



National Kidney Foundation®

For Those Who Give and Grieve



A 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 2011

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

Volume 19, Number 2

20th Anniversary

Dear friends,



TWENTY YEARS ago, *For Those Who Give and Grieve* started as an extension of a book by the same name. Published by the National Kidney Foundation, with the generosity of the Musculoskeletal Transplant Foundation, this newsletter became the first of its kind—for donor families from other donor family members.

Over the years, *For Those Who Give and Grieve* has offered us a way to connect with each other and offer understanding, comfort and hope. Along with the National Donor Family Council, it's given us a home where we can share "what helps when it hurts" as well as our poems and stories. It has provided us with insights and practical suggestions on bereavement, organ donation and working with transplant professionals. And, it has given us a chance to hear from grateful recipients themselves.

While much has changed with time, one thing still remains the same. Without any glossy fanfare, or fancy printing, our newsletter reflects our donor family journey with simple, heartfelt honesty.

Sincerely,
Rose D'Acquisto
Donor Wife,
Volunteer Editor-In-Chief



For Those Who Give and Grieve is supported by

MTF Musculoskeletal Transplant Foundation
Changing Lives Through Tissue Donation

LOOK *to the skies*

By Debra Crawley, Donor Mom

In memory of Kevin and Bradley Cybula



As I look to the sky
on a bright clear night
and see the stars shining
so clear and so bright

I try to see past the stars
to the heavens above
remembering my yesterdays
and the people I love

Time goes by so quickly
soon it is gone
the people in your life
have to move on

They move to the heavens
but remember you still
they will love you forever
it's their heavenly will

We will all be together
again someday
together again in our loving way
and as our loved ones look to
the evening skies
they too will remember you and I

For Those Who Give and Grieve

For Those Who Give and Grieve is published 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.

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DID YOU KNOW that

For Those Who Give and Grieve is online?

Over the years, we've published many helpful articles on topics requested by our donor family readers. From our most recently published issue, to issues dating back to 1995, you can view *For Those Who Give and Grieve* on our website at www.donorfamily.org

Also, if you would rather receive the newsletter by email to help us save printing costs, please send us an email at donorfamily@kidney.org and we'd be happy to accommodate your request.

WE FONDLY *remember...*



Mark A. Brown
April 20, 1959 –
April 7, 2000



Robert "Dutch"
Holland
November 11, 1946 –
March 18, 2009



Max Rose
January 8, 1989 –
January 3, 2009



Dick Damrow
February 18, 1949 –
February 24, 2009



Wayne "Mickael"
Johnson
March 7, 2007 –
May 25, 2009



Craig I. Ryder
March 18, 1949 –
April 20, 2009



Jared Zachary
Dubsy
June 14, 1994 –
May 26, 2009



Michael Frank Joyner
August 10, 1972 –
August 5, 2005



Truckee K. Sclafani
June 6, 1987 –
May 17, 2009



Michael Charles
Eagan
October 25, 1963 –
July 19, 2009



Katheryne
Keefer-Fort
November 12, 1986 –
January 8, 2009



Kaydon Reece
Stewart
August 8, 2007 –
March 30, 2009



Arnold Freeman
January 16, 1934 –
June 2, 2009



David Lawrence
Murphy
February 1, 1993 –
July 13, 2009



Barbara W. Stover
November 25, 1938 –
July 8, 2009



Amy Lyn Harrison
September 6, 1973 –
September 18, 2005



Mayela Orduña
March 1, 1990 –
February 17, 2009



Don E. Trapp
May 28, 1952 –
February 19, 2007



Herbert L. Hayes
February 25, 1945 –
June 18, 2008



Nikki Ronning
June 20, 1988 –
May 25, 2008



Erin K. Winham
February 2, 1968 –
May 19, 2001

DONOR FAMILY *voices* *Dealing with difficult spaces*

OFTEN THE LOSS OF OUR LOVED ONE IS STRONGLY ASSOCIATED WITH A PARTICULAR PLACE. It could be a room in our home, a location on the road, a hospital, or another location where a significant event related to that person's death occurred. Please share with us if there is such a place for you and, if so, how you handle the reactions to it.

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

My daughter died in her bedroom and the memory of her death seemed to block all the other happy ones. In our previous home, she had asked me one day if she could paint a small star on her bedroom wall. I answered yes, and I was expecting to see one small star on her wall. What I saw instead was a rainbow of stars, and as the years went on, the room became covered in graffiti art and hand prints. On the first anniversary of her death, the family and some of her friends got together and painted graffiti art on her bedroom wall. Now I can see laughter and feel a sense of closeness when I'm in there playing with her little girl. I know my daughter is with us both in there and it makes it just a little bit easier to be there.

— *Marelda Abney*

Jason was a high school baseball player and his uniform number was 31. Whenever 31 shows up, either in a newspaper article, picture, checkbook, etc., I believe this is Jason letting me know that he is with me. Also, since we are all energy, I associate a street light flickering or going out when I am driving as another sign that Jason is with me; all of which bring me comfort.

— *Arnie Zepel*

After my younger brother, Shane, was suddenly killed in 2003, I journaled every night after climbing into bed. It usually was telling him about my day, kids, thoughts or feelings. My journal wouldn't mean much to anyone else, but I treasure it. It gave me so much comfort when I needed it the most. I miss my baby brother daily, but knowing that he saved five people, he lives on.

— *Jennifer Webb Turnage*

My son, Rocky, died in a motorcycle accident. Motorcycles still make my heart jump. However, I take that anxiety and turn it into something positive. Speaking about motorcycle

safety and giving the Gift of Life helps me to realize that we cannot change the course of that terrible day, but we can help change the course for others. What an awesome gift and what an awesome legacy for my granddaughter.

— *Kelly Duren*

My younger sister died in a car accident. At first, I was drawn to the spot where the accident happened and my heart would race. Overwhelming sadness would grip me and I would just cry. Then one day, as I was approaching the area, I remembered how my sister used to make these funny sounds and, in particular, as a car would pass, she would make this sound like in "The Jetsons" as the cars passed each other. I laughed as I remembered her silly sense of humor and, in that moment, I knew I could pass by this spot and remember how she could make me laugh. I held onto that and it made it a little easier each time.

— *Denise Nathan*

My husband died very suddenly from a heart attack in the foyer of our home. For the first couple of months after he died, I would visualize that awful and chaotic scene every time I came down the stairs, and seriously considered moving. I'm glad that I didn't, however. Over time, that terrible memory faded and the many good ones of all the times we had enjoyed with our children in that home took their place.

— *Valerie Stalnaker*

My place to remember Bob is his chair. I know it sounds funny, but I can see him rocking and looking over at me, always smiling. I often sit in his chair and I feel such a warmth. A flush of memories come rushing in, and I feel good after sitting in his chair. I miss him every day, but I know he is right there beside me rocking away.

— *Jeanne McDaniel*

Dear National Donor Family Council,

WE SEND YOU AND ALL DONOR FAMILIES OUR GOOD WISHES from ourselves and from everyone connected to the Donor Family Network here in the United Kingdom. We are pleased to help you celebrate your 20th anniversary.

In 1996 our daughter, Rebecca, was studying in the U.S., and she settled with a lovely family in Glastonbury, Connecticut, as an au pair. Rebecca loved America, and happily her mother Jane was able to visit her during her stay. America will always have a special place in our lives.

Rebecca, at the age of seven, was the first one in the family to bring up the subject of being a donor after hearing a talk at school. We never gave it another thought until that November night in 1996. When the phone rang, we thought it was Rebecca, but it was her friend Donna. She struggled to get the words out. "There's been a car crash," she said. "Becky's dead."

An hour later, lost in grief, an image of Rebecca's green and black donor card sprang into Jane's mind. We telephoned Hartford Hospital and asked if Rebecca's wishes could be carried out. They told us, that although the major organs could not be donated, there were plenty of tissues that could. We told them to take what they could. Even then, in our tragedy, it already comforted us that Rebecca had been able to donate.

We were not aware of any organizations in the U.K. for donor families, so we started a local support group with a few other families. Within months, families from all around the U.K. wanted to know about us, so we became the Donor Family Network. We looked at what we were offered from the National Donor Family Council in America, took a lot of it [as our model], and refined other parts to suit a British way.

We became a Registered Charity in 2003, and we now have member families throughout the United Kingdom and in France, Portugal, Spain, Poland and the United States. We have helped many people from their initial grief to many years of being a donor family, and we get many letters from families thanking us for what we have done for them.



Rebecca Nix

Rebecca has led us down a very different route than the one we had planned for our family, but her legacy has meant that so much good has happened as a result. We know of at least 74 people and their families in America who will never forget their donor, who happens to be an English girl.

*Kind regards,
David and Jane Nix*

*We are pleased to help
you celebrate your
20th anniversary!*

THE MONKEY *bathroom*

By *Ida Kelleher, Donor Wife*



ON SATURDAY, DECEMBER 6, 2008, my daughter Marci, 12, and I were decorating the house for Christmas when we heard a sickening thud from the upstairs bathroom. We rushed in to find my husband, Mark, convulsing on the floor in the throes of a violent seizure. We called 911, but he died hours later from a deep inoperable brain hemorrhage.

Some weeks later, my son Michael, 20, was visiting. He, Marci and I watched a TV special on the recent discovery of a fossil that scientists think may be the missing link that proves evolution. Mark had always teased me about not believing in evolution, giving me toy monkeys and monkey birthday

cards, so when the narrator announced that the scientists had named the missing link “Ida,” we erupted in laughter. As it turned out, this gave us an idea.

Marci and I hated the upstairs bathroom where Mark had his seizure. That spring, Marci and I took everything out but the sink and the shower, and we retiled the floor. When I asked Marci how she wanted to decorate it, she said, “I want to do it in monkeys.” So now we have this crazy monkey bathroom with a monkey shower curtain and a monkey trash can. We put lime green and blue dots on the wall, and I even bought realistic plastic bananas and hung them on the dots.

When I go in there, I still feel Mark’s influence and his presence, and I get to relive for a few moments how he used to play with me. The best part is the change that it made in Marci. That room was a constant source of sadness for her, and we eliminated that. She’s also proud of the work we did together to fix it up. After we were done, she told me, “Daddy would want this.”



20 years later...

FOR OUR 20th ANNIVERSARY, *For Those Who Give and Grieve* wrote to everyone who helped to develop our very first issue back in 1991. As one of our first donor family editors, John Del Gatto was an important part of developing this newsletter in those early days. Here is his response to our letter.

Greetings,

Ironically, today, the day I received your letter, marks the 21st anniversary of my loving daughter’s departure.

Soon it will be the 21st anniversary of the recovery of her heart, liver and kidneys. It will also be an important anniversary for four women who waited in hope and had their lives saved or improved from my daughter’s donation. They ranged in age eight to 40 years.

As I gleam with pride over the huge generosity of my daughter, I cannot help but reflect on her still-missed presence in our lives today. She touched so many lives while she was with us, so it is fitting that she continued to touch others after she departed.

Continued on next page

20 years later... continued

In her honor, we created MOTRAIN (The Monique Del Gatto Organ and Tissue Awareness and Identity Network) to enhance awareness about organ and tissue donation with high school students.

To those who have given and to those who grieve, my heart and thoughts are with all of you. Life is so precious—past, present and future. Let's us do our best and continue to press forward with love, compassion and giving.

I tip my hat and send my love to the National Kidney Foundation for continuing in their efforts to serve in the donation and transplant community. NKF was so instrumental in caring for our family. We couldn't have done it without you. A very special thanks to Jayne Miller, my pillar, and Maggie Coolican, Rose D'Acquisto and so many others not named for keeping the torch lit for those who wait in hope and for those who grieve.

*With warmest regards,
John Del Gatto and Family*

Letter from a Grateful Soldier

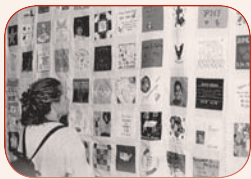
Dearest Family,

MY DEEPEST SYMPATHY FOR YOUR LOSS. I hope this letter provides some consolation to you. I am only 30, but was diagnosed with degenerative disc disease. This is partially due to heredity, and also to my time in the Army infantry, where I received two Purple Heart medals while deployed in the current conflicts. Most notably, I was once shot while scaling a building. The combat tours took their toll, as all of the additional gear and weight affect the spine.

In the past two years I went from being extremely fit and active, to being capable of only light activity. Then I underwent spinal fusion surgery, using your loved one's tissue. I'm recovering well now. The sciatic nerve in my leg has been saved as well. Without surgery, not only would my spine be irrevocably damaged, but I would have also lost my right leg.

God bless you for your sacrifice and I honor your loved one's legacy. Your loved one continues to change lives like my own and the lives of my family. I, too, hope to be a donor, and hope and pray that one day, when my life on earth is done, I'll be able to look down from heaven and observe a life being changed.

Sincerely,
A Grateful Soldier



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.

2011

- July 15 – 17** Washington, DC, Division of Transplantation, Health Resources and Services Administration, U.S. Department of Health and Human Services, *National Donor Recognition Ceremony and Workshop*, Erin Kahle, 800.622.9010
- September 21 – 24** Chicago, IL, Musculoskeletal Transplant Foundation, *MTF Scientific Symposium*, Cheri Lane, 732.208.9815

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 Erin Kahle 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 email 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.