Donation of Tissue for Research

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 what 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 & Spinal Fluid Resource Ctr
West Los Angeles VA Medical Center
11301 Wilshire Boulevard, 127A
W. W. Tourtellotte, MD, Director
Diane Guntrip, Coordinator
Los Angeles, CA  90073
310-268-3536
310-636-5199 *

University of Southern California
Alzheimer’s Disease Research Center
Department of Pathology
2011 Zonal Ave.
Los Angeles, CA  90033
Carol Miller, MD
323-442-1602
213-740-7777

The Forbes Norris ALS Research Center
2324 Sacramento St., Ste. 150
San Francisco, CA  94115
Stacy Chapman
415-600-3967
[www.Cpmc.org/services/als](http://www.Cpmc.org/services/als)

The ALS Treatment and Research Center
University of California, San Francisco
Department of Neurology
350 Parnassus Ave.
San Francisco, CA 94117
415-353-2122

**Florida**

Mayo Clinic - Florida
Department of Neurology
4500 San Pablo Road
Jacksonville, FL  32224
Pamela Desaro
904-953-6915

**Georgia**

Emory University
The ALS Center
101 Woodruff Circle, Suite 6000
Atlanta, GA 30322
Meraida Polak, RN
404-778-3807

**Illinois**

Northwestern University
Department of  Neurology
Medical School Tarry 13-715
303 E. Chicago Ave.
Chicago, IL  60611-3008
Nailah Siddique, RN, MSN
[Nsiddique@northwestern.edu](mailto:Nsiddique@northwestern.edu)
312-503-2712
Lisa Kinsley, MS
[L-kinsley@northwestern.edu](mailto:L-kinsley@northwestern.edu)
312-503-0154

**Indiana**

Indiana University, School of Medicine
Department of Pathology and Laboratory Science
Van Nuys Medical Science Building
635 Barnhill Drive, Room A-128
Indianapolis, IN  46202-5120
Bernadino Ghetti, MD
317-274-7818

**Kentucky**

University of Kentucky
Department of Neurology
Kentucky Clinic, L445, Wing D
Lexington, KY  40536-0284
Jan Hutchinson, RN
859-218-5064
Jessica Carpenter
859-218-5061
Maryland

JHMI/Neuromuscular Division
600 N. Wolfe St.
Baltimore, MD 21287
Lora L. Clawson, MSN, CRNF
410-955-8511

NICHD Brain & Tissue Bank
University of Maryland, Baltimore
Department of Pediatrics
655 W. Baltimore St., BRB 13-013
Baltimore, MD 21201
410-706-1755 or 800-847-1539

Massachusetts

University of Massachusetts Medical School
Worcester
55 Lake Avenue North
Worcester, Massachusetts 01655
Diane McKenna-Yasek
(508) 856-4697
(508) 426-0456 (pager)

Massachusetts General Hospital
55 Fruit Street
Boston, MA 02114
Merit Cudkowicz, MD
Matthew Frosh
Darlene Pulley, RN
617-726-6190

ALS Study
VA Boston Healthcare System
150 South Huntington Avenue
Boston, MA 02130
Contacts:
Eva Deykin PhD;
Sally Perkins or Christopher Brady— at either
857-364-6748 or 866-460-1158.
After hours, messages can be left at either
number

New Hampshire

Dartmouth Hitchcock Medical Center
Dept. of Neuropathology
1 Medical Center Drive.

Lebanon, NH 03756
Brent Harris, M.D., Ph.D.
603-650-7221

New York

Columbia University Medical Center
Department of Neurology
710 West 168th
New York, New York 10032
Hiroshi Mitsumoto, MD
ALS CENTER@columbia.edu
(This institution is only accepting donations for individuals who have been seen in their center)

North Carolina

Wake Forest University School of Medicine
Department of Neurology
Medical Center Boulevard
Winston-Salem, North Carolina, 27157
James Caress, MD
336-716-6704

Pennsylvania

University of Pittsburgh School of Medicine
Department of Pathology - BST
S-420 3500 Terrace St.
Pittsburgh, PA 15261
Robert Bowser, PhD
412-383-7819
412-958-8312 (pager)

University of Pennsylvania
Department of Neurology
10 Comprehensive Neuroscience Ctr
330 South 9th Street
Philadelphia PA 19107
Katelin Hoskins
215-829-5041

MDA/ALS Center of Hope
Drexel University College of Medicine
219 N. Broad Street, 7th Floor
Philadelphia, PA 19107
Main Office #: 267-507-2585

Updated 12/2011
A resource for organ and tissue donation other than brain and spinal cord tissue is:

Center for Organ Recovery and Education (CORE)
204 Sigma Dr.
Pittsburgh, PA 15238
800-DONORS-7