



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.

Holiday 2010

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

Volume 19, Number 1

CORNEA TRANSPLANTS HELPED ME *fulfill my dreams of nursing*

By Pelavi Mandalia, RN, BSN, Double Cornea Recipient

IN 1998, I WAS DIAGNOSED WITH KERATOCONUS, a degenerative disorder of the eye that causes the cornea to bulge outward.

I tried to wear contacts to treat this disease, but that approach proved unsuccessful. Twice the contacts popped out of my eyes, once when I was taking a math exam and the other time when I was driving. The contacts were extremely painful, and it sometimes took me over an hour to put them in my eyes.

While wearing the contacts, my eyes were extremely sensitive to light, and I experienced headaches and eye pain. Without the contacts, I was legally blind. My doctor recommended cornea transplants.

I received my left cornea in 1999 and my right cornea in 2001. I feel so blessed and honored to have received my bilateral cornea transplants. They were truly a gift. Now, the vision in my right eye is 20/20 without correction, and my left eye is 20/20 with correction. The transplants allowed me to complete the nursing program



Pelavi Mandalia, RN, BSN

at Seattle University. After I graduated with a Bachelor of Science in Nursing, I became a hospice nurse. In my present position, I have mentored many other nurses. I am halfway through a master's degree in nursing, and should have it completed soon.

Without the transplants, I could not have completed my education and fulfilled my lifelong dream of being a nurse. The transplants gave me an opportunity to see things

more clearly, literally and spiritually. This was, for me, a miracle. Because I was given so much, I feel the need to give something back. By sharing my story, I hope that I can inspire others to seek or provide help in facilitating sight-restoring—and life-changing—transplants.

One of my biggest regrets is not thanking the donor families right away. After reflection, this was probably because I had to go through my own grieving process first. Now, I feel that I could not have thanked the families enough, and I am anxious to rectify the omission. I feel my donors are with me in spirit, and that I am somehow connected to the families through my donors, even though I do not know them.

The families who choose to donate organs or tissues give to someone they do not even know. I can imagine how tragic and devastating the loss of a loved one can be, and such selfless generosity during a period of immense grief is truly humbling and can never be taken for granted.

For Those Who Give and Grieve is supported by

MTF Musculoskeletal
Transplant
Foundation
*Changing Lives
Through Tissue Donation*

ANDY *bear*

By Carolyn and David Wilks, Donor Parents

OUR SON ANDY WAS AN AUTISTIC 24-YEAR-OLD YOUNG MAN with many challenges in his life. Despite these challenges, he was blessed with an ability to reach out and touch many lives with his big smile and special qualities. After meeting Andy, he was someone you couldn't forget. He taught us to take notice of the important things in life. Andy died tragically in March of 2004 in an accident, but his spirit remains with everyone who knew him.

When Andy was 12 years old, his brother Jon joined the Air Force and left home for the first time. Jon and Andy had a close relationship and Jon was concerned that his leaving would be detrimental to Andy. The night before Jon left, he gave Andy a big brown bear that had belonged to him. He asked Andy to take care of his bear while he was gone and the bear would be his friend. From that time on the bear was known as "Jon Bear."



Andy never separated from Jon Bear; he couldn't go to sleep without his bear. The bear became his comfort and security; a real part of his brother he could hold on to. Jon Bear was used as a part of Andy's therapy programs at Johns Hopkins Hospital, went on all vacations and became a very important part of Andy's life. When Andy died, Jon Bear remained by his side. Anyone who knew Andy knew the significance of the bear. That simple act of brotherly love had brought comfort, joy, and security to a young man for many years.

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

Rose D'Acquisto
St. Paul, MN

ASSISTANT EDITOR

Douglas G. Harrell
Wilmington, DE

DONOR FAMILY EDITORS

Jan Frye-Hill
Winston Salem, NC
Judy Grogan
Auburn, WA
Julie Schlueter
Winsted, MN
Donna Warren
Palo Alto, CA

TRANSPLANT RECIPIENT EDITORS

Jack Fassnacht, Esq.
Chicago, IL
Laura Weber
San Jose, CA

ORGANIZATIONAL LIAISONS

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

PROFESSIONAL EDITORS

Charles Corr, PhD
St. Pete Beach, FL
Melinda Lockard
St. Paul, MN
Elizabeth McNamara
Orchard Park, NY

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

EDITORIAL DIRECTOR: Jennifer Martin

DESIGN DIRECTOR: Oumaya Abi Saab

In memory of Andy and his bear, family and friends have created a project called "Andy Bear." We distribute "Andy Bears" to individuals in need of hope, comfort, security, love and friendship. We make distributions to police and sheriffs' departments, group homes, nursing homes, fire and rescue squads, social services, hospitals, shelters, churches and individuals in need. We donated a large number of teddy bears to our county sheriff's office. The bears ride with deputies so that they will have something comforting to give to a distraught child.



bbb.org/charity

WE FONDLY *remember...*



Jeremy (Gomer)
Scott Ahlhelm
July 13, 1982 –
August 25, 2001



Ronald Paul Dillon
April 28, 1949 –
February 9, 2009



Ashton Marie
Goodenberger
February 16, 1989 –
June 5, 2005



Raymond "Mickey"
Bickel
November 23, 1942 –
May 7, 2008



Frank Duffy
November 15, 1951 –
August 26, 2008



Steve J. Green
October 24, 1965 –
May 13, 2009



Jennifer Dawn
Bradow
September 24, 1971 –
May 25, 1993



Mahlon George
Fisher
December 5, 1939 –
April 23, 2009



Kenneth Ray Hayes
January 4, 1942 –
March 18, 2009



Rodney Alan
Breitigam
March 30, 1963 –
May 1, 2000



Stanley O. Forker
March 29, 1951 –
June 20, 2007



Brett Allen Hern
August 10, 1982 –
November 9, 2000



Bradley Michael
Burns
February 6, 1978 –
June 9, 2002



Jessica Sue
Freiburghaus
March 31, 1982 –
April 3, 2009



Juan Pedro
Hernandez
June 24, 1986 –
May 4, 2008



Jacob Louis Daily
February 20, 1985 –
March 18, 2009



Makwaata Jane't
Frierson
July 29, 1982 –
November 26, 2008



Brian C. Hill
October 5, 1983 –
July 25, 2007



Kaitlyn Elizabeth
Dalton
December 8, 1988 –
August 24, 2008



Seth Steven Galloway
December 5, 1960 –
September 15, 2008



Lucy Hoddinott
September 10, 1936 –
June 18, 2008



Jill Dierckman
July 13, 1981 –
September 30, 2003



Donald E. Garland, Sr.
April 12, 1932 –
March 4, 2003



Cecil Holmes
February 3, 1943 –
April 9, 2009

continued on p. 7

DONOR FAMILY *voices* *holiday remembrance*

YOU MAY FIND, AS MANY FAMILIES DO, that the holidays are times when your feelings of grief and loss are strongest. To cope with this, it can be comforting to find a way to include honoring your loved one's memory in your holiday plans. If you plan to honor your loved one this holiday season, please share with us up to three ways that you will do so.

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



My husband Bob died on Halloween so that has always been a time to reflect and remember. There is no special ritual that I carry out, but I take time to—well, take time. Often, this means I will go away for the weekend with one of his family members or a loved one, and enjoy the company of a special person. And often, those trips bring surprises of their own that make us smile—a dog costume parade we came upon one year, a hike where we saw a moose. Being present and deliberate with myself and my surroundings during that time has become the ritual.

—Allison Hepler



My daughter, Tania, has been gone now almost nine years. A few years ago, I asked family and friends to write a letter recalling their favorite memories of Tania. I put these in a Christmas stocking. I hang this stocking every year with all the others, and on Christmas night, when all is quiet, I sit and read them. They bring a mixture of smiles and tears but, at the same time, sooth my heart a bit. I look forward to the day my grandchildren, Tania's niece and nephew, can read them and learn a little more about their aunt.

—Pam Legault



Our son Anand loved lights, so there is always a lighted Christmas tree with his name written on an ornament. At the gravesite, we place lights and flowers and I go to parties with one of his shirts and use his favorite cologne. His motto was "have fun" so we enjoy the lights as he was the light of our lives.

—Tribhawan Persaud

You are correct, the holiday season does magnify my grief. What I do this time of year is donate food for the needy in Anthony's memory. Anthony was killed by a drunk driver when he was 18 years young. We hold a fundraiser in his memory in the spring and the money that is raised is donated to some local organizations and charities. Throughout the year, I collect candles and on Christmas Eve my children and I go to the cemetery and put a candle on every stone around Anthony. There are over 400 stones in the section where Anthony is. When all the candles are lit we stand back and it is very emotional, yet beautiful. I think of my son every day...every minute of every day, yet the placing of the candles on the stones is what helps me to remember the reason for the season and that one day I will be with him again.

—Stacey Garrison



Each year since our son passed away five years ago and became a donor, I make a monetary donation to our local soup kitchen in his name. I also take whatever money I would have spent on him for Christmas if he were still alive, and purchase toys and donate them to a local foundation that delivers them to children in local hospitals during the holiday season. Last year I took my son's daughter, age nine, with me to do the shopping and it really made us both feel better.

—Susan Wareham

I DON'T KNOW WHY

By Iris M. Bolton

Reprinted with permission from her book "My Son...My Son"

I don't know why.
I'll never know why.
I don't have to know why.
I don't like it.
I don't have to like it.
What I do have to do is make a choice about my living.
What I do want to do is accept it and go on living.
The choice is mine.
I can go on living, valuing every moment
in a way I never did before,

or I can be destroyed by it and,
in turn, destroy others.
I thought I was immortal.
That my family and my children were also.
That tragedy happened only to others.
But I know now that life is tenuous and valuable.
So I am choosing to go on living,
making the most of the time I have,
valuing my family and friends
in a way never possible before.

My "TOP TEN"

By Debby Ramsey, Kidney Recipient

MY "GIFT OF LIFE" WAS GIVEN TO ME ON DECEMBER 11, 1984. I celebrated my 29th birthday in the hospital and came home on Christmas Eve.

In the 25 years since then, I have tried to take care of my kidney in honor of my donor, and live life to the very fullest. Here is my "Top Ten" list of things I've been able to do since my transplant:

1. Raised my son from kindergarten through college. He was four years old when I received my kidney transplant. We celebrated his 30th birthday in April 2010.
2. Became a foster parent and cared for 12 children.
3. Adopted twins and celebrated their 20th birthdays in July. One was at bootcamp in the U.S. Army at the time!
4. Coached high school gymnastics.
5. Directed a Children's Choir for 25 years.
6. Participated in the NKF U.S. Transplant Games in 2004, 2006, 2008 and 2010. Winner of two Silver Medals! Go Team Illinois! I competed in swimming at the 2010 Games.

7. Took over the family feed business and for the past 11 years have been successfully managing the store my grandfather started in 1924. It is currently the oldest operating business in our town, where my mom, my son and I carry on the legacy.
8. Had my story of taking over the business published in the *Chicken Soup for the Soul* series.
9. I also have enough energy, thanks to my donor and donor family, to have a second job taking care of four mentally handicapped ladies in a group home, four nights a week.
10. Last, but not least, I have volunteered to speak to different groups and school-age kids about organ donation and the need to register to be an organ and tissue donor. I'd love to do more of this in the future!

Of course, there are so many other things that I am thankful for over these past 25 years, but those are a few highlights.

With the holidays coming up, I am especially thankful to my unknown donor and that person's loved ones for allowing me to celebrate with my family. This is possible only because of their generosity in their time of tragedy. Their spirit of love allowed me the freedom from dialysis and other effects of chronic kidney disease. To them, I am forever grateful and honored to have received their gift.

CONTINUING *bonds and rituals*

By Charles A. Corr, PhD

ONCE UPON A TIME, BEREAVED PERSONS were often advised to “get through” their grief by “forgetting” the person who died. We know now that people do not just “forget” someone who has played an important role in their lives. On the contrary, most bereaved persons find comfort and solace in those continuing bonds.

Of course, relationships with individuals who have died are inevitably changed by the facts of death. When our loved ones die, we need to restructure our relationships with them. They change from being a physical presence in our lives to occupying a new and different place in our hearts and minds.

Rituals can contribute to restructuring these relationships in healthy and positive ways. Some rituals are personal and private, like meditation practices, but most rituals involve public activities and various forms of open behavior. All rituals seek to bring us together physically or psychologically. They provide guidance, comfort and meaning, especially in difficult times.

When a loved one dies, familiar rituals can offer solace and security in a time of confusion and pain. On many occasions, however, we need to adapt old rituals to our new situation or even to create new rituals to honor those who have died. The important thing for

individuals, families, and communities is to find or develop rituals that affirm the lives and legacies of their loved ones, express the joy and happiness that we shared together, help to maintain new, ongoing connections with the deceased, and bring some measure of consolation to those who are bereaved. (For ideas on how to honor a loved one, see the “Donor Family Voices” section in this issue.)



All rituals seek to bring us together physically or psychologically. They provide guidance, comfort and meaning, especially in difficult times.



GARY'S shirts

by Joann D. Goecks

HERE'S ANOTHER IDEA for donor families who want to use a loved one's clothing in a special way.

We had pillows made for our granddaughters from my late husband Gary's shirts. They were very special to each girl and really brought back loving memories of Gary wearing them. I hope someone else might be able to use this idea. It really helped us.

WE FONDLY *remember...* (continued from p. 5)



Leonard S. Jarmosco
October 17, 1935 – September 6, 2008



Gregory O. Rios
September 7, 1982 – July 17, 2000



Paul Randall McCorkle
November 8, 1955 – October 29, 2008



Humberto R. Ruano
October 6, 1936 – November 19, 2008



Michael Keith McLaughlin
April 22, 2009 – June 17, 2009



Catherine "Catie" Lincy Sned
and Addison "Addie" Quinn Sned
Catie: February 23, 2009 – March 4, 2009
Addie: February 23, 2009 – April 11, 2009



Ryan Clark Harlow Mitchell
July 17, 1988 – June 11, 2000



William L. Springer
March 19, 1933 – June 4, 2004



John Ellard Nichols
January 14, 1989 – February 23, 2006



David Thomson
March 21, 1990 – November 6, 2005



Marcella Nilges
August 22, 1948 – August 29, 2007



Michael Paul Thompson
January 18, 1962 – July 3, 2008



Michael Andrew Ortiz
June 15, 1985 – June 8, 2009



Walter Vance, Jr.
February 7, 1971 – November 2, 2002



Tiffany Lynne Richman
May 17, 1987 – April 16, 2004



Trevon Lonte' Williams
November 24, 1990 – May 19, 2009

Return Service Requested

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



The **Quilt** on Tour

Since 1995, over 2,000 families have created Quilt squares for "Patches of Love," the National Donor Family Quilt. The Quilt is an ever-growing memorial created by donor families in honor of our loved ones.

The Quilt travels to events throughout the world to pay special tribute to our loved ones while raising awareness about donation. Donor families, professionals, and organizations may reserve one or two panels of the Quilt for display. There is a small fee to cover shipping and maintenance of the Quilt.

Donor families can request their loved one's Quilt panel for display at local events, special occasions or holidays. Some families reserve a Quilt panel for family reunions, memorial services, weddings, birthdays or anniversaries.

Where Can the Quilt Be Displayed?

Families and organizations can display the Quilt almost anywhere, at both public and private events including:

- Local events honoring donors, such as donor recognition ceremonies, memorial events, dinners, brunches, picnics
- Family gatherings or milestone events, such as reunions, memorial services, weddings, anniversaries, birthdays or holidays
- Donor awareness activities (April is National Donate Life Month, but the Quilt can be reserved for a donor awareness campaign at any other time.)
- Educational workshops, support groups
- Shopping malls, holiday gift fairs
- Universities, schools, lecture halls, libraries
- Places of employment
- Places of worship: local churches, synagogues, mosques or other places
- Arts and crafts shows, art classes, quilt-making workshops
- Health fairs, health screenings, hospitals, nursing homes

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 to 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.