



## North American SUDEP Registry

*Studying Epilepsy Related Mortality to Help Save Lives*

1-855-432-8555|<http://sudep-registry.org>|[info@sudep-registry.org](mailto:info@sudep-registry.org)

### Who We Are

The North American SUDEP Registry (NASR) is a privately-funded, international & collaborative effort among Medical Examiners, Coroners, Epileptologists, Epidemiologists, Researchers and bereaved family members dedicated to better understanding epilepsy-related mortality incidence and uncovering its risk factors, causes, and mechanisms to improve future epilepsy treatment and prevention of Sudden Unexpected Death in Epilepsy (SUDEP). This study is approved by the NYU School of Medicine Institutional Review Board.

We facilitate the **donation of tissue, DNA and clinical information** from those who have suffered from SUDEP and promote the use of specimens, clinical data and other information to advance understanding and prevention of SUDEP and all epilepsy related mortality.

### How NASR can help Support Medical Examiners

We are interested in obtaining death-related reports, brain tissue (ideally whole and fixed in formalin for minimum 2 weeks), and DNA (ideally a purple top EDTA tube of blood) from cases of sudden death where the decedent had a past medical history significant for epilepsy. If you wish to have a neuropathology report generated by NASR, the brain must be received whole. If autopsy has been performed before enrollment, tissue and DNA can be donated in alternate forms; please reach out to NASR study member to confirm biospecimens have been stored appropriately before sending.

- For all epilepsy patients who have had sudden deaths and have enrolled in NASR we will cover all specimen shipping costs.
- Furthermore, if you require **neuropathology services** on the enrolled decedent and are unable to obtain this through your office, NASR can have a report completed and sent to you within 2 months. You can use the **855-432-8555 number or email Drs. Orrin Devinsky ([od4@nyu.edu](mailto:od4@nyu.edu)) or Daniel Friedman ([Daniel.Friedman@nyumc.org](mailto:Daniel.Friedman@nyumc.org)).**

### How Medical Examiners can help Support NASR

Medical Examiners and Coroners are crucial partners in the success of the North American SUDEP Registry. To collect high-quality clinical information, tissue, and DNA from as many epilepsy-related mortality cases as possible- we need your help! Your ability to effectively communicate the importance and ease of enrolling in the registry is crucial to the registry's success.

### When and How to Refer Families

In any case of an unexpected death in a patient with epilepsy, you can inform family members of the Registry as soon as the death is referred to your office.

Referring families to the Registry is easy. Provide them with the phone/web information below (or written brochure from NASR) and inform them they need to contact us to register. (You cannot call for them but you can give them the number to call and/or the website.) Inform them that registering as soon as possible- ideally before the autopsy- is ideal.

To order written brochures for the your office or to refer a case, email: [info@sudep-registry.org](mailto:info@sudep-registry.org), [od4@nyu.edu](mailto:od4@nyu.edu), or [Daniel.Friedman@nyumc.org](mailto:Daniel.Friedman@nyumc.org), or call 646-558-0898.

### Benefits to families registering with NASR:

- They will be helping to foster a better understanding of SUDEP.
- Families will be given access to numerous resources and support services, including grief counselors and peer support networks.

NASR SUDEP hotline 1-855-432-8555

For more information: <http://sudep-registry.org/>