

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 and is supported entirely by voluntary donations.

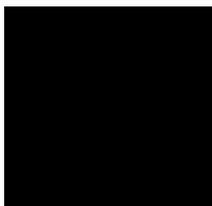
Winter 1999

Volume 7, Number 3

Come Join the National Donor Family Council: A Home for Donor Families

by Mary Ann Carpenter
National Donor Family Council Member, Volunteer Editor-in-Chief

Did you know you have a home? A home where you can share your story and become part of an ever-growing "extended family." We invite you and your family to come join us and, yes, bring along your friends.



Mary Ann Carpenter

Joining is easy! In each issue of the newsletter, there is a postcard that you can complete and send back to the National Donor Family Council. The postage is paid, so you don't even have to look for a stamp.

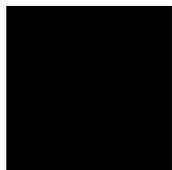
For some of you joining will be easy, while for others it might seem impossible. Your grief may consume all your energy. We, your "extended family," want you to know that even if you do not have the strength to join, you are not alone. Know that your loved ones will never be forgotten.

The National Donor Family Council is where our hearts join together to remember our loved ones. It is a safe place where you can bring your grief, questions and ideas. As a member you will continue to receive the *For Those Who Give and Grieve* newsletter. You will also receive the *Donor Family Connection* membership update and information on all other special programs and available resources. Some of you may wonder if you are currently a member. If you receive the *Donor Family Connection*, you are a National Donor Family Council member.

All of you are encouraged to come join us in our journey as we care for each other and find strength in one another.

Note: This may be the only issue of this newsletter you receive unless you join the council or request a free subscription.

We Fondly Remember



Christopher R.
Boehm
March 2, 1967-
July 7, 1998



Maria Balsler
December 17, 1971-
March 28, 1996



Anne Clare
Iwanowski
July 5, 1925-
July 12, 1996



Eric Christianson
February 2, 1973-
March 13, 1997



Malinda J. Garcia
September 10, 1974-
June 6, 1997



Mark R. McEachern
December 10, 1969-
August 30, 1997



In Loving Memory

Jennifer Schulze
February 14, 1976 - May 16, 1995

*Q*uiet, friendly, a wonderful smile
Eyes that sparkled all the while

Friends, volleyball, yellow roses, too
Wonderful student, sister and daughter were you

You gave when you died as you gave from the start
We love you and miss you with all of our heart 

Always,
Mom, Dad and Kimberly



Why?

*I*t was unfair she died young,
and every day I ask "Why?"
But she's still here with us
because she gave the gift of life.
Somebody lives thanks to her,
somebody sees through her eyes. 

Written by Maria Carr
in honor of Maria Balsler

Brother

*Y*ou gave me a Brother
You taught me to dream
You gave me a Brother
You made us a team

You gave me a Brother
You taught me to smile
You gave me a Brother
For such a short while

You gave me a Brother
You taught me to treasure
You gave me a Brother
Whose love you couldn't measure

You gave me a Brother
You taught friendship to grow
You gave me a Brother
Whose fate I couldn't know

You gave me a Brother
You taught me to love
You gave me a Brother
Who is now up above

You gave me a Brother
You gave me hope
He took my Brother
Teach me to cope 

Karen Pooler
written for her mother in memory of her brother,
Tony Riley, 1974-1996

Save the Date

**1999 National Donor Recognition
Ceremony and Workshop
April 17-18, 1999
Washington, DC**

**This event is sponsored by the Division of Transplantation, Health Resources and
Services Administration, US Department of Health and Human Services**

For more information, call the NKF at (800) 622-9010

DONOR FAMILIES



To My Angel

Jason Lee Creef
May 4, 1977 - August 29, 1997

You left me too soon and I miss you so - oh why, oh why did you have to go? They say time heals all wounds, but how can time heal a wound so huge? I know it will take an eternity if it's really true.

I think of the tree that hurt you and hope you didn't feel any pain. I have enough pain for both of us and would rather it be this way. God wanted you to be with him instead of me. Why am I not mad at God? He has a lot more than I do! I still love Him with all my heart and thank Him for the time I had with you. He had his reasons and I'll only know what they are when I see you again.

As you watch over me, please pray that I'll have the strength to make it each day in a positive way. You mean the world to me and I miss you so much. Can you see my tears falling down? I'm sometimes in

such despair, but when I pray, God sends some sunshine my way. I know you're safe in God's care and someday I will be there. I'm in no hurry, but I wouldn't mind being with you at any moment of the day. I'm ready to go when God wants me.

Son, I know you're my special angel and you're always with me. I just must say that I never knew life would be this way. I'm stronger now, but I'd rather be weak than have to experience this tragedy. I'm going to say so long for now and I want you to know that I love and miss you and will get through this somehow.

Love and God bless you always,

Mom
xoxoxoxox



Donor Family Friends



DF 106 My son died when I was in labor. He was born brain dead and was taken off the ventilator three days later. I'm looking for someone who has shared a similar experience.

DF 107 My 13-year-old son died in 1997 while inhaling an air freshener. I would like to hear from other parents who have lost a child in this tragic, sudden way.

DF 108 My 18-month-old little girl was murdered by her babysitter. I cannot understand this world. My pain is beyond endurance.

DF 109 I recently lost my sister; she hit a snow truck almost head on. She was 15, and I am 16. She was my best friend. I would like someone to write to who understands.

DF 110 Our 18-year-old son died in an accidental drowning in 1996. I would like to hear from any others who share this experience. It would help me deal with the loss.

DF 111 My two-year-old daughter passed away due to an acute asthma attack. I would love to correspond with someone who isn't uncomfortable talking about her.

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.



Many of you have requested information about the **United Network of Organ Sharing (UNOS)** and how the transplant system works.

Our next issue will feature an article about UNOS.



THOUGHTS FROM RECIPIENTS

In Loving Memory of My Donor

God's beautiful moments
Are today's beautiful memories...
You gave me the greatest gift of all...
You gave me LIFE
A beautiful moment that
can't be measured - only in the HEART. 

*Written by Kathy Miller
in honor of Lauren Bohr*



PERSPECTIVES

*M*y son was murdered in September 1997. He was 27 years old and left behind a four-year-old daughter. Shortly after his death, I realized that the gifts he gave may not help anyone. I dealt with the possibility of a recipient rejecting his organ. Facing up to this, I became strong.

The contact I made with recipients was wonderful. I knew that if any of them lost their fight for life, I would be strong for their families. I had already faced what they might now have to face. The gifts were not a promise of life, just a chance at life. The gifts we give are not lost if the recipient dies. The love that we give along with the gifts can last forever with the joining of donor and recipient families.

When we choose to be donors, we must also let go of our loved one. Organ donation does not stop death from happening. Our family has moved on, enjoying the lives of the recipients, and we hope that someday my son will also know the people he helped. 

*Beatrice Gibson,
Mark's mom*

In Remembrance

Memorial contributions are channeled directly into programs and educational resources for donor families and the professionals who support them.

In memory of:

Micala Graves Gehrke - by Mary Gehrke

William LaConteh Hearn - by Eveyln Hearn

Eric Christianson - by Arnold and Sue Christianson

Roy John Geringer - by Levern L. Geringer

Julie Stott - by Margaret and Ray Stott

Barbara Carter - by Clarence Carter

Jennifer Jean Obernesser - by Teresa Obernesser

To the National Donor Family Council - by Jim Moore

To the National Donor Family Council - by Helen Burdge

Visit the National Donor Family Council webpage at www.kidney.org.

Click on "donor families." Post your thoughts or memorial on our message board and respond to other donor families.

When the Grandparent is the Donor: What About the Grandchildren?

by Ann C. Fallon, PhD, CSW

Grandchildren generally form strong attachments to their grandparents. The bond may be even stronger when children see their grandparents daily, and the grandparents assume a parental role. They may become the children's confidants, rich sources of love, experience, guidance and tolerance.

Because of better health and greater public awareness, the number of older people becoming organ and tissue donors is increasing. Older donors may be grandparents who had been very much involved in their grandchildren's daily lives.

When a sudden death occurs, there may be the immediate reaction of shock, denial, grief and sorrow. Mourning begins to set in with the reality of the loss. The son or daughter of the older person either has to make all the arrangements or help the surviving parent make them. There are reality-based decisions to be made; dealing with the hospital and insurance companies; funeral arrangements and attending the service; and interaction with friends and family. Often the activity of those days allows the mind to delay the reality of the loss for a short time.

The children can grieve together, supported by other adults. But what about the grandchildren? The grandchildren may be left out for the most part because of the adult nature of what needs to be done. They are sometimes sent to be taken care of by neighbors or friends. They may be dressed up and brought through social and religious rituals that may seem strange to them. At this time, parents and other adults may be too busy to explain, or perhaps too sad to notice.

The grandchildren have undergone the same experience as the adults, yet may have had no opportunity for expression. Thrust suddenly into a strange situation, they will not necessarily open up to the person taking care of them. The grandchildren, acutely aware of the feelings of their

parents, bottle up their own feelings in an effort to spare the parent more grief.

A sensitive young child may express grief, but quickly realizes that such open expression may cause the parent to cry. Then the parent may withdraw from the child, because the child is a source of additional grief. However, the reaction also depends on the circumstances of the parent. A single parent, who may be more isolated than most, may turn to the child for support and unintentionally put too great a burden on him or her. Also, many adults involved in those days immediately after a death, thinking they're doing the right thing, praise the child for being brave or strong. The message they are sending to the young child is: be good, be quiet, keep your feelings to yourself.

Many times, the death of a grandparent is a child's first experience with death. At some point, an adult may need to take some time to allow the grandchild to ask blunt questions about death and about organ donation, to give the child space of his or her own to grieve. Looking at photographs is an ideal way to enable a child to begin to talk and reminisce, cry and vent the anger and grief. The parent, or adult friend or relative, might be able to take the child to the cemetery for a private visit away from the stress, confusion, strangeness and number of people involved in the funeral itself.

Children are not unlike adults in their grieving process and yet because they are not adults, they do not have the independence or choices available to adults. Adults must present them with opportunities to grieve and help them through this difficult time.

Ann Fallon, PhD, CSW, is a psychotherapist in New York City.

Editor's Note: For a list of resources to help children grieve, call the NKF at (800) 622-9010.

TEENAGERS SHARING



The Gift

by Blake Boswell



I am Blake Boswell, Glenn's son. I am 13 years old. It's been almost six years since my dad died and yet it seems like I was with him just yesterday. Last year, in sixth grade, I had to do a report on the worst day I ever had. The other kids wrote about their bikes being stolen or their cats running away, but I wrote about my dad's death.

My dad was six feet tall, had brown eyes and black hair, and weighed 175 pounds. He was strong and an all-around great person. In July of 1992, my dad had a heart attack and died. My mom decided to donate his organs. It was weird, because just a couple of weeks before he died, he said he wanted to donate his organs and tissue. I never thought that what he was talking about would come so soon. I was seven years old and my sisters were four and two at the time. When my mom told me that my dad had died, I was so upset. I could not believe I had played baseball with him just days before.

Weeks later I found out that my dad had given one of his corneas to a 14-year-old girl, and a 38-year-old man received a kidney and spleen. The most wonderful gift of all was his liver. A 21-year-old girl in Detroit had less than 48 hours to live. She was dying of hepatitis. She received my dad's liver and was able to return to college. My dad also donated any tissue that could be used.

I cannot begin to tell you how proud I am of my dad. Last month, our English class had to do a paper on the best gift anyone in our family has ever given. I wrote about my dad giving the gift of life. The gift that my dad gave is like no other. When you think of a gift, you picture clothes or toys. I am sad that he is gone, but happy that because of him other families did not have to go through what we did. You hear about sports heroes, well here is a real hero. He did not catch a football or make a shot at the buzzer or even hit a home run in the bottom of the ninth. He saved people's lives. I think that is the best kind of hero you can be!

Even though I wish he were here, I think he would rather be in the best place ever, Heaven. I miss my dad and always will, but with God's help, I can overcome anything. In the past year, I have become more involved in organ and tissue donation awareness. My family and I were in a TV commercial supporting organ and tissue donation. I also did a radio commercial. I went to a convention where I met other donor family members and recipients. I met a Redskins quarterback, Gus Frerotte. He's the son of a heart recipient. I let him know that I am a Dallas fan, and he said that was okay!

My dad and I were both really big Dallas Cowboys fans. He loved them so much that his patch on the National Donor Family Quilt is a Cowboys helmet. My dad and I always used to watch the Cowboys games together. We always used to order a pizza at midnight on Saturday nights. We always used to stay up late and talk. Now, I have no one to have a man-to-man talk with. I guess you could say that I get lonely without my dad around.

I could not have made it through my dad's death without my family. My mom, grandma, sisters and aunts have all been great. They have had to put up with me for 13 years. You start to ask yourself what more anyone could ask for – you have great friends and a great family. But then you think about it: a family is not complete without a dad.

My mom told me that just a few years ago, people did not think it was a good idea for recipients and donor families to get together. They were wrong. Seeing recipients alive and well helps us to cope with our loss. They give meaning to what seems senseless. I am proud to be known and recognized as Glenn's son. 

FOR THE NEWLY BEREAVED

About Loss and Grief

by AnnaKay Vajentic, RN, MA

Grief is a combination of all the feelings experienced with a significant loss. It can be expressed in a variety of ways. You may feel frightened, angry, numb, preoccupied, depressed, relieved, confused, anxious, ambivalent, irritable, guilty or victimized.

You may also:

- Sleep too much or too little, regardless of how tired you are
- Have changes in your eating habits
- Think that you see or hear the person who died
- Find yourself frequently tearful or unable to cry
- Be argumentative with others
- Always want to be with someone or tend to avoid family and friends
- Find that you aren't able to enjoy activities that you previously found pleasurable

Some ways that you can deal with your grief are:

- Seek out information for any unanswered questions you may have
- Confide in trusted friends and family members
- Join a group with others who have experienced a similar loss
- Express your thoughts and feelings through creative endeavors
- Obtain professional support through counseling
- Read books and view videos pertaining to loss
- Pay closer attention to getting adequate rest, nutrition and exercise
- Pursue pleasurable activities alone or with friends

As you continue on grief's journey, remember to be kind and gentle to yourself. 

AnnaKay Vajentic is a bereavement coordinator at Lifebanc organ procurement agency in Cleveland, Ohio.

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 National Kidney Foundation. The NKF reserves the right to edit all submissions. Please contact the NKF for article submission guidelines.

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The Quilt on Tour

Feb 1-7	NKF of Eastern Missouri	St. Louis, MO
Feb 14-20*	NKF of Mississippi	Jackson, MS
Feb. 27*	ROBI	Chicago, IL
Mar 1-5	University of Florida OPO	Jacksonville, FL
Mar 7	TRIO - El Paso	El Paso, TX
Mar 13-14	NKF of Wisconsin	Brookfield, WI
Mar 22 - 26*	NKF of Eastern Missouri	St. Louis, MO
March 24*	Theda Clark Medical Center	Nina, WI
March 24-31	Community Display	Bellevue, WA
March 25	NKF of Maine	Portland, ME
March 26*	NKF of Mass. and RI	Providence, RI
April 1-10*	Delaware Valley Transplant Program	Harrisburg, PA
April 9*	NKF of Mass. and RI	Boston, MA
April 10-11	NKF of East Tennessee	Knoxville, TN
April 11	Northeast OPO	Hartford, CT
April 17-18	National Donor Recognition Ceremony and Workshop	Washington, DC
April 23-25	HK Freedman Renal Center	Plattsburgh, NY
April 25- May 1*	Alabama Organ Center	Birmingham, AL
April 26	NKF of Maine	Bangor, ME
April 23-30	NKF of Hawaii	Honolulu, HI
April 27 - May 1	U of Wisconsin OPO	Madison, WI
May 1*	Cal Transplant Donor Network	Modesto, CA
May 5-10*	GOLD Support Group, Luther Hospital	Eau Claire, WI

* Indicates events not yet confirmed.

Information about the quilt can also be viewed on our website at www.kidney.org

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. **Please note that the quilt is not displayed in its entirety, and some events may be closed to the general public. If you would like to attend one of the displays, or are looking for a particular panel or square, please call the NKF for details.** For information on how to contribute a square, to request a panel of the quilt for an event in your area, or for up-to-date information, please contact the NKF at (800) 622-9010.

NDFC

Upcoming Events

All National Donor Family Council meetings and events are open to the public.

Our Executive Committee meetings are Scottsdale, AZ, July 22-23, 1999; and Miami, FL, November 4-7, 1999 (NKF Annual Meeting). Our Annual Meeting will include educational and support programs for donor families, patients and transplant recipients.

Save the dates!

Call the National Kidney Foundation for more information, (800) 622-9010. We would love to meet you.

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. The National Donor Family Council is a Gift of Life Initiative of the National Kidney Foundation.

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



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