



Notice of Funding Opportunity

Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry:
Barriers to Participation Funding Opportunity

TABLE OF CONTENTS

- I. Overview 4
- II. Full Text 5
- 1. Overview 7
- 2. Current SUID and SDY Case Registry Activities 7
- 3. Barriers to SUID/SDY Participation..... 8
- 4. Submission Requirements..... 10

I. Overview

Agency Name: *National Center for Fatality Review and Prevention (National Center/NCFRP)*

Funding Opportunity Title: *Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry: Barriers to Participation*

Dates:

1. Notice of Funding Opportunity Webinar: Monday, August 22, 2022, at noon eastern standard time. Webinar can be viewed here: <https://ncfrp.org/suid-sdy-case-registry/> .
2. Due date for applications: Applications will be accepted starting on September 15, 2022. Rolling applications will be accepted until all funds have been distributed. Proposals will be funded based on date received and feasibility.
3. Award Notification: Within 30 days of application submission.

Summary Paragraph:

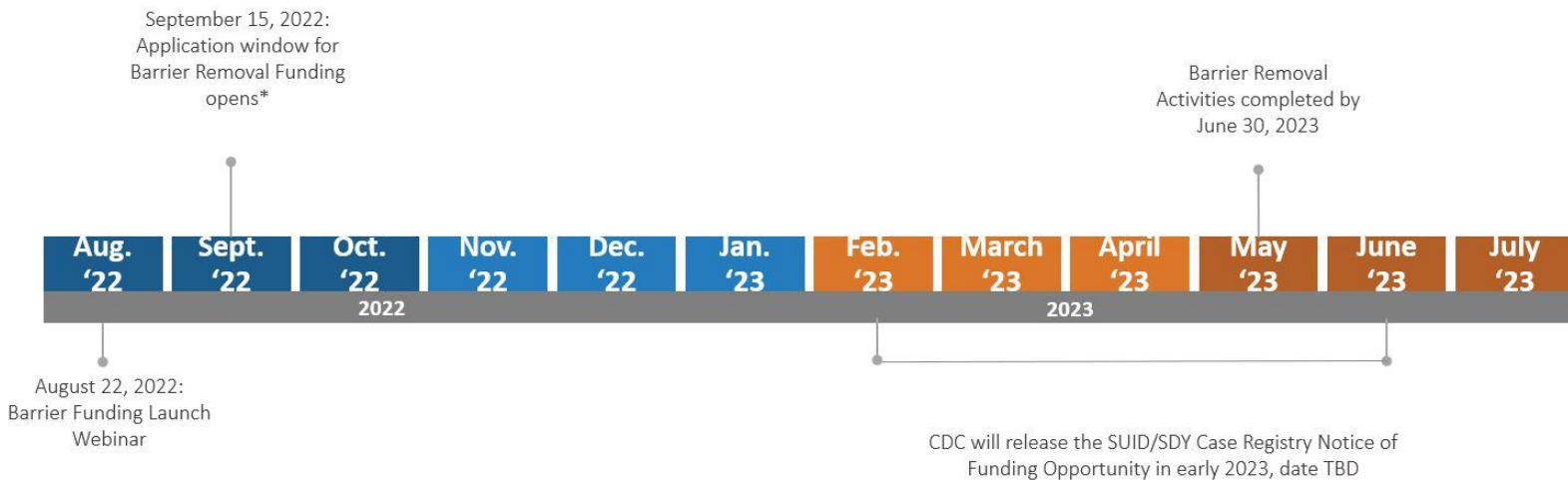
The purpose of this funding is to help identify and remove barriers faced by child death review (CDR) programs that limit their ability to apply for funds from Centers for Disease Control and Prevention (CDC) to participate in the SUID and SDY Case Registry. The funding should build capacity for sites to conduct Case Registry activities and prepare them to apply for [CDC's upcoming funding cycle](#). Recipients should use this funding to identify and address barriers to participation by building their capacity in 1 or more areas of SUID/SDY surveillance (case ascertainment, data quality, timeliness). The funds will be awarded to support CDR programs/teams/partners based on the program's/team's/partner's ability to identify and plan to improve one or more of the characteristics of data quality in the SUID Core Component or the SDY Expanded Component listed below. Funds will be distributed based on the following criteria:

- *1) The CDR program's/team's/partner's ability to identify data quality barriers and*
- *2) The ability and feasibility of the CDR program/team/partner to address the identified barrier(s) within the funding time frame.*

i.	Funding Opportunity Description:	Contract
ii.	Total Period of Performance Funding:	November 15, 2022-June 30, 2023
iii.	Average Award Amount:	\$50,000
iv.	Eligibility Information:	Open Competition
v.	Review and Selection Process:	Review Panel
vi.	Estimated Award Date:	Starting October 1, 2022
vii.	Cost Sharing and/or Matching Requirements:	N/A

Barrier Removal Funding Timeline

2022-2023



*Rolling applications will be accepted until all funds are distributed.

II. Full Text

A. Executive Summary

The purpose of this funding is to help identify and remove barriers faced by CDR programs/teams/partners, to build capacity for sites to conduct Case Registry activities, and to prepare them to apply for the [upcoming funding cycle](#).

The funds will be awarded to support CDR programs/teams/partners based on the ability to identify and plan to improve one or more barriers to implementing surveillance activities (listed below). Funds will be distributed based on the following criteria: 1) The CDR program's/team's/partner's ability to identify an appropriate barrier(s) and 2) The ability and feasibility of the CDR program/team/partner to address the identified barrier(s) within the funding timeframe.

The goal of the Case Registry is to conduct public health surveillance on unexpected deaths. SUID surveillance is the core component of the Case Registry. In addition to SUID, the current Case Registry allows for participation in an optional component expanding surveillance to include SDY. CDC and federal partners at the National Institutes of Health (NIH) developed the SDY component of the Case Registry to explore and provide greater understanding of SDY. SDY broadens the case definition and increases the age of death to at least 17 or the maximum age set by CDR legislation. By following NCFRP's protocols and by utilizing existing death investigation systems, current participants of the Case Registry strengthen their surveillance of SUID and SDY by ensuring 100% of cases are captured, unknown and missing responses are minimal, and timely data entry is completed. All current Case Registry participants are required to complete the SUID activities and some also conduct SDY activities. [View the previous Notice of Funding Opportunity for 2019-2023 surveillance](#). Both components will be part of CDC's new funding as well as a new prevention component.

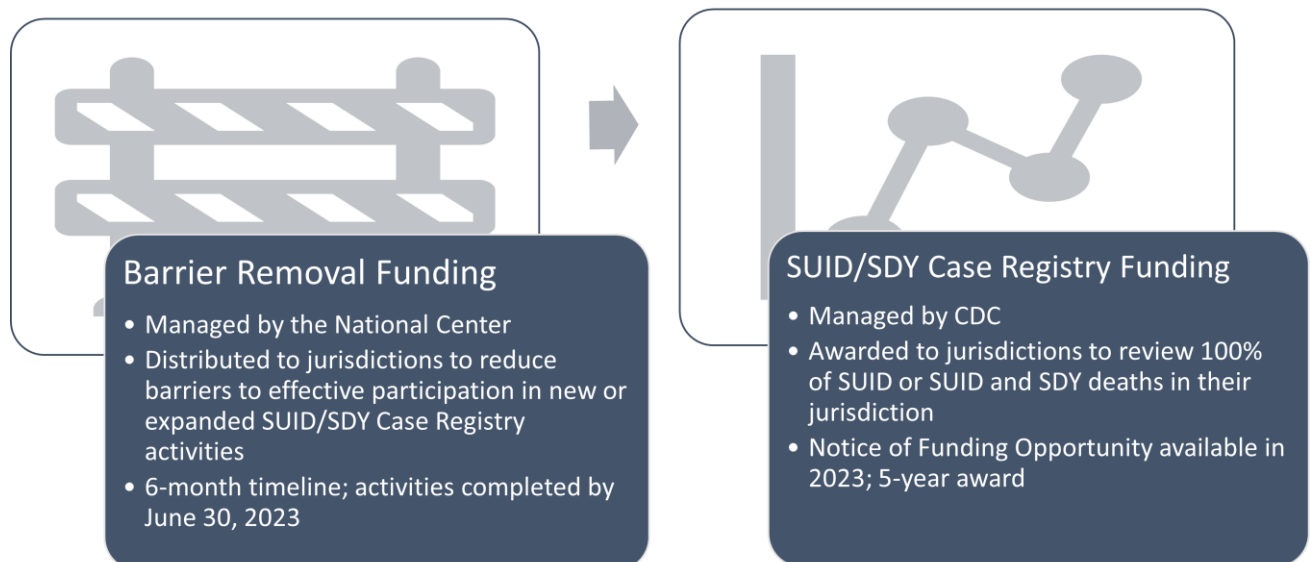
Current SUID activities include:

- *Identify all SUID cases*
- *Compile complete case information*
- *Conduct multidisciplinary reviews for every case*
- *Categorize every case using established criteria and algorithms*
- *Enter all case information into the National Fatality Review Case Reporting System (NFR-CRS)*
- *Review individual cases for data quality assurance*
- *Improve surveillance data quality and timeliness over time*
- *Disseminate data to inform policy and practice changes in agencies that serve families*
- *Identify risk and protective factors associated with these deaths*

Current SDY activities include:

- *Follow an autopsy guidance*
- *Collect a biospecimen at autopsy on all eligible cases*
- *Conduct a multidisciplinary advanced review*
- *Compile additional SDY-related variables into the NFR-CRS*
- *Offer every family of every case the opportunity to consent to save a biospecimen for later research (later research is outside of the scope of CDC's non-research Cooperative Agreement)*
- *Partner with the data coordinating center for NIH funded activities*

The Barrier Removal Funding and the SUID/SDY Registry Funding are two distinct funding opportunities.



B. Funding Opportunity Description

1. Overview

Sudden unexpected infant, child and adolescent deaths are tragic events affecting families and communities. In the United States, about 3,500 infants die suddenly and unexpectedly yearly from unexplained causes such as sudden infant death syndrome (SIDS) or accidental suffocation. These SUID, a major cause of infant mortality, account for about 16% of all US infant deaths. SUID is a subtype of SDY. SDY includes infants as well as children and young adults through 19 years old who die unexpectedly. Although very little is known about the incidence of SDY, it is commonly associated with unexpected death, cardiac conditions such as cardiomyopathy or arrhythmias, and possible genetic forms of epilepsy. Some studies suggest that 10-20% of SUID cases may be attributable to undiagnosed cardiac conditions. About 80% of SDY cases are classified as SUID.

Establishing the incidence of SUID and SDY is difficult because unexpected deaths due to arrhythmias, epileptic events, or infant suffocation are often unwitnessed events and leave no markers found at autopsy. Death certifiers designate varying causes-of-death given similar cases. Because of inconsistencies in reporting and classification practices, the ability to monitor national trends consistently and accurately or evaluate prevention programs for SUID/SDY is limited. The SUID and SDY Case Registry builds upon existing CDR programs and follows protocols developed by NCFRP. The Case Registry aims to uniformly document information about the circumstances and factors surrounding these deaths and uses a validated algorithm to categorize cases based on standardized criteria and levels of evidence available, leading to a better understanding of factors associated with SUID/SDY. Current funding recipients use case information for program planning and evaluation, modifying public health practice and policy, and reporting Title V Performance Measures; Title V funds are in 59 states and jurisdictions and seek to create federal and state partnerships that support health promotion efforts that seek to reduce infant mortality specifically through safe sleep. The current Notice of Funding Opportunity (NOFO) can be viewed here (URL: <https://www.goalpha.com/grant-opportunity/sudden-unexpected-infant-death-suid-and-sudden-death-in-the-young-sdy-case-r-299338/>).

2. Current SUID and SDY Case Registry Activities (subject to change in the funding cycle)

All current SUID/SDY participants are expected to conduct surveillance of SUID cases by implementing the following strategies:

Current Strategies
Identify all cases for child death review (CDR) within 30 days of death
Conduct a multidisciplinary CDR of all cases within 90 days of identification by having all data available for review
Categorize each SUID case at the CDR meeting according to established algorithms
Enter all case information within 30 days of review
Apply quality assurance checks/protocols on all cases within 90 days of entering case information
Analyze and disseminate data to internal and external audiences to inform practice and policy changes

In addition to the SUID activities, current participants of the SDY Component also implement the following strategies.

Current Strategies
Identify all cases for autopsy guidance within 24 hours of death
Conduct a multidisciplinary clinical advanced review for eligible SDY cases within 90 days of CDR and categorize every SDY case using an established algorithm
Establish incidence of SUID/SDY: Categorize each SUID case at the CDR meeting according to established algorithms
Collaborate with CDC and NIH's data coordinating center to ensure all activities outlined below under CDC funded collaborations are completed
Collect, store, and ship biospecimens to a biorepository
Review and submit protocols to local or a central Institutional Review Board (IRB) at the Case Registry Data Coordinating Center (DCC)
Develop a plan for collaborating with the DCC for use of the web-based Case Reporting System, NIH funded activities IRB, informed consent, and biospecimen shipping and storage

3. Barriers to SUID/SDY Participation

Barriers to SUID/SDY participation may include but are not limited to:

State & Local-level Capacity

- *High staff turnover*
- *Not enough staff (Case Registry tasks are too time-consuming for current staff)*
- *Key staffing positions remain vacant*
- *Additional funding needed for FTE*
- *Lack of pertinent information, including family and child's medical history, to share with local partners*
- *Potential state/jurisdiction requirements/constraints that limit participation (e.g., high floor to apply for funding opportunities, low leadership buy-in, low local partner buy-in)*
- *Need for more technical assistance and expertise on the Case Registry*

Case Identification

- *Challenges identifying all cases*
- *Lack of medical examiner/coroner (ME/C) partnership and participation to help with identification*
- *No connection to state vital records*

Multidisciplinary CDR and Advanced Review (AR) (SDY only)

- *Lack of interest from partners to participate in meetings*
- *Lack of knowledge about the Case Registry and the connection to CDR and AR*

- *Hesitancy/lack of sharing of case specific records for abstraction and case discussion*
- *Need for more technical assistance and expertise on the Case Registry*
- *Lack of equity lens—discussions around cultural norms/factors*
- *Lack of capacity to conduct family interviews and attempt consent (SDY only)*

Categorization

- *Lack of technical assistance/expertise in applying the Case Registry algorithm to each case*
- *Hesitancy/lack of record sharing so cases are incomplete and unable to be categorized*
- *Lack of equity lens—discussions around cultural norms/factors*

Data Completeness and Timeliness

- *Lack of details from death scene investigations (DSI) or autopsies (e.g., need for more doll scene reenactments, photographs and video of the scene, completed Sudden Unexplained Infant Death Investigation Reporting Form (SUIDI-RF))*
- *Lack of DSI resources, such as SUIDI kits and hands on training*
- *Lack of investigator knowledge about and/or willingness to use the SUIDI-RF and share records*
- *Lack of collaboration/communication among DSI agencies (e.g., law enforcement, ME/C, human services)*
- *Hesitancy/lack of record sharing by agencies including healthcare providers, social services, law enforcement, ME/Cs, child protective services, vital records, home visiting, etc.*

Autopsy Guidance

- *Delayed/incomplete autopsies, toxicology, microbiology and/or autopsy reports*
- *ME/C turnover*
- *Lack of ME/C participation*
- *Lack of knowledge about the Case Registry*
- *Lack of ability to train ME/Cs on the project*
- *Lack of capacity to store/ship biospecimen to SDY Biorepository (SDY only)*

Analysis and Dissemination of Data

- *Lack of resources to create data briefs and/or other products*
- *Lack of capacity to analyze data*
- *Unsure who to share data with to inform policy and practice changes*
- *Lack of SUID or SDY data*

4. Submission Requirements

Applicants responding to this funding opportunity must complete the NCFRP 2022-2023 SUID and SDY Case Registry: Barriers to Participation Grant Application. Applicants must:

- *Identify barrier(s) to participation and/or barriers to improving data quality for SUID and/or SDY*
- *Provide a feasibility plan to address each identified barrier within funding timeframe*
- *Describe the objectives for proposed project*
- *Describe how proposed objectives will be measured*
- *Identify internal and external partners that will be part of the proposed project*
- *Provide a 6-month workplan timeline*

For questions regarding submission, please contact the National Center at info@ncfrp.org.