

Tissue & Organ Donation

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Tissue Donation

The advancement of scientific discoveries towards treatments and a cure for Rett syndrome (RTT) depend on the ability of researchers to study how mutations in the MECP2 gene affect growth and development. You can help with this research by donating a sample of your child's blood or tissue if she is having a routine blood draw or undergoing a medical or surgical procedure (e.g., skin or muscle biopsy, endoscopy, scoliosis surgery). A known MECP2 mutation and completion of a clinical questionnaire is required for this research.

Coriell Cell Repository catalogs these samples and makes them available to researchers worldwide. One of IRSF's objectives is to expand the RTT blood/tissue collection at Coriell. Coriell currently has 43 cell lines available to researchers from individuals diagnosed with Rett syndrome. To date over 100 samples have been distributed to the scientific community for use in their research projects.

Coriell will send you a collection kit with complete instructions for the physician, lab, hospital or medical center and prepaid Fed Ex materials. Contact Paige Nues at pnues@rettsyndrome.org or call the IRSF office at 1-800-818-RETT (7388) for more information.

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Organ Donation

"From Knowledge Will Come a Cure"

The passing of a loved one, especially a loved one who has lived with a diagnosis of Rett syndrome (RTT), can be a very difficult time. You may find solace knowing that in death she can give the gift of hope to finding treatments and a cure for those living with RTT today, and for future generations to come. The best time to consider this option is before you have to.

Organ donation is critical to the dedicated researchers working tirelessly to unravel the mysteries of RTT. We urge U.S. and Canadian families to please consider this selfless and courageous gift to the Rett syndrome research community.

If you decide to support RTT research, contact the Harvard Brain Bank or IRSF as soon as possible after or near the time of death. The process must take place within 24 hours of passing, and before any preparations. It is important to know that this will not interfere with any funeral arrangements, including viewing. The kind and respectful staff at the Harvard Brain Bank will handle all arrangements directly with the hospital, hospice nurse, coroner, or pathologist.

For more information, contact the Harvard Brain Bank directly at 1-800-BRAIN BANK, or the IRSF office at 1-800-818-RETT (7388) or Paige Nues at pnues@rettsyndrome.org.

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