

Information about the Stanford Neuromuscular Biobank

What is the Stanford Biobank?

The Stanford Neuromuscular Biobank is a collection of biological samples from donors for scientific research. The Biobank stores samples such as blood, muscle, skin biopsies, spinal fluid, and other clinical specimens. The Biobank collects tissues from people with muscular dystrophy, myotonic dystrophy, related neurological disorders, and unaffected family members. Samples can be collected with your consent during routine clinic visits, during scheduled surgical procedures, or after death with your family's consent. The Biobank then organizes and stores these samples so that they can be shared with scientists throughout the world for research. These samples are tremendously valuable for determining how neuromuscular conditions affect the body, which will help develop meaningful treatment. This resource facilitates the involvement of subjects with rare disorders to assure researchers have access to necessary samples.

How do I enroll?

Enrollment in the Stanford Neuromuscular Biobank is relatively easy, and requires you to fill out two forms. The first form is the Intended Donor Information Form containing your personal information, and contact information for your next-of-kin and primary healthcare provider. The second form is the Research Consent Form which allows you to formally state your intent to allow the Stanford Neuromuscular Program to collect your tissue samples for research purposes. We ask that you include information about your funeral home on the Intended Donor Information Form if that has already been established; the mortician can be very helpful in facilitating the research. The Research Consent Form contains both your signature, and the signature of your next-of-kin, which will help assure your family of your intent. For an autopsy to occur, though, a consent from the institution performing the autopsy will need to be signed by the next of kin after death. We recommend you make several copies of these signed forms and store them in your personal records, as well as giving copies to your family, next-of-kin, primary healthcare provider, and designated funeral home. We also recommend you include your Research Consent Form in any medical directive, will and living will. Please mail us the original copy of both Stanford forms. If any of the contact information changes, we ask that you update us by emailing or calling our non-emergency contact information enclosed in this information package.

How will my donated sample be used?

The donated samples will be stored at Stanford for future research. Qualified researchers who require samples will apply to our Biobank, submitting a description of their research project and proof of institutional approval. Samples given to researchers will have all personal identifying information about the donor removed, and will simply include information about the medical condition of the donor (see question below regarding privacy for more information). We will not be able to provide families with information about where or how individual donor specimens are used, but we are happy to provide general information about projects and publications that have used Biobank samples.

What are the benefits of enrolling?

Specific neurological and neuromuscular disorders are often rare, so that researchers have difficulty procuring the samples they need for investigations. By donating to the Stanford Neuromuscular Biobank, you will help researchers make new scientific discoveries that may ultimately benefit individuals with the same condition that affects you and your family. The Biobank research team will take care of all arrangements, and any costs of donation, once you have notified us.

How will my privacy be protected?

All identifying information recorded in the Intended Donor Information Form and Research Consent Form will be stored at Stanford and not released to any other researchers. When samples arrive at our Biobank, we will label them with a unique identifying number. We will ask for specific medical information that we will associate with the specimens, but only Dr. Day and his direct team will have access to the identifying information forms linked to the unique ID number. Samples shared with researchers will only have the ID number, description of the type of sample/tissue, and characterization of the donor's condition. If at any time you no longer wish to be enrolled in the Biobank, please contact us by email or phone (see contact information below), and we will immediately remove your information and samples from our system.

How do I donate?

If you are scheduled for a procedure you believe may produce samples for donation, please email or phone our non-emergency contact listed below in time so that we can make arrangements to collect the specimen from your physicians. If you are the next-of-kin, primary healthcare provider, or funeral home representing a person enrolled in our Biobank for autopsy donation and you believe death is imminent, please contact one of our emergency contacts listed below. A single phone call is typically all you will need to make; we will take care of the rest of the arrangements. After the family member's death, the next of kin will have to consent for the autopsy at the institution providing that service. The autopsy is performed as soon after death as possible, usually within 24 hours. After the autopsy is completed, the remains are returned to the mortician. Care is taken throughout the procedure to preserve normal appearance, so that there is no restriction on the type of memorial service available to the family.

Who can I contact for more information?

If you have any questions about the Biobank, please contact our team of researchers by email at stanfordbiobank@lists.stanford.edu, or call our non-emergency contact phone number.

Non-emergency contact

Email: stanfordbiobank@lists.stanford.edu

Dr. Day's Lab: (650) 723-9574

Dr. Day's Office: (650) 725-7622

Emergency Contacts

Shirley Paulose, MS

Office: (650) 724-3792

Katharine Hagerman, PhD

Lab: (650) 723-9574

John W. Day, MD, PhD

Office: (650) 725-7622

Pager: (650) 723-4000

(have the page operator contact Dr. Day)