



University of Pittsburgh

The *Live Like Lou*



Center for **ALS** Research

University of Pittsburgh Brain Institute

Division of Neuropathology
UPMC Presbyterian
Room S701 Scaife Hall
200 Lothrop Street
Pittsburgh PA 15213
412-624-7897

Neuropathology Brain Bank

You have been asked to consider donating valuable tissue samples for research purposes because you or your relative has been diagnosed with amyotrophic lateral sclerosis (ALS) or a related illness. ALS clinicians and researchers at the University of Pittsburgh work closely with other researchers at the Live Like Lou Center for ALS Research, to provide tissue banking autopsy services and diagnostic opportunities for patients and their families. This project receives funding support from the University of Pittsburgh Brain Institute from donations.

Your involvement in our Research Center and the Tissue Bank Patient Registry would be an immeasurable contribution to understanding the underlying causes of the progressive symptoms associated with ALS and other neurodegenerative diseases. Additionally, autopsy is the best way to confirm a clinical diagnosis. A diagnostic report will be provided to the family. Tissue banking at the time of autopsy is also a critical part of this research because careful examination of brain and spinal cord tissue provides researchers with important neuropathological and neurochemical information about ALS. We also share tissue samples with investigators from other institutions increasing the value of your donation.

I would like to encourage you to seriously consider arranging for tissue banking autopsy services after you or your relative passes away, and to discuss it before hand with the funeral director when possible.

Enclosed is information about tissue banking autopsy services, and answers to commonly asked questions. Next-of-kin would have to give authorization after you or your relative's death before the tissue banking procedure could be performed. The service is free, and reimbursement for transportation of your loved one us provided. Send the invoice to Karen Weber at the address above.

Thank you for your consideration.

Sincerely,

David Lacomis, MD
Director of Clinical Research

Julia Kofler, MD
Director, Neuropathology Brain Bank

**ALS AND OTHER MOTOR NEURON DISEASE
BRAIN AND SPINAL CORD DONATION FACT SHEET**

Q: HOW WILL THE BRAIN DONATIONS BENEFIT ME AND MY FAMILY

A: An autopsy will confirm or reject the diagnosis of ALS and determine if there is other pathology such as dementia. A definite diagnosis will eliminate unnecessary concern of wondering each time your family medical history is discussed. An autopsy also could discover other abnormalities, and it may also provide evidence more suggestive of a genetic cause.

Q: WILL THE BRAIN AUTOPSY PROCEDURE DISFIGURE THE DECEASED?

A: No. An autopsy is performed very carefully so that it is not noticeable in any way, and does not prevent an open casket viewing or other desired funeral practice.

Q: WHO CAN AUTHORIZE A BRAIN AUTOPSY?

A: The participant's legal next-of-kin must authorize the brain autopsy before it can be performed.

Q: WHAT SPECIAL PROCEDURES MUST BE FOLLOWED AT THE TIME OF DEATH?

A: The next of kin should notify the ADRC* staff that obtain consent and coordinate the autopsy by calling 412-692-2700 as close as possible to the time of death. If it is an evening or a weekend, the answering service will contact the autopsy coordinator on call. The ADRC autopsy coordinator will initiate a three way phone conversation with the next of kin and obtain consent by telephone. In the state of Pennsylvania consent cannot be given prior to death.

Q: HOW WILL AUTOPSIES BENEFIT ALS AND RELATED MOTOR NEURON DISEASE RESEARCH?

A: Despite the ability to perform research studies in test tubes or in animals, certain types of research can only be performed in human autopsy tissue. Past experience has shown that advances in diagnosis and understanding disease pathways in ALS have only been possible because of research using human brain autopsy tissue. For example, human autopsy tissue was absolutely necessary for discoveries such as ALS and Frontotemporal dementia. In other neurodegenerative diseases, brain autopsy tissue was used for the discovery of biochemical abnormalities which have paved the way for future therapies currently in experimental trials. Finally, work pioneered at the University of Pittsburgh has used human autopsy tissue to develop brain imaging techniques in neurodegenerative disease.

*ADRC= Alzheimer Disease Research Center

Q: WHICH ORGANS ARE EXAMINED AT AUTOPSY?

A: Under normal circumstances, the brain and spinal cord are the only organs examined.

Q: WILL I RECEIVE INFORMATION ABOUT BRAIN AUTOPRY RESULTS?

A: Yes. There is a space on the autopsy permission form where the name and address of the legal next of kin can be written in order to receive a report of the results. This name and address will be obtained by the autopsy coordinator when the consent is obtained. After completion of the autopsy procedure, a report will be sent to the designated person within several months.

Q: WHAT IS THE COST OF THE BRAIN AUTOPSY?

A: There is no charge for the autopsy procedure for patients followed in ALS clinic.

Q: SHOULD I TALK TO MY FUNERAL DIRECTOR IN ADVANCE?

A: Yes, we recommend that arrangements be made in advance with your funeral director. This can help avoid increased stress at a very difficult time after the death of your relative. This is particularly true with preferences and desires such as a brain autopsy. If you do not have a funeral director, we would encourage you to consider selecting one in advance.

Q: HOW DOES THE DECEASED GET TO AND FROM THE BRAIN AUTOPSY SITE?

A: We recommend that transportation be arranged through your funeral director. However, if this is not feasible, the Center also can arrange transportation through a transport service. The cost of transport will be covered by the Brain Bank. Have an invoice of the transport charge sent to Dr. Lacomis at the address at the top, and he will arrange reimbursement.

Q: SHOULD I CALL THE ADRC IF DEATH IS IMINENT?

A: If death is imminent or the participant becomes very ill and the family wants to discuss the preparations, the next of kin, family member, or hospice staff are encouraged to notify Dr. Julia Kofler at the Brain Bank 412-647-2345 who can coordinate with the ADRC staff or ADRC autopsy coordinator who will be happy to review and discuss the procedures.

Q: WHO FUNDS THE ALS BRAIN AND SPINAL CORD DONATION PROGRAM?

A: The University of Pittsburgh Brain Institute provides funding for the program. The funds come from donations. If you or others are interested in supporting the Brain and spinal cord program, see the attached flyers regarding donations to the Live like Lou center for ALS Research within the University of Pittsburgh Brain Institute.