



HELP US DISCOVER  
CAUSES OF SUDEP

## PARTICIPATE IN OUR REGISTRY

- **What is the purpose of the Registry?**

The SUDEP Registry seeks to help identify risk factors and mechanisms leading to sudden unexpected death in people with epilepsy. Towards this end, we will try to collect DNA, brain tissue, and clinical data (e.g., medical records, EEG) for scientific studies about the causes of SUDEP.

- **Why participate?**

To make a difference and help other families. Your contribution will help us and other families to better understand the causes of SUDEP with the goal to help prevent future cases. Through our registry, we hope to improve surveillance and identification of SUDEP-related deaths and increase tissue and DNA donation that will help understand SUDEP. Ultimately, we hope to understand its causes and use this information to prevent future SUDEPs.

- **What is involved?**

This is a voluntary research study. Any information we obtain from our participants is vital to the success of the study. You will be able to withdraw from the study at any point. Once consent is given, we will proceed with a telephone interview (~30-45mins) after helping you gather all the information required. We will also request a release of medical records from your loved one's medical providers. If you contact us within the first 48 hours after the death of your family member, and you are interested in donating the brain, we will work with you to facilitate this donation.

- **Is my information kept confidential?**

Yes, we require written consent to obtain any medical records or information. Confidentiality is honored and no individual information will be released to anyone that isn't connected to this research without written consent from next of kin. You can view the Consent Forms and Medical Release form at the NASR website. The consent form contains detailed information on how we intend on keeping your records completely confidential.

- **How can I participate?**

For immediate response regarding tissue donations please call our toll-free number **855-432-8555**, we are available 24hrs/7days. Or for any other questions, comments or suggestions regarding NASR or SUDEP, or to schedule a telephone interview, we can also be reached at [info@sudep-registry.org](mailto:info@sudep-registry.org)

***Please visit our website to learn more at [www.sudep-registry.org](http://www.sudep-registry.org)***