



## 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.**



The ALS Association, 27001 Agoura Road, Suite 250, Calabasas Hills, CA 91301-5104,  
Phone: (800) 782-4747 / [alsinfo@alsa-national.org](mailto:alsinfo@alsa-national.org) / [www.alsa.org](http://www.alsa.org)

## 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 \*

The "Gift of Hope" program is active. Patients need to set up donation arrangements in advance and are encouraged to involve their family in the process. There is a 24/7 call center to report deaths.

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  
[Cpmc.org/services/als](http://Cpmc.org/services/als)  
(At this time, tissue donation at California Pacific Medical Center is available only for patients already being seen at this ALS Center and only on a case by case basis.)

The ALS Treatment and Research Center  
University of California, San Francisco  
Department of Neurology  
350 Parnassus Ave.  
San Francisco, CA 94117  
415-353-2122  
(The institution only accepts donations from patients who have been seen in their center)

### Florida

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

Emory University  
The ALS Center  
101 Woodruff Circle, Suite 6000  
Atlanta, GA 30322  
Meraida Polak, RN  
404-778-3807  
(This institution is only accepting donations for individuals who have been treated in their center).

### Illinois

Northwestern University  
Department of Neurology  
Medical School Tarry 13-715  
303 E. Chicago Ave.  
Chicago, IL 60611-3008  
Nailah Siddique, RN  
Grace Carlson-Lund  
[Nsiddique@northwestern.edu](mailto:Nsiddique@northwestern.edu)  
312-503-2712  
312-503-0160  
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  
Kathie Vanderpool  
859-218-5064  
Beverly Norton  
859-218-5061

## Maryland

JHMI/Neuromuscular Division  
600 N. Wolfe St.  
Baltimore, MD 21287  
Lora L. Clawson, MSN, CRNF  
410-955-8511  
(This institution is only accepting donations from patients who have been seen at this ALS Center.)

## Massachusetts

University of Massachusetts Medical School  
Worcester  
Brudnick Neuropsychiatric Research Institute  
55 Lake Avenue North  
Worcester, Massachusetts 01655  
(508) 856-2674

## 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 168<sup>th</sup>  
New York, New York 10032  
Hiroshi Mitsumoto, MD  
212-305-2940

## 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  
3600 Market Street, Suite 240  
Philadelphia PA 19104-2646  
Laura Klenke-Borgman  
215-829-5041

Drexel University  
School of Biomedical Engineering, Science &  
Health Systems  
3141 Chestnut Street  
Philadelphia, PA 19104  
Terry Heiman-Patterson  
215-895-2215

MCP Hahnemann MDA/ALS Center  
219 N. Broad St., 7<sup>th</sup> Floor  
Philadelphia, PA 19107  
Kristine Barr, RN  
Mary Palone  
215-762-5186

The National Disease Research Interchange  
Philadelphia, PA 19103  
Lisa Morris, Sr. Mgr. Odyssey Dept.  
800-222-6374 ext. 251  
National collection available.



## Vermont

Massachusetts General Hospital  
55 Fruit Street  
Boston, MA 02114  
Merit Cudkowicz, MD  
Matthew Frosh  
Darlene Pulley, RN  
617-726-9122

## Wisconsin

An ALS Association Certified Center  
Department of Neurology  
9200 W. Wisconsin Avenue  
Milwaukee, WI 53226  
Cedric Dennis, RN  
414-805-5220

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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

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