**Research Information and Consent for Use of Tissues**

**Name of \*Participant:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_** **(Deceased, loved one)**

**Relationship to the donor: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(Mother, Father Legal guardian)**

If you are a parent or legal guardian of an individual who may take part in this study, permission from you is required. When we say “you” in this consent form, we mean you or your child; “we” means the doctors and other staff.

You have agreed that samples from the donated organs to be used in a research study titled:

**The exploration of novel drug therapy avenues for Rett Syndrome and similar rare disorders by studying the molecular mechanism of MeCP2 mutations on the regulation and function of the brain in patients with Rett Syndrome; A Canada-wide project on Rett Syndrome**

and have signed a Research Participant Information and Consent Form.

As you are aware, this study requests that +brain tissue after death of the patient, to be sent to Dr. Marc Del Bigio, for gross pathological examination. Upon completion of the pathological examinations, all tissues will be transferred to Dr. Mojgan Rastegar laboratory for research and comprehensive molecular analysis by her laboratory. Dr. Rastegar and Dr. Del Bigio are both affiliated with the Rady Faculty of Health Sciences, University of Manitoba, and their labs are located in Winnipeg, Manitoba. You may contact Dr. Rastegar 24/7 at 204-290.5203 or alternatively visit www.rastegar.biochem.umanitoba.ca

*+In case that the patient has had clinical signs of metabolite deficiency or digestive track issues; a small piece of liver and intestine may also be collected for parallel analysis.*

By signing this consent form, you agree that the tissue requested for research purposes will be removed from the patient case file in the local pathology lab and will be shipped to Dr. Marc Del Bigio in Winnipeg for pathological examination. Upon completion of the pathological examinations, all tissues will be transferred to Dr. Mojgan Rastegar laboratory for research and comprehensive molecular analysis by her laboratory. Please note that clinical patient information will be provided to Dr. Rastegar, but will be de-identified. This means that Dr. Rastegar will not receive the name or any other direct identifiers. The samples will be assigned a unique code that does not include information about the patient (e.g. name, medical numbers, address, etc.). Dr. Rastegar may share biological samples extracted from these donated tissues with other researchers doing similar studies through collaboration, but these shared biological samples will always be de-identified. You agree that Dr. Rastegar research results containing de-identified clinical information could be presented in research communications that may include scientific texts, peer-reviewed publications, students’ thesis, grant applications, and research seminars.

We realize that this is a very difficult and emotional time for you and your family. We hope that the use of these samples in research will help those living with Rett Syndrome in the future.

- You can follow up and receive update on the results of the study through contacting Ontario Rett Syndrome Association.

- Participation in the study will be for an ongoing period of time subject to continued research funding. In case of the lack of funding for a period of time, samples will be properly preserved in Dr. Rastegar laboratory, until new funding is secured to resume active research.

- You may withdraw the use of these samples for future research at anytime by contacting Dr. Mojgan Rastegar (Mojgan.rastegar@umanitoba.ca) or Dr. Marc Del Bigio (marc.delbigio@umanitoba.ca). Volunteer withdrawal will only apply to future studies, and will not apply to previously completed, conducted, and initiated research experiments and data analysis. The de-identified results that are obtained prior to your volunteer withdrawal could still be included in public communications, including scientific texts, peer-reviewed publications, students’ thesis, grant applications, and research seminars.

Your signature on this consent also means that you understand that participating in this study will mean the donated organ(s) and brain tissues will be shipped to the University of Manitoba, Winnipeg, Manitoba.

You will receive a signed copy of this form.

My participant signature on this consent form means the following:

The matters associated with the donated tissue(s) requested for this study have been fully explained to me and all of my questions have been answered with regards to the process associated with organ donation of the deceased patient.

I agree that my deceased loved one to take part in this study and consent to the release of tissue(s) that is required for pathological examination by Dr. Del Bigio and comprehensive molecular research and molecular analysis in the laboratory of Dr. Rastegar. I agree that the results of her research can be published and shared in research formats (with de-identification of the patient).

**Statement of Consent**

I have read the Brain Donation Brochure and this consent form. I have had the opportunity to ask questions and discuss what is involved. I understand that my personal information will be kept confidential. The risks associated with the tissue requested for this study have been fully explained to me and all of my questions have been answered.

Parent/legal guardian’s signature\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date \_\_\_\_\_\_\_\_\_\_\_\_

Parent/legal guardian’s printed name\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature of individual authorized to provide consent\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date \_\_\_\_\_\_\_\_\_\_\_\_

Printed name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_