Consider giving the most precious gift.

In recent years, researchers have learned a great deal about amyotrophic lateral sclerosis (ALS), a fatal neuromuscular disorder – but there is still much more to discover. At this time, we still don’t know what causes ALS or how the disease is triggered. Investigators are searching for the answers to these and many other puzzling questions about ALS in their efforts to find effective treatments and ways to prevent the disease.

Because ALS is a disease of the motor neurons located in the brain and spinal cord, it is difficult to access this tissue in people living with ALS. Researchers often use donated postmortem tissue to study ALS. However, there is a scarcity of ALS brain and spinal cord tissue for research studies.

Tissue from people living with ALS is a critical resource for researchers. When ALS tissue and complete information about the donor’s ALS history are compared, researchers are able to piece together information that will eventually provide answers. Researchers compare ALS tissue with non-diseased tissue. They compare the tissue of people diagnosed with ALS with different histories, including variances in their age of onset and time of diagnosis, disease progression, care and treatment.

Persons with ALS and their families realize the importance of research into the cause of ALS because understanding the cause of the disease may offer the best opportunity for finding and producing effective therapies to treat and/or prevent ALS in the future. Many people have already played a key role in advancing the knowledge about ALS by providing blood samples, muscle biopsies and other specimens.

For some people, the decision or commitment to donate tissue upon their death may be difficult, especially when coping with the day to day challenges of ALS. However, many find that committing to be a tissue donor provides them with a sense of purpose or comfort in knowing that the donation will contribute to the quest for knowledge about ALS.

People living with ALS who choose to donate tissue need to plan ahead since there are few medical centers prepared to perform the tissue donation procedure effectively. There is also a limited window of opportunity after death to realistically harvest tissue. If you are considering tissue donation, contact your physician or a center listed in the attached document now for information specific to you and your local community.

To learn more about being a donor, discuss tissue donation with your primary care physician and/or your neurologist. Learn about how the donation process is carried out, the exact steps that will be expected of your family and the timeline required to fulfill the donation -- particularly if you live in a city other than where your ALS clinic and neurologist are located. Also, clarify
specifically how, by whom, and when the expenses for the donation process, including
transportation to the facility, will be covered.

For more information about where ALS tissue donation is available, contact The ALS
Association at (800) 782-4747 or refer to the attached listing of medical centers.

A lasting legacy can be the donation of brain and spinal cord tissue for ALS research.

FACILITIES ACCEPTING BRAIN AND SPINAL CORD TISSUE FOR ALS RESEARCH

California

Human Brain and Spinal Fluid Resource
Center
Gift of Hope Program (127A)
Building 212, Room 16
VAGLAHS, West LA Healthcare Center
11301 Wilshire Blvd
Los Angeles, CA 90073
Phone: 310-268-3536
Fax: 310-268-4768
24-hour pager: 310-636-5199
brainbnk@ucla.edu
Director: Rashed M. Nagra, PhD
Founding Director: Wallace W. Tourtellotte,
MD, PhD
Study Coordinator: Regina Schuyler
Silverman
http://brainbank.ucla.edu

UC San Diego School of Medicine
Department of Neurosciences
John M. Ravits, Prof of Clin Neuroscience
MTF Rm. 153 or 131 MC: 0624
Phone: 858-246-1254
Mailing Address:
9500 Gilman Drive # 0624
La Jolla, CA 92093-0624
www.neurosciences.ucsd.edu
Florida

University of Miami Brain Endowment Bank
1501 NW 9th Ave
2202 Life Science Bldg I,
Medical Campus, Locator: D4-5
Miami, FL 33136
Phone: 1-800-UM-BRAIN (1-800-862-7246) or 305-243-6219
Founder and Director: Dr. Deborah C. Mash
http://brainbank.med.miami.edu/

Mayo Clinic Department of Neurology
4500 San Pablo Road
Jacksonville, FL 32224
24-hour Contact #: (904) 953-2000
Catherine Ruiz – 904-953-6523 - ruiz.catherine@mayo.edu
http://www.mayoclinic.org/ (This institution is limited in the donations they are able to receive)

Kentucky

University of Kentucky
Department of Neurology
740 South Limestone Street
Kentucky Clinic, L445
Lexington, KY 40536-0284
Kathie Vanderpool, RN, BS, CCRP
Tel: 859-218-5064
Fax: 859-257-5477
http://ukhealthcare.uky.edu/kni/als/

Maryland

Johns Hopkins Medicine Brain Science Institute
Jeffrey D. Rothstein MD, PhD
The John W. Griffin Director, Brain Science Institute
Professor of Neurology and Neuroscience
Director, Robert Packard Center for ALS Research
Johns Hopkins University, School of Medicine
The John G. Rangos Sr. Building
855 North Wolfe Street; Room 270, 2nd Floor
Baltimore, MD 21205
Phone: 410-955-4504
Fax: 410-614-0659
http://www.brainscienceinstitute.org/
http://www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/als/
The University of Maryland Brain and Tissue Bank
University of Maryland, Baltimore
Division of Pediatric Research
655 W. Baltimore Street, Rm 13-013 BRB
Baltimore, MD 21201-1559

Illinois

Neuromuscular Disorders Program at Northwestern University Feinberg School of Medicine
633 Clark Street
Evanston, IL 60208
Clinical Nurse Specialist: Nailah A. Siddique, RN, MSN
312-503-2712
nsiddique@northwestern.edu
www.feinberg.northwestern.edu
This program does retrieve brain and spinal tissue only from patients who are seen at their facility (Northwestern University). On very rare occasion sometimes, but not always they are able to arrange a retrieval be done elsewhere, with the tissue coming to them.

(MUST make these arrangements in advance)
This program does retrieve brain and spinal tissue only from patients within driving distance. On very rare occasion sometimes, but not always they are able to arrange a retrieval be done elsewhere, with the tissue coming to them.

New York

Columbia University Medical Center
The Eleanor & Lou Gehrig ALS Center and
The Center for Motor Neuron Biology and Disease
630 West 168th Street
New York, NY 10032
Neil Shneider, MD, PhD
Assistant Professor of Neurology
212-305-1319
alscenter@columbia.edu
http://www.cumc.columbia.edu/dept/als/

Pennsylvania

Drexel University College of Medicine
Medical Director: Terry Heiman-Patterson, MD
Mary Paolone, MSRN
Nurse Manager/Clinical Nurse Counselor
MDA/ALS Center of Hope
Mobile: 610-733-5573
Office: 267-507-2590
Fax: 215-399-5894
mpaolone@drexelmed.edu
www.drexelmed.edu
www.alshopefoundation.org

National Disease Research Interchange
(NDRI) 8 Penn Center, 15th Floor
1628 JFK Boulevard
Philadelphia, PA 19103
Thomas J. Bell, PhD
Director of Scientific Services
Phone: 800-222-NDRI (6374) ext 247
Fax: 215-557-7154/215-557-8187
tbell@ndriresource.org
http://www.ndriresource.org
Penn Comprehensive Neurosciences Center
ALS Center at Pennsylvania Hospital
330 South 9th Street
Philadelphia, PA 19107
Clinical Research Coordinator: Kelly L. Almasy, RN, CRC
Phone: 215-829-5041
Fax: 215-829-6606
Kelly.Almasy@uphs.upenn.edu
Medical Director: Leo F. McCluskey, MD, MBE
Associate Medical Director: Lauren B. Elman, MD
www.pennmedicine.org/neuro/als
(This institution is only accepting donations for individuals who have been seen in their center)

University of Pittsburgh School of Medicine Center for ALS Research
UPMC Presbyterian, F875 (HPU 01 08 06)
200 Lothrop Street
Pittsburgh, PA 15213
Phone: 412-647-1706
Fax: 412-647-8398
ferasd@upmc.edu
Director: David Lacomis, MD
http://alsresearchcenter.org
(This institution is only accepting donations for individuals who have been seen in their center)

Texas

Baylor College of Medicine
One Baylor Plaza
Houston, TX 77030
Phone: 713-798-5694
Medical Director: Yadollah Harati, MD

Claire Johnson MacAdam, P.T., N.C.S., Clinic
Coordinator and Physical Therapist
macadam@bcm.edu
https://www.bcm.edu/healthcare/care-centers/neuromuscular/clinics-labs/amyotrophic-lateral-sclerosis-clinic

A resource for organ and tissue donation other than brain and spinal cord tissue (Musculoskeletal tissue, abdominal organs, skin, tendons, bone):

Center for Organ Recovery and Education (CORE)
204 Sigma Drive
RIDC Park
Pittsburgh, PA 15238
Phone: 800-DONORS-7 (1-800-366-6777)
Fax: 412-963-3563
mchristenson@core.org
http://core.org

A resource for whole body donation only, supporting medical research in ALS:
Bio Gift Anatomical and Surgical Education Center
17819 NE Riverside Parkway, Suite C
Portland, OR 97230
Julie Brethauer, Donor Coordinator
Phone: Office – 503-670-1799
24 hour – 866-670-1799
Fax: 503-670-1834
info@biogift.info
www.biogift.org

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