NATIONAL CFRP

Center for Fatality Review & Prevention

REMOVING BARRIERS:
TO THE SUID AND SDY CASE REGISTRY

SAVING LIVES BY TELLING STORIES

HOUSEKEEPING

Before we get started

- This webinar is being recorded and will be available on the National Center's webpage (URL: www.ncfrp.org).
- Participants are muted. Please use the question-and-answer box to ask questions.
- Due to the large number of participants, the speakers may be unable to answer all questions. Unanswered questions will be answered and posted with the recording.
- Contact the National Center (email: info@ncfrp.org) for any tech problems.

Speakers

Abby Collier, MS
National Center for Fatality Review and Prevention

Carri Cottengim, MA
Centers for Disease Control and Prevention

Meghan Faulkner, MPH
Data Coordinating Center

Overview of CDR

Technical Assistance and Training

On-site, virtual and/or recorded assistance, customized for each jurisdiction, is provided to CDR and FIMR teams.

National Fatality Review-Case Reporting System

Support the NFR-CRS which is used in 48 states and provides jurisdictions with real-time access to their fatality review data.

Resources

Training modules, webinars, written products, newsletters, list-serv, website and more.

Communication with Fatality Review Teams

Regular communication via listserv, newsletters and regional coalitions.

Connection with National Partners

Develop or enhance connections with national organizations, including federal and non-federal partners.

ABOUT THE NATIONAL CENTER

CDR Process

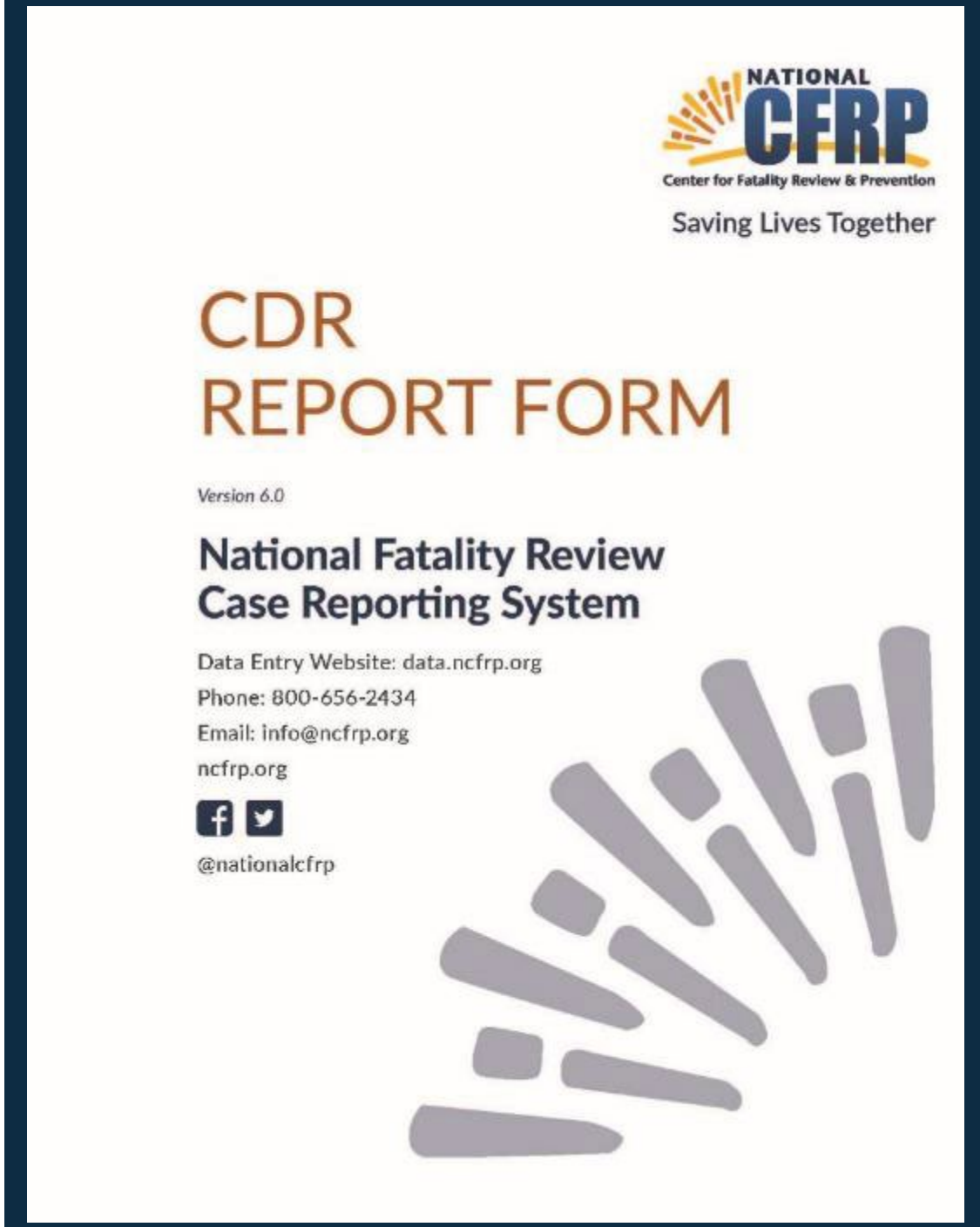
Best Practices in Reviews

National Fatality Review-Case Reporting System

A National Tool for CDR and FIMR Teams

The purpose of NFR-CRS is to systematically collect, analyze, and report comprehensive fatality review data that includes:

- Information about the fetal, infant or child and their family, supervisor at the time of the incident and person responsible (when applicable)
- Services needed, provided, or referred
- Risk and protective factors
- Findings and recommendations
- Factors affecting the quality of the review meeting



NFR-CRS Utilization

There are currently 47 states using NFR-CRS

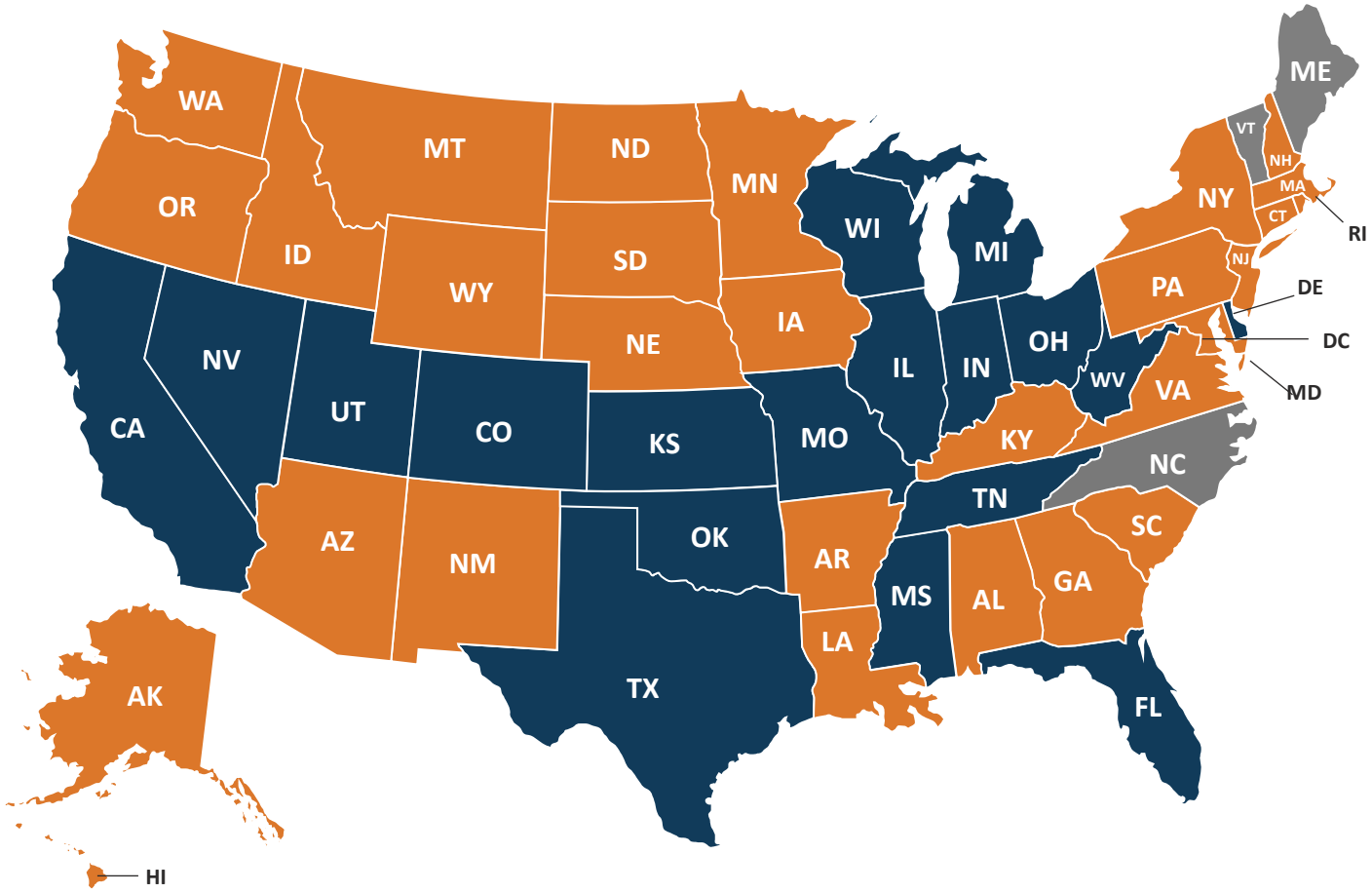
- 47 use NFR-CRS for CDR

Each state uses NFR-CRS differently. Some have comprehensive reviews whereas others may only use NFR-CRS in one jurisdiction.

States Using NFR-CRS for CDR

States Using NFR-CRS for CDR and FIMR

States Not Using NFR-CRS



Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion

The Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry

Carri Cottengim, MA

Health Scientist

SUID/SDY Case Registry

Agenda

1. History
2. Program Model
2. Current Strategies and Activities
6. Future

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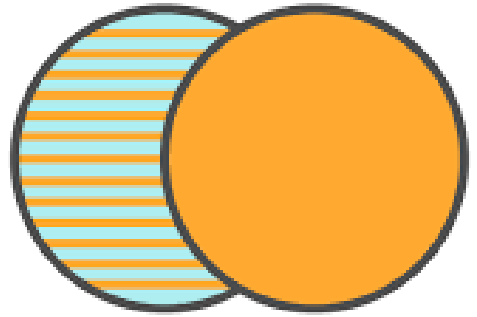
History of the SUID and SDY Case Registry

The SUID And SDY Case Registry: The What And The Why?

- SUID and SDY case definition
- Need to monitor unexpected and unexplained deaths and better understand related circumstances
- Differentiating explained deaths from unexplained deaths is challenging

Brief Overview of How SUID and SDY Overlap



All SUID cases are SDY cases

- Infant cases (< 1 year of age) that are categorized by the CDR team as *Explained Suffocation* do not proceed to the SDY Advanced Review but are still SDY cases.

All SDY cases are not SUID cases

- Infant cases (< 1 year of age) with some explained medical causes, including cardiac and neurological are SDY, and not SUID.
- Children 1 + are SDY, and not SUID.

- Conduct population-based SUID and SDY surveillance
- Monitor trends and describe demographic and environmental factors
- Provide information that will improve death investigations
- Inform prevention activities and reduce death rates

Planning Year, 2008

- 2 expert meetings at Centers for Disease Control and Prevention (CDC)
- Program model built on the National Center for Fatality Review and Prevention's existing protocols

Feasibility study, 2007

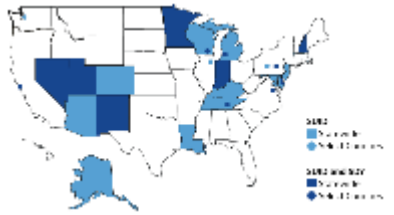
- Collaborated with National Violent Death Reporting System
- 7 states participated
- Recommendation: Use child fatality review as a program platform

SUID Pilot Program 2009 – 2012

- 5 states funded – 2 more added in 2011
- Active surveillance began January 2010

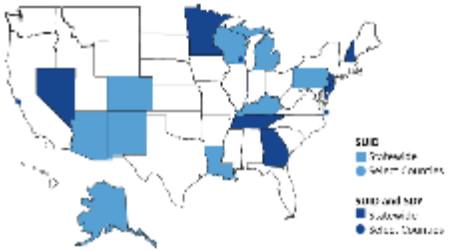
2018 – 2023 (current)

- Continued collaboration with the NIH for SUID and SDY surveillance through aligned 5-year funding cycle– the SUID and SDY Case Registry
- 1/3 of US SUID cases captured



2014 – 2018

- SUID surveillance continued
- The Sudden Death in the Young (SDY) Case Registry was launched
- Increased number of funded SDY Registry sites to 18 through collaboration with the National Institutes of Health (NIH)



2023 – 2028 (future)

- A new competitive funding announcement anticipated for 2023

Agenda

1. History
2. **Program Model**
2. Current Strategies and Activities
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SUID and SDY Case Registry Program Model

Case Registry: Program Model

- **Builds upon** Child Death Review **activities** and **protocols**
  - Avoids duplication of efforts
- Uses pre-existing variables in the **National Fatality Review Case Reporting System**
- **Strengthens ability** to review and monitor all cases
- **Enhances capacity** to improve death scene investigations and develop data-driven prevention strategies

The Case Registry is a…

- Process that must involve **multidisciplinary child death team, review**
- **Qualitative** and **quantitative** process
- Tool for **assessing and improving** case investigations
- Vehicle for driving **data to action**

Core Components

- **Case ascertainment**
  - Identify 100% of SUID and SDY cases in each funded jurisdiction
    - Notifications from medical examiners, coroners, law enforcement, child protective services, etc.
    - Vital stats cross-check to ensure all cases are found
- **Data completeness**
  - Limited missing and unknown data abstracted from multiple data sources on every case
  - Work to improve access and quality of primary data sources if they are not complete such as improving death investigations
- **Timeliness**
  - Cases take no longer than 375 days from date of death to date case is final

Key Areas We Focus On

- Data quality improvement – timeliness, completeness and case ascertainment
- Standardization of death investigation practices
- Improving case review processes
- Using data to inform prevention

- Differences with SDY areas of focus:
  - Standard autopsy protocol and saving a biospecimen on 100% of SDY cases
  - Offering 100% of families impacted by SDY the opportunity to store a specimen and be a part of the SDY Case Registry research and DNA banking through consent
  - Advanced review of each eligible case and completion of SDY module

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CURRENT STRATEGIES AND ACTIVITIES

Strategies & Activities	Short-Term Outcomes	Intermediate Outcomes	Long-Term Outcomes
Identify all cases for autopsy guidance within 24 hours of death (SDY Optional Expanded Component only) and for child death review (CDR) within **30 days of death**. **Review** 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. Conduct a multi-disciplinary **advanced review** for eligible SDY cases within **90 days of** CDR and categorize every SDY case using an established algorithm (SDY Optional Expanded Component only). **Enter** all case information within **30 days** of review. Perform **quality assurance checks/pro**tocols on all cases within **90 days** of entering case information by applying quality assurance protocols. **Analyze and disseminate** data to internal and external audiences to inform practice and policy changes of SUID/SDY.	Increased access to high-quality and complete, surveillance system data for SUID/SDY. Improved completeness, timeliness, and quality of SUID/SDY surveillance data for program improvement and public health purposes. Established incidence of SUID/SDY, including incidence of categorical types. Development of data briefs and other products used to inform programs and other key stakeholders. Increased community awareness of SUID/SDY.	Improved policies and practices of systems serving families at higher risk for SUID/SDY. Improved policies to standardize investigation practices, including review of medical records, scene investigation and autopsies. Improved policies to standardize death reporting practices	Reduce the incidence of SUID. Reduce the incidence of SDY. Standardize investigation and reporting.

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1. History
2. Program Model
3. Current Expectations
6. **Future**

Future

SUID and SDY Case Registry: (DP23-2306)

FY2023 new Notice of Funding Opportunity (DP23-2306) to expand the SUID and SDY Case Registry

- Multi-component NOFO
  - Component A: SUID
  - Component B: SDY
  - Component C: Data-informed Prevention
- Forecasted at https://www.grants.gov/web/grants/view-opportunity.html?oppId=341292

  Subscribe to receive updates

WSH2@CDC.GOV




NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

SDY Expanded Component Activities

Meghan Faulkner

Director, SUID and SDY Case Registry Data Coordinating Center

SDY

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

What cases are included?

- Death was sudden and unexpected
- Child was 0 – max age of CDR, and a resident of the funded state/jurisdiction
- **Exclude** terminal illness, homicide, suicide, intentional overdose, and obvious injury-related death

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

Current SDY Expanded Component Activities

- Apply standardized autopsy protocol, including biospecimen collection on 100% of cases

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

Current SDY Expanded Component Activities

- Offer consent with 100% of eligible families to allow for research and/or DNA banking for family use/future diagnostic testing*

*Must have IRB approval in place to attempt consent!

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

Current SDY Expanded Component Activities

- Conduct an Advanced Review on eligible cases
  - Categorize cases using standardized algorithm

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

Current SDY Expanded Component Activities

- Complete SDY module in the National Fatality Review-Case Reporting System
  - Includes child's medical history and family medical history

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

PRACTICAL STEPS

REVIEW

WHAT ADDITIONAL INFORMATION WOULD BE HELPFUL?

BUILD CAPACITY

Establish or reestablish CDR teams

Incorporate best practices into the review process

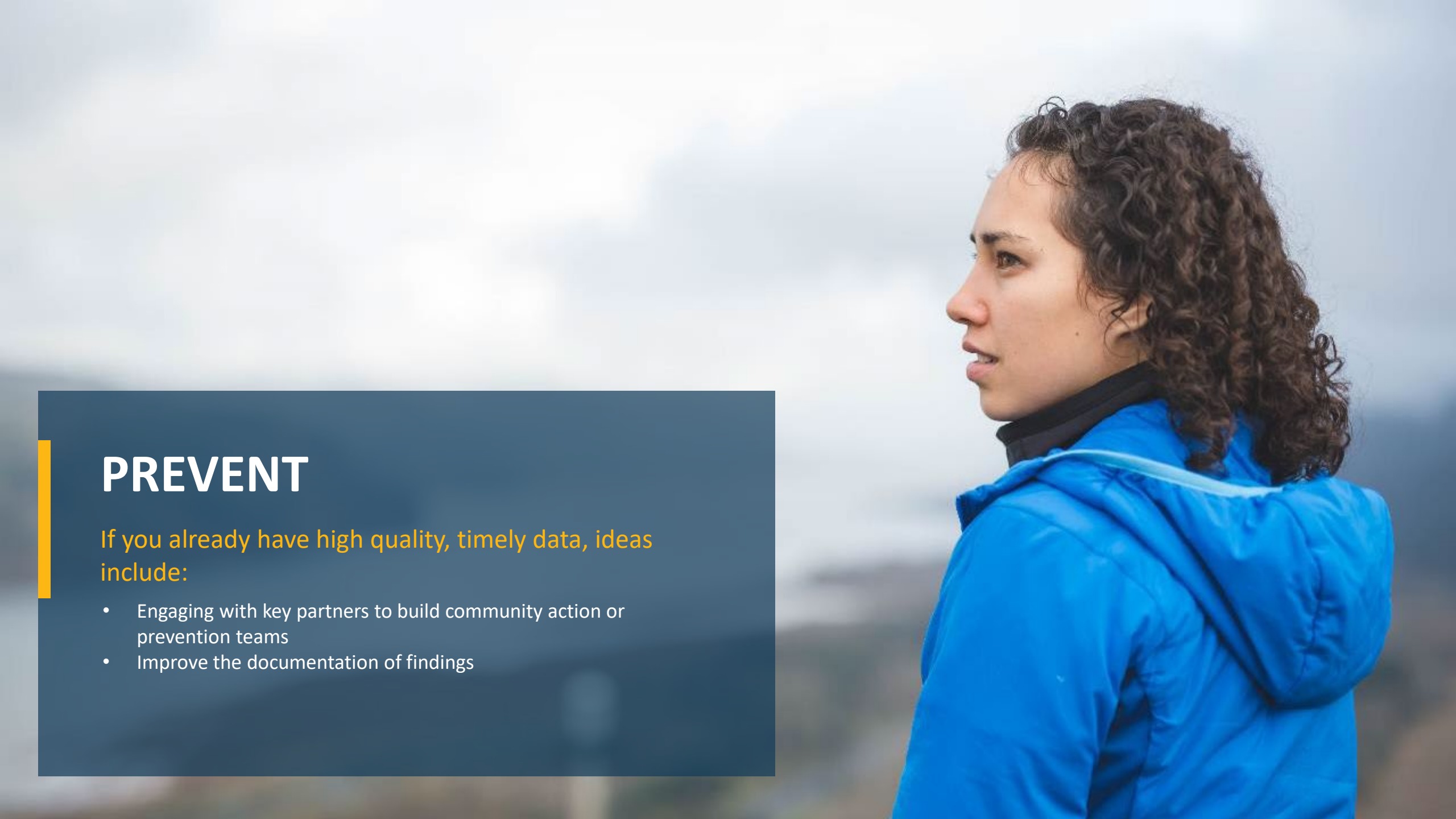
CATEGORIZATION

Provide training on the SUID or SDY algorithm in order to build consistency in categorization

DATA

THINK BIG! CHANGE SYSTEMS!

- Establish MOUTs or MOAs with other data sources or providers
- Implement the Case Registry benchmarks for timeliness and track progress
- Implement methods to ensure 100% case ascertainment which could include training to coroner/medical examiner offices
- Provide training and DSI kits to improve data quality and completeness
- Conduct family interviews to improve data quality and provide bereavement support
- “Catch up” on data entry within NFR-CRS



PREVENT

If you already have high quality, timely data, ideas include:

- Engaging with key partners to build community action or prevention teams
- Improve the documentation of findings

Current Awardee Ideas

Building on the Foundation

- Expand jurisdictions
- Consider SDY and build an Advanced Review Team
- Implement the SDY Autopsy Protocol and prepare to save biospecimens
- Engage in family interviews to increase data completeness and provide bereavement support
- Expand DSI training to additional jurisdictions or to provide investigation kits

Application Period

Applications will be accepted between September 15, 2022, and 11:59- ET on November 1, 2022.

Timeline

Projects can take no more than six-months to complete and must be completed by June 30, 2023.

Technical Assistance

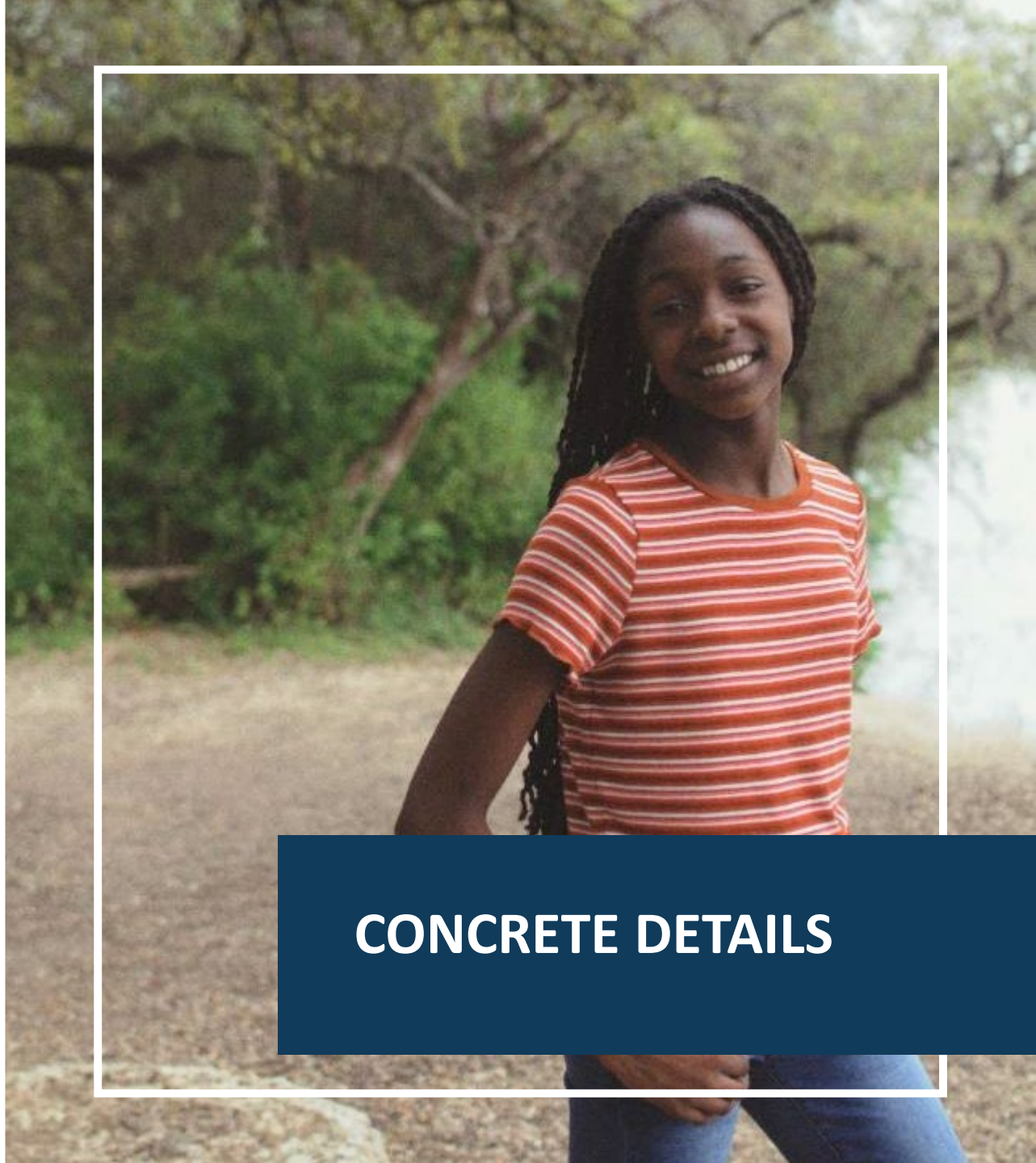
Enhanced technical assistance will be provided based on project goals and objectives.

Funding Amount

There is no funding ceiling and average awards are anticipated to be approximately $50,000.

Resources

All resources for this funding opportunity are available at https://ncfrp.org/suid-sdy-case-registry/



CONCRETE DETAILS

Resource Page for SUID and SDY Barriers

Home

Child Death Review

Child Death Review (CDR) is the multidisciplinary review of individual child deaths to help communities understand why children die and equip them to effectively prevent future fatalities. Click here to learn more about CDR.

View

Fetal & Infant Mortality Review

Fetal and Infant Mortality Review (FIMR) is the community-based, action-oriented process of reviewing fetal and infant death cases to improve maternal and infant health outcomes. Click here to learn more about FIMR.

View

Data

The National Fatality Review-Case Reporting System (NFR-CRS) is the data system supporting CDR and FIMR teams across the country. Click here to learn more about the NFR-CRS and data-related activities.

View

Center Resources

The National Center develops a wide range of resources to support the work of CDR and FIMR teams. Click here to explore our guidance documents for teams, webinars, training module series, and other helpful resources.

View

Resource Page for SUID and SDY Barriers

NATIONAL CFRP 20 YEARS
Center for Fatality Review & Prevention

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Home > Child Death Review

Child Death Review

Every year in the United States, almost 37,000 children die before their 18th birthday. The death of a single child is a profound loss to a family and community, bringing unjust suffering and the pain of unfulfilled promises. Understandably, when a community is affected by a child's death, it wants answers and a deep understanding of how and why the child died. These answers can help communities have a clearer understanding of underlying risk factors and inequities that they may not identify otherwise.

SUID & SDY Case Registry

Map of Programs

CDR in the U.S. Report

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