

**Principal Investigator:**

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**Institution:**

NYU School of Medicine

**SUDCRRRC**

SUDC Registry and Research Collaborative

**Co- Investigator:**

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**PURPOSE**

The purpose of the SUDCRRRC 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 SUDCRRRC annually since 2014.

**FOR MORE INFORMATION INCLUDING SUDCRRRC PUBLICATIONS:** [www.sudcrrc.org](http://www.sudcrrc.org)

**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**

Medicolegal Death Investigation offices will attain verbal confirmation from NOK for study contact.. The office will then 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 medicolegal death investigation office.

**INFORMATION RETURNED TO THE MEDICOLEGAL DEATH INVESTIGATION OFFICE**

- Comprehensive neuropathology report (within 12 weeks)
- Whole exome sequencing (>20k genes) report with genetic counseling and referrals for families as clinically indicated. Interpretation of results performed by Investigators at NYU, Children's Hospital of Philadelphia and the Mayo Clinic (MN).
- SUDCRRRC Case Review Report at completion of multidisciplinary review inclusive of above.
- Research updates as available.

**AUTOPSY SPECIMENS FOR ENROLLMENTS**

The study will provide prepaid customized shipping kits and reimburse for costs incurred to provide the below (if available):

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

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