

National Kidney
Foundation™

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 2007

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

Volume 16, Number 1

THE TRIP OF *a lifetime*

By Rose D'Acquisto, Donor Wife



FOR THE FIVE-YEAR ANNIVERSARY OF MY HUSBAND TONY'S DEATH, I decided I was going to do something I'd always wanted to do: take a trip to Greece. When the travel catalog arrived on a snowy, winter day in January, I pored over the photos of domed, white stucco homes with azure blue doors that matched the sea. There was a 13-day cruise around the Greek islands, leaving September 25, 2001—the exact date of the anniversary. It was a sign.

The idea of taking this trip of a lifetime somehow seemed symbolic. I'd learned the hard way that you can't put off doing what you really want to do in life, since there might not be a tomorrow. Tony was gone, but I was still here. I needed to live my life. This was my dream trip.

I took a deep breath and called my boyfriend, Paul. "Want to take a trip to Greece in September?" It was a big step for my heart, inviting him to share this trip and anniversary.



Paul and I had been dating for three years. He was divorced; I was widowed. This trip would finally be something that was exclusively ours. Paul jumped at the chance to go.

On September 9, I received my ticket and cabin assignment in the mail. I studied the list of shipboard events. I would need an evening gown for the Captain's Ball. I packed and repacked my suitcase in my mind, figuring out what I'd need for warm days and cool evenings. Paul and I dreamed of dances, Greek ruins and olive-scented markets.

A few days later, I watched as the news showed planes flying into the Twin Towers. I understood the stomach-turning shock of our nation and I felt the pain of the families who mourned for their loved ones. I was even more grateful for my upcoming trip. I needed to do something that was life-affirming.

When Paul called and told me to listen to my phone messages, I had a bad feeling. Our Greek island cruise had been cancelled. I called the travel company and pleaded, "This can't be...you don't understand what this trip means to me." When I resigned myself to the bad news,

I got desperate. "Okay, you've got my money. Where else can you send us?" I asked. The travel agent searched and said, "There is a Walking Tour of Provence trip that leaves on the 27th. Should I see if I can still get you on it?"

Before we knew it, Paul and I found ourselves on a plane to France—not Greece. We hiked up rosemary- and thyme-scented hills. We saw vineyards stained with the gold, crimson and purples of autumn. We ate savory meals at candlelit tables under a canopy of stars. We sipped wine at a noisy street café in Paris.

On the plane home, I thought about my dream trip to Greece that didn't happen. As it turned out, our unplanned trip to France ended up being wonderful in a whole different way. I realized that it was a lot like my life. The dreams I had planned with Tony were gone, but what life had waiting for me could be equally wonderful, in a different way. Maybe if I learned to look beyond the plans I had for my life, I could see that life was already happening—waiting for me to join the adventure.

THE SOFT *thank you*

By Douglas G. Harrell, Donor Husband

MANY YEARS AGO MY LOVELY WIFE CAROLYN TOLD ME, "If I die, I want to help people." When that sad day came to pass six years ago and her organs weren't viable, she donated tissue, including corneas, heart valves, bone and ligaments. As the weeks went by, I received letters telling me that her cornea and two of her heart valves had been transplanted. I was glad to know that I had been able to fulfill her wish.

Over the years, I have talked to people who've met the recipient or recipients of their loved one's donation. They seemed to receive immense satisfaction from seeing a person who is alive today because they were able to find compassion for a dying stranger in the midst of their own tragedy. Their gift has a face and a voice, and perhaps most precious of all, they hear a soft, "Thank you."

I've never tried to contact Carolyn's recipients. Deep down, I'm afraid that they may not comprehend her gift.

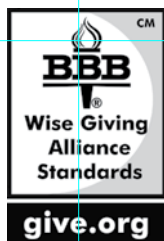
However, I have a friend, Peter, who received an anterior cruciate ligament (ACL), so I asked him what the gift meant to him. He told me that before his transplant he was effectively crippled. He had to be careful of every step and sports were out of the question.

After his surgery, he can now walk, run and even play sports with his wife, Leslie, and his children, Kate and Andrew. He asked me to relay a message for tissue donor families: "Thank you! Your generous gift has saved me from a lifetime of canes and crutches. I hope, when the day comes, that I can 'pay it forward' to many others."

Peter with his wife Leslie, their children Kate and Andrew, and dog Maggie on the beach in Sea Isle City, NJ.



Thank you, Peter. You've given Carolyn's gift a face and a voice, and from you I heard the soft thank you that every donor family member longs to hear.



For Those Who Give and Grieve

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Missing You

By Mela McLaughlin

In honor of Amy Ann Brigitte Palmer

We will laugh for you
We will cry for you
We will sing
and we will dance for you.
And when we smell the lilies in bloom
We will ache
from missing you.
I love you Chicklett.

Love, Mom.



GETTING *the support you need*

By Lara Moretti

THE DEATH OF A LOVED ONE CAN BE AN ISOLATING EXPERIENCE. It can feel like no one understands what you are going through. Even other members of your family can have trouble understanding how you are feeling. And, when those around you seem to have “moved on” and have gotten back to their lives, you can feel even more alone.

A bereavement professional can offer support, counseling, education and resources to grieving individuals and families. As a supervisor of Family Support Services at Gift of Life Donor Program, I support our many organ and tissue donor families in all of those same ways.

expected you to do the same, or when they do not know what to say. Meeting others in a support group can help you feel that you are not alone in this grief journey.

In addition to reducing your sense of isolation, a support group can teach you new and different ways to cope with your grief. When others share their experiences, they can help you expand your own coping methods and problem-solving abilities. The support group is also a safe place for you to share the wide range of emotions associated with grief. You can express feelings of anger, guilt, sadness, fear and even happiness, and have those feelings validated and supported.

group called Hearts of Gold. The mission of Hearts of Gold includes serving “as a community resource to provide support to donor families through their grief journey.” This support is shown in spoken and unspoken ways. Each new person is greeted with a warm welcome and is given a specially created Donor Family pin. Even if a family comes only one time to a Hearts of Gold meeting, they are always a part of the group and the support is always available to them. If a member starts to cry during our meetings, a box of tissues is passed silently, a hand is placed on a shoulder and heads around the room nod in understanding.

Meeting others in a support group can help you feel that you are not alone in this grief journey.

Support groups, however, offer a different kind of support that goes beyond what a professional can offer. There is something important and very unique about being with other donor families. It’s about being surrounded by people who have been where you’ve been, who when they say, “I understand,” really *do* understand.

One benefit of support groups is the relationships made with others in the group that may extend outside of the group meeting times. The death of a loved one affects your relationships with family and friends. Meeting new people who have also experienced a death can help alleviate the isolation that sometimes occurs when family and friends have either seemed to move on and have

Support groups can also be an important source of information. From community resources to practical tips on getting through a birthday or holiday, you can have a chance to learn from other donor families. Many grieving individuals wonder, “Am I normal?” A support group can provide the opportunity to learn about the complexity of grief from others who are also grieving.

At Gift of Life Donor Program, there is a donor family support

Your procurement or recovery organization might have a support group for donor families, or they can help you find a support group in your area. You might feel nervous about attending that first meeting, but the benefits you will receive from the group and the members will help carry you through this difficult time.

Editor’s Note: To ask about support groups in your area, contact your organ recovery organization or tissue bank. If you need help locating this organization for your area, e-mail the NDFC at donorfamily@kidney.org or call 800.622.9010.

Please also contact the NDFC for information about national events where you can connect with other donor families, such as workshops and sharing sessions at the U.S. Transplant Games and National Donor Recognition Ceremony and Workshop. You can also share with families online at www.donorfamily.org



A support group can provide the opportunity to learn about the complexity of grief from others who are also grieving.

THE PRIVILEGE *of caring*

By Charles Bearden, PA, CPTC

AS I APPROACH MY 30-YEAR ANNIVERSARY AS AN ORGAN RECOVERY COORDINATOR, many memories, the good and the bad, are bubbling to the surface. In this role, I approach families about the possibility of organ and tissue donation, and provide support and resources to families afterward. I have participated in the recovery of

Thrust together, involuntarily, in the absolute worst imaginable horror, donor families and donation coordinators are introduced. The relationship that develops is often profound. The respect and admiration that the coordinator feels for the family becomes the prime motivation to persevere in the face of a stressful and demanding reality.

that life can and will go on despite the unfathomable sadness of sudden and unexpected death. Your generosity and caring, and the Gifts of Life left by your loved ones, are lessons to all of us. Without donor families, I could never have survived the unrelenting exposure to the trauma, the loss and the finality of sudden death. I am still here, still working, thanks to all of you.

We are truly sorry for the circumstances that bring us together, but are honored that we could meet you.

I feel I can speak on behalf of all donation coordinators because I suspect that we would all say the same heartfelt words: thank you. We are truly sorry for the circumstances that bring us together, but are honored that we could meet you.

thousands of organs from hundreds of donors, and have lived to see amazing advancements in the field of transplantation. I have had the honor and the privilege of meeting many donor families.

Donor families have taught me so much about life—how as human beings we can be our best when things are worse than worst, and

A donor family member wrote this poem that has become one of Charles's most treasured possessions. He would like to share it with you.

I woke in the night
To the sound of wind
Howling like pain
But as I listened in fear
I too
Heard the sound of chimes
Like sweet music
To remind me
that even in darkness
there is a friend
And gently
I lay down to sleep again
to dream

Dear Charles,

Thank you for these wonderful words. I especially loved the poem you included. At the 2004 U.S. Transplant Games, the National Kidney Foundation commissioned an orchestral piece by composer Linda Tutas Haugen in celebration of 50 years of successful organ transplantation. It was entitled, "Transformations of Darkness and Light for Symphony Orchestra."

Linda told me that as she was working on the piece, she happened to visit her alma mater, St. Olaf College. Some years ago, the college erected a tower with chimes, engraved with the names of students who have passed away while enrolled at St. Olaf. When Linda found out that a number of the students had been donors, she knew she had to include chimes at the end of the piece. St. Olaf let her use the actual chimes for the performance, which were positioned all around the auditorium.

I'll never forget the experience of sitting and listening to those chimes. It truly felt like we were surrounded by the presence of our loved ones.

With gratitude,

Rose D'Acquisto
Donor Wife

Volunteer Editor-in-Chief, For Those Who Give and Grieve

WE FONDLY
remember...



Jeremy Daniel Youngman
June 14, 1976 –
October 20, 2001



Jacob Wayne Blastow
July 23, 1982 –
December 1, 1998



Damian S. Davis
March 6, 1978 –
November 15, 2004



Misty Bridges
May 19, 1981 –
February 1, 1997



James Christian DeMonbrun
December 15, 1982 –
November 6, 2003



NKF's "People Like Us" E-ADVOCACY NETWORK

GET INVOLVED AND MAKE YOUR VOICE HEARD on issues related to chronic kidney disease (CKD), donation and transplantation by joining the "People Like Us" E-Advocacy Network. By signing up at <http://capwiz.com/kidney> you will receive:

- ➔ **Information** about important public policy issues
- ➔ **E-mail alerts** when it is time to take action on legislation impacting CKD, transplantation, and organ and tissue donation
- ➔ **Sample letters** you can personalize and send to your Members of Congress with a click of your mouse.

You can also help build the National Kidney Foundation's E-Advocacy Network by asking your family and friends to join! For more information, contact Jayne Mardock at jaynem@kidney.org or 800.889.9559.



A NEW BOOKLET ABOUT PATCHES OF LOVE, the National Donor Family Quilt, is available now! Read about the unique history and meaning of the Quilt, learn how to make a Quilt square and find creative suggestions for displaying a panel of the Quilt in your area. To request a free copy, e-mail donorfamily@kidney.org or call 800.622.9010 and ask for a "Quilt booklet."

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SUICIDE AND GRIEF:

living beyond the "why's"

By Ben Wolfe

IN THE UNITED STATES IN 2004, there were a total of 32,439 suicides. Statistically:

- ▶ Every 16 minutes an American dies by suicide, with an estimated 811,000 suicide attempts each year.
- ▶ Behind accidents and homicide, suicide is the third leading cause of death for 15-24-year-olds.
- ▶ For those 65-85 years of age or older, suicide is almost twice the rate compared to 10-30-year-olds.

It is estimated that each suicide intimately affects at least six other people. Family, relatives, friends and neighbors who die as a result of suicide, however, are *not* statistics. They are our past, our present and our future!

There is a stigma attached to suicide. Like most things people do not understand, suicide survivors, the name given to those whose family members or friends died as a result of killing themselves, may be treated differently from other grievers.

Even the language used in dealing with suicide is difficult for those whose loved ones died from taking their own lives. Expressions we no longer use are, "It was a successful suicide," and "They committed suicide." Today we describe suicide with either "They attempted suicide," or "It was a completed suicide." Language itself can be hurtful!

Thoughts suicide survivors may contemplate include: "Could I have prevented it?" "Why did this happen and what could we have done differently?" "Had we only known how they were feeling we would have intervened!" "They were struggling for so many years that truly, now there is a sense of relief." "He was only 15 years of age, in 10th grade and had everything going for him...yet he killed

himself." "She was a mother, a spouse, a sibling and a daughter. How could she do this to her family?"

Each situation is different. Some who take their own lives do not die immediately and their families are able to spend time with them, in some cases for days or longer, before the brain death declaration. Other families donate tissue after the person's death, and organ donation is not an option.

After a suicide, does organ and tissue donation make a difference in a person's grief compared to those whose weren't able to donate? Research has yet to be clear about this, yet many families feel strongly the answer is YES! Additionally, does "delayed regret" become something of a "stumbling block" in one's grief further down the road if

What is important is how one makes meaning of the death, integrates it into their life and moves forward with a "new normal."

families had a chance to donate, but at the time chose not to?

We know that any death, regardless of how one dies, is complicated. We also know suicide, in most cases, is a violent act which can lead to many questions. Suicide survivors often experience a wide range of mixed reactions including: shame, embarrassment, humiliation, guilt and anger at the person who died. If the survivors were there when the suicide took place or if they found the person after they died, trauma reactions can also be intense. In many cases survivors feel others are blaming them for the suicide. It is also important to remember survivors are not only family members; they are also relatives, friends and co-workers. The ripple effect is broad and can affect

"hidden grievers" in ways often not recognized.

According to the American Association of Suicidology, "Survivors of suicide represent the largest mental health casualties related to suicide." They go on to state, "While there is some controversy as to whether bereavement after suicide is different from other types of losses over the long term, there is considerable evidence that survivors of suicide loss show elevated rates of psychological distress, complicated grief, and social problems when compared to most natural death survivors, and similar rates of difficulties when compared to survivors of other sudden, unexpected, and violent deaths (e.g., homicide)."

Like all grievers, what is important is how one makes meaning of the death, integrates it into their life and moves forward with a "new normal". For some suicide survivors, individual or family counseling can be beneficial, while for others support groups for those who have "been there" may be helpful. For still others, using Web sites such as www.suicidology.org can be helpful. Whatever our role, professionally or personally, we need to not turn away from survivors, but walk with them in their grief....it is a lifelong process.

Ben Wolfe is a Program Manager/ Grief Counselor at St. Mary's Medical Center's Grief Support Center in Duluth, MN. He is also a former member of the Executive Committee of the National Donor Family Council.

DONOR FAMILY *voices* *suicide and grief*

Editor's Note: We asked families affected by a suicide to share their thoughts on our e-mail list. Some of their responses follow. Please visit www.donorfamilyforums.org and click on the "Donor Family Voices Archive" to read the full responses or share your own experience. To join our donor family e-mail list, write to donorfamily@kidney.org and ask to "Join the NDFC e-mail list."

I never expected to receive a call saying that Jeremy had ended his life. I had to give it to God for me to be able to handle it. Jeremy wanted to be an organ donor. The recipients' eyes tell me that I made the right decision in my worst hour. Lean on your family and friends; they will let you know how much they love you so you can live again! There is no prescription for grief; everyone does what works for them. I try to laugh and stay positive because Jeremy would not want me to be sad.

—Pat J. Kupfer, Mother of Jeremy Daniel Youngman*

My son Jacob was 16 when he died from suicide. He was an organ, tissue and eye donor. I have a hard time talking about it, except with some family members. It has been almost nine years since his passing and I still carry a lot of guilt— why didn't I see it coming? What else could I have done? I have been in counseling and in a support group. I also find the U.S. Transplant Games to be very helpful in dealing with my son's death. Seeing all of those transplant recipients have a second chance at life makes me feel good. I am very proud that we made the decision for him to be an organ donor.

—Phyllis Keith, Mother of Jacob Wayne Blastow*

I lost my youngest son Damian to suicide. We have made it through, knowing that God is with us each and every day. To other families, please do not blame yourselves or think you did something wrong. I was at home along with his dad when he took his life and we could not save him. He spoke to me just minutes before; he was pretty calm. Do not be afraid to cry or talk about your loved one. Damian's pictures are everywhere in my home. God bless each one of you as you continue to live on with your precious memories.

—Enid Davis, Mother of Damian S. Davis*

I feel that young teenagers don't realize that what they are doing is permanent. It is a quick decision to end what is hurting at the moment. Being a survivor

has changed my life drastically. Talking about suicide is such a closed subject. It needs to be brought out in the open. I have had the pleasure of meeting Misty's heart recipient. I know that I made the right decision by donating.

—Beverly Key, Mother of Misty Bridges*

My son Dan was 40-years-old and a father of four. At first, I was very angry at him for choosing to leave us. I felt very guilty for not seeing how he was hurting. I have gone to therapy to try to understand how he could take his life. I spent hours writing it all down, why I thought he chose the way he did. Writing it all out, why I thought he did it and why he should not have, I came to understand that he was really sick and none of us could have stopped him. I have forgiven him. My grandson and I still go to counseling together.

—Mary Clark, Mother of Dan Kirk

My faith in God has helped me cope. I know that God was with James through his struggle...I know that God loved him and understood his pain, even when I could not! A friend who is a counselor said to me, "Joyce, if all you can manage to do today is breathe, you have accomplished a great deal." My older son said to me, "Mom, if you didn't recognize that James was suicidal, then no one else could have seen it." As much pain as I suffered from this act, I know that my child had to be suffering much more. I understand that there was nothing that I could have done to prevent it— postpone it perhaps— but not prevent it. James' corneas were used. I am delighted to know that a little girl can see and a woman also regained her sight. A little girl will be able to read and run and play and do all the things little girls should do! A woman can read to her grandbabies and see the color of their hair and eyes! I pray that they only see beauty in their lives. I am proud of my son, who made sure that I knew he wanted to be a donor. I love you, James!

—Joyce DeMonbrun Sanbowers, Mother of James Christian DeMonbrun*

* See photo on page 5



The *Quilt* on Tour

Please note: This schedule is subject to change. Call the National Donor Family Council at 800.622.9010 for the most up-to-date information. The entire Quilt is not on display at these events, and not all events are open to the public. Please call the contact person for more information.

2007

September 8 Sioux Falls, SD, Avera McKennan Transplant Institute, *3rd Annual Transplant Reunion Fair*, Becky Jansa, 605.322.3017

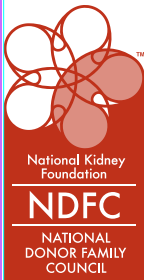
September 8-15 Seattle, WA, SightLife, *2007 Donor Family Gathering*, Lois Parker, 206.682.8500

September 29 and October 7 Rochester, NY, Finger Lakes Donor Recovery Network, *Donor Family Recognition Ceremony*, Roxanne Morsch, 585.272.4934

* One panel of the National Donor Family Quilt is displayed year-round at the National Donor Memorial in Richmond, VA. (This Quilt panel will sometimes be moved for display at other national events.) For more information, contact Marilyn Jones at 800.622.9010.

For information about reserving a Quilt panel, please contact the NDFC for updated information and pricing. The NDFC can be reached by e-mail at donorfamly@kidney.org or by phone toll-free at 800.622.9010. Please notify the NDFC of any special requests, including requests for a specific panel of the Quilt. Arrangements will need to be made to display the Quilt properly and obtain permission from the venue where the Quilt will be displayed.

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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