


Implementing Death Investigation
Recommendations from the
Sudden Death in the Young (SDY) Case Registry

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What is the Sudden Death in the Young (SDY) Case Registry?

The SDY Case Registry compiles and stores information about sudden infant and child deaths to help:

- Count the number and types of sudden deaths up to age 20*
- Understand the causes and risk factors
- Inform ways to prevent these deaths

*depends on state Child Death Review legislation



SDY Case Registry


- **Promotes standardization for:**
 - Case identification
 - Autopsy
 - Investigation
 - Categorization of cases
- **Fosters collaboration among:**
 - Local teams responsible for investigation and review of cases
 - Clinicians involved in evaluation of at-risk family members



Progress Update

- Surveillance began January 2015
 - 2179 cases identified
 - 1913 cases complete
- Research began December 2016
 - 168 genomes sequenced by SDY Case Registry researchers

Data as of 9/5/18



Development of SDY Case Registry Death Investigation Tools

- Convened an SDY Autopsy Protocol Task Force to develop guidance for standardized death investigation practices for SDY cases in Spring 2014
- Task force membership:
 - Medical examiners
 - Coroners
 - Death investigators
 - Pediatric-, cardiac- and neuro- pathologists
 - Emergency room physicians
 - Genetic counselors
 - Public health experts




SDY Case Registry Death Investigation Tools

- Provide guidance and recommendations on information to collect during:
 - Death scene investigations
 - Family interviews
 - Autopsies




SDY Case Registry Death Investigation Tools



The diagram shows two document thumbnails. The left one is titled 'SDY Autopsy Guidance' and the right one is 'SDY Autopsy Summary'. A red arrow points from the left document to the right document.

SDY Autopsy Guidance SDY Autopsy Summary


SDY Case Registry Death Investigation Tools



The thumbnail shows a document with a red heart rate monitor graphic at the top and a form with various fields below.

SDY Field Investigation Guide and Family Interview Tool

SDY Case Registry Death Investigation Tools



The diagram shows two document thumbnails. The left one is the 'SDY Field Investigation Guide and Family Interview Tool' and the right one is the 'CFRP Report Form National Fatality Review Case Reporting System'. Two red arrows point from the left document to the right document.

SDY Field Investigation Guide and Family Interview Tool CFRP Report Form National Fatality Review Case Reporting System

SDY Case Registry Death Investigation Tools Published

METHODS AND PROCEDURES **FPI**

Improving Forensic Pathologic Investigation of Sudden Death in the Young: Tools, Guidance, and Methods of Cardiovascular Dissection from the Sudden Death in the Young Case Registry

Sean P. Guille, Kisha Burns, Wendy M. Dunbar, Heather Neiland


ABSTRACT
 The Sudden Death in the Young (SDY) Case Registry, a collaborative, population-based registry across 10 states, has developed a set of pathologic and death investigation tools to improve and standardize forensic pathologic investigation of sudden death in the young. The tools were developed by a team of experts representing forensic pathology, pediatric, cardiac, and toxicologic pathology, forensic pathology, pediatric, genetic counseling, and public health. These tools focus on standardizing the review of dissections of cases of sudden death in health care facilities of the participating system. The tools provide the standard of dissection based on the type of case and location. By sharing the tools and following the recommendations of the dissection guide, the SDY Case Registry is providing a standardized approach to forensic pathologic investigation of sudden death in the young. *JAMA Pediatrics* 2018; 172(10): 973-978.

KEYWORDS
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 http://dx.doi.org/10.1093/pediatrics/kpy100




Assessment of Death Investigation Practices in Funded Jurisdictions

- Assessed autopsy practices among the 10 Registry states/jurisdictions who entered data into the National Fatality Review Case Reporting System (NFR-CRS)
- SDY Registry cases from 2015 through 2017
- Calculated:
 - How many cases had an autopsy and how many cases reported using the SDY Autopsy Summary or Guidance
 - Compared differences in the ability to categorize SDY cases among cases in which the SDY Autopsy tools were used versus those in which they were not used



Death Investigation Practices in Funded Jurisdictions

- Autopsies on SDY cases play a critical role in understanding and monitoring deaths.
- Utilizing tools developed by the SDY Case Registry increases the likelihood that enough information is available at review to categorize cases and may improve understanding of underlying etiologies.




Death Investigation Practices in Funded Jurisdictions

- The SDY Case Registry will work with current and future states/jurisdictions to increase autopsy rates in SDY cases and increase the implementation of SDY Case Registry tools into existing local practices.
- This will improve data collection that will be used to inform health statistics and prevention efforts.



Looking Ahead

- Registry funded for an additional 5 years 2019 – 2023
 - New states/jurisdictions funded in October 2018
- Upcoming presentations:
 - SDY Incidence: Population-Based Burden of Sudden Death in the Young in a United States Cohort - American Heart Association's Scientific Sessions November 2018




What's Next?



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graph TD; Prevention --> Data; Data --> Analyses; Analyses --> Interpretation_communication[Interpretation/communication]; Interpretation_communication --> Policy_Development[Policy Development and Practice Change]; Policy_Development --> Implementation; Implementation --> Prevention;
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To Learn More:
SDY Case Registry Data Coordinating Center Website



Website: www.SDYRegistry.org

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SDY Case Registry


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SDY Registry States/Jurisdictions
Minnesota, Nevada, New Jersey, New Hampshire, Wisconsin, Delaware, Georgia, Tennessee, San Francisco County in California, Tidewater Region of Virginia







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Questions?