



Christmas in my Car

By Paul Alexander

Ever since September, we've been seeing and hearing evidence of the holiday season in the stores, on television and on the radio. One person I counseled the other morning said she just kept pressing the TV remote to bypass the holiday commercials. Many of us would like to take that same remote and bypass the holidays completely!

Well, if you're dreading the holidays, or crying every time you hear 'Silent Night', you're not crazy. Please look into the mirror and tell yourself that you're not crazy. You can be your own first sign of hope this holiday season. The holidays bring with them a lot of power. We're supposed to celebrate; we're supposed to be happy and joyful and full of cheer! Well, some people don't feel full of cheer right now, and if someone suggests to you that you should be that way, perhaps you need to tell them your truth.

It's hard work to feel happy when all we can think about is our loss. It's hard work to paint a smile on our faces, and it seems that even if we're not smiling, people are quick to say, "You look good!" What do they expect? (Actually, sometimes I think I look better in grief than I normally do.) Maybe we should all wear body casts during the holiday season so people will know we need some extra tender care.

We may not feel like celebrating, and even if we decide to try to enjoy the day, we're just so into our grief that it hurts too much. We may feel the holiday is moving us farther away from our loved ones, and in our silent reflection, we fall to pieces when we realize that our loved ones will not share this holiday with us.

We may want to run away or go screaming through the local department stores yelling, "Stop the music, stop all of this – stop my pain!" But that won't go over too well; people definitely will look at you very strangely. (I can, however,

recommend the New York subways. There, you can do anything you want and just tell people you're grieving. Come to New York – we'll ride the subways!)

One morning last year, I had Christmas in my car. It just kind of happened. Now, I know that some people can't stand to hear Christmas music, but I love it. I love to cry and listen to Christmas songs. It works for me, and it gives me a sense of hope. Kathy Mattea (a country artist) and I had Christmas in my car on Nov. 16. No gifts, no wrappings, no trees, no tinsel – it was a forty-five minute Christmas. I didn't plan it; it just happened. It was a surprise Christmas. I had bought a tape I wanted to hear while I drove from Manhattan to Long Island. The tape was only \$9.99, so it was a very inexpensive Christmas, because my heart was open to the sadness I was feeling. I so often run away from the truth that the grief is mine.

She sang, "I have loved deeply, and yes I have a lot, but I have loved ... and loved so strongly." I kept putting on my windshield wipers to wash away the tears. It was a tender Christmas. Through the sounds of the music Kathy was singing, I didn't run away from who I was and the reality of my loss, as well as the reality of the love. I felt my soul that Christmas. As I drove, I came face to face with myself and I didn't run away.

I wish that for you, too. Moments of truth, of peace, of resting in the stillness of knowing it's okay to be without any judgments of what you are feeling and how you're going to spend the day. Christmas is a 24 hour day, but I had Christmas in 45 minutes, and no one (except you) knows. And you know what? No one else has to know that that was my gift for me!

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Helping children cope during the holidays

Holidays are a difficult time for those grieving the loss of a child. For most grieving children, however, the holidays still elicit excitement and a desire to celebrate. It is important for parents to find ways for their children to enjoy the holidays, despite the grief and sadness they feel.

- If you are not up to it, ask relatives or friends to do things with the children that are fun, such as sledding, baking cookies, shopping for presents, visiting Santa and attending school programs.
- Talk with your children about what holiday traditions they want to continue, skip this year or do differently.
- Allow your children some time away from the family. If they want to spend some time with their friends, let them do so.
- Know there will be times during the holidays your children will be sad. Encourage them to talk about the baby who has died. This can be painful, but it will allow them a chance to express their feelings.
- Start new traditions. As a family:
 - Sort through photographs and put together a holiday scrapbook or grouping of pictures of your baby.
 - Give gifts or spend time with others who are in need this holiday season. Helping others can be very healing.
 - Each day during the month of December, have your children write or draw something they remember about themselves and their sibling. Put the notes and pictures together to make a holiday calendar. Save the notes and pictures so you can use them from year to year.
 - Make gifts for family members such as a quilt or ornaments.
 - Decorate a tree or special place.
 - Donate money or a gift to charity in your child's name.
 - Select or make a memorial gift, such as an ornament, to give to each family member. This will be a reminder that your child still is part of your family, and always will be.
 - Set aside time when your family can share favorite memories of your child. Light a candle during special times when your family gathers together. This can be a way to include your child in the holidays and encourage others to acknowledge and share your grief. ❖

I hope...

By Debra Smith Jones
in Memory of Margaret Ann

To hear her voice

In her sibling's songs.

To see the sparkle in her eye

In the lights of the tree.

To find the gifts of Christmas

That cannot be bought -- Peace, Love and Hope.

Shower me with Love and Peace for my soul.

Give me your presence,

Not your presents.

Decorate my heart with

precious memories and tender care.

Let my tears fall freely

like new fallen snow.

Reach out your hand

Show us you care.

Send the Brightest Star

to guide us through these darkest hours.

Research review

By Ralph A. Franciosi, MD – *Franciosi is medical director of Pathology at Children's Hospital of Wisconsin and a professor of Pathology and Laboratory Medicine at the Medical College of Wisconsin.*

Baby sighs: Are they normal?

Recently, an informational list serve that discussed the incidence of Sudden Infant Death Syndrome (SIDS) had a posting in which a member sought comments from participants about an article in the *Seattle Times*. The article reported on the importance of sighs in the control of breathing during infant sleep. The implication was that abnormalities in sighs might be a risk factor for SIDS.

I located the manuscript that was the basis for the news article in the *Press Journal of Applied Physiology*. The authors were a collaborative group representing pediatric respiratory medicine (Bern, Switzerland), Biomedical Engineering (Boston, Mass.), and Clinical Sciences (Perth, Australia). They studied sighs in full term newborns. The article provides a baseline for

future studies of sighs in premature infants. They encouraged the study of sigh variation in pre-term infants, neurologically impaired infants and infants at risk for SIDS.

While an infant's sigh currently is investigational, it is the beginning of an exciting new area of multidisciplinary research that is essential in understanding SIDS. While there has been a 40 percent decline in the number of SIDS cases since the Back to Sleep campaign, we still need to understand why SIDS occurs. Research is uncovering abnormalities in fetal organization of the brain. It is tempting to accept the reduction in deaths as the prevention of accidental deaths, but such simple explanations do not explain the root causes that lead to SIDS.

In the past five years, a variety of

terms are reported on death certificates to diagnose a sudden unexplained infant death. The magnitude of this problem and evaluation of preventive strategies are threatened. A unifying approach is needed. There should be agreement among pathologists that unexplained deaths in infants be diagnosed as SIDS or Sudden Unexplained Infant Death (SUID). The diagnosis of SIDS is dependent upon reported national criteria; I would add that SIDS deaths must be sleep related. All non-SIDS cases should be diagnosed as SUID.

The uniformity of diagnosis will allow researchers to select both SIDS and SUID cases as needing further study. This will encourage researchers to pursue the root cause(s) of unexplained infant deaths. ❖

2005 Family Bereavement Conference to be held in Wisconsin Dells

The 2005 Family Bereavement Conference will be held April 22 and 23 at the Raintree Resort and Conference Center in the Wisconsin Dells. Last year, families ranked the Raintree very highly and we look forward to another successful family conference in 2005.

A planning committee made up of parents is underway. More details will come in our next newsletter and in conference brochures that will be mailed early next year. We will also be posting the brochure on our Web site at www.idcw.org. Please visit the site for more information on the program, services provided and other helpful information. ❖

Fundraising kits available

Many families consider fund raising for the Infant Death Center, but do not always know where to start. Children's Hospital and Health System Foundation, in collaboration with center staff, have developed a folder with information that can help you decide, plan and promote an event.

If you are considering a fund-raiser to benefit the Infant Death Center and would like a kit, call (414) 266-6197.

A letter to parents

By Larry Uglow, MS

“Holidays are wonderful! Or at least they used to be when my energy level was higher. The entire season seems to be lasting forever this year and I am wondering how I will survive those special holidays that always have been important to me. If I could only come up with a plan to help get me through, I would feel much better. Friends just don't seem to know what to do for me. I'm worried that I will ruin everyone else's holiday because I am so down. Last holiday season people were very understanding of my grief, but this year I'm not sure what to expect. If only I could come up with a plan to help me through it.” Have you found yourself saying or feeling any of these things?

Believing that there is a simple solution or one sure-fire way to get through can only lead to disappointment. Accept that during the holiday season you will have some sad times no matter what you do. When this happens, reach back and use the coping mechanisms that worked before. Find ways to work in a break when the intensity or duration of your grief seems to be too much. Also, let others know how to help you. It will benefit both your friends and family, and will help you take charge to ensure that your needs get met.

If others fail to mention your baby, you may want to do so. Dealing with others' avoidance of your loss requires a great deal of energy. You may find you feel considerably better when you acknowledge your child and memories.

Some ideas that have been shared by other families include:

- Attend a grief group in your area. Others are eager to share ideas that have helped them as well as talk about their dislike of the holidays.
- Light a candle or buy an ornament to help you to bring a reminder of your baby into your home for the holidays.
- Save your energy. Do only the things that you feel are most important for you and your family.



- Buy a gift for your child and donate it where it will be appreciated.
- Share memories.
- Attend a religious service of your preference.



- Leave town. Some people think it helps to get away for a while.
- Donate your time by volunteering where needed.
- Play games. Start a snowball fight or build a snowman with the neighbor kids.

Others have tried many different things to help themselves during the holiday season and there are certainly many more. Try things that may have worked in the past and if they don't



work, try something different. If you find something that brings you joy, make sure to do it again.

Joy seems to be one of the most difficult emotions for those whose baby has died. They worry, “How can I enjoy myself with what has happened?” and “What will others think of me?” Just as sadness, guilt and anger are a part of one's grief, so is joy. To move on you must experience it. As far as what others may think, you can't please everyone. So align yourself with people who won't rob you of a moment of joy.

The holidays themselves typically are only a day or two. Often, the months before them are worse. Remember, you have survived other times when you thought you wouldn't and you will survive again! Please feel free to contact the Infant Death Center offices for more ideas or to help clarify some of the feelings you may have. ❖

We are thankful

As we approach Thanksgiving, there are many people we want to acknowledge for their generosity:

- The many individuals, families and corporations who have donated to the program.
- The families and volunteers who have organized and executed fund raisers throughout the state.
- The CJ Foundation, the March of Dimes, Children's Hospital and Health System, and the Wisconsin Department of Health and Family Service, that have provided program support.
- Volunteers who give of their time and talents to assist in mailings, committees, programs and other activities that help us continue the program.
- Organizations that have partnered with us by hosting events, assisting in marketing and providing materials and/or staff to help us reach families.
- Everyone who has reached out to a bereaved family to offer comfort and to remember their child.

Your donations of time and funding help support grieving families who are dealing with the death of an infant, or professionals who want to ensure that the care they provide to bereaved families is sensitive and appropriate. Your generosity allows us to reach out to those who care for infants to inform them of the steps they may take to reduce the risk of a sudden and unexpected infant death occurring with a child they are caring for. ❖

Thank you. We could not provide the services we do without your help.

8th Annual Worldwide Candle Lighting to honor children who have died

National Children's Memorial Day, Dec. 12, will mark the 8th Annual Worldwide Candle Lighting. Everyone around the world is invited to light a candle at 7 p.m. in honor of all children who have died, symbolizing each child's eternal light.

As candles go out in one time zone, they will be lit in the next, creating a wave of light that will encircle the globe. Please join in the 24-hour memorial by lighting a candle, wherever you are, at 7 p.m. on Dec. 12. ❖



To make a gift

Children's Hospital and Health System Foundation is available to assist you if you or your organization is interested in making a donation to the Infant Death Center of Wisconsin in memory of a child or other person. Annual giving and memorials are handled through the foundation and recognition opportunities are available. 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. Please 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, however, it must be written in on the designated form. Your support of the program allows us to provide a continuum of services throughout the state. Please know this support is most appreciated.

Many companies provide a match to donations given by their employees. You may wish to check with your employer to see if such a program is available to you.

Center and satellite summaries

U P D A T E

Infant Death Center and South/ Southeastern Region

Anne Harvieux: (414) 266-2746 or
Larry Uglow: (414) 266-2745

Educational programs

Presentations on SIDS, risk reduction strategies, grief/loss issues and services provided by the Infant Death Center of Wisconsin were given on:

- Aug. 18 – National Fetal Infant Mortality Review
- Sept. 15 – Clergy breakfast at Interfaith
- Sept. 21 – Medical College of Wisconsin residents
- Oct. 21 – Waukesha Memorial Hospital
- Nov. 9 – Beloit Infant Mortality Collaborative
- Nov. 16 – Milwaukee Health Beginnings Consumer Issues

Informational exhibits

- June 8-10 – Wisconsin Coroners and Medical Examiners Association
- Aug. 7 – Martin Luther King Health Fair, Milwaukee
- Aug. 19 – Wisconsin Community Services Network
- Oct. 22 – Prematurity Summit, Oconomowoc
- Oct. 26-27 – Annual Forensic Science Seminar, Milwaukee
- Oct. 28 – Parish Nurses Conference, Lake Lawn Lodge

Other

- June 16 and Sept. 22 – Healthy Babies in Wisconsin Southeast Regional Action team meeting
- June 18 – Great Lakes Intertribal Council Program Advisory Committee
- Aug. 24 – Healthy Babies in Wisconsin Steering Committee
- Aug. 31 – Regional Council Meeting, Milwaukee
- Sept. 9 – FIMR/IDCW/Milwaukee Hospitals Collaborative
- Sept. 17 – Great Lakes Intertribal Council

- Program Advisory Committee
- Nov. 12 – Statewide council meeting
- Nov. 19 – Medical College of Wisconsin Residents Retreat
- Dec. 3 – Great Lakes Intertribal Council Program Advisory Committee
- Dec. 6 – Healthy Babies in Wisconsin Southeast Regional Action team meeting
- Dec. 10 – FIMR/IDCW/Milwaukee Hospitals Collaborative meeting
- Dec. 18 – Healthy Babies in Wisconsin Steering Committee

Support to Families

A support group for families meets at 7 p.m. every fourth Tuesday of the month. For more information, call (414) 266-2745.

- Nov. 7 – Memorial Program, Milwaukee

Collaborations

The center continues to be involved with:

- 4Cs of Milwaukee County
- Association of SIDS and Infant Mortality Program Professionals
- Fetal Concerns Program
- Great Lakes Intertribal Council Honoring our Children Project
- Healthy Babies in Wisconsin Steering Committee and Regional action teams
- La Causa
- March of Dimes
- Milwaukee Area Hospital collaborative
- Milwaukee County Child Fatality Review Team
- Milwaukee Fetal Infant Mortality Review Project
- Milwaukee Healthy Beginnings Steering Committee
- Data Evaluation Committee and Consortium
- Milwaukee Tobacco Free Task Force
- Racine County Death Review Team
- State of Wisconsin Bureau of Health Information
- State of Wisconsin Division of Public Health
- Supporting First Time Parents
- Waukesha County Child Fatality Review Team
- Wisconsin Association for Perinatal

Care

- Wisconsin Child Care Resource and Referral Network
- Wisconsin Early Childhood Association
- Wisconsin Maternal and Child Health Coalition
- Wisconsin Public Health Association

Northern/Western Region

Dora Gorski: (715) 843-1877

Educational programs

Presentations on SIDS, risk reduction strategies, grief/loss issues and services provided by the Infant Death Center of Wisconsin were given on:

- July 21 – Marathon County Child Fatality Review Team meeting
- July 27 – Northern Regional Community Council Meeting, Wausau
- July 28 – Neonatal Intensive Care Unit Transitional Planning Group at North Central Health Care Facility
- Aug. 5 – Health Marathon County Meeting including: Perinatal Action Committee, Tobacco Free Coalition, HEAL (Healthy Eating/Active Living)
- Aug. 11 – Western Regional Community Council Meeting, Eau Claire
- Aug. 11 – Western Regional Healthy Babies Action Team Meeting at Sacred Heart Hospital, Eau Claire
- Sept. 17 – Great Lakes Inter-Tribal Advisory Board Meeting, Lac de Flambeau
- Sept. 22 – Meeting with elders of HoChunk Nation
- Sept. 27 – Perinatal Action Community Meeting at Aspirus Hospital, Wausau
- Oct. 4 – Northern Region Community Council Meeting, Wausau
- Oct. 25 – Perinatal Action Committee Meeting, Aspirus Hospital, Wausau
- Nov. 8-9 – Wisconsin Indian Tribes Healing Our Communities Conference
- Nov. 10 – Western Regional Healthy Babies Action Team Meeting, Eau Claire

Center summaries continued

Nov. 15 – SIDS Risk Reduction
Presentation for Child Care Workers,
Wausau

Informational exhibits

Aug. 4, Sept. 1, Oct. 6 – Display at
Monthly Baby Fair at Aspirus Hospital,
Wausau

Sept. 1 – Display at the Wausau Family
Resource Center Baby Shower
Education Program for Expectant
Mothers

Sept. 23 – Association of Woman's
Health, Obstetric and Neonatal
Nurses Conference Display, Wausau

Oct. 23 – Health Fair, Minoqua

Support to Families

Support After Infant Death (SAID) sup-
port group meets the second Thursday of
every month at Children's Service Society
of Wisconsin in Wausau.

Northeastern Region

Beth Tourville: (920) 969-7903

Educational programs

Presentations on SIDS, risk reduction
strategies, grief/loss issues and services
provided by the Infant Death Center of
Wisconsin were given on:

Sept. 21 and 29; Nov. 2 and 3 – Marian
College Nursing Students

Oct. 2 – Fiesta Latina, St. Therese School,
Appleton

Meetings

July 16 – Northeast Wisconsin Regional
Call to Action Meeting, Green Bay

Sept. 29 – Northeast Wisconsin Regional
Council Meeting, Neenah

Memorial programs

Oct. 10 – Annual Walk to Remember,
Memorial Walk for Pregnancy and

Infant Loss, Bubolz Nature Preserve,
Appleton

Dec. 1 – Candlelight Memorial Program,
Memorial Park Arboretum, Appleton

Collaborations

Hispanic Interagency Council Meeting

Hmong Interagency Council Meeting

Great Lakes Intertribal Council Program

Advisory Council

Center for Grieving Children – Fox Valley

Fundraisers

Aug. 7 – Alexis Rose Mathison-Szozda
Memorial Golf Outing, Irish Waters
Golf Course

Gifts

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 June 1, 2004 and Sept. 30, 2004

In memory of

Ashley Hager

Mr. and Mrs. Russell J. Hager

Norah Marguerite Johnston

Mr. Kevin Doyle
Laughlin Constable, Inc.

Eldon Otto

Dick and Peggy Larsen

Mary Smith

Dick and Peggy Larsen

Cassidy Tiana Weyek

Mr. and Mrs. James A. Weyek

Please visit our Web site at www.idcw.org

Wisconsin Perspectives is the newsletter of the Infant Death Center of Wisconsin. The goal of this newsletter is to promote the statewide exchange of information regarding infant death issues.

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. Please 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.

To reach the center and the South/Southeastern regional office, contact Anne Harvieux at (414) 266-2746 or aharvieux@chw.org, or Larry Uglow at (414) 266-2745 or luglow@chw.org. To reach the satellite center in your region, contact Dora Gorski in Northern/Western Wisconsin at (715) 843-1877 or Dora.gorski@cssw.org, or Beth Tourville in Northeastern Wisconsin at (920) 969-7903 or Btourville@chw.org.

New arrivals:

Congratulations to the following families on their new additions:

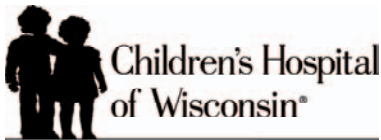
Riley Erin Conde was born Jan. 23 to Jennifer and Anthony Conde.

Abbigail Josie LaQue was born Nov. 9 to John Beyer and Shannon Shey.

Colman Sanuel McGuire was born Sept. 16 to Thersea and Michael McGuire

Kylie Erin Schwenker was born June 3 to Joseph and Cynthia Schwenker.

Michael Timothy Stewart was born Nov. 10 to Kalean and Joe Stewart.



A member of Children's Hospital and Health System.

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