multiple Sclerosis Coalition.

In Other News...

- The Personalized Medicine Coalition, a strong supporter of iConquerMS™, has published an essay about our initiative in its Fall 2015 newsletter.
Read it here: http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/pmc_newsletter_fall_2015.pdf
- iConquerMS.org has updated its Privacy Policy, on August 31, 2015.
Read it here: <https://iconquerms.org/privacypolicy>

iConquerMS™ Research & You

iConquerMS™ has been described as a research network comprised of people with MS and people who care about MS, who contribute health data, biosamples, knowledge and ideas to enable and accelerate MS research. Another way of thinking about iConquerMS™ is that we are building a “Research Engine” that involves people with MS in the entire process from idea generation to protocol development to project executive to dissemination of research results.

In each issue of the iConquerMS™ newsletter, we focus on emerging aspects of the research endeavor.

Ideas from iConquerMS™ community members

A core principle of iConquerMS™ is that participants can fuel research by providing ideas and expressing preferences about the research that is conducted. To date, we have received more than 80 different research questions and data collection ideas from our iConquerMS™ community.

Based on the suggestions received so far, topics of particular interest include risk factors/causes of MS, MS medications, and MS symptoms. iConquerMS™ community members are especially interested in diet/supplements, exercise, and non-medical therapies as well. Also mentioned so far as possible research topics were comorbidities (other diseases that can accompany MS), cognition (thinking/memory), and sexuality, among others.

In addition to the topics above, many suggestions have been made about our data collection processes, including ways of improving the existing questionnaires, proposed additional types of data that could be collected, or new methods of data collection (such as through fitness trackers).

All research questions and suggestions that are submitted are reviewed and tracked by the iConquerMS™ team and the Research Committee. In coming months we will be looking for ways to develop some of these ideas into new research studies. Keep the suggestions coming and watch for further information on how ideas from the community will drive iConquerMS™ research!

Pose a Question

iConquerMS™ members are invited to send in their research questions/topics that iConquerMS™ could explore. Look for “Connect a Research Question” near the top of your dashboard or just click this link after logging into your iConquerMS™ account: <https://www.iconquerms.org/suggest-research-question>

Your Views on Mood

In preparation for a potential research project on MS and mood, we surveyed iConquerMS™ participants. Very rapidly, we heard from 475 respondents – almost ¼ of our registrants – of whom over 95% indicated that mental health was an important area for research in MS. Just over half reported a diagnosis of depression, anxiety, or other mood disorder. Respondents indicated that they would participate in research involving Cognitive Behavioral Therapy, Mindfulness Training, Peer Support or Exercise, with 40-60% interested in each of the approaches. A research project team is now working to develop a full proposal for funding.

The iConquerMS™ e-newsletter is published periodically to disseminate updates about this initiative, to keep the MS community informed, and to bridge those living with the disease with the research community.

Executive Editor: Marcia A. Kean

About iConquerMS™

iConquerMS™ is an initiative by and for individuals living with MS who understand the need to contribute their ideas and their health data to fuel research. It is the only MS research initiative that is nonprofit, patient-governed, and part of a larger nationwide research network, called PCORnet. As part of PCORnet, iConquerMS™ is able to contribute health data to many research efforts, while also providing MS researchers access to data from millions of people from across the country.

For more information about iConquerMS™, visit www.iConquerMS.org, like us on Facebook at <https://www.facebook.com/iConquerMS> or follow us on Twitter, handle [@iConquerMS](https://twitter.com/iConquerMS).