



## iConquerMS™ is (almost) Everywhere!

Our initiative has many stakeholders. In fact, the world of MS research is a large and diverse ecosystem: people living with the MS; researchers, both academic and commercial; data scientists; physicians; nurses; caregivers; advocacy organizations; media, and interested members of the public.

As a result, there is no ‘one place’ where the story of iConquerMS™ should be heard. And not just ‘one subject’ of interest that we need to address.

Part of the outreach strategy for iConquerMS™ is therefore to be present at as many conferences as feasible, to describe the initiative and alert all the stakeholders with a reason to care. So far this year, representatives of iConquerMS™ have appeared at TEDx, the conference that spotlights innovations that will change the world; at BioIT World, where scientists confer on how to gain insights from data; at the American Association of Neurology annual meeting, the largest professional society in neurology; and at the National Quality Minority Forum’s Leadership Summit on Health Disparities, which brings together critical stakeholders to support the implementation of integrated solutions to the problem of minority-population health disparities and improving quality of care. And, of course, iConquerMS™ representatives attend the meetings of the Patient-Centered Outcomes Research Institute (PCORI), which has provided initial funding for our network, so that we can represent our initiative and help PCORI to define the research opportunities in MS that matter most to iConquerMS™ participants. In the aggregate, we’ve touched and informed thousands of different people through these settings.

Like ice-skating, speaking engagements look easy. Just an hour or two at the podium looking at a sea of encouraging faces, and one is finished, right? That’s all it takes.

But, as with most worthwhile endeavors, there’s more to it. Much more, behind the scenes – with hours of planning, organization, preparation and promotion.

In this issue, we cover some of the recent highlighted events where iConquerMS™ has been a featured topic. As you’ll see, people with MS are at the heart of these presentations, sharing their experiences and insights.

If you have ideas for additional conferences/events where we should appear, please let us know. Or, if you have plans to speak at local or national events, please let us know and we can share slides that might be useful, and alert others about what you’re doing.

iConquerMS™ may not be on Broadway this season, but we are definitely in the limelight to gain traction for our pioneering model of patient-driven research!

Sincerely,

A handwritten signature in black ink that reads "R. A. McBurney". The signature is written in a cursive, slightly slanted style.

**Robert McBurney, Ph. D.**

Principal Investigator, MS Patient-Powered Research Network (iConquerMS™)  
President & CEO, Accelerated Cure Project for MS

## “I Feel a Sense of Responsibility...”

### An Interview with Stephanie Butler

**Q:** The diagnosis of multiple sclerosis seems to have changed your view of the world and your own opportunities. In what way did all that unfold?

**Stephanie:** Well, in some ways my career has been a complete deviation from where I intended, and in other ways it's been totally aligned and natural, since I was already a neurological nurse when I was diagnosed. While I was in the hospital as an MS *patient*, I realized that I was becoming more empathetic in my role as a *clinician*. And, it seemed to me that other patients might find that kind of empathy to be really helpful. That led to my decision to become an MS-certified nurse. Now, I'm finishing my master's degree to become a nurse practitioner.

**Q:** What's your vision of what patient-powered research means, and the role individuals living with MS can play in building knowledge about the disease?

**Stephanie:** My vision involves mobilizing the younger population to participate. After all, who has more to gain than a young patient? And through that participation, we can accelerate research, and down the line, cure the disease. I believe that we should feel a sense of responsibility to participate. I'd even argue that it's an *obligation* for everyone in the community – you and your parents and your kids – to all get involved. I also think this is a two-way street with researchers – every researcher I've met is really excited about the idea of more patient involvement.

**Q:** How do you see the patient/researcher relationship evolving?

**Stephanie:** I believe we need more open communications between researcher and patient. Right now, 'research' is sort of an abstract concept for most of us. So we need a one-to-one dialogue that humanizes researchers and provides us with more understanding than just reading a published paper. I remember that I was at a public policy conference where there were researchers and we patients posed questions directly to them, and suddenly there was real electricity in the room! And that goes both ways, because one of the researchers subsequently said: "I went back to my lab afterwards, totally energized, and I plan to work even harder!"

**Q:** What's of special interest for you about iConquerMS™?

**Stephanie:** All the data that is getting collected is itself interesting. It's exciting for me to know more about who has MS...where they are located in the country...what we look like as a population...and so on. Potentially, researchers can identify trends that are new in these data. We're hoping to reach the target enrollment of 20,000 people living with MS, to make the 'big data' as useful as possible. I believe that iConquerMS™ will also make researchers more aware of the issues we face as patients.

Professionally, as a nurse practitioner, I want to be more involved in research, and I want to spread the word to patients about research involvement. I plan to discuss with patients the potential for empowerment through activism: in other words, how what's going on with them can help the larger research community and contribute to finding answers.

## “I Feel a Sense of Responsibility...”

(continued)

**Q:** What’s your take-home message for others living with MS?

**Stephanie:** Be involved. Have a sense of responsibility. And have a shift in mentality from “why me?” to “what’s next and how do I help?” People with MS don’t realize the power they have to be part of the solution!



*Stephanie Butler is a Neurosurgical ICU nurse who was diagnosed with multiple sclerosis at the age of 25. Shortly after being diagnosed, Stephanie realized that she could use her experiences as a patient to make a difference in the lives of others. She earned her certification as a Multiple Sclerosis Certified Nurse and started working in an MS Center. Her blog, [www.justkeepsmyelin.com](http://www.justkeepsmyelin.com), offers a unique perspective on multiple sclerosis from both a healthcare provider’s point of view, and through the eyes of a person living with the disease every day. Stephanie serves on the Membership Committee of iConquerMS™. Watch Stephanie’s TEDx talk [here](#).*

## Patient-Driven Data-Enabled Research: How Will it Work?

The iConquerMS™ initiative has appointed a Research Committee, comprised of research experts and people living with the disease with knowledge of research. The Research Committee’s role is to develop policies and oversee the process by which research proposals are received, reviewed, planned, approved and implemented.

As word spreads about iConquerMS™, research proposals are already being submitted from the MS research community. We are really excited that over 60 research topics have already been suggested from the network participants.

Criteria for approval and priority are as follows:

- Research has a focus on topic(s) important to people with MS
- Research proposal has been developed with input from people with MS
- Research is scientifically rigorous
- Research is feasible
- Research leverages data from other PCORnet partners

As proposals are approved and get underway, a listing of Research Projects Currently Underway will be posted to [www.iConquerMS.org](http://www.iConquerMS.org).

## What's New in iConquerMS™

### *Compare your data to all data in the iConquerMS™ network!*

Registered participants in iConquerMS.org can now view snapshots of the combined network data. To see how your responses compare to others, log onto your account or [Join Now](#).

### *iConquerMS™ is in the spotlight!*

June 2, 2015. We'll be presenting at the Health DataPalooza conference, Washington, DC, where thousands of stakeholders from academe, government, industry and the public gather each year to discuss the liberation and productive usage of healthcare data. (For more information, see [www.healthdataconsortium.org](http://www.healthdataconsortium.org))

### *Join iConquerMS™ for World MS Day*

This month, join iConquerMS™ and dozens of MS organizations across the globe in observance of World MS Day, May 27. All month, we'll be sharing stories from people with MS and encouraging you to do the same on social. Follow us on [Facebook](#) and Twitter, [@iConquerMS](#) to stay up-to-date on our activities. Join our World MS Day [Thunderclap](#) today!

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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 a 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](http://www.iConquerMS.org), like us on Facebook at <https://www.facebook.com/iConquerMS> or follow us on Twitter, handle [@iConquerMS](#).