

# For Those Who Give and Grieve



A quarterly newsletter for donor families, published by the National Donor Family Council of the National Kidney Foundation, to offer information about grief and support.

*For Those Who Give and Grieve* is provided to all families at no cost.

Summer 2003

Visit our *new* home for donor families at [www.donorfamily.org](http://www.donorfamily.org)

Volume 12, Number 1

## when others' attempts *to help fall short*

By Mark Somerfield, PhD

The late Erma Bombeck, in her timeless wisdom, once wrote, "What this country needs is a course in how to make people feel good." Many people, it seems, are just not very good at responding to others' misfortune. This is not for a lack of trying, as many who have lost a loved one can attest. Most people actually are well meaning, caring and guided by a desire to help. However, even well meaning individuals can say truly awkward, and sometimes downright bizarre comments in the face of others' devastating loss.

Examples of these comments are many and varied, and you probably have your own collection of insensitive or awkward responses to your loss. Many begin with the telltale phrase, "It could be worse...", as in, "It could be worse. At least you had time to prepare for his death," in reference to a loved one who passed away following a lengthy illness. In other instances people may offer gratuitous (and

sometimes ridiculous) advice. Social psychologists Camille Wortman and Darren Lehman cite the example of someone who was told to take her son's picture down following his death, presumably to ease the pain associated with looking at it. In yet other cases, people try to minimize your experience. Consider the statement, again cited by psychologists Wortman and Lehman, offered after the loss of a child: "You can have another child. It can't be that bad." Finally, for some, the worst comment is the one that suggests that the other person can relate to what you are experiencing, as reflected in the statement, "I know exactly what you're going through." Few people who haven't had your experience truly can relate to it.

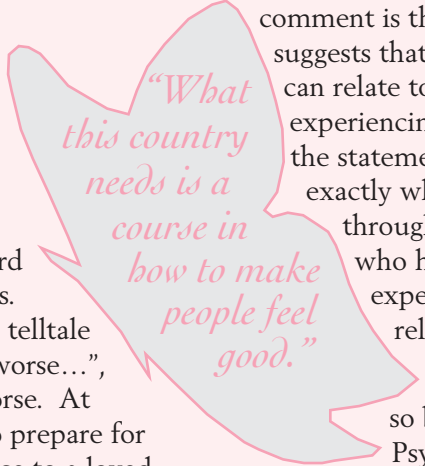
Why are people so bad at this? Psychologists have suggested a number of reasons. First, people lack experience in responding to traumatic loss; thankfully, such losses are relatively

rare in our modern everyday experience. Given this, people often fumble about and make odd statements intended to comfort. In short, Erma Bombeck was right: The country needs a course in how to make people feel better.

Second, contact with someone who has suffered the loss of a loved one makes people feel uncomfortable and more vulnerable to loss themselves; minimizing your loss helps them feel better about their own chances of suffering a similar fate.

Third, people carry misguided beliefs about how most others should react to loss, especially as related to the timeline for recovering from the loss of a loved one. After a time—often a year is the assumed period, for some reason—you may receive subtle messages that it is time for you to "come to terms" with your loss and "move on with your life." This is probably seen most often among those who have lost a spouse. The notion that

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# Dear Editor

Dear Ms. D'Acquisto,

Each time I receive the quarterly *For Those Who Give and Grieve*, I find some comfort in dealing with the loss of my brother, David Michael Jones, who passed away on February 8, 1998 and was an organ donor. Sometimes it seems like yesterday and not five years ago. Like many others, I know that each of us must take our own steps forward in dealing with our grief, and as I read each article in every newsletter, there is always something that touches my heart.

I would like to share a memorial my sister, Doris Crist, wrote about our brother. As you can see, she used his name in a way that describes him well.

I thank God every day for sharing him with us, even though it was only for awhile. To have had my brother as a friend truly was a blessing. To have him as my younger brother was one of the greatest gifts God has given me.

Again, thank you all at the National Donor Family Council for all your help and support in my families' time of need. To have been able to give a part of my brother to others truly honors him too.

Sincerely,  
Sandra Feinberg, Donor Sister  
Maryland

## Michael

Michael was a **M**aster of his craft, a carpenter by trade. **I**nvolvement in his community, he was a volunteer firefighter and always a good neighbor there with helping hand. **C**aring and sharing whatever the need may be. **H**e was happy, handsome and hard working. **A**lways quick with a joke or a helpful word of wisdom, if you were down he didn't walk away until you smiled. **E**ternally in the hearts and minds of everyone who knew him. **L**oves of his life, first and foremost his family; second, Michael loved the great outdoors. If there was a scent of deer in the air he would head for the woods. If the sun was shining he could hear the fish calling him by name. Michael could see beauty in every day. The beauty that we would sometimes overlook.

*Michael was a loving son, loving brother, loving husband, loving father, and to be his friend was to have a best friend.*



### FOR THOSE WHO GIVE AND GRIEVE

For Those Who Give and Grieve is published quarterly by the National Donor Family Council of the National Kidney Foundation (NKF). Opinions expressed in this newsletter do not necessarily represent the position of the National Kidney Foundation. The NKF reserves the right to edit all submissions. Please contact the NKF for article submission, guidelines or permission to reprint articles.

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## *“Griefburst” and 10 Year Anniversary*

By Pat Brown, Donor Mom

**G**rief experts say that periods of heightened sadness are a part of grieving. These periods can be overwhelming, come out of nowhere and be very frightening and painful. Even long after a death has occurred, something as simple as a smell or phrase can bring on a “griefburst.”

My most recent “griefburst” occurred a day after what would have been my son’s 10<sup>th</sup> birthday. Michael was born March 4, 1993, and died of SIDS six weeks later. The day of his “birthday,” my family had a cake complete with 10 candles, sang “Happy Birthday” and watched a video of baby Michael.

I was so proud of myself! Ten years after his death, my husband and I are happy, healthy and have three subsequent children. Sure, I shed tears while we watched the video, but I was a together woman who made it through the 10-year anniversary! But on the next day, March 5, I had a “griefburst” with such force that I knew I was never going to be completely done with my grieving process.


On that morning there was a snowstorm. My third grader had her eyes glued to the TV to be sure her school was closed. It was! Then the TV news anchor announced a special story about a marine and his newborn son. With curiosity I sat down and listened.

A marine Major named Hal Sellers had an infant son awaiting a heart transplant. He and his wife had to choose between duty to family and reporting to duty to our nation. Since there was nothing he could do to help four-month-old Dillon, he chose to help his military unit. Sellers reported to duty in a foreign country. Dillon had Hypoplastic Left Heart Syndrome, which is when the heart is unable to pump or circulate blood. He was on the transplant list at Loma Linda University Medical Center in California.

As I listened, I cried and cried. My son was an organ donor. His heart was transplanted at Loma Linda to an infant with Hypoplastic Left Heart Syndrome. As I watched, I knew our Michael had saved a baby just like Dillon. My baby was a hero. The grief and longing for him was overwhelming. Ten years seemed like only a few days since I had lost him.

Grief experts say you should allow yourself to experience “griefbursts” without shame, no matter


when or where they occur. “Griefbursts” are a normal part of grieving. During my “griefbursts,” I take great comfort in knowing that my son was an organ donor. During the past 10 years, I have been helped tremendously by the National Donor Family Council and their newsletter. It is with great pride that in my son’s tenth anniversary year, I can also say congratulations and thank you to the National Donor Family Council for 10 successful years!

(There is good news to report about Dillon. He received a new heart several weeks after the story aired and is progressing nicely.) 

### **when other’s attempts to help...**

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you need to “move on,” sometimes reflected in suggestions to get back into the dating scene, can be viewed as absolutely absurd among people who have lost a valued lifelong partner.

So, given the inability of many to respond in sensitive ways to your loss, what can you do when faced with these responses? As in many uncomfortable social circumstances, there are few ready solutions. It may be helpful to have a standard response available to respond in these situations. For instance, if someone makes a statement to the effect that it’s been a long time since your loved one died and you should consider moving on, you might reply by saying, “Thanks for your concern, but we still miss her very much and probably will for a very long time,” or, “Things do get a little better with time, but he is still very much in our thoughts.” Finally, it may be helpful to recognize that people are simply unskilled at responding to you in these situations. Seldom is any harm meant, and, too often, the person walks away feeling horrible about a weak or failed attempt to help. This probably will not take the sting out of an insensitive comment at the moment it’s offered, but it may help put it in perspective later on. 

### **About the Author**

*Dr. Mark Somerfield received his PhD in research psychology from the Johns Hopkins University School of Public Health. He has published extensively on stress and coping processes.*

# Donor Families Around the World

## Reflections on the 13<sup>th</sup> World Transplant Games

By Carol S. Hagiwara, Donor Mom

In 2001, as a representative of the Hawaii Donor Family Council, I flew to Kobe, Japan for the 13<sup>th</sup> World Transplant Games. The Japanese have been slow to embrace the concept of donation. It wasn't until 1997 that Japan adopted an organ transplant law, and the first transplant under this law did not occur until February 1999. The 13<sup>th</sup> World Transplant Games attracted 800 recipient-

Games, and himself a kidney recipient. Prior to the Games, it had taken some persuading to get Mr. Ohkubo to consider including donor families in the event.

But something remarkable happened during the Donor Recognition Ceremony, where a large heart of origami cranes was created as the symbol of the Games. Watching the heart take

and gracious toward all the donor families.

### Opening Ceremony

The Opening Ceremony was emotional. Enthusiastic recipient-athletes paraded into the arena with their teams, just like at the Olympics. Once they were seated, the donor families were welcomed into the arena with a spontaneous, extended, tearful standing ovation.

The healing started even before the donor family processional. A sole donor sister left the donor families that were grouped against the wall under the arena. She walked and stood with the energetic teenage dancers who lined the corridor and cheered the athletes as they passed into the arena behind their countries' flags. She reached out her hand and, as the athletes extended their hands and they touched, she realized the power of the decision she and her dad had made. Almost giddy, she ran back and grabbed a donor mom, and after a few moments the two of them ran back and grabbed a third person. The three of them stood there, touching the recipient-athletes, perhaps even touching someone they had saved. It was a very special experience.

While I had anticipated the emotional impact for the families, I was unprepared to hear "Let Me" (a song written for my daughter Amy) used for the processional. What an honor and privilege to realize that Amy was now touching people internationally.



athletes from 48 countries and over 200 media personnel. What a dramatic opportunity to demonstrate the miracle of transplantation to Japan, in Japan!

### Donor Recognition Ceremony

The Donor Recognition Ceremony was only the second in all of World Transplant Games history and the first ever in Japan. Although listed as the "cooperator" in the official program, the Japan Donor Family Club needed to obtain approvals from Mr. Michikata Ohkubo, the head of the Kobe World Transplant

shape, Mr. Ohkubo, standing next to me, started to cry. I touched his arm and told him that, together, we would affix our cranes. We did, and afterward bowed to each other. At that moment, we were not on different sides; we were part of the circle, and the circle had finally closed.

By the end of the evening, we no longer simply shook hands. At each personal encounter during the rest of the Games, Mr. Ohkubo and I exchanged hugs. And for the balance of the Games, Mr. Ohkubo was accommodating

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## Donor Families Around the World

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### *Closing Ceremony and Gala Dinner*

Mr. Yoichi Mazawa, a donor father who was instrumental in the passage of Japan's organ transplant law, was invited to join the other dignitaries speaking at the Closing Ceremony on Saturday afternoon at the track and field stadium. He spoke on behalf of the donor families, reminding everyone to remember the origin of the gift, congratulating the recipient-athletes and wishing them continued health and strength. He also publicly thanked the Hawaii contingent for its support and efforts helping the Japan Donor Family Club.

The Gala Dinner later that evening was a blowout

celebration. With two casks of sake opened, the party was starting to really heat up when the emcees announced a special presentation from Hawaii. A Kobe hula halau (school) had indeed come through for us. Twelve ladies, dressed in white muumuus and bedecked with their silk maile and our kukui nut lei gifts, were ready to perform a hula to "Let Me." I introduced the song in Japanese and English and the ballroom grew silent as the troupe performed. Immediately following the hula, there were hugs all around. The spirit of *aloha* had truly pervaded the Games.



*Michikata Ohkubo and other organizers of the 13<sup>th</sup> World Transplant Games.*

*Amy was 10 when our family consented to the donation of her corneas and heart valves in 1997 in Hawaii. A viral infection in her brain when she was three months old had left Amy severely handicapped. A child who was virtually blind gave two people sight. A child who would never walk gave two children the gift of dance. A child who would never talk has spread her song throughout the world.* 🌸

# it's official

In celebration of the 50<sup>th</sup> Anniversary of Transplantation, the 2004 U.S. Transplant Games will be held in Minneapolis - St. Paul from July 27 to August 1.

The Games, presented by the National Kidney Foundation (NKF), are the largest sports event in the world for people with life-saving organ transplants.

The U.S. Transplant Games have grown from 1,000 people in Indianapolis in 1990 to over 8,000 in 2002 in Orlando. The five-day event also features recognition and educational experiences for recipients' families, families who have donated loved ones' organs and/or tissues, living donors and medical professionals.



atching future newsletters for more information about donor family involvement the next U.S. Transplant Games, "The National Celebration of 50 years of Transplantation." Or look on-line at our Web site: [www.donorfamily.org](http://www.donorfamily.org)

# for *teens*

## what helps *when it hurts*

By Jennifer Cerney

When my dad passed away I thought that the world would end and I would never have any joy in my life again. Well...guess what? I was wrong.

Sure it was hard, but eventually I learned how to deal with it. I often would, and still do, go on long walks and just remember how happy I was when I got to be with my dad, Craig Cerney. We did so much together and I'm so lucky to have had a dad as great as him. I'm lucky to have memories to look back on, and I'm lucky that he no longer has to suffer.

My good friend, Courtney, taught me that I can't be selfish. I didn't get it at first, but now I realize what she means. She

taught me that I can't always want, want, want. She meant that I have to realize that he's in a better place, and I can't just want him back for myself to be happy. I have to realize that he is in a better place and that God took him for a good reason. I also have to realize that if he were still alive, then he wouldn't get to enjoy his life or live it to fullest. But now he gets to live in peace.

Some other things that help me are to listen to songs and let all my emotions out, crying, laughing on the good times and even saying what I'm feeling as if he were right there beside me the whole time. I also often watch home videos, write tons of poetry and look at pictures.

My brother isn't very open to talking about it, and he is one of the only people that I know who actually knows how I feel, so I have some alone time and think about everything: the good times, the hard times, and I wonder what it would be like if he were still here. Then it hits me—instead of wanting him back, I know that he is happy right where he is. And I smile, because I know he's doing great and I know that he's smiling right back at me, saying, "I love you and want you to know that no matter what you do, I'm right here with you through it all, Jelly Bean." And with that, I know that I have the perfect dad, watching over me right now, my guardian angel. 🌸

## *The Quilt on Tour*

Please note: This schedule is subject to change. Call the National Donor Family Council at (800) 622-9010 for the most up-to-date information.

### 2003

- |                   |   |
|-------------------|---|
| July 11 - July 13 | Washington, DC, HRSA - NKF, <i>National Donor Recognition Ceremony and Workshop</i> , Jennifer Martin, (212) 889-2210     |
| July 27 - July 30 | Hudson, WI, <i>The Third Annual Liver Transplant Family Educational Seminar and Picnic</i> , Amy Breummer, (715) 377-0631 |
| July 31           | New Brunswick, NJ, Phi Sigma Sigma, <i>Phi Sigma Sigma Summer Leadership Training School</i>                              |
| September 28      | Syracuse, NY, Finger Lakes Donor Recovery Network, <i>Donor Family Celebration</i> , Susan Michaels, (315) 425-1569       |
| October 5         | Oklahoma City, OK, Oklahoma Organ Sharing Network, <i>Donor Family Recognition Ceremony</i> , Terry Weir, (405) 840-5551  |



The quilt is created from squares made by donor families in honor of their loved ones. It travels in sections around the country to pay tribute to loved ones and to raise awareness of organ and tissue donation. **The quilt is not displayed in its entirety, and some events may be closed to the general public. If you plan to attend one of the displays, please contact the person hosting the event.** If you are requesting a particular panel or square to be displayed at one of the above events, would like to bring the quilt to your community, or would like information on how to contribute a square, please call the National Kidney Foundation at our national toll-free number, (800) 622-9010. Information about the quilt can also be viewed on our Web site at [www.donorfamily.org](http://www.donorfamily.org)

we fondly *remember*

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*Carl Little  
1963-1993*



*Sarah Rachel Woolery  
January 20, 1978-  
March 23, 2002*

*O*n the day Sarah renewed her driver's license, she asked about the donor sticker, and if we, her parents, had applied ours. We explained what this was all about and told her that yes, we had applied them. Sarah said, "Cool." As she finished her paperwork, we asked Sarah if she applied the sticker and she said yes, she had. We cringed at the mere thought of this, despite our pride at her sense of responsibility. Then the unspeakable happened. Our world changed forever.

We held Sarah's drivers' license in the hospital. We honored Sarah. Our mutual love is endless. We chose to follow her decision. Sarah had decided, as she did all her life, to make a difference. We merely followed her decisiveness.

Our broken hearts are nurtured by the legacy of our daughter in knowing that she saved the lives of four recipients.

For the rest of our lives we will remember with great pride and love that even with the heartbreak of her death, Sarah helped other people when no one else could. 🌸

*Sarah's parents, Herlin and Becky Woolery, and sister Patty Woolery, live in Ontario, California.*



*Kelly Giles*

*Kelly,  
Happy Birthday! (June 2) I miss you lots, think of you often. I love you so much!*

My wife died November 29, 2001, and my three kids and I miss her every day, but especially on her birthday. We would usually start the day with breakfast in bed, then spoil her all day. She loved the summer's warm weather, so having a June birthday was great! Many birthdays were celebrated in Milwaukee with Kelly's sister and family. She loved her sister so much—they became very close over the years and enjoyed raising kids and sharing family time together.

The first birthday after Kelly died, the kids and I went with her family to the lakefront in Milwaukee. We prayed, spread some of her ashes and reflected on all the special moments.

I miss the day to day sharing that we had. Kelly was part of my life for 17 years. She was my best friend and it will take awhile before my heart heals. God has a plan for all of us and we must be in tune with Him and enjoy our journeys together. 🌸

Love,  
Jim

# my favorite gifts: *what the National Donor Family Council means to me*

By Sarah Ockler



**D**onor families are among the most thoughtful, sincere people I have met. While working with the National Donor Family Council (NDFC), I opened holiday and birthday cards, thank-you gifts, Easter chocolates and simple “thinking of you” notes from families whom I had only met over the telephone. Along with their letters, families shared pictures and stories about their loved ones, leaving me in awe. Donor families have already given so much, I thought. I should be sending gifts to them! Yet, throughout my four years with the foundation, families continued to welcome and thank me in unique and meaningful ways.

While attending the 2002 Donor Recognition Ceremony at the U.S. Transplant Games last summer, I reconnected with a donor mom and dad whom I had met two years previously. Following the death of their 16-year-old daughter in 1999, the family attended NDFC events with their younger daughter, also named Sarah. After the ceremony, six-year-old Sarah handed me a small box containing a beautifully painted butterfly pin. Shy as she was, her little face beamed as her mom told me that Sarah picked out the butterfly just for me. I don’t know that I adequately expressed my appreciation at the time, as I was overcome with gratitude and pride. I wear the pin often and take compliments as an opportunity to tell people about this special donor and her family.

I cherish Sarah’s butterfly pin and each of the equally touching donor family gifts and cards I received over the years. But the gifts I treasure most cannot be worn,

wrapped or displayed. They are the life lessons most of us understand only in retrospect: every sunrise is a miracle—to see one, even more so; words convey less than hugs; one can never say “I love you” too often; helping another person can be more healing than helping oneself; listening is sometimes the best advice one can offer; “What is your son’s name?” is infinitely more powerful than “I’m sorry for your loss.”

In making the decision to donate the organs or tissues of a loved one, donor families have already given the ultimate gift—life to another person. The gifts they have given me came more easily—perhaps without notice. As the National Donor Family Council celebrates its 10<sup>th</sup> anniversary year, I wish to tell donor families that I did notice, and I thank each of you for your generosity and selflessness. Just as I proudly wear my butterfly pin, I carry your unspoken gifts and the memory of your loved ones with me always.

Best of luck to the National Kidney Foundation and National Donor Family Council on the next 10 years. I am honored to have worked with you. 

## About the Author

*Sarah Ockler is a former Donor Family Services Manager of the National Kidney Foundation. Now living in Denver, she continues to work with donor families, transplant recipients and health care professionals to promote organ and tissue donor awareness in Colorado and Wyoming.*

*The mission of the National Donor Family Council is to enhance the sensitivity and effectiveness of the organ and tissue recovery process, to provide opportunities for families to grieve and grow, and to utilize the unique perspective and experiences of these families to increase organ and tissue donation.*



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