

# 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.  
30 East 33rd Street, New York, NY 10016 (800) 622-9010

Winter Volume 4, Number 3


## 1996 Third Annual National Donor Recognition Ceremony April 13-14, 1996 Washington, DC

**Donor families from across the country come together to share, to remember, and to honor their loved ones who gave the Gift of Life. For more information, contact KATHLEEN CASEY at the NKF at 1-800-622-9010.**

### Sessions for families include:

- Families: Different Roles, Different Grief
- Grief: For Men, For Women, For Marriage
- Understanding Donation and Brain Death
- Donor-Recipient Communication Issues
- Getting Involved: The Legacy Continues

## Life's Weavings

*This Winter of your life will pass,  
as all seasons do.  
Stay in your season of Winterness as long as need be,  
for everything you feel is appropriate.  
There is no right way to grieve  
There is just your way.  
It will take as long as it takes.  
To Heal Again.* 

*Rusty Berkus*

From the Family Life Ministry Bereavement  
Newsletter, No.5, Diocese of Norwich, CT.

## We Fondly Remember...



*Leon Schmitt*  
April 29, 1959-  
January 8, 1995



*Peter Paul Novack*  
February 16, 1982-  
August 19, 1995



*Karen L. Musto*  
September 28, 1964-  
November 18, 1991

### CORRECTION

In the last issue Donald Botson's birthday was printed as 1922. His correct birth date is 1912. We apologize for the error.

## 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

**Katie Coolican** - With love, Don & Maggie Coolican and family

**Anthony Pavone** - Mr. & Mrs. Thomas Lore and Mr. & Mrs. Robert Mennillo

**Christopher Pennock**

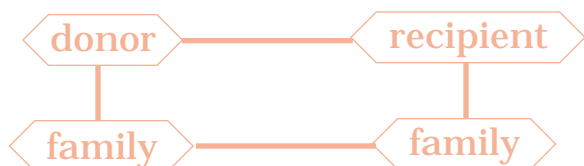
- Mississippi Lions Eye Bank
- Kristine Nelson
- Bob & Judy Zavalla

In honor of **Thomas Miller's** birthday -  
Karen Hurlbut

# THOUGHTS FROM DONOR FAMILIES



## Lives joined...



When my daughter Amanda became a donor, there were overwhelming emotions to deal with. At the time of her death, when the Procurement Organization (PO) approached our family, we said yes. If people could benefit from Amanda's organs and tissues, then we could at least find something positive from her untimely death.

We were told by the PO that within a few weeks, we would receive a follow-up letter with a brief history of the recipients. When the letter arrived ten days after Amanda's death, we experienced joy and jubilation. I read and reread every word and shared it with anyone that wanted to listen. Amanda's gifts had given so much life to so many. When the heart recipient also sent us a letter, I was overwhelmed with emotion...and again I shared it with those that wanted to listen.

Many transplant recipients want to send letters of thanks, but at the same time are overwhelmed and unsure. Some recipients feel guilt because they've been given a "second chance," others have found their way past this feeling and will communicate with donor families.

The grieving process is felt from both the donor and the recipient families. Tears are shed, emotions shared and healing begins. The parallels of our lives are joined...donor to recipient... family to family, through the gift of life.

Susan Burd-Barnes  
Las Vegas, NV

## The Hardest Part of Loving is Letting Go

I dreamt of him long before he was conceived and rejoiced at his being in the world when he was born.

I let him spend his whole first summer sleeping in his playpen outside the apartment door. He loved being outdoors, even then.

When he started to crawl, I put precious things out of his reach and let him explore his world on the floor.

When he started to walk, I stayed outside and let him explore the world enclosed by the apartment's courtyard and along the sidewalk around the block and all the wonders of the nearby park.

I let him walk the block to kindergarten and later, grade school, by himself.

In our new home, I let him play only in the yard at first, then down the street a little, then out into the neighborhood and finally, I let the whole wide world beckon to him.

I let him explore the water's edge at the lake and then the shallows, and finally he was swimming to the raft, where he could dive. A sailboat came later.

In sixth grade, I was awed and somewhat intimidated when his teacher told his father and me that his IQ was "off the chart." Membership in MENSA and INTERTEL would be part of his future.

In junior high and high school, I let him play football, with a lump of fear in my throat.

I let him wrestle and take part in track. I let him polevault and shuddered when he fell and hurt his back several times in his senior season.

I let him fail and feel hurt and alone when his Dad died.

I let reconciliation happen between us.

I let him change his mind three times before he settled on a college major.

I let him legally change his last name to the old world spelling.

I let him grow his hair long and go through the rebellion he never had in high school - a long, painful, hurtful time.

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Led by the National Donor Family Council, a work group of representatives from national organizations is developing national guidelines. These guidelines will standardize practices of professionals in facilitating communication between donor families, transplant recipients and professionals.

Maggie & Jayne  
Editors

Continued on page 3

**Thoughts of You**


by B. Dean, Chowchilla, CA



I'll think of you in sunshine,  
And I'll think of you in rain.  
I'll think of you with happiness,  
Not suffering or in pain.

I'll think of you with laughter,  
And I'll think of you with joy.  
I'll think of you forever,  
As my only little boy.

I'll think of you as charming,  
And I'll think of you as fun.  
I'll think of you as lucky,  
For the race of life, you won.

I'll think of you as carefree.  
And I'll think of you with pride.  
I'll think of you forever,  
Even though you had to die. 



**The Hardest Part of Loving...**

continued from page 3

I let him keep me up until three in the morning as he struggled to put his life on the right track and come into his own.

I let him make me see my own failings and my strengths in our relationship over the years.

I let him call me "Mamasita" and kiss the top of my head and tease me about my gray hair.

I let him love me as only a son can.  
On July 28, 1994, I let him go to his


**Memorial to My Son, Bob**

by Robert E. Dean, Memphis, TN

*Bob* you were grabbed, held down, robbed and shot. You fought back, your assailants did not like that. Your beauty, love of life, love of people, meant nothing to them. The knock on the door, the drive to the hospital...I was numb. I fell across you in intensive care. This could not be real. Not you. I lost it that night, "Not Bob!"

Your organs were donated. I protected you all of your life. The only scratch on you in 17 years was on your left chin, where you fell off the rope in the back of the house, in the backyard. I've never been as lonely in all my life. I see you everywhere I go. I'm afraid to touch your room, but I sleep in it. They said yours was the most beautiful funeral they had ever seen. I called everyone I know, Anthony came, even the father (in his 70's) of my best friend as a boy 6-12 years old, came to the reception.


We are selling our house. Our house is no longer home. I cry when I see the lawn mower; it was your lawn mower. I cry when I go down certain streets...you loved to walk.

I have been shaken to the core. What kind of world do we live in when a boy cannot walk down the street in his own neighborhood? I miss you, son. 

Love,

Dad

Creator, exactly 3 months past his thirtieth birthday.

Acute Leukemia, they say, took him away. I'd rather think that I loved him enough to let him go. 

Charlotte R. Ulibarri, Staff Chaplain, at Sacred Heart Medical Center in Spokane, WA.



## Council News...

### — Communications Guidelines

Can you help review the “National Guidelines for Communication Between Donor Families, Transplant Recipients, and Professionals.”? Call Kathleen Casey at 800-622-9010 to receive a copy.

### — We Fondly Remember...

To place your loved one’s photo in the “We Fondly Remember” section, please send a photo to *For Those Who Give and Grieve*, c/o the National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016. Black and white photos, no larger than 3” x 5”, are preferable. The photos will be returned to you. Be sure to include your loved one’s name and dates of birth and death.

### — The Legacy Continues

For many of us, one of the most helpful ways to learn to live without our loved one is by talking about them and our experience with donation. We can help to educate family, friends and our community by sharing what we have learned as a donor family. Whether we speak to one family member, a civic organization or a group of health care professionals, we can make a difference. As it’s been said “It is difficult to help someone without helping yourself.”

For more information about how you can get involved in educating the public and professionals about donation and transplantation, please contact Kathleen

## THOUGHTS FROM RECIPIENTS

Dear Donor,

I don’t know you, but I have great affection for you. I also know that we probably share more in common than your cornea which became the cornea in my right eye through a transplant just a year ago.

I know we share the love and zest for life, because your actions show the love for others and willingness to help others see the beauty you saw in life.

You had the foresight, generosity, thoughtfulness and unselfishness to donate your corneas before your death or through your relatives after your death. If others could know the good you have done, then maybe they would do the same.

I’ve always wanted to do something to make a difference in this life, and I can’t think of a more noble act than to prevent someone from going blind.

*Forever grateful,  
Terry Rindfleisch  
La Crosse, WI*

## We Love to Hear From You!

Dear Editor,

I would like to take this time to say “Thank you” for your donor family newsletter. It means so very much to me. I can read it and I no longer feel empty and alone. The poems are so deep and moving, and the personal ads are so touching.

*Teresa Atkins, Fairdale, KY*

Dear Editor,

Thank you for the newsletters. They always seem to come when I’m very low and depressed. It makes me feel that someone really cares, and reminds me that I’m not alone in my grief. And without fail, there is always a poem, letter or article that is uplifting and pushes me to go forward with my life one more step. Thank you!

*Janet Money, Heflin, AL*

*And thanks to all of you who have sent poems and stories and shared your experiences with us.*

*Jayne & Maggie, Editors*

## 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*

**Programs for Donor Families!**

*Contact: Kathleen Casey, 800/622-9010*

# WHAT HELPS WHEN IT HURTS

## A Note to Parents of Teens When A Brother or Sister Dies

by Ellen S. Zinner, Psy.D., University of Baltimore



What has happened to your family is tragic. Your grief may be overwhelming at times, and many people around you may let you know how difficult they believe your loss to be. Unfortunately, this affirmation of suffering is almost non-existent for the brothers and sisters of those who have died. Adolescent survivors, particularly, may be “forgotten grievers” because they frequently go unrecognized by others in their suffering and they themselves often hide their feelings from their peers and from you. Teens are too old to take on your lap and rock; yet still too young to deal with the myriad of feelings, thoughts, and behaviors that come with the loss of a brother or sister.

I hope you read and share the *accompanying article on page 6* with your teen. If sharing is difficult, perhaps leaving it in his or her room to read in private may be helpful. I want to add just a few more points about your role in helping your teenager best manage his or her bereavement.

The major psychological task of adolescence is forging a unique self-identity. The death of your child may make this process far more complicated for your surviving teenager. On the one hand, the tragedy itself may make your child more anxious and in need of staying close to parents. There may be demands for more attention. On the other hand, because emotions may be so raw at home and teens may be overwhelmed by their own emotional vulnerability, your teenager may choose to spend more time with peers, desperate to create a “life as usual.”

You can help by being patient and supportive. There is research that shows that some teens are more resilient than others in dealing with loss and that a positive self-image makes a difference in their ability to cope successfully with loss. The same research also shows that, regardless of the strength of self-image, the typical reactions of grief as described in the following article are found in the majority of teens for the first 18 months to 2 years following the death of a sibling.

You may see physical and behavioral

problems with your teenager for several years following this loss. Bereaved adolescents have reported more physical symptoms than non-bereaved adolescents for up to 4 years following the death of a sibling. Depression scores for bereaved adolescents have been shown to be higher than that of non-bereaved adolescents for up to 3 years after the death of a loved one. Younger siblings, those between the ages of 13 - 16, were found to be more negatively affected by the death of their brother or sister than were older adolescents.

Processing one’s feelings of grief is helpful. This includes you and your teen. It is important to make time to share. If your family has a history of open sharing, this is the time to make sure that this valuable attribute continues. It is helpful if you model appropriate ways of expressing grief. Make sure that special occasions, such as birthdays and holidays, include some tangible ritual in which your family can participate together in memory of your deceased child.

Don’t be hurt if your adolescent turns to others to share his or her feelings. You may still be too vulnerable to serve as a patient counselor. That’s okay. What is important is that your teenager has someone to talk to now.

Remember that you are still a parent. Your grieving may take almost every waking moment of your day, but somehow you must continue to parent your surviving children. This is not an easy task. But all your children need and deserve your attention. It is important to make plans to spend special time with your teens, to continue holiday celebrations, and to make sure that special events such as proms and graduations are not lost to your grief.


No one in your family will be the same now that your child has died. Helping your surviving adolescent to go on living, to become wiser and more mature than before, may be your biggest challenge. 🍂

*Washington Irving said, “There is sacredness in tears. They are not the mark of weakness, but of power. They speak more eloquently than ten thousand tongues. They are messengers of overwhelming grief, of deep contrition, and of unspeakable love.”*

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## To a Teenager Whose Brother or Sister Has Died

by Ellen S. Zinner, Psy.D., University of Baltimore

 You may feel alone and “different” now that your brother or sister has died. While it is estimated that about 90% of high school seniors have experienced the death of a family member or friend, the loss of a sibling is still rare. Whether your relationship was close and supportive or more competitive and argumentative, the bond between siblings is a strong one, based on growing up together. Even who you are - the “oldest” or “youngest,” the “big brother” or “little sister” - depends on your siblings. Therefore your brother or sister’s death may be the worst thing you have ever had to face.

This loss in your life can be a two-edged sword. You may experience uncomfortable thoughts and emotions for several years after your sibling’s death. But this crisis may lead to significant personal growth and maturity. I want to share with you what you might experience and how best to take care of yourself during this time of grieving.

**EMOTIONAL RESPONSES:** In one research project the majority of teens said that they felt confused, shocked, angry, lonely, numb, and guilty at the time of the death. All of these feelings were less intense, but still present for many teens, two years after the death. These feelings are common and normal for survivors of any age, and, for almost all grievors, they decrease in frequency and strength over time. But that time period varies from person to person, and you may feel some or all of these or other emotions (such as sadness, fearfulness, even relief) for several years. This is particularly true on special days or during special activities that remind you of your sibling.

**COMMON THOUGHTS:** You may think about your brother or sister a great deal. In the study mentioned above, 95% of the adolescent survivors said that when their sib had died they thought about him or her all the time. Even two years later, 91% of the teens said that they thought about their brother or sister frequently.

**6 SURVIVOR GUILT:** Another thought that occurs for many teens is that it is unfair that they are alive and their brother or sister is not. This is called “survivor guilt.” Survivor guilt is frequently present soon after a death occurs - we feel guilty about lots of things done and not done - but survivor guilt may pop up again particularly when you reach the age

that your brother or sister was when he or she died (if you were a younger sib) or when you achieved something that he or she was not able to do, like graduating from high school or college or getting married. The question of “why him and not me” is a hard one to answer.

You may find yourself worrying that something bad might happen again. We like to think that we and our families are magically protected; but now you know better. The fear that a second tragedy could happen to your family is very common for all survivors. It does take courage to grieve a significant loss and to learn to live fully again.

**SUICIDE:** Thinking about suicide is also relatively common for teen survivors. About one-third of the teens in the study had thoughts about killing themselves either to join their brother or sister or to stop the pain of grieving. A typical statement from these teens was: “I don’t know how to handle all my feelings right now. I feel so bad, and my mom and dad feel terrible. I thought about suicide just to get away from all this sadness. But that would only hurt the family more, and I don’t want to do that. It’s a dumb thought! John (his brother) would never have done that.” Suicidal thoughts are not unusual at times of stress, but you don’t have to act upon them.

**PHYSICAL PROBLEMS:** With so much going on in your head, how you feel physically is going to be affected too. You may experience headaches, stomach problems, and pain in your joints. Others complain of sleeping difficulties and severe nightmares. Some have problems with writing or playing sports.

**BEHAVIOR CHANGES:** The majority of teen survivors also report problems in school. Grades go down. Your ability to concentrate may be seriously impaired for months following your loss. You may also experience a change in how you interact with your friends. Talking about your loss may seem awkward, not talking about it may seem dumb. But finding the right friend to listen is hard, because most friends haven’t lost a brother or a sister.

**COPING:** Despite all the difficulties, learning to cope with a death this close to you can bring positive consequences. In a large study of college students who had been teenagers when their brother or sister died, almost all survivors identified some benefits that they had derived from their experience. These included having a

*Continued on page 7*

I am a young widow, can't seem to see the sunrise anymore. Sunsets have lost their meaning—to promise a bright new tomorrow. All letters welcome.

DF59

I am a 58-year old widow that lost a son from suicide. Would like to correspond with other survivors of suicide to help me get through this tragedy. I lost my husband two years ago so this has been a double tragedy. Please write.

DF38

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. DF59).

**To a Teenager...** continued from page 6

deeper appreciation for life; showing greater caring for loved ones, experiencing stronger emotional ties with others, and feeling greater emotional strength. This perception of increased maturity from having faced a personal tragedy sometimes made these students feel different from their peers. But they also reported that having one close personal friend with whom they could talk to made the difference in their growing from their experience.

**HELPING YOURSELF:** You may have heard the old saying that “time heals.” It is true, but healing often takes more work on your part and longer than you expect. What can you do to help yourself? *First*, give yourself a break. The death of a brother or sister is a huge loss which will draw on your emotional and physical energies for quite a while. Be gentle with yourself during this period.

*Second*, find yourself a listener. Talking out your thoughts and feelings to a friend or family member helps you make sense out of the confusion you are experiencing. If you are feeling overwhelmed or out of control, find a professional listener - a counselor or teacher - who can provide an experienced sounding board for you. It may also help to write down or record your thoughts.

**FOR THOSE WHO GIVE**



**AND GRIEVE**

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*Third*, look for benefits. A terrible loss has occurred; don't let it be a complete waste. What can you learn about life and death, about your family, and about yourself from this tragedy. Search for and be open to a gift of personal growth your brother or sister has left you. The pain and confusion of having had a brother or sister die will always be a part of your life history. It is now up to you to write the future chapters. Make them good!

# The Quilt on Tour

1996

January 29	NKF of Central New York	Syracuse, NY
February 13	NKF of Illinois	Chicago, IL
February 18	CT American Liver Found.	New Haven, CT
February 21-23	DOT/UNOS Meeting	Washington, DC
March 9-10	"Memory & Mourning: American Expressions of Grief," Museum of Our National Heritage Capital	Lexington, MA
March 16-17	Wisconsin Lions/Lionesses Convention	Madison, WI
March 24	25th Anniversary of Hartford Transplant Ctr.	Hartford, CT
April 13-14	National Donor Recognition Ceremony	Washington, DC
April 20	NKF of Wisconsin	Brookfield, WI
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	Portland, OR
May 4-5	Life Connection of Ohio Ceremony & Gift of Life Golf Tournament	Dayton, OH
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
August 4-7	North American Transplant Coordinators Organ	San Diego, CA
August 22-26	1996 U.S. Transplant Games	Salt Lake City, UT
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

In your summer newsletter for Donor Families Diane Lege's letter in Perspectives touched me. I too lost a 22 year old son on June 19, 1991. We donated all organs and tissues and a few months ago I finally heard from one kidney recipient. In our "Have a nice day society," I find it incredible that someone who receives the gift of life can not even acknowledge that gift. I wrote letters on three occasions that the hospital Transplant Unit assures me were forwarded along to the recipients. Did not the gift of sight, or the gift of a strong young heart mean anything to those who received them? Did the physician choose not to forward my letters? Or did the recipient simply not care to respond. I agree with Diane it is so very difficult to understand. To the recipient, I would like you to know the following:

After Steven's death his brother and sister really wanted to hear from the recipients. Tragically they have both since died. I question if I did the right thing in allowing Steven to be a donor. Because of these questions, I simply could not allow his brother and sister to be donors.

*Agencies need to encourage recipients to acknowledge donor families. As a donor family, we need to hear from you.*

Sincerely,

D'Arcy N. Lovetere  
Winsted, CT



**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.