The Sudden Death in the Young Case Registry: Collaborating to Understand and Reduce Mortality

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Knowledge gaps persist about the incidence of and risk factors for sudden death in the young (SDY). The SDY Case Registry is a collaborative effort between the National Institutes of Health, the Centers for Disease Control and Prevention, and the Michigan Public Health Institute. Its goals are to: (1) describe the incidence of SDY in the United States by using population-based surveillance; (2) compile data from SDY cases to create a resource of information and DNA samples for research; (3) encourage standardized approaches to investigation, autopsy, and categorization of SDY cases; (4) develop partnerships between local, state, and federal stakeholders toward a common goal of understanding and preventing SDY; and (5) support families who have lost loved ones to SDY by providing resources on bereavement and medical evaluation of surviving family members. Built on existing Child Death Review programs and as an expansion of the Sudden Unexpected Infant Death Case Registry, the SDY Case Registry achieves its goals by identifying SDY cases, providing guidance to medical examiners/coroners in conducting comprehensive autopsies, evaluating cases through child death review and an advanced review by clinical specialists, and classifying cases according to a standardized algorithm. The SDY Case Registry also includes a process to obtain informed consent from next-of-kin to save DNA for research, banking, and, in some cases, diagnostic genetic testing. The SDY Case Registry will provide valuable incidence data and will enhance understanding of the characteristics of SDY cases to inform the development of targeted prevention efforts.

Sudden death in the young (SDY) is a tragic event with longstanding impact on families and communities. Although the causes of SDY are myriad, sudden unexpected infant death (SUID), sudden cardiac death, and sudden unexpected death in epilepsy (SUDEP) are 3 examples that have inspired public health efforts at prevention. Healthy People 2020, a national health promotion agenda for the United States, includes in its objectives the need to reduce the rate of deaths of infants, children, and adolescents.\(^1\) Unfortunately, fundamental gaps in knowledge about the incidence, mechanisms, and risk factors of SDY may limit the identification of effective prevention efforts.

The majority of SDY occurs during infancy and has been termed SUID, a group of deaths that encompass sudden infant death syndrome, sleep-related accidental suffocation, and...
infant deaths of unknown cause. In the United States in 2013, SUID accounted for ~1 in 7 infant deaths.2 Some researchers suggest that up to 20% of sudden infant death syndrome cases may be due to ion channelopathies.3 Sudden cardiac death is another cause of SDY that attracts significant attention. Sudden cardiac death may occur at any age across the life span and may be associated with competitive athletics. Estimates of the incidence of sudden cardiac death in infants, children, and young adults vary from 0.5 to 2.3 per 100 000, depending on the population examined.4–10 Cardiac causes of SDY include hypertrophic cardiomyopathy, coronary artery anomalies, arrhythmogenic right ventricular cardiomyopathy, and ion channelopathies, among others.11 SUIDP is another cause of SDY that has been documented at all ages. It is seen in both idiopathic epilepsy (ie, cause is unknown) and genetic forms of epilepsy (eg, Dravet syndrome), and in association with ion channelopathies. Known risk factors for SUIDP include the presence of continued seizures, especially generalized tonic–clonic seizures, nonadherence with antiseizure medications, and polytherapy in individuals with refractory epilepsy. According to 1 review, the incidence of SUIDP in those <20 years old in the United States in 2014 was 0.11 per 100 000,12 but this figure is likely underestimated.13

Some causes of SDY are inherited, and surviving family members may unknowingly harbor conditions that place them at risk for SDY as well. Identifying heritable causes of death after a case of SDY is a critical step in enabling cascade screening of surviving family members and access to potentially life-saving therapies (such as β-blockers for Long QT syndrome and implantable cardioverter defibrillators for hypertrophic cardiomyopathy). Cascade screening may also decrease later complications and potential life-years lost due to a delayed or missed diagnosis.

Although SDY is acknowledged to be an important public health and scientific issue, there is significant scientific disagreement, fueled by lack of evidence, about the best approach to prevent it. Many promising efforts have focused on promoting safe sleeping environments and effective seizure control, as well as training the community on cardiopulmonary resuscitation and automated external defibrillators. But without a true understanding of the incidence, risk factors, and mechanisms of disease, it is difficult to know if such efforts are focusing on the right targets. Improved understanding of disease may allow for the design of more targeted and potentially more impactful interventions.

Some have called for the implementation of widespread enhanced cardiovascular screening programs (ie, with an electrocardiogram) to identify individuals with conditions associated with sudden cardiac death, an undertaking that would require significant financial and personnel resources. The success of such a screening program to identify conditions associated with a rare event like sudden cardiac death depends on the likelihood of disease in the population. Yet we lack fundamental data on incidence to inform discussions about the potential costs and value of such an effort. This knowledge gap on incidence persists in part due to a lack of standardized procedures for investigating, classifying, and reporting SDY in the United States.

In 2010, a working group of experts convened by the National Heart, Lung, and Blood Institute (NHBLI) at the National Institutes of Health (NIH) highlighted this knowledge gap on incidence and recommended the development of a registry to gather evidence about the epidemiology and etiology of sudden cardiac death in the young in the United States as a fundamental first step in advancing our understanding.14 The Institute of Medicine’s 2015 report, “Strategies to Improve Cardiac Arrest Survival,” also recommended the establishment of a national cardiac arrest registry that includes standard definitions and data elements.15 A 2012 Institute of Medicine report on the public health dimensions of epilepsy highlighted similar gaps in public health surveillance of SUDEP and corresponding gaps in the overall burden.16

**LEVERAGING EXISTING INFRASTRUCTURE**

Before proceeding with developing a new registry, NHBLI explored the landscape of existing programs and identified 2 promising potential partners: the National Center for Fatality Review and Prevention’s (NCFRP) Child Death Review (CDR) and the Centers for Disease Control and Prevention’s (CDC) SUID Case Registry.

**CDR**

CDR programs in all 50 states, the District of Columbia, Guam, and the Navajo Nation conduct comprehensive, multidisciplinary reviews of infant and child deaths. The purpose is to better understand how and why children die and to use the findings to take action to prevent future deaths, thereby improving the health and safety of all children.17 NCFRP,18 funded by the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau, is the resource center for state and local CDR Programs. Often mandated through state legislation, CDR programs use a common set of policies and protocols to identify and review cases at the state and/or local level through collaborations with medical examiners and coroners, law enforcement personnel, and other stakeholders.19
enforcement, medical professionals, social services, and public health representatives, among others. Forty-five states, including 1200 state and local teams, enter review findings into the Web-based data collection tool, the National CDR-Case Reporting System (CDR-CRS).20

**SUID Case Registry**

In 2009, the CDC developed a multistate surveillance system to improve knowledge about the circumstances and events surrounding SUID in the United States.21 This surveillance system, known as the SUID Case Registry, builds on existing CDR programs and infrastructure and enhances the ability of CDR programs to compile comprehensive, timely, and population-based data through the CDR-CRS. The CDC offers the participating states resources for increased staffing and capacity-building to improve data quality and timeliness. Both the SUID Case Registry and CDR rely on information from the death scene, medical examiner/coroner records, birth certificates, death certificates, and records from law enforcement, social services, and pediatric and obstetric medical encounters to understand circumstances surrounding these deaths. After the reviews, SUID information is integrated into the CDR-CRS. To differentiate unexplained deaths from accidental suffocations and allow states to reliably monitor category-specific SUID incidence and trends, the SUID Case Registry developed a classification system with a decision-making algorithm and standardized definitions.22

**THE SUDDEN DEATH IN THE YOUNG CASE REGISTRY**

After learning more about these successful platforms, the NHLBI initiated a collaboration with the CDC to develop the Sudden Death in the Young Case Registry, a prospective, population-based registry that builds on the NCFRP’s CDR-CRS Program and the CDC’s SUID Case Registry. The National Institute of Neurologic Disorders and Stroke at the NIH and the CDC’s Epilepsy Program became active partners as well, given their interest in understanding and preventing SUDEP. The SDY Case Registry benefits from the strengths of each collaborating agency: the CDC’s expertise in public health surveillance and the NIH’s expertise in research. The Michigan Public Health Institute (MPHI), which has been overseeing the NCFRP and CDR-CRS since 2002, was chosen as the data coordinating center, and the University of Michigan was selected as the Biorepository for the SDY Case Registry. By building on the platforms of the existing CDR-CRS and SUID surveillance systems, the SDY Case Registry eliminates the need for creating a new system, increases sustainability, and decreases implementation costs.

The SDY Case Registry has the following goals:

1. Describe the incidence of SDY in the United States through population-based surveillance.
2. Compile data from cases of SDY to create a resource of information and DNA samples for research into SDY.
3. Encourage standardized approaches to investigation, autopsy, and classification of SDY cases.
4. Develop partnerships between local, state, and federal stakeholders toward a common goal of understanding and preventing SDY.
5. Support families who have lost loved ones to SDY by providing resources on bereavement, DNA banking, and medical evaluation of surviving family members.

In creating the SDY Case Registry, a Steering Committee of NIH, CDC, and MPHI staff members sought guidance from an external committee of experts in adult and pediatric cardiology, neurology, epileptology, pathology, and advocacy. In addition, the Steering Committee convened an Autopsy Protocol Task Force of nationally recognized medical examiners, coroners, death investigators, and pathologists to develop standardized, comprehensive procedures for SDY Case Registry autopsies.

The SDY Case Registry was designed to expand the age range, scope, and geographic representation of the SUID Case Registry. The age range has been expanded to include all deaths in children from birth to <20 years of age. Although sudden cardiac death in the young often refers to deaths in individuals up to age 35 years, the statutes that govern the CDR system vary in age inclusion. As a result, the age range for the SDY Case Registry varies by jurisdiction, but is restricted to cases that are <20 years of age. The CDR-CRS has been expanded, with input from the external committee of experts, to include a module for SDY that includes additional questions related to cardiac and neurologic symptoms, activity/exercise, previous diagnoses, medications, treatments, seizures, family history, circumstances of the event, and resuscitation. The geographic reach of the SDY Case Registry has been expanded as well to fund 4 additional states and 2 jurisdictions that were not previously participating in the SUID Case Registry.

The organizational structure of the SDY Case Registry is displayed in Fig 1. The SDY Case Registry currently includes 10 states/jurisdictions whose surveillance activities are monitored by the CDC. MPHI houses the SDY Data Coordinating Center, which provides assistance to states/jurisdictions in compiling information into the CDR-CRS as well as improving case ascertainment.
data completeness, timeliness of reporting, and recruitment for research. MPHI manages the SDY Case Registry’s Biorepository at the University of Michigan, where blood and/or tissue samples are processed to extract and store DNA. MPHI also provides technical assistance to states/jurisdictions in improving CDR through a separate HRSA grant. Investigators funded by the NIH to conduct approved studies are able to access deidentified information and DNA samples in cases that have consented to research.

**Definitions**

For the purposes of the SDY Case Registry, “sudden” is defined as a death within 24 hours of the first symptom or death in the hospital after resuscitation from an out-of-hospital cardiac arrest. “Unexpected” is defined as the death of someone who was believed to be in good health or had a stable, chronic condition, or had an acute illness that would not be expected to cause death.

Cases are included in the SDY Case Registry if the death presented as sudden and unexpected and the child was <20 years of age. Because the SDY Case Registry is population-based, the decedent must have been a resident of the jurisdiction or state to be eligible for inclusion. The SDY Case Registry contains not only deaths due to SUID, sudden cardiac death, and SUDEP, but also many other causes of SDY. However, cases are excluded if, during the autopsy and initial investigation, the death was attributed to (1) an accident in which the external cause was the obvious and only reason for the death; (2) homicide; (3) suicide; (4) accidental or intentional overdose of drugs, even if this caused cardiac or respiratory arrest, with no previous history of other possible chronic disease or autopsy findings suggestive of another cause; or (5) terminal illness in which the death was reasonably expected to occur within 6 months. The SDY Case Registry is a public health surveillance system and is therefore designed to be inclusive of as many community-based cases as possible. Specific populations of interest (eg, SUID, sudden cardiac death, and SUDEP, among others) will be examined through stratification during subsequent analyses.

Although some studies in sudden cardiac death use a window of 1 hour from symptom onset in the definition of “sudden”, the SDY Case Registry uses a window of 24 hours due to the high number of SDY cases that occur during sleep. Because deaths in children are rare events, the likelihood of comorbid conditions confounding the initial identification of symptoms related to SDY’s should be low, and a longer window could be used appropriately. In addition, the SDY Case Registry does not distinguish between witnessed and unwitnessed deaths.

One limitation of the SDY Case Registry is that it does not include information on survivors of cardiac arrest. The SDY Case Registry Steering Committee recognizes that survivors of cardiac arrest can provide important clues to understanding risk and protective factors that enhance individual survival. Excluding survivors is an operational limitation, because the platform on which the SDY Case Registry is built is the CDR-CRS system. Future efforts should explore ways to develop complementary systems to include this important population.

**Guidance Documents/Tools**

Several tools were created to facilitate data compilation from primary sources for the SDY Case Registry. The goal of these tools is to reduce variation across states/jurisdictions with different mandates, statutes, and practices. The SDY Autopsy Guidance and the Autopsy Summary Tool were created with input from the Autopsy Protocol Task Force. These documents provide a standardized, comprehensive approach to autopsy that focuses...
on medical conditions and other
anatomic findings associated with
SDY. The Field Investigation Guide
and Family Interview Summary
Tool is a series of questions that can
be used by investigative teams to
collect information that is relevant
to determining cause of death as
well as understanding SDY. The hard
copy of the case report form and Web
version CDR-CRS are used to compile
all the information discussed at local
CDR and advanced review meetings.
Funded states/jurisdictions provide
ongoing feedback to help optimize
these tools in practice. In addition,
these tools are available online, and
external stakeholders are encouraged
to adopt their use and provide
feedback to the SDY Case Registry
Steering Committee on their utility.

Consent

Although federal regulations do
not require consent for research
involving the deceased, state-level
regulations vary. Given the sensitive
and tragic nature of the sudden
death of a young person, the SDY
Case Registry Steering Committee
consulted with the ethics team at
the NIH Clinical Center as well as
2 external ethicists and decided
to develop a process to obtain
consent from the family/next of
kin for several items separately:
(1) using blood and/or tissue
samples collected at autopsy for
DNA extraction and subsequent
SDY-related research; (2) allowing
the information collected at CDR to
be linked to the DNA sample; (3)
allowing recontact by researchers
for subsequent data gathering
or research studies; (4) allowing
recontact to return clinically
actionable results; (5) allowing
the deidentified DNA sample to be
included in NIH biorepositories
for future research outside of the
SDY Case Registry; (6) performing
diagnostic genetic testing; and
(7) saving a DNA sample for the family
to access for future genetic testing.
At the time of consent, teams also
provide resources to families for
bereavement and medical evaluation
for surviving family members.

Case Flow

The flow of cases through the SDY
Case Registry is demonstrated in
Fig 2. After a sudden death occurs,
cases are identified primarily
through medical examiners’ offices,
and the inclusion and exclusion
criteria are applied by the medical
examiner (Supplemental Fig 4).
Ideally, autopsies are performed in
accordance with the standardized
SDY Autopsy Guidance, and during
the autopsy, pathologists collect
and store a sample of blood for DNA
extraction. They are also asked to
save a liver and/or spleen sample, in
the event that the blood sample does
not yield sufficient DNA. If informed
consent is obtained from the next-of-
kin, the blood sample is shipped to
the SDY Case Registry Biorepository
at the University of Michigan for DNA
extraction and storage.

All cases are reviewed by CDR
teams per their usual protocol.
They use the CDR-CRS, which has
been expanded with input from the
external committee of experts to
include a module of questions related
to SDY. Eligible cases then undergo
an adjudication process by a separate
advanced review team comprised of
local cardiologists, neurologists, and
pathologists, among other subject
matter experts. This adjudication
process uses the SDY Case
Registry categorization algorithm
(Supplemental Fig 4) to classify
cases. After cases have undergone
final state-/jurisdiction-level review,
the CDR-CRS information and DNA
samples for which consent has been
obtained for research are linked in
a deidentified manner and are made
available for use in research studies.
Although cases are identified quickly
through the medical examiner’s
offices, the CDR and advanced review
occur over several months; therefore,
the time from identification of a case
to final categorization varies and may
take up to 1 year.

Invitae, a genetic testing company,
partnered with MPHI and the
Biorepository at the University of
Michigan to offer in-kind diagnostic genetic testing to 900 autopsy-negative cases in the SDY Case Registry over a 3-year period using a panel of arrhythmia and cardiomyopathy genes. Results may help medical examiners and coroners determine the cause of death and may inform risks and approaches to cascade screening for surviving family members.

**Technical Assistance and Evaluation**

Funded teams have committed to performing population-based surveillance in their states/jurisdictions. Each team uses multiple methods to identify any possible SDY cases and works closely with their pathologists as well as vital records to ensure all cases have been identified. In addition, teams partner with their medical examiners and coroners to ensure understanding of the case definition and appropriate application of the inclusion/exclusion criteria at the time of death to identify cases promptly and conduct thorough autopsies. States that previously participated in the SUID Case Registry have been performing autopsies in 100% of SUID cases and are able to translate that experience to the SDY Case Registry.²⁵ States/jurisdictions funded for the SDY Case Registry are expected to review all SDY cases through CDR in a timely manner and, as a requirement for funding, have demonstrated an ability to assemble advanced review teams with the appropriate expertise for adjudication and categorization of cases. To ensure timeliness, funded states/jurisdictions are also expected to enter and apply quality assurance protocols to the data within prespecified timelines after CDR and advanced review. Although the teams in each state/jurisdiction have a wealth of experience and familiarity with public health surveillance, consenting to save DNA for research, family banking, and diagnostic genetic testing are less familiar. Therefore, extensive efforts have been implemented by the SDY Case Registry staff, with guidance from the NIH, to build capacity and support teams in the funded states/jurisdictions in seeking consent from families.

To support these efforts, the SDY Case Registry staff perform technical assistance and evaluation to funded states/jurisdictions. Using the CDC's established guidelines for evaluating surveillance systems,²⁶ the SDY Case Registry is evaluated using 3 surveillance characteristics: case ascertainment, data completeness, and timeliness of reporting, which are integrated into the program's logic model. The MPHI and the CDC use the logic model activities to guide technical assistance to the funded states/jurisdictions. These activities are detailed in work plans that are updated twice a year and discussed on bimonthly calls and during an annual reverse site visit, which brings all team members from funded states/jurisdictions together for in-depth training. Technical assistance helps to improve data quality and decrease variation among states/jurisdictions due to diversity of program structures.

Quarterly, the MPHI and CDC provide each state/jurisdiction with a data quality summary that summarizes (1) case ascertainment; (2) completeness of key variables; (3) timeliness of case identification, data entry, case review, and data quality assurance protocols; and (4) consent and biospecimen totals. In addition, states/jurisdictions report quarterly the number of cases identified, entered, reviewed, and consented. The self-report numbers are compared with those in the CDC/MPHI-generated reports and examined to determine areas and strategies for improvement. These work plans, data quality summaries, and self-reports guide discussion and problem solving on bimonthly, one-on-one calls. Additional technical assistance is provided to states/jurisdictions via bimonthly office hour calls, during which the CDC and MPHI staff are available to answer questions and facilitate discussion regarding any areas of concern. The CDC and the MPHI also host periodic, topic-driven group training calls.

Another element of technical assistance is site visits. During site visits, SDY Case Registry staff attend a CDR meeting and an advanced review meeting to observe implementation of the SDY Case Registry categorization algorithm and meet with local staff to discuss the program and brainstorm solutions to barriers.

Progress is shared internally via a monthly newsletter that highlights questions, successes, and prevention activities. An annual report on the progress of the SDY Case Registry is also provided to the federal sponsors and external partners.

**Progress to Date**

In January 2015, the SDY Case Registry launched surveillance with 9 states/jurisdictions. In September 2015, an additional state was funded. Current participants include the states of Georgia, Tennessee, New Jersey, Minnesota, Nevada, Delaware, and New Hampshire as well as the Tidewater region of Virginia, the city of San Francisco, and select counties in Wisconsin (Fig 3). Five of these states/jurisdictions have previous experience with case ascertainment, data compiling, and CDR as participants in the CDC's SUID Case Registry.

From January 1, 2015 until October 15, 2016, 755 SDY cases were identified, and 562 cases have completed reviews and data cleaning. Of the completed cases, 90% have included an autopsy. DNA samples from 64 SDY cases in which consent
was obtained for research, family DNA banking, or diagnostic genetic testing have been stored in the Biorepository.

In April 2016, the NHLBI funded 3 research teams representing Northwestern University at Chicago, Vanderbilt University, and the University of Utah to work collaboratively with each other, NHLBI staff, SDY Case Registry states/jurisdictions, and the Steering Committee to use the data and DNA samples in the SDY Case Registry to explore the causes and characteristics of cases of sudden cardiac death in the young. A multidisciplinary team of researchers has also been funded by the National Institute of Neurologic Disorders and Stroke to study SUDEP through the Center for SUDEP Research. In the future, data and DNA samples will be made available to other members of the scientific community for additional analysis through investigator-initiated grant applications to the NIH.

CONCLUSIONS

The SDY Case Registry was built on the existing successful platforms of the CDR-CRS system and the SUID Case Registry. It supports population-based surveillance of SDY to inform our understanding of incidence. It also creates a research resource whereby information about cases can be linked to DNA samples and used to explore the characteristics of SDY cases. The SDY Case Registry will facilitate a better understanding of the incidence and causes of SDY through collaborative efforts at the local, state, and federal levels to enable the development of evidence-based strategies for prevention.

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External Committee of Experts: Dr Lisa Bateman, Dr Robert Campbell, Dr Sumeet Chugh, Laura Crandall, Dr Sam Gulino, Gardiner Lapham, Martha Lopez-Anderson, Dr Kurt Nolte, Dr David Thurman, and Dr Victoria Vetter. Autopsy Protocol Task Force: Dr Karen Chancellor, Dr Beau Clark, Dr Tim Corden, Kim Fallon, Dr Corinne Fligner, Dr Sam Gulino, Dr Wendy Gunther, Dr Jennifer Hammers, Dr Owen Middleton, and Dr Michael Murphy.

ABBREVIATIONS

CDC: Centers for Disease Control and Prevention
CDR: Child Death Review
CDR-CRS: Child Death Review Case Reporting System
HRSA: Health Resources and Services Administration
MPHI: Michigan Public Health Institute
NCFRP: National Center for Fatality Review and Prevention
NHLBI: National Heart, Lung, and Blood Institute
NIH: National Institutes of Health
SDY: sudden death in the young
SUDEP: sudden unexpected death in epilepsy
SUID: sudden unexpected infant death
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