

# 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 2003

You can visit us on the Web at: [www.donorfamily.org](http://www.donorfamily.org)

Volume 11, Number 3

## Grieving Children, Children Grieving

By Celia Ryan, DCSW, LCSW-C, CGT

*Clinical Social Worker and Certified Grief Therapist*

**O**ur natural inclination is to protect our children from the brutal reality of life, but how can we? It is a nightly fixture on our TV sets, a daily exposure in our communities and worse, a personal experience at home or at school.

In almost every home there has been loss of some kind. No one needs to die for there to be grief, because any change can produce a deep sense of loss. Divorce, death of a parent or grandparent, a pet's death, a serious illness, job loss or losing a home are clearly major loss events and there will be expected grief. Smaller but no less significant losses can be a childhood illness, a disability, a best friend moving away, not making the team and so on. Adults have few guidelines for themselves in grieving; after all, most schools don't offer a class on "How to Help Yourself Grieve," and *Grieving for Dummies* has yet to make the bestseller list! So how can we adults cope with our own grief and be appropriately responsive to our children, who are also struggling to make sense of the tragedy in their lives?

*\* Listen, listen and then listen again...* with your heart as well as

your ears! Try to put your own needs, expectations and prejudices aside to be "present" for your children. They need to know you care, and they need to know that YOU are OK. Often, children "protect" the adults around them at great cost to their own emotional needs. If you are grieving too and cannot attend to their needs right now, try to have another reliable adult who can listen and respond.

*\* Recognize there is no "right way" to grieve...* Men, women and children have different coping styles and will grieve in a way that works for them. Parents can help by encouraging and giving permission to their children to grieve in a way that is uniquely "right" for each child. Try not to impose adult expectations on children.

*\* Time does not heal...* unless grief work is going on. Time in and of itself will not magically take care of difficult feelings and experiences. In time a deep hurt is no longer as "raw" as it once was, but the pain of it will linger and may hinder current relationships or future coping. Parents can help their children by being sensitive to the needs of the



child at this time, and later as different developmental milestones are reached. Over time, these needs can and likely will change.

*\* Gender differences...* Although all persons grieve, there are distinct differences in the coping styles of boys and girls. A mother describes how her son and daughter coped with the death of a beloved grandparent: After an emotional weekend, my daughter said, "Mom, I need to stay home today and be by myself." Her son went to school and promptly got into a fight! Parents can help by being sensitive to the coping styles of their individual children and making suggestions and allowances.

*\* Be proactive...* Teachers can be your best support. Make sure the school knows what has happened and keep the communication open.

*continued on page 4*

## LETTERS TO THE EDITOR

I just wanted to take a minute to thank you all so much for the newsletter *For Those Who Give and Grieve*. I believe in my heart that you all know when I need a lift in my life, because within a day or two I receive your newsletter. My dad passed away in March of this year. He was 53. I am 34 and feel that I should not feel like a lost child at times about losing my dad, but I do.

I just wanted to share this one more thing with you. My daughter was four at the time of Dad's death and I explained to her that Papaw had gone to Heaven and that I had donated his organs and tissues. I had to explain what it meant to do that. She asked me why we did that and I told her to help save or improve other people's lives. Of course she asked why again, and I told her it was the right thing to do, that we do it because we care and we should do all we can to help others.

This past summer we met my boyfriend's nephew who is alive today because of donated bone marrow. He talked to her about being at St. Jude's and the other kids that were there with him. That night as I tucked Areanna in she smiled real big and politely informed me, "My papaw died so a bunch of sick kids wouldn't. I'm proud of my papaw and you too Mommy for helping those kids." I was amazed at her that night and I agree with her. My dad died so that someone else didn't have too.

Thank you all so much again for all you do.

*Rhonda of Tennessee*

As a regular recipient of your newsletter in Australia, I wanted to e-mail my congratulations on a personal level for the article by Arlene Barnett on the front page of the newsletter received today (*For Those Who Give and Grieve* Summer 2001, Volume 10, No. 1).

My family and I have always found the holiday period so very difficult as our son was killed two days prior to Christmas.

The expectations of others to "perform" the usual holiday routine has been overbearing as each day of the grief process is different to the next as detailed by Arlene. I have always found it difficult to be

"firm" with others in changing the usual routine to meet my needs and have found it difficult to explain adequately.

I intend to use the article as a reference for those that I am unable to convince.

Please pass on my thanks to Arlene.

*Ross Stone, donor father  
Silent Hearts Inc., The Australian Organ Donor  
Family Organization, Australia*

## FROM THE EDITOR



Tony was an artist with a master's degree in theatre design. He loved Italian food, romantic movies and Häagen-Dazs ice cream. His eyes sparkled like Christmas tree lights. He was funny, charming and dangerously handsome.

Sometimes he looked like a pirate. He loved chocolate with a passion.

He was a wonderful husband and best friend.

Because Tony was an organ donor, he helped save people's lives—like Mel, who was the liver recipient. Mel lives with his wife of 30 years, his grown children and grandchildren. Mel says that his family is surprised that now, since his transplant, he sometimes has cravings for chocolate.

I thought it appropriate, as the new volunteer editor-in-chief of *For Those Who Give and Grieve*, to introduce the heart of my story—the way in which I became acquainted with the National Donor Family Council. Through the sharing of our stories, as donor families and spouses, we are able to cry openly, rediscover hope and begin healing.

I invite you to share your stories, poems and remembrances with us.

*Rose D'Acquisto, donor spouse  
Volunteer Editor  
For Those Who Give and Grieve*

# THOUGHTS FROM DONOR FAMILIES

## Joshua


By Joyce Guthrie

*about her son Joshua, who was an organ  
and tissue donor in October 1998*

Joshua's hands were big, strong and callused. The calluses were the result of years of gymnastics training. Remember the expression: "Cold hands, warm heart"? Well, Joshua's version of that should have been: "Callous hands, tender heart."

Every day of his life he was helping someone with those callused hands. In his yearbook, he wrote that his favorite verse was from the book of Joshua: "Choose for yourselves today whom you will serve; but as for me and my house, we will serve the Lord." (Joshua 24:15)

Joshua used his hands to help many people in this world. He tenderly and lovingly cared for his brothers and sisters. He voluntarily helped people move, collected food for the needy, arranged a group trip to a Precept Teen conference and taught gymnastics. Gymnastics was his passion in life. He absolutely loved it. His callused hands cleaned, moved equipment, "spotted" children on challenging maneuvers and applauded good effort.

Although we had never addressed the issue of organ donation as a family, as Joshua lay dying on his hospital bed there was no doubt that we should donate his healthy organs to those in need—he would want it that way. So, his tender heart went to a wonderful lady who shares joy and compassion wherever she goes. Joshua's liver was given to a man whose life was extended—allowing him to watch his daughters grow into beautiful young ladies. Two people are off of dialysis, a man lives and teaches free from his fragile diabetes and two people can see the beauty of the world they live in—all thanks to Joshua's final gift. And Joshua's hands? Joshua's hands live on through everyone who was ever touched by this extraordinary young man. They live on in service, giving, tenderness and love. 


## After

By Marilyn Quinlan

My eyes looked up, I could not see  
Oh! The tears, how they blinded me  
The good, the bad all fused into one  
To separate it, I would become undone.

Suffice it to say as memories sweep in  
The faces, the places, the feelings begin  
As though time was not, nor will it be  
Because all of it must be a part of me.

The parents, the grandparents we all miss so  
Departed this life in love's richest glow  
So 'tis a tribute to them when tears  
come uninvited  
To again make us one... and forever united.

The thanks we feel, and blessings received  
Are a testament to those who first conceived...  
That death comes but we do not die  
The proof is there in the new child's eye. 

*My aunt, Marilyn Strickland Quinlan died in  
1998. We donated her corneas for transplantation.  
I came upon this poem at her house after her death,  
which she had written several years earlier. I found  
it very comforting and hope others will too.*

—Delane DeVine, RN, BSN, CCTC

## In Remembrance

*Memorial contributions and other public  
donations to the NDFC are channeled directly  
into programs and educational resources for  
donor families and the professionals who  
support them.*

**In Honor of:**

**Virginia Harkin**

by Barbara A. Barnett

**Bryan Hall**

by Janice C. Lehman

## Congratulations National Donor Family Council

By Trent Tipple, MD, kidney recipient and Chair,  
transAction Council Executive Committee



Photo by Jay LaPrete

Trent Tipple at the  
2002 U.S. Transplant  
Games.

On behalf of the members of transAction Council and all transplant recipients, it is my honor to congratulate you on your 10th anniversary. Your contribution to the transplant community is appreciated by all. You have become the voice of those who have given selflessly in the interest of recipients like me. The programs and services you provide have provided comfort and support for countless donor families over the last 10 years and will continue to do the same for many years to come.

We on the transAction Council look forward to working with you as we have in the past. As recipients, we know that it is your altruism that has afforded us the health we now possess. As a recipient of a kidney from a non-living donor, I am honored to meet each donor family. And, as one who has never met my donor family, I count each donor family I meet as my own.

## Grieving Children...

continued from page 1

Often we only learn about what could have been helpful after the fact. Encourage your school and community to provide information, education and helpful resources about loss, just as they do about drugs and alcohol and other important issues. *All of us* at some time will experience significant losses.

*\* Get support...* There are many resources in your community to help you, your family and your school when there is a loss of any kind. Knowing where to turn for help is the first step in coping with tragedy.

*Do you have any stories you'd like to share about helping your children cope with grief? We invite you write to us at National Donor Family Council, FTWGG, 30 East 33<sup>rd</sup> Street, New York, NY 10016. Or, send us an e-mail at [donorfamily@kidney.org](mailto:donorfamily@kidney.org)*

## The Quilt on Tour

Please note: This schedule is subject to change.

### 2003

- |                 |  |
|-----------------|--|
| March & April   | Los Angeles, Calif., OneLegacy, <i>Various Events</i> , Bryan Steward, (213) 401-1226  |
| April 1 - May 1 | Birmingham, Ala., Alabama Organ Center, Jane B. Geloneck, (334) 271-1690   |
| April 26        | Fullerton, Calif., National Kidney Foundation - <i>Gift of Life Run/Walk</i> , (800) 747-5527  |
| April 24 & 25   | Madison, Wis., University of Wisconsin OPO, <i>Douglas T. Miller Symposium on Organ Donation &amp; Transplantation</i> , Jill Ellefson, (608) 262-3248 |
| April 26        | Calif. Transplant Donor Network, <i>Annual Donor Recognition Ceremony</i> , Tracee L. Harris, (209) 527-6178   |
| April 26 & 27   | Honolulu, Ha. National Kidney Foundation - <i>Donor Family Recognition &amp; Gift of Life Walk</i> , Denice Kelikoa, (808) 589-5933                    |
| May 30 - June 4 | American Transplant Congress, <i>American Transplant Congress Annual Convention</i> , Lisa Wagenseller, (856) 642-4401                                 |

The quilt is created from squares made by donor families in honor of their loved ones. It travels in sections around the country to pay tribute to loved ones and to raise awareness of organ and tissue donation. **The quilt is not displayed in its entirety, and some events may be closed to the general public. If you plan to attend one of the displays, please contact the person hosting the event.** If you are requesting a particular panel or square to be displayed at one of the above events, would like to bring the quilt to you community, or would like information on how to contribute a square, please call the National Kidney Foundation at our national toll-free number, (800) 622-9010. Information about the quilt can also be viewed on our Web site at [www.donorfamily.org](http://www.donorfamily.org)

## *Finding Your Voice Through Personal Account Narratives*

By Raelynn Maloney, MA

When the core of our being is shaken the way grief shakes us, there is comfort in knowing we are never alone. In the moments when we feel off course, confused, lonely and cannot seem to find the words to describe our loss experience, we seek refuge in the spoken and written words of others; others who have journeyed to this painful place before us. Through the profound and heart-rending words of other bereaved persons, we find gifts of comfort, reassurance and courage that help us as we continue our own personal grief journey. What we often don't realize is that there is yet another gift hidden quietly between the lines of their stories. This gift is a personal invitation. They have found a forum for healing, for constructing their personal story, for giving voice to their own experience, and they are inviting us to do the same.

When someone we love dies, naturally as survivors we begin what will become a lifelong quest, a journey toward understanding, a pursuit of hope, a search for meaning. We seek answers to infinite questions within us. How can this be true? Why my child, my parent, my partner, my sibling or my friend? Why now? Where do I go from here? Will the pain subside? When will I begin to feel more like myself?

Many well-intentioned others will struggle awkwardly and in their effort to ease your pain will offer you "their" answers. Others, with a supporting presence, will listen and courageously bear witness to the unfolding of your personal account narrative—the discovery of your own voice. These are the gentle souls who have faith in your inner wisdom and believe that there is a personal knowing that will bring comfort if you are patient with yourself. They encourage you to trust your personal knowing rather than trusting others' claims regarding the "truth" about grief.

In my own work, I have witnessed the comfort found by bereaved individuals in creating a personal account narrative. That is, an account that is congruent with one's lived experience, rather than grounded in the expectations of others. Creating a personal account narrative is not a task that you will accomplish quickly and effortlessly. Account-making

is a process that facilitates the expression of your personal inner loss experience and encourages you to discover the channels of expression that are most fitting for you. What follows are several guidelines that may be helpful as you begin to uncover your own truth about grief, to give voice to your own experience. Consider this my invitation to you to express your grief congruently, from the inside out, rather than taking what others have "voiced" and applying this voice to your inner experience.

⇒ *Give Yourself Permission to Suspend.* Allow yourself to slow down, sit quietly and simply suspend momentarily from the frenzied life pace to which many of us have become accustomed. It is only when we are willing to quiet our souls that we can begin to acquaint ourselves with the inner experience we call grief.

⇒ *Take Your Time.* Calm the sense of urgency you may feel to find "answers" to your soul-directed questions. Allow your story to unfold in its own time, in its own way, at a pace that is comfortable for you. You may find it helpful to set aside time each day or week that will be devoted to immersing yourself in personal account narrative-making and facilitating the outward expression of your inner voice.

⇒ *Let It Flow.* Avoid the natural tendency to edit or correct your expressions of your own account. Just let it flow. You may be surprised at what emerges when you let go and accept that there is no "right" way, only "your way" of expressing yourself.

⇒ *Cultivate a Sacred Space.* Select surroundings that soothe you as you allow your story or account to emerge. Whenever possible, surround yourself with the sounds, aromas, colors, and images that foster a sense of calmness and serenity within you and facilitate the story's flow.

⇒ *Use Images to Guide You.* Visuals such as photos or video can help to facilitate the creation of an account of your loss experience. As you flip through pages in a photo album, view photos on your computer or watch a home video, pause occasionally. Talk out loud (by yourself or with others who knew

*continued on page 6*



the person) about the precious moments that have been captured and your memories of the person who died. You may wish to audio record your musings so that they can be put to paper at a later time.

⇒ *Start a "Memories and Moments" Diary.*

Create a diary in which you can record random thoughts and memories about the person who died—his or her personality, talents, accomplishments, favorite sayings or cherished moments you shared together.

⇒ *Sketch Your Account.* Perhaps words are not the mode of expression that best suits you, or words seem inadequate in conveying the depth of your experience. Try other creative channels for expression, such as drawing or painting your story. Use images as the voice of your inner experience rather than solely relying on the written or spoken word.

⇒ *Arrange a Musical Account.* Perhaps yours will be a musical account. Select a series of melodies or lyrics that capture the essence of the person you love, your feelings toward him or her, the gifts he or she gave during life and the memories that you will hold of him or her.

⇒ *Invite Others In.* As Richard Stone in his book *The Healing Art of Storytelling* poignantly reminds us, "Without listening there can be no story and without stories there is no healing." Take time to share your account with others. Allow someone else to hear or see what is deeply meaningful to you. Perhaps unknowingly you will be quietly inviting this person to give voice to his or her personal grief experience.

As you gain greater comfort in expressing your own voice through account-making, words or images generated by others will still likely resonate with you. This is okay. Just remember, when you do find someone whose voice sounds incredibly in sync with your own, it is still helpful to unearth any additional words or images you would use which are more personally congruent and meaningful. Then, listen to this expression and discover where this fits within the unfolding of your personal account narrative.

We all have an account, a story worthy of sharing. If yours is a story waiting to be shared, I would be honored to listen. 🌸

## 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 National Kidney Foundation. 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

▲ **Donor Family Editors**

Pat Brown, Perrysburg, OH

Janet Davison, Iowa City, IA

Dan Manley, Tulsa, OK

Nancy Stevens, Lake Jackson, TX

Pam Stivers, Melbourne, FL

Donna Wilkes, Port Orange, FL

▲ **Professional Editors**

Penny Colthurst, Ann Arbor, MI

Margaret Coolican, RN, MS, CDE, East Hampton, CT

Charles Corr, PhD, St. Petersburg, FL

Kimberly Kasprovicz, Syracuse, NY

Raelynn Maloney, Iowa City, IA

▲ **Organizational Liaisons**

AATB Sandie Henderson-Bancore

AOPO Margie Fischer

ARCTS Chyrrrel Mock

DoT Mary Ganikos, PhD

EBAA Jennifer Johnson

MTF Martha Anderson

ANET Mary Gainey, RNC

UNOS Fred Geiger

NATCO Laurel Williams, RN, MSN, CCTC

▲ **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  
Sara Kosowsky

Production Director  
Sunil Vyas

Production Manager  
Will Comerford

Editorial Director  
Sarah Ockler

Design Director  
Oumaya Abi Saab

## 2002 U.S. Transplant Games

By Kathy Snow

On March 11, 1998, my husband John and I made the difficult decision to remove our son Terry (age 19) from a ventilator and make the gift of organ donation. Our decision and Terry's gift have helped seven people in the states of Arizona, California and Nevada. This decision has led us down a path in life that we never anticipated and has been filled with great joy.

One year later, John and I had the privilege of meeting Tracy Copeland (liver recipient, Nevada). We spent the next four days together as though we were long friends and stayed in contact with e-mail, letters and phone calls. In October, 2001, we visited Tracy after attending a National Kidney Foundation (NKF) function in San Francisco. During that visit, I handed Tracy a flyer regarding the 2002 U.S. Transplant Games and she was hooked! She signed up for cycling and we decided to go as her cheering section.

The Games were rapidly approaching when John and I received a phone call from the Las Vegas NKF. Would we do the honors of representing the team at the Games? Of course our answer was "Yes."

On June 26, I marched ahead of Team Nevada in the Opening Ceremonies for the 2002 Games. I was amazed at what I saw as I walked onto the field. I had no idea about the scope of the Games, their meaning and the level of participation by transplant recipients and donor families. Even more overwhelming was the response when John and I walked in with all the donor families. I had a very hard time comprehending the hugs, pats on back, the applause and the standing ovation. I did not feel like the hero I was being recognized for. John and I felt that when we made the decision to donate Terry's organs, it was the right thing to do.

The Donor Recognition Ceremony on June 27 was held in a beautiful shrine, fitting for such a ceremony. As uplifting as the ceremony was, the greatest moment for John and I was receiving our medal. Tracy and her family were at the ceremony, sitting together with us. When it was time for us to receive our medal, I asked Tracy to please walk up with us. The steps seemed miles long as Tracy and I held hands. When we

received the medal, tears began to flow. Tracy and I hugged, cried, and said a few personal things to each other. Without Terry, I would have never met Tracy and her family. Without Terry, Tracy would not be here to help us celebrate the gift of life, participate in the Games or be a voice for organ donation.

Closing Ceremonies came and it was hard to believe that the week was over already. We made many new friends, were amazed at participation by everyone in all aspects and were not ready for the Games to end. We are hooked for life and will continue to participate in any way we can. I hope some day to meet the other organ recipients and hope they too will participate in the Games.

Many thanks to the National Kidney Foundation for supporting us in our gains and losses with the death of our son, and the NKF of Nevada for allowing us to represent their fine state in the Games.

*Kathy Snow is a donor mom and lives in California. She and her husband John served as the 2002 Donor Family Liaisons for Team Nevada.*



Photo by Jay LaPrete

### Things with Wings

Last summer, the 2002 U.S. Transplant Games saw the first ever "Things with Wings" gift shop operating

at the donor family headquarters hotel. Items included a variety of butterfly- and angel-themed gifts for families, friends and professionals.

If you would like to purchase an item, please contact us at (800) 622-9010 or by e-mail at [donorfamily@kidney.org](mailto:donorfamily@kidney.org). Proceeds from all sales help support programs for donor families.

The items for sale, pictured above, include the following (prices do not include shipping):

"Kelly" donor bear - \$10

National Donor Family Council mug - \$6

Bear and mug together - \$15

Sequined butterfly ornaments - \$5



## *New Year Welcomes New On-Line Home for Donor Families*

**T**hanks to a generous grant from the Health Resources and Services Administration, U.S. Department of Health and Human Services, the National Donor Family Council Web site, [www.donorfamily.org](http://www.donorfamily.org), has gotten a facelift! The site, which currently sees over 1,500 visitors each month, has been completely redesigned to reflect the needs and suggestions expressed by the Council's thousands of donor family members and volunteers.

At [www.donorfamily.org](http://www.donorfamily.org), donor families who may never actually meet one another personally will be able to reach out and share over the Internet through features like the Comfort Café, an on-line literary forum reflecting poetry and written tributes from families. Site visitors can also meet through message boards, an on-line pen pal network, an e-mail-based grief writing workshop and more.



Donor families, transplant recipients, health care professionals and friends will have the opportunity to memorialize donors through an on-line butterfly garden, daily Web site dedications, publications sponsorship and contributions to special NDFC projects in memory of a loved one.

The site will also feature local donor family activities, book reviews and recommendations, information about donor family events and NDFC volunteer and staff biographies. Longtime features such as the Patches of Love Donor Family Quilt and *For Those Who Give and Grieve* newsletter will be enhanced for easier viewing.

Please visit [www.donorfamily.org](http://www.donorfamily.org), the new on-line home for donor families, and let us know what you think! 🦋

*The mission of the National Donor Family Council is to enhance the sensitivity and effectiveness of the organ and tissue procurement 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.*



**National Donor Family Council**  
**National Kidney Foundation**  
30 East 33<sup>rd</sup> Street  
New York, NY 10016

PRSRT STD  
US POSTAGE  
PAID  
PERMIT 114  
CAROL STREAM, IL



Please help us "Cut Down" by notifying us when your address changes. It costs 37 cents if you forget.