

**Private Investigator:**  
Orrin Devinsky, MD  
**Institution:**  
NYU School of Medicine



**Primary Contact:**  
Laura Gould Crandall  
[laura.crandall@nyulangone.org](mailto:laura.crandall@nyulangone.org)  
**Phone:** 646-754-2230

## PURPOSE

The purpose of the SUDCRRC is to increase the understanding of the characteristics, circumstances, medical histories and pathologies of children from ages 11 months through 18 years who have died suddenly and unexpectedly, and in some instances, without explanation. The SUDC Registry and Research Collaborative will analyze cases of sudden unexpected deaths in these children to understand risk factors and causes, and develop preventative measures. The NYU Institutional Review Board has reviewed and approved the SUDCRRC annually since 2014.

## CRITERIA

### INCLUSION CRITERIA

Parent or guardian (willing to consent to study inclusion) of a child aged 11 months through 18 years who has died suddenly and unexpectedly where 1) the cause of death is undetermined at completion of the gross autopsy and the brain has been retained OR 2) the brain was not retained and the final cause of death is undetermined.

### EXCLUSION CRITERIA

Cases of apparent suicide, apparent homicide or accident where the external cause was the obvious and only reason for death.

## HOW TO REFER A CASE

M.E. will attain verbal confirmation from NOK for study contact for research and bereavement support. The M.E. will provide study contact with name and age of decedent, circumstances of death and contact information for NOK. The study will obtain consent and forward signed copies to M.E.

## AUTOPSY SPECIMENS

The study will provide prepaid, M.E. customized shipping kits in advance of case referrals and reimburse for costs incurred to provide the below:

- 1) Whole brain fixed in formalin for 2 weeks
- 2) Fresh liver in genetic specimen kit or viable whole blood sample
- 3) Autopsy report and ancillary study reports
- 4) Recuts of histology slides
- 5) X-rays and photographs.

## RESULTS RETURNED TO M.E. AND AVAILABLE RESOURCES

- Neuroimaging and comprehensive neuropathology report (within 12 weeks)
- Whole exome sequencing (>20k genes) report (within 6 months) with genetic counseling and referrals for families as clinically indicated. Interpretation of results performed by Investigators at NYU, Columbia University and the Mayo Clinic.
- The SUDCRRC and SUDC Foundation provide ongoing communication support to assist families with understanding the death investigation process, study findings, coping with their trauma and medical referrals.



## FAMILY RESOURCES

The SUDCRRC partners with the SUDC Foundation to provide comprehensive family services throughout enrollment and beyond. The family incurs no costs for study enrollment or service participation. They are connected to a parent peer support community that is available worldwide. For more information:

[SUDC.org](https://www.sudc.org) → Family Services

## FOR MORE INFORMATION

[SUDC.org](https://www.sudc.org) → Research & Medical Info

