

NIH and CDC launch registry for sudden death in the young

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A registry of deaths in young people from conditions such as heart disease and epilepsy is being created to help researchers define the scope of the problem and set future research priorities. The National Institutes of Health and the Centers for Disease Control and Prevention are collaborating to create the Sudden Death in the Young Registry.

"The sudden death of a child is tragic and the impact on families and society is incalculable," said Jonathan Kaltman, M.D., chief of the Heart Development and Structural Diseases Branch within the Division of Cardiovascular Sciences at the NIH's National Heart, Lung, and Blood Institute (NHLBI). "This registry will collect comprehensive, population-based information on sudden unexpected death in youths up to age 24 in the United States. It is a critical first step toward figuring out how to best prevent these tragedies."

Cases of [sudden cardiac death](#) or [sudden unexpected death](#) in epilepsy (SUDEP) are not routinely or systematically reported, and no commonly agreed upon standards or definitions for reporting currently exist. Complete information has not been collected on the incidences, causes, and risk factors for sudden death in the young. The lack of evidence fuels disagreements about the best prevention approach. Sudden cardiac death, also called sudden cardiac arrest, happens when the [heart](#) suddenly and unexpectedly stops beating and blood stops flowing to the brain and other vital organs.

Researchers know that the risk for sudden death in the young increases if

the person has a heart-related condition. Examples include hypertrophic cardiomyopathy (thick [heart muscle](#)), congenital abnormalities or disorders of the coronary arteries that supply the heart with blood, arrhythmogenic right ventricular cardiomyopathy (a heart muscle problem), long QT syndrome (a disorder of the heart's electrical activity), or other heart abnormalities. Additionally, individuals who have epilepsy may die suddenly and unexpectedly, without a structural or drug-related cause of death found at autopsy. Little is known about how often SUDEP occurs or about factors that put any individual with [epilepsy](#) at risk.

The registry will estimate the incidence of sudden death in infants, children, and young adults by collecting comprehensive data on each recorded case. The registry is an expansion of the CDC's Sudden Unexpected Infant Death Case Registry, which currently tracks sudden unexpected deaths in children up to age 1 in nine states.

State [public health](#) agencies will be able to apply to the CDC to participate in the registry in 2014. The registry will track all sudden unexpected deaths in youths up to age 24 in as many as 15 states or major metropolitan areas. Child death review teams from each state will examine findings from death scene investigations and will review and compile information from medical records, autopsy reports, and other pertinent data sources for each case. A panel of medical experts, medical examiners, and forensic pathologists will help to develop and guide the implementation of standardized autopsy protocols and case definitions.

Data will be entered into a centralized database managed by a data coordinating center at the Michigan Public Health Institute. After obtaining parental consent, blood samples from a subset of cases will be sent to a centralized biorepository. The data will not contain personally identifiable information. The resulting registry will become a resource for scientists to learn more about the causes of [sudden death](#) in the

young and ultimately to develop better diagnostic and prevention approaches.

The NIH's NHLBI will analyze data related to sudden cardiac death while the National Institute for Neurological Disorders and Stroke (NINDS) will participate in the registry by reviewing data on SUDEP.

More information: Resources

- NHLBI Working Group: Screening for Sudden Cardiac Death in the Young: www.nhlbi.nih.gov/meetings/workshops/scd-young.htm
- Screening for Sudden Cardiac Death in the Young: Report from the National Heart, Lung, and Blood Institute Working Group (Circulation 2011): circ.ahajournals.org/content/123/17/1911.full
- The National Center for Child Death Review: childdeathreview.org/
- Sudden Unexpected Infant Death Case Registry: www.cdc.gov/sids/CaseRegistry.htm
- NINDS Epilepsy Information Page: www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm
- CDC Epilepsy Program: www.cdc.gov/epilepsy
- Citizens United for Research on Epilepsy (CURE) funded research on SUDEP: www.cureepilepsy.org/research/cure_sudep.asp
- Epilepsy Foundation information on SUDEP: [www.epilepsyfoundation.org/abo ... /sudep/SUDEP-FAQ.cfm](http://www.epilepsyfoundation.org/abo.../sudep/SUDEP-FAQ.cfm)

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