



A Look Back: ACP's Accomplishments in 2015

Twelve years ago, Accelerated Cure Project invented a new model of disease-focused organization. In 2015, we have exceeded our early ambitions with a comprehensive, forward-looking portfolio of projects. As you may know, we create much-needed resources and remove obstacles so that all researchers - whomever they are and wherever they may be - can act quickly and in concert with organized patients to undertake studies to improve treatments and advance cures for MS and related demyelinating disorders. Four integrated programs power our impact.



- The **ACP Repository** is a unique and comprehensive resource of human data and biological samples (DNA, RNA, plasma, serum, white blood cells) for use by researchers and to date has supported 85 MS research studies worldwide.
- [**iConquerMS™**](#) is a large U.S.-based network of people who have MS and who are committed to participating in all aspects of research, from concept to health-care outcomes. It is organized to do two things: 1. Make sure that topics and issues of concern to patients with MS are explored through scientific research; and, 2. Build the infrastructure, processes and capacity to enable patient-centered research to be initiated and completed faster and more efficiently than at any previous time in history.
- The [**Multiple Sclerosis Discovery Forum**](#) is a free online publication that delivers timely news, explanatory journalism, data visualizations, podcasts, and scientific information about MS and related demyelinating disorders. Regular readers of the high-level content include researchers; patients and family; and, doctors, nurses, medical students and other health care professionals.
- **OPT-UP** (standing for OPTimizing Treatment-Understanding Progression) is a clinical research study we designed. It will meticulously follow 2500 people with MS at up to 20 U.S. clinics for five years. The study aims to generate robust evidence on which MS treatments work best for which patients and to increase our knowledge and understanding of progressive MS, so that new treatments can be developed to arrest or reverse this devastating neurodegenerative aspect of MS.

Each of the four programs is integrated with and supports the others. For example, biological samples and data gathered in the course of the OPT-UP study will populate, update and grow the size of the Repository, increasing the value and utility of that core Accelerated Cure Project asset and further accelerating MS research. Members of iConquerMS™ who want to have a voice in determining MS research priorities, will need to understand the basic science of MS and the processes of scientific research. This knowledge exists at MS Discovery Forum, originally designed to serve the news and information needs scientists, clinical researchers and other professional stakeholders.

Our four integrated programs made great leaps forward in 2015. The **Repository** provided samples and data to researchers, resulting in eight exciting new MS research projects and taking the total number of projects enabled by this resource to 85. One of the most promising research projects is from Dr. Tom Aune's group at Vanderbilt University in Nashville, Tenn., which is working on the development of tests to diagnose MS. Two previous sample requests from this group resulted in data that can predict which patients with "clinically isolated syndrome" (a single relapse) will progress to MS. The work has fueled three scientific papers so far. Dr. Aune's latest request will focus on diagnostic non-coding RNA profiles, including microRNAs.

[MS Discovery Forum](#) continued to report on what is known and not yet known about the causes of MS and related disorders, their pathological mechanisms, and treatments. Its audience grew beyond scientists. In founding MS Discovery three years ago, Accelerated Cure Project sought to spark communication among researchers, many of whom don't read the same journals, don't go to the same meetings, and don't experience much if any cross-fertilization of ideas. While this important need continues to be addressed, in 2015 we also learned that the regular readership of MSDF had expanded to include thousands of non-scientists—people with MS and their caregivers—eager for scientifically-complex material to better understand their disease and likely pathways to a cure.

The **OPT-UP** study took a couple of giant steps closer to launch by attracting the sponsorship of two additional sponsors, Genentech and the National MS Society. Together they joined founding sponsor, EMD Serono. In addition:

- The study protocol was finalized by ACP's Clinical Research Network investigators.
- An electronic data capture/clinical trial management system vendor was engaged, as was a clinical research organization to manage the nine study sites.
- Two of the sites (University of Texas Southwestern Medical Center at Dallas and the Shepherd Center in Atlanta) took the initiative to secure approval for their participation in the study from their institutional review boards (an important pre-requisite to an organization's participation in the study).

In just 12 months, [iConquerMS™](#), our patient powered research network, built a nationwide network of 2,700 people with MS that is contributing data and samples, as well as intelligence and ideas, to influence research on MS topics. It received a three-year funding renewal from the Patient Centered Outcomes Research Institute, known as PCORI, the non-profit organization created by Congress under the 2010 Affordable Care Act to figure out which medical treatments work best. Significantly, this evidence is largely missing in the treatment of people with MS.

The impact of iConquerMS™ goes beyond MS, since the group is part of an ambitious national enterprise called PCORnet that is organizing networks of people with other diseases (everything from autism to arthritis to Alzheimer's disease). Together, the 34 PCORnet partner networks cover more than 150 conditions and a wide variety of population groups in every state nationwide. A list of all partner networks can be found at <http://www.pcori.org/pcornet>. When combined, the network has mobilized and collected data from a staggering 90 million Americans. ACP is proud to play a part in creating this extraordinary resource for scientific research- a collection of Big Data about Americans and their health.