



Procedure for Requesting Biological Samples and Data from the Accelerated Cure Project MS Repository

March 2009

The Accelerated Cure Project Blood, Tissue and Data Bank solicits proposals requesting biological samples from investigators studying the causes or triggers of MS and related demyelinating diseases. To request specimens, please follow these procedures:

1. Submit a written proposal to the Accelerated Cure Project using the attached form. This proposal will contain information about your research plan as well as the number and type of specimens required. The proposal **must** include a description of your plans for contributing the data generated from use of the specimens back to Accelerated Cure Project for incorporation into the sample database. These plans must include type of data to be contributed, expected timing of the contribution, and quality control mechanisms to be applied to the data before contribution. Proposals are accepted and reviewed year round.
2. Your proposal will be initially reviewed by Accelerated Cure Project staff for completeness, alignment with the purpose of the repository, and our ability to fulfill the request. You will be notified if any problems are found and given the opportunity to make appropriate changes.
3. After the preliminary review is complete, your proposal will be reviewed by the Accelerated Cure Project Repository Oversight Committee, composed of representatives from Accelerated Cure Project, the Transverse Myelitis Association, the collection sites, and others. This committee will make a recommendation regarding whether to grant your request. Factors influencing this recommendation include:
 - Potential benefit to people with MS and/or related demyelinating diseases
 - Scientific merit of the application
 - Experience of the investigator
 - Adequacy of plans for contributing data generated through use of the specimens
 - Statistical validity of the study
 - Use of techniques designed to minimize the specimen volume required, if nonrenewable specimens are requested
 - Scale of experiment (data on more samples is preferred to fewer, inclusion of multiple diseases is preferred to a single disease)
4. Accelerated Cure Project will make the final decision on providing the samples and associated data. If Accelerated Cure Project cannot meet your needs, we will attempt to identify an appropriate alternative resource.

If your proposal is approved, you will be sent a letter of approval with a commitment from Accelerated Cure Project to provide the necessary specimens along with a materials transfer agreement. If your proposal is not accepted, you will be sent a letter stating the concerns that prevented your proposal from being approved, and invited to resolve any remaining scientific issues so that the proposal may be resubmitted.

Request for Samples from the Accelerated Cure Project MS Repository

Use as much space as you need to answer the questions.

Date:

Name of investigator:

Investigator's institution:

Address:

Phone number:

Email address:

Fax number:

Description of research to be performed and its benefit to people with MS or other demyelinating diseases, written in language understandable by non-researchers. Explain how the information to be generated by your research will potentially improve the lives of people with MS, TM, NMO, ADEM, ON, or a clinically isolated syndrome. For example, if your research could help to treat, cure, or diagnose these diseases, describe in simple language how the results would facilitate these outcomes.

Description of samples requested:

Be sure to include:

- Type(s) of sample (DNA, serum, etc.) needed
- Number and type(s) of subjects (MS, CIS, TM, ADEM, ON, NMO, controls) including special requests such as “RRMS – not on disease-modifying therapy” or “Controls – both parents”
- Any requirements concerning blood relationships between subjects (such as only one case per family, or only controls who are not genetically related to cases)
- Quantity/volume of each type of sample needed
- Contact Accelerated Cure Project at 781-487-0032 or sloud@acceleratedcure.org if you have questions about sample availability.

Detailed description of research to be performed using the samples:

Be sure to include:

- Description of techniques to be used in performing the experiment
- Description of results that are expected to be generated through this research
- Analysis of the statistical power of your proposed experiment
- Quality assurance/quality control processes to be followed

What important questions regarding the etiology, pathogenesis, biomarkers, or diagnosis of MS and/or related demyelinating diseases will your study help to answer?

Description of data elements from case report form (CRF) or previously returned research data needed to accompany samples:

Note: Our case report form can be downloaded here:
http://www.acceleratedcure.org/repository/downloads/ACP_CRF.pdf

Description of data to be returned to the Repository database upon completion of your experiment:

Be sure to include:

- Specific data elements that will be provided for each sample analyzed
- Data QA/QC processes to be followed

Note that a grace period will be allowed between completion of the experiment and submission of your data to the repository database to allow for publication and securing of IP rights.

Has your proposed study been approved by an IRB? If not, please describe your plans for obtaining IRB approval:

Have you obtained full financial support for your study, including support for sample/data acquisition costs? Our pricing policy can be found here:
http://www.acceleratedcure.org/repository/downloads/ACP_Cost_Recovery_Policy.pdf

If not, please explain:

How did you hear about the Accelerated Cure Project repository?

**Please direct all proposals and questions about the review process, and submit completed proposals to:
Hollie Schmidt (hollie@acceleratedcure.org, 1-781-487-0099)**