

Minnesota Sudden Infant Death Center

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Newsletter
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Goodbye to Goodbye

By Darcie D. Sims Ph.D.

"I didn't get to say goodbye." As a therapist, I have listened to thousands of bereaved lament their last words spoken to loved ones, and so many of them wept in grief over not saying goodbye. So much grief has been spent on not saying a farewell. So much additional hurt has been felt because someone did not get to say goodbye.

Sermons have been preached, books and poetry written about saying goodbye. Pictures have been painted, tears caught in bronze and sculpted arms left empty in the lament of goodbye. Almost no one believes there might be a reason to say goodbye, today. Most days are simply ordinary ones, and there seems no special reason to say goodbye. Hardly anyone knows it will be the last day or the last time. Why do we spend so much time and grief over not saying goodbye? Why do we wash away the words we did get to say over a lifetime of loving someone with the single lament, "I didn't get to say goodbye?" Why are those words so important that the lack of them creates a lifetime of additional hurt and pain?

Ceremonies are created and designed for the bereaved to say goodbye. We stand in line for hours to express our sympathies to the bereaved and to say "goodbye" to the deceased. Even if we have not seen the deceased in years, it seems especially important to come at the time of death to say goodbye. Funeral directors, mental health professionals and most of the world seem to believe that it is necessary to say goodbye in order to begin the healing process.

Goodbye? Why would I want to say goodbye? I wasn't through saying hello!

Twenty-five years ago, I did get to say goodbye. I knew the end of our son's life was approaching, and I got the chance to give one last hug and say one last sentence. I got the chance to say goodbye and I didn't take it. In the last moments of my son's life, and years later, of my parent's lives, I did not say goodbye.

With the very last breath of my son's life, I simply said, "I LOVE YOU." I was able to be with my mom in her final hours and I did not say goodbye. I said, "I LOVE YOU." And although I was not with my dad when he died, the last words I shared with him as I left him home on what was to be his last night, I kissed him and said, "I LOVE YOU."

Let go of the hurt you are experiencing if you did not get to say goodbye. You would not have said it, even if you had had the chance! You would have said, "I LOVE YOU." Goodbye is simply too final, too harsh, too forever. Surely your loved one knew you loved him. Surely your loved one knew you cared. And even if you don't believe they knew, you can do something about that right now.

Go outside, find your special star, and with all your might, whisper, speak or yell out loud, "I LOVE YOU!" Trust me, the universe is listening and your words of love will travel far to reach the heart of those no longer within hug's reach. I guess you could yell goodbye, too, if you really want to...but why?

Why let the grief of not saying goodbye rob you of the memories of what you did get to say and how you lived your lives together? Why let not saying goodbye steal away the joy of knowing your loved one was in your life and still is a thread in your fabric, to be woven forever around your heart?

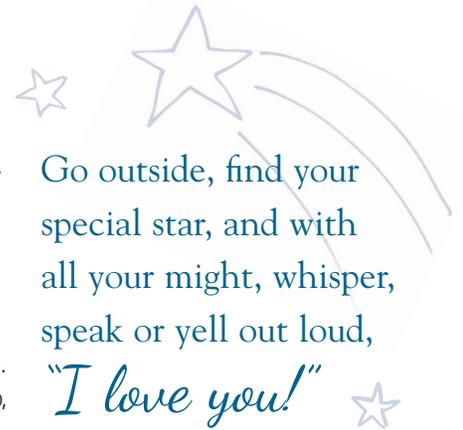
Goodbye? I'd rather live my life so that my last words are, "I LOVE YOU." We never know when an ordinary day will turn into a day that gets marked down in the family history as a not-so-ordinary day. But all of us can live our lives so we can leave with few regrets. Do not let the events of the past few years rob you of your hope, your passion, your joy in living. Let it become a lesson for all of us to live our lives as if there were only moments left, because that is all there really are anyway. Moments, just moments, one after another, each special and sacred in their own way, each waiting to be etched forever on our memory or lost in the sea of millions of other ordinary moments.

I learned so long ago that any moment can be the last one, so I no longer waste too many of my moments. Oh yes, there are days when I simply plod through the moments, not even aware of their passing. It often takes a cataclysmic event to shake me out of my reverie and reawaken me to the specialness of each moment.

Take advantage of the moments you have and spend them wisely. Spend them saying, "I LOVE YOU" instead of wishing you had said goodbye. Make a commitment to never let another moment pass without being aware of its passing.

Goodbye has always been a part of my life because I grew up military, married military and gave birth to military. My address changes more often than the weather. But I gave up saying goodbye long ago when I realized "I LOVE YOU" lasts far longer and feels so much better. Goodbye? I'm not through saying "HELLO" and "I LOVE YOU!"

Darcie Sims was a bereaved parent, psychotherapist and nationally known speaker and author. Darcie died in February 2014. She was a great friend to the MN SID Center over the years and a frequent speaker at past statewide annual parent meetings. Darcie spoke with great humor, empathy and compassion. Her sage advice was often "May love be what you remember the most"...



Around the Center

- **2013-2014 OVERVIEW:** In 2013 the Center received 67 referrals statewide. Thirty of these referrals were deaths attributed to SIDS (sudden infant death syndrome), SUID (sudden, unexpected infant death), undetermined or no anatomic cause. Thirty-seven referrals were sudden, unexpected deaths due to other causes, such as accidental asphyxia, suffocation, infection, etc. Compromised sleep environment was a risk factor in many of the deaths referred to the Center. Seven percent (7%) of the 2013 referrals occurred in licensed childcare. In 2014, 2% of referrals occurred in licensed child care or foster care. A dramatic improvement following the 2013 legislative changes in child care safe sleep regulations. Services were provided to approximately 115 families. Other activities included 2013 and 2014:

Distribution of information materials:.....	43,000
Education programs:.....	32
Media Interviews.....	10
Newsletter distribution:.....	3,500

SUPPORT: Metro area support group includes one meeting a month for parents, and special events through Children’s Hospitals and Clinics of Minnesota, such as handling the holidays, annual memorial service, Fall family day etc.

In December 2012 the **Ray Gregory Labat & Noah Joseph Rogers Funeral Assistance** fund was established through the generosity of parents Adam and Erin Labat in memory of son Ray Gregory and Jenna and Scott Rogers in memory of son Noah Joseph. Since that time others have contributed to this fund as well. The funeral assistance fund is made available to all families referred to the SID Center. From December 2012 to December 2014, 43 families have utilized this funeral assistance.

RESEARCH: Trend data continues to be gathered and shared with the Minnesota Department of Health to support infant mortality risk reduction public health efforts. This data informs public health messages about safe infant sleep practices at home and guides safe infant sleep regulations in child care settings.

PARTNERSHIPS: The Center works with many other agencies to promote care for bereaved families, to better understand causes of infant mortality and to develop strategies to reduce infant deaths. These partnerships include serving on the Minnesota Department

of Human Services (DHS) state child mortality review panel appointed by the Commissioner of Human Services, the advisory committee to Minnesota Department of Health’s (MDH) Pregnancy Risk Assessment and Monitoring System (PRAMS) funded by Centers for Disease Control (CDC) which collects data on maternal attitudes and experiences before, during, and shortly after pregnancy, the Hennepin County Safe Sleep Committee, the CDC funded SUID subcommittee led by MDH and DHS to better understand the complex causes of sudden unexpected infant death, Twin Cities Healthy Start, and the American Indian Community Action team, and the Minnesota Coroner’s and Medical Examiners Association.

- **Infant Mortality Reduction Plan for MN:** The MN SID Center is working with the MN Department of Health and others on a new statewide initiative to develop an infant mortality plan to reduce infant deaths. Several stakeholder meetings have been held to identify the priority areas. Recommendations were made to focus on health equity and address social determinants of health, reduce the rate of preterm birth, improve the rate of pregnancies that are planned, and reduce the rate of sudden unexpected infant death. A subcommittee to develop strategies to promote safe sleep is meeting regularly.

- **Death Investigation Guidelines:** The Minnesota Department of Health, the Minnesota Coroners’ and Medical Examiners’ Association, the Minnesota Bureau of Criminal Apprehension (BCA), and the MN SID Center came together to update the 2002 Minnesota death investigation guidelines to make them consistent with the Centers for Disease Control and Prevention’s (CDC) Sudden Unexplained Infant Death Investigation Reporting Forms (SUIDIRF). The SUIDIRF is a national effort to standardize death scene investigation across states and local jurisdictions. Such standardization will provide data that can help our understanding of causes and manner of infant deaths, guide communities to improve their responses, and ultimately inform preventive measures. The guidelines were implemented beginning September 2014. More information about the Minnesota SUIDIRF can be found on the BCA’s website under training and education.
- Although the newsletter is now printed and mailed only once a year, the Center’s website is updated regularly and is another source of information and links to resources. Check it out at www.childrensMN.org/sidcenter

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National Level Activities

FEDERAL LEGISLATION PASSES Stillbirth and SUID Prevention, Education and Awareness Act

The 2009 MN SID Center newsletter made readers aware of proposed federal legislation to address prevention of stillbirths and sudden unexpected infant deaths. The bill took many twists and turns but in 2014 the *Sudden Unexpected Death Data Enhancement and Awareness Act* was passed unanimously by both the House and Senate and signed into law by President Obama on December 18, 2014.

Specifically, the *Sudden Unexpected Death Data Enhancement and Awareness Act* will build upon existing activities at the Center for Disease Control and Prevention (CDC) to improve the quality and consistency of data collected during the death scene investigations and autopsies to better inform prevention and intervention efforts related to stillbirths, Sudden Unexpected Infant Deaths (SUID) and Sudden unexplained Death In Childhood (SUDC). This collaboration with the states to enhance current methods of data collection across existing surveillance systems will enable doctors and researchers to better track and prevent these deaths. In addition, the Act requires the Secretary of the Department of Health and Human Services (HHS) to disseminate information related to stillbirths, SUID and SUDC to educate the public, health care providers, and other stakeholders involved in investigating the deaths of infants and young children so that everyone is "on the same page."

20TH ANNIVERSARY – BACK TO SLEEP...SAFE TO SLEEP

This year marks the 20th anniversary of the National Institutes of Health (NIH) *Safe to Sleep* (formerly *Back to Sleep*) campaign. The *Safe to Sleep* campaign began in 1994 as a way to bring public attention to SIDS and to educate parents and caregivers on ways to reduce SIDS risk.

In 2012 NIH retooled *Back to Sleep* and launched the *Safe to Sleep* campaign. This national campaign expands the safe sleep message beyond back sleeping and addresses other sleep related causes of infant death such as accidental suffocation or asphyxia.

Before the campaign almost 5,000 babies died each year from SIDS. Since 1994 the overall U.S. SIDS rate has declined by 50%. More than 3 million *Safe to Sleep* campaign materials have been distributed nationwide and the rate of back sleeping among infants has increased by almost 300%.

Minnesota has witnessed similar improvements in the decline in infant deaths, the increase use of back sleeping and broad professional and public education. However more needs to be done. Promoting a safe sleep environment, breastfeeding, room sharing rather than bed sharing etc. will be key to reducing the numbers of infant deaths even further. In that knowledge, safe infant sleep is one priority of Minnesota's infant mortality reduction plan.

For more information about the *Safe to Sleep* campaign go to www.nichd.nih.gov/sts

A NEW FEDERAL INITIATIVE TO PROMOTE SAFE SLEEP

In November 2014, the National Action Partnership to Promote Safe Sleep (NAPPSS), a new initiative funded by the federal Maternal and Child Health Bureau (MCHB), convened an Expert Leadership Group to help guide the collaborative in making safe infant sleep the national norm. Safe sleep experts included professional and advocacy organizations, researchers, clinicians, as well as federal partners such as the Maternal Child Health Bureau, the National Institutes of Health *Safe to Sleep* campaign, and the Centers for Disease Control and Prevention.

Based on the belief that "safe sleep is everybody's business," NAPPSS is expanding the circle of traditional safe sleep champions beyond health and child care systems to engage new and diverse partners that touch the daily lives of families in many ways, from faith and business communities to media outlets. The Expert Leadership Group will advise this coalition of more than 50 members, helping them to envision and implement a National Action Plan and specific action steps to reduce sleep-related infant deaths throughout the nation.

Guiding this work is a core value and strategy voiced at an MCHB Research Roundtable by Rachel Moon, M.D., chair of the American Academy of Pediatrics' Task Force on SIDS and an advisory NAPPSS partner: "To adequately reduce sleep-related deaths. . . [we] need to have a conversation with parents, not just give them a list of what to do and what not to do." Developing effective ways to build trust and respect with parents and caregivers, by sensitively listening to their concerns and challenges, and working together toward possible solutions, is the heart of this new National Action Partnership.

For updates on infant safe sleep and NAPPSS visit www.nappss.org

Product Recalls

The Consumer Product Safety Commission (CPSC) recently issued a recall on an Ikea VYSSA crib mattress due to an entrapment hazard. This product was sold in stores nationwide and on line from August 2010 to May 2014. IKEA will replace the mattress or refund the purchase price. For more details call Ikea at (888) 966-4532 or go online www.ikeas-usa.com and click on the recall link.

When buying and using products safety comes first. The CPSC monitors the safety of thousands of products and issues hundreds of recall alerts each year. Anyone can sign up to receive alerts by going to www.cpsc.gov/en/Newsroom/Subscribe/ and choosing the specific type of recall alerts you would like to receive, i.e. "infant and children's products." A new option is using the recall alert app designed for your android phone. Go to the "Market" on your android phone and search for Recalls.gov to download the app. Recalls for products you see at your child's daycare center or a yard sale can be found easily by using the "Search" button.

... Your child still is a thread
in your fabric...woven forever
around your heart...

Thank You

The Minnesota SID Center is honored to be the beneficiary of family and community fundraising events and philanthropic giving. Fundraising events such as these enable the Center to continue its work to support families, educate communities, and participate in research.

A special thank you to all those who organized them as well as to those who donated or participated in them for your generosity, dedication, and support!

- To the second annual **Willmar Lakes Area Biking for Babies** event and the Willmar Lakes Area Convention and Visitors Bureau for donating \$450 proceeds to the MN SID Center. Held in August 2014, this family event included a community picnic and bike ride on the Glacial Lakes State Trail and the scenic trail around Green Lake. Watch for the 2015 bike event scheduled for August 16.



*The butterfly lights
beside us like a sunbeam...
and for a brief moment
its glory and beauty
belong to the world,
but then it flies on again,
and although we wish
it could have stayed,
we are so thankful
to have seen it at all...*

author unknown

- To Jenna and Scott Rogers for donating a portion of the proceeds from the **Fourth Annual Noah's Memorial Golf Classic** held at Medina Golf and Country Club in July 2014. This event in memory of son **Noah Joseph Rogers** contributed \$12,000 to the Ray Gregory Labat & Noah Joseph Rogers funeral fund of the MN SID Center. The 2015 event will be held on June 29. Check it out at www.noahsmemorialclassic.org
- To parents Erin and Adam Labat, aunt Abbie DeYoung, family and friends for donating \$16,500 proceeds from the third and fourth annual **Ray's Run** held at Rice Lake Park in Maple Grove in September 2013 & 2014. This 5K run/walk was held in memory of son Ray Gregory Labat and helped establish the Center's Ray Gregory Labat & Noah Joseph Rogers funeral fund. For more on **Ray's Run** story go to www.raysrun.org

*Nothing you say
will remind me
of my grief,
so share the memories,
speak their names,
ask me about them—
do everything you can
to remind me that
you have not forgotten*

author unknown

Not Guilt...Regret

By Kitty Saunders

One of our basic responsibilities as parents is to keep our children from harm. So when anything happens to them, we feel guilty whether we could have realistically done anything or not. When the ultimate tragedy occurs, we are devastated. How could we let it happen? Why didn't we stop it? If we have compounded our guilt with any degree of human error of commission or omission, we are beyond devastation. Even words, either of anger or left unspoken, haunt us.

Guilt implies intent. If we intended to harm our child, we can feel guilty of that. If we never intended harm to ever, ever come to our child, the correct name for our emotion is regret. The crushing pain is still there, but regret is softer, gentler, less judgmental and easier to forgive and to heal. It is also more accurate. If that name doesn't feel strong enough for our feelings, it will in time. Let it float there and try it now and then.

Not guilt...we feel regret...

*Reprinted from [Compassionate Friends](#) newsletter
South Central Minnesota Chapter, New Ulm*

2015 Newsletter Submissions – We welcome letters, poems and pictures from parents, grandparents, relatives, childcare providers and friends. Because of space limitations, we must sometimes edit these submissions. The editors attempt to give as many parents as possible the opportunity to share memories of their children.

Consider a Donation!

Donations are an important part of our support. They allow us to reach out to newly bereaved parents, provide literature to families, relatives and professionals, print the newsletter, sponsor parent support groups, conduct educational programs and participate in research. Please consider a gift to the Minnesota SID Center in your annual charitable giving. As a non-profit organization, we rely heavily on the generosity of our friends. To make a donation, you can complete this form and return to the Center, go online to donate at www.childrens.MN.org/sidcenter, or call us to request a donor envelope.

Thank you.

___\$500 ___\$100 ___\$50 ___\$25 _____Other

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