

# EMORY HEALTHY BRAIN STUDY

## BRAIN & SPINAL CORD DONATION PROGRAM

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The Emory Healthy Brain Study is dedicated to advancing research on Alzheimer's Disease and other neurodegenerative diseases. For most people, the time immediately following the death of a family member is very difficult. Discussing the decision to donate your brain and spinal cord with your family and making the necessary arrangements is best done well in advance of disease progression or death.

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### **Why is it important to examine the brain and spinal cord of individuals who do not have memory loss or Alzheimer's disease?**

Healthy brains are equally, if not more important, to study. The brains and spinal cords of individuals with mild cognitive impairment (MCI) and Alzheimer's disease can provide a wealth of information about abnormal brain changes and how they are different from normal aging. However, the brains of individuals without neurodegenerative disease also offer a wealth of information about aging and neurodegenerative disease diagnosis. Unfortunately, most people don't recognize the importance of brain and spinal cord donation. Without healthy brains for comparison, scientists cannot determine precisely which brain and spinal cord changes are related to disease and which are related to aging. For more information about the importance of brain and spinal cord donation visit the [Brain Donor Project](#), a national organization focused on increasing brain donation to advance science, leading to the treatment and cure of neurological, neuropsychiatric, and neurodevelopmental disorders.

### **When is the best time to make appropriate arrangements and communicate your intention to donate your brain and spinal cord for research?**

It is important to make the necessary arrangements well in advance of death. Thus, it is important to communicate your intention to donate your brain and spinal cord to your family. Your physician and chosen funeral home director also need to be informed of your decision to participate in brain and spinal cord donation.

### **Who can legally authorize a tissue donation or autopsy at the time of death?**

Per Georgia state law, autopsy or tissue donation can only be authorized by next of kin at the time of death. This is done by calling the Emory 24-hour autopsy phone number 404-900-9479 at the time of death. In Georgia, except in coroner's cases, only the person assuming custody of the body for burial, such as the spouse, parent, child, guardian, next of kin, or friend of the deceased person, may consent to the autopsy or tissue donation. If two or more persons assume custody of the body, the consent of one person is sufficient legal authorization for the performance of an autopsy or tissue donation.

### **Where is the brain and spinal cord donation performed?**

Individuals enrolled in the Emory Healthy Brain Study will be brought to Emory University Hospital where our autopsy team will remove the brain and spinal cord. If you live outside the Metro Atlanta area and the body cannot be transported to Emory, our team will work with the family to identify a local pathologist who is willing to do the brain and spinal cord removal and send the tissue to us for examination. The Emory Healthy Brain Study autopsy coordinator can help you locate a pathologist in your area.

### **What are researchers looking for when examining the brain and spinal cord?**

A neuropathological examination of healthy brains and brains showing neurodegenerative changes provides researchers with a host of neuropathology data, such as abnormal proteins, that are part of clinical and research diagnosis. Donated tissues are also shared with other researchers and used for discovery research.

### **What will the brain and spinal cord donation cost my family?**

For those individuals enrolled in the Emory Healthy Brain Study research program, there will be no charge for the brain and spinal cord neuropathological examination. The Emory Healthy Brain Study will arrange for the transport of your body to Emory for tissue donation at the time of death. Your designated funeral home must pick up your body at Emory Hospital after the removal of the brain and spinal cord.

### **What effect will a brain and spinal cord donation have on funeral arrangements?**

The removal of the brain and spinal cord, under the supervision of a pathologist, does not leave any apparent marks and should not affect any of the funeral arrangements, including having an open casket.

### **How will my family know the results of the neuropathological examination?**

Approximately six months after death, the results of the neuropathological tissue examination will be available. Emory Healthy Brain Study physicians will contact your family by phone to provide results. The report will then be mailed to the family members listed on the "Authorization to Release Autopsy Information" section of the Brain & Spinal Cord Donation Program Cognitive Autopsy Inclination Questionnaire.

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### **How to Enroll in the Brain & Spinal Cord Donation Program**

1. Discuss your choice to donate your brain and spinal cord with your involved family members. They need to know your intention to donate in order to carry out your wishes.
2. Complete the Cognitive Autopsy Inclination Questionnaire by following this [link](#) or using the QR Code below.
3. Keep the Brain & Spinal Cord Donation Program information in a convenient location. An Autopsy Service Card will be provided either in in-person or virtually. This card includes the 24-hour Emory autopsy service number your family can call at the time of your death.
4. Inform your family members where to find the Brain & Spinal Cord Donation Program information and give them a copy of the Autopsy Service Card.
5. Contact your chosen funeral home to inform them of your plans to donate your brain and spinal cord. The funeral home will need to pick up your body from Emory Hospital after the tissue donation is completed.

## At the Time of Your Death

1. Your family should call the 24-hour Emory Autopsy Service at 404-900-9479 within 12 hours of death. The call center will connect your family with the Autopsy Coordinator who will take the consent by phone for the tissue donation as required by Georgia law.
2. If it is not possible to call the Emory Autopsy Service within 12 hours of death, donation of brain and spinal cord tissue is still possible. Call the Autopsy Coordinator to discuss your options.
3. The autopsy coordinator will manage the transportation of the body to Emory Hospital and answer any questions your family may have about the autopsy procedure at that time.
4. Your designated person should confirm your choice to donate your brain and spinal cord with the funeral home director of your choice
5. Once the tissue donation is complete, Emory Healthy Brain Study personnel will contact your funeral home director to let them know your body is ready for transport to their facility.

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Thank you for your interest in the Emory Healthy Brain Study Brain & Spinal Cord Donation Program. Your donation will help advance research on Alzheimer's Disease and other neurodegenerative diseases.

If you have questions about the brain donation arrangements or procedure, email [healthybrainstudy@emory.edu](mailto:healthybrainstudy@emory.edu).

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For more information about the Goizueta Alzheimer's Disease Research Center or the Emory Healthy Brain Study, please contact us using the information below.

**Goizueta Alzheimer's Disease Research Center**  
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Atlanta, GA 30329

[www.alzheimers.emory.edu](http://www.alzheimers.emory.edu)

**Emory Healthy Brain Study**  
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[healthybrainstudy@emory.edu](mailto:healthybrainstudy@emory.edu)  
<https://healthyaging.emory.edu/ehbs/>

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To enroll in the Emory Healthy Brain Study

**Brain & Spinal Cord Donation Program**

Click this link: [Cognitive Autopsy Inclination Questionnaire](#)  
or use the QR Code to submit your details.

