

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.

Fall 2001

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Special Message from the National Donor Family Council

The staff and volunteers of the National Kidney Foundation's national office in New York City would like to thank all of our members and friends for your calls, e-mails and letters following the attacks on the World Trade Center. We take comfort in knowing that, just as in the streets of New York and Washington, families across the nation are keeping one another in their thoughts, prayers and hearts.

Remembering one another this holiday season.

Dear Donor Families and Friends,

We are deeply saddened and shocked by the horrific terrorist attacks upon our nation on September 11 in New York City, at the Pentagon, and in the crash of a commercial airliner in Pennsylvania.


We know that all Americans and many others around the globe have experienced trauma and grief in connection with these terrible events and their ongoing aftermath. But we recognize that for donor families the impact of these events is superimposed on the difficult encounters with personal loss and grief that we had already experienced.

We want to express our special concern for you at this sad time and to encourage you to take good care of yourselves. Where it is appropriate, we recommend that you share your reactions with or seek assistance from helpful persons and organizations. The volunteers of the National Donor Family Council are also available to you by calling (800) 622-9010 or e-mailing donorfamily@kidney.org.

We know that our country and its citizens will find ways to go forward, just as you have done through making the gift of life, contributing a square to the

National Donor Family Quilt, and other modes of coping with your personal losses. Life will never be the same, but we can all find new ways to continue in healthy living and shared loving.

If you find it appropriate, we invite you to offer constructive suggestions for coping to other members of the Donor Family Council, as well as to our counterparts in the Patient and Family Council and in the transAction Council, and to those in New York City and elsewhere from the National Kidney Foundation who have helped donor families in so many ways and over so many years.

Your suggestions and any other messages that you might wish to offer can be sent by e-mail to donorfamily@kidney.org or by regular mail to the National Donor Family Council, c/o the National Kidney Foundation, 30 East 33rd Street, New York, NY 10016. 

**MAY GOD BLESS YOU AND MAY GOD BLESS
THE UNITED STATES OF AMERICA.**

**-The Executive Committee of the National Donor
Family Council**



The Best Part of the Worst Day of My Life

By Dr. Douglas G. Harrell

I want to tell you about a woman who enriched the lives of everyone who knew her, and who, through her foresight, is now enriching the lives of people she never even met. I want to tell you about my late wife Carolyn.

Carolyn was cheerful and optimistic. She had boundless energy. She loved life and all it had to offer. I was the cautious one who worried. Carolyn usually assumed that things would turn out all right, and they generally did.

That's why it took me by surprise about seven years ago, when she came home with a new driver's license and told me that she had registered as a donor. "If I die," she told me, "I want to help people."

Until that moment, I never had any problem with the idea of donation. In my mind, it was always something that happened to other people. Carolyn's statement forced me to think about the possibility of her death, and how I would feel about donating her organs and tissues. I told her I was uncomfortable. I even asked her to change her mind. She smiled slyly, "It's my body and this is what I want!" I was disturbed, but said, "OK, if it's on your license, then that's fine, because I don't think I could make that decision."

Up to this point, everything about her had been light and joking, but now she was serious. "Doug," she told me, "no matter what is on my license, if anything happened to me, you

would have to give your consent. That's why I'm telling you."

I remember my reply clearly. "Carolyn, do you realize what you're asking me? On what would be the worst day of my life, you're asking me to undergo that additional ordeal?" But, she was adamant. I was surprised about how strongly she felt. I had initially thought it was a whim, but it was clearly something that



*Carolyn with her husband
Douglas*

she had given a lot of thought to and in the end, I had to promise.

That was seven years ago. In the meantime, I thought about it myself to the point where I realized that I agreed with her. When we moved to Maryland last January, I went to get a new driver's license. After a moment's hesitation, I signed up to be a donor. When I got home I proudly showed Carolyn my new license with the words DONOR/YES. It's strange to me now to remember how big her smile was, but that's the way Carolyn was with things that she cared deeply about.

Just two short months after I'd signed my donor card, the worst day of my life arrived. One Friday in March, I was in Louisville, Kentucky helping my mother make funeral arrangements for my grandmother, who had died the day before. Just before noon, I got a call that Carolyn had collapsed at work and been rushed to the hospital with a massive heart attack. I was able to speak to her briefly on the phone, which gave me hope, but 90 minutes later, after a brave struggle, she died.

Shortly afterwards, talking on the phone with my father, he asked me the question that I hoped I'd never hear. Did I want Carolyn to be a donor? At that moment I realized the great gift that Carolyn had given me with our conversation of seven years earlier. I didn't have to think; I knew she wanted to help others. I wanted that too, and I gave my consent.

There were two things I had to do. One filled me with sorrow, but the other buoyed my spirit. I knew that I had to get back to Maryland to see Carolyn and spend some time with her. I knew that I had to hold myself together so that I could make the arrangements for her to be a tissue donor.

I think we've all heard it said that the physical body of a dead loved one isn't what really matters, because the body is not the person, just an empty vessel. I can tell you that the time I spent with Carolyn there in the hospital, I felt differently. It's true that it wasn't animated with her fabulous spirit,

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The Best Part ...
continued from page 2


but this was the body of my wife, my soul mate and my best friend. It's how I had known her all our life together. If this were just an empty vessel, then I wouldn't care what was done with it. But I did care—very much.

I still felt so much love for Carolyn, and I knew that I could express this to her through the loving and respectful disposition of her body. And it was so important to her that her body be used to improve the lives of others. Making the arrangements for her to be a tissue donor was an act done out of love: her love of life, our love for the unknown people who would be helped, and my love for her.

Most people are familiar with the donation of a heart or a kidney. Before the day Carolyn died, I had never heard of tissue donation. Carolyn told me, "If I die, I want to help people." Sadly, her death has come to pass, but the sorrow I feel over the loss of Carolyn is lightened by the knowledge that people have been helped. Already, two people have had their sight restored, while two others have received either life-saving or life-prolonging heart valve transplants.

If I could speak to these people, I would tell them two things. First, I gave this gift you have received to you with great love from Carolyn and me. Always know that wherever you are, there are two beings that love you profoundly. Second, please don't ever feel guilty about what you

have received. Nothing could save Carolyn. You have made it possible for something life affirming to come out of her death.

On March 23rd, my beloved Carolyn died. It has been a great source of comfort to me to know that through her compassion and wisdom, two people are living richer lives, two people are leading longer lives and, perhaps, somewhere, a family has been spared the anguish that nothing could spare mine. We must all take responsibility to spread the word about donation among our friends and colleagues so that people in need are helped, and so that families in grief can benefit from the comfort that donation brings. Perhaps for them it will be like it was for me: the best part of the worst day of my life. 

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▲ **Editorial Office**

National Donor Family Council

NKF, 30 East 33rd Street

New York, NY 10016

(800) 622-9010

(212) 889-2210

FAX: (212) 689-9261

www.kidney.org

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To our Nathan, Moved on but not Forgotten

By Mrs. Patricia Martinez

*I*t's two years now since you've gone home
And we just want you to know

That in that special place you filled for us
There will always be a hole.

Your smell, your voice, your gleaming smile
And letting only Mom cut your hair.


Your practical jokes and laughter
Always filling the air.

The time we had together was very special
But way, way, way too short.

And now we're left with a big empty space
And feelings hard to sort.
It's hard to go on without you here
For too many of us, this we know.

But go on we must and in the style
That you, to each of us, always showed.

So be happy at home with your Lord on high
As we continue your example down here.

And know that to each of us touched by
your love
You will always be held especially dear. 



Happy 2nd Anniversary
Love Always,
Mom

The Spirit of Thanksgiving


By Dr. Douglas G. Harrell

The holidays will be upon us again soon. Everyone I talk to and every book I read says that the holidays are a difficult period following the death of a family member. This will be particularly true for me. Carolyn's favorite holiday was Thanksgiving.



Some years ago, Carolyn brought the family Thanksgiving dinner to our home, inviting everyone in both our families. As if it weren't enough, she would invite someone from another country who wouldn't experience Thanksgiving if they didn't come to our house. One year it was a fellow from Colombia who was studying English at the University of Delaware. Last year she invited a cousin of my brother's wife's family from Brazil.

Carolyn would take off the day before and cook a large number of dishes, which always amazed me. The most special element of the day for me was the spirit in which Carolyn did all this. It wasn't a chore; she truly loved doing it.

To keep Carolyn's special Thanksgiving spirit alive this year, I am inviting the whole gang over to our house. I'm going to take Wednesday off and cook up a storm. I've already started pulling out recipes that I think I can handle. I've been practicing in September and October so that I can prepare something edible. I'm going to enjoy doing it, even if nothing works out. If the turkey slides off the deck into the Susquehanna River, or the oven catches fire and ruins everything, I'm going to laugh about it and order in Chinese. I can't think of a better way of honoring Carolyn's memory than that. 



He Will Live On

Danny Summers

August 12 our loved one was involved in a tragic automobile accident. He did not survive.

Eighteen and a half years old. Son, grandson, brother, friend, with a lot to do, a lot of places to go—even a new job starting the next day.

Just a couple of months before – when time came to renew his drivers' license – he was asked, "Do you want to be a Donor?"

Mother said,—after a questioning stare—"It's up to you son, your Dad and I are, but it's up to you."

"If you and Dad are, then, yes. I will sign my license, too."—Never expecting death to be so near.

While out to see the girls, as most guys do, driving too fast on unfamiliar roads, he lost control going around "Dead Man's Curve."

Knock on the door, early a.m. calls—"there's been a bad accident"—they suspect he's brain dead from internal injuries.

Hasn't been confirmed —must go many miles to the hospital—

No, no, it can't be —it must be a bad dream.

There lays our loved one, never to look at us with those beautiful blue eyes

Brain dead—it was confirmed.

There stood a heart broken Mom and Dad, a brother in shock, an uncle, grandparents and an aunt.

His brother breathed, "he wasn't supposed to die like this," in a tragic automobile accident.

It was a process of waiting and testing and waiting for the donor team of surgeons to arrive.

Time to say "Goodbye" and let the doctors work.

"Lord our Savior and Sovereign, give us Grave and Strength in this time of grief."

He will live on with his HEART

Through someone with a life threatening heart failure condition.

He will live on with his LUNGS

Through someone suffering from emphysema, cystic fibrosis, or another life threatening lung disease.

He will live on through someone that will receive his LIVER

A person suffering from severe liver failure.

He will live on with his KIDNEYS

So that a person suffering from kidney disease won't have to rely on dialysis.

He will live on through the eyes of another person, through his CORNEAS

A person's sight is restored.

He will live on by donating SKIN


So young and healthy, to someone with burns.

He will live on through BONE donations

To someone requiring: reconstruction, limb salvage, correction of a birth defect, cancer treatments, spinal surgery or oral surgery.

He will live on through TENDONS

To someone requiring reconstructive joint surgery.


He will live on in all the lives he helped to save through ORGAN and TISSUE TRANSPLANTATION! 

His Grandmother Barbara E. Summers

In Loving Memory of John Anthony Dileo-1973-2001

Togetherness



Death is nothing at all—I am not gone. I have only slipped away into the next room. Whatever we were to each other that we still are. Call me by my old familiar name, speak to me in the easy way, which you always used to. Put no difference in your tone; wear no forced air of solemnity or sorrow. Laugh as we always laughed at the little jokes we enjoyed together. Pray, smile, think of me—let my name be forever the household word that it always was, let it be spoken without effect, without the trace of a shadow in it. Life means all that it ever meant. It is the same as it ever was; there is unbroken continuity. Why should I be out of mind because I am out of sight? *I am waiting for you, for an interval, somewhere very near, just around the corner.* 

Henry Scott Holland, Canon of St. Paul's Cathedral

Good Grief

By Herb Agee, Chaplain

Good grief! It's almost fall, the time most of our cherished holidays begin. It's time to be with our families and friends to celebrate. But holidays aren't always a time of celebration. When we have experienced the death of someone we love, the tendency is to dread the holidays rather than anticipate. But aren't we supposed to look forward to the holidays? Not everyone does.

Some people dread the season because of the money they spend and the stress they endure. They have lost the real meaning of the holidays. If you are dreading the holidays because of grief, you are not alone. But you can get through them. You can put real significance back into this time of the year, even in the midst of your grief.

First, decide what kind of holiday you want and do not feel forced into someone else's plans. You may want a really big celebration, but a quiet one is all right, too. Realize your own limits, both physically and psychologically, and plan accordingly. Listen to your body. You are not crazy if your body talks to you.

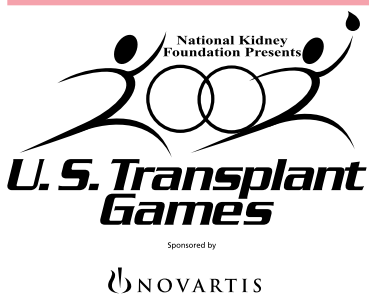
Next, it is usually good to be with family and friends whose company you enjoy. Remember to let them be there for you, don't shut them out. I have an aunt whose husband died six months prior to our family reunion. After an hour at the gathering, I noticed her standing alone at a window. I put my arm around her shoulder and asked how she was doing. She sighed, "Okay." "You know, I miss William," I said. She looked startled and asked, "Did you know that you are the first person who

has mentioned him to me?" I nodded, "That's because people don't want to make you think about him. They're afraid they'll make you cry." She started to cry, "I'm thinking about him all of the time." I hugged her tighter and whispered, "I know that, but they don't. They don't know what to say to you. Next time somebody asks how you are doing, say you're fine, but you miss William. That will let them know that it is okay to talk about him." "Really?" she said. "Yeah, really!"

Not only was everyone else afraid to talk to her about him, she was afraid to talk about him to them. A lot of pronouns here, but pronouns are our problem. It's the him or her that we miss and grieve, and the them and us that are afraid to talk.

One last thought. Be sure to acknowledge the person that is gone. Sometimes we try to ignore the fact of the loss and pretend that things are the same. But we know and can feel the difference. It is better to bring it up. Talk about missing them, share memories, light a candle, put a picture in a prominent place, cry, laugh, pray. Let the loved one who is gone be part of the holiday by loving them openly, in front of yourself and others.

Caring for yourself, realizing it's okay not to like the holidays, being with family and friends, and acknowledging the grief will go a long way in getting you through and bringing some meaning and significance back into the holidays. If not, remember that, like every other day that you've dreaded, the holidays too will pass.




SAVE THE DATES! The National Donor Family Council invites you to the 2002 U.S. Transplant Games at *Disney's Wide World of Sports™* Complex in Orlando, Florida June 25-29. Come see transplant recipients compete in Olympic-style events and participate in the Donor Recognition Ceremony, educational workshops and sharing sessions, a special quilt pinning and more.

6 For more information, email donorfamily@kidney.org or call (800) 622-9010.

THOUGHTS FROM RECIPIENTS

"Give my kidneys to one who depends on a machine to exist from week to week."

That was me six years ago. I depended on a machine to live, love, hope and care for my family and friends. I was young, life was young, but then my kidneys failed. All of my hopes and dreams were pushed aside by this terrible disease. I couldn't understand why this horrible disease had entered my life. I only knew it was there prohibiting me from living life to the fullest. All of a sudden, I was faced with sodium restrictions, fluid restrictions and the surgeries that it would take before I had a good access to dialyze with the pain of 14 gauge needles in my arm three days a week. Then in September of 1990, a 16-year-old boy, Shawn Carpenter, died of a brain aneurysm. His parents, Mary Ann and Bill, decided to give the gift of life through Shawn. When the call came that I was to receive a kidney, I was overjoyed. But when I learned of this young man, my joy faded. The self pity I felt for myself disappeared and all I could think of was the boy who would never know the joy of dating, borrowing the car, or one day having a family of his own. Life was unfair to both of us. Now I make the best of each new day, I'm studying to be a nurse. Shawn's parents and I talk on the phone often and my family and his have both benefited from the tragedies of our lives. Through all the sadness and pain, we found each other.

So please remember, all donor families are forever in the thoughts and prayers of each and every recipient. Your gift of love will forever be remembered. 

In my heart,

Shirley M. Parks

(Written prior to her passing. September 6, 1959 - October 12, 1998)

The Quilt on Tour

Please note: This schedule is subject to change.

- October 22-29 Atlanta, GA. *Georgia Transplant Foundation*. Pat Sortor/Chris Star. Georgia Transplant Foundation Wellness Conference, (770) 457-3796.
- Nov. 1, 9-11 Honolulu, HI. Organ Donor Center of HI. Christine Bogue, *National Donor Sabbath*, (808) 599-7630.
- November 4, 10 Georgia. *Lifelink of Georgia*. Skip Weisenbaker, (800) 544-6667.
- November 5-26 Hartford, CT. Northeast Organ Procurement Organization. Maggie Coolican. *National Donor Sabbath - Give Thanks, Give Life*. (860) 545-2256.
- November 10 Kentucky Organ Donor Affiliates. Jenny Miller, (859) 278-3492.
- November 10-11 Florida. *LifeLink Foundation* - Tampa. Charlayne Gray, (800) 262-5775.
- November 11-18 Knoxville, TN. Tennessee Donor Services. Kathy Richards, *Thanks for Giving Ceremony*, (865) 588-1031.
- December 1 Indiana. *Indiana Organ Procurement Organization*. Brenda.

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 the person hosting the event.** 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 Ockler for up-to-date information. Information about the quilt can also be viewed on our Web site at www.donorfamily.org.

Teen Sharing

Holidays Without Your Loved One

By Brooke Webster

Holidays are a very hard time for my family. It's when we remember that Ryan would be out of school and playing with his friends, but instead we sit and watch his friends play without him. Living without your loved one is hard enough, but to realize you face birthdays and favorite holidays without him makes life even tougher. My brother would be 15 years old this year. He would probably have his driving permit. I am pretty sure for Christmas he would be getting a new car, just like I did. But now I have to make it thorough my brother's favorite holiday without him.

I know my brother gave gifts of life when he donated his organs. He will live on forever in the lives of others.

We write back and forth with a man who received one of my brother's kidneys. Holidays are a time for him to be joyful and thankful for the life he has now, because if it were not for my brother he would not be

able to enjoy the holidays with his family. It makes grieving easier when we hear from my brother's recipients, especially around the holidays, because we realize how thankful they are and how giving my brother was.



Prayer gets my family through the holidays. We visit my brother's grave and put our gifts to him there. For example, we might put flowers or a plaque, or for his birthday we'll bring him balloons. I understand how hard every day is for teenagers grieving because we have lost someone that we love very much. But there is hope in knowing that one day we will all meet again and celebrate each day with one another. 🦋

Any teen that wishes to write Brooke may do so care of the NKF, [see cover below] or by e-mail to donorfamly@kidney.org

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.



NKF National Donor Family Council
National Kidney Foundation
30 East 33rd Street
New York, NY 10016



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