

FOR THOSE WHO GIVE AND GRIEVE



A quarterly newsletter for Donor Families published by the National Kidney Foundation, Inc. to offer information about grief and support.

For Those Who Give and Grieve is provided to all families at no cost and is supported entirely by voluntary donations.

National Kidney Foundation, Inc.

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DEAR READERS: *It is wonderful that so many of you have become members of the National Donor Family Council (over 800 so far!). We appreciate your support. Now that we are becoming a closer family, we'd like to explain who our members are. "Donor families" are families whose members and significant others donated organs or tissues after their death; families who would have liked to*

donate but couldn't due to medical or other reasons; and those families who did not donate, but might have if they had been given the opportunity. The desire to give is as important as the actual giving. Please continue to share your photos, poems, stories, quilt squares and perspectives with us. 🦋

**Thank you,
Maggie & Jayne, Editors**

Council News

The Legacy Continues...

Many families have asked us how they can become more involved in spreading the word about donation and transplantation. We have several programs that you can bring to your local media or community organizations which highlight the benefits and promote awareness and educate about organ and tissue donation.

Please contact the National Kidney Foundation for more information about local education efforts.

- **Getting the Word Out: The Legacy Continues:** a packet of materials to help you get started in raising awareness about donation and transplantation, including sample press releases and ad slicks.

- **National Donor Family Quilt media materials:** press release and accompanying fact sheets including photo for you to use with local media.

- **The Ultimate Second Chance** video: footage from the 1994 U.S. Transplant Games, see transplant athletes in action celebrating the Gift of Life, in this moving video (22 min., \$5).

Support for Families

- **For Those Who Give and Grieve** Donor Family Book, English and Spanish Editions: a bereavement book for donor families written by donor families.

- **Understanding Brain Death:** a short, easy-to-read pamphlet that will help you better understand brain death.

Quick Access!

- Visit the National Kidney Foundation's Website! Dial us up at <http://www.kidney.org> to find out what's new at NKF!

THOUGHTS FROM DONOR FAMILIES



Hope in the Gift of Life


by Linda Winkle

How can we explain or make sense of our funny, bright and very handsome 18 year old son Mac's death? We can't of course, but we get through it and go on with our lives as we must. On Monday, July 4th, 1994 for whatever his reason, Mac took a gun and ended his life. In those horrible first moments when I got to him, I took his hand and told him how much I loved him and prayed to God to take care of him. I meant of course to make him be all right, but I guess God needed him more than I did. I put him in God's hands to do what was best.

At the hospital we were told that his brain stem had been severed and there was little hope. The night was very long and as our family and friends came and gathered around us and him, we all knew to say our goodbyes to him. During the wait, my dearest friend

came to me and asked if I had thought about organ donation. At that moment I was stunned at the thought and could not conceive of my beautiful boy that way at that time. I had hope that he would open his eyes to me again.

When Mac was pronounced brain dead and the doctors asked if we would consider organ donation, I knew then that it was the right thing to do for him and for us. I felt very peaceful. His death would not be in vain and he would help others to live. This is truly the gift of life.

We are still grieving for Mac and we miss him every day, our lives will never be the same again without him. He lives in our memories, in our hearts, in the daughter he left behind and he lives through other people. This is the real hope in the gift of life. 


*In loving memory of Mac Winkle
February 2, 1978 - July 6, 1994*

My husband had always been - without hesitation - an organ donor. The gift of his eyes, ears and skin has helped me to feel that he is still physically around somehow, even though I don't see him, and it is a good feeling for me. I had never made my mind up about organ donation and made that commitment. I have now!

Michele Tillapaugh

Tim gave a special meaning to the word son. He and I were very close, and even though he was a teenager he never lacked expression of love. I miss his hugs and "I love you Mom."

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Those who received the organs we donated from Tim have healthier lives now, from someone who was vibrant, healthy and full of love. 

Jill Engle

To Dad and Mother

I am looking down on earth from here
And I see what you have done
You helped a lot of people
I am proud to be your son
It took a lot of moxie
To give up part of me
But my heart now beats for someone
And someone else can see
I would like to spend a lot of time
Just watching what they do
And if they did some splendid thing
I'd think I did it too
I still don't know if this was planned
I kinda think it was
I surely hope that that's the case
And my life was for that cause
I would love to be with you again
To ease your sorrowing
But if it meant retrieve my parts
I wouldn't change a thing


Your loving son,
Adam

This poem was written anonymously for Adam's parents.

In Memory of Bambi

11/24/72-10/17/93

by Linda Leuker, Mom

 Our beautiful Bambi is in heaven with all the stars above. My little deer will no more roam the beautiful grounds that we call home. The lights in the sky that shine so bright will let us know that she's alright, for up in heaven as we all know the beauty of it as she glows. We feel the pain so deep within that we think we could die. But yet we know our angel is watching us in the sky. May heaven shine so bright within for all the angels God has taken in.

I wrote this in loving memory of Bambi Kay Lueker who died October 17, 1993. Sadly missed by Mom, Dad, Cody, and all the family.

"Life" After Death

Helping Ourselves


The gift of life can be given, even after death.

My brother, James Keller, was a "giver"!

I realize that donating an organ is an unselfish act of love. A part of my brother has given others a better chance of life.

Holding onto that helps heal the "void" and dry the tears. We give our most sincere empathy to all who have lost a loved one. The grief is overwhelming, but we must go through it, to get through it. Let the tears be shed! For every tear that falls, we gain a new sense of strength.

If there was one piece of advice I could pass on to others, it might be, "Helping others and reaching out to their needs, whatever that need might be, helps in healing a broken heart."

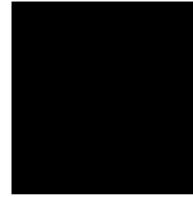
The 'void' will always be there, but the memories live on! 

Kaye Sharp, sister of James Keller, June 16, 1955 to October 22, 1992.

We Fondly Remember...



Kevin Charles Fowler
March 23, 1990-
June 29, 1993




Gene Miller
1937-1995



Kevin Paul Daniels
September 3, 1962 -
August 7, 1995

In Remembrance

 Memorial contributions made in memory of our readers' loved ones are channeled directly into programs and educational resources for donor families and the professionals who support them.

In memory of



Gene Miller - Kevin and Marlo Knapp

Francis Reed Beatty

Tom Brucks- Nova Brucks

THOUGHTS FROM RECIPIENTS

I Love Her Just the Way She Is

 In September 23, 1995 my mother and I got a call we had been waiting for for two years. It was Stanford Hospital calling to ask my mom if she was healthy enough to get a kidney and luckily enough she was. First, she had to find out what to do with me, her 10 (now 11) year old daughter. I was going to go to my grandma's but she wasn't home. My mom called my friend's house and I started to pack. It was kind of the worst time this could happen because we were going to move our furniture out and then in again because we were going to get a new carpet. My friend got there and I said goodbye and good luck and talk to you tomorrow. The next day the doctor called and said that mom was fine. Soon I got to see her. She looked fine, she had some pretty flowers. She stayed in the hospital for a week. Meanwhile I was having fun at my friend's house! Now she is very energetic. She runs around the living room and rides her exercise bike. I love her just the way she is! 

Rose Cabral
(daughter, age 11)

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DONATION AND RELIGION—Contradictory or Compatible?

by Chaplain Skip Wisenbaker, MAE, FCOG



When we find ourselves in a traumatic, sudden, or unfamiliar circumstance such as the death of a loved one, where do we turn? To whom do we turn? In the midst of a tidal-wave of emotions and denial, we seek strength, understanding, and the ability to somehow make decisions. How can we make these decisions? What do we fall back on fully, unencumbered, and with complete trust? For many of us, it is our faith, our religious training, that which we hold sacred. Many of us called upon this faith, this spirituality when we reached a decision about donation.

Many families that I have supported at the time of their loved ones death have said things often thought of as “religious,” to describe donation, such as “redemptive,” “something good has to come out of this bad situation.”; “In this the darkest time of my life, the option of donation was the only ray of light I could find.”

Currently, there are 38 statements from various religions about organ/tissue donation. Of these 37 respond about donation in the following ways:

- encourage donation;
- it is a matter for individual choice;
- acceptable with no restrictions;
- donation is acceptable...when the donor is not harmed.

The only recorded tradition which has no formal resolution concerning donation is Gypsy. On the whole, they are against organ donation. Their opposition is associated with their belief in the after-life. Gypsies believe that the soul traces its steps for one year after a person dies. All of the body parts must be intact because the soul maintains a physical shape.

The Lutheran Church-Missouri Synod, which was the first denomination to encourage donation, states, “We accept and believe that our Lord Christ came to give life and came to give it in abundance. Organ donation enables more abundant life, alleviates pain and suffering, and is an expression of love in times of tragedy.”

Some may wonder how Jehovah’s Witnesses respond to organ donation due to their belief *against* blood contamination through blood transfusions. Yet, a quote from the Watch Tower Bible and Tract Society states,

“Although the group (Jehovah’s Witnesses) is often assumed to ban transplantation because of its taboo against blood transfusion, it does *not* oppose donation of organs and tissue. All organs and tissues, however, must be completely drained of blood before transplantation.”

Others wonder about Judaism and donation with their beliefs concerning death and immediate burial. According to Orthodox Rabbi, Moses Tendler, Ph.D., Chairman of the Biology Department of Yeshiva University and Chairman of the Bio-Ethics Commission of the Rabbinical Council of America, “Organ donation is actually a ‘moral obligation’...It is the only ‘mitzva’, or good deed, an individual can perform after death (brain death). ...there is still some reluctance, as Conservative and Reform Jews might accept brain death more easily than Orthodox and Hasidic Jews, due to concerns about ‘defilement of the dead.’”

A question which may arise is: Has any denomination or faith group reversed their thoughts and official resolution concerning donation? The answer is yes! The Moslem Religious Council initially rejected organ donation by followers of Islam in 1983, but it has reversed its position, *provided that* donors consent in advance in writing. The organs of Moslem donors must be transplanted immediately and not be stored in organ banks. According to Dr. Abdel-Rahman Osman, Director of the Muslim Community Center in Maryland, “We (followers of Islam) have no policy against organ donation, as long as it is done with respect for the deceased and for the benefit of the (transplant) recipient.”

The Roman Catholic Church states, “Catholics view organ donation as an act of charity, fraternal love, and self sacrifice. Transplants are ethically and morally acceptable to the Vatican.”

The New Testament of the Bible relates Jesus telling us the second greatest commandment is “to love your neighbor as yourself.” This becomes then the measuring rod by which we can morally and ethically reach out to help another. For the more we love/accept ourselves, the greater our capacity to love/do for another.

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Donation and Religion...

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Several threads of commonality run through the texture of *all* the recorded resolutions by the denominations and faith groups...concern for respect for the donor; imperative that donation is an individual choice; donation as a “*moral*” choice—a “gift of life”—an “act of charity/love.” Faith and belief systems are made up of statements just like these concerning donation. They want the “believer” to “live out” his/her faith with an attitude of concern and caring and an ethical and moral expression toward others, as well as toward themselves.

Similarities interwoven throughout these resolutions concerning donation can be seen in a prayer by Rabbi Alvin Fine. The following paraphrased quote reflects on how diverse and yet similar we all can be in our individual beliefs and faith systems. Concerning donation and our “life (as) a journey...a sacred pilgrimage...” may this truly be a “Prayer of Unity.”

PRAYER OF UNITY

Birth is a beginning and death is a destination. And life is a journey:

From childhood to maturity and youth to age;

From innocence to awareness and ignorance to

knowing;

From foolishness to discretion and then, perhaps, to wisdom;

From weakness to strength or strength to weakness.

And, often, back again;

From loneliness to love, from joy to gratitude, from pain to compassion,

From grief to understanding, from fear to faith;


From the change we face to the next change we face.

Until looking backward or ahead,

We see that victory lies not as some high place along the way,

But in having made the journey, stage by stage a sacred pilgrimage.

Birth is a beginning and death is a destination.

And life is a journey, filled with change—a sacred pilgrimage—to life everlasting. 

Rabbi Alvin Fine

What Does My Faith Say?

Amish	Approve if there is a definite indication that the health of the recipient would be improved, but reluctant if the outcome is questionable.
Buddhism	Donation is a matter of individual conscience.
Catholicism	Transplants are acceptable to the Vatican and donation is encouraged as an act of charity.
Christian Science	No position, leaving it to the individual.
Greek Orthodox	No objection to procedures that contribute to restoration of health, but donation of the entire body for experimentation or research is not consistent with tradition.
Hinduism	Donation/transplant is an individual decision.
Islam	Moslems approve of donation provided the donors consent is in writing in advance and the organs are not stored but are transplanted immediately.
Judaism	Donation is a moral obligation, saving human life supersedes maintaining the sanctity of the human body after death.
Jehovah's Witness	Donation is a matter for individual conscience with the provision that all organs and tissues be completely drained of blood.
Protestantism	Encourage and endorse organ donation
Mormon	Donation/transplant is an individual decision.
Quaker	Donation/transplant is an individual decision.

Excerpts from Making the Critical Difference, Participant's Workbook, c 1990, National Kidney Foundation.

Disenfranchised Grief

by Kenneth J. Doka, Ph.D.

Elizabeth's best friend, Ann, died less than a year ago. Ever since childhood, they were inseparable, sharing sleepovers, friends, schools, and trips. Yet, when Ann had an accident and was in intensive care, visits were limited to family. She attended the funeral, but felt everything from the dress to the eulogy just did not seem like "Ann."

Mike, a fifteen-year-old high school student, does not like to think about his eighteen-year old brother who died while driving under the influence and crippling another student.

Mark, a 22-year-old moderately retarded man who lives at home, now refuses to sleep without a light. He easily cries and becomes frustrated. His regression is perplexing to his father. "It happened soon after his grandmother died." She, too, lived at the house. "But it's not like Mark really understood," his mother added.

All of these persons are experiencing grief. In each case, the grief is "disenfranchised"—the individuals' loss is not publicly recognized or acknowledged by others or sometimes even by themselves. Because the grief cannot be shared, disenfranchised grievers face special pain and problems. By understanding disenfranchised grief, we can sensitize ourselves and others to the burden of hidden sorrow and more effectively cope with our own disenfranchised losses.

Grief can become disenfranchised for many reasons. Every society has conventions about grieving—rules that define for whom, for what, and for how long people should grieve. In our society the "who" is generally family. Spouse, parents, grandparents, children, grand-children, and siblings have recognized rights to grief. The grief of others often is not considered.

Yet, we are attached to all sorts of people besides family. We can develop strong relationships with so many people—fiances, friends, co-workers, neighbors, teachers, and therapists. And when these people die, we experience grief. Sometimes we may have relationships characterized by strong mixed or ambivalent feelings; for example, toward an ex-spouse. Here too, though, we may grieve.

These relationships are open and understood, even if others do not always recognize the effects of loss. Even more complicated are relationships that are hidden, or viewed negatively. Lovers and persons who live together, whether heterosexually, or even platonically, face added burdens.

These latter relationships point to another aspect of disenfranchised grief. Sometimes it is not just others that inhibit grief. Sometimes, like Mark, we disenfranchise our own grief because we are ashamed or embarrassed to talk about the relationship or loss.

Our conceptions of who can grieve a loss are not only based upon relationships, but sometimes on the characteristics of the griever. Certain grievers like the very old or very young or the developmentally disabled are ignored. Many think they just cannot possibly understand. However, though they may not understand or express grief in the same ways as others, this does not mean that they do not feel the loss.

Sometimes grief is disenfranchised because the loss is not recognized. Many discount the loss of a newborn or a miscarriage. "It's not like they knew the child." Yet, this ignores the great attachment that can form during the months and even years of planning, hoping, trying and waiting. Humans can also form attachments with animals, deeply mourning their loss.

And finally, there are deaths that disenfranchise. Here, too, the shame of the loss is so great that grievers, even family members, are embarrassed to admit loss or share grief. Like Mike, Joan finds it hard to discuss her daughter's suicide. And Maria is ashamed to even mention her son or tell that he died trying to commit a robbery.

Each situation of disenfranchised grief, like any other grief is different. Individuals will react in their own way. But, disenfranchised grievers do grieve and share common problems.

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"I'm glad to be a donor mom. Not proud but humble. Because my son cared enough about people while he lived to help them after he died. He gave a gift of love!!! I don't say a part of my son still lives because when you give someone a gift it belongs to them." - Linda K. Capler

I'm a 35-year old mother who lost my 3 1/2 year old son. My 6-year old daughter is having a tough time. I'd like to hear from other parents with similar situations. I would also like to hear from parents who've experienced disapproval about their decision.

DF60

I'm a young widow, age 35, with two kids. My husband was killed in a car accident a year ago. I would enjoy corresponding with young widows or anyone who has lost someone special.

DF61

 **YOU HAVE MAIL!! DF 57 AND 58** were printed in the Holiday Issue, 1995, but we have misplaced your addresses. Please contact Kathleen Casey at NKf, 800/622-9010.

Names & addresses of people placing ads will be kept strictly confidential. Responses will be forwarded directly to you. Please send your ad to: *Donor Family Friends*, c/o The National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016. If you are responding to an above ad, please use the above address and include the ad number (ex. DF60.)

First Membership Meeting of the National Donor Family Council at the 1996 U.S. Transplant Games

Sponsored by  **SANDOZ**

Partners in Transplant Health

*Presented by the National Kidney Foundation
Salt Lake City, Utah August 20-24, 1996*

For the first time ever, over 800 members of the National Donor Family Council are invited to come together to discuss the issues most meaningful to them. Both educational and fun activities are planned, plus all the excitement of the competitive and inspiring Transplant Games.

Topics that will be discussed include:

- Communication
- Grief & Bereavement
- Brain Death and Donation
- Getting Involved!

We hope you can join us to share your stories, make new friends and, most of all, come away with a feeling of fellowship and renewal. For registration information, call Kathleen Casey at the National Kidney Foundation, at 800/622-9010. The Donor Family Program is supported in part by **Intermountain Health Care**.



The surest way we can honor the memory of those we think of today is for us to day by day continue to receive the gift of life with gratitude and to pass it on with open hands and hearts.

— Rev. Randy Corn

*Excerpt from "A Gift Given & Received,"
Volume 2 Number 4, For Those Who Give and Grieve.*

FOR THOSE WHO GIVE AND GRIEVE



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The Quilt on Tour

The National Donor Family Quilt will be very busy this Spring! It will be highlighted at the following meetings and events:

1996

April 13-14	National Donor Recognition Ceremony	Washington, DC
April 20	NKF of Kentucky	Louisville, KY
April 24	NKF of Iowa	Cedar Rapids, IA
April 24-28	Mid America Transplant Services	St. Louis, MO
April 27-28	Oregon Donor Program	Bend, OR
May 4-5	Life Connection of Ohio Ceremony & Gift of Life Golf Tournament	Dayton, OH
May 10	Iowa Statewide OPO	Iowa City, IA
May 18	NKF of Indiana	Indianapolis, IN
May 27-31	Carolina LifeCare Donor Awareness Week	Winston-Salem, NC
May 31-June 2	NKF of Alabama	Orange Beach, AL
June 2	New England Organ Bank	Boston, MA
June 19	NKF of Connecticut	West Hartford, CT
June 22	Michigan Eye Bank	TBA
August 22-26	1996 U.S. Transplant Games	Salt Lake City, UT
Sept. 4-5	Iowa Statewide OPO	Des Moines, IA
Sept. 22	NKF of Iowa	Cedar Rapids, IA
Oct. 16-18	MTF Medical Board Mtg.	TBA
Oct. 31- Nov. 4	NKF Annual Meeting	New Orleans, LA
Nov. 14-15	South Texas Organ Bank	San Antonio, TX

☞ *If you would like to view the quilt at any of these meetings or would like to submit a square, please contact the NKF at 30 East 33rd Street, New York, NY 10016.*



PERSPECTIVES

This is written in response to the "Perspectives" article in the previous issue:

Generally speaking, when we give a bridal gift, baby gift or a birthday gift, a thank you is not expected. Organ and tissue donation is an altogether different issue. If the donor requested to be a donor, then who is there to thank?

While it is nice to receive a thank you note from a recipient, the donation should be unconditional. It is far more important to me that a life can be saved, a part of my loved one lives on, in spirit anyway and something positive may come from such a tragic and traumatic experience.

"Greater love hath no man than this that a man lay down his life for his friends." John 13:34

Helen W. Hammond
Middletown, CT

Upcoming Annual Meetings

April

25-28 Association for Death Education and Counseling
Pittsburgh, PA

June

23-26 Sudden Infant Death Syndrome International
Bethesda, MD

July

5-7 Compassionate Friends
Long Beach, CA

26-27 International THEOS Foundation
Waco, TX

August

11-16 National Organization for Victim Assistance
Tulsa, OK

15-18 1996 World Gathering On Bereavement
Seattle, WA

November

1-3 American Association of Retired Persons
Salt Lake City, UT

NKF 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 32 cents if you forget.