

## THE LEGACY OF INFANT LOSS

By Karen M. Bullock

Upon the loss of a child, there is no mark that distinguishes you as a bereaved parent. Other than a few meaningful pieces of jewelry that I wear occasionally (usually to the infant death conference, memorial services or on an anniversary), I think I look pretty much like every one else. I suppose that is a blessing and a curse at the same time because so much of my heart is wrapped up in the fact that I am a bereaved parent – three times, in fact. Six years ago, we lost twin daughters – Gabrielle was stillborn and Katherine died at ten months. Two years later, we lost baby Anastasia when she was 6 weeks old.

The loss of an infant is unique in so many ways – as parents, they were literally a part of us. But mostly, we may have been the only ones who knew them. On one hand, you only had them for a short while, but there is the unimaginable loss of what they might have become. How would they have impacted your family? Would you have gotten along as they grew older? Can you ever be “normal” again?

Some people feel they have been plagued throughout their lives with the deaths of loved ones. I have attended many funerals of family members and friends, yet I do not feel this way. I have a large family and I guess that I am statistically more likely to have more losses. In the article “Kathleen Kennedy Townsend Looks Beyond Tragedy,” published in *Reader’s Digest* ([www.rd.com](http://www.rd.com)), Townsend talked about the many losses suffered by her family over the years.

While few of us have had to deal with death in such a public way, many of us do have a network of family and friends who truly care and want only the best for us. I thought there were some lessons to be considered even though her losses were not babies.

Her grandfather, Joseph Kennedy, wrote to a friend who lost a son, “I cannot share your grief, because no one could

*continued on Page 2*

IN THIS EDITION

**Personal viewpoint**  
Pages 1-2, 7

**Research review**  
Page 3

**Spring conference**  
Pages 4-5

**Center & satellite  
summary**  
Page 6

**Donors**  
Page 6

**Memorials**  
Page 7

**New arrivals**  
Page 8

## The Legacy of Infant Loss *continued from Page 1*

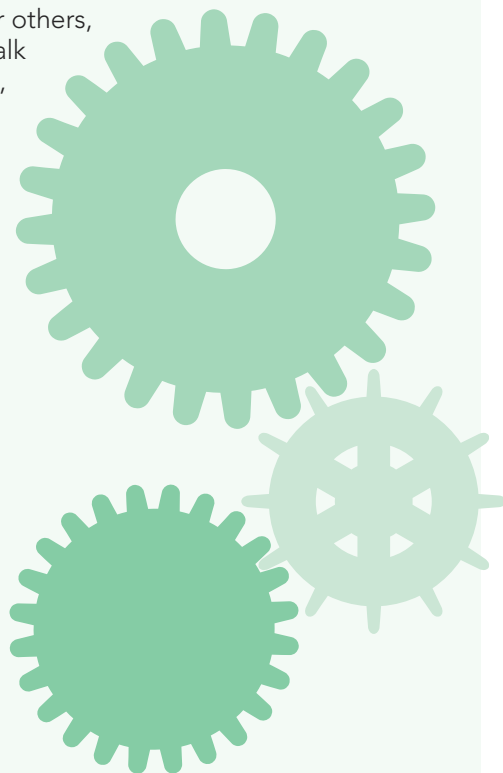
share mine." After the loss of Gabrielle, I desperately wanted to find someone who had the exact same scenario as mine. While our similarities may draw us to one another, giving us common ground and the ability to support and encourage one another through difficult times, the truth is that no one has had exactly the same experience as me. We all are different and so are our babies. This could never happen to another person in the same way it happened to you.

In that same letter, he wrote, "When one of your children goes out of your life, you think of what he might have done with a few more years and you wonder what you are going to do with the rest of yours." I have pondered, what is going to happen when I grow older? What if I don't have somewhere to go for a holiday when I am old?

There are many ways you might fill the time you have left. I have found in my life that there are definitely choices you will make in answering this question. I suppose you could try to forget what happened. You could become angry and bitter. Or you could do what many others, including the Kennedys, have attempted – to turn outward.

We always will honor and cherish our children, but at the same time, "We must live for those who are still with us." It is important to me that my children are not forgotten. I have done things that I enjoy and appreciate doing to help others in their memory, which is a good example to my two surviving children, Elizabeth and Zane, who, along with my husband, usually are involved, too.

There are so many things we can do for others, which may give us the opportunity to talk with others about our beloved children, if we want to. You don't need to specifically help the grief community, and you don't need to spend a bunch of money either. There are lots of places that welcome volunteers. When you look to fill someone else's need, somehow you also fill your own. Do not allow "bereaved parent" to define who you are. In living a good, happy, satisfied life, your child's legacy lives on - and so does yours. ↩



## RANDOM THOUGHTS *By Cecelia T. Perciballi-Clayton*

Do you know what you have taught me? Do you know what I have learned? Do you know how you have changed me? Do you know how I go on?

There are incredible voids in life. There comes an overwhelming sadness. There are the tremendous gifts of love and sharing. There are the deepest pains of loss and suffering.

I have learned that I see more with an open heart than with open eyes, and it is when I feel like I have hit the bottom that I find the roots and foundations that hold me together. When it looks like I have gone nowhere, I find myself in unknown territory. When I am too tired to go further, somehow I am guided to a new beginning, and the distance between the flames of a bonfire and the stars that dance among the pine trees is nothing.

The God I thought I knew is not the one whom I have come to know. More can be accomplished in remaining still than in all the movement I might try. A moment can seem an eternity, and a lifetime is never long enough.

Love does more than endure, love becomes the strength that keeps some alive. I can love beyond the physical and feel comforted by love that is no longer spoken. I hear clearly words that are unspoken and I am guided by wisdom from beyond. When I think I am ready, I find that I have more to learn.

*continued on Page 7*

## | RESEARCH REVIEW

### COVER, BUT DON'T SMOTHER

*By Jason Jarzembowski, MD, PhD – Dr. Jarzembowski is a pediatric pathologist at Children's Hospital of Wisconsin, an assistant professor of Pathology at the Medical College of Wisconsin and serves as the medical advisor to the Infant Death Center of Wisconsin.*

## JASON JARZEMBOWSKI, MD, PHD

Winter in Wisconsin ushers in both activities and risks unique to the season. As we struggle to keep ourselves and our children warm and safe from the elements, we must use caution not to create new hazards. One practice recently called into question is using blankets to completely cover infants in car seats or carriers, often for prolonged periods of time. Is this safe?

No studies addressing this exact situation have been published. However, investigations focused on head-covering of sleeping babies in cribs seem most relevant. A recent report (Mitchell EA, et al. *Pediatrics* 2008;121) included summary data from infant death registries in Germany and New Zealand, 726 cases in all. In their study groups, between 15 and 28 percent of infants who died from sudden infant death syndrome were found with their heads covered, and these children were more likely to be older (older than 26 weeks) and very sweaty. However, other surveys have found that about 30 percent of all infants will, at least once in their lives, be found in bed with their heads covered. So, while head covering usually is a benign event, it might be associated with an increased risk for SIDS. How can we tell?

Supporting a possible association between head covering and SIDS are several facts and physiologic plausibility. Investigators have calculated anywhere from a 3- to 108-fold increased risk of SIDS when infants experienced head covering (summarized in a recent meta-analysis: Blair, et al. *Arch Dis Child* 2008;93). Some studies report an increased incidence of SIDS during the winter in northern areas – times when babies

are more likely to be bundled up in extra layers while sleeping. Younger mothers and socioeconomically disadvantaged mothers – two population groups with higher rates of SIDS – are more likely to heavily cover their infants according to surveys. Finally, researchers have performed measurements within the enclosed spaces under blanket-draped infants' heads and shown that both temperature and carbon dioxide levels substantially increase. This would tie in well with prevailing theories that SIDS is typically the result of a stressful event (such as impaired breathing due to positioning or insufficient air exchange, temperature, subclinical illness, etc.) occurring in a predisposed infant.

Nonetheless, the argument is not so clear-cut. Some researchers hypothesize that head-covering is an agonal event, occurring during the end-of-life struggle, and therefore a result, not a cause, of SIDS. (Hence, they argue, the reason older children, who are stronger and more mobile, more often end up covered.) Unfortunately, many studies have collected relatively small numbers of SIDS cases, only a fraction of which are associated with head-covering. Also, it is difficult to correctly determine the rate at which head covering occurs in the overall population because investigators often only have access to death registries and informal surveys which may grossly underestimate the true incidence of these events. And, finally, practices and habits may vary greatly between different ethnic groups and populations, so the results of any given study may or may not be applicable to a particular community.

These intriguing findings pertain to

cribs – but what about car seats and carriers? Because no formal studies have been performed to address these particular scenarios, the exact risks (if any) are unknown. Until such data is available, infants in car seats or carriers should never be completely covered; their faces should be left showing by leaving any covers or blankets partially open or down, or using a face hole designed for this purpose. The risks of limited exposure to the elements are likely outweighed by the risks of suffocation or related injury.

Hence: cover, but don't smother. Although infants are, indeed, more susceptible to the cold, they do have some inherent protective mechanisms (like brown or "baby" fat) and short exposures are unlikely to do any harm, especially with appropriate clothing. One oft-used rule-of-thumb is to dress children in just one more layer than you yourself would wear under the circumstances.

A few words of final seasonal caution: wintry weather often causes slippery, dangerous roads with a higher incidence of accidents making proper car seat and belt use even more important. Monitor the weather and road conditions before hitting the road. Keep a blanket, charged cell phone and extra food/formula in your car for emergencies. Never leave a child unattended in a running car, not even while warming up a cold vehicle or while running a quick errand. With a few simple precautions and forethought, we can help keep our children – and ourselves – safe during the long, cold Wisconsin winters. ↩



## | THE 2009 SPRING FAMILY BEREAVEMENT CONFERENCE

### YOU ARE NOT ALONE

The 2009 Spring Family Bereavement Conference, **YOU ARE NOT ALONE**, will be held Friday, April 24, through Saturday, April 25, at the Holiday Inn West in Madison, Wis.

A committee of parents from throughout the state is planning the annual family bereavement conference. This year's conference includes:

- Keynote speaker Sherokee Ilse, a bereaved parent.
- A chance to meet other families who are dealing with similar situations.
- A memorial program.
- Breakout sessions providing an open forum for discussions.
- A program for adolescents (ages 10 and older) to share their grief, if they choose.
- An opportunity to take some quiet time to reflect, release stress and rejuvenate.
- On-site child care.
- Reduced room rates of \$70 at the Holiday Inn West, Madison.

**NOTE:** To get the reduced room rate, please book your room by Friday, April 10, and indicate you are attending the Infant Death Center conference. Rates double after April 10.

### MISSION

The conference is intended to help families develop the skills to integrate the death of their infant into their lives and increase their coping skills. A number of alternatives are available to assist individuals and families with networking and developing their coping skills. We encourage you to take a break, take time for yourself to think, release stress or just relax.

### ABOUT THE SPEAKER

Sherokee Ilse is a bereaved mother and an international speaker and author on pregnancy and infant loss. She has spoken at international and national conferences, meetings and support groups. Ilse combines her psychology, sociology and teaching degrees with her personal experiences to promote compassionate care for bereaved families.

### COST

Adults - \$15 each  
Children - \$5 each

Fee includes continental breakfast, lunch, conference materials and child care.

### INFORMATION

If you have not received an invitation, please use the form on Page 5 to begin the registration process or go to [www.idcw.org](http://www.idcw.org) to download an invitation.

# AGENDA

## The 2009 Spring Family Bereavement Conference: **YOU ARE NOT ALONE**

### FRIDAY, APRIL 24

7 p.m. to 8:30 p.m. Registration

### SATURDAY, APRIL 25

8:30 a.m. Registration

8:55 a.m. Introduction

9 a.m. Keynote speaker, Sherokee Ilse

10 a.m. Break

10:15 a.m. Breakout sessions

- Men's grief.
- Women's grief.
- Parenting after loss.

11:45 a.m. Lunch

12:45 p.m. Memorial program

1:30 p.m. Break

1:45 p.m. Breakout sessions

- Coping and stress management.
- Giving meaning to your child's life.
- Book club.
- Dealing with expectations in the first year after loss.

3:30 p.m. Closing comments

Breakout session topics are subject to change.

I would like to register for the conference:

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ ZIP \_\_\_\_\_

Number of adults attending \_\_\_\_\_

Number of children \_\_\_\_\_

I will be using child care  yes  no

### RETURN TO

Infant Death Center of Wisconsin  
MS C630A  
PO Box 1997  
Milwaukee, WI 53201-1997

## WHAT PARENTS HAVE SAID ABOUT THE CONFERENCE

*"There were people whose losses were recent and some whose losses had occurred years ago. There is no right path through grief. It really helped us get grounded, knowing that we were in the realm of 'normal' and that our emotions are OK. It helps to talk with others about issues we all have in common."*



*"It has given us the opportunity to share our experiences and to listen to others without being judged. We laughed and cried, but most of all we remembered. Remembering is what we have to do when all we have is memories."*



*"You can choose to discuss your feelings or just listen. You will discover different ways to communicate your grief and to memorialize your child. Tears will be shed and various emotions will emerge, and you will leave the conference feeling that someday the sun will shine again."*

**DECEMBER 2008 THROUGH APRIL 2009**

**EDUCATIONAL PROGRAMS**

Jan. 23 - Prenatal Care Coordinators, Milwaukee  
 Jan. 29 - Child Death Review Training, Appleton, Wis.

**INFORMATIONAL EXHIBITS**

Jan. 5-6 - Wisconsin Coroners Association Conference Display in Partnership with State Child Death Review, Wausau, Wis.  
 Feb. 7 - Wisconsin Family Child Care Association Conference Display, Chippewa Falls, Wis.  
 March 12 - UW-Extension, Fulfilling the Promise Conference, Wisconsin Dells, Wis.  
 April 3-5 - Hmong National Conference, Appleton, Wis.

**VIEWINGS OF "UNNATURAL CAUSES"**

Feb. 2 - Infant Mortality Coalition of Beloit, town hall meeting, Beloit, Wis.  
 Feb. 7 - Gateway Technical College, Racine, Wis.  
 Feb. 17 - Martin Luther King, Jr. Community Center, Racine, Wis.  
 Feb. 22 - Waymen AME Church, Racine, Wis.

**INITIATIVES INFANT DEATH CENTER OF WISCONSIN IS COLLABORATING WITH AT THIS TIME:**

Association of SIDS and Infant Mortality Program Professionals  
 Beloit African American Infant Mortality Coalition  
 Black Health Coalition of Kenosha  
 Black Health Coalition of Wisconsin  
 Center for Grieving Children  
 Central Wisconsin NICU Transitions Committee  
 Children's Service Society of Wisconsin  
 Cribs programs in Barron County, Bayfield County, Kenosha County  
 Lincoln County, Marathon County, Milwaukee County and Taylor County, and the cities of Neenah and Racine  
 Concordia Metcalfe Community Health Improvement Project  
 Dane County Child Fatality Review Team  
 Fetal Concerns Program, Children's Hospital of Wisconsin  
 Fetal Infant Mortality Healthcare Action Team  
 Great Lakes Intertribal Council Honoring our Children Project  
 Healthy Babies in Wisconsin Steering Committee and Regional Action Teams  
 Healthy Infant and Child Alliance Team Meetings  
 Healthy Native Babies Consortium ( Menominee, Stockbridge-Munsee and Ho-Chunk Nations)  
 Marathon County Child Fatality Review Team  
 Marathon County Start Right Program  
 Madison Health Department/Prenatal Care Coordination  
 Marathon County Healthy Babies  
 March of Dimes  
 The Medical College of Wisconsin  
 Children's Hospital of Wisconsin  
 Milwaukee County Child Fatality Review Team  
 Milwaukee Fetal Infant Mortality Review Project  
 Milwaukee Healthy Beginnings  
 Northeast Wisconsin Technical College  
 Northern Wisconsin NICU Transitions Planning Committee  
 Outagamie Death Review Team meetings  
 Racine County Death Review Team  
 Racine Fetal Infant Mortality Review Team  
 Racine Infant Mortality Coalition  
 Safe Kids Wisconsin  
 Spanish Center of Kenosha  
 State of Wisconsin Bureau of Health Information  
 State of Wisconsin Division of Health Services  
 United Way of Kenosha Infant Mortality Delegation  
 Waukesha County Child Fatality Review Team  
 Wisconsin Association for Perinatal Care  
 Wisconsin Child Care Resource and Referral Network  
 Wisconsin Early Childhood Association  
 Wisconsin Public Health Association

**PROGRAMS FOR FAMILIES**

SAID (Support After Infant Death) Group - Second Thursday of each month at Aspirus Hospital, Wausau, Wis. ☞

**DONORS**

- Ms. Kathleen Condon
- Mr. and Mrs. Daniel C. Haugh
- Ms. Tracy M. Jaglinski
- Mr. and Mrs. Michael Kscinski
- Meridian Industries
- Ms. Laurie Misslich
- Ms. Nancy Nawarawong
- Mr. and Mrs. Robert W. Plotz
- QuadGraphics Community Fund
- Ms. Susan M. Vorlob

**To make a gift**

Children's Hospital and Health System Foundation can assist you if you or your organization would like to donate to the Infant Death Center of Wisconsin. To reach the foundation office, call (414) 266-6100.

Periodically throughout the year, you may receive mailings from the foundation seeking support. Often there is a card enclosed with options for giving. Feel free to check the Infant Death Center as an option, or write in the center if it is not listed on the card.

The center also can be chosen as an option on your United Way designation form. Your support of the program allows us to provide a continuum of services throughout the state.

Many companies provide a match to donations given by their employees. Check with your employer to see if such a program is available to you. ☞

## | IN MEMORY OF

The Infant Death Center thanks the following individuals for their generous donations in honor of someone or in memory of a special child. These donations were received between Nov. 1, 2008, and Jan. 31, 2009.

**Alex Amundson**

Dick and Peggy Larsen

**David Joseph Crawford**

Mr. and Mrs. Perry Crawford  
Mr. Albert C. Lewis

**Chloe Anne Fischer**

Mr. and Mrs. Christopher J. Fischer

**Kera Jo Haase**

Mr. and Mrs. Bruce A. Otterberg

**Patrick Forest Harrington**

Reverend and Mrs. James L.  
Harrington

**Ellen Marie Hoffman**

Warren and Georgja Wilson

**Norris Mathison**

Dick and Peggy Larsen

**Madeline R. Thorpe**

Mr. and Mrs. Daniel N. Burnside

*Nature's spring palette softly covers  
winter's gloom with new life and hope.*

*Haiku by Diantha Ain*

## | PERSONAL VIEWPOINT

### Random Thoughts

*Continued from Page 2*

Tears will never stop and memories are never forgotten; laughter can happen; peace can reign. Darkness provides illumination and light can be blinding. Passion never leaves us, it merely changes form.

Friends can mean well and hurt deeply and strangers understand what they don't know. When I open my arms for a hug, and no one steps in, then I must remember how to love myself and I am capable of doing so.

I cannot take away another's pain. I can only allow myself to be present with the pain. I can only encourage the desire to do so. I cannot convince another that it will be better, only that it will be different. The most difficult thing to do is to do nothing. More is spoken with silence than with words.


I still get angry and annoyed, but I now know the worst that can happen – until the next time – and so I try to let the “little things” slide away. I am more patient and more kind, less tolerant of ignorance, but more willing to understand.

I know that I cannot change the world, but I can change the world of an individual who is lost. What I was so sure of is no longer, and things that I thought I forgot now come back to me as truths. True reality is not tangible and often not logical. When I least want to participate in life, life presents me with the most beautiful gifts. There are gifts that I give that I never knew I possessed, and gifts I receive come unexpectedly and without ribbons or bows.

Sometimes life seems unfair and unjust, yet it is all we have to work with. Sometimes it feels like it is too much effort to go on living, yet to give up is betrayal. Courage takes many forms, and to be “strong” can seem so very weak.

Pain strengthens, love heals, life is, sharing helps, the source of peace is in turmoil, joys surprise us, there is more, there is different, there is the legacy that nurtures, there is hope.

These are the random thoughts of a griever, a lover, a helper, a teacher, a student and a friend.

Reprinted with permission Bereavement Publications, *Bereavement Magazine*  
January/February 2001 



**WISCONSIN PERSPECTIVES** is the newsletter of the Infant Death Center of Wisconsin. The goal of this newsletter is to provide information to help reduce infant deaths and improve infant health.

The Infant Death Center of Wisconsin is funded by Children's Hospital of Wisconsin and a MCH Title V Services Block Grant, through the Maternal Child Health Bureau of the Health Resources and Services Administration, Department of Health and Human Services.

If you are receiving this newsletter for the first time, it is because you have been referred to the center at Children's Hospital of Wisconsin. Contact us at (414) 266-2743 if you wish to be removed from the mailing list. With any questions or comments about the program or newsletter, contact Anne Harvieux, program administrator, at (414) 266-2746 or [aharvieux@chw.org](mailto:aharvieux@chw.org).

To reach the center and the south/southeastern regional office, contact Anne Harvieux at (414) 266-2746 or [aharvieux@chw.org](mailto:aharvieux@chw.org) or Vivian Jackson at (414) 266-2745 or [vjackson@chw.org](mailto:vjackson@chw.org). To reach the satellite center in northern/western Wisconsin, contact Dora Gorski at (715) 218-8424 or [dora.gorski@cssw.org](mailto:dora.gorski@cssw.org). To reach the satellite center in northeast Wisconsin, contact Christine Armstrong at (920) 969-7903 or [carmstrong@chw.org](mailto:carmstrong@chw.org).

WISCONSIN PERSPECTIVES

## | NEW ARRIVALS

Congratulations to the following family on their new addition.

**Emma Amelia DeMeuse** was born Dec. 24, 2008, to Allison and Jeff DeMeuse.

*If you would like your baby's birth announcement in the newsletter, contact the Infant Death Center satellite or central offices.*



Children's Hospital  
of Wisconsin®

*A member of Children's Hospital and Health System.*

Children's Hospital of Wisconsin, Inc.  
PO Box 1997  
Milwaukee, WI 53201-0997

Non-Profit  
Organization  
U. S. POSTAGE  
PAID  
Milwaukee, WI  
Permit No. 2284