

## Consider giving the most precious gift: Tissue donation for ALS Research

### **The importance of tissue donation for ALS research**

Researchers have learned a great deal about amyotrophic lateral sclerosis (ALS) in the past few decades, but we still do not have all the answers explaining the cause or the progression of this disease. Because ALS is a disease of the motor neurons that are located in the brain and spinal cord, it is difficult to access this tissue in people living with the disease. Research using post-mortem nervous system tissue is critical to understanding ALS.

Examination of the brain, spinal cord, and nerves of patients with ALS, when combined with complete information about the donor's ALS history provides an important and irreplaceable resource to aid in understanding how and why ALS begins and what causes it to progress.

Dr. Glass is a board certified neuropathologist who has a great deal of experience in studying human tissue. The donation of your tissue is the most precious gift that you can give to ALS research. For some people, this decision or commitment to donate tissue upon their death may be difficult, especially when coping with the day to day challenges of ALS. However, it may offer a sense of purpose or comfort to know that one will be contributing to the continuing quest for knowledge about ALS.

### **When should arrangements for tissue donation be made?**

For most people, the time immediately following the death of a family member is very difficult. It is, therefore, a less than ideal time for making important decisions. It is essential to make a decision about

whether or not to make this generous donation well in advance, without stress and with consideration for the desires and interests of the patient and family. The patient's doctor, nursing home personnel or hospice staff (if appropriate) and the funeral home director should also be informed of the family's decision.

### **Who can legally give consent for tissue donation and when is this done?**

In Georgia, except in coroner's cases, the person assuming custody of the body may consent to the donation of tissue. The procedure can only be authorized *at the time of death*. This is done either by signing a form in person or by giving your consent by telephone to an authorized Emory Department of Neurology staff person.

### **Where will the procedure for tissue donation take place?**

The procedure will be performed at Emory University Hospital by Emory staff, and is typically accomplished in a matter of a few hours.

### **What effect will donation of nervous system tissue have on funeral arrangements?**

Donation of nervous system tissue should not affect any of the funeral arrangements. It is still possible to have an open casket if you wish. The removal of the nervous system tissue, under the supervision of a pathologist, does not leave any apparent marks.

### **Is there a cost associated with tissue donation?**

For those patients seen by Emory physicians, there will be no charge for the removal of nervous system tissue or neuropathological examination. If it is not possible to transport the body to Emory and it is necessary to have an outside pathologist remove the nervous system, a fee may be charged to you for this service. In addition, you should check in advance with your funeral director who may or may not charge you a fee for transporting the body to and from Emory Hospital.

### **How do we obtain the results from the procedure?**

We will forward copies of the report to the patient's physician and to the family members you list on a release of information form. The family may also contact the physicians and staff of The Emory ALS Center if they have additional questions.

### **If you have any more questions or are interested in donating tissue for ALS research, please contact either:**

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ALS CENTER *Imagine a cure*