



Accelerated Cure Project MS Repository

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We are creating a new model of research around a large-scale shared resource (a sample and data repository) that allows the amplification of research results through passive collaboration without requiring researchers to change how they work. We can effectively multiply the value of research results through an independent network of sharing.

Accelerated Cure Project for Multiple Sclerosis is dedicated to curing MS by determining the causes.

We believe that knowing the causes will lead to the fastest route for a cure. Knowing the causes will:

- Provide targets for treatments, cures, and prevention
- Allow repair strategies to work
- Identify markers to speed up and refine drug trials
- Provide definitive diagnosis and segmentation for treatment
- Enable the creation of better animal models

MS shares two characteristics with many diseases that we don't know the causes of:

1. MS is most likely a family of diseases, not a single disease. This means that a study done on 100 people "with MS" might actually include 5 different disorders and thus insufficient power to identify a cause. What causes MS in one person may be different than what causes MS in someone else.

We need to study very large numbers of people in order to have sufficiently sized sub-populations of people with the same root causes so that we can determine what they are.

2. MS appears to be multifactorial - it is not caused by a single gene, a single virus, a single nutritional deficiency, etc. It is thought to be caused by a set of genes that confer susceptibility and an environmental trigger. Identifying these root causes requires researchers from different disciplines looking at the same people so that their results can be put together.

In order to address these characteristics, a very large population of people with MS and matched controls (people similar to those with MS, but who do not have the disease) needs to be studied over time by researchers in different fields.

By studying the same people, the results from two research studies in different areas can be put together. By studying a large group of people we can find meaningful sub-populations who share a common genetic background and trigger. By studying over time we can see what changes occur that might be clues to what is causing MS.

Our MS Repository is that population. We are collecting samples (currently blood, later spinal fluid and post-mortem brain tissue), and clinical and epidemiological data from a large group (up to 10,000) of people with MS and matched controls.

We make these samples available to researchers investigating the causes of MS in exchange for the return of any per-sample data generated using these samples (allowing time to secure their IP and publication rights). This additional data is made available to other researchers who use the

repository in the future. Access to samples is regulated by an oversight committee who reviews applications for use.

Researchers are extremely eager to have access to a resource like this, but are unable to create it themselves for three main reasons:

1. It is expensive. At \$2.5M to collect the first 1000 samples, the cost is out of the range of most research grants, which are typically in the \$50K - \$250K range.
2. It is administratively difficult. Collecting 1000 samples in a reasonable time requires 5-10 sites around the country participating. Several full-time staff are required just to manage this project. Researchers do not have this kind of support.
3. It is not publishable. While the use of a resource like this will produce many published papers, the creation is a time and effort intensive project that is not publishable itself. Researchers need to publish to advance their careers and get grants.

As a nonprofit we are not stopped by any of these reasons. We can raise the money, do the administrative work, and not worry about publication.

By creating a large, shared resource that requires data sharing in return, we can revolutionize MS research without requiring a significant change in the way research is currently conducted. This model creates a variety of leverage situations that amplify any individual research that is done using the repository:

- Researchers at sites participating in the collection of samples get priority access to the repository. By collecting samples from 100-200 subjects themselves, they get access to samples from 1000+ subjects.

This allows experiments to be conducted at a scale not possible otherwise.

- Because all researchers use samples from the same people, their results can be combined and cross-correlated to produce results that could not otherwise be obtained from stand-alone experiments.

This allows collaboration to occur without having to get researchers to collaborate officially. We get more information out of the system than was put in directly. Direct collaboration is enhanced, also.

- Researchers who get access have a powerful tool when applying for grants. By getting access to such an expensive resource, other funding agencies need only fund the additional work of analysis, leveraging their money tremendously.

This enhances the appeal of grants to other agencies and increases the likelihood of getting funded.

- Donors contributing to the repository are funding many, many experiments at once and not only a single effort.

This allows people to get more bang for the buck by funding a shared resource.

- We collect samples from subjects with other demyelinating diseases (such as TM, ADEM, NMO, etc.), and each disease can use the others as a control while studying their own.

We can leverage the efforts of creation of this resource across multiple diseases, benefiting all of them simultaneously.

In summary, by creating a shared resource that requires participating researchers to share their results, we create more experiments, larger experiments, more collaboration within and across institutions and diseases, enhance funding, and ultimately determine the causes of MS and other related disorders.

Other Facts:

- We have already collected well over 1,000 samples and made them available to researchers at multiple institutions. Current status of our collection and distribution is available at www.acceleratedcure.org/repository/status.php
- While we have started out collecting blood, we intend to add spinal fluid and post-mortem brain tissue as funding allows.
- This study is longitudinal, allowing us to track trends within individuals with MS. Because we also recruit unaffected first-degree relatives, we have the opportunity to watch some of them convert to having MS.
- We are working with the following vendors to conduct the study:
 - Clinical Research Organization: Omnicare, Inc.
 - Electronic Data Capture: DSG, Inc.
 - Sample Storage: Seracare, Inc. (Genomics Collaborative Subsidiary)
- Collection sites:
 - UMass Memorial, Worcester, MA
 - Beth Israel Deaconess Medical Center, Boston, MA
 - MS Research Center of New York, NY
 - Johns Hopkins, Baltimore, MD
 - Shepherd Center, Atlanta, GA
 - Ohio State University, Columbus, OH
 - University of Colorado/Rocky Mountain MS Center, Aurora, CO
 - UT Southwestern, Dallas, TX
 - Barrow Neurological Institute, Phoenix, AZ
- For further information contact:
 - Sara Loud, Repository Director sloud@acceleratedcure.org 781-487-0008
 - www.acceleratedcure.org/repository/

"The project represents the largest and most comprehensive ascertainment of historical, epidemiologic, genetic, and clinical data on multiple sclerosis to date. The protocol has been carefully and expertly formulated and refined. Further, the highly coordinated team that has been assembled at the Accelerated Cure Project, is among the most professional, dedicated, and effective that I have had the privilege to work with during the course of my academic career."

Elliot M. Frohman, MD, PhD
University of Texas Southwestern Medical Center at Dallas

"The data gathered in this project will certainly be of benefit to MS researchers. Having blood samples to go along with clinical data could provide insights into genetics and immunology, and how these impact response to therapy and disease course."

Ben Thrower, MD
MS Center at Shepherd