

RLS Research Opportunities

Research is essential to the development of better treatments and discovery of a cure for RLS. The early pioneers of the RLS Foundation identified the need for additional RLS research and established the Research Grant Program in 1997. The RLS Foundation is the only organization with a dedicated RLS Research Grant Program. Thanks to the generous support of our members, the Foundation has funded 48 grants totaling nearly \$2 million.

In addition to financial support, there are several ways to help advance RLS research. First, clinical trials allow individuals to participate in new research studies to help researchers develop and evaluate potential new therapies. Brain donation is the ultimate gift that helps researchers further their understanding of RLS by identifying the underlying causes, develop new treatments and, hopefully, find a cure for RLS. Finally, donating to support RLS research will help to eliminate RLS for future generations.

Clinical Trials

Clinical trials are one form of clinical research involving a researcher or researchers who directly observe a person or group of individuals to collect data and answer a scientific or medical question about the safety or potential benefit of an intervention such as a medication, device or behavioral change. Clinical trials are used to determine whether new biomedical or behavioral interventions are safe, successful and effective.

Types of clinical trials

Clinical trials are designed to provide information about different types of outcomes. For example:

Pharmacokinetic (PK) studies, involving pharmaceutical products, are designed to determine what the body does to the product. PK studies are usually the first phase of study and are performed to determine proper dosing. Dosing may be different for different populations based on age, sex, race, genetics and differences in metabolism.

Pharmacodynamic (PD) studies are designed to examine what the product does to the body. These studies are used to examine the ability, safety and clinical activity of a drug or device. Some studies combine a PK component and a PD component.

Efficacy studies establish the overall risks and benefits of any intervention. These studies require a large number of participants and must incorporate the proper design to allow the results to be analyzed and generalized, or applied to the general population.

Getting involved in clinical research

People volunteer to enroll in clinical research. Volunteers receive written notification of the potential risks, benefits, alternatives and responsibilities before agreeing to participate. A clinical research volunteer may receive some form of compensation for time and expenses, but not all clinical research offers compensation. Participants may withdraw from the trial at any time without consequences.

Giving consent

One of the primary safeguards for study participants is that they are informed about the potential risks, benefits, alternatives and responsibilities of the clinical trial before they agree to participate. When a potential study participant understands the risks, alternatives and responsibilities, they formalize the decision to participate by communicating with the study investigator or representative and by documenting the agreement in writing. The interactive process of receiving information, asking questions and indicating agreement is known as the consent process. For children or others who are not legally able to provide consent, a parent or legal guardian provides permission for the person to participate. Federally funded clinical research has many safeguards in place to protect those who volunteer to take part. For study participants, especially those with complex illnesses, “protected” does not mean “risk-free” – all studies carry some risk. For more information on clinical trials, visit <https://www.nia.nih.gov/health/what-are-clinical-trials-and-studies>.



Brain donation requires:

- preregistration
- notification when entering hospice or at time of death
- permission from the donor's next of kin to complete the donation process



RAISE AWARENESS

PROMOTE ADVOCACY

IMPROVE TREATMENTS

SUPPORT RESEARCH

FIND A CURE

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Brain Donation

Research using brain tissue after death is one of the most promising avenues for researchers to learn how to prevent and cure brain disorders like RLS. One donated brain can provide tissue for hundreds of independent research studies. The gift of brain donation can help researchers identify new diagnostic tools and potential new therapies that will have a lasting impact on overall health. The legacy of donation offers future generations the possibility of improved health and, ultimately, a cure for RLS.

The NeuroBioBank at the National Institutes of Health has partnered with the Brain Donor Project to help potential donors register for brain donation. The Brain Donor Project is a tax-exempt 501(c)(3) nonprofit organization that aims to increase the supply of human postmortem brains donated for scientific research. To preregister for brain donation, follow these two steps: (1) complete and submit the online pre-registration paperwork; (2) complete, sign and return the paperwork to their specified brain bank. Next, it is important to share a brain donation decision and arrangements in advance with family and friends. This will ensure your wishes are fulfilled and ease any emotional stress at the time of death regarding the gift of donation. To preregister for brain donation, visit braindonorproject.org/brain-pre-registration

It is important to update any brain donation paperwork every five years. For individuals who have not preregistered within the past five years, contact the Harvard Brain and Tissue Resource Center at 1-800-BRAIN-BANK to determine if brain donation is possible. There is no way to ensure that a brain will be used for RLS research unless it is preregistered.

RLS Research

Here are some ways to get more information and participate in RLS research:

- www.rls.org/clinical-trials
Find a list of some of the current RLS clinical trials.
- www.clinicaltrials.gov
All clinical trials are required to register here to publish their results
- www.researchmatch.org
Register here to be contacted by researchers interested in RLS subjects
- www.rls.org/donate
Donations can be designated to be used for research.

Conclusion

There are a variety of ways to become active in RLS research. Participants in clinical trials can play a more active role in their own healthcare, gain access to new research treatments before they are widely available, and help others by contributing to medical research. Brain donors are able to share the ultimate gift with future generations who will benefit from the knowledge gained from the legacy they leave behind. Finally, every donation, regardless of amount, helps move the RLS community closer to a cure.

The RLS Foundation is dedicated to improving the lives of the men, women and children who live with this often devastating disease. Our mission is to increase awareness, improve treatments and, through research, find a cure for restless legs syndrome.

This publication has been reviewed and approved by reviewers from the RLS Foundation Scientific and Medical Advisory Board.

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