



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 2009

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

Volume 18, Number 1

THREADS *of compassion* By Lynn Baudo, Donor Mom

No one knows how he or she will react when tragedy strikes. In October 2003, I was faced with such a life-altering challenge when our 23-year-old son Brian was fatally injured in a motorcycle accident and became an organ donor. His gift gave a second chance to three people he never knew.

Brian was in a coma for 14 days before he died. It was a very difficult time for our family and friends. We spent many hours at the hospital sharing prayers, hugs, stories and tears, and I started to knit again. My daughter and my son's girlfriend became interested in knitting, so I taught them. As we knitted, we shared stories about Brian. We even had a few laughs when some of Brian's friends attempted to knit. That was a Kodak moment.

Knitting became a passion and Brian's girlfriend and I continued to knit every week. It didn't matter what we were knitting, our common bond was, and is, Brian. We both agreed that it would be nice if our knitting had a meaningful purpose that was connected to him.

At the 2005 National Donor Recognition Ceremony in



The Comfort Shawls provide warmth and comfort to the person receiving them, giving something tangible to hold on to.

Washington, D.C., I witnessed a touching presentation. A shawl was given to a young mother whose infant son had recently become a donor. I was so moved by the uplifting effect this simple shawl had on this heartbroken mother that I became inspired.

I organized *Threads of Compassion*, a volunteer group who shares a love of knitting and crocheting for the purpose of making Comfort Shawls for new donor families. The shawl provides warmth and comfort to the person receiving it, giving something tangible to hold on to at that moment and for days, weeks and years to come.

Since beginning the project, we've created more than 1,093 shawls. Building a relationship with these wonderful volunteers has been the most rewarding experience. I cannot express how much it means to me that they compassionately share their talent, friendship and belief in this meaningful project.

Although Brian's death has forever changed my life, I have chosen not to mourn the day he died. Instead, I celebrate the life he lived and the gift of life he gave. His confident outlook and zest for life are now my strength and inspiration. I am stronger, more sensitive, more aware and understanding of the pain and suffering of others. In my ongoing transition through my sorrow, I was able to turn tragedy into a positive mission. The *Threads of Compassion* shawls carry a powerful message of hope to those, who in their darkest hour, give the gift of life in the spirit of love.

Editor's Note: If you know of a similar project in your area, please let us know! You can e-mail donorfamily@kidney.org or write to the National Donor Family Council at the address on the last page of this newsletter.

WE FONDLY *remember...*



Bobby Wayne Covert, II
February 11, 1993– April 22, 2008



Mikal A. Davis
July 21, 1981 – March 6, 2008



Katrina A. Gustafson
February 16, 1988 – January 22, 2004



Dan Hearl
March 27, 1946 – May 18, 2004



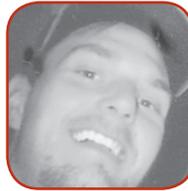
Christopher Mattison
September 17, 1975 –
October 30, 2003



Nicholes Torres
June 5, 1989 –
September 9, 2006



Sean Michael O'Rourke
June 30, 1980 –
May 12, 2005



Jason Scott Wilson
August 10, 1977 –
August 5, 2000

If you'd like to share a photo of your loved one for this newsletter's We Fondly Remember section, please e-mail it to



donorfamily@kidney.org

or mail it to:

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



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 NKF. The NKF reserves the right to edit all submissions. Please contact the NKF for article submission guidelines or permission to reprint articles.

EDITOR-IN-CHIEF ASSISTANT EDITOR

Rose D'Acquisto Douglas G. Harrell
St. Paul, MN Wilmington, DE

DONOR FAMILY EDITORS TEEN EDITOR

Susan Dillon Downingtown, PA
Jan Frye-Hill Winston Salem, NC
Judy Grogan Auburn, WA
Jan O'Bryan-Wilson Kansas City, KS
Mia Lester

TRANSPLANT RECIPIENT EDITORS

Jack Fassnacht, Esq Chicago, IL
James Gleason Beverly, NJ

PROFESSIONAL EDITORS

Suzanne Ball, Seattle, WA
Elizabeth McNamara Orchard Park, NY
Benjamin S. Wolfe, MEd, LICSW Duluth, MN
Charles Corr, PhD St. Pete Beach, FL

ORGANIZATIONAL LIAISONS

American Association of Tissue Banks: Sandie Henderson-Boncore
Association of Organ Procurement Organizations: Robin Cowherd
Eye Bank Association of America: Kara Petry
Musculoskeletal Transplant Foundation: Maggie Coolican

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.donorfamily.org | E-mail: donorfamily@kidney.org

EXECUTIVE EDITOR

Gigi Politoski

MANAGING EDITOR

James McCann

PRODUCTION MANAGER

Jamie Biegeleisen

EDITORIAL DIRECTOR

Jennifer Martin

DESIGN DIRECTOR

Oumaya Abi Saab



bbb.org/charity

Please indicate that it's for the *FTWGG* newsletter and include your name and contact information, along with your loved one's name, date of birth and date of death.

If I had just One More Day with you!

By Reecie Miller, Donor Mom

I remember watching you sleep at night,
Praying the angels would guard you tight.
I hoped and dreamed for your life to be,
Filled with more than my eyes could see.

I had no idea
That we had few moments to share,
That you would leave my arms
And return to God's care!

How my heart aches to hold you once more,
To hear you say, "Mama"
And watch you run to the door.

If God would grant me
Just one more day with you,
These are the things
I would want us to do!

I would gently wake you up
And run my fingers through your hair,
Whispering, "Good morning, handsome,
Mommy's right here!"

We would play peek-a-boo
With the sheets.
Then I'd kiss you all over
And pinch your sweet cheeks!

We'd go swimming in the pool
Like we always would do,
But today we'd stay a little longer
A little longer than we should!

I would let you run through the house naked
And I would laugh while you ran.
Then I would pick you back up
And want to do it all again!

Life is too short to worry
About all the small things.
Time is way more precious
More precious than it seems!

Editor's Note: To read the full poem,
visit www.donorfamily.org and visit
the *Comfort Café*.



Join us for the *Coffee House Conversations*™ Telephone Series!

The National Kidney Foundation's **People Like Us** hosts free monthly *Coffee House Conversations*™ telephone calls for our constituents—donor families, living donors, transplant recipients and kidney patients. We are planning a call just for donor families on:

COPING WITH GRIEF AND LOSS AFTER DONATION

OCTOBER 2009 (date to be announced)

TIME: 7:00 p.m. – 8:50 p.m. EASTERN TIME

If you'd like more information about this call as it becomes available, e-mail us at donorfamily@kidney.org or call us toll-free at 800.622.9010 ext. 177 to ask about the "Donor Family *Coffee House Conversation*."

Please note that this is the *only* announcement that will appear in this newsletter before the October call, so make sure to let us know if you'd like more information!

DONOR FAMILY *voices*



DO YOU HAVE A SPECIAL MEMORIAL SPACE where you honor the memory of your loved one? Big or small, indoors or outdoors, other donor families would like to hear what you do...it could help spark ideas of our own!

Editor's Note: We asked families these questions on our donor family e-mail list; some of their responses follow. Please visit www.donorfamilyforums.org to read the full responses or to share your own experience. To join the e-mail list, write to donorfamily@kidney.org and ask to "Join the NDFC e-mail list."

My 6-year-old son Ryan died after a car crash. A friend built a 3-foot high cross to put in the ground. I added his name and dates, decoupage pictures and painted butterflies, sunflowers and rainbows on the cross. It turned out beautifully and it is a personal and lasting tribute to my angel son.

—Peg French



I like to plant special flowers for Michelle. Her garden is so serene and beautiful, full of the life she enjoyed, birds singing and flowers swaying in the breezes. It is her essence there more than anywhere else. We added a cement bench and a beautiful Blue Spruce tree. I also created a Web site for Michelle.

—Cindy and David Greever



My son Michael committed suicide in 2008. I have several places where I have put his ashes—under his favorite apple tree in his dad's yard, the ocean near where he lived with my sister for a year, my backyard under a birdbath. I placed some in my future burial plot, and I have a special place that only he and I know. All of the places have special meaning and bring me comfort.

—Melissa Bothum



After I lost my 26-year-old daughter Amber, who was a Licensed Practical Nurse, I kept the bedroom that she shared with her son the same with all her pictures, as well as a scrapbook with dried flower arrangements from her funeral. I also have a shadow box someone made with a shirt, a picture of Amber, her nursing pins and other things she loved. When my grandson comes to visit, he loves to go in the room and just look at all the stuff. I have angels all around her things.

—Debbie McCray



Mike died at age 40 when his little girl was six. He was able to give life to three people through organ donation. His wife Gina had many different sizes of teddy bears made out of Mike's shirts and jeans. We have one on a table with a ribbon that says, "I was once worn by someone so dear, who through loving memory will always be here. So when you hug me up close, just remember, Mike loves you too."

—Don and Shirley

On my son's birthday, my family planted a Japanese Maple tree. It was so fragile at first and we worried as it weathered each year's severe winter, but each year it got stronger and fuller. It continues to grow, prosper and bring us beauty everyday. It is a living witness to our son's life and to his eternal presence with us now.

—Maureen Fleagle



My husband Bob died at age 52 of heart problems. The next spring, my son and I made two flower gardens in our yard. The physical work of making a garden and the pleasure of seeing flowers that Bob loved helped us both.

—Sherry



When my son died suddenly at the age of 20, we had a Celebration of Life instead of a traditional funeral or wake. We displayed two "story boards" that had pictures of DJ. We included handwritten poems and remembrances, along with paper for those attending to jot down their feelings. Those who contributed, sifted through photos, glued, pasted and shared stories said it was incredibly helpful because it directed us onto a path of remembering the good and the smiles as opposed to anger and resentment. The grieving never ends. Those boards are displayed in my office and help move us forward on our journey of healing, a journey we are traveling on together because of this project and our mutual love.

—Shelly



My husband was a Navy Aviator so I have his American flag in a frame and a battery-operated, programmable candle that comes on each night in my family room on top of our bookcase. It is sort of my own little eternal flame.

—Anne Dobbs



I have covered pillows with my son's shirts so I can "hug" him. We also have a room set aside with all his memorabilia on the walls. We will be planting a tree at the cemetery by his grave.

—Nancy Martinez

HOW A MEMORIAL SPACE

can help a grieving person

By Rev. Jennifer Malewski, MDiv, BCC, CT

Creating a personal memorial space is a way of honoring a loved one and inviting positive spiritual feelings into our home. A memorial space can include anything that reminds you of your loved one. It might simply include a photo, along with a few possessions or symbols of that person.

The memorial space doesn't need to be huge or elaborate—it can be something fairly simple and unobtrusive on a dresser, bookshelf, outdoor area or another location. It is a sacred space with special articles of remembrance. Many of us have an instinctive need to remember those who are most valuable to us in an atmosphere of music, candles, poetry, readings, incense, flowers, plants, arts and crafts. This space may be secular, spiritual, religious or a combination of all of these areas of life.

The space can be a portable or permanent fixture in one's daily

habitat. It promotes the grieving process as normal and gives the griever personal meaning. It fosters good memories of the loved one, provides comfort and gives us a safe place to mourn, pray, read and remember. This space lets us express our emotions and can reduce stress, anxiety and depression. It shows that grieving is not about forgetting. Grieving is a sorting process. Its presence lets our grieving heal us and allows us to remember with love instead of pain. One by one we take hold of the things that have become a part of who we are and build ourselves up again.

A memorial space lets us remember one person or many persons from our family of origin and special others. Hispanic households, Buddhist oriental homes and Zoroastrians' habitats have had memorial spaces in their homes for decades, sometimes centuries. In a 2001 study, researchers found that creating this space is the second most important ritual activity

that helps the bereaved. (The first most important activity is designing a remembrance ceremony or celebration.)

Many of us feel comfortable using a memorial space as often as it feels right to do so—daily, weekly, monthly or yearly on an anniversary date or on holidays.

For myself, in my simple space are the photos of my Mom, Dad and only sister, with candles lit at holiday time, a small ceramic angel, a porcelain flower my sister gave to me and an embroidered cloth from my Mom's family. This is all I need to bring me comfort and good memories of them. I hope you, the readers of this piece, find what is best for your memorial space and that it brings you comfort and peace as well.

Rev. Jennifer Malewski is the Staff Chaplain at the University of Kansas Hospital in Kansas City, KS.

Donor family voices (Continued from page 4)

We created Patti's Park at our farm and had an angel put there. She was our angel.

—Jeanne Szuber



At my son's funeral there were beautiful sunflowers everywhere. Since that time I have surrounded myself with sunflowers in memory of him. I have them painted on both my cars and in many places throughout my home. Each time I look at my collection, I think of my sweet boy and the gift of life he gave.

—Pam Charron



I think the best thing we can do is some type of memorial that gives to others in memory of our children. We started a nonprofit for Lance that concerns motorcycle safety.

—Kathy Malone

My son Nathaniel's Cymbidium Orchid and Cypress tree are symbolic to me because they persevere through stormy weather, and yet in their own time with sunshine and rain, they slowly and quietly emerge strong and healthy again. That growth process represents my grieving process.

—Jean Bolds



My husband Terry was Buddhist, so I have a small area in my patio with a statue of Buddha and many colorful flowers planted around it. There is also a fountain nearby that is comforting. I can see this serene setting from every room in my home. Inside, we have fresh flowers and several candles that we light with incense each day to show respect and gratitude to Terry.

—Roxanne Kuramoto

WRITING *to my donor's family*

By Mary Wu, Kidney Recipient

Hardly a day went by during the nearly 15 years after my second kidney transplant that I did not think about my organ donor and her family. The little that I knew was that she was four years old when a mirror fell on top of her, and that I received both of her tiny bean-sized kidneys at age 12 that grew with me as I aged.

sundaes and sweetened lemon ice tea that tickled the tongue, I received the news I had been anticipating: My donor's family was found! For once in my life I was speechless. Then I was told the bad news: My donor's family did not wish to receive my letters, but they wished me the best of luck in life. My excitement subsided and I felt hurt and rejected. It did not

"I wrote as a comfort to me, a bridge to them and, most of all, a promise to always remember my organ donor, her family, this gift of life and everything involved with my second kidney transplant."

When I thought about her and her family, I felt guilty having gained this beautiful life full of ups and downs from her accident. I believed that if I lived out my life to the fullest, then I was giving what little I could back to her and her family for this priceless gift of life that pumped through me. Without even meeting them or knowing anything at all about them, I felt so close and connected to them.

Trying to reach my donor's family was a huge process. I wrote and rewrote to them in my loopy handwriting on carefully chosen colored stationary. The letter went to the New York Organ Donor Network (NYODN) and their coordinator tried to find the family. The coordinator was honest with me and said that it was going to be extremely difficult to find my donor's family because of all the years that had passed. This did not diminish my determination.

About six months later, on a hot, sultry and steamy summer day that was meant for ice cream

occur to me that my organ donor family would not want to have more contact with me. I reasoned that they must have been the most selfless people for choosing to donate their daughter's precious kidneys in their time of tragedy, so they would want to hear from me to know that their daughter lived on in some way.

The coordinator advised me not to give up and to write them every now and then because she had experienced organ donor families abruptly wishing to receive and read the letters many years later. She tried to make me feel better by saying that many other organ donor families would have loved to receive the beautiful letter that I had written. My family and friends echoed the coordinator by telling me that parents' grieving over the loss of a child never ends, and to still maintain minimal contact in hopes that maybe they would change their minds.

This was a delicate situation with no right answers. On one hand, I



Mary Wu, Kidney Recipient

understood that my letters could open a painful wound of memories, reminding them their daughter was no longer here while I am. On the other hand, I did not understand. How could a family who chose to make the most difficult decision that no family should ever have to make not want to read my letters and know that their daughter's life lived on?

It has almost been a year since I mustered up the courage to write the first letter. I still make it a point to write as a comfort to me, a bridge to them and, most of all, a promise to always remember my organ donor, her family, this gift of life and everything involved with my second kidney transplant.

I will not lie—I still hope that one day my organ donor's family will change their minds and receive the box full of my letters. But, for now, I continue to write to keep them and my wavering connection to them alive in my heart, mind and soul.

DONOR WIFE

holds her head high with husband's bone

By Douglas Harrell, Donor Husband

Growing up, Jean Reyes de Gonzalez had a low opinion of herself. Her father, a waiter on a Navy ship, was gone for months at a time, leaving Jean in the hands of abusive relatives. The sum of these experiences left her bitter and angry, but all of that changed when she met John Amato.

John was a happy-go-lucky guy who worked at the parts department of a local car dealership. He played the drums at his church and genuinely liked to help people when he could. They were married on October 30th,

“Receiving John's bone made me not feel so alone. He was instrumental in healing my heart and mind, and in death, he healed my body.”

1997. “It wasn’t until I met John that I found out what it was like to be loved. When I married John, God healed the psychological wounds of abandonment. John loved me unconditionally.”

Jean’s nightmarish past was behind her. John was an attentive and romantic husband, often bringing her small gifts of a perfect rose or a stuffed toy for no particular reason. She was truly happy for the first time in her life, but it was not to last. On May 31, 2000, John was unable to go to work due to severe back pain. A trip to the emergency room proved negative for a heart attack and he was given pain medication and sent home. Later that night, he collapsed and

died from an undiscovered aortic aneurysm. When asked, Jean had no reservations about John being a donor. “John and I had spoken about donation and what we would do if the other died. I knew that John would not say no. He was all about helping others.”

Through her job with the Office of the Chief Medical Examiner in Farmington, Connecticut, Jean was already familiar with tissue donation. At one point, she had even been responsible for coordinating the recovery of cornea donations.

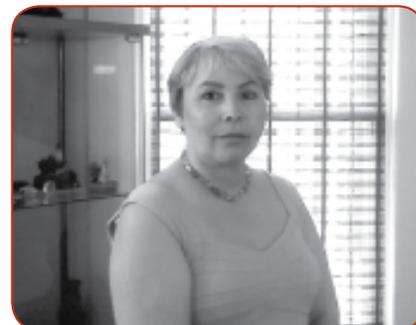
Only a month after John’s death, the grief in Jean’s heart was gradually accompanied by a severe pain in her left arm. She was told that she had a herniated disk in her neck and would need a cervical fusion with donated bone. “The surgeon told me I needed surgery and explained what needed to be done. Bone is used as scaffolding. Your own bone grows over it. I started wondering if I could use John’s bone. I finally decided to call the OPO to see if any was available. When I finally asked, John’s bone was at the point of being prepared for final use. A piece of it was prepared to suit my need.”

In honor of John’s gift, Jean spends a portion of her time

volunteering to spread the word about donation. She is a frequent speaker for the Musculoskeletal Transplant Foundation (the tissue bank that handled John’s bone), and she has spoken at the National Donor Recognition Ceremony in Washington D.C. In addition, she served two years on the Executive Committee of the National Donor Family Council.

Jean is now happily married to Eladio Gonzalez, a police officer she met at work. Eladio is supportive of her continued involvement with donation. “I think it is a great way for her to honor John. I know he is a very important part of who she is—perhaps the most important part,” said Eladio.

Jean adds, “Receiving John’s bone made me not feel so alone. He was instrumental in healing my heart and mind, and, in death, he healed my body. Going through the experience has made me more compassionate toward others. The physical pain of the surgery and the emotional pain of John’s death have changed me forever. I feel more capable. If I could get through that, I can get through anything.”





Please help us "cut down" our costs by notifying us when your address changes. E-mail us directly at donorfamily@kidney.org. It costs 44 cents if you forget.



The Quilt 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.

2009

July 17–19 Washington, D.C., U.S. Department of Health and Human Services, Health Resources and Services Administration, Division of Transplantation, *National Donor Recognition Ceremony and Workshop*, Marilyn Jones, 800.622.9010

2010

**July 30–
August 4** Madison, WI, National Kidney Foundation, *2010 U.S. Transplant Games*, Marilyn Jones, 800.622.9010

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 donorfamily@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.