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.

Spring 2008 Visit our home for donor families at **www.donorfamily.org** **Volume 16, Number 4**

"WHY DIDN'T THEY WRITE?"

insights from transplant recipients…

By Jim Gleason, heart recipient

In the movie *Return to Me*, there was a touching scene about the difficulty many transplant recipients experience in writing to their donor family. In this scene, Grace, a heart recipient, still hasn't mailed the letter she wrote after receiving her transplant a year ago. Her sister offers the encouragement she needs to finally mail the letter. Though this is a fictional story, it does capture the fears and hesitations of many recipients.

While donor families and recipients aren't under any obligation to communicate, many do so. Others want to, but never do. I asked some recipients for insight about why they hadn't written to their donors, even to express a simple thank you. Their answers show that even if the donor family hasn't heard from them, recipients are incredibly grateful for the gift.

Perfection/inadequacy: Many write but throw it away, thinking that it isn't good enough. They want the letter to be perfect and don't feel that they can find the "right words." Tony shares: "I haven't written to my donor family because I just don't know what to say. Words cannot describe how thankful I am to them for giving me a second chance at life! That was a miracle in itself. It is overwhelming because [without the transplant] I wouldn't have my daughter. There are no words to express my feelings for saving my life and giving me a child."

> *"I haven't written to my donor family because I just don't know what to say. Words cannot describe how thankful I am to them for giving me a second chance at life!"*

Ken, a liver recipient, wrote to his donor family after a year. He said: "You never received any of the other letters I previously wrote because I felt none of them were good enough to express my feelings. This attempt may not be as good as I would wish, but I feel ashamed that so much time has gone by without thanks from me. If I keep striving for perfection, it will delay the message to you even longer."

Fear: Some recipients write but hesitate to actually mail the letter, fearing that it might somehow cause more pain. Does the family want to hear about the recipients of their loved one's gifts? How can we express our thanks for such an incredible gift given during a time of intense loss?

Grief vs. celebration of life: Pat wrote, "There wasn't any way to say how grateful I felt to have gotten this chance at a normal life . . . without feeling that hearing all our good news would cause sadness and hurt to the donor's family." Sandy affirms, "As the years rolled on, I found it much harder to write because now I didn't know what to say. I was still equally excited, but felt as if I was saying, *look at me—I am doing great while your loved one is no longer here.*"

Privacy: John is a recipient who wrote shortly after his transplant and received a loving response. He would like to write again, but wants to respect the family's privacy, not wanting to intrude further on their lives. Richard also wrote, but tore up the letter many times. He, too, felt that the family may want their

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Changing Lives Through Tissue Donation

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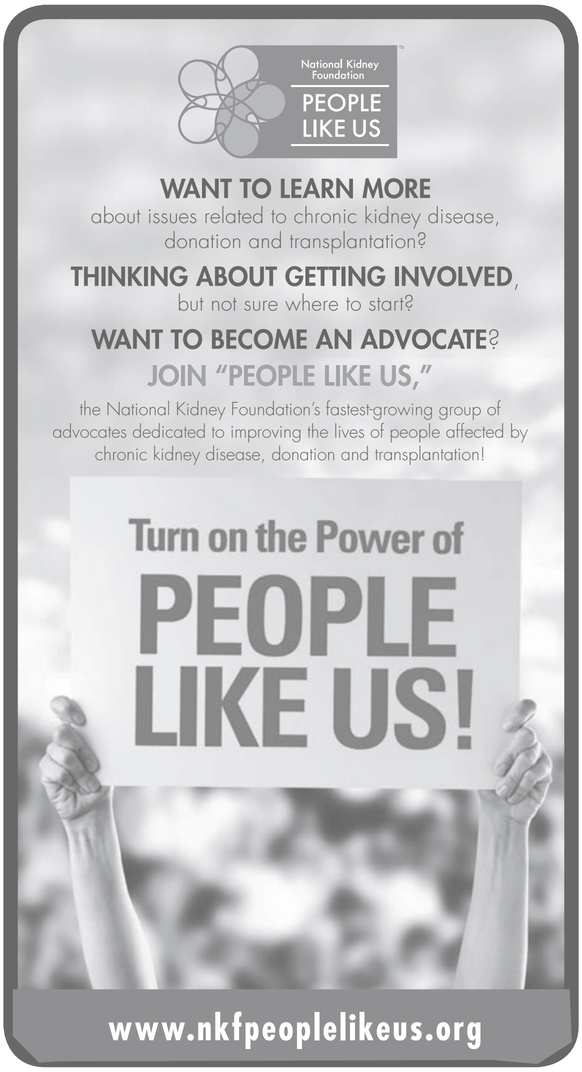

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For Those Who Give and Grieve

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.

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WE FONDLY *remember…*


Stephen Lawrence Adamczak
June 28, 1999 –
May 21, 2001


Joshua Joseph Ayrassian
September 21, 1985 –
January 11, 2004


Terrence Bernard
August 17, 1982 –
November 23, 2006


Candace S. Brodeur
October 24, 1947 –
April 14, 1995


Brian M. Jackel
October 11, 1982 –
January 27, 1998


Timothy Wayne Lemaster
June 11, 1980 –
April 14, 2001


Jonathan S. McGowan
September 28, 1976 –
October 13, 1995


John S. McGowan
February 10, 1948 –
July 5, 1996


Derek Miller
May 4, 1981–
March 24, 2001


Adam Jonathan Morales
June 3, 1985 –
September 12, 2004

"Why Didn't They Write"…

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privacy. Instead, he keeps the donor and their family in his daily prayers of thanks.

Ignorance: Some recipients learn about the possibility of communication later on, but feel that it might be too late. Joan, a liver recipient, shared that after a long time has passed there can be an added fear of "reopening wounds" for the family.

Another heart recipient said: "I finally sat down one afternoon to write the note and told myself that no matter how it came out, I would send it. I did mail the letter. You would think that deciding to write a letter would be an easy task compared to the decision that faces the donor family at the worst time of their lives. Sometimes we need to look at the big picture, and, fortunately, we recipients get a second chance to do just that."

As the recipient of a heart transplant 13 years ago, on behalf of recipients who still wrestle with the issues above, let me send our love and thanks to donors and donor families everywhere—if not in letters still locked in our hearts, at least in daily thoughts and prayers for you and your loved one.

Editor's Note: For more information about this topic or to request the brochures "Writing to Transplant Recipients" (for donor families) or "Writing to Donor Families" (for transplant recipients), call the NKF at 800.622.9010 or send an e-mail to **donorfamily@kidney.org**

THE HAVES *and the have nots*

By Rose D'Acquisto, Donor Wife

The first time I attended the National Kidney Foundation's U.S. Transplant Games, I was overcome with emotion as I watched transplant recipients of all ages participate in various athletic competitions. On that same trip, I was surprised to discover that the donor families had their own competition going on. It centered on the question "Have you met your (husband's, daughter's, mother's, brother's, etc.) recipients?"

Contrary to talk show scenarios that show a tearful donor family embracing their loved one's grateful recipient for the first time, it's not that common for these types of meetings to take place. And, while many donor families receive thank you letters, there are also many donor families who do not.

That's what makes the Transplant Games an amazing experience for us to share as donor families. Whether we have or haven't met our loved ones' recipients, the spirit of their donation is everywhere at the Games. As we watch kidney recipients golfing, heart recipients swimming and lung recipients running, we see first-hand what a "second chance at life" can mean. And, more than ever, I'm proud that Tony's exuberance for life has become a legacy. It's all the thanks I need.

At the 2008 Games, when I'm asked the inevitable question "Have you met . . . ", I know what my answer will be. I'll smile and give a nod toward the stadiums. "I think so," I'll say, "because every recipient here seems to have Tony's love for life in them."

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NKF 2008 U.S. TRANSPLANT GAMES

July 11–16, 2008
Pittsburgh, PA

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visit

www.transplantgames.org

or call

800.622.9010

ASK *for what you need*

By Charles A. Corr, PhD, CT

THE DEATH OF SOMEONE you love is like a cosmic punch in the stomach. It knocks you off balance and drains your energy. After such a major disruption to the normal course of your life, you need the help of caring friends.

Many friends will show up and instinctively do the right things. God bless them. Many others won't know what to do or say, however well-intentioned they are. For these people especially, it is important to ask for what you need.

You may be shy and hesitant to do so, but real friends will welcome your guidance. They want to help, but may not always realize what you need.

You may need practical assistance notifying people about the death of your loved one, answering the phone, making funeral arrangements, preparing meals and helping to make sure you are not overwhelmed.

It is also important to let people know how to behave around you. They may be reluctant to talk about your loved one for fear of hurting you. You may need to encourage folks to mention the name of the person who died so that his or her memory is not lost. Invite them to tell you their stories about that person.

For those closest to you, ask them to be with you and just listen. They don't have to do or say anything. It will usually be enough if they are patient, let you experience and express your grief and allow you to find your own ways to cope. The presence of a caring person can be a balm in this difficult time.

A Husband's Letter to His Friends and Co-Workers

Note: *Shortly after the sudden death of my wife Carolyn, I wrote the following letter to my friends and co-workers. I hope that this letter will help give you ideas of how to "**Ask For What You Need**" from those in your own life.*

– Doug Harrell, Donor Husband

Dear Friends and Co-Workers,

Thank you all for the outpouring of love and support you've given me and my family over a very trying week. My family is in awe of the way my friends pitched in to make the reception after the service so wonderfully special. Whenever I feel sorrow about losing Carolyn, I will also feel gratitude, for I have been blessed far beyond my worth with friends such as you.

I have never walked in these shoes before, and before this happened, I never knew how to act around someone who had suffered a severe loss. Given that grief is a very personal experience, perhaps I still don't know, but remembering my discomfort in the past, I want to tell you how you can help me.

If you haven't yet had the opportunity, go ahead and tell me that you're sorry, but after that don't feel a need to act solemn. That's what the visitation and service were for. Now, we are past that stage. You can act normally, talk about absolutely anything, make jokes, laugh. I need that.

We only know that Carolyn died of a heart attack and that it came without warning. We don't know why. Please understand that my choice is to live in the "what is," and not in the "what might have been." Don't be afraid that you might say something that will cause me pain. Although I may not show it, Carolyn is never far from my mind. In fact, my biggest fear is that people will stop talking about her or will feel uncomfortable when I do. The thing that makes me happiest is when people tell me some fond memory they have of her. If you see me in the hall and you want to lift my spirits, the best thing you could possibly say is something about her like, "I really loved to hear Carolyn laugh" or "I'm really going to miss her smile."

In the last week, three things have softened the blow for me. The first is the love that all of you have shown me. The second is the stories you have shared with me about the Carolyn you knew, and the third is knowing that somewhere out there, she is bringing hope into the lives of others. Because of Carolyn's convictions, someone who was crippled will walk, someone who was blind will see and a child who was dying will live. If you feel as she did, please be considerate of your loved ones and give them the same source of energy and courage that Carolyn gave me on the day she died by making your wishes [about organ and tissue donation] known to your immediate family.

With Love,
Doug Harrell and family

DONOR FAMILY *voices* — *Getting what you need*

THE PAIN OF LOSING A LOVED ONE CAN BE MADE WORSE if family, friends or co-workers begin to treat you differently. Many people aren't sure how to act around someone who is grieving and may be uncomfortable.

Did you notice any changes in the behavior of people you know, and, if so, did you try to help them understand how you wanted to be treated?

Did anyone respond in ways that were particularly helpful or compassionate? What did you want people to do or say?

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

Our daughter Cricket had a social worker from whom I learned something important. When we walked into a large meeting room together, Dolly said in a loud voice, "I need a hug." Three friends approached her at once and met that need. Many times since then, I have remembered that and have felt the freedom to just say, "I need a hug."

— *Bev Kirk*

* * *

The two most comforting things I heard were "I'm so sorry" and, from a mother whose two sons had died, "It won't get any better." I needed to know that I wouldn't wake up years later and not feel my son Adam's absence. We get better at coping with it, but that's different.

— *Ellen Gillette*

I wouldn't want people to go through other family members to ask how I am. Ask me how I am, not my family. Some people continued to ask how I was and still talked about my son, Ryan. That made me know he wasn't forgotten.

— *Alison Mohn*

* * *

When my husband died, my adult children acted like I was unable to make any decisions for myself. I finally had to tell them I might be sad, depressed and scared, but I was working through my grief and getting my bearings back. I let them know that I wouldn't always be doing what they thought was right. They were o.k. with that. Because they heard me, I have been able to gradually regain my confidence and continue on my journey of healing. What I found helpful were those who simply said "I am so sorry," "I am thinking of you" or "praying for you." All the promises of "getting together soon" are hurtful if not followed through. I especially appreciate those who referred to my husband by name or spoke of what he meant to them. I still remember their words.

— *Judi Worley*

* * *

When my son died, I told my friends that I wanted to be left alone to grieve and try to make sense of it. I told them that when I was ready to get back to the real world, I would let them know. They honored my request and I will always be grateful.

— *Anna Parham*

* * *

I found that people looked at us with a feeling of uneasiness, not quite knowing what to say. They wanted so much to take away the grief that we were experiencing. The gift that our son gave to his recipients has helped to soften the grief. We have been very open with others and share that experience with them.

— *Sheila Baxter*

> *I found that if I talked about my son Brian it made others feel more comfortable and let them know that it was o.k. to talk about him too.* — *Susan Seidel*

* * *

After my four-year old daughter Danielle died in an auto accident, the most helpful person was one friend who sat with me, helped me with my housework and listened. I believe that we all mean well and care for those who are grieving, but we are limited to our own experience. We often say, do or share the wrong things . . . it's part of it.

— *Daphne Mayer*

* * *

After the first year, people were scared to ask me how I was feeling. It seemed that I was able to bridge this area of uncomfortableness by bringing up memories of my husband Louis.

— *Felacita King*

* * *

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TISSUE TRANSPLANT INFORMATION: *why the long wait?*

By Maggie Coolican, RN, MS, FT and Robin Cowherd, MPA, CT

IF YOUR LOVED ONE DONATED TISSUE (such as bone, connective tissue, cardiac tissue, veins or skin), you may have wondered why you didn't hear about the outcome of the gifts right away. You may have received a letter that told you what tissues were recovered, but not how those gifts were used. There are many reasons why tissue transplant information is not available immediately after donation.

At the time of your family member's death, an extensive medical/social history was completed. In addition, there was a review of the current medical records and a variety of tests mandated by the Food and Drug Administration, the federal agency responsible for regulating the preparation of tissue for transplant.

> *Donated tissue … does not have to be transplanted immediately and can, in many cases, be saved for up to five years.*

The tissue is kept for a period of time after recovery to further review the medical history. If an autopsy was performed, results must be obtained before the tissue can be released by the medical director for preparation. In some states, it may take up to a year or more to obtain the autopsy results. In addition, donated tissue does not have to be transplanted immediately, and in many cases can be saved for up to five years.

Once all of the medical reviews and testing have been completed and the medical director has released the tissue, it is then prepared for transplant. Preparing the tissue can take several weeks. The need for different tissues is determined by contacting the surgeons in the local area where the donation occurred.

The number of tissues from one donor may vary from a few to over 100. Each donor is treated with respect, and the desires of the donor and family are honored as much as possible.

After being prepared for transplant, the tissue is distributed to hospitals about 9–12 months after the donation. Surgeons who transplant the tissue are asked to complete a card stating the age and gender of the recipient, the type of tissue used and the surgery performed. This card is sent back to the tissue organization. However, this is not a mandatory reporting process and may not provide the information the family desires. Generally, if a family requests an update 12–15 months after the donation, information about where the tissue was distributed and how it was used can be obtained.

Some families do not want any information about the tissue that was donated and, therefore, many organizations do not automatically send information to families. However, most organizations are happy to provide the information upon request of the donor family. To obtain updated information about the tissue that your loved one donated, contact the organization that recovered the tissue at the time of your loved one's death. (If you need help finding this organization in your area, ask the National Kidney Foundation for assistance by e-mailing **donorfamily@kidney.org** or calling 800.622.9010.)

Why is Tissue Needed?

Tissue transplants can dramatically change and improve the quality of life for many individuals and may even save lives:

- Tissue is needed to replace bone, tendons and ligaments lost because of cancer, degenerative joint disease, arthritis and other conditions or injuries.
- In many cases, bone transplants can prevent the need for amputation or multiple surgical sites during spinal fusion. It can also be used in dental and periodontal surgeries.
- Skin is urgently needed for patients with severe burns and can mean the difference between life and death.
- Heart valves replace those damaged by disease or deformities and offer the chance of an active life for many children and adults.
- Inner ears can help restore hearing for certain types of deafness.
- Eye tissue restores sight.

From the National Kidney Foundation brochure, "Your Loved One's Gifts: Understanding Tissue Donation." For a free copy of the brochure, e-mail **donorfamily@kidney.org** or call the NKF toll-free at 800.622.9010.

more donor family voices

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The loss of our only son was devastating. One dear friend went beyond the "card and a casserole" by coming to our house and doing what needed to be done: washing dishes, doing laundry and even cleaning the bathroom. The ones who truly care are the ones who listen to our endless thoughts, stories and pain. They know we will never "get over it" and will always need their shoulders.

— Peggy Matthews

* * *

The most wonderful thing you can do for a grieving person is to mention the deceased's name. Those who continued to talk about my son and call him by name meant more to me than anything. Also, don't avoid the grieving person in public—don't make grieving people feel like they are invisible!

— Stephanie Willis

* * *

Relatives, friends and acquaintances won't know what to say. The best thing is to give the grieving person a hug and say, "I'm sorry." Realistically, nothing else can or should be done. I tell people, "Yes, you will see tears. If it bothers you to see a 60-year-old man cry . . . tough!"

— Steve Gardner

I am grateful that a few friends became aware of approaching "storms" of grief. Instead of avoiding me, they patiently waited for the storm to clear and for me to crawl to shore. They never passed judgment and had no expectations, just a warm blanket of love and compassion.

— Patricia Nelson

* * *

I had to tell family and friends that it was o.k. to talk about our daughter Justy and ask questions. The worst thing is for family and friends to stay away because they think you need time. The grieving person needs to feel as normal as possible, that life will still go on the same as always. I have found that an hour lunch is just enough time to talk about everything important and skip everything that is too touchy. Everyone can take a friend in need to lunch.

— Mickey Rose

* * *

Before I lost my husband, I am sure that I acted awkwardly around grieving people. It is very hard to know what to say or do. I found that the only thing I really wanted was for someone to just listen and acknowledge my loss.

— Laurel Schwass-Drew

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.

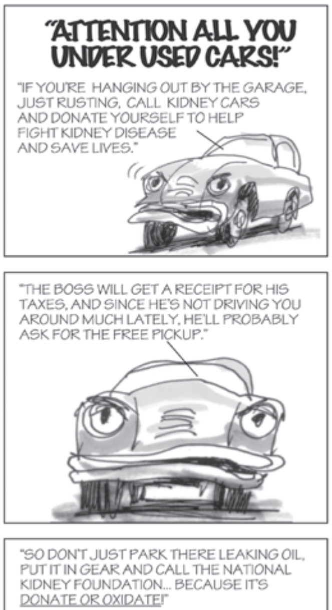
2008

April 13–19	Maumee, OH, Life Connection of Ohio, *Donor Recognition Week*, Sally Towslee, 419.893.1618
April 18–21	Montgomery, AL, Alabama Organ Center, *Transplant Picnic*, Jane Geloneck, 334.271.1690
April 23-27	San Diego, CA, Lifesharing, *Padres Game/Salt Creek Grill*, Sharon Ross, 619.521.1983, ext. 123
April 26	Modesto, CA, California Transplant Donor Network, *Celebration & Remembrance Ceremony*, Trace'e L. Harris, 209.613.7266
May 17	Seattle, WA, SightLife, *2008 Donor Family Gathering*, Lois Parker, 206.682.8500
July 11–16	Pittsburgh, PA, National Kidney Foundation, *2008 U.S. Transplant Games**, Marilyn Jones, 800.622.9010 or 212.889.2210

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.

* The entire Quilt will be on display at the 2008 U.S. Transplant Games.

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.



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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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