



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.

ONE STEP *at a time*

By Rose D'Acquisto, Donor Wife

In the weeks and months that followed my husband's death, my life felt like a record playing on slow speed. Exhausted from grief, I spiritlessly did what needed to be done, too wiped out to do anything more.

I felt far removed from the woman who used to have boundless energy for dancing, reading, singing, shopping, cooking and laughing with friends and family.

Two years later, I was desperately tired of feeling tired all the time. A friend gave me the number of

suck it up and get back in the gym, which made me want to crawl back into bed just thinking about it. Instead, I was told the best thing I could do for myself was to start walking.

At first, I could barely walk to the end of my block. Slowly, I worked my way up to two-, four- and six-block walks. Early mornings were my favorite time of day. Quiet and still, I could take in the day at my own pace. Sometimes I cried, letting the tears flow freely, as there was no one around to tell me not to. Other days, I stopped to listen to birds as



Rose D'Acquisto

That fateful day I walked out of the hospital a widow, I remember thinking how strange the world seemed. The sky never looked so blue, the grass never so green. I saw life, in all its vibrant, shocking, technicolor glory.

On my walks today, I appreciate the way the sun warms my

“Sometimes I cried, letting the tears flow freely, as there was no one around to tell me not to. Other days, I stopped to listen to birds as they trilled brightly, or to smell the dizzying perfume of spring lilacs.”

a fitness instructor who could suggest ways to get my energy back. I was afraid I'd be told to

they trilled brightly, or to smell the dizzying perfume of spring lilacs. And slowly, one step at a time, I could feel myself growing stronger.

face, how brilliantly blue the sky is and how life—especially my own—has never seemed so precious.

WE FONDLY remember...



Samantha Bender
September 8, 1987 – July 10, 2006



Heather Nicole Coker
September 1, 1979 – September 5, 2002



Nathan Daniel Davidson
October 21, 1987 – June 4, 2008



Linda J. Eleiott
February 27, 1955 – June 11, 2007



Bryan William Haber
October 8, 1965 – November 3, 1997



Rex V. Hancock
December 28, 1953 – July 25, 2005

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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:

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30 East 33rd Street
New York, NY 10016

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.

TISSUE RECIPIENT *is off to the races*

By Douglas Harrell

After 16 years of impaired mobility, Glenn Menarde's life has moved from a canter to a gallop. Glenn is the starter at Delaware Park Racetrack, but before that he was responsible for getting the horses into the gate. "Back in 1993, one of the horses threw a fit and tore my knee apart, including ripping the anterior cruciate ligament (ACL). I should have had it fixed at the time, but I just nursed it along. Finally, this year, walking back and forth between the short and long races, under the rails and over the turf course, my knee began to swell and a few times it gave out on me. It got to the point that I had to do something."



Eagles fan Glenn Menarde ices his knee while watching the playoff game with partner Joe'Lyn Rigione.

Glenn went to an orthopedic surgeon. One option was to have three pieces of his hamstring removed and fashioned into a replacement ligament. Glenn was taken off-guard by his other option—using donated tissue.

"I was familiar with organ donation," he said. "In fact, a fellow I work with just received a double lung transplant and he's doing great, but I was shocked to learn that the tissue I needed was available from a tissue bank."

His partner, Joe'Lyn Rigione, was also unfamiliar with tissue donation. "It's just unbelievable," she said. "You hear about organ donors and it's a great thing, but who ever thought of donating to help someone who needed an ACL? It's really neat. It adds so much to somebody else's life."

Glenn doesn't have any information about his donor, but plans to write the family. "I'm still amazed that someone was kind enough to donate," said Glenn. Joe'Lyn added, "He was limping all the time. His quality of life was totally deteriorating and he couldn't do anything he wanted to do. To think that families donate tissue to enable other people to get back to normal living is amazing. It's incredible."

WE FONDLY remember... (cont'd)



*Brandon Keith Long
October 22, 1987 – March 12, 2007*



*Tribhawan Gyananand Persaud
April 17, 1984 – October 2, 2005*



*Diane Ostrander
August 4, 1961 – May 2, 1998*



*Kevin Michael Snowdale
September 18, 1975 –
January 25, 2006*



*Matthew Pelkey
February 28, 1970 – March 17, 1999*



*Katherine Ann Vanover
May 28, 1986 – July 11, 1988*

Who were you?

By Tami Gardner

In September 2007, Joe Gardner received a heart transplant. He said, "This experience has changed my life completely and given me back all the dreams that I felt I had to give up. I am back in college now and spending all my free time with my daughter. God bless my donor and his family for caring enough to give to another. They will always be in my heart."

After the transplant, Tami, Joe's sister, wrote this poem "in loving memory and appreciation to the donor."

Were you someone's son?
Were you their precious and only boy
Who filled his mother's heart
With laughter and with joy,
Were you someone's big brother?
Were you the first to do everything?
Did you pave the way?
For the little sisters who watched all you did
And knew you'd be great someday.
Were you someone's father?
Were you the daddy who looked down
Into those beautiful eyes of blue?
On the day she was born did you look at your
little girl and marvel at how much she looked
like you?
Were you someone's friend?
Did everyone who knew you come to love you in
a special way?
Did you bring sunshine into every room,
Even on a rainy day?
Did you make a difference?
Because you were in it, was the world a
better place?
Does just the thought of you bring a smile to
every face?
I know your mother must be hurting and missing
her baby boy.
But I wanted to say thank you

For bringing back my
mother's joy.
If you had a brother or
sister, I know they must
be sad.
But I want to say thank you,
For making this sister's heart
so glad.
If you were a father and you are looking down
from heaven, watching your child grow,
I want you to look over and see the child,
Who needed her dad more than you'll ever know.
I am sure your friends are missing you
And treasure the memories of when you
were here.
Those memories are the precious times
They will always hold dear.
You have given the gift of life.
You have given a brand new start.
Part of you still lives on
With every precious beat of my brother's heart.
I don't know who you are or what you dreamed
to be.
But when you gave the gift of your heart,
You gave us back our family.
Thank you!



Joe Gardner, heart recipient, with his sister Tami.

DONOR FAMILY *voices* *Movies minus the drama*

A bowl of popcorn, a cozy chair and you're all set for a movie night at home. Except for one thing...finding a "safe" movie. We're making a list of DFF-rated movies (Donor Family Friendly). Gentle, charming and funny movies that can provide heavy hearts with a welcome escape.

Here are a few favorites shared by *FTWGG* readers and editors. If you have movies to add, we'd love to hear from you! Please visit www.donorfamilyforums.org to read the full responses or share your own ideas. To join the e-mail list, write to donorfamily@kidney.org and ask to "Join the NDFC e-mail list."

- Silent film comedies (Buster Keaton, Harold Lloyd)
- Laurel and Hardy and Marx Brothers movies
- Bringing Up Baby
- My Fair Lady
- Singin' in the Rain
- The Wizard of Oz
- The Court Jester
- Oh God!
- Lilies of the Field
- Anne of Green Gables
- Danny Deckchair
- Mary Poppins
- The Miracle Worker
- The Bishop's Wife
- Father Goose
- Flipper
- High School Musical
- The Sound of Music
- You've Got Mail
- Victor, Victoria
- The Water Horse: Legend of the Deep
- Ratatouille
- Alvin and the Chipmunks
- Cars
- Ice Age
- The Kid
- The Emperor's New Groove
- Bad News Bears
- Rudy
- Herbie: Fully Loaded
- Kentucky
- Spencer's Mountain
- Field of Dreams
- August Rush
- Facing the Giants
- The Other Sister

THE GIFT THAT HEALS: *stories of hope, renewal and transformation through organ and tissue donation*

Author Reg Green

Book review by Jim Gleason, Heart Recipient

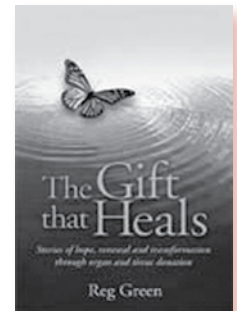
In 1994, 7-year-old Nicholas Green died tragically while his family was on vacation in Italy, and his family agreed to organ donation. The story was widely covered and donation rates in Italy went up dramatically overnight. From the thousands of stories Reg has since heard from others touched by donation and transplantation, he has selected 42 of the very best for this book.

In *Chicken Soup for the Soul* style, the book offers personal stories about organ and tissue donation from donor families, living donors, recipients, transplant coordinators and doctors. It includes the stories of an organ transport pilot struggling to get through the flight ban in the immediate aftermath of 9/11; liver recipient and Olympic medal winning snowboarder Chris

Klug; basketball great Sean Elliot; a pastor who received a heart from a parishioner; and twins who overcame cystic fibrosis through lung transplants.

The stories from recipients share a common theme, elegantly expressed by one recipient: "This was one of the best things that ever happened to me. It made me realize that everything in life is important. I don't care whether it's rain or sunshine. I enjoy every minute of the day."

An audiobook version is also available.



TELL *your story*

By Douglas Harrell, Donor Husband

Ever since my first wife died, I have wanted to share her story with others. Many times I've imagined myself in front of a classroom teaching about donation. On occasion, I have even tried to write a presentation, but I never got very far. There was a lot about donation I didn't know. I didn't feel ready for public speaking.

One day I was checking the Gift of Life Donor Program Web site and saw they were offering volunteer speaker training. I jumped at the opportunity to learn from experts.

Throughout the training, we received helpful tips about the type of information to include in a presentation. I learned the most, however, from the stories we heard from speakers such as Kay, who told us about a free spirit named Rusty. In his short life, Rusty was a Marine, rode

into early retirement. He became very weak and suffered frequent bouts of total disorientation. "One day, I didn't even recognize my own children." Then, Brock showed us a picture of a handsome young man named Steve Scholz. When Steve was fatally injured in a traffic accident, his family donated the liver that saved Brock's life. Brock is now back working for the security department of a bank and enjoying life with his wife and three children.

"The most powerful arguments in favor of donation are the stories of hope, fear, loss and a love greater than loss—stories that are told by donor families, living donors and recipients."

bulls in the rodeo and even worked briefly in the circus before returning to college full-time on the GI Bill. Sadly, his plans were cut short when he became the victim of a brutal assault. "I know this," Kay said softly, "because I am Rusty's mother." Following her son's expressed wish, Kay donated Rusty's organs and tissue so other families would not have to walk in her shoes.

Another speaker, Brock, related how liver failure forced him

What I realized from the power of these presentations is that speaking about donation is not about medical science or statistics. It's not about how or why. It's about *who*. The most powerful arguments in favor of donation are the stories of hope, fear, loss and a love greater than loss—stories that are told by donor families, living donors and recipients. We are each on a journey that is entirely our own and others can learn from us. Tell them your story.

Speak Out

Practice a one-minute "elevator" speech about your donation experience that you can deliver anytime the opportunity presents itself, even if it is to an audience of one.

Get Involved

The best place to start is your local donor organization. If you need help locating this organization, ask the National Donor Family Council for assistance (e-mail donorfamily@kidney.org or call 800.622.9010 and ask for "Donor Family Services"). Check their Web site and call their volunteer coordinator to see what resources they have. Some offer training seminars for speakers, but don't feel that speaking is the only way you can help. They may also need people to staff booths, sew quilt squares, make phone calls and perform many other activities.

Meet Other Donor Families

Check with your donor organization about local events. You may also be interested in attending the federal government's National Donor Recognition Ceremony and Workshop to be held on July 17–19, 2009, in Washington, D.C. To receive registration materials, please e-mail your request to donorfamily@kidney.org or call the National Donor Family Council at 800.622.9010. **The registration deadline is May 15, 2009.**

Join NKF's People Like Us

People Like Us is a growing movement to empower, educate and encourage people to become effective advocates on public policy and other issues related to their health, organ donation and transplantation. For more information, visit www.nkfpeoplelikeus.org and www.kidney.org/takeaction

DONOR FAMILY MEMBERS—

the ultimate advocates for donation

By Faith Cortright

In my position as Volunteer Coordinator with the Gift of Life Donor Program, I've been privileged to work with an amazing group of individuals who are passionate and energetic in their promotion of organ and tissue donation.

Over time, I've seen an increase in donor family members looking to share their experience. Often, their

opportunity for the speakers to share the legacy of their loved one and to find their own strength and purpose. No story is the same and every story is important, putting a name and a face on donation.

Donor family members also provide immeasurable support by assisting at community health fairs and by playing an active role in our various volunteer groups. One

through recognition ceremonies and other special programs throughout the year.

Whether distributing t-shirts at our annual Dash for Organ Donor Awareness, stuffing invitations for an upcoming event or simply providing support and friendship for those more recently bereaved, the efforts of these individuals are examples of a strength that touches the lives of everyone affected by donation and transplantation. There are many opportunities to share whatever gifts, skills or time you may have to offer.

Donor family members inspire with their tender words and encourage others to make the decision to help others in their greatest time of need.

stories aren't without a few tears from members of the audience. These engagements provide an

such group, Hearts of Gold, is a donor family support/action group. They support new donor families

Faith Cortright is the volunteer coordinator for the Gift of Life Donor Program in Philadelphia, Pennsylvania.

DEAR EDITOR OF

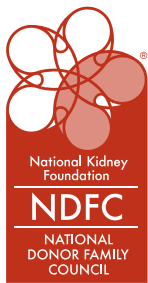
For Those Who Give and Grieve,



The story of the t-shirt quilts ("The Christmas Quilts" by Kris Herman, Fall/Holiday 2008 issue) was wonderful and I am sure it touched many hearts.

I wanted to share with you another idea for keeping "wrapped in your loved one's love." Here is a quilt made from shirts and ties of my husband, Paul. It was made by my sister-in-law, Peggy Frisinger.

Sincerely,
Leona Jewett, Donor Wife



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Please help us "cut down" our costs by notifying us when your address changes. E-mail us directly at donorfamily@kidney.org. It costs 42 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.

2009

- May 9** Spokane, WA, SightLife, *Donate Life Celebration*, Lois Parker, 206.682.8500
- May 16** Seattle, WA, SightLife, *Donate Life Celebration*, Lois Parker, 206.682.8500
- May 30–
June 3** Mt. Laurel, NJ, American Society of Transplant Surgeons and the American Society of Transplantation, *American Transplant Congress*, Kristin Howard, 856.439.0500
- 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.