

## Our Health Data Has Power

## iConquerMS<sup>™</sup> Newsletter · VOLUME 1 · ISSUE 1 · November 2014

## Ready, Set, Conquer!

On November 23, 2014, the iConquerMS.org portal was officially launched, open to all who live with multiple sclerosis and their loved ones and friends.

The bold mission of iConquerMS<sup>™</sup> is to drive a new generation of patient-powered research into the causes and symptoms of MS, to better understand the effectiveness of current MS treatments, and to answer many questions that are important to people with MS. iConquerMS<sup>™</sup> is building a bridge between those with the disease and the research community that we hope will lead to new knowledge and improved outcomes for all those living with MS.

This initiative has the financial support of the Patient-Centered Outcomes Research Institute (PCORI), an innovative enterprise mandated by the U.S. Congress in the Affordable Care Act. iConquerMS<sup>™</sup> is woven into the fabric of PCORI's new national research network as a Patient-Powered Research Network.

iConquerMS<sup>™</sup> is building on the learnings from prior research endeavors — we stand on the shoulders of those who have come before us — to achieve the following unique attributes.

## iConquerMS™:

- · Is by and for patients.
- Has a governance structure with a majority of members who are people living with MS, and guidance from these individuals comes via a Governing Board as well as Research, Communications, and Membership committees.
- Is part of a national research network, and has the financial support of the Patient-Centered Outcomes Research Institute.
- · Is connected to a nationwide network of MS clinics, who are contributing time, resources, and expertise.
- Is collecting an extensive breadth and depth of information from people with MS.
- · Is seeking an unprecedented level of diversity among participants.
- Leverages 21st century informational technology tools to integrate and analyze the 'Big Data' that is collected, to maximize its research potential.
- Uses social media and other digital tools to enhance and sustain an online community for participants.
- · Is conducted by a nonprofit entity.

Accelerated Cure Project for MS, or ACP, has created two unique and complementary research initiatives. iConquerMS<sup>™</sup> is a large-scale online research initiative, in which data of all kinds are contributed by people with MS to fuel discovery. Our recently launched OPT-UP Study is a clinic-based research investigation into the best uses of MS therapies and the causes of progressive disability in MS. Combined, these two initiatives are a powerful force for conquering MS.

The iConquerMS<sup>™</sup> welcome video asks: 'Can one person have power? Can 10... or 100... or 1,000... or 10,000 people have power?' At ACP, we believe that each individual — those living with MS, their loved ones, and friends — has huge power to make a difference, and we invite everyone to use that power against MS.

Thank you for being a participant in iConquerMS<sup>™</sup>! We look forward to keeping you up to date with the progress of iConquerMS<sup>™</sup> in future issues of this newsletter.

Sincerely,

R. N. Mc Burney

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