

Williams Syndrome Tissue Donor Information and Registration Packet

The Gift of Knowledge!

- ♥ *Becoming a tissue donor is simple.
Discuss your decision with your family.
Complete and return the attached donor registration form.*

- ♥ *There is no cost to you or your family.
All costs related to tissue donation are paid for by The Salk Institute for
Biological Studies and University of Maryland Brain and Tissue Bank.*

- ♥ *All major religions support tissue donation.
Most religious groups support organ and tissue donation as a charitable gift of life
consistent with the basic tenets of these faiths.*

- ♥ *Tissue donation does not interfere with funeral or burial
arrangements.
Tissues are removed by people specifically trained for tissue recovery.
The donor's body is handled with respect and dignity.*

*This research is funded by the
National Institute of Child and Human Development
and conducted at
The Salk Institute for Biological Studies
& University of California, San Diego*

Each child is a treasure box, and when they die, they take with them the key that would unlock the mysteries of diseases. When you as a parent decide to donate tissue to researchers, you are donating the key to that treasure to future generations.

Dr. Rodríguez, NICHD Brain Bank, Miami

We would like you to know about the Williams Syndrome Tissue Donor Program, that encourages individuals and families to make precious brain tissue available to scientists in order to advance Williams syndrome research and solve the mystery of this disorder.

THE NEED FOR BRAIN TISSUE

Critical basic research is lagging behind because of the scarcity of brain tissue for Williams syndrome research. So far, researchers have documented irregularities in several brain areas. The next step is a comprehensive, comparative investigation of brain areas and brain development with the new techniques now available. Without this tissue, studies that could lead to the understanding of Williams syndrome cannot be done.

With brain tissue, scientists can go far beyond the limits of other technologies and study Williams syndrome at a cellular and molecular level. It is possible to study the pathways of the brain to help understand both normal and abnormal development. What is learned about neurodevelopment can be applied to day-to-day educational programs to make the most of developmental periods and the brain's capacity to change. What is learned about cells and neurotransmitters in the brain can lead to new treatments.

In research supported by the National Institute of Child and Human Development, the Salk Institute's Laboratory for Cognitive Neuroscience, in conjunction with University of California, San Diego and the University of Utah Brain Institute, are conducting in-depth studies of the relationships between genes, brain structure and function, and behavior in Williams syndrome. Part of this research involves studying differences in cell size, shape, and functioning using donated brain tissue. This type of research has been instrumental in making new discoveries about a wide variety of conditions, including Huntington's disease and Parkinson's disease, and similar promise holds for individuals with Williams syndrome.

A BENEFIT TO FUTURE GENERATIONS

Research takes time and patience. Parents of children with Williams syndrome are often skeptical of cures, but hopeful that it will be possible to enhance the ability of their children to learn and participate more fully in society.

AN EXPRESSION OF COMPASSION

Virtually every religion encourages us to have compassion and to act to help others. Tissue donation may be, for you, one of the ways to help future generations. Registering to donate brain tissue does not mean that we anticipate you or your child to die an early death. It does mean, however, that you are prepared to act if such an unexpected and unfortunate event were to occur. Religious groups including Protestant, Catholic, Jewish, and other faiths support organ and tissue donation as a charitable gift of life consistent with the basic tenets of these faiths.

BECOMING A DONOR

Becoming a registered brain donor is easy. Any person 18 years of age or older who is their own guardian can simply complete and return the enclosed "Brain Donation Registration" form. In the cases of children or individual's with a guardian, that guardian can also fill out the form, though we strongly urge guardians to discuss the issue with the prospective donor to learn of their views and wishes. The next most important thing to do after registering is to inform your family that you have registered to be a brain donor with the Salk Institute's research.

Although sometimes a difficult subject to face, brain donation is one that should be considered well in advance of any tragedy. Time is of the essence in organ donation, which must be completed within minutes to hours of passing. At the time such an unfortunate occurrence, emotions and thoughts are understandably directed elsewhere, which is why thinking about brain donation ahead of time is important. Also, it is frequently best if the family discuss the idea of donation openly to avoid misunderstandings, and to facilitate the donation process. Following the donor's death, the legal next-of-kin must verify the donor's intent-to-donate and must provide the Salk Institute with written authorization for the donation and for the acquisition of medical records. A simple phone call is all that is needed to start this process. Our laboratory will then handle all the arrangements for donation at no cost to you or your family.

TISSUE RECOVERY

A pathologist or neuropathologist performs tissue recovery in coordination with the funeral arrangements. Your loved one is treated with the utmost respect and dignity and the procedures used will not affect any funeral arrangements, including viewing, that you wish to make. The Salk Institute and University of Maryland Brain and Tissue Bank assume all costs related to obtaining tissue.

IN AN EMERGENCY

It is important that the donation procedure occur *within 24-hours* (preferably sooner) of the time of death of the donor. At the time of imminent death or immediately following the death of the donor, contact us at the Salk Institute for assistance:

1-800-434-1038

Our team specialist will contact a local pathologist to assist with tissue recovery at your area hospital. We will work directly with your local hospital and/or physician to make arrangements for tissue removal and provide donation instructions.

STEPS FOR SUCCESSFUL TISSUE DONATION

If you are interested in brain donation we recommend the following steps:

1. Have a family discussion about brain donation. Be sure your family members understand your intention to donate.
2. To register a potential donor, complete and return the attached "Williams syndrome Tissue Donor Program Registration" form.
3. Make preliminary arrangements for brain removal through your physician or social worker. If the donor is hospitalized and death is a possibility, let the hospital know of the donor's wishes so they can be prepared.

4. When death is impending or at the time of death, call The Salk Institute's Laboratory for Cognitive Neuroscience at 1-800-434-1038 and provide the following information.
 - a. Name, age, and location of donor, time and cause of death (if known),
 - b. Name, address, and phone number of legal next-of-kin.
5. The legal next-of-kin will be required to sign a "Consent for Donation" following the death of the donor, which authorizes the donation of the brain to the Salk Institute's Laboratory for Cognitive Neuroscience for use in their research.

PLEASE ASK QUESTIONS

The staff at the Laboratory for Cognitive Neuroscience and all collaborating centers genuinely appreciate your interest. We are available to answer your questions by mail or phone. Just call toll free: 1-800-434-1038 or 858-453-4100 ext.1222.

The Salk Institute
Laboratory for Cognitive Neuroscience
Williams Syndrome Donor Registration
10010 N. Torrey Pines Rd., La Jolla, CA 92037

WILLIAMS SYNDROME TISSUE DONOR PROGRAM REGISTRATION
The Salk Institute for Biological Studies Laboratory for Cognitive Neuroscience
(858) 453-4100 x1222 (800) 434-1038 FAX: (858) 452-7052

Completion of this registration form provides important information needed to coordinate tissue recovery in the event of death of the donor. After the **Laboratory for Cognitive Neuroscience** receives this registration form, you will receive a packet containing Anatomical Gift Act forms and Access to Medical Records forms and other materials.

DONOR INFORMATION

I, _____ wish to register myself (or my dependent) as a tissue donor with the **Laboratory for Cognitive Neuroscience** at the Salk Institute for Biological Studies.

NAME OF DONOR _____ DATE OF BIRTH _____
STREET ADDRESS _____
CITY _____ STATE _____ ZIP CODE _____
PHONE (day) _____ PHONE (evening) _____

PLEASE PROVIDE A BRIEF MEDICAL/FAMILY HISTORY

(Please continue on reverse side if additional space is needed)

DIAGNOSES: _____ DATE DIAGNOSED _____
_____ DATE DIAGNOSED _____
_____ DATE DIAGNOSED _____

PARENT, GUARDIAN, or HEALTH CARE PROXY INFORMATION

NAME _____ RELATIONSHIP TO DONOR _____
STREET ADDRESS _____
CITY _____ STATE _____ ZIP CODE _____
PHONE (day) _____ PHONE (evening) _____ FAX _____

PLEASE MAKE A COPY OF THIS FORM FOR YOUR RECORDS AND RETURN TO

The Salk Institute, Laboratory for Cognitive Neuroscience
10010 N. Torrey Pines Rd., La Jolla, CA 92037