

# FOR THOSE WHO GIVE AND GRIEVE



A quarterly newsletter for donor families, published by the National Donor Family Council of 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.

Spring 1997

Volume 5, Number 4

## We Fondly Remember



*Bryan Neal Sides*  
September 4, 1973-  
July 9, 1995



*John T. Shay*  
May 10, 1971-  
June 2, 1995



*Jose M. Fuentes*  
December 10, 1979-  
July 1, 1996



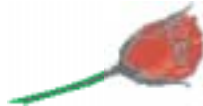
*Dustin W. Sammons*  
March 25, 1977-  
April 4, 1996



*David Alan Trojan*  
February 11, 1948-  
March 3, 1996



*Carmilla Hastings*  
June 13, 1952-  
August 23, 1995



### The Rose

by Jeff DiGeronimo


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.

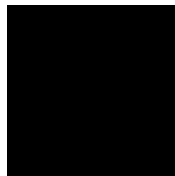
I walked across evergreen meadows,  
I sought she who is gone,  
I looked for her soul in the misty dayglow,  
but there she was not.  
I walked on.

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.*



*Stefan L. Kalamon*  
June 11, 1974-  
April 27, 1996



*Keith Henry Kennedy*  
February 27, 1962-  
April 11, 1994



*Delbert Becker*  
October 4, 1923-  
May 25, 1996



*Lynn Becker*  
February 14, 1949-  
November 15, 1996



*Christopher Vess*  
March 16, 1978-  
December 11, 1994



*Terri Ann Amrhein*  
June 28, 1960-  
November 16, 1994

# THOUGHTS FROM

## *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.


2

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.

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.

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.

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.

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. 



## The Right Thing

by Jeff Amrhein



In 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. 🍂



## 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

## He Made a Difference

by Lisa Bollard

In memory of Robert J. Bollard III:  
July 15, 1967 - July 3, 1995

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. 🍂

## 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.

4 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. 🍂

## THE PRIVILEGE OF CARING

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 participating at the local level. If you are interested 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 

# WHAT HELPS WHEN IT HURTS

## 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.

## 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, Inc.

Opinions expressed in this newsletter do not necessarily represent the position of the National Kidney Foundation, Inc.

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## 🌸 Council News 🌸

### 👉 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.


## 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

May 3	NKF of Georgia	Atlanta, GA
May 3-6	Alabama Organ Center	Birmingham, AL
May 8-10	NKF of Middle Tennessee	Nashville, TN
May 8-14	Regional Organ Bank of Illinois	Chicago, IL
May 13-19	*NKF of Ohio	TBA
May 14-20	Sandoz Transplant Celebration of Transplantation	Chicago, IL
May 18	New England Organ Bank Donor Recognition	Portland, ME
May 22	*NKF of Southeast Texas Fundraiser	TBA
June 1	NorthEast OPO/ Connecticut Eye Bank Donor Family Gathering	New Britain, CT
June 6	NKF of Oregon & Southwest Washington 30th Anniversary	Portland, OR
June 7-14	Delaware Valley Transplant Program	Philadelphia, PA
June 14	*Ohio Valley Life Center	Cincinnati, OH
June 16-22	NKF of East Tennessee	Knoxville, TN
June 22	Iowa Statewide OPO	Iowa City, IA
June 28	NKF of Wisconsin, Kidney Information & Networking Day Seminars	Brookfield, WI
June 29	New England Organ Bank Donor Recognition Ceremony	Newton, MA
July 8	International Society for Organ Sharing	Washington, DC
August 7	NKF of East Tennessee	Knoxville, TN
Sep. 12-28	Eastern States Expo '97	E. Longmeadow, MA
Oct. 2	NKF of South Carolina	Columbia, SC
Oct. 4	*Delaware Valley Regional Transplant Program	Philadelphia, PA
Oct. 10	NKF of Michigan	Ann Arbor, MI
Oct. 22-26	TRIO Annual Meeting	Chicago, IL
Oct. 28-Nov. 2	NKF Annual Meeting	San Antonio, TX
Nov. 10-16	Center for Donation and Transplant	Albany, NY
Nov. 16-23	Tennessee Donor Services	Knoxville, TN
Dec. 6	Southwest Organ Bank	Dallas, TX

*\*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  
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