

Study Title: Rocky Mountain Multiple Sclerosis Center Tissue Bank
Principal Investigator: John R. Corboy, MD
COMIRB No: 09-0952
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You are being asked to give us some information because you have expressed interest in donating tissue to the Rocky Mountain Multiple Sclerosis Center Tissue Bank (RMMSCTB) after your death.

If you join the agree, you will fill out 2 forms

- Donation consent: lists your contact information and the contact information for your next of kin. You will sign indicating your desire to donate
- Donor enrollment form: a questionnaire asking for some basic medical history information

When you return those forms to us, along with this form signed and dated, we will send you a donor card for you to keep on you (in your wallet, etc). This card will identify you as a potential donor and give information on who should be contacted upon your death.

The purpose of the RMMSCTB is to collect and provide tissue for research on the causes and potential treatments for MS and related diseases. The RMMSCTB has been obtaining and distributing brain tissue from MS patients for MS research for over 30 years.

The permission you are giving now is only for us to maintain your contact and health information in a database of people who are interested in donating. There are separate processes involved with completing the donation; your next of kin will complete these after your death.

The only possible risk or discomfort is potential loss of confidentiality. Every effort will be made to protect your privacy and confidentiality: the information you provide will be kept protected and secure and only accessible by RMMSCTB staff.

This research is being paid for by the National Multiple Sclerosis Society.

You have a choice about being in this study. You do not have to be in this study if you do not want to be.

If you have questions, you can call the RMMSCTB at 303-788-4030 ext 120. You can call and ask questions at any time.

You may have questions about your rights as someone in this study. If you have questions, you can call the COMIRB (the responsible Institutional Review Board). Their number is (303) 724-1055.

Who will see my research information?

The University of Colorado Denver (UCD) and its affiliated hospital(s) have rules to protect information about you. Federal and state laws including the Health Insurance Portability and Accountability Act (HIPAA) also protect your privacy. This part of the consent form tells you what information about you may be collected in this study and who might see or use it. The institutions involved in this study include University of Colorado Denver and University of Colorado Hospital.

We cannot do this study without your permission to see, use and give out your information. You do not have to give us this permission. If you do not, then you may not join this study.

We will see, use and disclose your information only as described in this form and in our Notice of Privacy Practices; however, people outside the UCD and its affiliate hospitals may not be covered by this obligation.

We will do everything we can to maintain the confidentiality of your personal information but confidentiality cannot be guaranteed.

Post Card Consent

The use and disclosure of your information has no time limit. You can cancel your permission to use and disclose your information at any time by writing to the study's Principal Investigator (PI), at the name and address listed below. If you do cancel your permission to use and disclose your information, your part in this study will end and no further information about you will be collected. Your cancellation would not affect information already collected in this study.

John Corboy, MD: 12631 E. 17th Ave, mailstop B185, Aurora CO 80045

Both the research records that identify you and the consent form signed by you may be looked at by others who have a legal right to see that information, such as: 1) Federal offices such as the Office of Human Research Protections (OHRP) that protect research subjects like you, 2) People at the Colorado Multiple Institutional Review Board (COMIRB), 3) The RMMSCTB study team, 4) Officials at the institution where the research is conducted.

The information about you that will be seen, collected, used, and disclosed is described earlier in this form.

Scientists at the University of Colorado Denver and the hospitals involved in this study work to find the causes and cures of disease. The data collected from you during this study are important to this study and to future research. If you join this study:

- The data given by you to the investigators for this research no longer belong to you.
- Both the investigators and any sponsor of this research may study your data collected from you.
- If data are in a form that identifies you, UCD or the hospitals involved in this study may use them for future research only with your consent or Institutional Review Board (IRB) approval.
- Any product or idea created by the researchers working on this study will not belong to you.
- There is no plan for you to receive any financial benefit from the creation, use or sale of such a product or idea.

Agreement

I have read this paper about the study or it was read to me. I understand the possible risks and benefits of this study. I understand and authorize the access, use and disclosure of my information as stated in this form. I know that being in this study is voluntary. I choose to give my information to be stored in the RMMSCTB database.

Signature: _____ Date: _____

Print Name: _____

Witness Signature: _____ Date _____

Witness Print Name:

Witness of Signature

Witness of consent process