

Anger

Irritations ... the world is out to get me. Friends, family, no one can do anything right. Trivialities I could always let go of before now loom large. Those who offend receive my wrath. Anger smolders near the surface to erupt at the slightest provocation. My sensibilities are damaged, my mind one enormous bruise exposed to the world and injured by the slightest touch. Friends have not forgotten me. They continue to reach out, though their efforts are often met with displeasure and contempt. It's just me against the world. This anger consumes all. It's the focal point of my existence.

I've signed up for painting lessons to fill the time, to fill the void. Today's artistic attempt must be a still life – a conch shell, a vase, a music box must be arranged in some pleasing order. But it's all wrong, there's no life in this shell. I can't get it right. "Shells are the most difficult," the instructor says. She, with the brush, dabs a little here, a little there.

"Why are you putting red here?" I ask.

"Because I see red," she answers.

But I cannot see red, nor do I see any rhyme or reason to her strokes. I'm left with a shell I can't recognize.

"Build on the values," she says.

What values? This is a nonsense I can't handle. I won't remain. I walk out, never to return.

It's Easter-time and I must shop for the Easter baskets. Going into the stores, I wish someone would notice Alex's absence and ask about him. I'm incensed when his life and death are ignored. But when it does happen, I don't know how to reply. My moods are so sullen, I often surprise myself in my reaction to others.

We've had a special picture made of Alexander, and the children accompany me in my search to find just the perfect frame. I've brought the picture, holding it up to this frame and that frame. Such a kindly clerk, she meant no harm. "Oh, you don't have that one with you." I want to destroy her and could have. It was on the tip of my tongue, "No, he's not with me. He's dead!" But I think better of it and simply reply, "No." What is it about human beings that make us want to lash out and hurt others when we are hurt?

In public places I often see parents with tired, fussy children. I have always cringed when frustrated parents physically abused their small children, but now my reaction is violent. It upsets me so that I cannot remain nearby and I want to scream at them that they don't know what they are doing. I see in that screaming child the suffering of my own dead son.

"Be thankful that you have your other children." How many times have I heard those words, and how strange and inadequate they sound to me now. Of course, I'm grateful for the children, grateful to have something left. But Alex's death is an irreplaceable loss. Why don't these people know that? "It's meant to be ... God's will ... he's better off ... you've been chosen as a shining example for others." Deliver me from people who have all the answers!

Doctors are high on my list of enemies. Of the six doctors who saw Alex in the last few months of his life, I'm not speaking to any of them. Phil, a medical student and personal friend, can see both sides. But today he looks like a doctor. So much anger – had it not been for a great deal of wine, I would

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not have been able to say those things. Years of suppressed rage and hatred toward the medical community are vented, and he is the target. My accusations are totally out of order and very unfair. Phil will allow me my anger and my pain, but friends are hard to come by these days. I must not abuse the ones I have.

It's Little League season, the first game of the year is ahead of us. This is my oldest son's activity and has nothing to do with Alex. Or does it? I've made no mental preparation for this first, allowing it to come upon me without realizing the implications. Driving to the game, my mind is racing. Alexander was born during baseball season. He attended his first game at five days of age, never missing a ball game until now. It was jubilation that exquisite day, the day of his birth. He had not been born two minutes when plans were being made for Alex's baseball career. By the time he could stand, the coaching had begun. And now comes the total realization that Alexander will never play ball.

I can feel the impending disaster, but it is too late. Entering the gate, too many sensations, too many people are crowding in on me, These are summertime friends, many we've not seen since last year. It was inevitable; it had to happen sooner or later.

"Hello, hello. Good to see you. Where's your little guy? I'll bet he's getting big."

"No. He died."

They shrink from us; we've ruined their day. They avoid us like the plague for the rest of the season. I need not repeat it again and again. The word spreads like wildfire, and

we're spared many more embarrassing encounters. We're generally ignored and I add it to my growing disgust about people in general.

We're at a social disadvantage. We can present to the world only what we are, be that good or bad. There is no finesse for presenting an image which is not real, to show ourselves in any better light. The social games that are played on all levels seem ridiculous to me now and totally beyond my emotional capabilities. I can only participate in open, honest relationships and will accept nothing less in return.

At this point others are ready to see us move on. But for us, the pain is still acute, the enormity of our loss is only now becoming totally apparent. While my need for understanding is increasing with each passing day, the resources of most of my friends to help is nearly exhausted. Friendships based on my former life may or may not fill current needs on both sides. Tragedy strips human beings of the protective covering they use to hide from their own inner fears and insecurities.

The attitudes of others toward us are not so much determined by how much they care, but rather by their own personal attitude toward life and death. For some, our situation is far too great a threat to their own personal equilibrium. They can choose to escape from my pain, but that choice does not exist for me.

I am becoming more and more selective in seeking out sounding boards, those to listen, those who can understand. Grief has become too complicated, too confusing to share with anyone whom has not been personally touched by crisis. No other perspective can bring any source of

strength. As old friendships are put on hold for "someday," miraculously new support people surface to fill the void. I've never had a stronger sense of being watched over and cared for by God Himself. Invariably when the road is too rocky, the right person is sent to show me the way. Those who can no longer help in the emotional sense must still be praying for me, because aside from a weak, "help me," I've little to say to God.

The religious questions hang heavy. Since Alex's death, God and I have a healthy respect for each other, yet I keep my distance. If anything, my spiritual conviction has multiplied, feeling His presence in the most unsuspecting ways. I've questioned, not God's existence, but rather His good judgment and His love for me.

Prayer is still the ultimate stumbling block. Hundreds of prayers were offered for Alexander's healing. There are those who will argue that Alex was healed, the most perfect of healing. I cannot disagree, yet this concept is not compatible with my expectations. I wanted him healthy and alive. "Ask and you shall receive." Why didn't it work?

Prayers, once food for the soul, now feel strange to me. Each time a prayerful thought occurs my mind is triggered. Why weren't my prayers answered? Why? Why? Why?

Between my husband and me, the mood is abrasive. Small quirks are magnified out of proportion, little irritations we'd learned to tolerate in each other years ago come back to haunt us. The old insecurities, those helpless childhood feelings, come to the surface to get in the way of mature interaction. We struggle to

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Research review

By Ralph A. Franciosi, MD – *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.*

The folic acid vitamin story

In 1991, the Medical Research Council of Great Britain determined that pregnant women who consume enough synthetic folic acid before and during the early weeks of pregnancy did not have infants with folic acid-preventable spina bifida and anencephaly (neural tube defects). In the United States, the highest rates of neural tube defects occur among Hispanic women and the lowest among African American and Asian women. The current U.S. Public Health Service and Institute of Medicine recommendations are that women of reproductive age should consume 400 mcg of synthetic folic acid daily to prevent these neural tube defects. Currently, this level is best obtained through vitamin supplements.

In 1998, the U.S. Food and Drug Administration required the enrichment of cereal grain products (corn and wheat flour) with folate. There has been a statistically significant decrease in neural tube defects among Hispanic and non-Hispanic Caucasian births following the enrichment of cereal grains. The estimate of folic acid consumption of women of reproductive age is 200 mg of synthetic folic acid per day.

There is a public health debate about increasing the folic acid fortification levels in cereal grains. Questions that are being addressed include eating habits, access to folate-enriched grains, (corn tortillas are not fortified), addition of other vitamins (e.g., vitamin B12) and the safety of increased fortification.

As this debate continues, medical professionals still agree that women of childbearing age should be encouraged to use a daily multivitamin with 400 mcg of folic acid. ❖

¹ MRC Vitamin Study Research Group. Lancet. 1991; 338:131-137

² Centers for Disease Control and Prevention. MMWR Recomm Rep. 1992; 41 [RR-14]: 1-7

³ Mills JL, Signore C. Birth Defects Res A Clin Mol Teratol. 2004; 70: 844-845

⁴ Quinlival EP, Gregory JF. Am J Clin Nutr. 2003; 77: 221-225

⁵ Rader JI, Schmerman BO. Pediatrics 2006; 117:1394-1399

Helpful medical terminology

- **Gestation:** the length of time from conception to birth (length of pregnancy).
- **Infant:** a child under 1 year.
- **Neonate:** an infant less than 28 days old.
- **Postneonate:** an infant between 28 days old and 1 year.
- **Prematurity:** a shortened pregnancy in which delivery occurs any time prior to completion of week 37 of gestation (pregnancy). Prematurity is commonly referred to as a pre-term birth.
- **Premature:** an infant that results from a premature birth.
- **Term gestation:** the delivery of an infant between 38 and 42 weeks of pregnancy.
- **Post-term:** the delivery of an infant after 41 completed weeks of gestation. Post-term is commonly referred to as post-dates pregnancy.

What is an Apgar Score?

The Apgar Score refers to a scoring system applied to a newborn infant immediately after delivery. Virginia Apgar, MD, was an anesthesiologist at the Columbia Presbyterian Medical Center in New York City, caring for pregnant women. She was concerned about the newly delivered baby and devised a standardized assessment of the baby's condition. The Apgar Score records the infant's heart rate, respiratory effort, muscle tone, reflex irritability and color. These five components are given a number score from 0 to 10 with the best score 10 and the worst score 0. The Apgar Score does not predict outcome. The original Apgar Score is being updated. ❖



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keep some semblance of our former selves, to tap back into the safety of the dynamics that allowed our relationship to exist all these years. I live with the constant fear that another tragedy will befall us before we have picked ourselves up. That helpless out-of-control feeling permeates all.

The children are defensive, argumentative, difficult to get along with, their nerves on edge, their self esteem also hanging in the balance. They must surely feel as if their existence in life is of no value, that Alexander was everything to us. It's not so, and yet his loss has become an unreal, all-consuming focus in our lives.

Joe and Bethany are in constant confrontation, far more damaging and serious than the normal sibling squabbles. And together the two older converge on Amanda, tormenting her 6-year-old existence. Their world has fallen in and manifests itself in anger. The three of them are at each other constantly.

Amanda, who has not shown any outward signs of grief for weeks, suddenly shares the depths of her emotional turmoil. It's just a minor mother-daughter confrontation, "Put on your

shoes." But it explodes from inside of her. "My life is ruined. Nobody knows that I have feelings, that I am sad and that Alex is dead. Nobody cares. My friends don't care. Why didn't they come to the funeral home? It was for children, too."

Just a baby, but she faces the same social problems we adults face. Many of her friends have been instructed to avoid talking about Alexander. To Amanda it is an insult, a sign that they don't care about her or her grief. Death is part of life and life should not be ignored.

One morning I heard her talking back to Sesame Street. They were singing a song differentiating living creatures from inanimate objects. Joyful moppets sang, "I'm alive, I'm alive." And she screamed back, "So what? My baby brother was alive, and now he's dead!"

Grief represents for us a series of surprises. The fabric of each day is punctuated by hostility and outrage. We hurt and we fight back, and our pain manifests itself in anger! ❖

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Don't tell me that you understand,

Don't tell me that you know.

Don't tell me that I will survive,

How I will surely grow.

Don't tell me this is just a test,

That I am truly blessed,

That I am chosen for this task,

Apart from all the rest.

Don't come at me with answers

That can only come from me,

Don't tell me how my grief will pass

That I will soon be free.

Don't stand in pious judgement

Of the bonds I must untie,

Don't tell me how to suffer,

And don't tell me how to cry.

My life is filled with selfishness,

My pain is all I see,

But I need you, I need your love,

Unconditionally.

Accept me in my ups and downs,

I need someone to share,

Just hold my hand and let me cry,

And say, "My friend, I care."

Somewhere you haven't been

By Barbara Cuce



It was a bitter cold winter on Jan. 13, 1994, when Christopher was born, but tears of joy and happiness soon turned into tears of anxiety, anger, emptiness and finally, loss.

Words could not express the feelings we had when Christopher passed away. Perhaps shock and disbelief were the first emotions to surface. When it happened, people were all around us, visiting, calling, sending cards – and this was the right thing to do. It seemed to hold us together. But soon the phone calls became less and less, the visits infrequent and people went on with their own lives. They didn't realize that our lives had been changed forever. I would never be the same. Before, I had been happy and full of life, but now, my life was changed forever, and all my dreams were shattered.

I began to realize that people shied away, either because they didn't know what to say or because it could be a reality for them and they couldn't

deal with that. In any case, other feelings of loneliness also began to sink in. People who know what had happened either ignored me or said something inappropriate. Often, they don't realize that the death of a child is not something you get over in one week, one month or one year. It's something you carry with you for a lifetime. You just learn to live with it.

I don't blame these people. Most of us don't want to deal with death, but I wish people could be more sensitive to others' feelings. They need to allow time to listen to us, let us cry, talk or just be silent. It's better to recognize grief that others may be experiencing than ignore it. It did happen and my baby was real, even though perhaps to them he wasn't.

It has been nine months and I never thought I could have made it. Each day is a struggle in a different way. In the very beginning, there were days I didn't want to get out of bed or I cried all day. Though there were days I didn't feel I had anything to

live for, I have walked through it. I have looked at my grief and dealt with it through counseling and support groups. I've been able to share my pain. I only hope that one day I can help someone else walk through his or her pain.

My life will never be the way it was before. Perhaps people who were friends at one time will learn to accept me as the new person I am and stop trying to make me the person I used to be. Everyone wants to do the right thing and I've learned the right thing is to listen and not be judgmental. Allow us to grieve the way we need to. It's like a roller coaster ride – there are ups and downs. Let us remember this walk is not a race, everyone moves at a different pace. The pain is real and only time can lead us down our journey to healing and one day feeling happy again. ❖

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Center and satellite summaries

U P D A T E

Infant Death Center and South/ Southeastern Region

Anne Harvieux: (414) 266-2746
Vivian Jackson: (414) 266-2745

Educational programs

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

- March 4 - African American Health Fair, Beloit.
- March 28 - B.A.B.E.S., Appleton.
- May 31 - Concordia Parish Nurse Conference, Mequon.

Informational exhibits

- March 4 - African American Health Fair, Beloit.
- March 28 - Regional Prenatal Care Coordination Training, Milwaukee.
- April 5 - Fetal Infant Mortality Hospital Collaborative, Milwaukee.
- April 17 - Essential Tools for Life, Milwaukee.
- April 24-25 - Wisconsin Association for Perinatal Care Conference, Milwaukee.
- April 29 - Latino Health Fair, Beloit.
- May 13 - Women of the World Conference, Milwaukee.
- May 24-25 - Wisconsin Public Health Association meeting, Wisconsin Dells.

Other

- Feb. 17 - Meeting with Beloit Memorial Hospital Obstetrics and Gynecology Committee.
- Feb. 22-24 - Attended Caring Connection Conference, Philadelphia.
- March 8 - Meeting of Healthy Babies in Wisconsin Southeast Regional Action Team.
- March 13 - Meeting of the Beloit African American Infant Mortality Coalition.
- April 20 - Meeting of Healthy Babies in Wisconsin Southeast Regional Action Team, Milwaukee.
- April 24 - Meeting of the Beloit African American Infant Mortality Coalition.

- May 4-6 - Regional Healthy Start Meeting, St. Louis.
- May 9 - Meeting of Healthy Babies in Wisconsin Steering Committee, Madison.
- May 15 - Meeting of the Beloit African American Infant Mortality Coalition.
- June 26 - Meeting of Healthy Babies in Wisconsin Southeast Regional Action Team, Milwaukee.
- July 26 - Wisconsin Maternal Child Health Coalition, Madison.

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.
- April 7-8 - Family Conference, Wintergreen Resort and Conference Center, Wisconsin Dells.
 - May 7 - Memorial Program, Zoofari Conference Center, Milwaukee.

Collaborations

- The Infant Death Center of Wisconsin continues to be involved with:
- Association of SIDS and Infant Mortality Program Professionals.
 - CHIMC.
 - 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 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.
 - Racine County Death Review Team.
 - Family Resource Center of Sherman Park.

- 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

- April 27 - Presentation on the American Academy of Pediatrics to the public health nurses and Start Right home visitors, Marathon County.
- June 7 - Presentation at a baby-sitting clinic, Lincoln County.
- June 24 - Presentation at Women, Infants and Children Conference, Appleton.
- August 22 - Ninth Annual Public Health Nursing Conference.

Informational exhibits

- March 1, May 3 and June 7 - Display at New Beginnings Birthing Center open house, Aspirus Hospital, Wausau.
- June 29 - Display at Women, Infants and Children Conference, Appleton.

Media interviews

- March 10 - Interview with Diane Rodd about SIDS on Wisconsin Rapids radio station.

Other

- March 31 - Honoring Our Children meeting, Lac du Flambeau.
- May 2 - Infant Death Center of Wisconsin staff meeting, Portage.
- May 3 - Neonatal Intensive Care Unit Transitions Planning Committee meeting, Wausau.

Center summaries continued

May 11 - Media training, Milwaukee.
May 22 - Perinatal Action Committee Meeting, Marathon County.
May 31 - Western Region Healthy Babies Action Team Meeting, Eau Claire.
June 5 - Western Region Community Council meeting.
June 5 - Northern Region Community Council meeting.
June 23 - Statewide Community Council meeting.

Northeastern Region

Pam Bracewell: (920) 969-7903

Educational programs

March 16 - B.A.B.E.S., Appleton.

Other

Feb. 19 - Meeting with staff at St. Joseph's Church, Wautoma.

Feb. 28 - Healthy Babies in Wisconsin Northeast Regional Action Team meeting.

April 28 - Northeast Regional Community Council meeting.

Collaborations

The Northeast regional office continues to be involved with:

- The Center for Grieving Children.
- Hispanic Interagency Council.
- Hmong Interagency Council.
- Northeast Healthy Babies in Wisconsin Regional Action Team.

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, and May 31, 2006.

Mr. Michael N. Buresh
Ms. Kathleen Condon
Mr. and Mrs. Robert M. Dulski
Ms. Christina L. Fladhammer
Emma Jalin Oldenburg Annual Memorial Ride & Poker Run
Ms. Terri Lasley
Ms. Deb A. Litterer
Mrs. Arlene S. Mann
Ms. Laurie Misslich
Ms. Nancy Nawarawong
Mr. and Mrs. Robert W. Plotz
Ms. Renee A. Prink
Mr. and Mrs. Anthony P. Schiel
United Way of Greater Milwaukee
Ms. Sheri Wilde
Mr. and Mrs. Warren L. Wilson
Ms. Patricia L. Wolfgram

In memory of

Kenneth F. Butterfield

Mrs. Arlene S. Mann

Matthew Alexander Gauthier

Mr. Michael N. Buresh

Ellen Marie Hoffman

Mr. and Mrs. Warren L. Wilson

Taylor Marie OKray

Ms. Patricia L. Wolfgram

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Mrs. Arlene S. Mann

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Ms. Terri Lasley

Joey Von Bank

Mr. and Mrs. Anthony P. Schiel

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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 Vivian Jackson at (414) 266-2745 or vjackson@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 Pam Bracewell in Northeast Wisconsin at (920) 969-7903 or pbracewell@chw.org.

New arrivals:

Congratulations to the following families on their new additions:



Samuel Malachi Hapka was born June 6, 2006, to Nicole and Andrew Hapka.

Solomon Suaria Jaipuri was born May 24, 2005, to Sandy and Sabba Jaipuri.

William James Kobow II was born Feb. 15, 2006, to Antonia Kopaczewski and William Kobow.

Lauryn Kathleen Nichols was born Jan. 14, 2006, to Michael and Michelle Nichols.

Jenna Christine Zurn was born June 26, 2006, to Jenni and Jeff Zurn.



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