Upon the measure of this ashen page,
I tell the wounded story
about the death of a rose of a virgin age,
in a sonnet of wistful melancholy.

Bitter gusts give shivers to send
when I think of that doleful night.
In Fury’s play, Perdition did end
a rose in the bloom of life.

Never again is she to spawn
her petals on a Summer’s eve.
Nor is she to be a soothing balm,
a calm on which to cleave.

But she touched all who have sought
the allure of her docile pose.
From my pen the words go forth
of the story of the beauty of the rose.

I walked across evergreen meadows,
I sought she who is gone,
I looked for her soul in the misty dayglow,
but there she was not.
I walked on.

I lifted the eyes to Heaven’s stead;
The rainbow spoke in prose,
“Mourn not your love for she is not dead,”
and I saw in his arms my beautiful rose.

Dedicated to the memory of Amy Federici, who was a victim of the Long Island Railroad tragedy.
A Letter to My Son
by Bev DeSanto
For Ricardo Ray DeSanto: January 4, 1977 - August 21, 1993

Dear Rick:
You have become the common link between known and unknown, but who would think that one so young could play such a role as the giver of life, to make others whole.

We are the known, your family and friends. They are the unknown, whose lives didn’t end, because in your death you chose to give all that you could, so that others could live to finish their mission, which was almost cut short, knowing a transplant was needed, their last resort.

It was so difficult for them to continue to hope thinking each day was their last, how could they cope with the knowledge that others would have to agree to let go of a loved one and set them free so that this miracle called sharing a life could take place, bringing joy out of sorrow, because now, the recipient could think about tomorrow.

I, as your mother, can once again smile, knowing in my heart that your gift was worthwhile. So many others can experience a better quality of living because of your decision to keep on giving joy to those you left behind . . . The known and the unknown, one of a kind.

I was so proud, and continue to be, that you made this decision with no prompting from me.

I hope and I pray as you look down from above that you can see how you’ve helped so many with your love, and that you know that all of us here have learned so much, both the known and the unknown, we’ve all felt your touch. Thank you, sweetheart, for all you have done. I will love you forever, my precious son.

Love,
Mom

Our Boy Ryan
by Joseph and Jean Parker
For Ryan Parker: October 16, 1979 - April 27, 1994

Our boy Ryan, it was just a year ago, though it seems but yesterday that you closed your eyes in a dream-less sleep and we put your possessions away.

Now our hearts are not whole and never will be, we’ll just do the best that we can. We trust in our Lord, but still can’t help think you would have made a heck of a man.

Our other children remain in the nest and have lives of their own it’s true, while in the house where you used to play it seems we’re alone without you.

We’re not really alone, for we feel you here with your cockeyed smile, full of joy, while your siblings still grow, you’ll always be our loving 14-year-old boy.

When riding a horse or wrestling a foe, you always gave all that you could. Whatever the task, you never gave up; sometimes you tried more than you should.

Many years from now, as strange as it seems so bitterly then we wept, that the child we lost and mourned as dead will be the only child we kept.
For Those Who Give and Grieve, Volume 5, Number 4

DONOR FAMILIES

The Right Thing
by Jeff Amrhein

On November 16, 1994, I lost my wife, my companion, my best friend and the wonderful mother of our daughter. She died quite suddenly and without warning at the young age of 34.

She left behind a loving family and many good friends. We had never talked about organ donation, but when the doctor told me that nothing else could be done for her, a very kind-hearted nurse mentioned organ donation.

My wife helped many victims of abuse and other violent crimes, so I knew that this would be something she would want. I was not really sure about organ donation, but after finding out how many people Terri helped, I was convinced I had done the right thing.

He Made a Difference
by Lisa Bollard

In memory of Robert J. Bollard III:

Robert Bollard was an energetic, hard-working man, living every moment to its fullest. He put in 70-hour work weeks and still made time for his wife and five-year-old son. He loved playing drums in his band and tinkering with his toy trains.

Bob was adventurous in everything he did, but the same adventure that brought him so much life also caused his death. While riding his dirt bike, he hit a tree. He didn’t suffer long.

When faced with the decision to donate, I reflected on his regular trips to donate blood and knew it was the only natural thing to do, a symbol of his giving nature and a tribute to his last moments on Earth. It has been a year and four months now, and although the pain seeps back in when I least expect it, I also reflect on the people he may have helped and gain some small piece of comfort that even in his death he made a difference.

Letter to the Editor

Dear Editors:

Thank you for a great newsletter.

Just two weeks after my wife Marie’s death and tissue donation, I received For Those Who Give and Grieve, along with a letter from the eye and tissue bank. This letter helped me during a very dark period in my life. I learned that two people had their sight restored through cornea transplants, thanks to Marie’s donations.

I need no contact from the recipients. The knowledge that her eye tissue was helpful is all I need.

Thank you and keep up the good work.

Sincerely,

Jim Moore

The Season of Spring
by Margaret B. Coolican, RN, MS, Professional Editor, Donor Family Member, NDFC Chair

A time for growth and new life. A time for longer, warmer days. A time for robins and daffodils. A time for cheery hellos from folks who are anxious for the cold and snow of winter to be over.

But some of us who are grieving may not care about warmer days or robins or daffodils. For us, spring may be the first season or another season without our loved one.

For others, spring may be a special time to renew our faith and hope that life will continue in a different way without our loved ones.

However you are feeling, please take care and know we are here to support you in any way that we can.
FOR THE NEWLY BEREAVED

by Mary Ann Carpenter, Editor-in-Chief

It is very important to take care of yourself while you grieve. Especially in the early response to grief, you need to take extra care of your body because grief is hard work.

A member of the Compassionate Friends told me that she became very ill about six months after her son died because she forgot that her body needs a balanced diet. The stress of grieving affected me physically, so I had to take extra care of myself to avoid getting sick. I found these simple instructions and made them my daily routine:

❥ Eat a balanced diet that includes protein, vegetables, fruit and whole grains. Avoid junk food.

❥ Drink six to eight glasses of water, juice or milk per day. Avoid caffeine or alcohol because they cause dehydration.

❥ Exercise daily. Walk, stretch, bike, skate, swim or do something else you enjoy.

❥ Try to maintain your normal rest patterns even if you are unable to sleep.

I needed to be reminded to take care of me. I would like to take this opportunity to remind you to please take good care of yourself.

THOUGHTS FROM RECIPIENTS

Thank You

by Carole Bergman, cornea transplant recipient, Long Island, New York

An incredibly astounding gift. Priceless beyond worth. The power to see the beauty And the lovelines on Earth. To see the sun set in the west. Be aware of each new dawn. Perceive the radiance of a flower. Witness a child new born. To know the rapture and the wonder Of recognizing cherished faces. The love reflected in their eyes. No other sense replaces. To thrill to a baby’s first smile. A delight beyond mere measure. And with this most amazing gift, To grant those we love more pleasure. Behold the beauty of the Rose. A bird with fluttering wings.

Comprehend Earth’s awesome treasures, All of life’s magic things. To read a book or paint a flower. Sculpt with marble, wood or stone. Compose songs, orchestrate the music, Create a special poem. More than diamonds, rubies, Emeralds, gold or jade, Is this fantastic favor, The miracle of sight you gave. To have the freedom just to walk And never blindly fall. A privilege greater than moneyed wealth. The greatest gift of all. The exhilaration and the marvel, Of being able just to see. Words could never thank you half enough For the riches you’ve given me.

Mother’s Day Wish: We would like to extend our thoughts and prayers to all mothers and children on Mother’s Day. Though our loved ones are no longer physically with us, we can take a moment to remember their smiles, their love and our special relationships with them.

For Those Who Give and Grieve, Volume 5, Number 4
Dear Donor Family:

I wish to express my respect and honor for your caring decision to donate. It is not an easy decision to make. Sometimes the decision is made easier because of previous family discussions, but it can be difficult following a tragic event. I want you to be assured that your loved one received quality care both before and after your decision was made. Your loved one left this life and allowed a new beginning with dignity.

As a critical care nurse, I have seen the tragedy and the joy of organ donation. The tragedies of a young mom dying before receiving a transplant; a family trying to reach a donor decision about a child. The joy from the gift of donation allows the precious gift of time to grow up or to see your child grow up.

As a wife and a mother of three sons, I have discussed organ donation with my family and pray that should the occasion arise, I will have the strength and love to honor my family’s request of donation.

-Glenda Jackson, RN
Northside Hospital, Atlanta, Georgia

What Is UNOS?
United Network for Organ Sharing

This national organization is contracted by the government to manage the transplant list. UNOS is involved in the consent and donation process in hospitals and procurement agencies. The organization is divided into 10 regions throughout the U.S., and each Regional Committee is comprised of professionals and at least one patient and family representative. Each Regional Committee meets periodically to discuss and vote on issues pertinent to donation and transplantation. Many of you have expressed an interest in attending a meeting or finding out more about UNOS, please contact UNOS at (800) 292-9548, or visit the network’s website at http://www.unos.org for more information. A list of scheduled meetings, which are open to the public, follows:

- May 1-2  UNOS Region 8, Denver, CO
- May 2  UNOS Regions 3/11, Vienna, VA
- June 6  UNOS Region 7, Chicago, IL
- June 12  UNOS Region 2, Baltimore, MD
- June 19-21  UNOS Region 4, Conroe, TX
- Sept. 19  UNOS Regions 3/11, San Antonio, TX
- Oct. 22  UNOS Region 9, Albany, NY

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:

Lisa DeCampo—Carol LeBlanc
Helen S. Davis—Karen and Paul Hartigan, the Casey family, Barbara and Mike Musto, Donald J. and Margaret B. Coolican, Marilyn Veillette, Carol and James Stack, June and John Capoccitti, Jan and David Schichtel
Eric L. Gautney—Carol Gautney
Finding Out About Tissue Recipients

Dear Donor Families and Friends:

Last week, I received a call from the mother of a young man who died a few months ago. She was inquiring about the recipients of the heart valves that her son donated. I have been involved in the recovery and transplantation of tissues for seven years and still feel the frustration of being unable to supply such information. I do send a letter of thanks to the family, but sometimes can only give general information about how the gift will benefit someone.

When talking with families suffering from a death of someone dear, I, like others in my position, want more than anything to take away some of their pain. We all hope that the gift of organ and tissue donation can be consoling. Knowing specific information about the recipients may make the gift more real and personal for you.

When tissues are donated, however, it’s difficult to find out this information. With the exception of corneas, most tissues are not transplanted right away. Many months may pass before a tissue graft is transplanted. Heart valves, skin, bone grafts and veins may all be preserved for a long time and are not transplanted until a doctor requests them. We rely on the medical facility to provide us with information on recipients, but they are not obligated to do so. Sometimes, we can find out about recipients, so please contact the coordinators at your local agency if you want this information. Please remember, though, that it may not always be possible.

Although you may never know the age or gender of the recipients, that does not diminish the importance of your gift, nor lessen the recipients’ gratitude. Last year, at an area church, the minister told the group about a bone graft he had received during spinal surgery. As he related how well he was doing and that he now had no pain, he said, “Just think, someone whose name I will never know decided to help me.” He then asked me to express his thankfulness to all donor families. I believe no words can adequately express the gratitude and admiration of both recipients and those of us who have talked with you. I will simply say, “Thank you.”

-Gail Wiesner, RN
LifeNet Tissue Services,
Virginia Beach, Virginia

Each year, approximately 500,000 Americans receive tissue transplants.
Special Thanks
The National Donor Family Council (NDFC) was very honored to receive its first donation from a local procurement agency. Translife, of Orlando, Florida, directed a holiday donation to the National Kidney Foundation of Florida, to be used specifically for local donor family support activities. Translife’s recognition of the Council’s efforts to meet the needs and expectations of families is deeply appreciated. We applaud Translife’s efforts on behalf of the Council, which is supported entirely by voluntary donations. Thank you, Translife.

We’re Going to Texas!
Family and friends, gather at the National Donor Family Council meeting in San Antonio, Texas, from October 31 - November 1 during the NKF Annual Meeting. All families are welcome. We will have an opportunity to share with each other and transplant recipients, enabling us to learn more about grief and organ and tissue donation, and to recognize and remember our loved ones who have given the gift of life. Please contact the Council at (800) 622-9010 for additional information, or if you would like to participate on the Texas Hospitality Committee to welcome other families from throughout the United States.

1998 U.S. Transplant Games
Meet us in Columbus, Ohio, from August 5-8, 1998, for the U.S. Transplant Games. The Games are an opportunity to meet other donor families, participate in special workshops and meet and watch transplant recipients participate in Olympic-style athletic events. No other event so dramatically demonstrates the miracle of organ and tissue donation and the bond between donor families and transplant recipients.

Member Services
Local Donor Family Councils are being piloted in five states: Wisconsin, Utah, the Philadelphia-area of Pennsylvania, Florida and Louisiana. If you live in these areas and are interested in becoming involved, please call the NDFC or your local NKF Affiliate. If you live in another area and see a need for local services, call the NDFC for helpful resources.

New Resource for Families
Many resources have been developed for you by other donor families and professionals to meet your needs:

- Butterfly Pin: This is a wonderful way to raise awareness about donation and transplantation and to recognize and remember our loved ones, who have given the gift of life.

- For Those Who Give and Grieve (book): This special book for donor families discusses how you may be feeling after the death of your loved one. The third edition, with an updated bibliography, is now available. The second edition is available in Spanish.

- The Gift of Life Bookmarks and Folders: These are designed to recognize and remember our loved ones who have given the gift of life. Call NDFC, NKF Affiliates or your local procurement agency for ordering information.

NOTDAW: Get Involved
April 20-27 is National Organ and Tissue Donor Awareness Week (NOTDAW). Many events have been planned to help us remember our loved ones and to raise awareness about donation. Please call your local organ, eye or tissue procurement organization or the NKF Affiliate in your area for information about local programs.

National Communications Guidelines
In April, NDFC member Lynn Wellman joined forces with the New England Organ Bank and Boston-area hospitals to develop a protocol for donor families and transplant recipients to distribute the National Communication Guidelines locally. This is a great way to get involved in your community. Please contact the NDFC if you would like to volunteer.

IR$ Extra!
Everyone who receives tax refunds this year will receive something special from the Department of the Treasury—a donor card. Seventy million households may be reached with the crucial message, Share Your Life, Share Your Decision.
Please help us "Cut Down" by notifying us when your address changes. It costs 32 cents if you forget.

DONOR FAMILY FRIENDS

This national support network is for families whose loved ones have died and donated organs and/or tissues. If you need support, write a short note (approximately two sentences) about your loss and send it to Donor Family Friends, c/o The National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016. You will be assigned a number (e.g., DF 81), and responses will be forwarded to you.

To respond to a family, send cards or letters to Donor Family Friends. Don’t forget to include the DF number that you are responding to. We may also be able to match you with a family who has experienced a loss.

DF 63: I am a 22-year-old mother of a three-month-old child. My two-month-old daughter died from shaken baby syndrome, for which my husband is in jail. I would like to hear from anyone who lost an infant.

DF 66: I am a 45-year-old widow. My husband was killed in a car wreck 15 months ago. We would have been celebrating our 25th anniversary. I am having a hard time because both of my children are now a good distance from home.

DF 67: A few months ago, my 18-month-old son was killed. Grieving is easier when you can share with people who are going through the same loss. I would like to hear from anyone who lost a child.

The Quilt on Tour

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*Schedules are subject to change. Please call the National Donor Family Council at (800) 622-9010 for more details. The entire quilt may not be available at all locations.

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