

How Does The Donation Process Work?

1. At the time death, family members or caretakers should immediately call the HBTRC at 800.BRAINBANK (800.272.4622). **It is critical to call as close as possible to the time of death, since the brain must be recovered within 24 hours. HBTRC staff are available 24/7, 365 days a year.**
2. HBTRC staff will guide your family member or legal representative through the consent process.
3. The HBTRC staff will coordinate with qualified professionals in the local area to recover the brain tissue, which often takes place in a funeral home or hospital.
4. A few days after the brain donation, the HBTRC will send your family member or legal representative instructions about releasing the donor's medical records and completing a questionnaire, which can be returned within weeks of donation.

Frequently Asked Questions

1. Is there a cost associated with my donation?

No, there is no cost to you or your family.

2. Will being a brain donor interfere with funeral arrangements?

No, the brain recovery is done discreetly and should not affect the outward appearance or interfere with funeral arrangements.

3. Can I change my mind?

Yes, you may withdraw your registration at any time.

4. Where will my brain be stored?

Brain tissue and associated information will be securely stored at the HBTRC.

5. Who will have access to the brain tissue to ensure its best use?

Scientists selected by the LRA will use a rigorous review process to determine who can access the valuable samples.

6. How will my donation help others?

Your donation will allow researchers to see what changes occur in brain tissue among people with lupus. This could improve the way NPSLE is treated for others in the future as well as generations to come as we continue to work toward a cure!

7. Can I still be an organ donor?

Yes, you can be both an organ donor and a brain donor.

Please check out our website at www.lupusresearch.org for information on the research we are supporting.



Brain Bank Program

"Breaking through the Fog"

Your brain donation makes a difference!

Lupus Research Alliance
275 Madison Avenue 10th Floor
New York, NY 10016
646-884-6084

Website: LupusResearch.org/brainbank

Email: brainbank@lupusresearch.org

To make an immediate brain donation, contact the Harvard Brain Tissue Resource Center (HBTRC) at 800.BRAIN.BANK (800.272.4622)

Lupus

And Your Brain

"I keep forgetting things!"

"Ugh...I just can't think!"

"My doctor said my lupus caused a seizure."

- The brain is one of the many organs that can be affected by lupus.
- Neuropsychiatric lupus (NPSLE) describes a wide range of brain- involved symptoms. These can range from "brain fog" to stroke or psychosis.
- Up to 95% of individuals with systemic lupus erythematosus (SLE) experience NPSLE symptoms¹.
- Yet our understanding of NPSLE is quite "foggy" compared to other aspects of SLE.

Researchers Must Study The Brain To Understand It

The Lupus Research Alliance (LRA) is funding important research and a clinical trial to address NPSLE. However, to gain a deep understanding of what's going on in the brain, it's critical to look at human brain tissue.

So, we are asking people with lupus, to make one of the most meaningful contributions to advance our understanding of NPSLE. Please consider donating your brain to lupus research upon your passing.

The LRA and the Harvard Brain Tissue Resource Center (HBTRC) have developed a program to recover donated brains from deceased individuals with lupus.

The decision to register to donate an organ for research is not an easy one and hopefully one that will only be fulfilled far into the future. But, committing to donate an organ after you pass away is a priceless gift and legacy that you can bring to advance lupus treatment for others with lupus and for generations to come.

How Do I Donate?

1. First, discuss with family and health professionals your desire to donate your brain after your passing. This is very important as a family member or caretaker will need to facilitate the donation process at the appropriate time.
2. To donate, you must be 18 years of age or older, have lupus and reside in the continental US. Potential donors should sign up to receive registration forms at: lupusresearch.org/brainbank.
3. The LRA will mail you forms and a pre-stamped envelope to complete your registration. The forms must be returned either by **mail or fax**.
4. Registration with the HBTRC is not required for brain donation and does not automatically mean you will be a donor. But it is a good way to tell your family, caretakers and health professionals your wishes.

1. Schwartz, Noa, et al. *Nature Reviews Rheumatology* (2019):