

# 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 1998

Volume 6, Number 4

## Life Emerges Once Again in Spring

by Cindy Jo Greever  
Donor Family Editor



 What becomes of the many people who have experienced a death in the family? How do they pick up the pieces and go on? How is their darkness overcome by light?

It is important to understand that we can and we do survive! It is healthy to lean on others who have experienced death and have learned to overcome the pain death brings. Death is part of life and yet so many don't know how to deal with it when it comes. Sometimes death comes suddenly and unexpectedly, like a storm, swooping down and taking your loved one when you least expected it and with no preparation. But even when there is time to prepare, death is a cruel form of life that leaves one forever changed.

My nine-year-old daughter, Michelle, was killed suddenly when struck by a car on her way to school. For me, there was no preparation. Nothing made sense for one so young to be called to Heaven. But I have thought of the lives Michelle touched by donating her organs and corneas. There is comfort in knowing Michelle's death was not in vain.


So even as death can come like a vulture in the night, there can be new hope given in the lives of others, shedding a light that can outshine any darkness. The darkest hours of death can eventually emerge as a bright light of life. From the coldest winter emerges spring with newness once again, the songbirds have returned reminding us of the victory

of peace from death. A peace that comforts and holds hearts for an eternity with love, memories and devotion. For once we love, that love is never lost. And once a garden grows, it never truly dies, it only sleeps for a while in that season called winter. But spring will come my friends, I promise. Our loved ones want us to carry on and be happy just as they would do for us.

We never get over the death of our loved one, but we learn to live with it, and in time, as we reflect back, we see that healing has taken place. We have been encouraged to go on, even when we thought we never could.

I like to think of spring, when the snow has melted and the signs of new life emerge as a comparison on grief. I know that our daughter was born to life eternal the day she parted this earth. I am comforted in knowing she gave life and sight to others through donation. I have been inspired by the gift of life and to know she lives on in others and that "ONE SWEET DAY" we will unite for all eternity as the prayer she memorized days before she went to Heaven promised.

So what has become of the broken hearted? They are okay, growing one day at a time with the hope and knowledge that life emerges once again in the spring... The song bird will be there to remind you.

Love and peace be with you and comfort you. 

# THOUGHTS FROM

## The Treasure

by David Stanton, donor father  
In Memory of Virginia Stanton, cornea donor  
July 18, 1977-February 3, 1993

Dear Readers:

*The death of a child can lead to feelings of guilt, anxiety, depression, and even failure as a parent. Men, I think, more so than women, tend to hide their feelings over loss. I have no research on this, only my own pain. My oldest child, and only daughter, died over four years ago.*

*I mentally berated myself for so long it seemed normal. I blamed myself for what happened, and consequently my life wasn't the same. My wife suffered because of my guilt. My other children know only an angry man whose primary goal is to protect them from tragedy. Life has not been much fun.*

*Lately it seems there is a ray of light breaking through the storm clouds. I wish it hadn't taken this long to arrive, and I know I still have a long way to go. Yet I feel as if I'm not alone, that there are other fathers who have felt as I, and are unable to overcome their grief. For them, for me, and for our families, I pray that the sun shines brightly tomorrow!*

*The enclosed writing is written as the third person would see it; the events are true. Just as the drama of life never ends, neither does the story, it only leaves hope for the future. I have never shared this writing with anyone, because the risk of sharing seemed too great. That day is past.*

-David Stanton

*Heat rises quickly from the desert floor, like ducks taking flight from a hunter's shot, distant mountains blurring in the mirage. A narrow stand of road meanders over a hill, disappearing into an arroyo, only to reappear on the next rise. Skittering from its hideout beneath a Palo Verde, a tiny gecko searches for scarce food. It is a stark moonscape, a land of quiet, unspoiled desolation.*

*Imperceptible at first, there arises a sound misplaced, a low moan, growing like an expanding balloon into a low-decibel wail. A man, sobbing, is mourning the loss of his most precious first born child. Taken*

*abruptly from him by angels, it is his private hell, a prison he cannot escape.*

*Dreamy, effervescent, naïve, the teen could not foresee the treachery that was to be her fate. Her senses were acute, yet dulled, like a deer fixated on approaching headlights, as she drove down the lonely road. The pungent smell of damp kaliche, visions of craggy edifices looming, sounds of gravel peppering the chassis, and girl-talk combined in a frenzy as she savored the taste of adolescent freedom. It was a splendid moment, a mindprint portrait, eternally etched.*

*Images from the past overwhelm the father's conscience, much as gangrene spreads, relentlessly, to a soldier's extremities, destroying life. Atop a solitary monolith he silently sits; meditation the only prescription for his broken heart. A gentle breeze, soothing and caressing, closes his eyes and hypnotizes his mind as it merges with the long ago departed offspring.*

*The hill on Lost Dutchman Boulevard appears suddenly. Like the view from the pinnacle of a roller-coaster, it is both steep and perilous. Frightened, the girl abruptly turns the wheel in a desperate attempt to avoid pending doom. The car obeys her request... but gravity defies the command. Tires lose their grip, and the vehicle rolls endlessly downward, ejecting unrestrained objects in a chaotic menagerie of plastic, metal, and blood.*

*He pines for the solution to mysteries that have for so long tormented. But lo, as if immortal and having to watch each love die before he, the pain relieves. The frightened babble of a child permeates. A gaping wound, hemorrhaging, begs for a father's touch, yet he cannot mend it. Finally, at last devastating scream... "DAAAAAAAAADDY," shoots guilt-tipped arrows through his heart.*

*She lay amidst the scrabble and wreckage, life slowly slipping away, faintly responding to strangers in the surreal light. The whirl of helicopters, aroma of burnt rubber, somber expression of medics, and feel of warm desert soil beneath her, these were her final sensations of life. She uttered her last*

# DONOR FAMILIES



## Daddy


by Katrina Mayes

In memory of Reggie Mayes, May 24, 1947-December 13, 1991



had a dream that you came back  
You hadn't really suffered a heart attack.  
I hugged you  
Your touch was true.  
Mom came in  
And kissed you again and again.  
The tears flowed from our cheeks  
As we told you we missed you for weeks  
and weeks.  
Your mustache was still there,  
Just as dark as your hair.

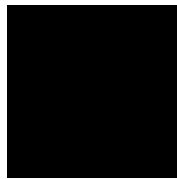


Your grin so bold  
Your wedding band so gold.  
As you leaned over to whisper in our ears  
All the memories came back through my  
tears.  
You said we'd be together again,  
You told me what a good girl I've been.  
You said you had to go away,  
But promised to watch over us day  
by day. 

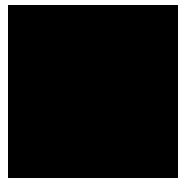
## We Fondly Remember



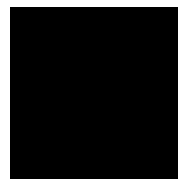
Sean Gorley  
October 24, 1986



Derek Walsvick  
March 5, 1972 -  
November 28, 1990



Jonathan Reed  
Branson  
July 2, 1981 -  
May 11, 1995



Keith Malcolm Perry  
October 30, 1979 -  
December 24, 1994



Gary Paul Tillman  
April 2, 1976 -  
May 6, 1996



Jason Ernst  
July 25, 1975 -  
May 21, 1996



Philip Schoenbauer  
January 11, 1977 -  
November 29, 1995



Richard Thomas Pensivy  
February 11, 1987 -  
April 8, 1997



Allan L. Reinhardt, Jr.  
August 19, 1925 -  
June 22, 1997



Christopher Dalton  
October 20, 1969 -  
October 28, 1996



Scott Ryan Kruse  
December 18, 1977 -  
July 2, 1996



Eugene J. Brandemour  
December 20, 1921 -  
September 28, 1997


## The Treasure *continued from page 2*

mortal words on this spot, and was rushed away.

*Of all the misfortune in his two-score existence, he could not forgive himself for this. Provider, confidant, protector; if only two fatherly traits were good enough, maybe he would be kissing his daughter at her graduation or wedding. Instead he meekly stands before her hospital gurney and places a final kiss on her cold and ashen, yet peaceful, face.*

The doctors had tried to work a miracle, but the trauma was too severe. A torn aorta, like a

burst radiator hose, spilled vital nutrients. As the blood quickly drained, so did life. At 1:10 pm her physical being extinguished. Still, even in death, she lives. A stranger now sees through youthful eyes, a father through memories.

*He casts his eyes, now fully opened, at the distant horizon. Sunlight dances off the shimmering pyrite creating a panorama of color and shape. He is peering through his daughter's eyes now, bounding down the road with her, senses not yet jaded by life's turmoil. Peace and tranquility will, one day, be his. The flesh of his daughter is gone, but her memory lives forever. She has shared the treasure of life with him.* 

# WHAT HELPS WHEN IT HURTS

## Difficult Times: Holidays, Birthdays and Other Special Days

Patricia D. Baller, RN, BSN, CCRN  
Professional Editor

I can hardly believe that it's been over 15 years since the deaths of my mother and father from cancer. Organ and tissue donation was not mentioned to my family. I do not share the experience with you of being a donor family member, but I do share the overwhelming experience of losing a loved one.

The holidays immediately following my parents deaths were the most difficult for me. My strategy for coping was to keep very busy. Volunteering to work extra time or double shifts, becoming involved in charity work, working with the poor or less fortunate families gave me a sense of peace and helped me forget the significance that the holiday held for my family.

As the years passed, I discovered other ways of dealing with important days. Now, on my mother's birthday or Mother's Day, I am able to celebrate by participating in an activity that she used to enjoy or that we enjoyed together;

maybe shopping or a long walk, or even a day at the beach. For my father's birthday and Father's Day, I go golfing. My father loved to golf. Even though we didn't share this activity together when he was still alive, I'm sure he would have been either pleased or amused at my efforts to master the game. I can only imagine the pointers he would have wanted to give me.

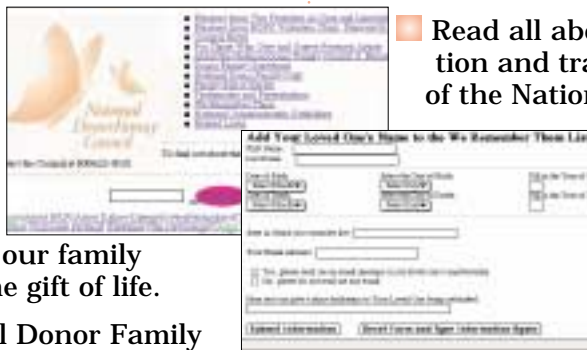
What has happened to me over time is that I no longer try to escape the holidays or special days. I plan, celebrate, and decorate as we used to as a family. The way they would have wanted me to.

It has taken me a long time to reach this point, and there have been many ups and downs along the way, but I can honestly say that these efforts have helped me to continue to be part of a family that I lost so very long ago.

## Reach Out to Hundreds of Families With the Touch of a Button

The National Donor Family Council's Donor Family Home Page will be one-year-old on June 1. If you haven't already visited, we hope you will stop by to help us celebrate our birthday! Some features and opportunities include:

- We Fondly Remember perpetual memorial: add your loved one's name and a short message to the list of our family members who gave the gift of life.
- Photos of the National Donor Family Quilt and updated schedule.
- Monthly chats with bereavement and transplant professionals to start soon—please join us!



- Deciding whether to attend the National Donor Recognition Ceremony at the 1998 U.S. Transplant Games? For photos and families' comments, check out this site.

- Read all about what's new in donation and transplantation and projects of the National Donor Family Council.

- Post your story on the message board (guest book) and reach out to new friends!

[www.kidney.org](http://www.kidney.org)

### MAKE THE CONNECTION...VISIT THE MESSAGE BOARD (GUEST BOOK)


"...I love this Website and have found comfort in the fact I am not the only one suffering... may we all find peace..." Quote from the Website



# FOR THE NEWLY BEREAVED

## Exploring Your Feelings

by Kenneth J. Doka, PhD

 Often when a death first occurs, we can't or don't wish to believe it. We feel it's a bad dream. We believe that our loved one will walk through the door, that life will return to a normal pattern again. We hope that this column will offer you some help as you learn to live without the one you love.

Patricia Murphy, a leading grief counselor, once described the work of grieving as one of the hardest tasks an individual has to do. It is very difficult. Building a relationship with someone takes years of effort. Letting go, too, involves similar effort. Grieving is a long complicated process that involves our emotions, our intellect and our behavior. Grieving involves a number of tasks.

Often the first task is our ability to recognize that a loss has occurred. However, this doesn't

mean that we are ready to emotionally accept the loss or to adjust to life without our loved one. It only means that we intellectually realize that the loss has occurred—that a person we love has died.

Often funeral rituals serve to help us accept reality. The time of the funeral, the somber break in routines, the rituals themselves, all are vivid reminders that a loss has occurred.

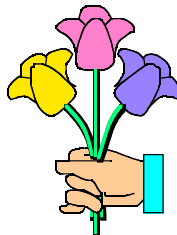
It also may help to talk freely about our loved one. Often we may find ourselves repeating the details and circumstances of the death. This, too, can be healthy. For it can be a way for the reality of that death to seep into our consciousness.

*Reprinted from For Those Who Give and Grieve, Volume 1, Number 1.* 


## THOUGHTS FROM RECIPIENTS

Dear Donor Family,

The month was July 1992, when my ex-husband received his kidney transplant at the St. Mary Hospital in Long Beach. Many times we want to send a letter or a card to the donor family, to say "thank you" for saving my ex-husband's life. But we didn't know where to send the card to. Today I read several thank you notes from the recipients to the donor families, in the National Kidney Foundation's newsletter for recipients, *Transplant Chronicles*. Like Cynthia Johnston said "better late than never." Thank



you Cynthia, for refreshing our memories.

After all these years we never said "thank you" to the donor family. It's been bothering me so much. Please forgive us for not saying "thank you" right away, not because we are heartless, but because we didn't know how to begin. Again, "thank you" for saving my ex-husband's life. 

*Ms. Minh-Duc  
Laundale, CA*

## In Remembrance

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

For the National Donor Family Council—from Ruth W. Drahnann

In memory of **my son**—from Francine Scharf



## PERSPECTIVES

### To Whom It May Concern:

My son was killed June 11, 1996. He was 20, going into his 3rd year at the Air Force Academy. He was in top condition mentally and physically. So when the question of organ donation arose, the answer was yes. James would want his organs donated and his organs were strong for someone else.

I remember thinking, when a letter was received listing the donors (in general terms), of James' organs, that someday I would like to meet the recipient of James' heart. That person would be a special person.

One night last fall, the phone rang, it was the wife of the gentleman who had received James'

heart. She had found out who we were and called. Her husband had been very ill and James' heart had brought them hope. But, her husband had died a month after the transplant.

As time has passed, I find sorrow not only in my son's death, but in the fact his heart is not a part of a living person.

The understanding I had of organ donation is that sometime in the future, as both parties agree, there could be a meeting of those involved. There is a reason for this rule.

I wish I did not know the recipient of James' heart died. The wife should not have called. The donor names should not have been released, not in this scenario. 🍂

Carol Pitetti, James' Mom

## NATIONAL KIDNEY FOUNDATION LEGISLATIVE PRIORITY *Improved Coverage for Transplant Medications*

Last year two very important bills were introduced in Congress that have tremendous potential for improving the lives of transplant recipients. These bills, Senate Bill 1481 introduced by U.S. Senator Mike DeWine (R-OH) and House Bill 1061 introduced by U.S. Representative Charles Canady (R-FL), remove the current three year limit on Medicare coverage for anti-rejection medications for many transplant recipients. Sen. DeWine, the author of the Senate Bill, donated his daughter's organs after she was involved in a fatal car accident.

Both bills attempt to decrease the risk for rejection of transplanted organs by eliminating the tremendous burden experienced by transplant recipients who lack

health insurance coverage for outpatient drugs. Many kidney transplant recipients find that upon termination of their Medicare coverage for these drugs, not only are they unable to get other insurance coverage but cannot afford the out-of-pocket expenses for these essential medications.

Efforts are underway by the NKF and others within the renal and transplant community to gain support within Congress for the passage of these bills. To be successful in this tremendous endeavor, we need your help in clarifying the issue of need and effect of this pending legislation.

Passage of these bills will help maximize our loved ones' gifts. We would like to know your views on this issue! You can mail or fax your stories and perspectives to Tracey Pribble, NKF, 1911 North Fort Myer Drive, Suite 801, Arlington, VA 22209 fax: 703/522-8586. You should also let your representatives

know about your feelings and ask them to cosponsor this legislation. 🍂



*This article was taken from the January 1998 edition of Capital Kidney Connection, NKF's public policy newsletter. If you would like to receive Capital Kidney Connection, please contact NKF's Office of Scientific & Public Policy at (800) 889-9559.*

## Dear Teenagers


Dear Valerie: The worst day of my life was July 3, 1993. I will never be able to forget it no matter how I try. That day, I lost the most important person in my life: my cousin. We lost him to a bullet wound to the head.

It's really strange how things work out in life. For two years, I lived with my aunt after an argument with my mom. I believe there was a good reason for it to happen that way. I got to spend so much time with him, and we became really close. His friends were my friends.

I was only 18 then, now I'm 22 and the pain is still fresh in my heart. I keep hearing the last few words that my cousin said as he left the house, "It's going to be a long weekend, let's see if I can get through it!"

The boys who had shot my cousin had shot my aunt's house just minutes before they murdered him. It could have just as easily been me that was shot that night.

Listen to me going on and on. I guess that all of this is still inside me, and I haven't let it out like I should have. It feels good to have someone to talk to. My family tells me I shouldn't dwell on the past, but they can't tell me how to feel because they don't know what all he and I went


through when we went out. I was closest to him no matter what anyone else might say. They can never take that away from me. I would be happy to hear other teens' stories. It does help to talk about it. 

*A grieving friend, Teresa Alaniz  
[Written in response to Teen Editor Valerie Ramos' letter, Vol. 6, No. 3]*

## DONOR FAMILY FRIENDS

**DF 92** My 17-month-old daughter was run over in my driveway, and I miss her so much. I want to talk with someone who's not scared to talk about her. Please let me tell you a little about my baby.

**DF 93** I am a single mom with 3 daughters (ages 10, 12, 16). My son (10) was killed in a car accident on Oct. 14, 1997. We are struggling to go on and would like to correspond with others who understand.

**DF 94** My son Teegan, 3, died in an accident at home. I would like to hear from anyone who lost a child. 

*To submit or re-run a Donor Family Friend ad or to respond to a family, send all correspondence to Donor Family Friends, c/o The National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016.*

## FOR THOSE WHO GIVE AND GRIEVE

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**National Donor Recognition Ceremony Reminder:  
Columbus, Ohio, August 5-9, 1998**

 **DEADLINE** approaching for the National Donor Recognition Ceremony! If you haven't already signed up, we hope you re-consider! Hundreds of families and thousands of transplant recipients will come together in the largest gathering ever!

- Columbus, Ohio—family vacation destination: in addition to the education and support workshops, the social events, and the inspirational athletic events, you can also share in the excitement of the world-renowned Ohio State Fair!
- If you've put off making a quilt square, here's your excuse. In the presence of donor families who share your experiences, you may pin your quilt square to the National Donor Family Quilt—bonding your loved one's memory with 1,000 others.
- Great value for the money! With university accommodations and meal plans, you can spend 5 days in Ohio for a very reasonable amount. But rooms are going fast!

The National Donor Recognition Ceremony and Workshop is sponsored by the Division of Transplantation, Health Resources and Services Administration, U.S. Department of Health and Human Services in collaboration with the National Kidney Foundation's (NKF) National Donor Family Council and co-sponsored by many transplant-related organizations.

**Autumn National Gathering:** If you are unable to join us at the Transplant Games in Columbus, we have another great opportunity for you: the National Kidney Foundation's Annual Meeting will be held in Philadelphia, PA, October 23-25, 1998. The donor family program will include education, support and some surprises! All for the very reasonable registration price of \$10. *Please call the National Kidney Foundation at 800-622-9010 for a Registration Brochure—and mark your calendar now!* 


## The Quilt on Tour

May 1	NKF of Connecticut	W. Hartford, CT
May 1-2	Jacksonville Organ Retrieval	Jacksonville, FL
May 2	California Donor Network	Modesto, CA
May 3-11	Life Connection of Ohio	Dayton, OH
May 12	NEPATSG	East Stroudsburg, PA
May 17	Northeast OPO	Hartford, CT
May 17	New England Organ Bank	Rockport, ME
May 17	LifeSource:	St. Paul, MN
May 19-29	ROBI	Chicago, IL
June 8-12	Virginia's OPA	Midlothian, VA
June 14	New England Organ Bank	Framingham, MA
Aug. 5-8	1998 U.S. Transplant Games	Columbus, OH
Aug. 20-23	San Diego Quilt Show	San Diego, CA
Sept. 13	New England Organ Bank	Bedford, NH
Sept. 18-Oct. 4	"Big E"	West Springfield, MA
Sept. 25-26	ANET	Cocoa Beach, FL
Oct. 3-4	NKF of East Tennessee	Knoxville, TN
Oct. 18	New England Organ Bank	Providence, RI
Oct. 22-25	NKF Annual Meeting	Philadelphia, PA

Information about The Quilt can also be viewed on our Web site: [www.kidney.org](http://www.kidney.org)

*The quilt is created from squares submitted 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. Since it may not be displayed in its entirety, please call if you plan on seeing the quilt. 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.*

**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.* 

**NKF** National Donor Family Council c/o  
National Kidney Foundation  
30 East 33rd Street  
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