



National Kidney
Foundation™

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.

Fall/Holiday 2007

Visit our home for donor families at www.donorfamily.org

Volume 16, Number 2

COPING WITH GRIEF

during the holidays

By Ralph L. Klicker, PhD, Upstate New York Transplant Services

HOLIDAYS CAN BE EXTREMELY DIFFICULT for those who have experienced the death of a loved one. At a time when everyone is supposed to be happy and enjoying themselves, the bereaved can feel sad, lonely and depressed. Here are some suggestions to help you cope with your grief.

Think ahead. If you give some thought to the challenges you may encounter during the holidays, it may help you to be more prepared. You may find that when the holiday actually arrives, it will be less painful than you anticipated.

Lower your expectations. Go easy on yourself. Remember, you are going through a physically and emotionally stressful time. If shopping is too difficult, try using a catalog or the home shopping programs on television. You may even decide to reduce or eliminate gift-giving and letter-writing this year. You may not want to participate in all of your usual activities or accept every invitation you receive.

Practicing holiday traditions. One of the most difficult aspects of the holidays to deal with is "traditions." A death in the family may mean that a much-loved tradition may lose some of its joy.

It may even end. However, you may choose to start new traditions to honor your loved one.

It's O.K. to cry and feel bad.

Whatever you do, allow yourself to cry when you feel the need to cry. Ignore any advice you hear such as "be strong" or "don't cry." Crying helps you both physically and emotionally. It reduces stress and calms anxiety.

It's O.K. to feel good. Give yourself permission to feel good, to laugh and even to have fun. Some bereaved individuals feel guilty if they find themselves enjoying an activity. Feeling good and laughing is your body's way of letting you relax and regain some strength for a few moments during your grief. It is a normal and healthy reaction. You are in no way being disrespectful to the memory of your loved one if you enjoy yourself.

Find someone to talk to.

Find someone who will listen to you without trying to give answers to your problems. You need someone who will let you say the words that are bottled up inside of you, even if it's over and over again. This person may be a family member, friend or clergy member. You may also want to consider visiting a professional grief counselor.

Memorialize your loved one.

Do this in a way that is meaningful to you. Choosing an activity that your loved one would have approved of can make it even more meaningful. An activity that the entire family can participate in can strengthen the bonds of togetherness and sharing. It is also appropriate for individual family members to create a memorial activity that is personal and private—something that is between just them and the deceased.

The following suggestions came from bereaved individuals who memorialized their loved one or started new traditions:

- * Purchase a small evergreen tree from a nursery. Decorate it and replant it after the holidays.
- * Light special memorial candles each day during the holidays or use one large candle and light it each day.
- * Display a single fresh flower during the holidays.
- * Have a special time when the family shares holiday memories of your loved one.
- * Offer a dinner prayer or toast to your loved one.

continued on page 2

Coping with Grief During the Holidays

continued from page 1

- * Write a letter to your loved one saying all that is in your heart. Keep it in a special place or make a ceremony of burning it in a fireplace, burying it or letting it float away in a river, lake or ocean.
- * Put some of your favorite photos or videos in one tribute video with his or her favorite music, or make a special photo album. Keep it as a treasure to look at when you need to.
- * Give objects that were special to your loved one away to others who loved him or her, as treasures for them to keep. Include a note telling why it was special.
- * Give money in the amount you would have spent on gifts to a charity in your loved one's name.
- * Purchase a gift for your loved one and then donate it to a charity.

It can help to discuss your needs with other family members. Everyone grieves in different ways, so be honest about what you need and be patient with each other during this time.

WE FONDLY remember...



Matthew D. Bennett
October 27, 1995 –
April 1, 2005



Terrence Jerrell Bradley
August 4, 1992 –
July 18, 2004



Stacy A. Budzinski
December 26, 1976 –
March 18, 2002



Austen "Gage" Crowell
November 23, 2005 –
April 25, 2006



Kristen Ann Egrie
August 22, 1974 –
May 21, 2002



National Kidney
Foundation

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 NKF. The NKF reserves the right to edit all submissions. Please contact the NKF for article submission guidelines or permission to reprint articles.

EDITOR-IN-CHIEF

Rose D'Acquisto
St. Paul, MN

DONOR FAMILY EDITORS

Susan Dillon
Downingtown, PA
Jan Frye-Hill
Winston Salem, NC
Judy Grogan
Auburn, WA
Douglas G. Harrell
Elkton, MD
Richard P. Mullane
New York, NY
Jan O'Bryan-Wilson
Kansas City, KS

PROFESSIONAL EDITORS

(cont'd)
Elizabeth McNamara
Orchard Park, NY
Benjamin S. Wolfe, MEd, LICSW
Duluth, MN
Charles Corr, PhD
St. Pete Beach, FL

TEEN EDITOR

Mia Lester

TRANSPLANT RECIPIENT EDITORS

Jack Fassnacht, Esq
Chicago, IL
James Gleason
Beverly, NJ

PROFESSIONAL EDITORS

Rebekah Arsenault
Tampa, FL
Suzanne Ball
Edison, NJ

ORGANIZATIONAL LIAISONS

AATB Sandie Henderson-Boncore
AOPO Robin Cowherd
DoT Jade Perdue, MPA
EBAA Rusty Kelly
MTF Maggie Coolican

EDITORIAL OFFICE

National Donor Family Council
NKF, 30 East 33rd Street
New York, NY 10016
800.622.9010 • 212.889.2210
Fax: 212.689.9261

www.donorfamily.org

E-mail: donorfamily@kidney.org

EXECUTIVE EDITOR

Gigi Politoski

MANAGING EDITOR

Sara Kosowsky

PRODUCTION MANAGER

Jamie Biegeleisen

EDITORIAL DIRECTOR

Jennifer Martin

DESIGN DIRECTOR

Oumaya Abi Saab



give.org

THE CIRCLE OF LIFE: *One family's rare story*

Brian's story:

In April 2006, I received news that my kidneys had pretty much ceased to function. In the next week, I would have to start dialysis. I had prepared for a kidney transplant for nearly one and a half years, testing my blood monthly, waiting for the phone call that there was a match. Two days after receiving the bad news that I'd need to begin dialysis, I was sleeping in. My home phone rang and I ignored it. Then my cell phone rang. Then my pager went off. Who was being so persistent in trying to reach me? My curiosity got the best of me and I got up. The messages said to call the hospital right away—there was a kidney match.

This began my amazing race for a new beginning. I tried to keep calm, but inside I was scared. Then, there was a rush of uncertainty...*am I doing the right thing?* It's now been a little over a year. I am doing well and I am forever grateful.

Joseph's story

Told by his sister, Dianne Christenson:

The bittersweet side to this story is that only 21 days after Brian's successful kidney transplant, his cousin Joseph (my brother) had a tragic accident while riding a four-wheeler. Joseph suffered from an irreversible head injury. The doctors did everything they could, but there was no hope for his recovery.

As Joseph's family and friends, we discussed what we thought Joseph would have wanted. We talked about his smile, his outgoing personality and his willingness to help anyone in need, no matter what the task. When we were faced in our time of crisis with having to make the decision about donation, we reflected back on Joseph's life and Brian's experience. The only obvious choice was to donate his organs to help another live. One by one we went around the table...*yes, yes, yes.*



(From left to right) Joseph and Brian

We knew what he would have done, had he been able to make the choice.

Joseph was able to donate his heart, both kidneys and liver. All of Joseph's recipients are doing extremely well—two were a near perfect match. We are so proud of Joseph, my Mom and Dad, and especially God for making it all possible. With LifeCenter Northwest and the transplant centers, Joseph got one more huge chance to make a difference, to help someone in need—his last earthly gift, the miracle of life.

Donation helped our family in the process of healing. We feel that being able to help someone in their time of need helped us in our despair. Joseph will forever be missed.

MORE WE FONDLY *remember...*



Donella June Gardner
September 26, 1966 –
February 13, 2001



Robert E. Gilbert
March 2, 1941 –
February 1, 1998



Myles J. Goulart
April 1, 1988 –
August 4, 2006



Deloris "Dee" Hammer
August 5, 1966 –
November 9, 2006



DeeDee Michelle Kisner
August 18, 1966 –
October 17, 2005

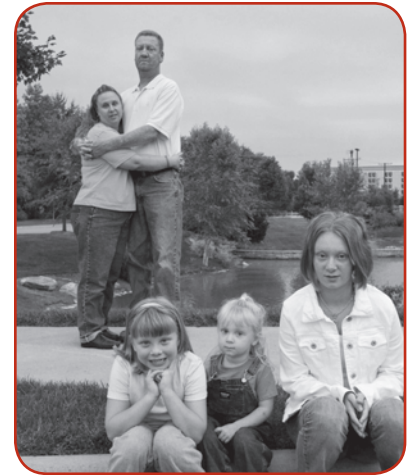
A HOLIDAY *gift*

By Kim Underwood

A FEW DAYS BEFORE CHRISTMAS OF 1996, Jan Frye Hill learned that her husband of three months, Jim, had been struck by a car. He had extensive head injuries and, as a registered nurse, Jan knew that he probably would not wake up. She told Jim's doctors, "I need you to know that my husband wanted to be an organ donor." Jim was someone who made everybody love life. He had contributed in life, and she knew that he would want to contribute in death when the time came. After Jim died, Jan gave the go-

learned that Terry had received one of Jim's kidneys. The Halls told Jan that when they had learned Terry would be receiving a kidney from a man killed in a car accident, they sat down and gave a prayer of thanks that in such a moment of loss, a family had given a gift to strangers.

The Halls and Jan became friends. The Halls have three daughters, two of whom were born after their father received his transplant. Knowing that her husband's kidney had made it possible for those two



The Hall Family: Sandi and Terry with children Corinne (8), Leslie Grace (4) and Katie (14).

As soon as Terry saw Jan, he had a strong feeling that they were connected in some way.

ahead for donation. Jim's heart, kidneys, liver cells and corneas were transplanted.



Jim and Jan on their wedding day.

Jim had only recently expressed his desire to become a donor. He made that decision because a liver transplant saved the life of Jan's mother, Erlene. "He saw what a big thing it was in my mother's life," Jan said.

In 2000, Jan shared her story at a local event that Terry Hall, a kidney recipient, attended. As soon as Terry saw Jan, he had a strong feeling that they were connected in some way. Eventually, the families

girls to come into the world helped her heal, Jan said. She has also found healing nourishment by volunteering and helping others through grief and loss.

"I still miss Jim every day and have come to accept that no matter how much time has passed, I will always miss the sound of his voice, his laughter and, most importantly, the warmth of his hugs," Jan said.

Kim Underwood is a writer living in Winston-Salem.

A HAND OF *thanks*

By Jan Frye Hill, Donor Wife and Tissue Recipient

AS A DONOR WIFE, I have been on the giving end of transplantation. Here's how I came to be on the receiving end, almost 10 years later.

In 2005, my mother Erlene, who had received a liver transplant 12 years earlier, had to be rushed to the hospital to be treated for an infection. In the rush, I tripped and fell onto the concrete. I had multiple injuries, including a concussion, fractured nose and right wrist, and damage to my vertebrae. After six weeks in a wrist cast I needed surgery, which required a bone graft from a deceased donor. The surgery was performed in January 2006. After another eight weeks in a cast, I regained the use of my dominant hand. What a joy it was to be able to care for myself again! I now know the value of tissue donation firsthand, and I am so grateful.

My mom recovered and just celebrated the 13th anniversary of her liver transplant, as well as her 54th wedding anniversary. Both of us appreciate the decision of our donors and their families, and we thank them for improving our quality of life!

DONOR FAMILY *voices* *Time, hope and healing*

SOME PEOPLE SAY THAT WITH TIME COMES HEALING. Have you found this to be true? As time marches on and a new year approaches, what “gift” of hope can you share with others who are newly grieving?

Editor's Note: We asked the above questions to donor families on our e-mail list; some of their responses follow. To read the full responses or share your own experience, please visit www.donorfamilyforums.org. To join the e-mail list, write to donorfamily@kidney.org and ask to “Join the NDFC e-mail list.”

My gift of hope would be that no one can sustain the rawness of the pain they are currently feeling. Open your life to others. You are a different, “new” person. Your life has changed and you must change with it.
— Colleen Sullivan

*

Grieving is such a personal process. Life is never the same. There is the physical pain, the emotional pain, the spiritual pain. I have chosen to treat each day and the memories of our daughter and grandson as gifts. This attitude of thankfulness gives me a better outlook. You never get over the loss, but life has new meaning for each of us.
— Patti Knight

*

The loss of my first husband and son was 15 years ago. I always hated it when people told me to give it time. I had to live every minute of that time and it was incredibly difficult. However, I have found that over time I have learned to live with them being gone. They will always be a part of me, even though we are separated for now.
— Merry Smith

*

I don't think I'll ever heal from losing my son Joe. The pain has eased from the initial shock, but the hurt will always be with me. For people who are newly grieving, I encourage you to immerse yourself in family and friends. Don't make the mistake I did and withdraw. Remember the memories and try not to think about the “what ifs.” Grief has no rules to follow; go about it on your own terms.
— Tony Zubia

*

It has been three years since my dad died. The best thing someone told me was that it gets a tad better each day, but never goes away. Time helps with the pain, as does helping others.
— Lisa Thompson-Warren

I remember when I was newly grieving and someone would say that cliché “Time will heal,” and I would respond that I did not have the time! Now, 26 years later, each anniversary gets a little easier. I believe that they live on through organ donation, and that my lifetime is so small compared to the eternity I will have with them.
— Sue (Steidle) Clones

*

Time alone does not heal. What helps is making a conscious effort to do what brings you joy in small ways, every day. That's it, just one day at a time. No one can give you the perfect advice because all of our needs and losses are different. Mostly, be kind to yourself because no one has this grief thing mastered. I have found creative ways to appreciate what I have around me that is alive, and in doing so, have discovered what really creates healing in my life.
— Kelly LaDuke

*

Yes, with time the pain eases. Does it go away? No. To this day, 12 years later, I can be driving and a memory of Christopher surfaces. A hole opens in the back of my throat and my soul falls through. I then must stop, reel it in, patch the hole, pet the memory, put it back on the shelf and go on.
— Steve Gardner

*

I'm not sure if it was the “time” passing so much as it was what we were able to do with that “time.” It's been over 10 years since my 14-month-old granddaughter Kierra died. The first two years were a nightmare and the pain was very real and always very fresh. I was able to begin to refocus the pain and anger into efforts about shaken baby awareness and prevention. In reaching out to other families who were experiencing the same thing, the healing became more obvious to me. Knowing that there is a little girl named Katie who carries Kierra's heart also confirms that the loss of her life was not in vain.
— Pamela Rowse, RN, BS

TRANSPLANT RECIPIENTS

honor their donors

WE ASKED ORGAN AND TISSUE TRANSPLANT

RECIPIENTS: *Do you do anything special to remember your donor around the holidays or around your transplant anniversary date? Do the holidays carry any special meaning for you now that you have been given the "gift of life"?*

Here are some of their responses.

For my transplant anniversary I put the donor family on the prayer list at our church. While it is one of the happiest days of my life, it is one of the saddest days of theirs. I never forget that. Each year, we make a donation to our local recovery organization in the donor's name. I don't feel obligated to, but I want to make sure that she's not forgotten—she certainly won't be forgotten by me or my family.

— Eric

Thank you...for giving me a second chance so I can finish my duty and my legacy for others.

— Joost

I received a heart transplant on November 22, 2006. My donor was named Sara. My special way to honor Sara is that I planted some of her favorite flowers in my yard and garden. I also got a tattoo of a heart with my transplant date and Sara's name worked into the background design. I received my heart the day before Thanksgiving...so that holiday will always be special from now on.

— Peggy

Each year, I walk the Seattle half-marathon on the Sunday after Thanksgiving. It's a way to honor

my donor who was training for the full marathon when he was hit by a passing truck. I had never even thought of doing anything like this before my heart transplant.

— Ronald

My family and I cook a yearly Memorial Dinner at my church in honor of my donor.

— Tracy

On the anniversary of my gift of new life, I light a candle memorial and say a prayer for my donor. I never take it for granted. Only God knows how long it will last, but I am grateful I have been able to work, see my kids grow up, finish college, sing in church and spend time with my husband. I am truly blessed.

— Arleen

On January 30, 1987, I received a kidney from a deceased donor. Every year since then, I have found some way to celebrate the day. It usually starts out with a silent prayer for my donor and his family. I always tell my co-workers that organ donation works and I'm the proof. Twenty years ago, I gave my word to an unknown young man to honor the day for him. I've kept my word and he's rewarded me with a healthy kidney. God bless him and his family.

— Lori

I have written to my donor family several times since my transplant, usually at the holidays and my transplant anniversary, but have never heard back. I know she was a 42-year-old. I celebrate with my family on each anniversary and my

children give me flowers. I keep the family in my prayers.

— Janice

Every holiday, birthday and anniversary is a special day for me, thanks to my organ donor. Before the transplant, my birthdays were nothing to celebrate. My donor made my life, birthdays and holidays brighter and happier than they have ever been in the past. She will always be remembered for her selfless act and for the second chance at a normal life that she has given me. I will always treasure the gift she has given me.

— Lazaro

My son received his two kidneys from an infant. Every day is a special day thanks to the donor and family. My church had a fund raiser where people could purchase an "acorn" or "leaf" for a special tree. I purchased a leaf that is engraved, "In memory of a seven-month-old kidney donor for (my son's name)." This leaf will always be in view, have people reading it and also make them think about organ donation.

— Linda

I have a Mass said for my donor. Since I don't know the identity of the person who gave me the Gift of Life, I put his/her name as: "My Kidney Donor." I count the number of people who are at Mass on that given day, and note that these people are honoring my donor by being at the Mass.

— Donna

Sunlight

By Desiree Woodland, Donor Mom

Sunlight streaming in through the open window
Warmth that tries to penetrate my soul,
Remembering the warmth of having you in my life.
And now that you are gone, how can the sunlight break through?
What will allow my cold, sad heart to be warmed once more?
I will always miss you.
But I can remember the warmth of your presence when I read that a child
can now see because of donated corneas, or someone's heart is now beating
because of a new valve, or a mother no longer has to make the drive for dialysis
because her child now has a kidney.
These are gifts you left behind that bring warmth to other parents' hearts.
So, I remember this, and in some strange way this forces me to sense the warmth
of the sunlight breaking through to my own heart.



*Ryan Marshall Woodland
Beloved son and brother
June 2, 1981 – May 1, 2006*

After the 2007 National Donor Recognition Ceremony and Workshop

By Sam and Jan Messina

Our 25-year-old son Matthew was killed by a drunk driver four years ago. More than 100 people from ages 17 to 75 were given the gift of life or a greater quality of life through the donation of his organs and tissues.

After Matt's death, we became involved with the Center for Donation and Transplant and the Musculoskeletal Transplant Foundation, both of whom sponsored us in attending the National Donor Recognition Ceremony and Workshop in Washington, D.C., this past July.

Our time was filled with an inspirational trip to the National Donor Memorial Garden, informative and healing workshops on Sticking Together When Falling Apart; Children: The Forgotten Mourners;

Brain Death; Dreams and Signs; and Sudden and Accidental Death. We saw the hope and healing that comes from the remembrance quilts, the strength and power of the Donor Recognition Ceremony and the heart-felt sharing with others who became friends over the weekend.

No matter what your personal faith or spiritual beliefs may be, the donor families, living donors, recipients, professional staff and volunteers who devote their lives to this work have seen something very special—that with all of the heart-ache and trouble that abounds, the world and the people in it are filled with more potential, wonder and hope than we sometimes realize. All of you make that true.





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. The entire Quilt is not on display at these events, and not all events are open to the public. Please call the contact person for more information.

2007

November 10 El Paso, TX, Musculoskeletal Transplant Foundation, *Donor Family Remembrance Event*,
Leona Jewett, 915.855.0278

* One panel of the National Donor Family Quilt is displayed year-round at the National Donor Memorial in Richmond, VA. (This Quilt panel will sometimes be moved for display at other national events.) For more information, contact Marilyn Jones at 800.622.9010.

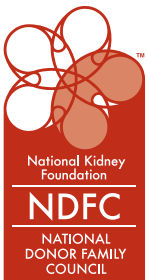
For information about reserving a Quilt panel, please contact the NDFC for updated information and pricing. The NDFC can be reached by e-mail at donorfamily@kidney.org or by phone toll-free at 800.622.9010. Please notify the NDFC of any special requests, including requests for a specific panel of the Quilt. Arrangements will need to be made to display the Quilt properly and obtain permission from the venue where the Quilt will be displayed.

SUBSCRIBE TODAY!

You may have received this newsletter directly from the National Kidney Foundation OR from another organization such as your local organ recovery organization, eye bank or tissue bank. If you received the newsletter from another organization, please contact the NKF to make sure that you're on the mailing list for future issues.

For a free subscription, please contact the NKF by sending in the RESPONSE CARD included in this issue. Be sure to write on the card that you want to subscribe. You can also call the NKF toll-free at 800.622.9010 or e-mail donorfamily@kidney.org with your full name and mailing address.

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.



National Donor Family Council
National Kidney Foundation
30 East 33rd Street
New York, NY 10016

Non-Profit Org.
U.S. Postage
PAID
Shakopee, MN
Permit No. 211



Please help us "cut down" our costs by notifying us when your address changes. E-mail us directly at donorfamily@kidney.org. It costs 41 cents if you forget.