National Kidney Foundation®

For Those Who Give and Grieve

A newsletter for donor families, published by the National Donor Family Council of the NKF, to offer information about grief and support.
For Those Who Give and Grieve *is provided to all families at no cost.*

Summer 2012 **Volume 20, Number 1**

Honoring the Memories of My Son and Husband

By Cheryl Eshenour

Editor's Note: Last year, Cheryl Eshenour of Hershey, PA, was awarded the MTF Nicholas Miller Award for Excellence in Donor Family Care. We asked Cheryl to share how she got involved with volunteering, and to give us insight into some of the projects with which she has been involved.

My son Jonathan died in 1997 from injuries he suffered in a bicycle accident. Initially I was too grief-stricken to think of anything else, but four months after Jonathan's death, I was interviewed on TV for a local program on organ donation.

Before Jonathan's accident, we had never discussed organ donation as a family. It was very hard for me and Jonathan's father and brothers to have our first conversation in the hospital as we watched him slowly slipping away. Because of this, I felt that it was important to share our story. I wanted to help others realize that any of us could face the decision of organ or tissue donation at any time. That was the beginning of our involvement in support of donation.

One cause that is very near and dear to my heart is the need for appropriate, donation-conscious grief counseling for donor families. Jonathan's accident happened over the summer, and although trips to Philadelphia to meet with a grief counselor with the Gift of Life Donor Program (GOLDP) took the entire day, that was okay. When school started that fall, my husband, Randy, and I sought out someone local. After two visits with this local counselor, one of my sons asked if we could go back to the counselor at the Gift of Life.


Cheryl Eshenour with her sons Matthew (left) and Nathan (right)

The problem was that the local counselor was not adequately trained in the organ and tissue donation process. We realized that our family felt the need to continue to speak with a qualified grief and donation counselor, and we also knew that there had to be other donor families outside of the Philadelphia area who would be experiencing the same issues. A few years later, I was fortunate enough to serve on the advisory committee for the Governor Robert P. Casey Memorial Organ and Tissue Donor Awareness Trust Fund and I made them aware of this need. I'm proud to tell you that, as a result, Pennsylvania now has a network of over 200 counselors trained in how donation affects grief and mourning. Since May of last year they have helped 20 families, and that number will continue to grow.

Another cause that Randy and I felt very strongly about was the need for a safe place for people to bike and hike. Jonathan, his father, and brothers were avid bike riders. At the time of Jonathan's accident and death, our community did not have a comprehensive trail system, nor did they have the funding for one. So, we gathered a group of friends to discuss creating an event. We decided on a memorial bike ride, walk, and silent auction with all money raised to be used in the development and construction of a recreational trail system in Derry Township (Hershey, PA) in Jonathan's memory. Over the 10 years we held the "Bike It—Hike It For Jon," we raised $380,000 toward the recreational

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trail system. When I drive past the trail now and see people using it, it warms my heart knowing that because of Jonathan's accident, people who live and work in our community now have a safe place to ride and walk.

Sadly, we lost Randy in 2008 to brain cancer. When we knew he was terminal, we asked about donation, but it was not possible. Realizing that he did not meet the criteria for organ or tissue donation was very disappointing to both of us. I feel that the one regret Randy had in life was that, due to his active cancer, he was not able to be an organ or tissue donor.

However, when Randy was ill, he told me that he hoped I would continue volunteering for the transplant program. He asked me to find a way to give to the program for him. When Randy died, all money that was donated to Gift of Life in memory of Randy was, and continues to be, used for donor family services. Because of Randy's request, in death he has been able to help other donor families.

Randy wanted to be an organ or tissue donor. Even though he was not able to help a potential recipient directly, our family could help recipient family members with a guest room at the Gift of Life Family House. My sons and I have underwritten a room in memory of Jonathan and Randy, and in so doing, we have been able to fulfill one of my husband's last requests. Through all of the work that I have done on behalf of donor families, and now recipients, I feel that I have been able to honor the memories of my son and my husband.

Ideas for Honoring Your Loved One

- Light a candle
- Play his or her favorite music
- Set a flower at the dinner table
- Release a balloon outside
- Share stories with friends, learn stories you might not have known about your loved one
- Make a meal he or she enjoyed and have a gathering with family and friends
- Create a new tradition in their memory
- Write a letter or a poem to him or her
- Create a journal of memories, stories, or photos of your loved one
- Visit a place you both liked

Dear Friend,

My name is Rose D'Acquisto and I'm a donor wife. At the hospital, when I was asked if my husband Tony and I had talked about organ donation, I remembered an insignificant conversation we had about it before he was going to renew his driver's license. Little did I know how important that conversation would become.

When I became a widow at 34, it was the loneliest feeling I've ever experienced. That's why I'll never forget the first donor family event I attended. From the moment I walked into the room, I felt I was with people who understood me. I saw pain in their eyes. And I also saw courage—which made me realize my own.

As the volunteer Editor-in-Chief of *For Those Who Give and Grieve* for the past 10 years, I've thought about that first meeting with every issue of the newsletter I've worked on. More than anything, I've wanted to share stories, articles and poems that let you know that you're not alone in your grief journey. Whether you're a single mom, a grandfather, a young wife, or even a twin, we want you to know we understand and care.

For the past 20 years, *FTWGG* has been provided to donor families free, thanks to the support of the Musculoskeletal Transplant Foundation and other organizations. Now, as these charities face funding cuts, we find ourselves needing additional support. This year so far, we have funding for one more issue of the newsletter. We're still hopeful we can do more than that.

If you've found comfort from *FTWGG*, please consider supporting this resource that's been valuable to so many families like yours. Whether it's five dollars or whatever you might be able to provide, your generosity will benefit so many who are searching for comfort and understanding in their grief.

If you can help, please visit **http://donate.kidney.org/ftwgg** to donate online.

Thank you so much!

Sincerely,

Rose D'Acquisto

Rose D'Acquisto

DON'T MISS ANY ISSUES!

In order to provide the greatest number of newsletters with our limited funds, we may start offering the *For Those Who Give and Grieve* newsletter by email only.

Don't miss any issues! Please make sure to provide your email address to us, so we can notify you about future issues if a print version is no longer available. Please visit **www.kidney.org/ftwgg** to let us know your email address. We will email you when new issues of the newsletter are available.

For Those Who Give and Grieve

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Facebook Unites Tissue Recipient with Donor Family:

Friendship Leads to Special Ride Together at the 2012 Tournaments of Roses Parade

By Melinda Lockard, Musculoskeletal Transplant Foundation

When an unknown person requested to be his friend on Facebook, tissue recipient Joey Ianiero hesitated and then accepted the invitation. This chance meeting opened the door to a remarkable friendship between Joey and Brandon Pettit, the stepson of Joey's tissue donor, which culminated in the two young men riding together in the Donate Life Rose Parade Float in the 2012 Tournament of Roses Parade.

The California sun was not the only thing beaming during the recent parade. Both young men were thrilled to share this experience. During the parade, Joey carried a photo of Brandon's stepfather, Thomas Pettit. Pettit's generous donation of an Achilles tendon enabled Joey to continue his college baseball career. Joey was visibly moved by the parade crowd's reaction to the float and commented that "many spectators were weeping."

Brandon Pettit was proud to represent his stepfather on the float, who died in a wood cutting accident and whose tissue was recovered by MTF's Recovery Partner, The University of Texas Southwestern Medical Center.

"The opportunity to ride in the parade was unimaginable," said Brandon. "I can't think of how often I thought 'why me?'" In addition to Brandon's participation as a float rider, his stepfather's portrait in flowers, called a floragraph, was also on this year's float.

The float theme this year was "One More Day." Through their life-changing experiences, the families of organ and tissue donors, living donors, and recipients of life-saving and life-enhancing transplants know intimately the preciousness of time. The float was adorned with clocks of various shapes and sizes, and because of its visual appeal, it won the Judge's Special Trophy for outstanding showmanship and dramatic impact.

"Who knew such positive things could come from such a tragedy?"both young men said, practically in unison!

Brandon (left) and Joey

The Eye Bank Association of America Celebrates the 29th Annual National Eye Donor Month

March 2012 marked the 29th annual National Eye Donor Month celebration. Each year since 1983, the Eye Bank Association of America (EBAA) has promoted March as National Eye Donor Month to raise awareness of the need to donate eyes, and to celebrate donors, their families, and corneal recipients.

To find out more about National Eye Donor Month, please contact Patricia Hardy, EBAA Manager of Communications, at **trish@restoresight.org**.

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Can Our Loved One Continue to Be a Part of Our Family?

By Maggie Coolican, Donor Mom

"I didn't want to mention her because I thought it would make you sad."

"All the stockings were hung but his…no one seemed to notice but me."

One fear when a loved one dies may be that they will be forgotten, that no one will mention his or her name or share special stories about them; "It's almost like they never lived."

Each member of our family may be grieving in a very different way. There is no specific or special "right way" to grieve, but our differences in the way we grieve may lead to additional stress at an already difficult time. Some families and friends will allow grief to flow openly, while others will want grief contained or hidden.

> *"If your friends and family see that you are okay talking and sharing stories about your loved one, they will be too…"*

Our relatives and friends may be uncomfortable around us; grief is difficult to observe. Even those we consider very close to us may find our tears and sadness challenging. Our friends and family may not be able to be present for us, and they may be afraid they will say or do the wrong thing, only increasing our pain. They may want to help, but usually do not know how.

Past traditional grief work models suggest the importance of withdrawing emotional energy from our deceased loved one, letting go, and moving on without them. That may be too difficult to accept…a life without the one we love. The fear of trying to go on with life without ever talking or even thinking about our loved one may be painful and overwhelming.

Today, those ideas of mourning are being challenged. Theorists suggest that continuing a relationship or ongoing bond with the deceased is what occurs more often. You have acknowledged that your loved one is no longer here, you know your relationship has changed, but he or she can continue to be a presence in your life: "…death ends a life, not a relationship." (Albom, M., *Tuesdays with Morrie*, p. 174, 1997)

You may carry something that belonged to your loved one, feel their presence, and even chat with them on occasion. When we are grieving we may have to be the teacher; we may have to lead our family and friends and let them know how to be supportive. Suggest that not only is it okay to talk about our loved one and say their name, but it is also comforting and important to us that they not be forgotten, that they continue to be a part of our lives. You may even do this by sending your family and friends a letter letting them know that you would like them to speak about your loved one.

Provide opportunities to memorialize and celebrate the life of your loved one. Design a photo book or special tree or garden, include them in family gatherings, remind folks about something funny they did or how they might respond if they were present. Generally, if your friends and family see that you are okay talking and sharing stories about your loved one, they will be too.

Over 25 years ago, when Katie, the youngest of our six children, died suddenly at the age of six, we knew that she would always be in our hearts but we also wanted to keep her as a special part of our large family. We talked about her, had a special angel tree each Christmas, and put some big hoop earrings on her grave when she would have been in 8th grade and allowed to have pierced ears! As our family continued to grow with marriages and grandchildren, Aunt Katie was not forgotten… just before Christmas this year my seven-year-old granddaughter was asked to write a story about a special person in her family. Selecting from a host of grandparents, aunts, uncles, and cousins, she chose Aunt Katie who had died 22 years before she was born! This is what she wrote:

> My Aunt Katie is special to me because
> she was the best Aunt ever. She had long
> black hair. She was tall and beautiful. She
> died because of a heart attack. She was
> the best! Her dog was named Bo. She had
> brown eyes. I wish she was not gone.
> She had lots of talent. One talent was
> making cookies. I love her and I miss her.

We can learn to live without the one we love, but continue to keep them a part of our family. It may take time and tears, but knowing our loved one has not been forgotten and that his or her legacy continues may be an important part of our grief journey and the new world in which we live.

Donor Family
VOICES

Being a Donor Family Member

When our loved one became a donor, they changed the lives of others. What may have surprised us is how much their gift of life also changed ours. What has it meant to you to be a donor family member?

We asked families this question on our donor family email list; some of their responses follow. If you would like to join the email list, write to **donorfamily@kidney.org** and ask to "Join the NDFC email list."

The night that the hospital told us our 20-year-old daughter Katie Lynn would become a tissue donor, we really didn't understand the impact her decision would have on our lives. Friends and family members would come up to us and say, "I just wanted you to know that, because of what Katie did, I changed my driver's license to become a donor." Becoming a donor family has been a wild ride, up and down with emotions, memories, and the hope that someday everyone will say, "Hey, I changed my driver's license to become an organ/tissue donor." What a tribute that would be to all of those who gave the gift of life.

—Robin Buskirk

That gift of life saved my life that day by creating a sense of purpose and beauty where, without it, there would be none.

—Kelly Schmitt, Donor Daughter

Eighteen years later, I'll never be able to count all of the changes it brought to my life. I don't even remember how I got involved with the NDFC and LifeGift of Houston, TX. But I needed both, and both changed my life. LifeGift put me and donor mom Helen, who is now one of my best long-term friends, to work. We did [work at] health fairs, various organizations, schools, and just about anywhere for donation.

The NDFC gave me many reasons to live and love again. There was the beauty and heartbreak of the Donor Recognition Ceremony. There were the classes, the Quilt, the hugs. The most important life-affirming experiences were related to sharing my soul with other donor family members, living donors, recipients, and their families.

It was heart soothing to meet people who thanked me just because my husband donated. Seeing them use the gifts of their donors to live was the greatest gift I've ever been given or experienced.

And you know...the huge hole in my heart healed a little at every event. The joy of living wormed its way back into my soul. If I'm lucky, I'll get to be a donor.

—Willa Pilcher, Donor Spouse 1994

We Fondly Remember...

Darry J. Blanchard
November 6, 1940 – November 12, 2005

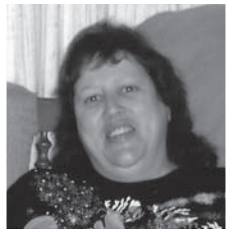
Tyler Jordan Bond
October 18, 1994 – January 22, 2009

Christine Victoria Breen
April 12, 1972 – January 13, 2009

Eva Giselle Cordeno
October 4, 1989 – September 13, 2008

Elizabeth Mindou Duffy
April 2, 2006 – April 15, 2009

Terry T. Ellingwood
April 17, 1964 – March 24, 2006



Marsha J. Frederick
July 20, 1959 – December 26, 2007

Kevin Todd Greer
October 18, 1982– January 13, 2008

Brenda Joyce Haven
March 19, 1952 – October 13, 2008

Pauline Marie Hughes
April 19, 1950 – April 21, 2006

Michael John Knowles Jr.
November 15, 1980 – December 2, 1998

Michael Allen Kotkowski
June 4, 1981 – May 31, 2009

Bethaney Louise Lawton
May 29, 1983 – November 1, 2003

Ricky Allen Leckrone
January 1, 1958 – October 28, 2008

Lloyd Leidholm
January 28, 1933 – March 12, 2008

Charlie Mckean
September 6, 1957 – May 4, 2008

David Alan Miller
March 19, 1957 – August 4, 2007

Renee Ardel Myers
June 20, 1964 – July 31, 2009

Russell Stratton
February 13, 1962 – June 19, 2009

Damian Jevon Summer
February 17, 1991 – October 16, 2009

Anthony E. Wojtowicz
November 5, 1946 – February 22, 2008

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The Quilt on Tour

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.

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 back issues of *For Those Who Give and Grieve* on our website at **www.donorfamily.org**

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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