



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.

Winter 2010

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

Volume 18, Number 3

KATIE'S *legacy*

KATIE COOLICAN was the youngest of Maggie and Don's six children—a happy, freckle-faced, curly-haired tomboy. She was a first grader when she collapsed on the playground from a sudden brain hemorrhage. Katie's parents chose to donate her organs and tissues so that others could live.

Katie's death impacted many in her small New England town, and eventually around the world. "We quickly understood that her death was not something we would ever get over, but would learn to live with," said Maggie. "Friends, neighbors and strangers provided daily support and dedicated a playground in her memory in 1984. Her graduating classmates created a page in their senior yearbook for her. Katie's donation educated many children and adults and continues to help us."

Maggie's family received no support from the transplant organizations, except for one letter following Katie's donation. Then they were left to grieve alone. At that time, there were no books, pamphlets or support groups about grief after donation. There were no quilts or special memorial services or floats

to remember Katie or other donors and their families.

Maggie began to speak out about the care and support that she felt donor families deserved, and in 1982, she became the Founding Chair of the National Donor Family Council (NDFC) under the auspices of the National Kidney Foundation. With the NDFC, she published the Bill of Rights for Donor Families, the National Communication Guidelines and other resources for donor families. Maggie also created Patches of Love, the National Donor Family Quilt.

"Katie continues to be an inspiration to her family."

She personally sewed the first 25 panels containing 1,750 "patches of love," putting Katie's patch on the final panel that she sewed. (Another donor family member is now sewing new patches onto the quilt, which is an ongoing project.)

Maggie worked with Hartford Hospital to create a two-year, follow-up bereavement program for families, which has been replicated throughout the country. She also participated on several national boards and committees, including the United Network for Organ



Katie Coolican

Sharing, American Medical Association Organ Task Force, Advisory Committee on Organ Transplantation (ACOT) and the Association for Organ Procurement

Organizations (AOPO) Donor Family Services Council. She was a founding member of Donate Life Connecticut.

In 1991, Maggie began working at the organ procurement organization in Connecticut, now LifeChoice Donor Services, and later at the Musculoskeletal Transplant Foundation where she continues to support and advocate for improved care and follow-up for donor families. She has published *Katie's*

Continued on page 5

letter from the editor



A friend once asked, "Isn't it hard being around other donor families at all those events you volunteer for? Doesn't it make you depressed, reliving memories of the most difficult days of your life?"

Actually, it's quite the opposite.

For me, being with donor families gives me hope. Listening to extraordinary stories of love, loss, and selfless giving, I'm mindful of the greatness of the human spirit.

For the New Year, we share with you stories of donor families, recipients and professionals whose lives have been touched by organ and tissue donation. And how, in big and small ways, they continue to "pay it forward."

Compassionately,

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



bbb.org/charity

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.

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WE FONDLY remember...



Dawn Parsons Hamilton
August 21, 1967 –
December 10, 2008



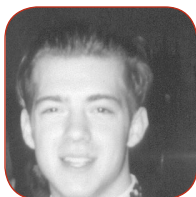
John A. Mancisio
June 25, 1958 –
May 6, 2008



Richard James Lanway
December 5, 1964 –
December 24, 2003



Michael Steven Moore
February 27, 1979 –
April 10, 2008



Jeffrey F. Maksym
December 7, 1973 –
June 27, 1998



Unity Clyde Samuel Owens
November 21, 2007 –
December 1, 2008

KATIE'S *legacy* (continued from page 1)

Legacy in the American Journal of Nursing and the *For Those Who Give and Grieve* book, of which nearly 125,000 copies have been distributed. She is an editor for the *For Those Who Give and Grieve* newsletter.

Katie's legacy was honored in a florigraph (a portrait in flowers) on New Year's Day in the 2010 Rose Parade in Pasadena, CA. Her image was part of the Donate Life America float which honors millions of people touched by organ and

tissue donation, including donor families, their deceased loved ones, living donors, transplant recipients and those waiting for a transplant.

Maggie continues to work tirelessly as an advocate for donor families, helping to ensure that all those involved in donation know that "in order for there to be a transplant, there needs to be a donor and a donor family. Donor families deserve compassionate, consistent care and support, as do all grieving individual and families," she says.

Katie, who is featured in a children's coloring book about donation, *Precious Gifts*, continues to be an inspiration to her family.

"We should never take life for granted," said Maggie. "What we can do is learn from Katie's life. Go out and be an active, positive, smiling, happy, loving person and never expect anything in return."

REFLECTIONS *from the road*

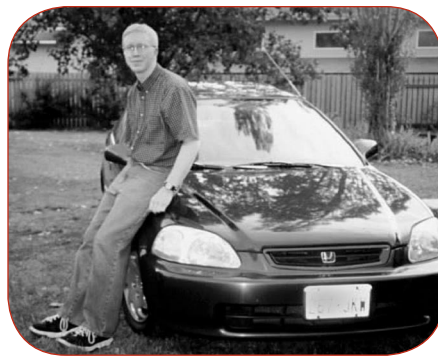
By Carolyn Donnelly, Donor Mom

MY SON NOLAN passed away in September 2003. When we approached the 5-year mark, I found that my heart had finally caught up with my head. My focus had returned to life in the present, not just "what used to be" or only existing in a "holding pattern."

After Nolan died, I remember thinking that if I only s-t-r-e-t-c-h-e-d my arm out, I could almost touch those days when he was unhurt and all was right with my world. But as soon as this thought crossed my mind another one came, "No, this is real; this is what has happened, and time only flows in one direction."

My next desperate thought was that I wished I could fly to some far off time in the future because I sensed that then, it wouldn't hurt so painfully. Once again came the realization that, no, it doesn't work that way. The only way to get down that road was to walk it, one step at a time, one day at a time.

And so the years have passed by and what once was experienced as a heavy robe, covering head and body (blocking and dimming sights and sounds and my perceptions of the outside world, isolating me) has lightened to something more akin to a filmy veil. I can see through it, feel, and interact with the world. Others, unaware of my loss, don't even notice the veil now.



Nolan Donnelly

Will the veil always remain? I tend to think so, because it was bought at so dear of a price.

If I could go back in time and be in charge of the "script" of life, of course Nolan would be here. However, that most painful event of losing him was also the seed which led to growth within me. I have always been a reflective person but now I feel that I am much richer and deeper than I was before. I am growing through this unwanted loss.

DONOR FAMILY *voices* *reaching out to others*

SOME DONOR FAMILIES HONOR THEIR GRIEF BY REACHING OUT TO OTHERS. From creating nonprofits to changing legislation, they're ordinary people like us, trying to make good come from something tragic. Do you have an inspiring story to share? We asked families these questions on our donor family email 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 email list, write to donorfamily@kidney.org and ask to "Join the NDFC email list."

On the 4th anniversary of my daughter Susan's death, I started the "Susan Perkins Fund" to support donor awareness and workshops for donor families. Susan's wonderful gifts of life and their unmeasured effects on many families have been my rays of sunshine and hope.

– *Bobbie Boyer*



Evin received a heart transplant when he was 15, and we became a part of the speaker's bureau of the Washington Regional Transplant Community (WRTC). He also started Students for Organ and Tissue Donation at James Madison University. He passed away in 2007 and provided two people with the gift of sight. To honor my son, I continue to work with WRTC to encourage donation.

– *Carla Shoap*



We started a support group for parents who had lost children with another family. We invited many who had lost children years before us. What a blessing they were! We learned we can survive.

– *Pat Capps*

We have a Facebook group in honor of my son Dixon Giackino. We ask people to sign up to be organ, blood and bone marrow donors. We are fundraising to provide scholarships for graduating seniors, and we also would like to be able to provide grants to people with addiction issues—anything we can do to keep Dixon's memory alive and to help others know what a gift it is to give of yourself.

– *Tara Hamilton*



We have a golf outing every year in memory of Chris and teach people about organ donation. I also volunteer for the Gift of Life to help me cope with my son's death.

– *Barb Bass*



My 10-year-old son, Jesse, was hit by a car while riding his bike. He was not wearing his helmet. A rally was held at his school where we gave away bike helmets. A member of our local city council worked to pass a law requiring any child under 16 to wear a helmet. I still cringe when I see a child riding without one, but I am encouraged that perhaps an impression was made on some children about the importance of wearing a helmet.

– *Jodie (Schoening) Nicely*

WE FONDLY *remember...* (continued from page 2)



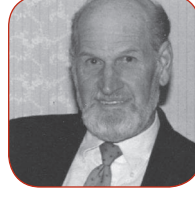
Amber Dawn Poynter
January 23, 1981 –
January 19, 2009



Brian K. Stahl
December 21, 1970 –
February 19, 1999



Jerry Raymond Rutherford, Jr.
September 25, 1987 –
November 2, 2008



John B. Stover
March 12, 1926 –
January 3, 2006



Yusuf Sharif Sawitsky
April 8, 1979 –
November 11, 2003



Alison M. (Ali) Wesley
February 13, 1972 –
July 2, 1997

WRAPPED IN LOVE: *remembering our loved ones*

By Maggie Coolican, Donor Mother

QUILTS HAVE BEEN A SOURCE OF COMFORT, love and a way to remember for hundreds of years. This is especially true in the United States, where quilts have been made to honor those affected by AIDS, 9/11 and of course organ and tissue donors. Since the advent of Patches of Love, the National Donor Family Quilt, most organ and tissue recovery agencies have developed their own local quilts to honor donors in their area.



Photo: Erica Berger

“Quilts, teddy bears, a special garden, photos, poems and journaling can help us remember that our loved ones...can continue to be a part of our lives.”

Today, more and more families are making quilts and other memorials to honor and remember someone who died. Remembering with rituals and tangible memorials is a wonderful way to always keep our loved ones in our hearts and as

part of our families. Although they are no longer with us physically, rituals can connect us to each other and to the person we have lost. Rituals and memorials also help us find our “new normal,” as we learn to live without our loved one.

One family took the dresses of a little girl who had died and had them made into teddy bears for all of her cousins. In the Fall 2008 issue of *For Those Who Give and Grieve*, Kris Herman poignantly wrote about making quilts for her children, and in the Winter issue, Leona Jewett shared her t-shirt and tie quilt made by her sister-in-law.

Another donor family member, Sandy Forstner, makes quilts in her dad’s memory. “My sister and I made 16 lap quilts for our dad’s grandchildren and great-grandchildren. In the center of every quilt we used one of his pockets embroidered with a tree stump, an axe and his nickname “Gaga” on it. In the

pocket of each quilt, we put a small item of Gaga’s that would mean something special to that particular child. Both the Herman and Forstner quilts were displayed at the recent Donor Family Ceremony in Wisconsin. When Sandy’s



Maggie Coolican

husband died recently, her sister had each family member write a memory about “Uncle Butch”, chose a photo that depicted the memory, and put them all in an album for Sandy and her two children.

There are so many ways that we can honor and remember our loved ones who have died. Quilts, teddy bears, a special garden, photos, poems and journaling can help us remember that our loved ones can always be with us in spirit, that they can continue to be a part of our lives, and that we do not have to “get over” our grief but can learn to live with it...sometimes having something tangible to hold on to can help.

Editor’s note: Visit www.donorfamily.org to view Patches of Love, the National Donor Family Quilt, learn about local quilts, and find other ideas for honoring a loved one.

TISSUE DONOR GIVES RENEWED LIFE *to Air Force Technical Sergeant*

By Melinda Lockard, Musculoskeletal Transplant Foundation

NOT ONLY DOES HE DO HIS PART TO SUPPORT HIS COUNTRY, but

Jeremy Starr is also doing his part to raise awareness of the impact of tissue donation. The decorated Air Force Technical Sergeant* represented the Musculoskeletal Transplant Foundation (MTF) on the Donate Life Float in the 2010 Tournament of Roses Parade in Pasadena, CA on New Year's Day.

Currently assigned to the 305th Aerial Port Squadron at McGuire Air Force Base in New Jersey, Starr was on active duty in Italy in 1999 when he was backed into a hole while playing football and snapped his knee. The result was a torn anterior cruciate ligament (ACL) and two meniscal tears.

"I can outrun most of the younger personnel in my unit. It is a great feeling and I owe it to my tissue donor."

His knee was repaired in 2001, but while stationed in Korea four years later, he re-injured his ACL and was told his military career was probably over. Then, in the spring of 2006, while stationed at Hickman Air Force Base in Hawaii, he met the surgeon who would save his career.

Lt. Col. Daniel White, MD told Jeremy that the injury had caused his left leg to bow, a condition which would prevent him from remaining in the Air Force, where he enjoyed a career leading over 60 military personnel daily.

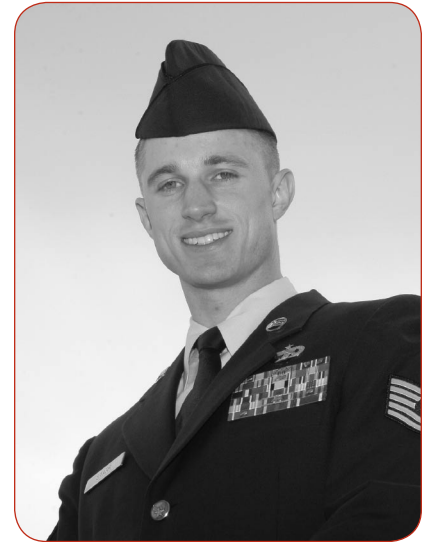
Dr. White performed a two-phase surgery. First, he corrected the bowing of the knee with a procedure called a tibial osteotomy. Then he used a donated tendon and meniscus allografts to repair Jeremy's ACL and to replace both meniscus. Extensive physical therapy followed both surgical procedures.

An exceptional athlete in track and field since high school, Jeremy was delighted when he ran his first mile recently in just 10 minutes.

"This has allowed me to continue my career in the military and my love for cross-country running," said Jeremy. "Even at 30 years old, I can outrun most of the younger personnel in my unit. It is a great

feeling and I owe it to my tissue donor, Dr. White and MTF."

Jeremy is the recipient of three Air Force Commendation Medals, five Air Force Achievement Medals, Combat Readiness Medal, three Good Conduct Medals, National Defense Medal, Kosovo Campaign Medal, Afghanistan Medal, War of Terrorism Expeditionary Medal, War on Terrorism Service Medal, Korea Defense Service Medal, NATO Medal, and numerous letters of appreciation.



Jeremy Starr

"MTF was privileged to have Technical Sergeant Starr represent us in the Tournament of Roses Parade," said Bruce Stroeve, MTF President and CEO. "Jeremy brings honor to his country as he serves in the military, and he brings distinction and respect to the field of transplantation as a tissue recipient. We are very proud of his accomplishments."

*Jeremy Starr participated in the Donate Life Rose Parade on an individual and voluntary basis. His voluntary participation does not constitute US Air Force or Department of Defense endorsement for, sponsorship of, or preferential treatment toward MTF or its affiliates.

LAST *ascent*

By Lia White, for her friend Paul Andrew McDaniel

Paul was an avid mountaineer with a deep passion for the rock and ice. At age 22, he passed away from a stroke. He gave the gift of life to four people through vital organ donations and helped 80 more with tissue donation. Paul's family has established the Paul Andrew McDaniel Foundation to raise awareness about strokes and organ donation and to get national community involvement on these issues.



Paul McDaniel

The news came to us, like an avalanche.
Abruptly and rapidly the words flowed like snow.
Down a surreal mountainside, reality mixed with the air and water.
Is he really gone?

From a distance we can see him walking towards us,
He was ready for his first climb of the day.
With his harness, chalk bag, and climbing shoes, he smiled.

As he started to climb up he took his passion with him,
Upward he continued, and we could see the sun beam off his carabiner.
He climbed so quickly he was almost out of our sight.

Maybe he had Mt. Denali or Mt. Everest on his mind,
So calmly and patiently he pushed on.

We could hardly see him at the top,
As the ropes vanished, so did his harness and shoes.
Still nothing stopped him from his final climb.

We keep expecting him to rappel back down to us,
But he does not.
He continues to climb.

One last look up and there he was,
He turned around and threw his chalk dust into the air.
As he turned back he then continued effortlessly without us,
Leaving us with the limitless love he gave when he was here.
We will miss him.





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



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.

2010

- April 24** Modesto, CA, California Transplant Donor Network, 2010 Honor & Remembrance Ceremony, Trace'e L. Harris, 209.613.7266
- 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 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.