



News From Your National CDR Resource Center

THE FAR END OF SUMMER

Summer is the season synonymous with childhood and like childhood always comes to an end. In Ray Bradbury's *Dandelion Wine*, twelve year-old Douglas brings out a yellow Ticonderoga pencil to record his upcoming summer with his younger brother. "Tom, I'm going to keep track of things. You realize that every summer we do things over and over we did the whole darn summer before. Like making dandelion wine, like buying new tennis shoes, like shooting off the first firecracker of the year, like making lemonade, like getting slivers in our feet...That's one half of summer, Tom.' 'What's the other half Doug?' 'Things we do for the first time ever. Like finding out that maybe grandpa and dad don't know everything in the world.' 'What other crazy stuff you got written there?' 'I'm alive!' 'Heck Doug, that's old.'"

Your Resource Center received funding for its tenth year beginning July 1st. Heartfelt thanks go to the U.S. Maternal and Child Health Bureau at HRSA for supporting our work for a decade. CDR is strong throughout the country, even in the midst of serious and devastating state budget woes. There are now more than 1,250 local CDR teams in the U. S. Long time supporters of CDR in Idaho, the last state without CDR, are working closely with their Governor's Office to find a way to create and support local teams. Our scope of work this year includes working with the U.S. protectorates and federated states in the Pacific Basin and Caribbean to establish CDR programs. Hopefully by next summer we can color in the whole map of the U.S. and our neighbor islands.

Our national meeting in Atlanta this past April was a terrific event—thanks to all of the state coordinators in attendance and to the funding from the CDC. Forty-seven states were able to attend and most everyone took on a leadership role. Long, complex and fulfilling discussions took place over two days as CDR leaders shared experiences and suggestions for improving the CDR process. We have posted summaries of the discussions on our web site.

Your work with child death review continues to find ways to make Doug's words true for all children: summer delights, futures that get better and better and children in the middle of it all.

"And then, quite suddenly, summer was over. Doug knew it first when walking downtown. Tom grabbed his arm and pointed, gasping, at a dime store window...'Pencils, Doug, ten thousand pencils! Nickel tablets, dime tablets, notebooks, erasers, a hundred thousand of them!' 'Tom, if this year's gone like this, what will next year be, better or worse?' 'I got a hunch,' said Douglas. 'Next year's going to be even bigger, days will be brighter, nights longer and darker, more people dying, more babies born and me in the middle of it all.'"

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A New Name and Image

It was a bittersweet moment but after ten years we have retired our name, the National Center for Child Death Review, and our red, white and blue images. We are now officially the **National Center for the Review and Prevention of Child Deaths**.

After hearing from many of you, we have kept our tag line: *keeping kids alive*. We

worked with a health marketing firm, the EDGE, to create branding that would emphasize our focus on preventing deaths without losing our focus on doing the work of case reviews. We believe the new name, our colors and our incorporation of stars as background images represent the immense sadness of child deaths but also the hope and promise of reviews to keep other children alive. Early this Fall we will have a new brochure customizable for the key disciplines participating in reviews. All of our materials and images were created so that you can also customize them for your own program. Contact us to obtain the images and we'll gladly help you.

The National Center for the
**REVIEW &
PREVENTION
OF CHILD DEATHS**



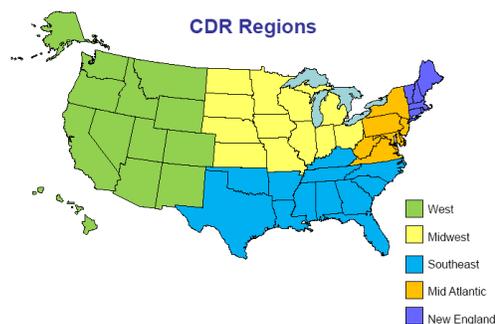
Welcome Linda Potter

We are very happy to announce that Linda has joined the Center as our new Director of Policy and Program Innovations. Linda will be exploring new arenas for us, including family engagement in the review process; improving our reviews of vulnerable children, especially children with disabilities; and working to translate our review findings into national policy, practice and programs. Linda has spent most of her career as an advocate for persons with disabilities, including seven years advocating for the rights of disabled children in foster care. She recently spent ten years as the CEO of United Cerebral Palsy of Michigan. Linda has a law degree from the University of Washington and is currently working on her Certificate in Public Health from the University of Michigan.



Building Regional Networks of Support

Our 2012 HRSA funding includes a small amount of support to encourage networking among CDR states by region. Up to \$5,000 is available to support conference calls, meetings, trainings, or other



networking opportunities identified by state CDR program leaders. This fall, representatives from the five regions arbitrarily created by the Center will meet to discuss ways in which they can work to grow regional networks. Please contact these persons if you have ideas for your region. The leaders we are working with are:

Allison Anderson, West

Susan Rodriguez, Southeast

Abby Collier, Midwest

Anne Pedrick, Mid Atlantic

Marc Clement, New England

New CDR Program Leaders in States

Many new leaders joined our CDR world in 2011 in the states of Arizona, Arkansas, Louisiana, Massachusetts, South Carolina, Virginia and West Virginia. In Arkansas, Pam Tabor is working to pass state



Pam Tabor Calling Her Arkansas Hogs at the National CDR Coordinator Meeting

legislation to support local teams and is organizing two pilot teams in central and northwest Arkansas. In keeping with the wonderful spirit of sharing among CDR leaders, Michigan invited Pam to attend their annual CDR training. Pam then went on a week long road trip through Texas under the mentorship of Susan Rodriguez. They drove over 1500 miles visiting new and established teams. Pam reports that these experiences gave her months of advantage in her learning curve for CDR. Susan's reward for being so helpful was that she was given the parking spot closest to her health department entrance—a real prize in the hot Texas summer. Louisiana, Massachusetts and South Carolina have been without CDR coordinators for extended periods. Welcome to Kristie Bardell, Elizabeth Welch and Amelia Shiver, respectively. Jeff Bowles left his position in W. Virginia, and was quickly replaced by Trish McCay, who is also managing W. Virginia's Domestic Violence Fatality Review program.

Marla Herrick is the new coordinator in Arizona. Ginny Powell reports that Emily Gambill has been hired to help organize local CDR teams throughout Virginia. Emily will eventually manage the state team efforts as well. Contact information for all is available on our state spotlight webpage. Welcome to all of you.

Tracie Martin, DC Fatality Review, Receives Award

Congratulations to Tracie Martin, who was recognized for her leadership and stewardship of child death review in Washington, DC. Tracie is a senior fatality review specialist in DC. She was a 2011 winner of the Cafritz Award for Distinguished DC Government Employees. This honor is given to persons who exemplify the best in public service. Tracy was honored as an impassioned advocate for children who no longer have a voice and as a person who, despite external pressures and demands, tirelessly works towards solving problems in innovative ways that inspire others and positively impact the community. Tracie was one of six honorees (out of 30,000 DC employees). Tracie was honored in May at a special ceremony held at the George Washington University Center for Excellence in Public Leadership. The Honorable Vincent Gray, Mayor of Washington DC, was one of presenters of the award to Tracie.



Frontline and NPR Stories on Child Deaths



PBS and NPR had a series of stories on radio and television focused on death investigations in the United States, emphasizing the variety of and inconsistencies in systems across the states. Part of their series included stories on abusive head trauma and what they describe as questionable convictions. NPR also ran a separate story on “Re-thinking SIDS: Many Deaths no Longer a Mystery.” These stories are archived at:

<http://video.pbs.org/video/1972939471>

<http://www.npr.org/2011/07/15/137859024/rethinking-sids-many-deaths-no-longer-a-mystery>

Update on the National Coalition to End Child Abuse Deaths

The Center is a founding member of the National Coalition to End Child Abuse Deaths. The Coalition was organized to bring greater national attention to child abuse deaths. The Coalition was organized after a 2009 National Summit convened by Michael Petite, the CEO of Every Child Matters. The Center supported Kim Day, formerly the CDR coordinator in Maine, as she worked to build the Coalition as part of her internship for her MSW program. Kim has since been hired full time as the Coalition Director. Tamara Tunie, who stars as Dr. Melinda Warner, the medical examiner on Law and Order Special Victims Unit, is the Coalition's celebrity spokesperson.

Last year, the Coalition asked Congress to do three things: hold hearings on maltreatment deaths, create a National Commission to further study the problem of fatal maltreatment and develop a national strategy to prevent future deaths. The good news is that the House Ways and Means Human Resources Subcommittee held a hearing July 12th, coinciding with the release of the Government Accountability Office (GAO) report on child maltreatment fatalities.



Teri Covington, Tamara Tunie, Michael Petite, Kay Brown-the GAO representative, Dr. Carole Jenny- a child abuse pediatrician from Rhode Island, and Jane McClure Burnstain- a child welfare policy analyst from Texas were invited to speak. Teri's comments focused on how the child death review process helps to better count and understand child deaths. She provided examples on how CDR led to prevention and policy changes in each of the 10 committee members' states. She asked for a National Commission, and provided further suggestions in writing including national CDR

legislation that could support many of the functions of CDR. A number of congressmen recognized the importance of CDR in fatal maltreatment. Congressman John Lewis (D, GA) stated that he has been in Congress for almost 25 years and attended many hearings, but "...this is one of the most painful. What some of you have said is almost unreal, unbelievable but I know it's real, I know it's believable...it's not something we should sweep under the rug. We should face it and face it head on."

You can view the hearing and read transcripts at <http://www.c-spanarchives.com/program/Malt>



Tamara Tunie with Anne Pedrick,
Delaware CDR Director



Founding Members of the Coalition at the White House Meeting

Christen Kryzowski, National District Attorney's Association; Kim Day, Every Child Matters Education Fund; Suzanna Tiapula, National District Attorney's Association; Teri Covington, NCRPCD; Teresa Huizer, National Children's Alliance; Joan Zlotnick, National Association of Social Workers

Following the hearing, the National Coalition to End Child Abuse Deaths met with staff from the President's Domestic Policy Office at the White House. We reiterated much of what was presented at the hearing and asked for President Obama's leadership in drawing nation attention to the more than 2,700 children who die from abuse every year.

Based on interest from both parties, we anticipate that a bill will be introduced in the U.S. Senate in October to establish a National Commission to further study and recommend national action to prevent child maltreatment fatalities.

The GAO Report on Maltreatment Fatalities

Dave Camp (R,MI), Chairman of the House Ways and Means Committee, commissioned a GAO study on the issues surrounding the reporting of fatal child maltreatment. Our center was a key informant to the GAO staff as they studied the problem and prepared their report. The GAO also made site visits and met with CDR staff in California, Michigan and Pennsylvania. Released in July, 2011, the report was titled CHILD MALTREATMENT: Strengthening National Data on Child Fatalities Could Aid in Prevention. Child Death Review was referenced many times in the report as an effective approach to understanding deaths. Some of the report's conclusions include:



Chairman Dave Camp, House Ways and Means Committee, and Chairman Geoff Davis, Ways and Means Human Resources Subcommittee, share the GAO Report with Tamara Tunie.

- More children have likely died from maltreatment than are reflected in the national estimate of 1,770 child fatalities for fiscal year 2009. According to our survey, child welfare officials in 28 states thought that the official number of child maltreatment fatalities in their state was probably or possibly an undercount. A major reason for the likely undercounting of child maltreatment fatalities is that nearly half of states report data to NCANDS only on children already known to CPS agencies.
- In addition to what is known nationally through NCANDS data, extensive information on the circumstances surrounding children's deaths from maltreatment is collected by the Child Death Review Case Reporting System, operated by the nongovernmental National Center for the Review and Prevention of Child Deaths (NCRPCD).
- Although NCRPCD regularly collaborates with federal organizations to analyze child fatality data and develop strategies to prevent child deaths, there has been little routine information sharing between NCRPCD and NCANDS on child maltreatment fatalities.
- Half of states (23) reported needing additional assistance in collecting information and reporting data on child maltreatment fatalities or near fatalities. For example, several states mentioned that assistance with multidisciplinary coordination could help them overcome difficulties.

The full report is published on our website: www.childdeathreview.org/

CAUSE: Coalition Against Unsafe Sleep Environments



The Coalition Against Unsafe Sleep Environments was launched this spring in an effort to bring together persons working with sleep related infant deaths programs, policies, and research as well as and consumers to support safe infant sleep initiatives.

More than 100 individuals and agencies have joined CAUSE. The coalition hopes to bring attention to sudden and unexpected infant deaths (SUID) and encourage the involvement of injury prevention professionals in addressing injury related sleep related deaths.

Founding members include Cribs for Kids, Safe Kids USA, the Northwest Infant Survival and SIDS Alliance, and our center. There is as yet no formal leadership structure for CAUSE. As membership grows, the plan is to develop a leadership committee and sections to focus on specific topics. Judy Rainey, the National Policy Director for Cribs for Kids, is managing the CAUSE listserv. CAUSE is an offshoot of PAUSE: Parents Against Unsafe Sleep Environments. PAUSE is comprised, in part, of parents who accidentally suffocated their infants and are now dedicated to preventing infant suffocations. They have a PAUSE Facebook page and an email group: safesleep@groups.facebook.com

To join CAUSE, go to: <http://fs16.formsite.com/sidspa/form7/index.html>

To participate on the CAUSE list serv:erv: infantsafesleep@listserve.com

The CDR Case Reporting System:

We now have 40 states enrolled or in the process of enrolling to be able to submit their CDR data into the NCDR Case Reporting system. Our latest additions include Arkansas, Florida, Louisiana, and Montana. As of August 15, we had almost 100,000 deaths reported into the database.

We received a surprise phone call this spring from a nationally renowned data systems company that works with NASA to design applications for NASA space flight, including the Space Shuttle. Vantage Systems, Inc. offered to rebuild our CDR National Case reporting system as a gift, with no cost to us. They have since been working on building new software that will include many new features and make the system more user friendly and stable. Vantage Systems heard about our need for new software from the National District Attorney's Association Center for the Prosecution of Child Abuse. Mary Ahan, a staff attorney there, spoke about our need for software improvements to her father, Mike Ahan, the VP of Vantage Systems Inc. The rest is history. A senior programmer at Vantage, Garth Ogle, is doing most of the programming. Garth's wife just gave birth to their first child, little Fritz.

We reported in our last newsletter that the Case Reporting System, while still a relatively new system, has caught the attention of a number of federal agencies, including the CDC, the Consumer Product Safety Commission, the National Highway Traffic Safety Administration, the National Transportation Safety Board, the GAO, and SAMHSA. We met with the Youth Team at NHTSA this past spring to further discuss partnerships and the use of our data to better understand child motor vehicle deaths. We are working with the CDC to link data on violent deaths in the NCDCRS system to those in the National Violent Death Reporting System (NVDRS) to determine how well each is collecting violent death data and offer improvements to states to fully identify and record all child violent deaths.

When we asked Mr. Ahan why his company was donating this extremely generous gift to us, he replied, "Children have no power or say in what happens to them. It is our responsibility and duty to protect them and use our knowledge and lessons learned from the previous child's death to prevent the repeat. Therefore, having a comprehensive and reliable database with a user friendly interface is essential to achieve this objective. We hope that by using our knowledge in developing highly reliable systems for NASA missions, we are able to develop such a system for your organization. If through our efforts we save just one child's life, we have recovered every penny we have invested in creating the system."

Healthy People 2020



Child death review once again has a place in the U.S. Healthy People Objectives for the next ten years. The objectives are designed to encourage collaboration across sectors, guide individuals toward making informed health decisions, and measure the impact of prevention activities. We have maintained our first objective from 2010, but decreased the outcome measure from 100% of external deaths reviewed to 90%. A new objective for SUID deaths was added.

The revised objective is:

Injury and Violence Prevention 4: Increase the number of States and the District of Columbia where 90 percent of deaths among children aged 17 years and under that are due to external causes are reviewed by a child fatality review team.

The new objective is:

Injury and Violence Prevention 5: Increase the number of States and the District of Columbia where 90 percent of sudden and unexpected deaths to infants are reviewed by a child fatality review team.

Using reviews completed in 2007, states are making progress towards reaching these goals. Fourteen states reported reviewing 100% of all external deaths, and six reviewed more than 80%. All states combined reviewed 57% of all external deaths in the U.S. in 2007. Fifteen states reviewed 100% of all their SUID deaths, 7 states more than 80% and combined all states reviewed 68% of all SUID deaths in the U.S.

The SUID Case Registry Partnership

Each year in the United States, approximately 4,500 infants die suddenly of no immediately obvious cause. These sudden and unexpected infant deaths, known as SUID, are often not fully investigated and, when they are, cause-of-death data and other data related to the events leading to the death are not collected and reported consistently. Many SUID deaths get classified as SIDS, suffocations or undetermined-even when the circumstances are identical.



Georgia's CDR program visits New Mexico's SUID/CDR

The CDC Center on Reproductive Health awarded grants to seven states to pilot the new SUID-CR over the next three years. We are working closely with the CDC, and states are using an expanded version of the CDR Case reporting system to report out on their SUID deaths. We conducted site visits to the funded states in partnership with the CDC this past year, and every state visited another. In late August, all states came to

Atlanta and met with national SUID experts. Early results from the registry are highly encouraging. All of the five states first funded have significantly improved the quality and completeness of data submitted through the case report and the percent of SUID deaths reviewed. Some states report almost no missing data on their SUID deaths. There should be an expansion of the project next year, so hopefully more states will be able to participate.

The Pilot SUID States

Colorado, Georgia, New Hampshire, Michigan, Minnesota, New Jersey, New Mexico

CDR on the Navajo Nation

The Navajo Nation is the largest community of American Indians. It is located in the four corner region of the Southwest U. S. The Nation is planning to pilot a CDR team. Currently teams in Arizona, Utah, Colorado and New Mexico review Navajo child deaths on local or state teams. Nancy Bill, the Injury Prevention Director at the U.S. Indian Health Service, has offered to support a half time position at the Navajo Health Department to coordinate the team. We have made site visits to Window Rock, Arizona, the government center of the Navajo Nation, to discuss the logistics of organizing a team. The Navajo Health Department is interested in expanding the review focus to vulnerable adults as well as children. This team will be the Dine' people reviewing Dine' deaths.

The Wind River Reservation, representing the Shoshone and Arapahoe People, is also interested in organizing a team.



Nancy Bill at the Navajo IHS Office



Sunset on the Navajo Nation



Window Rock, near the Navajo Seat of Government

Preventing Auto Backovers

Kids and Cars informed us that the National Highway Traffic Safety Administration is now requiring that automotive manufacturers eliminate the blind zones behind vehicles that cause at least 50 children to be backed-over by cars every week in the U.S., including two fatalities a week. It is believed that the announcement will lead to the installation of rearview cameras in cars manufactured in the U.S. Kids and Cars estimates that in 2012, 10% of all new vehicles will have rearview cameras, with 100% of all vehicles by 2014. This is one of the most significant improvements to transportation safety since seatbelts and airbags were required in vehicles.



On the Horizon

- The American Academy of Pediatrics will be holding a special session on child death review at their annual member meeting in Boston this Fall. Last year the AAP passed a resolution requiring the Academy to provide administrative support to encourage pediatrician involvement in CDR; and they also used a policy statement supporting and encouraging CDR among pediatricians. The Center will be distributing a special brochure on the role of pediatricians in CDR at the meeting, as well as providing refreshments. Dr. Eric Batra, the medical director of CDR in Pennsylvania, is the AAP representative to our national advisory board. Dr. Batra is giving a keynote address at the national meeting on sleep related deaths.
- Keep your eyes and ears out for the release of the new AAP guidelines on safe infant sleep. We anticipate it will be released at the Fall AAP meeting. We have heard that all recommendations will be closely tied to research demonstrating specific risks and protective factors for babies. These guidelines can really help legitimize your safe infant sleep messages.
- Our work plan with MCHB includes convening a meeting of leaders from other review processes, including FIMR, Domestic Violence, Citizens Review Panels, and others. We plan to hold this meeting in December. We would also like to invite states or communities that exemplify models for coordination. If you are one of these states or know of communities, please let us know. We also anticipate that the U.S. Administration on Children and Families will be convening a national meeting of representatives from every state's major review processes in 2012.

HAVE A SAFE FAR END OF SUMMER



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