

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.

Fall/Holiday 2008

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

Volume 17, Number 2

the Christmas QUILTS

By Kris Herman, Donor Wife

Christmas of 2007 was my first one without my husband Tim, who had passed away in June following a ruptured brain aneurysm. It was also our kids' first Christmas without their dad. Knowing it would be an extremely difficult "first" for all of us, and not really looking forward to Christmas, I kept trying to come up with a special gift idea for the kids—something that Tim could be part of, if only in spirit.

One day, I realized just how many t-shirts Tim used to have! Suddenly it became abundantly clear what to do for the kids for their special Christmas gift. There were enough t-shirts to make quilts for me and



for each of our four kids. The quilts would be the work of my hands, but mostly would be a gift of love from their dad.

I used twelve 15-inch squares in each quilt. On the back of each quilt I had a label embroidered with a message and an eagle, which has significant meaning for us.

Once I had all the quilt tops finished, my friend Mary Smith made it her top priority to get them all quilted for me.

Finally, Christmas Day arrived. There were lots of tears and hugs as the kids opened their gift bags and realized what was inside. They loved the quilts and I loved watching as they unfolded them and touched every square. The love they felt for their dad was almost tangible. It was very cathartic for me, and a definite labor of love that will be treasured by the kids forever.

I made a quilt for myself too. When I wrap up in it, looking at all the squares and feeling so cozy, I almost feel as if I'm wrapped in



Tim's arms. My favorite square has a pocket from a flannel shirt that had belonged to my dad, and after he passed away in 1991, Tim often wore that shirt.

I really miss our quiet moments together at the end of an ordinary day, but even more than that, I miss waking up next to Tim every morning to begin another ordinary day. Now, the memories of all those moments bring me comfort and a sense of peace that settles over me as I wrap up in the quilt. That is also when I think of Christopher Robin's words to Winnie the Pooh: "If there is ever a tomorrow when we're not together, promise me you'll always remember you are braver than you believe, stronger than you seem, and smarter than you think. But the most important thing is, even if we're apart, I'll always be with you."



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For Those Who Give and Grieve

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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

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WE FONDLY remember...



Dana Dal Santo
1948 – 2007



Lea Ann Hairston
January 10, 1979 –
November 24, 1996



Tim Ehmke
May 17, 1980 –
March 12, 2007



Gary Jones
April 16, 1946 –
May 25, 2007



KC Lani Alii Estabilio
May 1983 –
October 1998



Matthew Longsworth
May 4, 2002 –
March 24, 2007



DONATED SKIN

saves burn victim

On what should have been another lazy summer day in June 2006, the Pawling family was suddenly faced with a life or death situation.

Richard and his two siblings were riding dirt bikes when he and his sister Nicole collided. His gas tank exploded, splashing them both with burning gasoline. Nicole was burned on her arms, legs and face, while most of Richard's clothes were set ablaze.

"I was not really scared," said Richard. "I remember the pain and it was hard to breathe. I was wondering if I was going to die." Richard's brother Chad came to their aid, extinguishing the flames, and his mother Wendy rushed them to the burn center. Wendy recalls, "That is when we really got the eye opener. The doctor told us Nicole would be in for a month or two, but that Richard would be in for three to six months, *if he made it.*"



The Pawling family: (left to right) Kelly, Wendy, Richard, Nicole and Chad.

With third degree burns over 65 percent of his body, Richard's recovery was not assured. "I had a lot of infection issues," he said. "My kidneys shut down and I was on dialysis for a month. My liver was starting to shut down. If people had not donated skin, I believe my chances of survival would have been slim to none. I am glad that doctors have figured out how to use donated tissue to help heal burns, as I am sure this helped save my life."

Parents Kelly and Wendy are justifiably proud of the way their children overcame the difficulties resulting from the accident. Now two years and 26 surgeries after

his ordeal, Richard's life is getting back to normal. Making up for lost time, he was able to graduate high school with his class and begin college in the fall.

"Today, my life is back the way it was for the most part," said Richard. "I have a few issues, but I can usually work around them. I worked as a farm hand for the summer and this really helped to build back my muscle tone. In my spare time, I love to ride my motorcycle, swim and hang out with my friends."

Richard adds, "I try to tell people how important it is to donate organs and tissues. So many people aren't aware that skin can be donated. If I could send a message to the family who donated my tissue, I would say "Thanks! You helped save my life."

WE FONDLY *remember...*



Haley Eileen Nichols
December 11, 1989 – April 21, 2005



Nathaniel Eugene Piqué
March 14, 1974 – December 8, 2006



Virgil D. Petrik
August 12, 1931 – May 18, 1998



Ava Marie Schrodos
August 13, 2007 – August 14, 2007

RENEWED *grief*

By Lani Leary, PhD[©]

Grief is hard work. While we work physically, emotionally, mentally and spiritually to labor through our grief, we often come up against sudden, unexpected challenges that renew and add to our heartache. Grief work can feel close, raw and exhausting, but it can be even more difficult when we experience additional losses.

A sudden, temporary upsurge of grief, or “grief burst,” can happen for a number of reasons. Your reaction can come as a response to the anniversary of the death, a birthday or other meaningful holiday. A favorite season that has special memories may bring back a wave of longing and grief. Or, everyday, small things—smells, sights, sounds—can bring a surge of grief.

Unexpected grief can be triggered when you reach an age that is associated with the death. For example, when celebrating your birthday means living more years

than a sibling, you may feel guilt along with renewed grief. An experience such as a wedding or graduation, even if it comes decades after the loss, can trigger waves of grief response.

Additional, subsequent losses can exaggerate and compound your sense of being alone or left behind. Loss of a job, loss of a home, loss of a marriage, loss of mobility or health, the death of a pet or loss of a dream all remind you that you are vulnerable and suffer cumulative losses and deaths in many forms.

For example, when the pet of a deceased daughter dies, you lose more than just a beloved animal. You may experience that as losing an invisible connection to your child and a way to remember her. These additional losses can be devastating because of what they mean to us—not just the loss of the person or object, but also the secondary loss of the link to our loved one.

Each secondary loss requires its own set of grief reactions, from disbelief and anger to the exhaustion that comes from sleeplessness and sobbing. This loss and the renewed grief that you will feel is a long process, and not one event. No one can expect you to move through this at either their pace or quickly because it is “just” a day or a season or a song or a pet. These require an adjustment period. You have to respond to the conflict between the world that you had learned to live in, and one that cannot be.

Others may not understand your renewed grief. It may be helpful to ask your family and friends to respect the disorder and confusion of this renewed grief for you. You can ask them to be with you in a supportive, non-judgmental way so that you can feel all of the painful emotions that surround whatever is causing your grief. That will be your “way through grief.”

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DONOR FAMILY *voices* *Renewed Grief*

CAN YOU REMEMBER AN EVENT OR SITUATION THAT TRIGGERED YOUR GRIEF AGAIN UNEXPECTEDLY? Did friends or family members understand or were they baffled by your reaction? What helped you cope with it?

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."

This certainly explains my extreme reaction to the death of our old cat. I've never reacted that way to a death of a pet! Plus, my son Jeremy had named him... this cat had lived on after Jeremy died. It is beneficial for people to understand that these "renewed grief bursts" are normal. I don't expect others to understand; that takes way too much energy on my part. Instead, I'll turn to my online group of friends who understand.

— *Gabrielle Pierce*



I call them "Bolts from the Blue." I had always been a nagging mom about getting my son to brush his teeth, and after he died, I dissolved into tears by the toothbrush display in a store. A sweet elderly lady came to my rescue, put her arm around me and offered a tissue. I thanked her and started to explain, but she stopped me, saying that she just knew I needed a tissue. She patted me on the back and continued down the aisle. The tissue is in my box of keepsakes today and I will always remember her wordless understanding.

— *Diedra (Dee) Thompson*



My daughter and I were very close. There are many things that will trigger my grief again and again—trimming a Christmas tree because we used to do that together, finding her flip-flops in the attic, driving by her college apartment, going to her church when they have chosen to sing one of the songs used at her funeral mass.

— *Miguel A. DeLeon*



After four years, these moments continue to happen. I call them "Tyler moments." The first birthday after he had passed away was an especially hard "Tyler moment." It would have been his 20th birthday and I felt such a great amount of sadness. These emotions hit, but they usually don't last long. I have learned to expect them. Then, I think of the joy that Tyler brought to our lives and I go on.

— *Sheila Baxter*

I used to always know when my sons were home because I could see light under their doors. That's how I knew they were safe and I could sleep. One night after Brad's death in 2001, I saw light under his door. (My husband had been in the room earlier and forgot to turn the light off.) The grief hit me, like he died yesterday, and I cried the rest of the night. These things happen to all of us. Others have been through the same thing, survived and gotten stronger—and we will too.

— *Sandra Cooper*



Shortly before his third birthday, my sweet grandson gave the bravest gift of life. Recently, I saw a little statue of a frog dressed as a pilot and it was suddenly difficult for me to breathe. In an instant, it seemed the air had been sucked out of the room. This little statue seemed symbolic of the joy we shared. Fighting back the emotions rising inside me, the frog pilot came home with me. Somehow, this silly little frog brings great joy in remembering all we shared together.

— *Sheila Murphy*



When I hear our song, "Stardust," or any big band music, it brings tears again, as does smelling his shaving lotion or seeing men in plaid shirts like he used to wear. But with the help of God, I'll continue until we meet again.

— *Anne Wiener*



I lost my son to suicide in 2003. When I heard that suicide is one of leading causes of death in the nation, it made me feel like a "failure" again that I hadn't been able to stop it or see it coming. My biggest comfort is a collage that I put together of his life. The National Donor Family Council message boards are also comforting and make me know I'm not crazy for still having these feelings after five years.

— *Pat Cape*

TO MY DONOR'S *Family*

This is a long-overdue message of appreciation to you.

Eight years ago, I was 35 years old and the mother of a two-year-old daughter and a sixth-month-old son when my husband and I went out for an early morning tee time on Memorial Day.

The anticipation of a late spring morning at the golf course came to an abrupt halt when our car was hit by another. Our car was totaled and we were lucky to be alive. I suffered a complex fracture of my right leg and needed to have surgery in order

to walk without a limp and pain. I was blessed to receive a gift of bone tissue to bridge the gap in my fractured leg. I received this gift from you and your loved one.

I live in the Twin Cities area and am now in my mid 40s. I work full-time and am happily married to my husband. Our two children are now 10 and 8, healthy and happy. I thank you for the selfless gift you gave at the time that your loved one died. I know nothing about you...except

that you made a powerful decision when you said "yes" to donation at what I can only imagine was a very difficult time in your lives.

Please know that I honor the memory of your loved one, my donor. My life is better because of your gift. My family's lives are better because of your gift. The world is better because of people like you. Thank you so very much.

With appreciation and prayers,
Brenda

more donor family voices continued from page 5

One day after work, I passed a woman at the end of a driveway holding a toddler. I knew they were waiting for her husband to come home. My wife used to do that too. I immediately started to cry. The vision still bothers me, months later. My friends understood, but the pain is still very real and deep. The love that my wife had for me and our children helps me cope, along with my knowledge that she is watching over us. However, I still cry every time I pass that driveway.

— *Jim Baldinger*

My grief is exacerbated with each and every milestone that my nephew reaches in life. His mom, my sister, died five years ago and it feels like the "elephant on my chest" every time he moves up a grade, gets a report card, plays an instrument, falls down, learns to skateboard, swim or even has a new friend. I haven't found the right coping mechanism just yet, but I'm working on it. Still coping...

— *Kathleen Hatala*

I went to the beach, which was my husband's favorite place to go. It triggered a response that I did not expect—depression, isolation, loneliness. I thought I was going crazy and no one seemed to understand. These questions could not have come at a better time... when I read this it was like, "Ok, you are not alone; you are not going crazy."

— *Barbara Allen*

Stress! One thing I've learned in the five years since my daughter passed away is that if I let my life get too busy and things start to stress me out, then I relapse into my grief. To survive on a day-to-day basis since her loss, I have learned to compartmentalize my emotions and life. When one compartment starts to overflow, it causes my "loss compartment" to fill up even fuller and I stop coping with everything else in my life and start grieving all over again. I've just learned to say "no" more often and keep my personal and business life as uncluttered as possible.

— *Jennifer Brown*

My niece Carmen's high school graduation triggered thoughts of my father (her "PopPop") who passed away nearly thirteen years ago. As I watched my niece walk across the stage to pick up her high school diploma, all these memories came flooding over me. My father played an integral part of those early days of her life. Dad would be so, so proud of Carmen...and I know his spirit is beaming with pride.

— *Tina Pierce*

It's been almost 13 years since I lost my 16-year-old daughter Tiffany. When I found her bathrobe, I had a sudden memory of her standing in that robe with a towel around her head. The shock sent me into a flood of tears and the old "punched in the stomach" feeling returned. I coped by reminding myself that Tiffany doesn't want me to be sad, and she was a recycler who would have told me to get rid of that ratty old bathrobe. I keep her in my heart.

— *Billie Lomonaco*

PEOPLE LIKE US

By Rose D'Acquisto, Donor Wife

It's hard to believe that it's been 11 years since my husband Tony died and I became a donor wife.

In all these years, I still haven't met anyone who's had to make the decision to donate their loved one's organs or tissues—at least not in my everyday life. But as a member and volunteer of the National Kidney Foundation (NKF) and the National Donor Family Council (NDFC), I've had the opportunity to meet hundreds of other people like me: other donor wives, donor husbands, donor parents, donor siblings, children of donors and donor grandparents.

That is what I appreciate about the NKF's People Like Us grassroots advocacy program.

It empowers people like you and me, our families and our friends, to become advocates on issues that impact donor families, transplant recipients and kidney patients.

This year, on March 13, I was invited to Washington, D.C., to participate in a *People Like Us* event on World Kidney Day. I was one of a group of 25 advocates made up of kidney patients, transplant recipients and donor family members who went to Capitol Hill to meet with our Members of Congress. As each of us met with our Senators and Representatives, we shared our stories. And, we asked for their support—namely, to increase funding for a Centers for Disease Control (CDC) pilot program that would provide early testing for chronic kidney disease (CKD).

So why, as a donor wife, does a CDC pilot program for early detection of kidney disease matter to me? It's estimated that 26 million adults in our country now have CKD and another 20 million more are at increased risk. There's a strong possibility that one of our friends, co-workers or even a family member already has kidney disease—or is at high risk with high blood pressure and/or diabetes.



CKD, when detected early, is treatable. As much as I believe in organ donation, I also believe that we should be doing everything we can to educate people so they won't end up needing dialysis or a kidney transplant. This is the first program by the CDC to focus on early detection of kidney disease, rather than end-stage kidney failure.

Another big issue has been pre-dialysis education. A six-week program for kidney patients will provide valuable information on nutrition, dialysis options and more. This legislation was finally enacted in July 2008, representing a huge victory for NKF and its *People Like Us* advocates, thousands of whom had visited, e-mailed and called their representatives.

When patients are engaged in their health care, it can mean better outcomes. As a donor family member, it's important to me that everything possible is done to ensure that patients have good outcomes. As donor families, our hope is that our loved ones' recipients cherish the second chance at life they've been given.

Finally, *People Like Us* advocates are working on legislation for immunosuppressive drug coverage. Medicare currently only provides drug coverage for 36 months following most kidney transplants. If a recipient isn't able to pay for anti-rejection drugs after that time, they may lose the transplant. We need to ask our legislators to extend coverage for the life of the transplant so that our loved one's gift of life is protected from possible failure.

What I've learned in these years of being involved with the NDFC is that donor families, transplant recipients and people with CKD are all connected—we've all been touched by kidney disease, organ donation and transplantation. By taking a stand together, we have a stronger voice. Through *People Like Us* and its electronic advocacy tool, the *Take Action Network*, we can make a difference.

For more information about *People Like Us* and the *Take Action Network*, please visit www.nkfpeoplelikeus.org, e-mail us at peoplelikeus@kidney.org or call 800.622.9010.



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.

2008

October 10 Houston, TX, The Living Bank, *Texas Stars for Life*, Lori Roy, 713.961.9431

October 12 Maumee, OH, Life Connection of Ohio, *Donor Recognition Program*, Tracy Kropp, 419.893.1618

2009

April 4 Modesto, CA, California Transplant Donor Network, *Kidney Gift of Life Ball*, Trace'e L. Harris, 209.550.0188

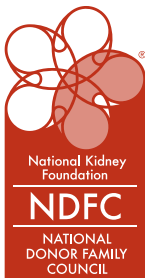
One panel of the National Donor Family Quilt is displayed year-round at the National Donor Memorial in Richmond, VA. (This Quilt panel will sometimes be moved for display at other national events.) For more information, contact Marilyn Jones at 800.622.9010.

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.

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National Donor Family Council
National Kidney Foundation
30 East 33rd Street
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