



## NATIONAL CENTER FOR FATALITY REVIEW & PREVENTION

December 2016

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### Greetings from the Director

by Teri Covington

Dear Colleagues,

I hope you all had a wonderful Thanksgiving weekend. We at the Center are so grateful for our partnerships with you and for the work you do to keep children safe and healthy. Below is brief description of our annual

report to our funder at HRSA, MCHB. You'll see that we had many opportunities in 2016 to work with you, to support you, and to learn from you. We are so thankful that so many of you continue to volunteer your time to help grow the resources needed for our work through participation on work groups, offering to review materials and train your colleagues, and sharing your best practices and review outcomes. I've been working on appreciating the value of gratitude and found this quote by Albert Schweitzer to be especially meaningful to me this year: "At times our own light goes out and is rekindled by another person. Each of us has cause to think with deep gratitude of those who have lighted the flame within us."



Gratitude is especially meaningful to me as Vick Zittle retires from Pennsylvania CDR this December. I have always thought of Vick as the soul of CDR. Over the 20 years we've known each other, she more than any other person could speak with passion, purpose and meaning on why reviews matter for families and children. We will miss her greatly.

We expect that 2017 is going to be full of transition as the national level. We are hoping that our newly elected leaders will understand and value the work we all do in fatality review. We will work hard to be your voice in promoting FIMR and CDR to the new leaders. This week, our CEO, Dr. Renee' Canady, sent a Thanksgiving message to encourage all of us to apply the core values of our parent organization, the Michigan Public Health Institute, to our work. She wrote, "...strive for authentic relationships and dialogue that will advance the principals of social justice...and remember to always lead as servants who focus on the needs of others; lastly, incorporate all of these to be a beacon of excellence wherever you find yourself this holiday season."

Best wishes this holiday season and beyond,

Teri

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## What we did last year.....

Each year the Center tracks and categorizes what we did during the year and reports our work to our federal funders at the Health Resources & Services Administration (HRSA). We thought you might be interested too.

This year, we interacted with every state but one for TA or training. Remember, though, when we give a national presentation we don't often know where everyone listening is from, so we may well have reached the last state. We sent out more than 6,000 copies of our various publications; the publication most frequently requested was our Case Report Form that participants in our CDR-Case Reporting System use.

We received 1,117 requests for services (examples of services requested are technical assistance, training, presentations, and some of our meetings and work groups). Through these requests, we reached more than 16,000 individuals (there could be more at presentations; we rarely have a precise count). We record each service request, including who requested it. We count contacts with people in the following categories (individuals

could be in the count more than once if they called more than once or multiple times with different issues/questions/requests each time). We interacted with the following:

- 1,835 staff of state MCH agencies (including 906 CDR coordinators; 189 FIMR coordinators; 18 joint FIMR/CDR coordinators; and 724 other state MCH agency staff)
- 637 CDR coordinators affiliated with organizations or agencies other than MCH
- 80 individuals from federal agencies
- 2,305 individuals from national organizations
- 350 child abuse professionals
- 87 Healthy Start individuals
- 1,036 other CDR and FIMR staff
- 274 individuals from a variety of our committees and work groups
- 1,165 health providers/professional and health consumers
- 750 educators
- A few families and a few reporters

We are pleased with the amount of interaction we had last year, and we look forward to even more in the current year and, especially, working with all of you who work so hard to keep children safe and healthy.

## FATALITY REVIEW COORDINATORS

*Farewell to the following coordinator:*

Shannon Rupp, CDR, Arizona

*Welcome to new coordinators:*

Dallas Williams, CDR, Arizona

Karen Nash, CDR, Wisconsin

Allison Ayers, CDR, Virginia

Let us know of departing and new  
FIMR and CDR leaders in your state.

## PACIFIC ISLANDS WORKING COLLABORATIVELY ON INFANT MORTALITY AND FIMR

The National Center is pleased to recognize new efforts to bring FIMR to the Pacific Basin, officially known as the US Affiliated Pacific Islands (USAPI). The USAPI include Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, the Republic of the Marshall Islands, the Republic of Palau, and the Federated States of Micronesia.



For 18 months, the Pacific Basin Infant Mortality Collaborative Improvement & Innovation Network (CollIN), a partnership of federal, island, and local leaders, has been exploring how to improve access to quality birth and death certificate data in the islands.

When that program ended recently, the Maternal and Child Health Bureau (MCHB), HRSA decided to continue the work on infant mortality in the region through a FIMR CoIN, a Collaboration Innovation Network. MCHB, in partnership with the Association for Maternal and Child Health Programs and the National Center, launched the CoIN with its USAPI partners in November. Its aim is to, ***"Improve fetal and infant mortality review and prevention systems in the Pacific Basin.... More first birthdays."*** US Virgin Islands and Puerto Rican infant mortality programs have also joined the FIMR CoIN efforts.

One of the goals of the program is to develop programs in the Pacific Basin to review fetal and infant deaths. In addition to work with the FIMR CoIN, the National Center is also currently consulting with Guam on development of its Child Death Review program.

The National Center is excited that fetal and infant mortality review programs are developing in the islands as part of an overall collaborative strategy to improve infant mortality, and we look forward to our work as part of the effort.

## INITIATIVE TO IMPROVE DATA QUALITY

In July 2015, NCFRP undertook a data quality (DQ) initiative to improve the quality and consistency of data entered into the Child Death Review-Case Reporting System (CDR-CRS). As an initial step, the Center convened a Data Quality Workgroup of representatives from 7 state CDR programs. The workgroup identified a list of priority variables in the CDR-CRS that would be used for monitoring data quality. The variables were chosen based on their importance for informing prevention or service improvements.

Once the priority variables were identified, NCFRP prepared a national aggregate data quality summary report of all CRS data and sent each state that had entered 30 or more cases from 2014 to present a state-specific DQ summary report. The summaries show the proportion of missing and unknown entries for each priority variable of the deaths entered. A DQ summary report will be sent annually to each state that enters 30 or more deaths into the CDR-CRS in the reporting year.

There are many potential uses of this summary information by states and teams. For example:

- Information from the report can be used for training local teams, especially when paired with the new [Priority Variables Definitions and Guidance document](#).
- States can use the report as a rationale for starting a data quality effort or for monitoring an existing effort.
- SPSS syntax is available upon request for states that want to run the DQ report more frequently (e.g., quarterly), or stratify the report by teams/counties.
- An anomaly in a particular section might merit investigation. For example, a high proportion of missing or unknown in Section E on death investigations may indicate that the Medical Examiner is not attending CDR meetings or that officials are not providing death scene information at reviews.

Technical assistance from the National Center is available to states that want to improve their data quality, such as how to use the data quality summary report or implement DQ improvements. Contact the National Center or [Patti Schnitzer](#).

### **Additional information on the data quality initiative**

- An introduction to the data quality initiative was presented to users of the child death review case reporting system (CDR-CRS) in June 2016 and is [archived with slides](#).
- Get a copy of the [DQ summary with the National data](#).

## **New Resources for the Field**

### **Tips for Effective Review of Pregnancies Impacted by Zika**

The National Center, with assistance from our partners at HRSA and CDC, developed a document for teams to use when reviewing deaths or pregnancies affected by the Zika virus infection. It will be sent to the CDR and FIMR listservs during the week of December 5, and will also be available at that time on our website. [www.ncfrp.org](http://www.ncfrp.org)

### **Effective Review of Natural Infant Deaths Webinar and Guidance**

The Webinar presented November 16, 2016, is now available on the National Center website: <https://www.ncfrp.org> It is accompanied by an updated guidance document, *Tips for Effective Review of Natural Infant Deaths*. We want to give special thanks to presenters Jason Jarzembowski, MD, PhD, Children's Hospital of Wisconsin and the Medical College of Wisconsin, and moderator Diane Pilkey, Senior Nurse Consultant at HRSA, who is our Project Officer.

*Webinar materials on the website include:*

Video Archive - pass code "Effective"

Webinar slides (PDF)

*Tips for Effective Reviews of Infant Natural Deaths* (PDF)

Responses to questions posted during the webinar (PDF)

Long-time CDR Coordinator  
Retiring

Your CDR-Case Reporting System

by Teri Covington



Retiring Pennsylvania CDR  
Coordinator Vick Zittle

Vick Zittle has been the coordinator of the Pennsylvania CDR program since 1995, and she is taking a well-deserved retirement as of the end of the year. The Center recognized Vick at the Pennsylvania State CDR annual meeting in November, presenting her with an award as an American champion for children.

A number of you sent congratulatory messages to Vick that we shared with her at the Pennsylvania meeting, including:

"Since the day I started in child death review, Vick has been a mentor, and she was the first child death review director I met from another state. Her passion and wisdom for this work was apparent from that first meeting. She has a knack for always capturing the 'heart' of child death review and always bringing us back to the true focus of the work we do."

"I have also always been impressed by Vick's willingness to be a road warrior in order to be sure that all of her local teams received the TA they needed in order to effectively conduct their reviews."

"She was always quick to answer questions, provide guidance and offer words of encouragement, and she always went out of her way to help newcomers and see the positive in our work."

"I remain amazed by Vick's unwavering commitment to the review process and how she would never let any setback stop her from finding a way to keep things moving

In order to strengthen compliance with HIPAA requirements about confidentiality of data, we added an online reminder for database users. Each state has full access to its data, including identifiers, and can enter identifiable data as its laws or policies permit. However, the National Center staff only have access to de-identified data, and the data we release to researchers is always de-identified.

Before we provide data to researchers, we exclude 43 variables that may contain identifiable information. However, there are a number of places in the CRS where narrative/open text answers can be entered. We do not have the capacity to check and strip each text answers, so we are reminding users not to put identifiers in open text fields. If we are made aware of identifiable information in the open text fields, we will notify the state CDR coordinator so the case can be edited.

## Federal Hearing on Crib Bumper Pads



In October, Center director Teri Covington was invited by the US Consumer Product Safety Commission to provide data from our Case Reporting System on infant deaths in sleep where bumper pads were involved. Teri and a number of other national experts provided information and data about whether crib bumpers lead to suffocation of sleeping infants.

After the testimony, the Commission voted to recommend that stores not sell bumper pads and that consumers not buy them, but it did not ban and/or recall them.

forward. That dogged determination served as an example to me all these years."

Vick, you will be truly missed!

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## AAP SECTION ON CHILD DEATH REVIEW

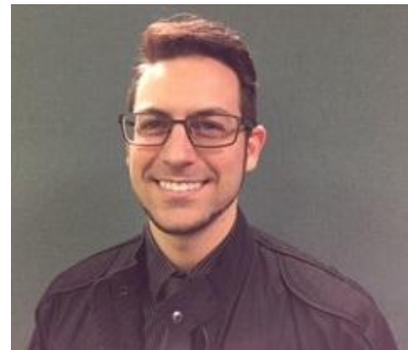
Two years ago, the American Academy of Pediatrics announced a new provisional section (sections are topical sub-groups of the Academy) on Child Death Review. The mission of the Section is to, "Improve health and well-being of infants, children, adolescents, and young adults by supporting pediatricians involved in reviewing death and helping prevent fatalities and near fatalities." Erich Batra, who is a practicing pediatrician and the medical director for the CDR program in Pennsylvania, is the chair of the section.

Teri Covington, Center director, and Linda Potter, associate director, attended the section's annual meeting at the AAP National Convention in San Francisco in October. Two pediatricians who chair State CDR teams in Arizona and Mississippi gave presentations about their CDR programs, highlighting successes and challenges; and a panel of pediatricians active in CDR shared their experience and insights.

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## Center Welcomes Erik Buczkowski

The National Center is pleased to welcome Erik Buczkowski to its staff as a Data Analyst. Prior to coming to us, Erik worked in the Center for Healthy Communities at MPHI. He is from Michigan and has a Bachelor's Degree in Biomedical Science from Central Michigan University and a Masters Degree in Public Health from Grand Valley University. He will be working on data projects related to Child Death Review, FIMR, and the Sudden Death in the Young and the Sudden Unexpected Infant Death Case Registries.



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## THE SUDDEN UNEXPECTED INFANT DEATH AND SUDDEN DEATH IN THE YOUNG CASE REGISTRIES

In addition to providing resources and the Child Death Review - Case Reporting System (CDR-CRS) database for CDR programs around the country, NCFRP is also a partner in two case registries using the CDR-CRS, the Sudden Unexpected Infant Death (SUID) Case Registry and the Sudden Death in the Young (SDY) Case Registry.

### **SUID Case Registry**

The SUID Case Registry began in 2010 and builds on existing Child Death Review programs to conduct population-based SUID surveillance with improved data quality and quicker data entry into the CDR-CRS. The Centers for Disease Control funds 8 state CDR

### **SDY Case Registry**

The SDY Case Registry is an expansion of the CDC's SUID Case Registry. It is designed to increase understanding of the prevalence, causes and risk factors for sudden death in the young, and to inform strategies to prevent future deaths. Sudden death in the

programs to participate and offers them technical support and resources to improve SUID case identification and their data entry. SUID Case Registry grantees complete the process below for all SUID cases:

CDR Teams identify SUID cases from medical examiner, coroner, or state vital statistics office.

For each case, multidisciplinary CDR Teams review information from death scene investigations, autopsies, medical records and other medicolegal reports.

CDR Teams identify actionable strategies that may reduce SUID and improve case investigations.

CDR Teams record findings into a web-based reporting system.

CDR Teams analyze the data to monitor SUID trends and associated characteristics.

CDR Teams use data about trends and associated characteristics to inform strategies and recommendations to reduce future deaths.

#### **SDY/SUID grantee jurisdictions:**

Delaware, Georgia, Nevada, University of San Francisco, Tennessee, Virginia, Minnesota, New Hampshire, New Jersey, Wisconsin

**SUID only states:** Alaska, Arizona, Colorado, Kentucky, Louisiana, Michigan, New Mexico, Pennsylvania

In coming newsletters, we will highlight the work being done in the SUID and SDY Case Registry grantee states and jurisdictions.

young is defined as the death of a young person not otherwise expected to die. It is funded by the National Heart, Lung, and Blood Institute (NHLBI), the National Institute of Neurological Disorders and Stroke (NINDS), and CDC. The SDY Data Coordinating Center at NCFRP, the SDY Biorepository at the University of Michigan, and 10 grantees round out the Registry's components.

In Phase I of the SDY Case Registry, Child Death Review teams in the grantee jurisdictions compile comprehensive data about sudden and unexpected deaths in residents  $\leq 19$  years of age and enter the data in to the CDR-CRS. Cases undergo a standard

CDR review, and in a subset of cases, a DNA sample is collected and stored in the SDY Biorepository for availability to researchers. Additionally, all SDY Registry cases are reviewed locally by experts in sudden cardiac death, sudden unexpected death in epilepsy, and pathology. The Phase II research, funded by NHLBI and NINDS, is still in its early stages.

#### **Phase 1: SDY Case Registry**

Build on existing Child Death Review programs to develop a surveillance system for SDY cases

Conduct Advanced Review (clinical and forensic) to categorize SDY cases

Collect and store DNA for future research, banking, and diagnostic testing

#### **Phase 2: Research**

Make the SDY case information and DNA samples available to investigators

Support studies using SDY case information to evaluate causes of and risk factors for SDY

We encourage CDR programs to apply for funding for these Case Registries in future funding cycles. In the meantime, if you're interested in improving your data from and reviews of SUID and SDY cases, there are some steps you can take:

- Use the CDR-CRS to monitor SDY and SUID cases by using and tracking the registry variables, which are available to all CDR programs.
- Encourage forensic pathologists in your area to use the [SDY Case Registry Autopsy Guidance/Summary](#) and to save blood and/or tissue samples for future DNA testing by families or medical examiners.

You can find more information on the [Case Registries online](#), and a website specifically for families about the SDY Case Registry is coming soon! You can also contact [Meghan](#)

## UPCOMING WEBINARS

**Recognizing and Responding to Vicarious Trauma in Fatality Review**, Wednesday, December 14, 2:00 p.m. - 3:00 p.m. ET. [Click here to register.](#)

**Building Partnerships for Effective Fatality Review**, Wednesday, January 11, 2017, 2:00 p.m. - 3:00 p.m. ET. Registration details to follow.

## UPCOMING EVENTS

**State FIMR Coordinators Teleconference**, Wednesday, December 7, 2016, 2:00 p.m. - 3:00 p.m. ET

**Disparities Workgroup Teleconference**, Thursday, December 8, 2016, 2:30p.m. - 3:30 p.m. ET. For information, contact [Rosemary Fournier.](#)

## NATIONAL CENTER MAILING LISTS

You can join the **Child Death Review Listserv** and/or the **Fetal and Infant Mortality Review Listserv**. If you join either, you'll also receive the newsletter. Or you can choose to receive the newsletter only and can change any selection any time by contacting [info@ncfrp.org](mailto:info@ncfrp.org).

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If you have comments, suggestions, or questions about this newsletter, contact Linda Potter: [lpotter@mphi.org](mailto:lpotter@mphi.org).

This newsletter was made possible in part by Cooperative Agreement Number UG7MC28482 from the US Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Its contents are solely the responsibility of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by, HRSA, HHS or the U.S. Government.

