

# *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.

Winter 2000

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## *Come Meet a Transplant Recipient*

**I**n August of 1998, my wife and I journeyed to Columbus, Ohio, to attend the 5th Annual Donor Family Recognition Ceremony sponsored by the Division of Transplantation and HRSA and held in conjunction with the U.S. Transplant Games. We knew there would be people there from all the states but had no idea there would be 550 donor family members and 1,550 recipient athletes ranging in age from 17 months to 76 years. We had met a few recipients before while helping out our organ procurement organization, but not this variety of people. As the athletes wore green badges and the donor families wore blue, it wasn't hard to pick us out. If you have ever wondered, as we have, "Do your recipients know the size of your sacrifice?" The answer is "Yes!" Walking through the athletic areas, we were constantly stopped with hugs, handshakes or some "thank you" tears. A 60-year-old father who had never met a donor thanked us for being able to watch his daughter grow up, thanks to a new heart. The mother of a teenage girl who received a much

needed kidney went on to write a children's book called *Good Kidney/Bad Kidney* used in numerous parts of the country. And on and on. . . Moving? Oh boy! My wife and I are undecided to date about meeting our recipients, but we have seen the happy results of our decision in so many others.



***Transplant recipients lit candles to pay tribute to donors***

This June we will be doing it again. This time in Orlando, Florida, at the "Giving, Grieving, Growing™" conference put on by the National Kidney Foundation and the National Donor Family Council. This conference again will be held in conjunction with the U.S. Transplant Games, both at Walt Disney World® Resort. Come join my wife and me for a rewarding week of sessions, athletic games, sightseeing, shopping and just meeting people who understand. 

*Steve Gardner*  
*[Father of Christopher*  
*1981-1995]*

*Never Let Go*

by David M. Stoutzenberger

As you're wondering why  
and tears tool down your eyes,  
Remember the good times of the past  
and the memory forever last.  
Then remember the friends that  
you've made and all the things  
you did every day.

Though your time with us has  
come and gone  
and the tears are still rolling on,  
your memory it stays forever strong.  
If you think we'll forget you soon,  
think again, I see no blue moon.

It's been a pleasure getting to know you  
and a privilege to be able to say,  
Yes you've made a difference in our lives,  
more than words can say.  
And in our hearts is where you are  
and where you'll always stay.

Someday, if by chance a time should  
come and you start to feel alone,  
I pray that it's a comfort for you to know  
of all the lives  
you've been an impact to  
and all the hearts that won't ever let you go.

*David wrote this several weeks before his death.  
It was submitted by his parents Mr. & Mrs. K.E.  
Stoutzenberger.*

*To My Son Michael*

by Laurie Pajak

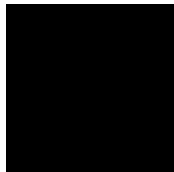
My heart has been shattered:  
Broken pieces never to be found.  
Those pieces went with you when  
You were heaven bound.  
The night you died,  
There was a teardrop in  
the corner of your eye  
I left it there so God would see  
He took you far too soon from me.

My grief for you runs so deep  
Many nights I cannot sleep  
Knowing you will never walk thru the door  
Knowing I'll never see you anymore.

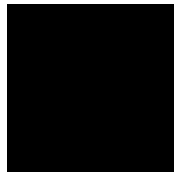
My only son with crystal blue eyes  
I miss your bright shining smiles.  
You will always have my heart  
and my love  
I think you will know as you  
look down from Heaven above.



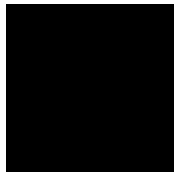
*We Fondly Remember*



*Kelly Lynn Wallisa  
July 12, 1993 -  
August 16, 1998*



*Dan Linzmeier  
January 13, 1975 -  
November 10, 1996*



*Herman W. Giegerich  
August 8, 1952 -  
October 26, 1995*



*Lori Frey  
November 26, 1958 -  
September 15, 1998*



*David W. Schmel  
July 24, 1957 -  
May 10, 1998*



## *Morning Mourning*

by Christine McGowan, donor mom

*For my sweet son, Jonathan  
September 28, 1976-October 13, 1995*


**M**orning is always a difficult time. Grief awakens vigorously refreshed, even though I do not. I awake to greet another day without you.

Weather has no bearing on my grief. On sunny morning, I yearn to see your sunny dimpled smile. When it is raining, I grieve for those early kindergarten days when you would stomp in each puddle on our walk to school—how you loved it when it rained!

Early in the day, my mourning is so forceful and alive. The thought of the long hours that stretch ahead is almost too much to bear. There seems to be

no distraction great enough to take my mind from thoughts of you. My grief is all encompassing.

Somehow the afternoon passes into night. The intensity of evening mourning is not as strong. It's just overwhelming sadness that lacks energy. Evening grief is worn out from the struggle to get through the day.

During the night, my body and mind sleep fitfully but my grief rests soundly. It awakens revitalized to begin the mourning cycle once again. 



## *Our Angel*


by Nicole Ann Chaloupka

In every person's life there are different stories told Always filled with meanings of memories we hold. Tears are cried and hearts are broke and some feel left behind The pain can tear us inside out and make us lose our minds. But just when things can not get worse and you're ready to give in, close your eyes and listen close and you can hear his wings. Our Angel sees just how we hurt and how lonely we've become.

He sees us missing him and awaits the time we come.

Always there beside us helping us more each day helping us bear the struggle and leading us on our way.

So if ever you feel lonely without the one you love remember he is with you watching from above. when you feel the wind blow

think of the one you miss Because it is your Angel blowing you a kiss. 



*In memory of Jason Lee Ernest: submitted by his mother.*

# Flight of the Spirit

by David Stanton

Alone a raven soars above the sacred mountain, gliding on wisps of air from the Great Spirits breath. Hidden from view a tiny Free-tail' dodges and darts deep within the spelunker's<sup>2</sup> chasm. Alone they nurture a solitary element, but together they mentor as dual liberators, seeking to save the wretched. With grace and serenity they fly to the frontier of Father Sky and the womb of Mother Earth, to rescue the shipwrecked from the cave of despair, professing the wonders of the Creator.

Tears of rain cascade from the cheeks of the Spirit who hears the cries of his children. The mournful sound echoes through the land much like the howl of coyotes at twilight. The four winds, blown gently from perfect lungs, fan wings of inner-peace, sending night vision into the darkness. The avis' of flight infiltrate the senses of tortured souls with their soothing song of compassion. Listen to the hypnotic sound of the Aspens swaying, they plea. Feel the bite of melting snow as it flows over



your feet. Smell the pinon scented air's fragrant aroma, taste the earth, kiss the sky. These senses, sent from the wilderness, are true. They are a sign from the departed, a link with your sons and daughters, fathers and mothers.

The earth is alive, a living, breathing being. In its bosom are the ghosts of ancestors, passing the wisdom of the ages to all that seek it. Do not deny the gift, for it is from those whom you love, and those who love you. The earth and sky go on infinitely, the ancient ones who dwell within, are eternal guides. Go forth, out of the darkness and you will find abundant peace. It is the dowry of the Spirit.

1. Free-tail - Mexican Free-Tail Bat, a species which roams throughout the southwest.
2. Spelunker - a person who explores caves

David is a donor dad who has adopted many of the wise and virtuous beliefs of the Native Americans of the Southwest, particularly, the Hopi Nation. 🌸

# Coping with the Death of a Newborn or Infant

by Vivian Dolkart, MSW

The death of a newborn or infant (or child) is one of the most intense and painful experiences that a person may have. A parent doesn't expect to outlive a child, especially a baby. The fact appears to contradict nature. The grief of the surviving parents seems to go on and on.

The death of an infant can leave you longing and aching for what might have been. The child's death can represent lost dreams, hopes and a future you would have created together. However, many bereaved parents have found helpful ways to work through their grief. Don't push yourself over your limits; take things slowly. Be good to yourself. Realize that you can't just snap out of grief and that you are doing the best you can. Allow for periods of depression, sadness and fatigue. It may help to take your time with decisions and to delay any major changes during this time.

## Coping and Getting the Support You Need 🌸

Many parents find that talking with others is helpful. Find a bereaved parent support group in your area, and attend a meeting. Sharing your feelings often tends to make the emotions seem more acceptable

and easier to bear. It helps to realize you are not alone. Do not pressure your spouse to attend with you if this is not his or her preference. You may also find it comforting to read about grief, especially the books written for bereaved parents.

## Grieving as a Family 🌸

Be gentle with yourself and your spouse or partner. Do not blame yourself or your mate for what you were powerless to prevent. Be aware of unrealistic expectations you may have for yourself or your mate. Try to remember that your spouse is doing the best he or she can. Remember, there is no timetable for healing. Everyone goes through grief differently, even parents of the same child. A couple, unlike when they shared easier times together, may suddenly find that in their time of greatest need, they must mourn as individuals. Seek out people who care and will listen. Grandparents frequently mourn the loss of what might have been, as do their children.

An often forgotten member of the family at such a stressful time is the dead child's siblings. It is important

*Continued on page 6*

# Remembering Our Loved Ones

by Margaret B. Coolican, MS, RN, CDE

**S**ometimes finding a special way to remember your loved ones can be helpful as you learn to live without them. By creating a memorial, you can also help a loved one leave a legacy and keep them a part of your life.

Finding a special way to memorialize a family member may take time. This process is unique to each family. You may want to think about the following:

- ⊗ something your loved one liked to do or had dreamed of doing
- ⊗ something he or she was good at or not so good at
- ⊗ a place he or she had been to or wanted to go

The following are a few suggestions that other families have found helpful:

- ⊗ A fishing tournament

- ⊗ A blood drive
- ⊗ Building a playground
- ⊗ A scholarship fund
- ⊗ Donating books to a library
- ⊗ Planting a garden or tree
- ⊗ Wearing a special piece of jewelry
- ⊗ Beginning a collection of angels, butterflies or elephants
- ⊗ Creating a memory book or box
- ⊗ Designing a quilt square
- ⊗ Making a quilt from favorite clothes
- ⊗ Donating money or time
- ⊗ Lighting candles
- ⊗ Decorating with special ornaments
- ⊗ Wearing a photo pin
- ⊗ Adopting a needy secret friend of similar age
- ⊗ Writing a poem, story or song
- ⊗ Gathering family and friends to celebrate his or her life. 

## In Remembrance

Memorial contributions and other public donations to the NDFC are channeled directly into programs and educational resources for donor families and the professionals who support them.

### In memory of:

**Philip A. Montella, Jr.** - by Mr. and Mrs. Philip Montella, Sr.

**Shawn Carpenter** - by Mary Ann and Bill Carpenter and Lifelink of Georgia

**Dan Linzmeier** - by Sherry Linzmeier and Family

**For all donor families** - by LifeLink of Georgia

## Reaching Out Through Internet Chatting

**Join us on the third Tuesday of each month from 9:00-10:00 pm ET for a supportive and educational chat with donor families and bereavement and medical professionals!**

**2/15/00 Cultural Aspects in Dealing with Death**

**3/21/00 Tissue and Eye Donation**

**4/18/00 Communication with Recipients**

### Visit

**[www.kidney.org/recips/donor/chatinfo.cfm](http://www.kidney.org/recips/donor/chatinfo.cfm)  
or call 800/622-9010  
for more information.**



## PERSPECTIVES

### To Whom It May Concern:

*This letter is in response to "The Grief of Siblings, The Forgotten Mourners" and I was so glad to see this article because for me, it's how I feel a lot of the time. People have said to me, he was just your brother, you can get over it—and every time it stings!*

*For me, my siblings have always been my best friends. When my brother passed away at age 29, it was devastating and still is. I grieve for him and think of him every day. He is always with me. We are a close-knit family and my brother meant the world to me. I get angry when they say he was just your brother. He was a brother who loved his sisters. Life does go on but there is always a big hole there without the people we love. Thank you for validating feelings of us siblings who have lost too. We also live with this loss every day of our lives.*

*Susan Bouchey,  
Sister of James Avery Bouchey*

## Coping with the Death...

*Continued from page 4*

for you to tell the child what has happened at his own level of understanding. Left alone, his imagination takes over and he may experience unnecessary fear and guilt. Expressing your feelings honestly and allowing your child to express his, is the best way you can help.

### Other People in Your Life

Family members and friends may find it difficult to be with you during your time of mourning. Some may distance themselves from the grieving parents, adding to the feeling of isolation. Often, those who have not come to terms with their own feelings about death don't know what to say or do. Speak openly with them about your child and your feelings. Respond to helpful or seemingly thoughtless comments by telling them that you loved your infant as an individual who cannot be replaced. Suggest ways in which they may help you, such as preparing a meal.

### Surviving

Hold on to hope. With time, work and support you will survive. You may never look at your life in the same way, but you can learn again to appreciate life and the people in it.

*Vivian Dolkart is a psychotherapist in Nashua, New Hampshire.*

## The Quilt on Tour

*Please note: This schedule is subject to change.*

|                        |  |
|------------------------|--|
| March 1*               | Philadelphia, PA, NKF of Philadelphia, Mayor's Office & Philly Enquirer, Contact: Karen McGrath, 215/923-8611                                |
| March 4-5              | El Paso, TXTRIO, 5th Annual Michael J. Knipp Memorial Walk and Run, Contact: Marie Phillips, (915) 534-4430                                  |
| March 11               | San Antonio, TX, NKDFC Giving, Grieving, Growing™ Program, Contact: Sarah Acosta 800/622-9010. Entire Quilt on Display!                      |
| March 13-17            | St. Louis, MO, NKF of Eastern Missouri and Metro East, National Donor Month, Contact: Chris Tobnick, 800/89-9585                             |
| March 18-25*           | Independence, KS, Independence Museum, Quilt Fair, Contact: Mary Woods, 316/331-6463<br>Independence Museum/ Box 294/ Independence, KS 67301 |
| April 1<br>Birmingham, | Birmingham, AL, 0000 Alabama, Organ Center, 5000th Kidney transplant at U of Al at<br>Contact: Margaret Tresler, 800-252-3677                |
| April 10-21*           | Springfield, MO, Mid-America Transplant Services, National Donor Awareness, Contact: Marsha Buck, 417/886-2515                               |
| April 15               | Sacramento, CA, Golden State Donor Services, 7th Annual 5K Run for Donor Awareness, Contact: Tracy Bryan, 916-567-1600                       |

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. **The quilt is not displayed in its entirety, and some events may be closed to the general public. If you plan to attend one of the displays, please contact Sarah Acosta.** If you are requesting a particular panel or square to be displayed at one of the above events, would like to bring the quilt to your community, or would like information on how to contribute a square, please call Sarah Acosta at the National Kidney Foundation at (800) 622-9010 for up-to-date information. Information about the quilt can also be viewed on our website at [www.kidney.org/recips/donor](http://www.kidney.org/recips/donor).

# THOUGHTS FROM RECIPIENTS

## Sad Celebration

by JS

We have organs for you!  
I heard them say  
Oh, what a happy, happy day!!  
My "Steel Magnolias" family  
Now would not be losing me!

What brought me more than  
my own joy  
Was the thought of my little boy;  
My transplant took place  
when he was five  
And now his mom would stay alive...

In thinking the what, the when, the how  
I forgot the last—it hit me now...  
The one I forgot... it was "the Where"  
For now someone's loved one  
wasn't there...

A family had lost a loved one sweet;  
Would I have a chance these folks to meet?  
I had the joy the great relief  
They had the pain. They had the grief.

A day of sun—a day of rain  
My day of joy—their day of pain...  
To Kelly, my tribute and  
commemoration.

Funny thing. Kelly's mom said  
in her second letter to me  
"I wonder if the tears will ever  
stop...maybe never..." and so it is.

Jen

## 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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# Donor Family Friends



**DF 128** I am a widow, age 56. My husband was everything to me, my best friend, my children's father, someone I had been with since I was 20 years old. I miss him so much. I would like to correspond with widows or widowers.

**DF 129** My father passed away peacefully in 1996. It has taken me some time to correspond with the two recipients of his kidneys. The time that has passed has helped me heal. He wanted to be an organ donor, and so do I.

**DF 130** My mother passed away May 1, 1999. I wasn't lucky enough to be there in time to let her know I loved her before she went into a coma. My aunt passed away on May 9. Then on June 18, my father passed away and I was notified after the fact, so I didn't get to let him know I was there. He wanted to be a donor. I would like to correspond with anyone who has gone through a similar experience.

 **For Those Who Give and Grieve** is looking for a teenage donor family member (with Internet access) who would be willing to work on this newsletter as a volunteer editor. If you are interested in working on this publication, please contact our editorial office, **FTWGG**—Teenage Sharing at 800-622-9010 or [donorfamily@kidney.org](mailto:donorfamily@kidney.org)

**DF 131** I became a widow in September of 1996. It has been quite a battle raising two teenagers without my husband. I truly miss him every day. How do you feel the sun's warmth again?

**DF 132** My son passed away in August 1995, after an automobile accident. He was just 11 years old. I also lost my mom the same year and several relatives thereafter. I would love to hear from anyone who has lost a loved one.

**DF 133** My youngest son died of asthma at age 14. I am a single father and am interested in corresponding with single or other parents who lost a child. I have two other children, age 16 and 20, and request pen pals for both of them; someone who also lost a sibling.

**DF 134** I lost my 14-year-old daughter in a car accident August 3, 1998. She was away on a trip when it happened. I really need to correspond with someone who understands, and needs understanding, too.

**To submit or repeat a Donor Family Friend ad or to respond to a family, send correspondence to Donor Family Friends, 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. Do you have a child who wants a pen pal? Encourage young ones to write us for a Donor Family Friend!**

**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.*

**NK** National Donor Family Council  
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 33 cents if you forget.