

Going it alone

By Sally Reese Wilson

A new issue of Wisconsin Perspectives arrives. I devour every word hoping to relate in some way or learn something new that might help me understand. I always relate, but yet something always is missing. It seems like all the articles are written by someone who is not alone. They have their spouse, are pregnant, or have a new baby. Yet, I am alone, and I started thinking I can't be the only one. I hope that by sharing my story, it might help someone else who will read it and realize they are not the only one.

Even though we were "old" parents and were told that we should maybe give up, we didn't. We wanted a baby, and our Derek was born Nov. 7, 1999. He was beautiful in every way. We would spend hours marveling at how perfect he was; how he was just too good to be true. Then, on March 1, 2000, I got the call that changed our world, "Your baby isn't breathing." The rest is an overwhelming pain that seemed unbearable at times. Over the years, this pain has turned into a dull, constant ache that rears up in full force when I least expect it.

When I received a phone message from my ex-husband after almost three years, I was amazed at the painful memories it stirred in me. I had tucked all of this deeply away, but now I realized how much we both had missed by not being able to share our grief with each other. I had kept it to myself this entire time.

I am not the type of person who shares feelings and emotions easily. When our Derek died and my marriage ended a short time later, I was totally lost. I missed my baby terribly, and the one person who shared this incredible little boy with me was not available to share my grief. I tried grief groups, but being very private, they just didn't work for me. I tried individual counseling, and she asked all the right questions to

get me to open up, but she didn't know him or love him like I did, so how could I share? I have family who would have loved to help, but yet no one knew him like his Mom and Dad. Even though I didn't share my grief with them, my mom and three other children are the reason I survived.

As time passed and I ventured into new relationships, I was faced with "How do I bring my baby's memory and my grief into this new relationship? How can anyone who hasn't experienced it ever understand?" There were times when I let my grief show, but when I saw how uncomfortable it made him, I quickly learned to hide it ... "I don't feel good" always seemed to work. When I was sad at Christmas, he wondered, "Why would Christmas make you sad?" I wanted to shout, "Don't you understand, I miss my baby. I only had one Christmas with him and I want more. I want him here to share this day with me." When you tell me that I'll see him again in Heaven one day, I believe that, but try and understand that one day seems so far away when all I want is to hold him and smell him now.

All I really wanted was for him to say was, "Show me your pictures; I'd like to see them. Tell me what he was like, what you did with him. Tell me what happened that day," and then truly listen. I've read the books; I know it is up to me to initiate these types of conversations because others are too scared to broach the subject. Yet, these things are really difficult to say. I really don't have any great words of wisdom to share. If you are like me and are trying to bring your baby's memory into a new relationship, hand him or her this article. Maybe it'll open the doors to something we've been longing for.



in this EDITION

Personal viewpoints

Pages 1, 2 and 5

Research review

Page 3

Special feature

Page 4

Center and satellite summaries

Page 6 & 7

Memorials

Page 7

New arrivals

Page 8

By John Hyter, M. Div.

Reprinted with permission from the Northwest Ohio SIDS Support Network Newsletter

Memory is one of the most important tools we have to help us heal from the grief caused by the death of someone we love. Remembering experiences we shared with them and the stories others tell about them is a source of comfort for most of us. Eventually, happy memories even can bring us joy. As we relive those times in our hearts, we experience again the richness our loved ones brought. Memories also are frequently attached to special things, like pictures or personal items that belonged to the one who has died and become very precious to us. The memories and the things attached to them help us feel connected to the one we love and become sources of comfort and encouragement in our healing.

What happens when that precious one who dies is a very young baby and the store of memories left to survivors is very small? When a baby dies, those who love the child are left with a few memories and large dreams of what might have been. It especially is difficult when the baby dies suddenly and unexpectedly. But everyone who loses a child – regardless of cause – shares this in common: a large part of their grief is for the death of the dream. They spend a lot of time thinking about and hurting over what never will be.

Together, the loss of the baby and the loss of the dream make the healing journey more difficult. It is more difficult because the dream keeps coming back to remind us of our loss. Sometimes we can anticipate when this will happen. We often expect to have a hard time at holidays, birthdays, the anniversary of the death and other special days. Sometimes it takes you by surprise. You may be in a

store and see a child who is the age of your child would now be, and it hits you. Or you may subconsciously be keeping track of the milestones your child should be reaching. He would be starting school now. We should be shopping for her first prom dress. And it hits you. The pain is as fresh as the day the child died.

How do you deal with this? I wish there were a good, simple answer, but there isn't. Here are some thoughts:

Remember what grief healing is. It is **not** getting over it and going on with life as if nothing has happened. Grief healing IS learning how to live with it, how to adjust your life so that you can somehow carry on in spite of the loss. Understanding what is happening to you because of your grief is an important first step. The more you understand, the less power the pain has over you. You will be able to find comfort in the memories and the special things connected with your baby's life, but the lost dream still is out there. From time to time, it will come to remind you of what you have lost.

Remember that you are not alone. Others who love you and love your child are walking at your side. Some may be better able to understand what you are going through. Turn to them when you need support. There also are others who have been through what you are going through. Find them.

Finally, remember that Moms, Dads and others touched by this loss will experience and cope with it differently. Be kind to each other. Try to be aware of what the other is going through at the moment and reach out with love. ❖

Thank you

The Infant Death Center of Wisconsin families and staff would like to express their appreciation to the CJ Foundation for the support they provide. Because of the CJ Foundation, center staff were able to provide training to public health nurses across the state last year. This past spring, a grant provided major funding for the family conference. Without support of funders such as the CJ Foundation and the individuals and families who donate to the center, we would not be able to continue to provide the current level of services. ❖

Have you visited our Web site lately?

We constantly are working to improve the Infant Death Center of Wisconsin Web site. Check it out at www.idcw.org.

The Web site has been developed to be a tool for parents, caregivers and those supporting bereaved families. We recently redesigned the site. We hope you find it helpful and welcome your feedback. ❖

Pick 'n Save WE CARE program benefits IDCW

When shopping at Pick 'n Save, use your grocery purchases to benefit the Infant Death Center.

To sign up, go to the customer service counter at your local Pick 'n Save and ask to sign up for the WE CARE program. Select Children's Hospital of Wisconsin - Milwaukee or organization #110625. All money donated will go to the center.

❖

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.*

National expert speaks at Children's Hospital

On May 9, I had the pleasure of welcoming Carl E. Hunt, MD, a nationally recognized SIDS researcher and one of the original proponents of the back sleep position, to Children's Hospital. Hunt, the director of the National Center on Sleep Disorders Research at the National Heart, Lung and Blood Institute, part of the National Institute of Health, spoke at grand rounds.

Hunt's talk, titled "Bench to Bedside," covered the following areas:

- What is SIDS - pathophysiology.
- SIDS risk factors.
- Gene environment interactions.
- Clinical management of at-risk infants.
- Reducing the risk for SIDS.

SIDS is defined as the unexpected sudden death of an infant under 1 year of age that remains unexplained after a thorough case investigation including a complete autopsy, examination of the death scene and review of the clinical history.

According to Hunt, 20 percent of the cases that are presented to the coroner/medical examiner as sudden unexpected infant death (SUID) are the result of a medical disease or disorder such as congenital heart malformation, unintentional (accidents) and traumatic child abuse.

Approximately 80 percent remain unexplained. Based on national diagnostic criteria, the majority are SIDS cases but the remainder (non-SIDS) remain undetermined. The current challenge to pathologists following the SIDS reduction due to sleep position is

to address cases of SUID that are not "classic SIDS."

The recognized risk factors for SIDS are:

- Prone/side sleep position.
- Cigarette smoke.
- Racial/ethics/socioeconomic factors.

In the United States, prone sleep position for infants has decreased from 70 percent before 1992 to 17 percent in 1998. This change has been accompanied by a 40 percent decrease in the SIDS rate. In addition, there has been a 25 percent decrease in reported maternal smoking during pregnancy.

Hunt referred to the avoidance of the "g" word - referring to genetic. Possible genetic mechanisms include brain stem abnormality in automatic control of breathing and other autonomic dysregulation. He explained that the national genome project has opened a new avenue for understanding SIDS. The interaction of environmental risk factors (for example, prone sleep position), with a person's unique genetic constitution is referred to as a polygenic disease/disorder. For example, multiple genes interacting in complex ways with multiple environments can result in an infant that experiences SIDS. The research, demonstrating abnormal structure and function in the brainstem areas controlling breathing, is under the control of genes that are being studied. We are just at the early stages of understanding the possible implications of genetics in relation to SIDS as well as many other diseases and conditions.

According to the research, infants who are placed on their back to sleep

may have secondary benefits as well. Researchers have discovered that in addition to reducing the risk of SIDS, infants who sleep on their backs:

- Are not at greater risk for any health problems.
- Have significantly fewer maternal reports of fever at one month of age or trouble sleeping at 6 months of age.

In addition, there are significantly fewer outpatient visits for:

- Ear infections at 3 months for both back and side sleepers.
- Ear infections at 6 months of age for back sleepers.

We anticipate this information may help motivate parents who have yet to embrace the back sleep position.

Hunt reinforced the need to continue educating parents about safe sleep environments and suggested that we need to develop new strategies to reach populations that are at a high risk for SIDS and are more likely to utilize unsafe sleep practices.

Hunt also strongly feels that SIDS research must continue despite the decrease in SIDS cases. As research continues, we can decrease the number of SIDS cases even further by reducing risk factors.

The Infant Death Center is committed to working with families, healthcare providers, community agencies and other individuals to reduce the incidence of SIDS in Wisconsin. We will work to identify strategies that are relevant to populations at high risk and historically been more likely to use unsafe sleep practices.

Time moved on

By Lisa Sculley

Reprinted with permission from the newsletter of the Florida SIDS Alliance.

Time moved on for me today. Another year, as I awoke. Today is the day. Today is the day that you came to us eight years ago, and brightened our lives with your presence. As dawn came light filtered through the windows and poured over my bed, and I curled closer to my pillow. I wanted to lay and remember that day. But time moved on and pressed against our family, pushing us out of bed and on to a morning busy with the ordinary things that life brings – missing combs, misplaced shoes and pants that must be ironed. Places we had to be called out to us, urging us to hurry and not be late. The hustle and bustle of a new day began; the moment passed and the heaviness with it.

Time moved on for me today and people swirled around me, oblivious to the remembering of my heart. Greetings and questions and handshakes and good-byes, with not a mention of your name. In the midst of a song, I remembered and tears tickled the corners of my eyes. But time moved on, the moment passed and the heaviness with it.

Time moved on for me today, watching my daughter play with other children and feeling the sweet weight of her as she climbed into my lap for a snuggle. I longed for the snuggle that you would have given me, but then remembered, at 8, you probably wouldn't snuggle. You probably would pull a prank instead. And I remembered. But time moved on and the playtime was done. Bags were gathered, the car was loaded and the movement passed, the heaviness with it.

Time moved on for me today at a restaurant where our family gathered around a table for five. There should be

six. Or should there? Would there have been another if you were with us still? Could I choose between you and her? How could I? But children and husband vied for my attention, pushing questions out of my head. Time moved on, the moment passed and the heaviness with it.

Time moved on for me today, rushing past me just like your life rushed passed. Too fast. Too fast. Not enough time to love you. Not enough time to know you. Soon the day was gone, the sun sinking below the trees. I wanted to sing "Happy Birthday." I wanted to visit with you and sit and remember. But time moved on for me today. The moment passed, the heaviness remained.

Time moved on for me today as I sat in a darkened room, holding the little one that is in my life now. Rocking her gently, I longed to hold you and rock you, too. I longed for what I didn't have, and the moment came, and the tears flowed. Listening to the nighttime sounds of a family "snuggling in," I remembered and I cried. It felt good to cry. And the moment passed, the pain faded and the heaviness with it.

Time moved on for me today and so did life. Today, I remembered not only what I lost, but also what I had. And it was wonderful and rich and sweet. I also remembered what I still have and what I have gained. I realized that life does move on and am glad. Moving on is not forgetting; memory doesn't die. You died, but your love remains. And moments pass and the heaviness with them.

Life moved on for me today. Another year passed. And I remember. And I always will. ❖

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. 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.

Fund-raising kits available

Many families consider raising funds 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, has 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.

Personal viewpoints

Note: Everyone deals with grief differently. These are the personal reflections of our families as an expression of their grief.

I only had 12 days

For those 12 days ...
I had you to myself.
It seems to be such a short time to be changed so profoundly.

For those 12 days ...
I came to know you and love you.
You came to trust me with your daily care.
Oh, what a life I had planned for you.

For those 12 days ...
When I lost you, I lost all hope for a normal life.
All my plans, dreams and aspirations gone.
A slice of my future simply vanished overnight.

For those 12 days ...
It was not enough time to convince others how special you were.
To let everyone know how much you meant to me.
How odd, I am the only one mourning your passing.

For those 12 days ...
I lost a major piece of my heart.
Is it normal to cry all night over a tiny unfinished baby?
Or get depressed and upset with everyone else day after day.

For these 12 days ...
My little one.
You darted in and out of my life too quickly.
It seems that was all the time God gave us to bond.
To become one as mother and son.

For those 12 days ...
I may never understand why things went the way they did.
You are gone to be in a better place.
I will miss you and I love you.
Praying you are watching down on me from the heavens above.

Love, Mom

*Written by Tiwanna Agee in memory of her son
Magic Agee (Dec. 5, 2000 – Dec. 17, 2000) ❖*

Arms stronger than mine

There you were in the midst of the storm,

Shattered and torn.

There you were in the pouring rain,

Tattered in pain.

Your wings were broken when you needed to fly.

Your back was burdened when you wanted to try.

I held you in my arms through the storm and rain.

I knew I wasn't the one who would stop the pain.

For a moment I gave you my sweet embrace.

And now you're gone without a trace.

You couldn't carry your burdens another day.

God knew there must be a better way.

So He took you from the midst of the storm.

He threaded your heart because it was torn.

He gave you strength when you were tired and worn.

His arms spread over you so you could heal and be
restored.

You're one of many His arms are for.

You're in the place where love ever shines.

You're in arms stronger than mine.

*Written by Brenda Grasley for Ashley Lynn (Jan. 13,
2003 – Jan. 15, 2003). ❖*

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:

Feb. 14 – Wisconsin Child Care Administrators Association.

March 14 – Association of SIDS and Infant Mortality Programs.

April 14 – Wisconsin Association for Perinatal Care.

May 5 – Martin Luther High School.

May 9 – Dr. Karl Hunt Presentation, Children's Hospital of Wisconsin.

May 19-21 – Wisconsin Public Health Association.

June 11 – Wisconsin Coroner and Medical Examiner Association.

Aug. 5 – Wisconsin Community Services Health Fair.

Educational programming for outreach workers is being planned statewide from July through the end of the year.

Informational exhibits

Feb. 13-14 – Wisconsin Child Care Administrators Association.

April 11 – Potawatomi Health Fair.

April 12 – Milwaukee Journal Sentinel Health Fair.

April 15 – Alverno College Health Fair.

May 10 – Women of the World Health Fair.

June 11-12 – Wisconsin Coroner and Medical Examiner Association.

July 23 – Wisconsin Community Services Health Fair.

Upcoming exhibits

Aug. 16 – Waukesha County Health Fair.

Aug. 17 – Praise in the Park.

Sept. 11 – Krause Health Fair.

Programs for families

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

Other

June 23-24 – “The Gathering” sponsored by Honoring our Children and Milwaukee Healthy Beginnings Healthy Start Projects.

IDCW is the lead agency and participant in Healthy Babies in Wisconsin: A Call to Action.

Collaborations

The center continues to be involved with:

- 4C's of Milwaukee County.
- Association of SIDS and Infant Mortality Program Professionals.
- Dane County Pediatric Death Review.
- Fetal Concerns Program.
- Great Lakes Intertribal Council Honoring our Children Project.
- La Causa.
- March of Dimes.
- Milwaukee Fetal Infant Mortality Review Project.
- Milwaukee Healthy Beginnings Steering Committee, Data Evaluation Committee and Consortium.
- State of Wisconsin Bureau of Health Information.
- State of Wisconsin Division of Public Health.
- Supporting First Time Parents.
- The African Infant Mortality Workgroup.
- 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.

Western Region

Phillip Nielsen: (608) 791-9410

Educational programs

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

March 19 – WWTC Child Care Students.

May 23 – Bereavement In-service for the Pediatric Advance Life Support participants.

Other

March 4 – Wisconsin Maternal Mortality Review Team meeting, Madison.

April 25-26 – Infant Death Center Annual Parent Conference, Merrimac.

May 29 – Infant Death Center Western Region Community Council, La Crosse.

April – June – A Public Health Practice Course on Epidemiology and Biostatistics, Madison.

Programs for families

The La Crosse Pregnancy and Infant Loss support group meets from 7 p.m. – 8:30 p.m. the third Wednesday of each month at Gundersen Lutheran Medical Center (La Crosse) in the Mooney Center Patient Education Room. Call (608) 791-9410 for more information or to register.

The annual La Crosse Pregnancy and Infant Loss support group memorial program “Walk to Remember” is scheduled for September. Call (608) 791-9410 for more information or to register.

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:

March 15 – Oneida Wellness Day at

Center summaries cont.

Washington Commons, Green Bay.

Upcoming events

Oct. 19 – 2nd Annual Walk to Remember, Appleton – a memorial walk and tree planting at Bubolz Nature Preserve is open to anyone who has experienced a miscarriage, stillbirth or infant loss. No registration necessary. Call (920) 969-7903 for more information.

Other

June 18 – Northeast Wisconsin Regional Council Meeting.

June 20 – Great Lakes Inter-Tribal Advisory Council Meeting, Lac du Flambeau.

July 12 – Alexis Rose-Mathison Szozda Memorial Golf Outing, Irish Waters Golf Course, Freedom.

Programs for families

Remembering Through Sharing support group meets at 7 p.m. the first Wednesday of the month. No registration is necessary. Call (920) 729-2087 for meeting location and information.

Northern 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:

March 15 – Project Bridges Childcare Conference.

April 14 – **Babysitting Workshop** at the Lincoln County Family Resource Center. Talked to eleven- and twelve-year-old prospective babysitters about risk reduction practices and proper care of an infant.

Apr. 18 – Child Fatality Review Team meeting, Marathon County.

March 14 – Northern Regional Community Council Meeting, Wausau.

March 21 – Great Lakes Inter-Tribal Advisory Council meeting, Lac du Flambeau.

June 16 – Helping Children Through Grief and Loss, Merrill.

June 12 – Northern Regional Community Council Meeting, Wausau.

January–June – A culturally relevant video on SIDS with emphasis on risk reduction recommendations was developed by the Great Lakes Inter-Tribal Council through a grant from the CJ foundation.

Fundraising

March 1 – Lucht Family volleyball and dart tournament raised funds for the center in memory of their son James Lucht.

Programs for families

SAID (Support After Infant Death) meets at 7 p.m. on the second Thursday of every month at 705 S. 24th Ave. Suite 402 in Wausau. For more information, call Dora Gorski at (715) 843-1877.

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 Feb. 1, 2003 and May 31, 2003.

In honor of

Lynn Mohr
Harley-Davidson, Inc.

Cory Pofahl
Mom and Dad

Alexander Ashley
Mr. and Mrs. James C. Ashley

Jack Michael Cleveland
John and Liz Marzion

Matthew Ferron
Mr. and Mrs. Gerald E. Barlament

Ellen Marie Hoffmann
Mr. and Mrs. Warren L. Wilson

Mark Galen Magler
Reid and Karen Magler

Mariah Rickman
Mr. and Mrs. Eric Rickman

In memory of

Lauren Elizabeth Anheuser
Alpha Phi Alumnae Association

Kera Jo Haase
Mr. and Mrs. Bruce A. Otterberg

Merle Hillman
Dick and Peggy Larsen

Cassidy Tiana Weyek
Mr. and Mrs. James A. Weyek

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 Phillip Nielsen in Western Wisconsin at (608) 791-9410 or Nielsen.Phillip@mayo.edu, Dora Gorski in Northern 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:



Molly Roberts was born Jan. 9 to Jody and Ryan Roberts.

Justin Andrew King was born April 1 to Cheryl and Greg King.

Nathan Robert Armstrong was born April 8 to Allison and Steve Armstrong.

Kollin Ethan Harrah was born April 18 to Tori and Kabe Harrah.

Emily Miranda Kienast was born May 1 to Nikki and Thomas Kienast.

Ayvon Marbell Hughes was born May 15 to Simone Toombs and Antonio Hughes.

Sydney Makenna Pederson was born May 23 to Michelle and Michael Pederson.



John Russell Schultz was born June 12 to Linda and Dave Schultz.



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