

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 1999

Volume 8, Number 1

Life After Death Can Be a Perilous Journey


*M*y journey began in January 1986 on the day my son Scott died. The road was frightening and lonely. I thought that I could not survive the pain of such a terrible loss. I did not want to be there!

Sometimes I liken my trip to an H. G. Wells novel. I'm a time traveler in a strange new world. I can travel forward and backward; sometimes I travel in circles. I have fought monsters and floated through transparent dreams. The great English philosopher Francis Bacon said, "time is the greatest innovator." A dark moment in time made it necessary for me to take a different route and discover the tools that I needed to find my way. Along the path I have met other travelers who have shared their time, experiences and innovative coping methods.



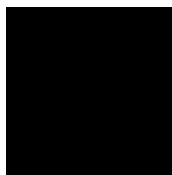
Now my time must be shared with others who are weary and discouraged. Maybe we can travel along together. The length of time spent as helpmates is not important. It is the care and comfort we give to one another that makes the perils of life tolerable after a death.

Linda McBeath-Lindahl

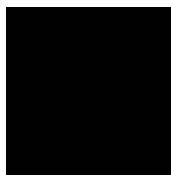
Editor's Note: It is our pleasure to introduce Linda McBeath Lindahl as the new volunteer co-editor. She is also the coordinator of the Donor Family Aftercare Program at the University of Miami OPO. We will continue our journey together, giving support to one another and remembering our loved ones in this newsletter. 



We Fondly Remember



Steven Shanor
November 10, 1980-
April 19, 1998



Christine Cecilia Celusak
July 20, 1996 -
August 24, 1997



Craig Howard Kittrell
February 26, 1980-
May 28, 1998



Kate Bytwerk
June 26, 1984-
October 12, 1996



Kevin DeWayne Johnson
December 5, 1983-
September 20, 1997



Jamie Michael Paul
Nelson
April 2, 1976-
June 22, 1998



At Night

In Loving Memory of Manuel Molina

May 15, 1974 - July 3, 1993

At night, it's really hard to sleep
knowing that when I wake up the next morning,
you are still not going to be there
to give me another memory
to remember all the humor, pleasure
and leadership
boxed inside your loving body.

At night, I wonder if you felt the hands
and lips of people (that love you and care for you)
that one last time
and know that I see your smile
through life's wind chimes.

At night, I lay awake thinking of that
dreadful July night because I know now
that it was not your time to go,
even now no one knows
how much my sorrow grows.

At night, I realize how much
you really meant to everyone and it hurts
to find out that some of them
weren't true friends at all,
but don't worry, Manuel,
I'll make sure that the ones who really count,
won't forget who you were,
because through me, live the memories of you!!!

Love you always,
Teresa Alaniz

Last Wish

by Carlene Lemieux, RN

My husband suffered a massive stroke that left
him brain dead. He had expressed his wishes to me
that he wanted his organs to be donated in the event
of his death.

I am a registered nurse and know that organ and
tissue donation is crucial. Still, I had some reserva-
tions. In the end, my better judgment won. I
consented to donate his organs and have never
regretted that decision.

Three months after his death, I received a letter
with information about the recipients. Tears filled
my eyes when I learned that two people received
the gift of sight because of his corneas, two people
will no longer need dialysis treatments, and severely
burned children are healing because of skin grafts
from him.

Organ donation is the Gift of Life. One person
died and at least five others' lives were improved.
Dealing with the loss of my husband has not been
easy. Knowing his death helped so many people has
made my loss less painful.



The NKF Website got a facelift—

www.kidney.org is now easier to navigate and offers you more!

VISIT THE NATIONAL DONOR FAMILY COUNCIL WEBPAGE.

Click on "Organ and tissue donors and recipients" and then "National Donor Family Council." Click on "Donor Family Message Board" to post your thoughts or memorials and respond to other donor families. Join our Internet chats with bereavement and donation experts at 9 -10 pm ET the third Tuesday of each month. Go to www.kidney.org at 9 pm and click on the flashing message to join the chat.



The Gift... Without the Grief

by Steve Gardner

After a day of seminars, sports and shopping at the Fifth Annual National Donor Recognition Ceremony and Workshops last summer, my wife and I stopped at the lobby bar for a drink and a breather. Some fine folks from Missouri soon joined us, a donor wife and a living donor who had given her brother a kidney. Aside from being donor families, we had something else in common; we were all volunteer speakers about organ and tissue donation for our local OPOs.

After exchanging our stories, the donor wife and I were comparing the different descriptions of grief we gave in our presentations. In general discussion, I mentioned that living donation was an example of “the

gift...without the grief.” The living donor looked at me and asked, “Do you resent living donors?” Realizing I had stuck my foot in my mouth, I tried to explain. I hope I convinced her that I had never intended anything but happiness for her before I lost it in tears.



As a husband, father and engineer, my job is to fix things, from leaky faucets and broken toys to control systems. The living donor had the ability to fix her loved one. I had to say goodbye to mine. Resent you? Not in a million years, dear lady! Envy you? Oh, dear God yes! 🌸

Steve is the father of Christopher (1981-1995).

Lost Love

In Loving Memory of My Dad
October 5, 1952 - March 7, 1996

I hear your voice
But yet you're not there
I still look for you
But I don't see you anywhere.

Are you gone forever?
Will I remember your face?
How will I feel...
When I want to leave this place?

Your jokes, your smiles and frowns,
There are so many things I miss.
I will never again hear you say...
“I love you”
or give me a goodnight kiss.

There's so much left undone,
So many things still to do,
How can I accomplish them...
When I don't have you?
When God took you
I didn't understand!!!
It just hurt so much
And I miss your loving hand.

I miss you so much
This just can't be.
I really don't believe
God took you from me. 🌸

Christina Beaver

WHAT HELPS WHEN IT HURTS

Selecting Music for Relaxation

While you may think of music only as a source of entertainment, listening to it also can be a great way to relax. Music helps you to relax by affecting your environment and influencing physiological responses such as pulse and blood pressure. The type of music you choose to relax to is entirely up to you. Music preferences are personal and can change with your mood.

People respond to music based on their past experiences with it, cultural background, associations with the music, and current emotional and physical states. Because music is inspired by someone's emotions and you respond to it on an emotional level, it may bring tears, especially when you are grieving. At times, you may choose particular songs that connect you with your feelings in difficult times, and you thereby receive validation from the music.

There are some general characteristics within music that have been shown, through research, to induce the relaxation response. Instrumental (harp and guitar are among the most calming) selections are preferable because hearing and thinking about lyrics could demand close attention and distract you from relaxing. The following list includes pieces

that have been found to have these characteristics. Given that music preferences are personal and vary, try first searching for these pieces at the library and discovering their effect on you before purchasing them.

Classical:

- *Moonlight Sonata, 1st Movement, No. 14, Opus 27*: Beethoven, Ludwig Van
- *Nocturne in G*: Chopin, Frederic

Popular Instrumental:

- Main theme from *On Golden Pond*: Dave Grusin

Relaxation/Meditation:

- *The Lost Art of Listening*: Kurt Kaiser
- *Sea Gulls...Music for Rest and Relaxation*: Hap Palmer

Brenda Calovini is a certified music therapist. She works with people who face the challenges of chronic illness, life-threatening illness and autism.

Note: Call the NDFC at (800) 622-9010 or visit the NDFC Webpage at www.kidney.org for a list of additional music selections to help you relax.



In Remembrance

Memorial contributions and other public donations to the NDFC are channeled directly into programs and educational resources for donor families and the professionals who support them.

In memory of:

- Kevin G. McCue** - by James and Florence McCue
Andy - by Billy Anderson
Larry - by Ethlene Wise
Eric Christianson - by Arnold and Sue Christianson

To the National Donor Family Council - From:

- Viola D. DeLand
Gloria J. Gooler
Rebecca Celusak
Jim Moore
Paula L. Bewley

FOR THE NEWLY BEREAVED

Widening the Circle of Support

by Debbie James, MSN, RN, CCRN, CNS

I received a phone call from a mother who had donated the organs and tissues of her 19-year-old daughter. “Is there a support group for people like myself?” she asked. Someone had given her my name and number. I felt sick to my stomach because I had been asked this question many times and again had to tell a grieving mother “no.” A voice inside my head said, “What’s wrong with you?” Having no good answer, I called colleagues of mine whom I knew to be dependable, caring risk takers - a social worker, a clergy member and a member of the local organ and tissue procurement organization. All of these calls resulted in the development of the Donor Family Support Group of San Antonio, Texas.



Support groups can help you understand complex issues like brain death and allow you to share your experiences with others.

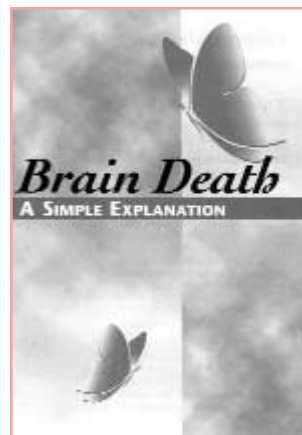
Parents who had donated the organs and tissues of their children attended the first two meetings. As they discussed their experiences, an obvious bonding began to happen. The parents described their greatest source of pain to be the fear that they somehow participated in, hastened or were responsible for their child’s death. As they talked, my colleagues and I realized that these bereaved parents did not completely understand brain death. How had brain death been described to them? With whom had they discussed brain death? When and where was brain death talked about? How many

times? Was the ventilator referred to as a “life support machine”?

We invited a caring neurologist to be a guest at our next meeting. He discussed donation, pronouncement of brain death, offering families the option of donation and consent. He saw the confusion of the group regarding brain death and slowly and kindly described the differences between brain death and coma. He gave examples of coma, persistent vegetative states and brain death. The group shed many tears, shared expressions of understanding and spoke words of appreciation.

I am not criticizing those health care providers who attempt to help you understand brain death. As health care professionals, we often have difficulty making sense of sudden, unexpected trauma and death. Sometimes, in our effort to avoid pain, we do not discuss or repeat information that is so vital to your peace of mind. Please contact your local organ procurement organization, your physician or the National Kidney Foundation’s National Donor Family Council if you need more information about brain death. You are not alone in your questions and perhaps you will seek out a support group, or start one like I did, to have a forum to address these questions.

Debbie James, MSN, RN, CCRN, CNS, is a clinical care specialist at Methodist Hospital in San Antonio, Texas.



Editor’s Note: The NKF/NDFC brochure “Brain Death: A Simple Explanation” is a useful resource that defines brain death in a comprehensive, yet comforting, manner. Call the NKF at (800) 622-9010 for a copy of the brochure or ordering information.

THOUGHTS FROM RECIPIENTS


Someone Else's Heart

by Patti Baller, RN, BSN, CCRN

It was a beautiful mid-October day; the sky was blue and the leaves were various shades of gold and red. I was at work having difficulty concentrating because of a very special call I was expecting. I was excited when I received the call that my eight-month old cousin Jacob was discharged from the hospital, less than two weeks after heart transplant surgery.

Jacob was diagnosed with a congenital heart defect a few short hours after he was born, and he needed a new heart. As a registered nurse, I worked with Jacob's cardiologist and cardiothoracic surgeon to care for Jacob at home while he waited for his new heart. I prayed that he would receive a new heart and survive the surgery. My prayers were answered.

As I drove to Jacob's home, all I could think about was the child who lost his or her life and the grieving family. I wished they knew how their decision had positively changed the course of another child's life. When I arrived, I walked quietly into the living room where Jacob was sleeping. I knelt down beside him and gently placed my stethoscope against his chest; I heard the very peaceful beating of his new heart from that special someone else.




A few tears dripped from my eyes onto Jacob's hand, and I brushed them away quickly. While driving home, I could no longer hold back the tears. I was crying for the donor child whom I will never know, whom I will never forget and always pray for — God Bless You. 





Writing to a Transplant Recipient


Many donor families wait for the day when they receive a card or letter from the recipient who received the organ or tissue of their loved one. Sometimes that day never comes. Transplant recipients may think that a simple thank you isn't enough. They search for the right words to offer sympathy and thanks for their Gift of Life. They may also think a letter or card may bring more pain to the donor family.

Frequently, when the donor family sends the first card or letter, the recipient feels more able to respond with a card or letter. If you would like to communicate with recipients, here are some suggestions:

-  Write about your loved one—his/her first name, the kind of person he/she was, things he/she liked to do.
-  Write about yourself—your first name, information about your family, your job, things you like to do.
-  Explain how you feel about the donation and transplantation.

-  If you would like to correspond with the recipients, let them know.
-  Do not sign your full name to the correspondence (first name only please).

Once you have written, place the card or letter in an unsealed envelope and send it to the organization that recovered the organ and/or tissues of your loved one with a separate sheet of paper that includes your full name, address and the name of the donor. The organization will request permission from the recipients to forward your letter to them. Ask the organization to notify you when the correspondence is sent out. Please note that not all recipients will write back, and often the whole process takes several months.

Adapted from the National Communication Guidelines, a collaborative project of 13 transplant organizations. If you would like additional information or to obtain a brochure on the Guidelines, call the NKF at (800) 622-9010. 

TEENAGERS SHARING

I Miss You!


Dedicated to Jason Blanco
from Jennifer

I keep telling myself this is all a big bad dream, but in my heart I know the truth. You've gone away forever and you're never returning to this side of the world. I kept thinking to myself that you'll never see me grow up, turn 18 or go to my prom, or even get married. But as I was thinking more and more about it, I began to realize that you'll catch every moment of it.

I know in my heart that you're in a place as bright as the sun and as beautiful as the white clouds that look like pictures when you stare at them. When I look at those clouds, I see the reflection of your beautiful face and I hear your

manly voice echoing through the wind. In my heart, I know you'll always be in good hands.

Sometimes I wonder who is going to answer all my important questions, like what kind of future do I have living in such a world. You're the only one who would understand me. Now you're not here to answer that for me or to look out for me when trouble appears.

I never got to tell you how much I loved you, because I never thought brothers and sisters ever told each other those words. If I only knew we would separate so soon, I would have told you how much I loved you as my brother. I would love the chance to see you once more and hold you in my arms so I could say goodbye. Goodbye for now—from your sister who lives off your memories! I love you! 



If you would like to submit a letter or story to Teenagers Sharing, please direct all correspondence to:

FTWGG Teenagers Sharing, c/o National Kidney Foundation
30 East 33rd Street, New York, NY, 10016
or e-mail donorfamily@kidney.org

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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.

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Donor Family Friends

DF 117 My first born son died in December 1996. He was 17. I have wondered for so long how his recipients are doing and would love to hear from them and meet them. I miss my son so much—when Christmas comes I cry and cry, but I also think of the families of the recipients and the happiness my son brought to them. I wish them all well and hope they never forget the gift.

DF 118 My mother, Carolyn, and 10-year-old daughter, Tyanna, died in a horrible house fire in 1996. I would like to correspond with my daughter's recipients and any grieving parents who never had the chance to say "goodbye" or "I love you."

DF 119 In October 1997, my 16-year-old stepson, Andy, was hit and killed. He was a Christian and also wanted to be an organ donor. At 44, I am now a divorced male and ex-stepparent who would like to hear from and help others who have lost children.

DF 120 My 16-year-old daughter was hit by a drunk driver while she was on her way to school. She was my only child. Please share your similar experience with me.

DF 121 My husband, David, died tragically this year at the age of 40, and I had to make a decision that I thought I would never have to make—to donate his organs. I would like to correspond to anyone who has gone through a similar experience. 

To submit or repeat a Donor Family Friend ad or to respond to a family, send all correspondence to Donor Family Friends, c/o The National Kidney Foundation, 30 East 33rd Street, New York, NY 10016. Please include the number of the DF you are responding to in your letter.

The Quilt on Tour

Please note: This schedule is subject to change.

- July 24-25 NKF of Oregon and SW Washington, *Celebration of Life Weekend/Regional Transplant Games*; Portland, OR. Contact: Fred Bachofner, 503/282-0990
- July 25 NKF of Northern California, *Sports, Fun & Fitness Day/Donor Family Recognition*; Foster City, CA. Contact: Melanie Bekiri or Cindy Lee, 650/349-5111
- Sep. 12* Donor Alliance, *Donor Appreciation*; Denver, CO. Contact: Jennifer Laub, 303/329-4747.
- Sep. 12* LifeSource of the Upper Midwest, *Donor Family Gathering*; Bloomington, IN. Contact: Susan Duhamel, 651/603-7800.
- Sep. 16-18* Gift of Life Agency, *Donor Family Ceremony*; Ann Arbor, MI. Contact: Penny Colthurst, 800/482-4881
- Oct. 1 NKF of West Texas, *5th Annual Patient and Family Symposium*; Lubbock, TX. Contact: Lana Rolfe, 806/799-7753
- Oct. 3 New England Organ Bank, *Donor Family Ceremony*; Trumbull, CT. Contact: Pam Albert, 800/446-6362
- Oct. 4 NKF of Connecticut, *Donor Awareness Activities*; West Hartford, CT. Contact: Jacqui Connolly, 860/232-6054
- Oct. 24 New England Organ Bank, *Donor Family Ceremony*; Providence, RI. Contact: Pam Albert, 800/446-6362

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 individual listed above.** 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 if you would like information on how to contribute a square, please call the National Kidney Foundation at (800) 622-9010 for up-to-date information. Information about the quilt can also be viewed on our website at www.kidney.org.

* Not yet confirmed.

Organ & Tissue
DONATION
Share your life. Share your decision.™

The mission of the National Donor Family Council is to enhance the sensitivity and effectiveness of the organ and tissue procurement 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.

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



Please help us "Cut Down" by notifying us when your address changes. It costs 33 cents if you forget. 