



Accelerated Cure Project Repository Overview

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 virtual 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 its causes and mechanisms.

We believe that knowing the causes and mechanisms of MS will lead to the fastest route for a cure by:

- Providing targets for treatments, cures, and prevention
- Allowing repair strategies to work
- Identifying markers to speed up and refine drug trials
- Providing definitive diagnosis and segmentation for treatment
- Enabling the creation of better animal models

MS shares three characteristics with many diseases that have not yet been cured:

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 subpopulations 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.
3. MS is a dynamic disease. Not only does the clinical course often change over time in people with MS, but the factors that are involved in initiating the disease and driving ongoing disease activity may also change over time in affected individuals.

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 people 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 and clinical and epidemiological data from a large group (currently over 3,000) 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. As an example, at \$2.5M to collect the first 1,000 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 1,000 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 points that amplify any individual research that is done using the repository:

- Researchers conducting studies in a wide variety of disciplines (genetics, genomics, proteomics, metabolomics, infectious disease, immunology, etc.) can obtain access to the repository and samples and data from 3,000+ 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 requiring researchers to collaborate officially. We can extract more information out of the system than was put in directly. Direct collaboration is enhanced, also.

- Researchers who obtain access have a powerful tool when applying for grants. Because researchers do not need to shoulder the entire cost of collecting and processing samples, 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 wanting to support MS research to maximize the effect of their donation by funding a shared resource.

- We collect samples from subjects with other demyelinating diseases (such as TM, ADEM, NMO, etc.), thus providing a ready source of highly relevant control samples for anyone studying any of the included diseases.

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 are enabling more and larger experiments, promoting collaboration within and across institutions and diseases, enhancing scientific funding, and ultimately will determine the causes of MS and other related disorders.

Other Facts:

- We have already collected over 3,000 samples which are available to researchers at multiple institutions. The current status of our collection and distribution is available at www.acceleratedcure.org/repository/status.php
- This study is longitudinal, allowing us to track trends within individuals with MS.
- We are working with the following industry-grade vendors to conduct the study:
 - Clinical Research Organization: Theorem Clinical Research
 - Electronic Data Capture: DSG, Inc.
 - Sample Storage: Seracare, Inc.
- Collection sites:
 1. UMass Memorial, Worcester, MA
 2. Beth Israel Deaconess Medical Center, Boston, MA
 3. MS Research Center of New York, NY
 4. Johns Hopkins, Baltimore, MD
 5. Shepherd Center, Atlanta, GA
 6. Ohio State University, Columbus, OH
 7. University of Colorado/Rocky Mountain MS Center, Aurora, CO
 8. UT Southwestern, Dallas, TX
 9. Barrow Neurological Institute, Phoenix, AZ (not currently enrolling)
 10. Stanford University, Stanford, CA
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