



THE OTHER SIDE OF GRIEF

By *Darcie D. Sims*

I used to search for rainbows. They were special symbols for us. Our son, "BIG A," died during the night in a fierce thunderstorm and, as the dawn broke, the storm ended. As we emerged from the house, we were greeted by a beautiful rainbow spanning the mountains outside of Denver. We felt it was a message from BIG A and from God that he had made the journey and was all right, and that we would be, too. So, rainbows have been special to us. And we searched for them to remind us of BIG A.

We began to collect rainbows. People sent us rainbow items. Eventually, our house began to look like a rainbow gift shop. We had rainbow dishtowels, bath towels, pictures, a shower curtain, tea pot, hot pads, toilet seat cover, jewelry, artwork and, best of all, rainbow toilet paper (for special occasions). I wore a small enameled rainbow on a gold chain around my neck and never went anywhere without it.

We spoke to rainbows whenever they appeared. Just a quick "Hey there, BIG A," or maybe just a wave – or later on, a glance and a smile were enough. But we always acknowledged the presence of our rainbow child and said a silent prayer of thankfulness for the reminder of our love.

Incredibly, rainbows came to us on BIG A's birthday and again on his death date for the first five years after his death. They were symbols and we clung to them.

For five years, rainbows somehow peeked through the incredible weights of those days and helped to ease the painful memories into gentle reminders of the love shared, of the love we still have.

We grew comfortable in our yearly ritual, and by the fourth year, we began to release a lot of the pain of our son's death. I still wore the rainbow as a constant reminder, and we grew more confident in our ability to "handle" our grief. It all hinged, however, on seeing a rainbow on those two important days during the year. We could go for days and maybe even a week or so without much pain as long as we knew our rainbow would be coming eventually. We grew dependent on those outward symbols of our son's life to keep us close to the joy we had known. Without those tangible reminders, we tended to sink into despair and remembered first the details of his life's struggles.

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THE USE OF DNA EVIDENCE IN THE DIAGNOSIS OF SUDDEN UNEXPECTED INFANT DEATHS

By Raplh A. Franciosi, MD - Dr. Franciosi is program director of Perinatal and Infant Pathology at Children's Hospital of Wisconsin, a professor of Pathology and Laboratory Medicine at the Medical College of Wisconsin and serves as the medical advisor to the Infant Death Center of Wisconsin.

Placing infants to sleep on their backs decreased the number of Sudden Infant Death Syndrome cases in the U.S. by 50 percent. The reason for this decline was assumed to be the inability of a sleeping infant to breathe oxygen when placed facedown.

Did the infant have a predisposing abnormality? None was apparent after careful post mortem examination, which included medical history, scene investigation and autopsy.

Hannah Kinney, MD, an expert on SIDS, reasoned that SIDS was related to the inability of one in one thousand live born babies to maintain breathing during sleep. However, the abnormality was not detected by routine studies. She proposed the Triple Risk Model to explain SIDS. The Triple Risk Model for a developing infant states three conditions must be present for SIDS to occur:

1. A vulnerable infant (predisposed biologically).
2. A critical window of time after birth (first year).
3. Environmental stressors, for example, prone sleep position.

A research report, summarizing her 20 years of research, demonstrated a potential biologic cause for SIDS (Journal of the American Medical Association: Vol. 296, Nov. 1, 2006).

The medulla, a critical area in the brainstem, has many nerve cells that influence respiratory drive, blood pressure regulation, thermoregulation, upper airway reflexes and arousal. These cells perform a critical role in the generation of breathing rhythms and the body's response to low oxygen and high carbon dioxide.

The research report documented an abnormality in the syntheses, release and clearance of the neurochemical serotonin. This chemical is responsible for the messages between the nerve cells in the medulla that control the vital functions essential for life. An additional finding was a significant decrease in serotonin receptors in males (SIDS is more frequent in boys).

This molecular study provides a scientific basis for the decline in SIDS that resulted from the Back to Sleep

campaign. It provides an explanation for the vulnerable infant proposed in the Triple Risk Model, a critical time window, for example, the first year of life, and environmental stressors, such as upper respiratory infections, which are common to all infants the first year of life.

Molecular insights into sudden and unexplained infant deaths

DNA evidence often is essential to solve violent crimes. Similar technology now is available to researchers attempting to understand the cause of unexplained infant deaths. A recent report indicated that 9 percent of sudden and unexplained deaths are caused by a gene mutation that affects heart rhythm (Arnestad, M ET AL; Prolonged QT Interval Circulation, Jan. 8, 2007).

As specific DNA tests become available, the number of unexplained infant deaths will decrease. However, approximately 2,000 unexplained infant deaths nationwide remain. These are identified by a variety of terms on death certificates. Fortunately, the U.S. Vital Statistics Center classifies all the terms used to identify these deaths (such as SIDS and unexplained infant deaths, under one statistical code – SIDS). This approach allows researchers to identify cases that need further study.

The tragedy of losing an infant suddenly and unexpectedly is an emotional trauma for families. They receive some comfort in knowing this death is experienced worldwide. Their grief is addressed through the support of other parents and professionals. The awareness that these deaths will be available to researchers ensures an explanation that is medically evidence-based.

Variation in SIDS diagnosis on death certificates

SIDS currently cannot be diagnosed by a specific test. The diagnosis depends on a thorough case investigation by the medical examiner or a qualified pathologist. Although the SIDS diagnosis should conform to a national definition, the interpretation by a pathologist from the medical history, scene of death and autopsy allows variation. The Centers for Disease Control and the National Association of Medical Examiners are developing guidelines to improve the accuracy of SIDS diagnosis. ↗

PERSONAL VIEWPOINT

The other side of grief *continued from Page 1*

The year there was no rainbow

At year six, however, the sky was too clear and I sensed a change was coming. We lived in southern Texas and September dawned bright and hot and clear. I panicked. I didn't want to change. I'd already changed enough! His birthday was a warm September day, with no traces of clouds or rain. But I remained confident. After all, we'd gotten a rainbow on this day for five years. Why shouldn't I expect one this year, too? Besides, I needed a little boost this year. It had been harder than I expected.

And so, I went through the day always glancing at the sky. My mind wandered through the memories of BIG A's life, and other family members called to share thoughts throughout the day. By 10 p.m., I sat on the front stoop and waited. By 11:30 p.m., I was lost and at 12:01 a.m. the next day, I cried. No rainbow had come.

We didn't get a rainbow on his death date either. As much as I wanted a rainbow to come, as much as I needed a rainbow to appear out of the hot, cloudless September day, the sky remained clear at year six. Goodbye happened all over again.

Goodbye? I wasn't through saying hello!

We grieved all over again – this time for the skywash that had held out the promise of hope all these years. If only we would get our rainbow on those important dates, then we could cope the rest of the year with the loneliness, despair and pain that (although different) was still there. I ached again, longing for my rainbow to come and remind me that our life with BIG A really did happen. It was as if he died all over again that year.

And so we retreated back into grief, a long-time companion. But something else happened that year. Just as we retraced our steps through the valley, we noticed our despair felt different. It didn't seem to last as long. The gloom faded more quickly whenever it came. We laughed more often in spite of our renewed grief.

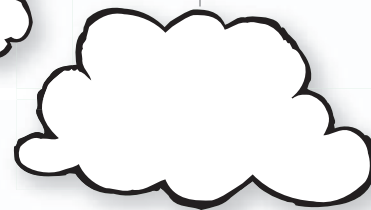
The truth about grief

I wrestled long and hard and finally discovered the awful truth of grief – my loved one, our beloved son, had died, but we had not. We were left among the living, left to carve out an existence that had to endure not only the pains of life, but the joys as well. And suddenly, survival wasn't enough. If we were to be stuck in life, then we wanted to live again.



I didn't want to remember only the awfulness

of death. I wanted to recall the joys, the life he brought, the music of his presence in our life. Slowly, painfully, we learned we did not need the symbols to remind us of our son and the joy and love we share. We learned to release the darkness in hopes of there being light in spite of the terribleness of the storms we endured!



Some say the path to healing (I do not like the word recovery – it sounds too medical to me. I can recover from a broken arm or the chicken pox, but recovery from grief just doesn't seem to fit) begins when we learn to say goodbye. Goodbye to what? To whom? Goodbye to our loved one? I think not! I can say goodbye to the life we lived together, but never to the memories and the moments of the life we shared! I can pick and choose how those memories affect me. Just knowing I have choices is the beginning of the other side of grief.

Most of us still have time frames against which we measure ourselves. See if you can think about letting those "oughts," "shoulds" and time frames go. See if you can say goodbye to those dictates. See if you can live your grief instead of just surviving it.

Experience and express your emotions

Live your grief with all the passion you once lived your life. Even the shadows have something. Experience the hurts, acknowledge the pain, let the tears flow. If we can allow ourselves to experience and express the painful and deep emotions of grief, then we may gradually become aware that the well of hurt is not quite so full. The intensity and duration of the pain has changed as we have lived it. When once you hurt continuously, perhaps now you are discovering a few moments of respite from the searing heat. Perhaps now you can discover an entire day without a painful memory. Perhaps smiles come more easily when the memories flood in. Perhaps you have learned to cry and laugh at the same time.

Don't postpone, deny, cover up or run away from your pain. Be with the pain – now. Everything else can wait. An emotional

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THE SPRING FAMILY BEREAVEMENT CONFERENCE

ON THE WINGS OF TOMORROW

The Spring Family Bereavement Conference, *On the Wings of Tomorrow*, will be held Friday, April 13, and Saturday, April 14, at the Olympia Resort and Conference Center in Oconomowoc, Wis.

A parent committee throughout Wisconsin is planning the annual family bereavement conference. Features include:

- A keynote presentation by Darcie Sims, a bereaved parent and national speaker.
- An optional open forum for parents Friday evening.
- A chance to meet other families who are dealing with similar situations.
- A memorial program.
- Breakout sessions that provide an open forum for discussion.
- 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.
- Reduced room rates at the Olympia Resort and Conference Center (\$70 per night).
- On-site child care.

This conference is intended to help families develop the ability to integrate the death of their infant into their lives and increase their coping skills, while providing the opportunity to

talk with other parents. A number of alternatives are available to help individuals and families. The hotel grounds allow for walks and quiet time. We encourage you to take a break, take time for yourself to think, release stress or just relax.

As you look at the agenda below, you may notice some changes to the program based on feedback we have received from families. Morning sessions will be expanded to one hour and 45 minutes. We will ensure group sizes allow for good discussion.

About the speaker


Darcie Sims is a bereaved parent who has shared her family's story with other bereaved parents through her writings, workshops and presentations.

Cost

Adults - \$15 each
Children - \$7 each

Fee includes registration and continental breakfast and lunch on Saturday, April 14.

Information

Information will be mailed shortly. Call (414) 266-2743 for more information. If you have not received an invitation, use the form below to begin the registration process. 

The Spring Family Bereavement Conference: *On the Wings of Tomorrow*

FRIDAY, APRIL 13

7 p.m. to 9 p.m. Registration and optional open forum discussion

SATURDAY, APRIL 14

- 8 a.m. Registration
- 8:25 a.m. Introduction
- 8:30 a.m. Keynote speaker
- 9:45 a.m. Break
- 10 a.m. Breakout session
 - Women's grief.
 - Men's grief.
 - Family members' expectations.
- 11:45 a.m. Lunch
- 12:45 p.m. Memorial program
- 1:30 p.m. Break
- 1:45 p.m. Breakout session
 - Dealing with sudden and unexpected infant deaths.
 - Spirituality and loss.
 - Parenting after loss.
 - Helping children deal with grief.
- 3:30 p.m. Closing

Fee includes registration and continental breakfast and lunch on Saturday, April 14.

I would like to register for the conference:

Name: _____

Address: _____

City: _____ State: ____ ZIP: _____

Telephone number: (____) _____

E-mail address: _____

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

GRIEF IS LIKE A JIGSAW PUZZLE*By Victoria Guthrie, Tampa, Fla.*

Grief is not a smorgasbord where you go down the line picking a little of this and a little of that. Grief is like a jigsaw puzzle. Some people get all the edge pieces together first and work from the outside in. Others dump everything out on the table at once and dive right into the middle. Some never even open the box at all. They just look at the picture on the lid and wonder why what's inside the box doesn't match or make sense.

You meet a lot of people when you start a jigsaw puzzle. Some are full of advice or they may try to make the puzzle look the way it ought to be instead of the way it is.

But, once in a while, you meet someone who shares his or her own finished puzzle and helps you to make some sense of yours. Then you find it is not as hard as before. Some of the pieces fit together more easily, and you sigh with relief ... and remember. ↪

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**A DEATH HAS OCCURRED***Paul Iron*

A death has occurred and everything is changed. We are painfully aware that life can never be the same again, that yesterday is over, that relationships once rich have ended. But there is another way to look upon this truth. If life now went on the same, without the presence of the child who has died, we could only conclude that the life we remember made no contribution, filled no space, meant nothing. The fact that this child left behind a place, that cannot be filled, is a high tribute. Life can be the same after a trinket has been lost, but never after the loss of a treasure.

Reprinted with permission from *Minnesota Sudden Infant Death Center Quarterly Newsletter* spring, 1998.

The other side of grief*continued from Page 3*

wound requires the same priority attention as a physical wound. Set time aside for mourning.

The other side of grief is not freedom from pain nor is it a return to the original picture or dream. It is acknowledging and living your grief. It is finally understanding that we don't get over grief. We get through it.

The heart can mend the hurt and learn to grow and expand, not crumble and die, never to love again. It's to love life once again, despite the twinges of hurt and the catches of pain that will grab hold of us on occasion the rest of our lives.

A tapestry of love

Now as you look back, it is amazing to see the life fabric, no longer ripped apart with a gaping hole, but mended with tiny stitches. Left, perhaps a bit lumpy, patched with time, effort and love. The fabric of our lives has many tears and just as many mends. Old threads and new ones have blended together and have been re-woven into a pattern not quite the same as we had originally planned. It becomes a tapestry of love – our history, to pull around us in time of need, to keep us warm, to shelter us from the storms and to comfort us in the trials.

I used to think BIG A's life was just last week, but now I can count the years accurately. Now I know his life is intertwined with mine and "just last week" has become always ... now ... within.

I have come to know that in letting go of the hurt, I have gained all the wonderfulness that was Austin's life. Our son lived his life surrounded with love and joy. He filled our life with happiness and music. He lived his life at the top of his lungs. I can do no less in his memory.

He brought light to our life. He laughed and giggled and sang. So did your loved ones. Find that music again.

Listen, the summer breeze carries the sounds of remembered love. Capture it! Carry it always in your heart. The sounds of love cannot fade.

I don't need to wait for rainbows to come any more! The rainbow really lives within me. That is the other side of grief. ↪

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Anne Harvieux

**South/Southeastern and
Northeastern Regions:
(414) 266-2746**

Vivian Jackson

**South/Southeastern Region:
(414) 266-2745**

Dora Gorski

**Northern/Western Region:
(715) 843-1877**

EDUCATIONAL PROGRAMS

Oct. 12 - "Giving Bad News,"
Brookfield, Wis.

Oct. 16 - Maternal and
Child Health Leadership
Conference,
Washington, D.C.

Nov. 27 - Milwaukee County
Paramedics, Milwaukee.

March 29 - Presentation to the
Northern Region of Women,
Infants and Children Nurses
on the American Academy of
Pediatrics recommendations.

INFORMATION EXHIBITS

First Wednesday of the
month - Display at New
Beginnings Birthing Center
open house, Aspirus
Hospital, Wausau, Wis.

Jan. 25 - Display at the
Hispanic Health Fair,
Curtis, Wis.

Feb. 10 - Display at the
Hispanic Women's Health
Fair, Wausau, Wis.

March 3 - Beloit African
American Infant Mortality
Coalition Health Fair,
Beloit, Wis.

March 13 - Fulfilling the
Promise, Wisconsin
Dells, Wis.

March 17 - Latino Health Fair,
Beloit, Wis.

April 21 - Watertown Children's
Fair, Watertown, Wis.

OTHER/COLLABORATIONS

- Beloit African American
Infant Action Team.
- Beloit African American
Infant Mortality Coalition.
- Great Lakes Intertribal
Council Honoring Our
Children Program Advisory
Committee.
- Healthy Babies in Wisconsin
Steering Committee.
- Lincoln County Public Health
Department director and
staff – facilitating Cribs for
Kids project.
- March of Dimes and
Association of Women's
Health and Neonatal and
Obstetric Nurses Prematurity
Summit Planning Committee.
- Marathon County Healthy
Babies Committee - plan
education and improve
access to health care and
promote the health of infants
in Marathon County.
- Northern Wisconsin
Neonatal Intensive Care Unit
Transitions Planning
Committee.
- Northeastern Wisconsin
Healthy Babies in Wisconsin
Regional Action Team.
- Racine Infant Mortality
Coalition.
- Southeastern Wisconsin
Healthy Babies in Wisconsin
Regional Action Team.
- Western Wisconsin Healthy
Babies in Wisconsin Regional
Action Team.

PROGRAMS FOR FAMILIES

Nov. 5 - Memorial program.
Dec. 14 - Special Christmas
candle lighting memorial
for the SAID Group.
SAID Group meets the second
Thursday of every month at
Children's Service Society

of Wisconsin, Wausau, Wis.
April 13-14 - Spring Family
Bereavement Conference,
Olympia Resort and
Conference Center,
Oconomowoc, Wis.

COLLABORATIONS

The Center continues to be
involved with:

- Association of SIDS and
Infant Mortality Program
Professionals.
- Black Health Coalition.
- Community Health
Improvement Project.
- Dane County Child Fatality
Review Team.
- Fetal Concerns Program.
- Fetal Infant Mortality
Healthcare Action Team.
- Great Lakes Intertribal
Council Honoring our
Children Project.
- Healthy Babies in Wisconsin
Steering Committee and
Regional Action Teams.
- La Causa.
- March of Dimes.
- Milwaukee Birthing Project.
- 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 and Faith Based
Community Health
Committee, Black Health
Coalition.
- Racine County Death Review
Team.
- Spanish Center of Kenosha.
- 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.

DONORS

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Ms. Sheri Wilde
Mr. and Mrs. Warren L. Wilson

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 Oct. 1, 2006, and Dec. 31, 2006.

Alex Amundson
Dick and Peggy Larsen

Erik Baumler
Mr. and Mrs. Brian R. Baumler
Mr. and Mrs. Richard Baumler

Vincent Paul Cannariato
Col. Pops Popcorn Co.

Edna Christianson
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David Joseph Crawford
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Patrick Forest Harrington
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Mrs. James L. Harrington

Ellen Marie Hoffman
Warren and Georgia Wilson

Andrew Schoech
Mr. Philip E. Schoech and
Ms. Rita C. Sweeney

Madeline R. Thorpe
Mr. and Mrs. Daniel N. Burnside

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

IN HONOR OF

Family Services: Anne, Maggie, and the whole 6th floor crew
Mrs. Arlene S. Mann

Below is a list of Web site links that may be helpful resources to you:

Infant Death Center of Wisconsin, www.idcw.org

Learn about the Infant Death Center, read online articles from *Wisconsin Perspectives*, and information about grief, loss and risk reduction.

Children's Hospital of Wisconsin, www.chw.org

This site provides an online magazine, information on health and safety, as well as other pertinent information.

Crisis, Grief and Healing, www.webhealing.com

Find links to a wide range of Web sites including ideas on how to honor your child and articles from grief therapists.

The National SIDS/Infant Death Resource Center, www.sidscenter.com

This site provides access to, "The Death of A Child, the Grief of Parents: A Lifetime Journey", to assist families in their grief as well as other information on sudden infant death. It also provides information on safe sleep and SIDS risk reduction.

The Compassionate Friends, www.compassionatefriends.com

The Compassionate Friends assists families in the positive resolution of grief.

M.i.s.s. Foundation, www.misschildren.org

This site provides support to families and seeks to increase public awareness and decrease infant mortality.

National Institutes of Health, National Institute of Child Health and Human Development, www.nichd.nih.gov

Provides up-to-date information on the Back to Sleep campaign, safe sleep environment and federal initiatives to educate the public.

A Place to Remember, www.aplacetoremember.com

This site offers support materials and resources in dealing with a crisis in pregnancy or an infant death.

Safe Kids, www.safekids.org

Safe Kids is dedicated to the prevention of childhood injury. Safety tips are updated regularly.

U.S. Consumer Product Safety Commission, www.cpsc.gov

This site provides information on product recalls and ways to reduce the possibility of injury or death from consumer products. It includes information on throwing a baby safety shower. This site also provides an interactive section for children on safety in the home.

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. 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 Vivian Jackson at (414) 266-2745 or vjackson@chw.org. To reach the satellite center in Northern/Western Wisconsin, contact Dora Gorski at (715) 843-1877 or Dora.gorski@csw.org. To reach the satellite center in Northeast Wisconsin, contact Anne Harvieux at (414) 266-2746 or aharvieux@chw.org.

NEW ARRIVALS

Congratulations to the following family on their new arrival.

Micah Marie Cannariato was born June 27, 2006, to Paul and Stacy Cannariato.

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



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