

CMD Tissue Repository

Accelerating Research for Congenital Muscle Disease

Congenital Muscular Dystrophy • Congenital Myopathy • Congenital Myasthenic Syndrome

Thank you for your interest in donating to our tissue repository. The CMD Tissue Repository (CMD-TR) is located at the Medical College of Wisconsin as a module within the Children's Hospital of Wisconsin Research Institute in Milwaukee, Wisconsin. The overall aim of the repository is to discover effective treatments and eventually find a cure for inheritable muscle diseases. Your gracious donation will help us reach that goal. Your gift of tissue will be made available to scientists who are working on therapies and potential cures for congenital muscle disease (CMD). There is no cost to you.

There are a few ways in which you can donate.

- 1) Left-over muscle biopsy tissue: If you've ever had a muscle biopsy done, there may be tissue remaining at your hospital that could be transferred to the CMD-TR. Stacy Cossette can help find out and coordinate all aspects of tissue transfer. If you agree, the tissue repository manager, Stacy Cossette, will help you review and sign the required forms. The forms you will sign include some or all of the following:
 - a. Consent form – signed by parents or patients at ages 18 years and older
 - b. Assent form – signed by children able to do so between age 7 and 18
 - c. HIPAA form – signed by adults
- 2) Spare tissue: This option occurs through a surgical procedure such as scoliosis surgery, contracture release, or muscle biopsy. Arrangements are made in advance with your surgeon for any spare tissue obtained during the planned surgery to be collected and shipped to the CMD Tissue Repository instead of being discarded. This would pose no extra risk to you or your family member.
- 3) Blood: You also have the option of donating blood for the establishment of cell lines (in addition to a donation of spare tissue), which can be done during a medical procedure. If you agree to donate blood, there is a check box you can mark on the consent form, which Stacy Cossette can help you complete.
- 4) Autopsy: During a health crisis or unfortunate passing away there is enough stress already, so pre-consenting is suggested to help inform family of your wishes to have tissue donated after an untimely passing. This is a tremendous gift to help in the search for effective treatments.

Please contact Stacy Cossette upon receipt of this information. You can call her at 414-955-4685 or email her at scossette@mcw.edu.