

Accelerated Cure Project for Multiple Sclerosis



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Mission

Accelerated Cure Project for MS (ACP) is a national nonprofit organization whose mission is to accelerate a cure for multiple sclerosis (MS) by rapidly advancing research that determines the causes and mechanisms of MS. Its goal is to produce knowledge that can be used to stop the effects of MS and prevent MS in people who are at risk. It also helps scientists develop safer, more effective treatments and create new methods for diagnosing MS.

ACP was founded in 2001 by Art Mellor, a high-tech entrepreneur who had been diagnosed with MS the previous year.

Strategy/Approach

ACP focuses its efforts on finding ways to cure MS, not simply slow down its effects. It will work together with any organization that will lead to the production of the best ideas and to increased opportunities for leveraging its efforts. ACP believes in sharing knowledge with individuals with MS and their families, clinicians, researchers, and other MS organizations to build an informed MS community.

- **Cure Map** – ACP focuses its resources within the concept of a **Cure Map**, a framework it has constructed in conjunction with key researchers and scientists to clearly spell out a concrete approach to isolating the cause or causes of MS.
- **ACP Repository** – A large-scale collection of highly characterized biosamples and data from people with multiple sclerosis, selected demyelinating diseases, and unaffected controls are available to scientists at any organization conducting research that contributes to ACP's mission. All data generated through analysis of the repository samples are contributed back to ACP, resulting in an increasingly valuable and comprehensive information resource that can be analyzed to reveal new insights about MS.
- **MS Discovery Forum** – In partnership with EMD Serono, Inc., Max Planck Institute for Molecular Genetics, and Massachusetts General Hospital's Institute for Neurodegenerative Disease, ACP has built an MS-focused online research community that will enable MS scientists to connect with each other and keep up-to-date about the latest research findings through participating in Webinars and online discussions and using other online tools to enhance research productivity.
- **OPT-UP** – The Optimizing Treatment – Understanding Progression (OPT-UP) Program is an MS outcomes clinical study and collaborative research program designed to enable an era of optimized MS

treatment. It is built upon the foundation of the MS Repository and is unique in that it includes a Community Advisory Panel comprised of patients who influence the study.

- **Multiple-Sclerosis Patient-Powered Research Network (MS-PPRN)**—Funded by the Patient-Centered Outcomes Research Institute (PCORI), the MS-PPRN will engage the existing ACP Repository network of over 3,200 participants, while adding an ADA-compliant, patient-driven and controlled portal (iConquerMS). This network can be accessed regardless of geographical location and patients will be able to provide de-identified electronic health record information or biological samples to support research activities.

Research Portfolio

- The MS repository currently includes more than 3,200 biosamples and more than 250 million data points available for the benefit of all researchers.
- Participants in the repository have a network of 10 MS clinics located across the United States available to them, and they may return to contribute updated data and new samples.
- Research using their bio-samples has already generated one blood test that may help diagnose MS.
- Each sample is accompanied by more than 40 pages of clinical and epidemiological data contributed by the subject and the enrolling neurologist.

Partnership Practices

ACP collaborates with academic researchers, nonprofits, and industry to achieve its mission. It operates with the philosophy that working together and sharing results transparently will produce the best ideas and outcomes. For example, ACP partnered with Fast Forward, LLC, a wholly owned subsidiary of the National Multiple Sclerosis Society, to advance the MS Repository.

ACP partners with biotech and pharmaceutical companies. Its industry partnerships are structured in a traditional project sponsorship fashion. For example, the organization's recently launched Multiple Sclerosis Discovery Forum is a free resource for MS scientists, which was made possible through the support of founding donor **EMD Serono**.

In 2013, **Orion Bionetworks**, a cooperative, multi-institution alliance funded by **Janssen Research & Development, LLC**, was launched and includes ACP as a partner. The cooperative alliance focuses on integrating clinical, biomarker, and imaging

data with real-world patient data from existing databases into a causal computational disease model for multiple sclerosis. Other partners on this project include Exaptive, Institute for Neurosciences at Brigham and Women's Hospital, GNS Healthcare, MetaCell, PatientsLikeMe, and Thompson Reuters.

Financials

ACP is a 501(c)(3) nonprofit health organization. The most recent financial information available is from 2011.¹

Year ending 12/31/11:

- Revenue: \$1,132,559
- Assets: \$1,432,560
- Gifts received: \$1,400,000
- Expenditures: \$2,577,412

Key Accomplishments

- The MS Repository includes samples and data from more than 3,278 subjects. It has supported more than 63 research studies aimed at creating new treatments, better diagnostic methods, and strategies for preventing MS. It includes 19 data sets containing more than 250 million data points that are contributing to a more comprehensive understanding of MS.
- In 2010, the repository expanded to a total of 10 clinical sites throughout the United States.
- ACP was awarded the Global Leadership in Innovation and Collaboration Award from the Center for Innovation and Change Leadership in 2011. The award is given each year to an organization that fosters and inspires innovation and collaboration.
- ACP has a 4-star rating (awarded by Charity Navigator) for its financial health, accountability, and transparency, which is the highest any organization can receive.

Leadership

Accelerated Cure Project is governed by a **Board of Directors** and supported by a **Research and Development Advisory Board** and a **Technical Advisory Board**. It is managed by a permanent professional **staff** based in Massachusetts.

- **President and CEO:** Robert McBurney, rmcburney@acceleratedcure.org
- **Operations and Repository Director:** Sara Loud, sloud@acceleratedcure.org
- **Development Director:** Karen Crumback, karen@acceleratedcure.org
- **VP of Scientific Operations:** Hollie Schmidt, hollie@acceleratedcure.org

¹ Information obtained from Accelerated Cure Project for MS Website, http://www.acceleratedcure.org/sites/default/files/ACP_2011_Annual_Report.pdf