

# Accelerated Cure Project for MS

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*Accelerating research towards a cure for multiple sclerosis*

## Teamwork Makes the Dream Work

The Accelerated Cure Project (ACP) is a small organization, comprised of [6 hard working individuals](#), making a big impact toward curing MS worldwide. 2018 has been a year full of productive collaborations. We've made significant strides in our mission, thanks to a cooperative effort with our partners.

- **Many of our readers have participated in the ACP Repository. Wondering how we manage all of the data we're collecting?** ACP Repository samples continue to advance MS research around the globe. Every sample is associated with a rich set of data, both patient and clinician reported. Researchers using samples are returning their results to the Repository database for sharing with other researchers. ACP will be using BC Platforms' data management system and global network to manage and grow the Repository. This represents a major step toward realizing the vision for the ACP Repository as a catalyst for a cure.
- **Ever wish you had more of a say in research and drug development?** ACP and EMD Serono have entered into a first-of-its kind partnership to ensure patients' complete experience with MS is captured and considered in the drug development process. This is an unprecedented opportunity for the collective voices and insights of people with MS to be heard and to drive real progress in research, drug development, and ultimately in the fight against MS.
- **Are you curious how the fight against MS is being globalized?** More and more, clinicians and researchers are collecting feedback from patients on their symptoms and functioning to determine what symptoms and quality-of-life impacts are most important to them. Many different questionnaires are currently being used across the globe to collect this important information. ACP is working with the Italian MS Society to standardize these surveys so they can be translated and used to improve healthcare and quality of life for people with MS worldwide.

- **Wonder how the MS community could be better informed and more engaged in research?**

[RealTalk MS](#) is a successful podcast series (established by Jon Strum), which currently reaches thousands of listeners. With the joint goal of promoting and conveying research results and activities to the MS community, ACP and Jon Strum will work together to increase the reach and visibility of both RealTalk MS and iConquerMS. This synergistic partnership holds great promise for both programs.

- **Did you know organizations are joining forces in the fight against MS?** ACP recently announced a powerful collaboration with the National MS Society to facilitate their common goal, a world free of MS. This partnership holds great potential for speeding progress toward better MS treatments and, ultimately, a cure.

The ACP Repository's purpose is to be an easily accessible source of samples and associated data for the research community. Scientists and clinicians who use these samples must agree to return their research results back to the Repository database for sharing with other researchers. At present, the database contains a diverse collection of information collected from Repository participants, as well as genomic and other research data generated by scientists. Ideally this wealth of knowledge could be analyzed in its entirety, enabling the ACP Repository to be a rich "open source" resource that can be mined by researchers. [BC Platforms](#) is a world leader in providing genomic data management and analysis solutions for large-scale collaborative research projects. Their expertise lies in integrating phenotype data (such as data collected from ACP Repository subjects) with genetic data. Their data management platform is HIPAA compliant and offers flexibility, as well as data security. BC Platforms has also established a global network, [BCRQUEST.COM](#), which combines the datasets of biobanks around the world. ACP will be using BC Platforms' data management system and BCRQUEST.COM to manage and grow its Repository. All collected and returned data will be integrated into one easily accessible data management system. The BC Platforms data management system will also allow ACP to streamline the process of selecting samples based on investigators' specific research requirements. Being able to service more requests for Repository samples means more studies can be done -- accelerating the research needed for better treatments, diagnoses, and cures. This represents a major step toward realizing the vision for the ACP Repository, and will further facilitate collaboration between ACP and researchers.



[EMD Serono](#) researchers strive to improve the lives of people living with MS by offering better therapies and support services, made possible by cutting edge research. Until now, input from people living with MS hasn't been routinely considered in the drug development process throughout the industry. The U.S. Food and Drug Administration (FDA) recently released guidance related to [Patient-Focused Drug Development \(PFDD\)](#). These documents outline a systematic approach to ensure patients' experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and evaluation. ACP and EMD Serono have entered into a groundbreaking collaboration that is well aligned with this guidance. This partnership will ensure patients' complete experience with MS is captured and meaningfully incorporated into the drug development process. As part of this program, members of the iConquerMS community have been invited to participate in a PFDD Council. The Council will work closely with the iConquerMS project team and team members from EMD Serono to undertake truly patient-focused drug



development. The iConquerMS patient portal will be used to gather new PRO data and iConquerMS participants will provide input across all stages of the study through workshops, document reviews, focus groups and surveys. The collaboration between iConquerMS and EMD Serono, the first of its kind in MS research, is an important opportunity for the collective voices and insights of people with MS to be heard and to drive real progress in research, drug development, and in the fight against MS.



ACP is working with individuals and organizations worldwide to advance MS research. One such organization is the [Italian MS Society](#). There are many MS treatment options. Each carries a different level of therapeutic benefit and risk. Unfortunately, there isn't enough information available about the effects of various treatments on the symptoms, disabilities and quality of life of people with MS. This makes it difficult for people with MS and their physicians to make therapeutic choices. [Patient reported outcomes](#) (PROs) are designed to collect important information for treatment selection and other aspects of living with MS. At present, there are a very large number of

surveys designed to collect PRO data, with little standardization or harmonization. Researchers need to determine how these varied data can be translated and used to improve healthcare and quality of life for people with MS. To address this issue, ACP and the Italian MS Society (both focused on collecting PRO data) are working together to standardize and unify PRO measures across cultures. This collaboration aims to establish a system and tools for collecting, presenting and interpreting PRO data for use in research and in shared healthcare decision-making so everyone involved can speak the same language. The end result will bring outcomes that matter most to people affected by MS into research and ultimately, every aspect of their care.

[RealTalk MS](#) is a successful podcast series (established by Jon Strum), which currently reaches an audience of over 4,500 listeners. Weekly episodes offer a wealth of information and encouragement to people affected by MS. With the joint goal of promoting and communicating research results and activities to the MS community, ACP and Jon Strum will work together to increase the reach and visibility of both RealTalk MS and iConquerMS. This partnership holds great promise for both programs. The increased visibility through Jon's podcasts has the potential to boost iConquerMS enrollment, and enables more effective



communication of iConquerMS research activities and results to the MS community. RealTalk MS, in turn, will receive input on podcast topics of interest from the iConquerMS community, as well as connections to potential interviewees who are doing important and interesting work in MS. In addition, both teams will work together to seek funding to support these activities, which increases their sustainability.

ACP recently announced a powerful collaboration with the National MS Society (the Society) to facilitate their common goal, a world free of MS. The two organizations will work together to speed the pace of research for better treatments and a cure for MS. Through this



collaboration, the Society will partner with ACP to leverage the iConquerMS network to drive engagement of people with MS in the design, conduct and impact of MS research, as well as increase input and involvement

from clinicians, researchers, and others affected by MS. Through this collaboration, the Society will have access to the iConquerMS platform, data, and participant input for its research activities, such as policy surveys, quality of life questionnaires, data analyses, and other activities conducted by the Society to support its goal of delivering breakthroughs to a cure. The Society will provide financial and in-kind support for the initiative, including promoting and recruiting for iConquerMS research opportunities and sharing questions and topics for research among Society support groups and membership. ACP will continue its efforts to increase enrollment in the iConquerMS network, and contribute this platform to enable people with MS to live their best lives, and advance cures for MS. The collaboration between the Society and ACP holds great potential for speeding progress toward better MS treatments and, ultimately, a cure.

Since its inception, collaboration has been central to ACP's mission. In COO, Sara Loud's words, "To me, the collaborative nature of our work is most exciting... A complex disease like MS is unlikely to be cured in a fragmented research environment. The ACP Repository is really such a brilliant (and definitely novel) approach to fostering collaboration by requiring researchers to return their research results back to us so that we can share them with other researchers... We've taken this collaboration a giant step further through iConquerMS by bringing the most important experts on MS, the people affected by the disease, front and center into research. The 'people-power' of iConquerMS means that people affected by the disease are driving, shaping, and contributing to MS research in brand new ways — ways that will ensure that research gets done on topics that matter most to them."

