Dear Death Investigator,

We need your help to prevent epilepsy mortality. Most people with epilepsy live a full and healthy life. However, thousands of people die from epilepsy each year. Some people with epilepsy may lose their lives from accidents or the underlying cause of their condition, such as tumors or genetic syndromes.

However, the leading cause of epilepsy-related death is believed to be **Sudden Unexpected Death in Epilepsy**, also known as SUDEP. It is critical for the epilepsy community to work with death investigators like you who can accurately report these deaths, collect data, and support research to give us a better understanding of the causes of this potentially preventable outcome of epilepsy.

[Insert your family story]

As noted in the 2012 Institute of Medicine report, *Epilepsy Across the Spectrum*, people with epilepsy succumb to sudden death at a rate over 20 times higher than the general population. Despite the importance of the problem and the implications for intervention, SUDEP has not previously received widespread professional attention or patient education and awareness. The IOM report stressed recognition and prevention of SUDEP and identified lack of SUDEP awareness by death investigators as a significant problem. To accurately count the number and distribution of SUDEP cases, determine its cause, and — ultimately — seek opportunities for prevention, more accurate forensic data is needed.

The Epilepsy Foundation SUDEP Institute and the North American SUDEP Registry (NASR) would like to offer their services to assist death investigators. Below are just some of the ways they can help.

**Facilitation of tissue, DNA, and clinical information donation**

The NASR facilitates the donation of tissue, DNA, and clinical information from those who have suffered from SUDEP. The registry also promotes the use of specimens, clinical data, and other information to advance understanding and prevention of SUDEP and all epilepsy related mortality.

* For all epilepsy patients who have had sudden deaths and have enrolled in NASR, all specimen shipping costs will be covered.
* If **neuropathology services** are requiredon the enrolled decedent and death investigators are unable to obtain this through their office, NASR can have a report completed and sent to you within 4 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)**).**
* NASR can provide epilepsy experts to assist in death review teams.
* **Learn more about additional services at:**<http://sudep-registry.org/medical-examiners/>

**Assistance with Training for Death Investigators**

In a partnership with NYU School of Medicine, the Epilepsy Foundation SUDEP Institute developed a CME webinar on Investigating Epilepsy Deaths. The webinar helps death investigators understand deaths in epilepsy, including SUDEP, and accurately record these cases. It is endorsed by the National Association of Medical Examiners (NAME), the International Association of Coroners and Medical Examiners (IAC&ME), the *American Board of Medicolegal Death Investigators (*ABMDI), and the North American SUDEP Registry (NASR). NAME is also developing a position paper on epilepsy death investigations that should be published by summer 2017. Learn more and register for the webinar at: <https://www.pathlms.com/investigating-epilepsy-deaths>

**Assistance with Supporting Families**

Losing a loved one is tragic and confusing, especially when the death was sudden and unexpected. These families need information and emotional support that often cannot be provided by the death investigation team. The Epilepsy Foundation SUDEP Institute services for families include:

* Accurate information regarding SUDEP and other causes of epilepsy-related deaths.
* Ongoing individual or family support through licensed bereavement care providers and grief counselors who are also mothers who lost children to SUDEP.
* Learn more about the services at: <http://www.epilepsy.com/learn/impact/mortality/sudep/support-bereaved>

Thank you for taking the time to read this letter and for helping us better understand and prevent SUDEP.

Sincerely,