

# UNIVERSITY OF MINNESOTA

*Twin Cities Campus*

*Paul and Sheila Wellstone Muscular Dystrophy Center*

*Mayo Mail Code 206  
420 Delaware Street S.E.  
Minneapolis, MN 55455-0392*

*612-626-0822  
Fax: 612-625-8488  
E-mail: [mdcenter@umn.edu](mailto:mdcenter@umn.edu)  
<http://www.mdcenter.umn.edu>*

## Post-Mortem (Autopsy) Tissue Donation Information

We want to thank you for considering body donation to myotonic dystrophy research. There is a great deal more to learn about how and why myotonic dystrophy affects the muscles and other organs. We are hopeful that the more we understand about myotonic dystrophy, the closer we can come to a cure.

Myotonic dystrophy is a multi-systemic disease, meaning that it affects several organs in the body. Specifically, myotonic dystrophy is associated with cataracts, endocrine problems (such as diabetes and other hormone abnormalities), heart problems, and muscle weakness and stiffness. It is not well understood how the genetic changes associated myotonic dystrophy can cause such a wide variety of clinical symptoms. Many individuals have played a key role in advancing the knowledge about myotonic dystrophy by providing blood samples, muscle biopsies and other tissue. An autopsy allows study of tissues that cannot be done in other ways, and can help explain how the myotonic dystrophy genetic change is affecting different organs.

When a person wishes to have an autopsy performed for the purpose of obtaining tissue for research, there are several issues that need to be addressed. Consent for the autopsy must be obtained from the next of kin. Each institution may have its own form or you may use the Provisional Autopsy Form included in this packet. The autopsy can be performed at the University of Minnesota if possible, or we will work with other facilities as necessary. Once the autopsy is completed the funeral home will transport the body back to the funeral home. Following the autopsy a funeral can occur as per the families' wishes. We have funds to help cover the costs of the autopsy.

The enclosed forms are designed to facilitate the autopsy and notify the individuals that are involved in the autopsy process. If you are interested in the autopsy study, we ask that you fill out the information form and the provisional authorization forms. These forms provide us with the name of your next of kin, primary care provider and funeral home to assist in arranging the autopsy study. We also ask that the witness for the provisional authorization be your next of kin, so that he or she is aware of your wishes. You may want to make several copies of the provisional authorization form. One copy is for your records. You can give the remaining copies to whomever you feel needs one; we recommend you provide one to your primary physician, the funeral home, hospice if they are involved and your next of kin. Once you have completed the forms please send them to the appropriate individuals. By notifying individuals in one's family, primary physician, the funeral home and the research team ensures that everyone is aware of your desire to participate in autopsy studies, and simplifies decision-making during the difficult time after death. We can certainly assist in completing these forms if that would be helpful.

We hope this letter has helped answer some questions regarding autopsy studies. If you or your family has questions or concerns you want to discuss, please do not hesitate to call us at 612-626-0822. Feel free to fax forms to Cameron Naughton at 612-625-8488 or send them to the address listed above.

Thank you again for your consideration of autopsy studies for research – a critical part of our efforts to understand and treat this disease.

# AUTOPSY STUDY INFORMATION SHEET

## Patient Information

Printed Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_  
Phone number (with area code): \_\_\_\_\_  
Date of Birth: \_\_\_\_\_ Social Security Number: \_\_\_\_\_

## Next of Kin Contact Information

Printed Name: \_\_\_\_\_  
Relationship to Patient: \_\_\_\_\_  
Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_  
Phone number (with area code): \_\_\_\_\_

## Primary Physician Information

Printed Name: \_\_\_\_\_  
Hospital/Clinic Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_  
Phone number (with area code): \_\_\_\_\_

## Funeral Home Information

Funeral Home Name: \_\_\_\_\_  
Contact Person (if available): \_\_\_\_\_  
Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_  
Phone number (with area code): \_\_\_\_\_

# PROVISIONAL AUTHORIZATION FOR ANATOMICAL DONATION

For (donor's name): \_\_\_\_\_ D.O.B: \_\_\_\_\_

**Instructions:**

- 1) Complete this form. Make as many copies as needed.
- 2) Keep one copy for your records. Mail the other copies to your primary care physician, the funeral home, next-of-kin and to Dr. Karachunski or MDCenter staff.
- 3) When death occurs, we have to get consent from the next of kin, therefore please notify us of any address or phone changes of yourself or the next-of-kin.

**Consent of Donor:**

In the hope that this donation will further the medical understanding of neurological disease, I, \_\_\_\_\_, an adult, do hereby authorize and direct that upon my death, an autopsy be performed for the removal, retention and use of tissues for diagnosis and/or research purposes.

\_\_\_\_\_  
Signature of Donor Date

\_\_\_\_\_  
Signature of Witness (Next of Kin) Date

**Next of Kin Contact Information:**

Printed Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone number (with area code): \_\_\_\_\_

If you have any questions regarding autopsy studies please do not hesitate to call 612-626-0822.

**In the event of a death you may contact the following numbers at any time:**

**Peter Karachunski, MD**

Office (612) 626-0822

Pager: (612) 899-7635

Cell: (612) 770-5205

karac001@umn.edu

**Cameron Naughton**

Office: (612) 625-4882

Pager: (612) 899-5964

naug0009@umn.edu