

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.

Spring 2003

Visit our *new* home for donor families at www.donorfamily.org

Volume 11, Number 4

What Helps When It Hurts Restructuring Relationships: Four Examples

By Charles A. Corr, PhD

When a loved one dies, we need not conclude or assume that a relationship is no longer possible with the deceased. In fact, a formidable task in mourning is to restructure the relationship to the deceased person in ways that permit ongoing connections or continuing bonds. The person who died can be present to us in various ways—in our hearts and in our minds, and through memories and the many legacies that he or she left to us.

Four widows whom I know restructured relationships with their deceased husbands in different ways. They described what they had each done about their wedding rings.

GLEND A removed her wedding ring after the death of her husband and put it away in her jewelry box. “We were married until death parted us,” she said. “Now I am no longer married to him.” She did not mean that she no longer loved her former husband. But she wanted to emphasize through her actions that death had separated them and that the separation was a permanent one.

MARIE still wore her wedding ring on the third finger of her left

hand. “He is dead,” she said, “but we are still connected.” She said she and her husband had had a long, happy and fulfilling marriage. She was quite content with that legacy and did not intend to seek out a new relationship with another man.

NANCY explained that after her husband had died, she moved her wedding ring from the third finger of her left hand to her right hand. The ring itself was an important heirloom from her grandmother. Nancy did not want to take it off completely or to hide it away. More importantly, she was determined to do something that would act as an outward sign of her changed situation. And, although she no longer thought of herself as married, she wanted to maintain some tangible indicator of a continuing bond with her deceased husband.



PATRICIA carried this idea further. She removed her husband’s wedding ring and had a jeweler refashion it, along with her own wedding ring, into a new piece of

jewelry, a pendant that she wore around her neck every day. “I now have a new relationship with my deceased husband, and my lovely pendant symbolizes that new relationship.”

Attitudes toward wedding rings are only one way to restructure relationships when the deceased was a spouse. These apply to only one type of bereavement, but they are a good metaphor for what happens in all healthy bereavement: acknowledging the reality of a death; experiencing the grief associated with that loss; learning to live without the deceased; and restructuring one’s relationship with the deceased in order both to honor that relationship and to find ways to go forward with healthy and productive living. As our wedding ring example shows, each bereaved person can do this in his or her own individual way.

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Dear Editor



Enclosed find article from *Hadassah Magazine*, Fall 2001 (Here and There Section).

“Bringing Shabbat to Life” is a wonderful way to bring home the need for donors and the Mitzvah (observing God’s commands) of donating organs.

This type of publicity should be pushed in all churches. Church people should be dedicated to life, and they are. They should be a source of organs—a good source. I’m sure the clergy would be happy to cooperate.

Yes, we gave my beloved wife’s liver to someone—and they live. I wish she could have received a kidney—but that’s another story. 

Yours,

Rabbi Schechter

Editor’s note: The first National Donor Sabbath was in November, 1996. For more information, visit www.organdonor.gov

Appreciate

FOR IOWA’S GOVERNOR

In December 2002, **Iowa Governor Tom Vilsack and the Iowa Funeral Home Director’s Association** honored organ, tissue and eye donor families from all over their state. Governor Vilsack is very familiar with issues surrounding donation. His sister received a heart transplant, and his brother-in-law became an organ donor when he died in 1996. The governor said the holidays were a perfect time to meet with donor families. “It’s a difficult time,” he said, “and these folks need to be thanked. These families have sacrificed so much.” Donor families attending the ceremony received a certificate honoring their loved one, a long-stemmed rose and the opportunity to view the Iowa Donor Networks’s memory tree. The governor’s staff hopes to host a similar event each year.

FOR THOSE WHO GIVE AND GRIEVE

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donor families thoughts from

Why Not a "Thank You"?

By Pat Brown, Donor Mom

Spring has sprung and the year 2002 is a memory. Every year at this time, I think about the new year, new life, plants blooming and thank-you notes. Yes, thank-you notes.

My parents always taught me to write thank-you notes for gifts or presents that I had received. Since my birthday is in the spring, I have just completed writing thank-you notes for birthday gifts and, not too long ago, for holiday presents. Each time I write a thank-you note, I wonder...why have I not received a thank-you note for the organs that my son donated?

It has been 10 years since we lost our infant son (in, of course, the spring) and I still wonder if a thank-you note will ever come. We donated his heart and liver and corneas. Yet, still, no note of thanks.

Sure, the transplant agency sent us a beautiful note of thanks that is framed and hanging in our family room. It is our son's "diploma" that we will cherish forever since no further honors are coming his way.

Some donor families do receive notes and even arrange meetings with the recipients. How jealous I am when I read about those meetings. How wonderful that their thank-you notes have arrived and often in person.

Still no note for us. It hurts. My family often wonders who has his organs. Are they still living? We do not wish to intrude into their lives, but only wish to know what our son meant to them. Perhaps their lives are hard, with medications and complications, and there is no time to write a thank-you note. We cannot understand their life, nor can they understand our need for a thank-you.

I think of the many people who do things for my family that I never thank. The garbage man who bravely comes each week and the policeman that helps keep our area safe. I never do thank them. So

it may be with my son's gift. We gave his organs without expecting anything in return. It was my son's gift of life. I know in my heart that all donor recipients must be thankful for those special donor families and their loved ones who made life possible for them. I will hold this thought in my heart as my thank-you note. 

Pat Brown is a contributing editor and lives in Toledo, Ohio.

My Hero

By Evelyn Gonzalez, Donor Mom

In February 2002, I had to make one of the toughest decisions of my life. The machines were turned off. How blessed am I? I was there when that delicate child stepped into my life and I was there when she stepped out. My family and I always felt very strongly about organ and or tissue donation before Ashley Marie's death.

I cannot believe how supportive and loving our transplant coordinator (John E. McCumber, RN, BSN) was with my family and me. We all love you so much and God bless you.

I don't know how long this grieving process will take, or if I will ever be myself again. I still wake up making plans as if Ashley Marie was still here with me. Then, all of a sudden, reality hits me hard...my angel is gone, and I break down in tears. I know that the only two important things that keep me going every day is my youngest child, Matthew, and to know that a part of my daughter is still alive somewhere in someone else.

Ashley Marie

Our precious angel we love you so,
it breaks our hearts to see you go.
We'll always remember your angelic face,
and now you're off to a Special place.
So just because you're not here with me,
it's in our hearts you'll always be.

*Love you forever,
Mommy, Augie, Matthew and family*



On a Cold Winter Day: Surrounded by "Patches of Love"

By Maggie Coolican



It was a very cold Sunday afternoon and the lake was frozen solid. The sky was bright blue and the sun was shining. There were so many children ice-skating and playing hockey and many adults ice fishing and ice boating. Lots of other children and adults were walking briskly around the lake trying to keep warm.

I spent the afternoon at my cutting table that faces the lake "squaring" the many "Patches of Love" waiting to be added to the National Donor Family Quilt. Each patch or square is designed by families like you, in memory of a loved one who has died and made a donation decision. As I picked up each square, I was reminded of the pain and the love

that it must have taken to design each square. How can you put someone's life on an eight-inch piece of fabric?

Periodically, I would look out the window at the hustle and bustle of life on the lake and it made me think about each person that each square represented. When was the last time they went skating? Did they ever learn how to skate? Did they love to go fishing with dad or grandpa? Had they even learned how to walk before their death?

How privileged I am to be a part of this special project constructing "Patches of Love," the National Donor Family quilt. How trusting you are to share your

loved one with me—and others—as the quilt travels

throughout the United States, and, on occasion, other parts of the world. Thank you for sharing your loved one with all of us.

To submit a Square to the National Quilt, please contact National Donor Family Quilt, 30 East 33rd Street, New York, NY 10016, or you can send an e-mail to donorfamily@kidney.org

If you are interested in helping to sew or refresh the National Quilt or if you would like to assist in the creation of a Kid's Quilt (National Donor Family quilt made by kids), please e-mail donorfamily@kidney.org 

The Quilt on Tour

Please note: This schedule is subject to change.

2003

April 10-28	Chicago, IL, National Kidney Foundation - IL <i>National Organ and Tissue Donor Awareness</i>
April 22	Richmond, VA, United Network for Organ Sharing, <i>National Donor Memorial Garden Dedication</i> , Janis Kelley (804) 782-4607
April 24-25	Madison, WI, University of Wisconsin OPO, <i>Douglas T. Miller Symposium on Organ Donation & Transplantation</i> , Jill Ellefson, (608) 262-3248
April 25	San Jose, CA, UCSF, <i>Donor Family Recognition Ceremony</i> , Heather Orava, (408) 345-3516
April 26	Fullerton, CA, National Kidney Foundation - So CA, <i>Celebrate Life Walk/Run</i> , Amy Yang (714) 447-7725
April 26	California Transplant Donor Network, <i>Annual Donor Recognition Ceremony</i> , Tracee L. Harris (209) 527-6178
April 26 & 27	Honolulu, HI, National Kidney Foundation - HI, <i>Donor Family Recognition & Gift of Life Walk</i> , Denice Kelikoa, (808) 589-5933
May 2 - May 5	Lima, Ohio, <i>Celebration</i> , Gary Lee, (419) 257-2405
May 18 - May 18	St. Paul, MN, Life Source, Donor Family Gathering, Jill Mussman, (651) 603-7847
May 30 - June 4	American Transplant Congress, <i>American Transplant Congress Annual Convention</i> , Lisa Wagenseller, (856) 642-4401
July 11 - July 13	Washington, DC, HRSA - NKF, <i>National Donor Recognition Ceremony and Workshop</i> , Jennifer Martin, (212) 889-2210

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

for *teens* *Introducing Our New FTWG&G Teen Editor:* Jennifer Cerney

Hi! My name is **Jennifer Cerney**. I go to middle school, and I'm in the eighth grade. About three years ago, my dad passed away and became an organ donor. I was heartbroken, but when I found out that he saved four people's lives by donating his organs, I wanted to cry. Not because I was sad or angry, but because I was so happy. I have met two of the people who received his organs, and one of them is truly like a part of my family. Her

name is Marsha. She only had 11 hours to live when she received my dad's liver. It made me so happy to hear this because she has so many friends who care for her, and a family that loves her very much. She has a 21-year old daughter named Elizabeth, and a husband who loves her very much named Mark.

I go to a grief support group called Y.A.G.S. (Young Adult Grief Support) that helps me very much. It's for kids and teens between the

ages of 6 to 19. We talk about our loved ones that have passed away and help each other get through the hard times. One other thing that really helps me is keeping a scrapbook of my dad and me.

I would like to hear from any teen reader. You can write to the National Donor Family Council, *For Those Who Give and Grieve*, 30 East 33rd Street, New York, NY 10016, or you can send an e-mail to donorfamily@kidney.org 

Dreamland

By Jennifer Cerney, Age 13

*I*n my dream I went to this place
Where I saw my loving dad's face
Surely I knew where I was
I was in the great heavens above
Here's the story as told by me
It is very interesting as you may see
I was lying in a field full of flowers
At the corner of the field was a tower
Pink and pretty it seemed to be
But I soon found I needed a key
I looked around everywhere
"Look behind the tower, you will find the key there"
I heard someone behind me
I turned around to see who it was
But when I turned around I saw no one
I wasted no time and ran right to the back
There the key was, right by a sack
I ignored the key and opened the sack
Inside was a picture of me and my brother
To the side of us was my dad and my mother
Very happy, I smiled to see
How happy me and my family could be
Then I picked up the key and opened the door
There my dad was sitting on the floor
I opened my mouth but no words came out
"Why did you leave?" is what I wanted to shout
Finally after the shock had passed
I asked why he couldn't last
He said God wanted to take away his pain

I replied, "Ever since you left I have known nothing but rain"

A moment of silence passed us by
Then I looked at him and started to cry
I asked if we would be together from now on
He said he wasn't sure but he'll try to hold on
Then we had a fun filled day
And we even passed God's way
Just when my hopes were about to rise
I found that I had to say my goodbyes
For I woke up in my bed
With the memories of this place
And the joy of seeing my dad's face 

So Much

By Danielle Christina Singh, Age 13

*L*ife isn't much,
just something worth keeping.
Losing a loved one so sweet and so dear.
A friend in heart, that just disappears.
Losing someone is so much, and think
of all that could have been done.
So many thoughts go through my head.
What to do from here on end?
Things that have been taken from me.
A dad, a loved one, and even a friend.
So many people lost so much, but thank
God for the people we had, for the people
we have, and for the people yet to come.

AOPO Donor Family Council

By Pamela L. Albert, RN, BSN, CPTC

*AOPO Donor Family Council Chair and
Director, Donor Family Services
New England Donor Bank*

The AOPO (Association of Organ Procurement Organizations) Donor Family Services Council was established in November 1998 as a group of transplant professionals working with donor families to network, share ideas and advocate for the needs of families.

Highlights of the work being done by the Council include the continued efforts of the Tissue Subcommittee to outreach to tissue banks across the country to ensure that recipient information is collected and available to share with donor families.

The Family Support Services and Staffing Model Committee is working to collect information and data to review the national experience with donor family standards as well as develop an industry-wide inventory of family support services and staffing models.

The Council is currently collaborating with the Public Education/Public Relations Committee to develop and implement a national strategy for using the term “deceased” rather than “cadaveric.”

The Council is also represented on the UNOS National Donor Memorial Committee. Members of the AOPO Donor Family Council continue to work in collaboration with the National Kidney Foundation’s National Donor Family Council to ensure that the voice of donor families is heard and represented on a national level. 

When Language Hurts

By Margaret B. Coolican, RN, MS, CDE

“Harvest,” “cadaver,” “recover,” “procure,” “only tissue”...these are words and phrases that are used and heard frequently when discussing organ and tissue donation. Some of them may be very offensive to some of you.

For many years the National Donor Family Council and some professional organizations have promoted improving the language of donation so that it is more acceptable to you, the families of organ and tissue donors. Today, “recover” or “procure” has replaced “harvest” in most areas; however the word “cadaver” continues to be a problem. Several years ago the National Donor Family Council (NDFC) requested input from families and chose “non-living” to replace “cadaver”...as there are living donors and non-living donors. Education of professionals about using these new terms has been ongoing. The AOPO Donor Family Services Council (see article on this page) is also committed to re-educating professionals to use the term “deceased” rather than “cadaver.”

Do you have an opinion about language that is used in your area? Are there words that could replace words that make you uncomfortable or that are offensive to you? We want to hear from you! Please contact National Donor Family Council, *For Those Who Give and Grieve*, 30 East 33rd Street, New York, NY 10016, or you can send an e-mail to donorfamily@kidney.org 

“Gift of Life” Cross Stitch Pattern

The “Gift of Life” butterfly logo is now available in a cross-stitch pattern! If you would like a copy of this pattern, please send a check for \$3 per pattern to: National Donor Family Council, National Kidney Foundation, 30 East 33rd Street, New York, NY 10016. Checks should be made payable to the National Donor Family Council. Please write “cross-stitch pattern” on your check, and be sure to include your mailing address.



Donor Family Support Group, Santiago, Chile

By Angelica Finlay, Volunteer Chairwoman

On December 12, 1997, my son Andres decided to spend a weekend at La Serena, a beach resort located in the north of Chile. That Sunday, December 14, he was taking a taxi back to his hotel when all of a sudden, the taxi was struck by another car. He and the driver were getting out to inspect the damage when a third car came out of nowhere at high speed, with no headlights, and with a drunk driver, and hit my son. Andres was seriously injured. My daughter and I flew immediately to La Serena.

As soon as we arrived at the hospital, the physician in charge of the intensive care unit told us Andres was seriously wounded and in a coma. We decided to bring him back to Santiago in a private plane to the best hospital, but there was nothing the doctors could do. He died on December 17, 1997, at approximately 6 o'clock p.m. The physician who declared him brain dead immediately offered us the option of organ donation. I couldn't believe it—he was asking for my son's organs! I thought he was crazy. Minutes later, I remembered my son always wanted to become an organ donor. That's why I agreed, but I was not entirely convinced. When I arrived home that night, I felt a great peace and serenity because I felt I had done the right thing. Even though I had lost my son, I had given a gift of love to four others. Andres gave us a lesson of love and generosity.

Since then, I have collaborated with the Transplant Corporation on ways to increase organ donation awareness. I have built a support group for families because when they are asked about donating, it is a very emotionally traumatizing moment. For donor families, it is difficult to understand the overwhelming emotions that can occur. Families are sometimes left alone and nobody asks if they need something, or how they feel...and, maybe, just holding a hand can help.

Our organization provides complete information on issues concerning transplantation and organ donation in Chile, including legislation, testimonials, how and when it was founded, and about "Donation Week," which takes place every year during the last week of September. You can visit our Web site at: www.trasplante.cl

Andres Leighton Finlay was a 31-year old father of two kids, Felipe and Camila.

Giving, Grieving, Growing™ Program

Last year, donor families had several opportunities to attend Giving, Grieving, Growing programs (GGG) in their area. LifeQuest Organ Recovery Services hosted a GGG program in Gainesville, Florida, and the National Kidney Foundation of Eastern Missouri & Metro-East hosted a program in St. Louis, Missouri.

The GGG provides an opportunity for donor families to attend workshops on such topics as Parental Grief, Sudden Death, the Death of a Spouse and the Grief Journey. Sharing sessions on a variety of donation and grief topics allow families to share their experiences with others that have donated the Gift of Life. Late afternoon sessions include a coffee house and quilt pinning where families can read poems, tributes, talk about their loved one or pin a quilt square on the national or local quilt. The GGG concludes with a candlelight memorial ceremony.



The GGG Program is occasionally held in conjunction with a similar program for transplant recipients. The combined program, The Circle of Life, allows donor families and transplant recipients to attend workshops independently and also together. Sharing with each other provides a full day of special experiences for both the donor family and the transplant recipient.

To find out if a GGG Program will be coming to your area, check the *For Those Who Give and Grieve* calendar or contact the National Donor Family Council at donorfamily@kidney.org

Sisters Forever

By Karen Bonick

"For there is no friend like a sister, in calm or stormy weather; To cheer one on the tedious way, to fetch one if one goes astray, To lift one if one totters, To strengthen whilst one stands."

"Goblin Market," Christina Rossetti

There truly is no friend like a sister. I was blessed with a little sister 22 years ago. She was my best friend. She was an answer to a prayer. She was a blessing. She was my precious gift from the Lord.

It never seemed possible that one sister would be left alone. But there are no guarantees in this life—my sister taught me that. Diane taught me so many things. She taught me so much more than I ever knew. My sister taught me that love is a verb. She realized that life was a gift and that every moment needs to count. Diane knew that it means more to give than it does to take. My sister's life was a testament to these beliefs, and even in her death she continued to give as she did in life, giving life to several people through the donation of her organs. And the greatest gift my sister has given me, the gift that

has helped me through this loss, is the gift of hope. She gave this amazing gift to my family and the families of those she helped.

The little sister taught the big sister about the things that really matter in this life. She brought me back to what is important, the things that matter, the things that make life worthwhile—the things that last—even after death. She gave me wonderful gifts that I carry with me today, gifts that shape my life. I share these gifts with my parents, my brother, my husband, my friends, and my son. Diane is a part of me. We are sisters forever—that will always be.

Diane Mary Bianucci is Karen Bonick's sister. Diane's gift of life helped five people. Diane passed away in April 1999.

we fondly
remember



Kim Lee

January 1, 1962-

May 1, 1998

*Visit our new home for
donor families at
www.donorfamily.org*



The mission of the National Donor Family Council is to enhance the sensitivity and effectiveness of the organ and tissue recovery 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.



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