

Accelerated Cure Project for MS

September
2017



*Accelerating research towards a
cure for multiple sclerosis*

The Accelerated Cure Project - Progress Toward a Cure

The Accelerated Cure Project's founder, newly diagnosed with multiple sclerosis, had a vision and a plan to find a cure for the disease that he struggled with. He met with MS researchers from academia and the pharmaceutical industry to learn about MS and current research and was disappointed with the lack of success. He decided that a different approach was necessary and founded a non-profit organization, now known as the **Accelerated Cure Project**, whose mission was to accelerate progress toward determining the causes of MS and ultimately finding a cure. Since its inception in 2001, the Accelerated Cure Project's mission has expanded to also include improving diagnoses and optimizing treatment outcomes for people with MS. We are grateful for the generosity and support of many donors, volunteers, partners and study participants who have enabled us to make significant progress toward that goal.

The Accelerated Cure Project's initial scientific project was to develop a [Cure Map](#), a comprehensive and detailed plan of research focused on understanding what was known about disease origins, the state of MS research, and what gaps in knowledge existed. ACP's founder and his team reflected that the primary causes of diseases, including MS, could be grouped into five categories: abnormal genes or genetic function, infectious agents (bacteria, viruses), toxins (poisonous substances), nutrition, and trauma (physical injury or mental stress). Given the complexity of MS, it is believed that more than one of these

factors in concert is likely to be the cause. Listing and investigating the possible causes of MS through development of the Cure Map helped to reveal potential promising areas of study.

From analysis of the Cure map, it became clear that research efforts toward a cure would be accelerated if there were a readily available source of biospecimens and associated clinical information for the research community at a reasonable price. This resource would enable investigators to focus their time on their research rather than sample acquisition. The [ACP Repository](#) was developed as a source of these materials. To foster collaboration within the research community and to enhance the offering, users of ACP Repository samples must agree to return their research results back to the Repository for the sharing with and future benefit of all researchers. Working with a network of 10 leading neurology clinics throughout the US, samples and data were collected from over 3,200 participants between 2004 and 2011. These samples and data were collected from people with and without demyelinating disease. The ACP Repository continues to serve as a valuable resource for the scientific community. To date, Repository samples and data have been used in over 100 studies, more than 50 of which have returned their results to the Repository database to date, encompassing nearly 700 million data points altogether. These samples and data have enabled research studies in Multiple Sclerosis, Transverse Myelitis, Neuromyelitis Optica, and Clinically Isolated Syndrome. These studies have been conducted on a wide variety of topics, including diagnostics, genetics, immunology, risk factors and treatments/therapeutics.

To further foster collaboration in the scientific community, the [Multiple Sclerosis Discovery Forum](#) (MSDF) was launched in April, 2012. The MSDF is an interactive online venue that educates investigators who study MS and other demyelinating diseases, and provides an online venue for them to connect and share ideas. Its vision is to open paths toward new discoveries through this open communication. Currently, MSDF remains available online as a resource for researchers and others interested in learning more about MS but no new content is being developed due to a lack of available funding. With additional funding MSDF could continue to serve the scientific community as a resource for information about MS research findings, opportunities for researchers to discuss and debate the implications of new findings, resources, and much more.



The importance of understanding the MS experience from the perspective of people with MS (PwMS) is essential to improve their



treatment and care. With this in mind, ACP partnered with the Complex Adaptive Systems Initiative at Arizona State University and Feinstein Kean Healthcare to create [iConquerMS™](#), a national people-powered research network for MS. Funded by the [Patient-Centered Outcomes Research Institute](#) (PCORI), iConquerMS was launched in February 2015 as a part of a national research network called [PCORnet](#). Governed and driven by people living with MS, iConquerMS was developed to improve health, healthcare, and quality of life for people with MS by connecting those affected by MS, clinicians, and researchers, and inspiring them to work together to accelerate innovation, research, and the application of new knowledge. To date, over 4,100 individuals have participated. The initiative's [portal](#) enables all people living with MS to play an active role in research. Participants are able to easily and privately take surveys about their daily experiences and symptoms, and share their medical records. The portal also contains information about research in general, and participants can receive updates on recent discoveries and suggest areas of research that are of interest to them. In 2016, iConquerMS launched the [REAL MS™](#) (Research Engagement About Life with Multiple Sclerosis) initiative, a research study that will follow participants over time. Every six months, participants in REAL MS are invited to provide updated information related to their experiences with MS including treatment status and response, symptoms, and any relapses they may have experienced. Each launch of REAL MS surveys also incorporates feedback from the community for new areas to study, including the recently launched Wellness survey focused on complimentary and alternative medicine. The collected information is pooled with similar information from thousands of others living with MS, participating in iConquerMS. Researchers can use the collected data to detect patterns that would not be visible otherwise, and use these patterns and insights to figure out the causes of MS, determine who will respond best to various treatments and find new, improved treatments. REAL MS also offers researchers the opportunity to conduct special data collection activities via iConquerMS; to collect biosamples; and to recruit individuals with certain characteristics for their studies.

In general, minority populations are severely underrepresented in scientific research read more in the article [Clinical Research- A Journey Toward Diversity](#). This makes it difficult to understand many disease processes and what treatments are effective for people of

different ethnicities. There is a tremendous need to involve minority communities in the design and development of research, and to increase their enrollment in clinical studies. For example, [recent studies](#) show that African Americans may have the highest risk not only for MS, but for more aggressive forms of the disease. Additional studies are needed to better understand why this population is at greater risk. In October 2016 ACP led an effort to develop the [Multiple Sclerosis Minority Research Engagement Partnership Network](#). In this survey-based initiative, information is being collected to better understand how people with MS from different ethnic backgrounds and races view medical research, with the goal of developing solutions that will increase minority enrollment in MS research studies, including iConquerMS.

ACP has partnered with a number of organizations over the years in its quest to improve diagnoses, treatment outcomes, and ultimately develop a cure for MS. ACP has received tremendous support from donors and volunteers who are inspired by our mission and approach. Leading neurology clinics have worked with ACP to recruit thousands of research participants from their patient populations. These research participants and their families have generously given their time to make the clinical studies sponsored by ACP a success. We, at the Accelerated Cure Project, are grateful for all of our supporters. You have enabled us to make significant progress in our mission. We look forward to the future as we continue to work together to promote scientific collaboration and enable researchers worldwide to make more breakthroughs in MS research at a faster pace.