

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.

Winter 2009

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

Volume 17, Number 3

new programs send thousands of letters to **DONOR FAMILIES**

Each year in the United States, there are about 1.5 million tissue transplants (such as bone, corneas and skin for burns). Over the past three years, some tissue recovery agencies have developed new programs to provide letters of gratitude to donor families from recipients of tissue transplants. These programs provide thousands of patients with the opportunity to thank the family for the precious gift.

The donated tissue is delivered to a hospital, surgical center or dental office to be used for a medical procedure. In the packaging that contains the tissue, a card or form explains the process for a recipient to write an anonymous letter of thanks.

After the surgery, a member of the medical team ensures that the recipient or family receives the information about writing to the donor's family. The recipient is encouraged to explain how the

gift has helped him or her and to write about the activities of life that have been restored due to the transplant. The letter is given to the organization that prepared the tissue, and they distribute it to the family.

Over the past two years, about 5,000 letters from grateful tissue recipients have been delivered to families. Both parties must express a mutual desire for the letters.

Donor families have said that the letters confirmed their decision for tissue donation and helped in their mourning process, confirming the legacy of their loved one. Many recipients are glad to be able to express their gratitude for these "gifts of life."

While these thank you programs have yielded wonderful results, more work needs to be done. Additional education is needed for professional staff to ensure

that the information about writing the donor's family is given to the recipients. More tissue recipients need to understand that it is possible to write a letter and how important the letters are to donor families.

For further information, visit Pathways (www.1000thanks.com) or contact Cyndie Colarusso (colarusso@1000thanks.com). You can also contact Maggie Coolican at the Musculoskeletal Transplant Foundation (maggie_coolican@mtf.org) or Robin Cowherd at LifeNet Health (robin_cowherd@lifenethealth.org).



Donor Recognition Ceremony, July 2008

Photo: Jason Cohn



LETTER *from the editor*

Dear friends,

Before I attended the U.S. Transplant Games for the first time, everyone told me what an amazing experience it would be. Getting hugs and thank you's from transplant athletes, sharing stories and tears with other donor family members. The Games were all that and more.

What I didn't expect was the crash that followed when I came home. Back to co-workers who complained about paper cuts. Back to a life where nobody talked about Tony. I was bluer than blue.

What a blessing it was that I met Jan Frye-Hill, another donor wife, at those Games. She had given me her phone number and I called her when I got home. She was having a tough time too and I discovered I wasn't alone.

We hope you discover that as well when you read *For Those Who Give and Grieve*. Perhaps you'll find comfort in Ben's article about "post-event letdown." Or, you'll hear your thoughts echoed in "Donor Family Voices." We hope that in every issue, you see that you are not alone. We're here—to listen, to encourage and to be a friend along your grief journey.

Sincerely,
Rose D'Acquisto
Donor Wife, Editor-in-Chief



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...*



Adam C. Ports
May 17, 1984 –
November 20, 2002



Loren Denise Spellers
July 13, 1965 –
November 16, 2004



Evin Shoap
January 20, 1984 –
March 25, 2007



David Charles Starr
September 5, 1971 –
January 26, 1991



Michele Ballengee Sluss
April 22, 1970 –
October 28, 2002



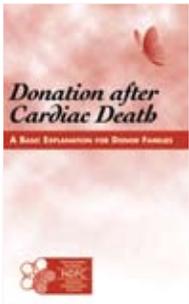
Mark Sutherly
February 4, 1949 –
September 16, 2001



UNDERSTANDING *the donation process*

AFTER DONATION, many families have questions about their loved one's gift, how death was declared, and the organ donation process.

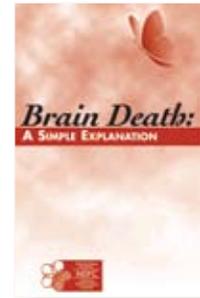
There are two ways in which someone can be a donor after death: either after brain death or after cardiac death has occurred. Both are legal definitions of death.



Brain death means that as a result of severe trauma or injury to the brain, the body's blood supply to the brain is blocked and the brain dies and cannot be revived.

In **cardiac death**, the lungs stop breathing and the heart stops beating.

For more information, please request a free copy of the National Donor Family Council's (NDFC) new *Donation after Cardiac Death* booklet and/or *Brain Death: A Simple Explanation* (also available in Spanish.) To learn about all of our publications and programs, visit us online at www.donorfamily.org or request a copy of the NDFC's **Catalog of Resources**.



Please e-mail the NDFC at donorfamily@kidney.org or call toll-free 800.622.9010 with your request. Be sure to include the name of the publication(s) that you are requesting, along with your name and mailing address.

WE FONDLY remember...



Mimi Vella, DDS, MS
February 11, 1933 – August 29, 2007



Derek Walsvick
March 5, 1972 – November 28, 1990



Devon Vigil
November 10, 1985 – July 18, 2007



Amy Denise Wilson
May 30, 1984 – April 9, 2007



Journey Lane Wall
June 18, 2007 – June 21, 2007



Sarah Rachel Woolery
January 20, 1978 – March 23, 2002

GOING HOME AFTER DONOR EVENTS: *letdown or re-writing your address book?*

By Ben Wolfe

When donor families meet for events like recognition ceremonies, memorial programs or other special events, it can be an emotional roller coaster ride, including both emotional “highs” and challenging “lows.” Donor family events provide opportunities to share stories with others who validate how you feel, who understand when you laugh or cry.

These gatherings can provide you with “windows in time” to recapture previous memories, share how you are feeling today, and know that you are among kindred spirits. Being able to listen to others along their journey and talk about your loved one with “fellow travelers” is an invaluable opportunity.

Grief sometimes deletes people from your address book. Some people no longer call or stop by, but donor family events can add new people to your address book...people who “get it” and give you encouragement and hope.

If you have attended a donor family gathering, you know it can be emotionally uncomfortable, but also meaningful in your grief work. Who are the people that share their lives with you at these events? They may be people you’ve never met before or people you see only at such events, but they all have unique stories to share, stories that often aren’t shared back home.

Grief sometimes deletes people from your address book. Some

people no longer call or stop by, but donor family events can add new people to your address book...people who “get it” and give you encouragement and hope.



Donor Recognition Ceremony, July 2008
Photo: Jason Cohn

When you get home from an event, you may be uplifted by the way your loved one was remembered or you might, for a

period of time, feel a letdown or sense of being overwhelmed with life’s responsibilities. You may be exhausted from the intensity of the event itself. And you may encounter people who don’t want to talk about the event or the person who died. You need to ask yourself, “What was my reason for going?” and “What was shared and learned?”

In his book *When Bad Things Happen to Good People*, Rabbi Harold Kushner, whose 14-year-

old son died, said, “I had to stop asking WHY it happened. It served no purpose. Instead, I needed to ask myself, now that it happened, what can I do about it?”

Now that you are home, do you need to do anything different with your life? Do you allow yourself to laugh and not feel guilty, knowing that others have felt the way you do and found it possible to laugh again? Do you need to eat better, exercise a little more or do something special for yourself? Maybe it will be journaling, gardening, mentoring a young person or promoting donation in your community.

Carol Crandle states, “It is not through time that one heals, but rather, what you do with the time.” After donor family gatherings, it is important to appreciate that the event was a way to integrate your loved one’s death into your life story. Sam Cook, a friend of mine and outdoor writer in Northern Minnesota, once wrote, “Go. Get out there. Feel the wind. Taste the rain. Find the magic.” My hope for you is when you get home from your next donor event, you will “find the magic.” You will remind yourself that you not only helped those around you, but, in turn, you helped yourself.

Ben Wolfe is a Program Manager/ Grief Counselor at St. Mary's Medical Center's Grief Support Center in Duluth, MN. He was also an Executive Committee member of the National Donor Family Council.

DONOR FAMILY *voices* *After the Event*

EVEN THOUGH THEY LOVE US, often our friends and neighbors can't give us the support that we find among other donor family members. At functions like Donor Recognition Ceremonies, the U.S. Transplant Games or local events, we get a chance to meet people with stories similar to ours.

If you have attended a donor family event, what was the event and what did you get out of it that you don't get in your everyday life? How did you feel at the event? Did you experience a letdown when the event was over? If so, how did you cope?

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."

Donor families are very much revered at the NKF's U.S. Transplant Games and I felt so loved by all the transplant recipients and their families. As I watched recipients participate in volleyball, track and field and other events, it struck me that life is a circle. Life does go on through donation and the recipients have been given a "second chance at life."

— Beth Ballard



I attended a Donor Quilt Ceremony in March 2008. I was a bit nervous at first. However, after I left I felt understood. Many of the clichés spoken to me after Johnathan's death really did not ease the deep depression, isolation and withdrawal; I am working very hard to forgive the person who murdered him. After I left the donor ceremony, I began to see things differently: the blue sky, trees swaying in the wind, the beauty of the sunrise and sunset. All these gifts were given to the person who received Johnathan's corneas.

— Kay Bowe



In 2002 my husband and I went to the Transplant Games, where we met Donald, a heart recipient. Donald made us understand what a great miracle organ donation is and the gratitude that recipients show. My son's untimely death at the hands of a drunk driver was not a total waste—he lives on in all the people that received his gifts.

— Celina Lopez



I attended a lunch for donor families in Central Park and an event at St. Patrick's Cathedral. The people made me feel so special and I was moved by the love they shared with me. I felt so proud that Chris, my only child, was still making people happy.

— Patricia Robson

A Donor Recognition Ceremony in Lincoln made me feel that I am not alone. It was nice to talk to people who have the same feelings and know that they truly understand what I am going through. It was a little bit of a letdown when it was over.

— Janet Shafer



Each year the Governor of Wisconsin hosts a "Medal Ceremony" where the donor families are presented with a medal that has their loved one's name on it. Even though it didn't stop the hurt I am feeling over the loss of my wife, I was able to see many people in the same situation as myself. It was a very nice ceremony.

— Al Wright



As a mother who has lost a child, I have found much solace in going to gatherings with other donor families. The Living Legacy Foundation's luncheon was probably the most uplifting experience I've had since losing my son Cole. Cole really has left a legacy, not only in the wonderful memories I carry, but also in the physical lives of at least two people.

— Marta Baldwin



I have been going to the TransLife Donor Remembrance Day for over a decade and keep returning for one simple reason: The people there understand how I feel because they are in the same "boat." Nowhere else in my day-to-day world can I find that connection with other people, especially other parents who have lost a child. I feel sad while I'm there and sometimes tears roll down my cheeks, but I am happy to keep my child's name and memory alive.

— Billie Lomonaco

HEALING WITH “*The Grief Recovery Handbook*”

By Douglas G. Harrell

IN EVERY RELATIONSHIP, no matter how loving, there are aspects that we would like to improve.

That’s why when a loved one dies, we may find ourselves struggling with strong feelings over the lack of a resolution it seems we will never achieve. For example, a wife or husband may be haunted by guilt because the last conversation was an argument, or a son or daughter might harbor resentment over feelings of abandonment suffered as a child.

If you experience such feelings, they can be obstacles to working through your grief. Such feelings can leave you unable to let go of your pain because of the unresolved issue, and can make it difficult for you to remember or talk about your loved one. Since your loved one is no longer with you, it may seem that you will never be able to find peace.

In *The Grief Recovery Handbook*, authors John W. James and Russell Friedman observe, “Over time, the pain of unresolved grief is cumulative. Whether caused by a death, divorce or other type of loss, incomplete recovery can have a lifelong negative impact on a person’s capacity for happiness.”

When your loved one died, your physical relationship with that person ended abruptly, but your emotional and spiritual relationship did not. More than likely there are many things you still feel a strong need to say. This is normal and it is important for your emotional recovery that you find a way to get these things off your chest.

In order to deal with all of your unresolved issues, James and Friedman have prepared a process that they recommend you follow. The most important element in that process is writing a one- or two-page letter to your deceased loved one that includes three components. First, you need to apologize for the things you feel you could have done better; second, you need to forgive the person for the things he or she did or did not do that hurt you; and finally, you need to express to your loved one anything else that has significant emotional importance to you. As a very short example, a son or daughter’s letter to a deceased father might look like this:

Dear Dad,

Even though you were so ill over the last few weeks, I still cannot believe you are gone. I miss you so much. There are a few things I never got to say to you, but they are important and I want to tell you now. I am sorry I allowed myself to get so wrapped up in my job that I did not come out to visit you as often over the past few years as I used to. It’s ironic that I did not find the time for you given how upset I was at the long hours you worked when I was a child. Now I understand that it isn’t easy, and I forgive you for not being there for me as much as I wanted you to be. Finally, I need to tell you that I was always very proud of you.

Goodbye Dad,
Sandy

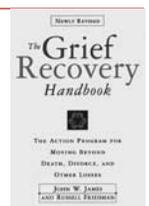
In the letter, “goodbye” is used in the same way as when you hang up the telephone. It signals an end to this communication, but not to the relationship. Every time you find yourself upset over something left unsaid, you can write another letter. James and Friedman strongly suggest that you read your letter to another living person. They feel that the presence of another person is necessary for you to truly feel that the communication has been delivered, and thereby complete the unfinished part of your relationship with the deceased.

My first wife, Carolyn, and I had a wonderful relationship for most of our 20 years together. However, in the three years before she died, she was traveling two to three weeks a month, and it had become an issue between us. As I grieved, I felt a strong need to understand what I was going through, and I found *The Grief Recovery Handbook*. I worked on the exercises with my mother-in-law as my partner, and they helped me to resolve my feelings over Carolyn’s decision to be gone so much in the years before she died.

Ultimately, I feel that my grief work, though very difficult at the time, helped me to be able to accept Carolyn’s death and to move past the pain of losing her to a place where I could remember and enjoy the wonderful life we shared. If you have an unresolved issue with a loved one who has died, I highly recommend that you investigate *The Grief Recovery Handbook*.

The Grief Recovery Handbook
(Revised Edition).

John W. James
and Russell Friedman.
Harper, Perennial, 1998.



Join Us!

11th National Donor Recognition Ceremony and Workshop (NDRCW)

July 17–19, 2009

Omni Shoreham Hotel, Washington, D.C.



A donor family member shows the Gift of Life Donor medal.

- **HONOR** your loved one's gift and legacy at the federal government's Donor Recognition Ceremony.
- **SEE** the entire National Donor Family Quilt with over 2,300 patches and bring your own Quilt patch. (Please note that only one Quilt square can be created per donor. Contact the NKF for more information about making a Quilt square.)
- **JOIN** workshops and sharing groups created just for organ and/or tissue donor families.



Scott Johnson, age 9, heart recipient, at the 2006 U.S. Transplant Games.

2010 U.S. Transplant Games

July 30–August 4, 2010

Madison, Wisconsin

- **CHEER** on the transplant recipient athletes and see the impact of a loved one's gift in action! Athletes have ranged in age from 18 months to 80 years. One heart recipient said, "My heart fills with joy at the sight of all those recipients. Donor families can see that their decision was the right one."
- **REMEMBER** those who gave the gift of life at the Donor Recognition Ceremony.
- **SEE** the entire National Donor Family Quilt and learn how to make your own Quilt patch.
- **LEARN** and **SHARE** at special workshops for donor families.

For more information, e-mail donorfamily@kidney.org with your request. Please include your name and mailing address.



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



Please help us "cut down" our costs by notifying us when your address changes. E-mail us directly at **donorfamily@kidney.org**. It costs 42 cents if you forget.



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.

2009

April 3-5 Eau Claire, WI, Luther Midelfort, *Remembrance Ceremony*, Chaplain Aimee Wollman, 715.838.1472

April 4 Modesto, CA, California Transplant Donor Network, *Kidney Gift of Life Ball*, Trace'e L. Harris, 209.550.0188

July 17-19 Washington, D.C., Division of Transplantation, Health Resources and Services Administration, U.S. Department of Health and Human Services, *National Donor Recognition Ceremony and Workshop*, Marilyn Jones, 800.622.9010

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.

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.