



University of Pittsburgh *Center for ALS Research*

The Stephen Tuttle ALS Tissue Donation Program

*Consider giving the most
precious gift . . .*

ALS Research . . . Hope for the future

Amyotrophic lateral sclerosis (ALS) is a disease that results in the death of motor neurons in the brain and spinal column. Because no effective treatments or cure currently exist, patients and their families must witness the progress of the disease without the power to stop it. What can be done to help identify the causes of ALS so that effective treatments can be developed?

A critical part of the solution lies in continued scientific research. During the past decade mutations in a number of genes, including superoxide dismutase (SOD-1), have been identified in patients with inherited ALS. This has focused research efforts on the role of oxidative stress in regulating the death of motor neurons.

The discovery that reduced levels of specific types of glutamate transporters within the spinal cord of ALS patients has highlighted another mechanism that may contribute to motor neuron cell death. This helped lead to the development of riluzole (brand name Rilutek), which impedes the action of glutamate and was the first drug approved for the treatment of ALS.

These discoveries, and others, were made possible partly by ALS patients who donated brain and spinal cord tissues after their death. Continual donations of tissue samples are needed to further this vital research and further our understanding of how to treat this disease.

It is only through these generous contributions from patients and their families that research continues into the cause of and treatments for ALS.

Affiliations

The Stephen Tuttle ALS Tissue Bank is a nationally recognized service that works closely with the UPMC ALS Clinic and The ALS Association, Western Pennsylvania Chapter. The ALS Tissue Bank is a component of the Center for ALS Research and the Pittsburgh Institute for Neurodegenerative Disorders.

Are there other ways to be involved?

Donating tissues for research is not the only way you can help. Monetary support and public awareness are important components for continued research support. Consider making a gift today or hosting an event to raise awareness and funding. Contributions are tax-deductible and can be for any amount. Please make checks payable to ***University of Pittsburgh*** and include ***Center for ALS Research*** on the memo line.

Mail to:

***Center for ALS Research
University of Pittsburgh
Biomedical Science Tower S-408
200 Lothrop Street
Pittsburgh, PA 15261***

For current information about the Center for ALS Research at the University of Pittsburgh, please visit our website at:

www.alsresearchcenter.org

When baseball legend Lou Gehrig died of amyotrophic lateral sclerosis (ALS), a disease many people had never even heard of gained a household name: Lou Gehrig's disease. However, ALS was never a rare disease. People of all races and socioeconomic classes suffer from its increasing paralysis. ALS is a disease in which the nerves that control a person's muscles slowly die causing those muscles to become paralyzed. It slowly robs its victims of their ability to move, talk, eat and finally to breathe, while leaving their minds intact.

The Stephen Tuttle ALS Tissue Bank

The Stephen Tuttle ALS Tissue Bank facilitates ALS diagnostics and research in the Pittsburgh area and around the country. This program examines and stores spinal cord, muscle, and brain tissue samples from ALS patients and control subjects.

ALS clinicians and researchers work closely with the Center for ALS Research and the Pittsburgh Institute for Neurodegenerative Disorders at UPMC Health System to provide neurological diagnostic services, a critical part of biomedical research that also can provide a definite diagnosis of ALS for family members.

Facts about the Tissue Donation Program

- Examination of tissue samples from the patient will confirm or reject the clinical diagnosis of amyotrophic lateral sclerosis. Having a definite diagnosis can eliminate surviving family members' lingering questions or concerns.
- The tissue removal is performed very carefully so that it does not prevent an open-casket viewing or other desired funeral practice.
- Most major religions support tissue and organ donation. Feel free to discuss your participation with your spiritual adviser.
- Prior to death, an individual or family member can indicate intent to participate by signing a provisional consent. However, after death, the person's legal next of kin must authorize participation prior to any tissue donation. Discuss donation with your family to make sure that they know your wishes.
- The spinal cord and brain are the only tissues examined and removed, along with two samples of muscle and cerebrospinal fluid.
- There is no charge for the procedure when performed as part of this program.
- If you enroll in the tissue donation program, you should alert your funeral director and make initial arrangements for him or her to provide transportation. The program director of the ALS Tissue Bank will also contact the funeral director to coordinate transportation.

Why donate tissue?

People have many reasons for donating tissue for research. By donating tissue, you will be making an invaluable contribution to the future of research into ALS and other neurodegenerative diseases. Your selfless act could make an immeasurable difference for future patients with ALS. In addition, tissue examination is the best way to confirm a clinical diagnosis of ALS.

How will the tissue be used?

Tissues will be stored at the Center for ALS Research for use in current and future research projects. Samples from this tissue bank will be available to ALS researchers both at the University of Pittsburgh and around the country.

Only a few ALS tissue banks currently exist in the United States. Investigators share these scarce and vitally important tissue resources and obtain the best quality research.

How do I enroll?

Advance planning makes the enrollment process easy and efficient. You need only fill out and return a preliminary consent form. Application forms and guidelines for discussing your wishes with your family are available by contacting:

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