

Minnesota Sudden Infant Death Center

IN THIS ISSUE

- Around the Center – p. 2
- National Activities – p. 3
- Lodge Opportunity – p. 4
- Donations – p. 5-6

Newsletter
Volume 35
Spring 2016

Children's Minnesota | 2525 Chicago Ave. S. | Minneapolis, MN 55404 | 612.813.6285 | 1.800.732.3812

Spring Fever

By Susan Arlen, MD

Spring: Tender green buds sprout, baby birds and other animal young greet the world, the air is warm and fresh. The clear, blue daylight sky lasts until early evening giving way to soft, clear nights. There is new growth, rebirth.

When we were untouched by grief and sorrow, spring was joyfully anticipated. It was a time of freedom from bulky coats, cold weather and short dark days – a time when everything seemed possible. Children laughed as they played outdoors and pungent barbecue aromas wafted through the air mixed with the odor of freshly turned earth.

Spring symbolizes youth, hope, and the possibilities that emerge after a long, dark winter. Young mothers hold the hands of their children and lovingly guide them through the wonders and discoveries of the new season. Middle-aged children hold the withered hand of an aged parent and delight in the opportunity to once again savor this beautiful season.

Spring is a gateway to the future. Animals and vegetation bear the young that will perpetuate their species. Graduation is the symbolic end of childhood and the commencement of the path to adulthood.

Spring is the poignant frail loveliness of a time that almost is too beautiful and full of hope. It is that period of perfection that exists for only a fraction of time in the context of each year – or in an entire lifetime.

Fortunate are those individuals for whom the experience of that perfection still exists! For the bereaved, painful memories that can wound will have to suffice until new opportunities are found to add beauty and perfection to their precious store of beautiful times.

Permit yourself to remember what was your pleasure; though its absence brings you pain. It and its memory, are a part of you and your precious treasure trove of life experiences. To deny yourself these sacred memories is to deny a part of yourself.

Only by remembering what was, and by experiencing the pain of what is, can the bereaved begin to permit themselves to look forward again. No, it will never be the same. It will never be as perfect as in memory; it will be different. Your world now is different – not better, nor worse, but different.

You may feel pain when you see parents hand in hand with their children; but you know that the source of your pain was once your greatest pleasure. To hurt, to yearn, to long for and to miss means that you have indeed loved very, very deeply.

Love and memories never die. They are now a part of you, as they will be forever. You eventually will begin to realize that you can feel joy again and you can anticipate again. It is not disloyal to your loved one's memory, and new joys will not erase your treasured memories.

The absence of pain can mean either allowing yourself to experience joy again or numbing yourself of feelings. Permit yourself happy feelings even though they may be tiny and fleeting at first. Don't you deserve some joy and happiness now?

You must begin to look at the world again through your new glasses, the ones without the rose-colored lenses. You must permit yourself to search out small and quiet sources of pleasure at first. Should you be denied the scent of lilac or the sight of clear, blue sky, or the sound or feel of a breeze against your skin? This may not be the spring of your life, but it is spring.

You are different now. It is time for you to awaken from the icy tentacles of despair that gripped your heart and soul, and kept them hibernating from the world. It is time to thaw; but when you do, you will not melt and fade away. You may feel strange at first, then almost without realizing it, you will begin to feel warm again.

Is that a robin I hear? Good spring, dear reader.

This article is reprinted with permission from Bereavement Magazine, March/April 1992, Bereavement Publishing, Inc., 5125 North Union Blvd., Suite #4, Colorado Springs, CO 80918.

Permit yourself to remember what was your pleasure; though its absence brings you pain. It...is a part of you and your precious treasure trove of life experiences.



Around the Center

- **2015 OVERVIEW:** In 2015 the Center received 66 referrals statewide. Twenty five of these referrals were deaths attributed to SIDS (sudden infant death syndrome), SUID (sudden, unexplained infant death), undetermined or no anatomic cause. Forty-one 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. Four percent (4%) of the 2015 referrals occurred in licensed childcare. Services were provided to approximately 115 families.

Other activities included in 2015:

Distribution of information materials:	16,000
Education programs:	15
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 June 2016, 88 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. Center staff are members of mortality review team as part of the MN Department of Health CDC funded SUID case registry described on page 3.

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.

In 2015 a partnership with the Minnesota Hospital Association resulted in standards about teaching and modeling safe sleep practices in hospitals being added to the Minnesota Hospital Association’s Perinatal Patient Safety Roadmap, an evidenced based recommendations/standards for Minnesota hospital practice and policy.

EDUCATION: Reaching out to health care providers, social service agencies, community groups, parents, caregivers etc. about safe sleep and supporting bereaved parents has always been an important component of the Center’s work. This includes a broad array of presentations at state wide meetings, community baby showers, or through media i.e. radio, TV, press releases and Twitter. Highlights of the 2015 presentations were: the Faith Nurse Network statewide meeting, St Louis County public health agency, Solid Ground Transitional Housing for families, MN Department of Human Services staff, Southside Community Health Workers, American Indian Family Center, several statewide webinars for the Minnesota Hospital Association and two radio conversations on KMOJ FM.

- 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. The website has recently been redesigned. Check it out at www.childrensMN.org/sidcenter

Check out SID
Center website
www.childrensMN.org/sidcenter

Want to share the newsletter? It’s also available electronically on our website. With the newsletter being published once a year, we will be relying more heavily on our website to share information and updates with you. Check it out at www.childrensMN.org/sidcenter

Sudden Unexpected Infant Death Case Registry

By Naomi Thyden, Epidemiologist,
Minnesota Department of Health

In 2010 the Minnesota Department of Health (MDH) Division of Injury and Violence Prevention was awarded a Centers for Disease Control and Prevention (CDC) grant making Minnesota one of eleven states to participate in a national pilot to develop a sudden unexpected infant death (SUID) case registry. In 2014 the grant was expanded to include infants through adolescents to create the sudden death in the young (SDY) case registry. The purpose of the registry is to create a state level system to categorize SUID/SDY standard definitions, monitor the incidence and types of SUID and SDY that occur, describe and understand risk factors, etc. and ultimately improve systems of care for families.

MDH and the Minnesota Department of Human Services (DHS) partner with the CDC to gather information about sudden deaths of infants and children in Minnesota. Together they work with medical examiners, police departments, hospitals, clinics and others to collect and analyze this information which is then used to guide programs and potentially save lives.

MDH, in partnership with CDC, also works with families who have experienced the sudden death of a child to collect DNA for purposes of research and genetic testing. Some families may be contacted by MDH and invited to participate in this research part of the Sudden Death in the Young Case Registry. Participation is completely voluntary.

More detailed information about the work of the Minnesota case registry and sudden unexpected infant deaths (SUIDs) in Minnesota will be published in an article in the July/August 2016 edition of Minnesota Medicine. To read the article go to www.mnmed.org/news-and-publications/mn-medicine-magazine

More information about the Sudden Unexpected Infant Death (SUID) Case Registry can be found at: www.cdc.gov/sids/caseregistry.htm

For information on the Sudden Death in the Young (SDY) Case Registry go to: cdc.gov and search for "sudden death in young".

Infant Safe Sleep Week November 2015

Press Release, Minnesota Department of Health

To draw attention to the importance of having a baby in a safe sleep environment, Governor Dayton proclaimed November 1-7, 2015 safe infant sleep week in Minnesota. Minnesota's Departments of Health (MDH) and Human Services (DHS) are calling for no co-sleeping with infants and for Minnesota infants to sleep without blankets and pillows as data mounts that unsafe sleep environments account for nearly all unexpected infant deaths in Minnesota.

A Minnesota Department of Health analysis of sudden unexpected infant deaths (SUID) in 2014 found that of the 56 babies who died suddenly and unexpectedly, 52 were in an unsafe sleep environment. About half of the babies were sharing a sleep surface, such as a bed, sofa or recliner with another person. The other half were in an unsafe sleep position, such as being placed on their side or tummy, had loose objects around them such as pillows or blankets, or were not placed on a firm surface such as a crib mattress.

Parents, families, hospitals and child care providers can help reduce the risk of sleep related infant deaths by following safe sleep practices... "Data has clarified our message to parents and improved our understanding of what babies need to sleep safely," said Health Commissioner Dr. Ed Ehlinger. "We can save dozens of infants a year by supporting communities, retailers, parents, grandparents and caregivers in their efforts to have infants sleep alone, on their backs, in safety approved cribs free of pillows and blankets.

To decrease risk of suffocation, dress babies for the temperature and do not cover them with a blanket. Soft items such as blankets, pillows, crib bumpers, and toys in the crib pose a hazard. It is also important for the infant to sleep separately from other sleeping children and adults since research has found that this is hazardous. A safe sleeping environment during naptime is just as important as it is during the night time sleeping. Beds and other places such as a couch or recliner can be dangerous for infants.

"These prevention measures save lives. Since we've increased training in safe sleep practices for child care providers, Minnesota has seen a dramatic decrease in infant deaths in licensed child care," said DHS Inspector General Jerry Kerber. "In 2013, the number fell to three infant deaths in family child care and in 2014 there was one infant death – which is still too many."

Everyone who cares for babies can engage in safe sleep practices by placing infants on their backs in a safety approved crib free of blankets, pillows, bumpers and stuffed toys, in a smoke-free environment. For more information, visit the MDH safe sleep web page.

2017 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.

Faith's Lodge Opportunity – October 2016

Faith's Lodge, a retreat center in Danbury, Wisconsin, is sponsoring a no cost weekend for families who have experienced the sudden death of a baby from any cause. This special weekend will be held from Thursday October 27, 2016 through Sunday October 30, 2016.

Programming details include such things as facilitated group discussions with a licensed grief therapist, chair massage, yoga mindfulness and heart stone memorials. Participants are welcome to join as many or as few program activities as they would like.

Set in tranquil woods, Faith's Lodge is located in northwestern Wisconsin near the town of Webster, less than two hours from Minneapolis/St. Paul metro area and

less than one hour from Duluth. Founded in 2007 by bereaved parents Mark and Susan Lacek, Faith's Lodge mission is to support parents and families coping with the death or medically complex condition of a child by providing a peaceful environment to reflect on the past, renew strength for the present, and build hope for the future.

This no cost weekend is sponsored through the generosity of Williams Wings Foundation (www.williamswings.org) in memory of William Douglas Luecke.

For more information or to register, contact Faith's Lodge at www.faithslodge.org, by email at info@faithslodge.org or call **715.866.8200**.



Butterflies Make Me Happy

By Lynn Vines

Sometimes in our grief, we truly believe we are going crazy. We hurt so bad we do not think we can manage to go on living without our precious child here with us. Part of the grieving process is learning how to do just that. Some parents need the reassurance that their child is okay. I think the human mind can only take so much pain and jumps at the chance to see signs from their children, reassuring them that they are okay.

The way I look at it, if you get comfort from a dream or a sign...enjoy it. You have suffered enough, and if believing in signs, butterflies, dreams or whatever else gives you comfort and hurts no one else, it is your right as a bereaved person. Are these signs real, or just in my imagination? Can I prove they are messages from my son, Eric? Does it even need to be proven? No, I cannot scientifically prove it. But I know that dreams, butterflies, signs and enjoyment in nature makes me feel closer to my son and therefore I will continue to enjoy them. It hurts no one, I

am not obsessive about it and anyone who chooses to think I am nuts for believing in such things, can think I am nuts.

We have all heard how the butterfly is a symbol of rebirth. Whether it is our child moving from this world onto a higher plane, or a bereaved parent emerging from the cocoon of grief into a world without our child here with us, butterflies are a comfort for many. When I am missing my son and see a butterfly flittering from flower to flower, I smile and feel better. When I am in a happy mood and see a butterfly, I enjoy the beauty of such a delicate creature. Taking the time to slow down and watch such a fragile creature going about its business is calming and I do not think anyone should discount the benefits from having a calming moment.

About four months after Eric died, I had a dream about him. I woke myself up from tears of joy running down my face. I knew he was okay...what a relief that was. I still

The Heart Remembers



Even if the mind sometimes forgets details and colors

Or dates and places...the heart has an unfailing memory.

So, it is safe to go on thinking about other things, to let your mind have thoughts which do not include your dead child...

Though life does go on, and the times come when your world spins for hours and days without the grieving memory...

Your love is safe... because the heart remembers always...

Sasha Wagner

hurt terribly and missed him more than I thought I could endure, but I felt comforted by the dream. Some could say it was my subconscious trying to sort things out, but I choose to believe it was his way of trying to comfort me. Either way, it made me feel better. Maybe it is because bereaved parents walk around in such a fog and function on automatic pilot that we are moving slow enough to notice the signs that are around us. Maybe dreams are one way for us to accept messages we need to hear and take into our hearts without logically trying to interpret them. Maybe faith is what we rely on when nothing else makes sense and we instinctively know we need something to hold on to. Whatever it is, just give me a second helping, I like feeling closer to my son!

Lynn Vines, The Compassionate Friends, South Bay/Los Angeles, CA. In memory of son, Eric. Reprinted from newsletter of The Compassionate Friends of Carson City.