

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.

Summer 2002

You can visit us on the Web at: www.donorfamily.org

Volume 11, Number 1

National Donor Family Council Celebrates Ten Years!

By Ellen Kulik, Donor Mom and NDFC Volunteer Chair

*A*s the volunteer Chair of the National Donor Family Council, I am privileged to preside during this tenth anniversary year. I am the "new kid" on the block compared to legends like Maggie Coolican ("Mother Mag"), Vicki Crosier, Barbara Musto ("Mama Musto"), and the National Kidney Foundation's own Gigi Politoski. As I reflect on the history of the NDFC the phrase, "You've come a long way, baby," comes to mind.

When a small but dedicated group gathered in the early 1990s to discuss forming a national council for donor families, donor family care and support was much different than it is today. Many families felt that they had given the Gift of Life and were then left to grieve alone. For several years, some families searched for understanding and support, taking their message across the country. With the help of these devoted families, the National Kidney Foundation (NKF) embraced the idea that donor families should not be "invisible," but full partners in the donation and transplant circle. With the NKF's support, donor families were able to access resources like the *For Those Who Give and Grieve* book and newsletter, resulting in thousands of donor family calls and letters in search of answers and hope. As other

members in the transplant circle—doctors, nurses, coordinators and recipients—belonged to national groups, it was time for donor families to have equal representation. Finally, in the fall of 1992, a group of donor families and health care professionals joined the National Kidney Foundation in forming the first national organization for all donor families—those who donated organs and tissues, those who wished to donate but were unable because of medical or social reasons, those who wished to donate but were never approached, and living donors—the National Donor Family Council!



The National Donor Family Council celebrates years of hard work, love and caring.

continued on next page

Ten years and 10,000 members later, look how far we've come!

Then...

1990: Most donor families were not offered any follow-up bereavement support or annual recognition ceremonies.

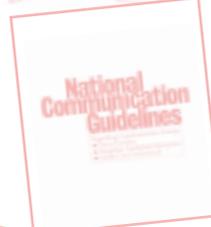
1990: One donor family, representing all donor families, is honored at Opening Ceremonies with a bouquet of flowers from a recipient at the U.S. Transplant Games in Indianapolis.

1991: First printing of *For Those Who Give and Grieve* newsletter.

1992: NDFC and University of North Carolina conduct the first national donor family survey. Responses from 1,300 families are used to develop needed resources, framed in the Bill of Rights (1994).

1995: Maggie Coolican develops the idea for a National Donor Family Quilt.

1995: Thirteen national organizations meet with the NKF to develop the National Communication Guidelines, opening the doors of communication between donor families and transplant recipients in most areas of the country.



Now...

2000: Most organ recovery organizations have staff dedicated to follow-up care. Recognition ceremonies are held nationally and in most local areas.

2002: 1,100 donor families attended the U.S. Transplant Games and received a 20-minute standing ovation as they walked onto the field carrying panels of the National Donor Family Quilt.

2002: Over 40,000 people receive complimentary issues of *For Those Who Give and Grieve* quarterly.

2002: NDFC continues to develop resources based solely on the needs expressed by donor families. Dozens of print and Web resources are now available free of charge to families through the NDFC.

2002: The Quilt has grown to over 20 panels representing over 1,500 "Patches of Love" and many states have their own local quilts.

2002: After distributing thousands of copies, the NKF will reconvene with the national organizations in September to review and update the Guidelines to most effectively meet the needs of the donor families and transplant recipients.

As you can see, donor families have accomplished so much in 10 years. We could not have done this without the help of volunteers, organ and tissue procurement professionals and government agencies who have defined and improved the donation process and donor family care, while developing valuable resources and programs. Many donor families and professionals have offered their time and expertise to further our efforts, and we offer our most sincere thanks to each of them!

Please join us as we celebrate 10 years of laughing, crying and caring for donor families. Life really does go on.

For those of you who have been a part of our history, we thank you. We invite you to send us your remembrances and thoughts of the NDFC for possible publication in the newsletter or Web site. Please mail to donorfamily@kidney.org or the National Donor Family Council, FTWGG, 30 East 33rd Street, New York, NY 10016.



Angel of Mine

For Renee Orr Richards

January 29, 1942 - January 13, 1998

By Tanya Gardiner

Mom, you are now an angel,
Taken to Heaven above.
To leave souls here on earth,
Touched by your divine love.

As you walked the earth,
You tenderly held my hand.
You showed me how to be like Jesus,
And follow His commands.

You held me in your arms,
And taught me many things.
You wiped my tears through sorrow,
And with laughter you made my heart sing.

My thoughts are filled with memories,
Of the many times we've shared.
Through the good and through the bad,
I always knew you cared.

It's time to let you go now,
For God has called your name.
Take his hand, he'll lead you,
There's a message to proclaim.

There are souls who have waited,
To feel your gentle touch.
As an instrument to God,
Your Spirit will give them much.

I'll live my life as you have taught,
And continue sharing your love here.
For one day I'll see your face,
As God and the angels gather near. 



Does It Matter?

By Reg Green

A year or so after our seven-year-old son, Nicholas, was shot by highway robbers in Italy, my wife Maggie and I traveled on a bus with the recipients of his organs. Just the immediate families were there, mothers and fathers, brothers and sisters, but together we filled half half the bus. I looked around at the excited young faces and I asked myself: Did one little body do all this? The answer I thought, was yes. It changed the lives of everyone on that bus beyond recognition.

And not only their lives, but those of grandparents, aunts and uncles, friends, neighbors and teachers. All were saved from the desolation my wife Maggie and I have felt since Nicholas died. I realized again that if we had refused a donation and shrugged off their troubles as none of our affair, I don't think we could have looked back without a deep sense of shame.

This gift is in the hands of the family of every potential donor. So, to them I say this: those whose fate you hold can suffer the same devastating blow that you have just suffered or they can be reborn. You may never again have the chance to make such a difference to the world.

I sense that public opinion around the world is ready for a change. That donations will no longer seem a little horrifying or something we prefer to leave to others, but quite simply "the natural thing to do." At almost every function Maggie and I attend, someone will come up and say: I wish I'd done that. They feel they have lost everything and gotten nothing back and they sense that, although we lost everything too, we did get something back. They are right. For the rest of our lives those of us who donated can remember, with pride, that even in the act of dying, our loved ones helped others when no one else could. 

Nicholas's story was featured in "Nicholas's Gift," a television movie starring Jamie Lee Curtis and Alan Bates and in the video "The Nicholas Effect."

THOUGHTS FROM RECIPIENTS

An Open Letter to Donor Families

Ten years ago last December, my husband received a kidney from a family that lost their seventeen-year-old. We had a seventeen-year-old and I know how hard it had to be for them. We are not letter-writers, but meant to thank them all these years.

The donation gave my husband back his life; it gave my seven children back their father. We are all so grateful. I would like to have this open letter passed on somewhere so that donor families may know that even if you do not hear from the recipients, it is not because we are not grateful, but simply overwhelmed at your generosity at a time when you are going through such trauma. May God bless you all.

You gave a very fine man back his life so he could serve his community and love his family. Thank you again. I shall always pray for you. 

Mary Graves
wife of kidney recipient

The Quilt on Tour

Please note: This schedule is subject to change.

- July 20–21 OR, National Kidney Foundation of Oregon and Washington, *OHSU All Transplant Picnic Kidney Walk*, Fred Bachofner, (503) 963-5364
- July 24–28 Crystal City, VA, Phi Sigma Sigma, Michelle Snyder, (703) 418-1234
- August 25 National Kidney Foundation of Southeast Texas, *(NKFSET)- Annual Kidney Walk*, Marion Johnson, (713) 952-5499
- September 13–15 CA, National Kidney Foundation of Southern California, Jeanette Martinez, (310) 641-8752
- September 27 KS, Midwest Transplant Network, Hospital Symposium, Marcia Schoenfeld, (913) 262-1668
- October 5 St. Louis, MO, NDFC *Giving, Grieving, Growing™ Workshop*, Sarah Ockler, (800) 622-9010
- November 1–11 GA, Life Link of Georgia, Chaplain C.H. (Skip) Wisenbaker, (404) 266-8884

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 the National Kidney Foundation at our national toll-free number, (800) 622-9010. Information about the quilt can also be viewed on our Web site at www.donorfamily.org

THOUGHTS FROM DONOR FAMILIES

My Mother

By Susan Deighton

My mother, Elizabeth H. Wagner, was avid when it came to donation. Her sister received a life-saving kidney transplant three years ago and from that point on, Mom proudly displayed every bumper sticker and button she could get her hands on that emphasized "The Gift of Life."

On December 15, 1997, Mom was diagnosed with breast cancer. A series of tests showed that the cancer had spread to the liver, lungs and spine. Although the prognosis was grim, Mom requested chemotherapy. The oncologist explained that due to the severity of the spinal tumors, it would be necessary to begin with radiation prior to chemotherapy.

After 15 treatments, tests showed that the spinal tumors had shrunk significantly and Mom was scheduled for chemotherapy. Mom did quite well after the first treatment—she did have trouble swallowing for a couple of days due to the burn in her esophagus, but sickness was minimal. Two and a half weeks after the treatment, tests indicated that the masses in both breasts were gone, and those on the spine, liver and lungs were now minute. I can't begin to explain how thrilled we all were with this news. The future was suddenly looking much brighter.

On February 3, 1998, Mom and I spent the day browsing some local stores—something we hadn't done in quite some time. We had just gotten back in my car to head home when Mom had a massive stroke. I was about a mile from an ambulance building when it happened and there was a full crew on standby when I arrived. Luckily I was able to contact my father who was nearby at an appointment. By this time, Mom was conscious and understood

when I told her that Dad was on his way and that we would be right behind her. Dad arrived just prior to the ambulance leaving for the hospital. Halfway to the hospital the ambulance pulled over. My father and I knew what that meant, and we just kept driving. The ambulance arrived at the hospital shortly after we did—CPR was performed as they removed her from the ambulance. We were escorted to a small private waiting room by a nurse and were asked about a Do Not Resuscitate order. We both agreed that due to the extent of her illness, it would not be fair for her to go through any more suffering.

My mother's corneas were the only tissues that could be used. This gave my father and I such unexplainable pleasure, knowing that a part of someone so precious could be given to another in need.

We received a letter shortly after Mom's passing that said two people benefited from my mother's gifts. As part of my need for "closure," I would like to know if it is possible to find out who the people are that received this part of 'my' life. 🌸

A note from the NDFC

If you would like to find out more information about the recipients of your loved one's organ or tissue donations, contact the organ or tissue recovery agency that handled the donation. If you would like to write the recipients, you may send your letter to the recovery agency, where they will forward it to the recipient. All initial correspondence is anonymous to protect the privacy of both families. For more information on writing to transplant recipients, contact the National Kidney Foundation at donorfamily@kidney.org or (800) 622-9010 for a free copy of *Writing to Transplant Recipients: A Guide for Donor Families*.

***We
Fondly
Remember***



*Jamie Elizabeth Wrenn
April 18, 1983 -
November 26, 2001*



*Jason Scott Wilson
August 10, 1977 -
August 5, 2000*



P E R S P E C T I V E S

Concerns About Tissue Donation

Dear NDFC,

I saw on a *60 Minutes* report that tissue donations were being sold to for-profit companies for cosmetic surgeries. How can I be sure that this won't happen if I become a donor?

-Concerned

Dear Concerned,

I also saw the *60 Minutes* program and, like you, found it disturbing.

The law is clear: tissue cannot be bought or sold. However, tissue recovery centers (both non-profit and for-profit) may charge a reasonable fee for procurement, processing, storage and distribution of tissue. While few would argue that money is necessary to stay in business, many people are uncomfortable with the vagueness of the term "reasonable fee." In order to avoid abuse or profiteering, the government may have to step in and clearly define guidelines for these services.

Regarding appropriate use of tissue donations, most people expect that when they donate their precious tissues, or those of a loved one, these tissues will be used for medically necessary procedures such as joint reconstruction, vision enhancement or aid for burn victims. The *60 Minutes* program implied that tissue (specifically skin) is being taken away from those who truly need it and sold at inflated prices for cosmetic purposes. Immediately after the program aired, tissue industry spokesmen denied these charges, declaring that 97 percent of all usable tissue collected is used for medically necessary purposes and that less than three percent is used for purely cosmetic procedures.

It is also important to keep in mind that some cosmetic procedures may in fact be necessary to the person electing to have the surgery, such as accident victims who undergo reconstructive surgery. If you are uncomfortable with donating tissue for cosmetic use, you can place restrictions on which tissues are donated and on how these tissues are used. If the donation is accepted with the restrictions, you can be assured that your wishes will be followed. If your limitations are deemed too restrictive, you may not be able to donate tissue.

I hope that I have addressed your concerns and

that you will still consider tissue donation. With the help of caring people like you, the system will only continue to improve.

Sincerely,

Mark Norquist

*Donor Father and NDFC
Executive Committee Member*

A note from the National Donor Family Council on tissue donation: The gift of tissue is a gift of life. We support tissue donation as an end-of-life option for families and recognize its life-enhancing capacity to help thousands of people who are awaiting tissue transplantation. We believe people should be provided with all the facts to make an informed decision. With regard to tissue donation, this information should include a discussion on the need for tissue donation, the conditions and processes of tissue donation, and the implications of tissue donation for later events, such as funeral arrangements.

For more information, we encourage you to read the *NDFC Position Statement on Tissue Donation*, the *NDFC Informed Consent Policy for Tissue Donation* and the *Donor Family Bill of Rights*, available on-line at www.donorfamily.org. You can also request additional information from your local organ or tissue recovery agency.

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 Honor of:

Peter J. Norton - by Rhonda and Gary Nestle, Soccer Panther Families, George & Kitty Carthart, Nina & Tom Glen, Boy Scouts of America, Adrian O'Donn Cheslack & Martin Einstein, Arista Investors Corp, Richard & Joyce Bowen, Iris & Eric Green and John & Cheryl Hodges

James To - by Kevin To

All donor families - by Kevin Moser

I Am

*In memory of our Dad—Craig Cerney
We love and miss you*

By Jennifer Cerney

I am a fun and caring girl
I wonder what will become of me
I hear voices in my head shouting DO THE
GOOD, AND IGNORE THE BAD
I see the future ahead of me telling me
what I'm going to be
I am a fun and caring girl

I pretend I am a gymnastic Olympian
I feel my dad's hand touching me
I touch the cold and frosty winter flakes
I worry about the people of the world
I cry when I look back at the memories
of me and my dad
I am a fun and caring girl

I understand I'm not all perfect
I say you should be yourself, and don't worry
about what others tell you
I dream one day peace will shine through darkness
I try to be the best I can be, and accept
what all comes to me
I hold memories of childhood locked
in my heart forever
I am a fun and caring girl. 

Ode to My Brother

*In loving memory of William Leroy Arnhold
from Mom; sisters Brandi & Jodi; sons
Leroy & Cole*

*Y*ou sleep with angels
And suffer no more
Your pain is gone
You've become a star
The time we shared
Was much too short
Your life flew by
Like a shot in the dark
You touched us all
My brother so dear
What we wouldn't give
To have you near
And though we cry
We know you're free
So soar with the angels
As things should be..... 

With love,
Brandi

Mrs. Ruby Arnhold
February 16, 1999

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 or permission to reprint articles.

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MORE THOUGHTS FROM DONOR FAMILIES

To My Only Son

Craig Howard Kittrell

February 26, 1980 – May 28, 1998

You left me sooner than I could have ever imagined. Son, you were so special to me. I miss the deep talks and the things we did together. I asked God many times in my prayers to let you know how much I miss and love you. You will live forever in my heart and live through my memories of your life on earth. I know in my spirit that you are about God's work in Heaven. The day you accepted the Lord as your personal Savior at 10 years of age you said, "I am God's warrior and He has something special for me to do." We always said, when that special time arrived, we would know in our spirits what it was, and we did. Why am I not mad at God? Because He has you, so no harm can come to

you and you are happy doing what God has for you. I now know and understand God's preparations that we went through, and also the things you said to me before you went away. I love God with all my heart, soul, and mind and thank Him for such a wonderful gift and the time I had with you. The tears still fall from missing you so much. But if I start getting into despair, God always rescues me with a special revelation that dries all tears. I know you are safe in God's arms as His "Spirit Warrior." Now I understand why you told me God gave you that name, before you went away. I am ready to go when God is ready for me. His work in my life is to be completed. God's peace and comfort is with me, until I will be with God and you. 

*With all my Love,
Mother
Mrs. Sue Norman*

Donor Family Friends

DF 160 My wife passed away November 2001, three years removed from being diagnosed with a brain tumor. We were married 13 years with three children: two daughters (nine and seven) and son (three). I would like to correspond with others.

DF 161 My grandpa died when I was nine. He donated his heart, skin and eyes. I would like to correspond with others.

DF 162 My 23-year-old son donated his kidneys, heart, cornea, tissue and bone in 1997. Ten months later, my husband passed away. I am 46, with a daughter and two beautiful grandchildren. I would like to correspond with others.

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!

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 37 cents if you forget.