

Update on the SDY Case Registry

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DATA COORDINATING CENTER FOR THE
SUDDEN DEATH IN THE YOUNG
CASE REGISTRY

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 CDR legislation



SDY Case Registry Goals

Establish the incidence of sudden death in the young in the United States

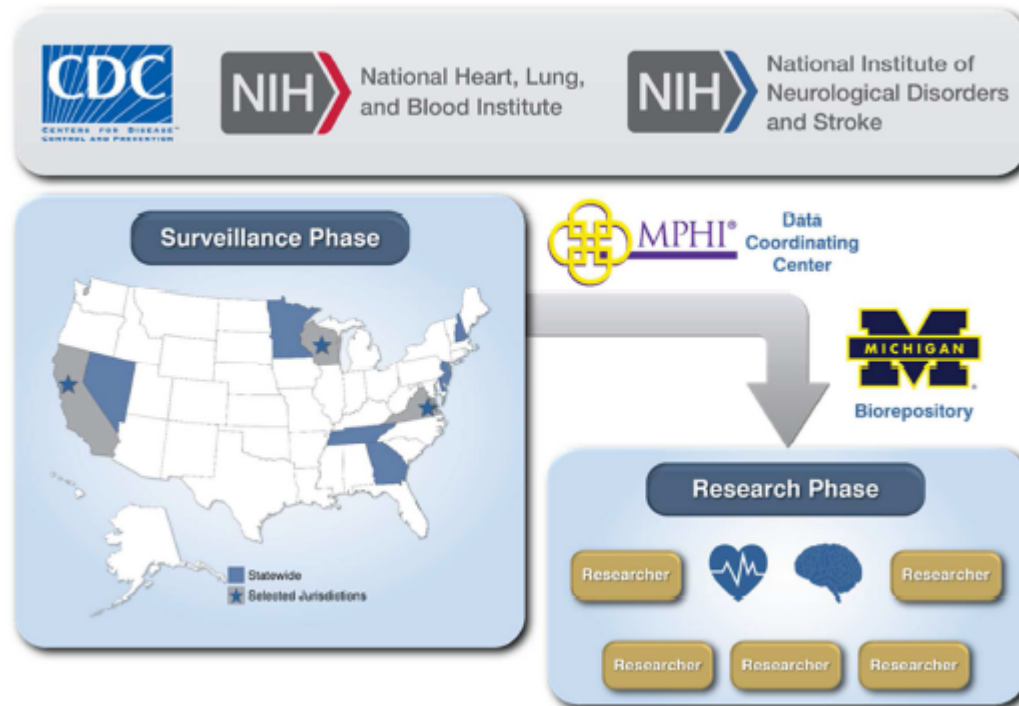
Surveillance

Investigate causes and risk factors for sudden death in the young

Research



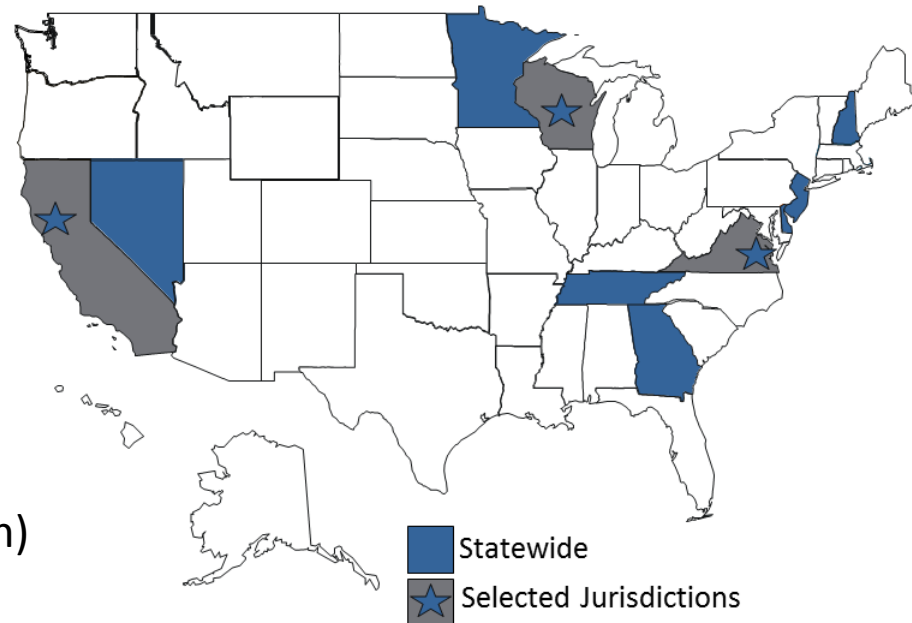
SDY Case Registry



SDY Case Registry

Participating states include:

- California (San Francisco)
- Delaware
- Georgia
- Minnesota
- New Hampshire
- New Jersey
- Nevada
- Tennessee
- Virginia (Tidewater Region)
- Wisconsin (selected jurisdictions)



SDY Case Registry Process



Surveillance Update

- Surveillance started January 2015
 - 1520 SDY Cases Identified
 - 1160 Cases Cleaned
- Next steps: use categorization data to determine incidence



Research Update



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Samples



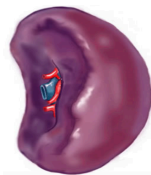
EDTA Blood



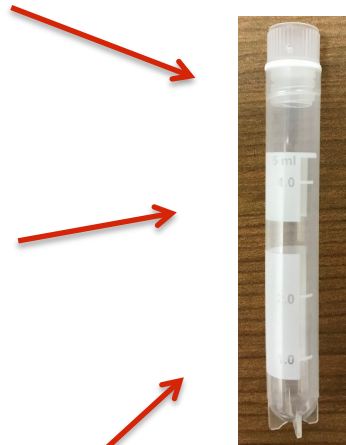
Heart



Liver



Spleen



cryovial



-20°C or -80°C



Successful DNA
Extraction for
99% of samples



NHLBI-Funded SDY Researchers



Channelopathies and cardiomyopathies
among sudden deaths in the young

Alfred George and Elizabeth McNally



Role of genetic variants in sudden death
in the young

Prince Kannankeril

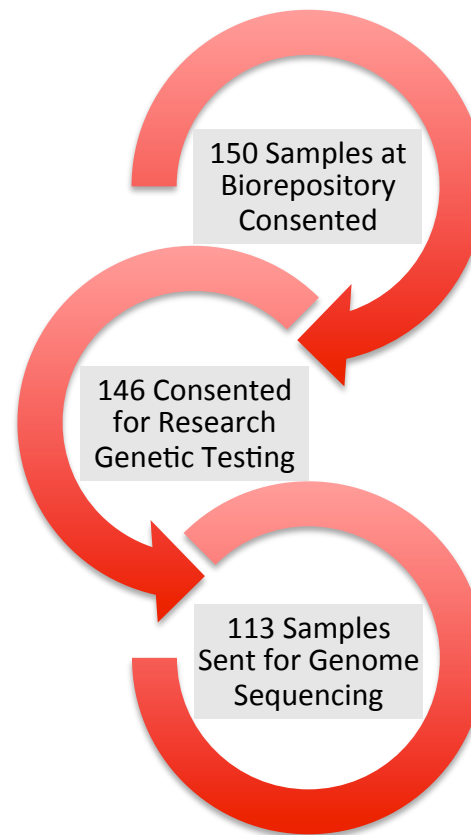


Integrating genomic and clinical
approaches to sudden death in the young

Martin Tristani-Firouzi and Mark Yandell



Consent and Research Genetic Testing



Looking Ahead

We are
here

2014-2018

2019-2023

- Registry funded for an additional 5 year cycle
- Increase number of states/ jurisdictions
- Increase resources for consent/ biospecimen activities



How Can I Be Involved?

- Encourage your forensic pathologists to use the SDY Case Registry tools and save biospecimens for DNA banking and/or future genetic testing
 - Freeze blood in plastic K2EDTA vacutainers and/or freeze fresh tissue
- Encourage your CDR team to use the SDY Case Registry Variables the Case Reporting System – they are accessible to all teams: www.ncfrp.org
- If you are in a funded state/jurisdiction contact your public health office and offer yourself as a resource



Resources



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Remember if you cannot test, attempt to bank DNA

- GeneTests:
 - <https://www.genetests.org>
 - Search DNA Banking



SDY Case Registry Data Coordinating Center Website



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SDY: Sudden Death in the Young

The Sudden Death in the Young (SDY) Case Registry gathers information to learn more about young people who die suddenly and unexpectedly. Babies, children and young adults up to age 20 are included in the SDY Case Registry. It has been hard for death investigators to find the causes for many sudden deaths in young people. It has also been hard for public health agencies to count the true numbers of these deaths. This means that doctors, scientists and families really do not have a good understanding of how often these deaths happen and what causes these deaths, which makes it more difficult to prevent more deaths like these. The SDY Case Registry will gather and store information about sudden child deaths to help:

- Count the number and types of sudden deaths in babies, children and young adults up to age 20
- Try to understand the causes for the deaths
- See if some children are more at risk of dying than others
- Find ways to prevent these deaths

Contact the SDY Case Registry Data Coordinating Center: Info@SDYRegistry.org

Count

Understand

Collaborate

Prevent

Website: www.SDYRegistry.org



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Genetic Counselors

findageneticcounselor.com

www.nsgc.org/postmortem

postmortem@nsgc.org

- Information Sheet for Families
- Template for Sample Release from ME/C offices
- Letter of Medical Necessity for Insurance



HEALTHCARE PROVIDERS

[About Genetic Counselors](#) | [Experience the Benefits of a Genetic Counselor](#) | [Genetic Counseling](#)

POST MORTEM GENETIC TESTING FAQs

What is Post Mortem Genetic Testing?

Post mortem genetic testing is when the sample is collected after the patient has died. The cause of death. Genetic testing is a medical test that searches for alterations in chromosomes. The appropriate test depends upon an individual's medical and family history. Typically, genetic



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Webster Cardiac Genetics Laboratory

Our Work ▼

Lab Members

Family Care

For Coroners

About Us

A potential research option for patients and families who have survived a sudden cardiac event at a young age.

Information below to contact the Webster lab to learn more about eligibility criteria and hear more about the study.

CONTACT INFORMATION:

Website: labs.feinberg.northwestern.edu/webster

Phone: 312-227-2525

Email: gregory.webster@northwestern.edu



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SDY Registry Grantees

Minnesota, Nevada, New Jersey, New Hampshire, Wisconsin, Delaware, Georgia, Tennessee, San Francisco County in California, Tidewater Region of Virginia



Sudden
Death in
the Young



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Acknowledgements: SDY Case Registry

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SDY Autopsy Protocol Committee: Karen Chancellor, Beau Clark, Tim Corden, Kim Fallon, Corinne Fligner, Sam Gulino, Wendy Gunther, Jennifer Hammers, Owen Middleton and Michael Murphy

SDY Ethicists: Amy McGuire and Sonia Suter

Questions?

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