

# 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.

Spring 2004

Visit our *new* home for donor families at [www.donorfamily.org](http://www.donorfamily.org)

Volume 12, Number 4

## what to do *with our memories*

By Barbara Musto, Donor Mom

**WHEN MY 27-YEAR-OLD DAUGHTER KAREN DIED,** *one of my greatest fears was that, in time, both family and friends would forget all the beautiful memories of her. I constantly went through dresser drawers and boxes, searching for objects that would bring me a new memory.*

Then one day during one of these searches, I came across a tiny, pink plastic treasure chest. I heard Karen's voice telling me to open it. Inside were seven of Karen's baby teeth. This was like winning the lottery. I had always felt cheated—when Karen died, no one had thought to cut a lock of her gorgeous black hair. Now I had a part of her to hold onto.

One day at a craft show, I came across a wooden box in the shape of

When I look back at this time, I realize it was a beginning for me. "Is there something positive that I can do with Karen's memories?" I thought. Today, I do just that: I participate as a speaker in organ/tissue education programs in hospitals, schools and churches. I spread the message about the "gift of life," but I also get to talk about Karen's life and the memories that I hold most dear.

*When I look back at this time, I realize it was a beginning for me. "Is there something positive that I can do with Karen's memories?"*

a tooth with a little angel mouse painted on it. It was perfect—not only is Karen an angel now, but when she was young her friends called her "Mouse" because she was so tiny. This box, with her baby teeth nestled inside, sits on my bedroom dresser and will always hold a special memory.

Some of the ways we can memorialize our loved ones are:

♥ **Make a quilt square** for "Patches of Love," the National Donor Family Memory Quilt. Your loved one will be remembered along with many other donors. This quilt travels throughout the



United States and has also been displayed in other countries. For information check out [www.donorfamily.org](http://www.donorfamily.org) or call 800-622-9010.

♥ **Make a quilt square** for your local quilt. Many organ procurement organizations have quilts. Families are welcome to use these quilts at their churches, schools and any other local functions.

♥ **Some support groups** have started memorial gardens to honor their donors. The United Network for Organ Sharing (UNOS), in Richmond, Virginia, recently broke ground for a memorial garden.

*continued on page 2*

## From the Editor

Dear Friends,

In this issue of *For Those Who Give and Grieve*, we are taking the opportunity to share with you the ways in which donor families can honor their loved ones. Whether it's by lighting the Empire State Building with the important message of organ donation or making a quilt patch, it's both healing and comforting to share our memories with others.

My husband, Tony, and I used to volunteer for ZooBoo, a Halloween "trick or treat" event for children held at our local zoo. Volunteers dressed up as characters from favorite children's stories to hand out treats to the kids. Tony, the dashing, handsome man that he was, played Prince Charming. As the children came up to him for treats, he'd get down on one knee in front of little "princesses" in costumes and say, "At last, my princess—you've finally come!" They'd beam from ear to ear.

After Tony died, I received a special gift from my friends at the zoo: an engraved brick for a friends-of-the-zoo plaza. Today, if you visit our zoo in St. Paul, you will see the brick I dedicated to my husband:

### **Tony D'Acquisto – Forever My Prince Charming**

May you find many special ways to honor your loved ones and the gift of life they gave. And remember to share your wonderful ideas with all of us!

Sincerely,  
Rose D'Acquisto  
Donor Wife and Volunteer Editor

*what to do with our memories...*

*continued from page 1*

♥ **Create a scrapbook or shadow box.** You can tell your loved one's life story with these creative projects and always have memories at your fingertips.

♥ **Join a support group.** Get together with other families, whether in person, on the telephone or online. We all love to talk about our loved ones—who better to share our memories with than those who understand? We all need someone to talk to.

Each morning when I get up, I thank God for giving me the strength to keep Karen's memories alive. This is what enables me to get through another day and to reach out to other families in need. 🦋

## **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.

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# the privilege *of caring*

## Baby Butterflies

By Karen Hickey, LifeChoice

**I** AM THE ADMINISTRATIVE ASSISTANT FOR LIFECHOICE DONOR SERVICES and have the privilege of working with our Donor Family Advisory Council. One of our annual Council events is a donor family-transplant recipient picnic. Last summer, the picnic was held on LifeChoice's picturesque office grounds in Windsor, Connecticut.

The Council planned a dedication of three butterfly bushes, donated by a donor family as a memorial for all LifeChoice donors and families. Butterfly bushes, or *Buddleia davidii*, usually bloom from mid-July until the first frost, and are popular plants for attracting hummingbirds and butterflies. LifeChoice thought a butterfly release would be a meaningful addition to the dedication, as butterflies are a

symbol of hope and new life and the symbol for the National Donor Family Council and the Gift of Life. Rather than purchase butterflies, which can be costly, another family donated the funds to order a butterfly kit that contained the live larvae of Painted Lady butterflies. That's where I came in!

Because we could not "grow" the butterflies in our office, I took the larvae home and oversaw the



*Butterfly bushes flourish at LifeChoice's picnic.*

maturing of 30 butterflies. What a wonderful experience! Because I knew how meaningful butterflies are to many donor families, it was so important to me that they survived. I was anxious that they wouldn't mature into butterflies; when they did, I was afraid I wouldn't be able to keep them alive until the picnic. Fortunately, with helpful tips from another donor family experienced in growing butterflies, as well as some TLC from me, they all survived.

The day of the picnic was perfect. After dedicating the bushes, the butterflies were released and enjoyed by everyone, especially the children. And the butterflies didn't just fly away—they landed on the children's fingers and stayed there. The children then walked over to the butterfly bush and gently placed each butterfly on a flower. It was an emotional and inspiring experience. I was privileged to be able to give this special gift to the families who have given so much. 🦋



*A Painted Lady butterfly visits one young picknicker, left.*

# the gift of *love*

## Coming Full Circle

By Tracy Tappen, Musculoskeletal Transplant Foundation

**SOMETIMES WE HEAR OF DONOR FAMILIES** who have been previously touched by donation or transplantation. They might have been a transplant recipient or participated in a directed donation. Directed donations are common in organ transplantation. Often, a family member is the best match for a patient who needs a kidney or liver transplant. When that happens, the family member can donate directly to that individual.

However, in tissue donation, directed donation is becoming a more common request. Tissues that can be donated include heart valves, bone, corneas, skin, veins and connective tissue. Until recently, directed tissue donation was rarely discussed. As tissue donation awareness spreads, some patients realize it's possible to be close to their loved one once again through the tissue donated by the family member. The family member can be a part of the recipient in a unique way.

Robin Heitmann realized after her son's death in April 2003 that bone tissue donated by her son, Hal, could be used in her back surgery. Her surgery in July was a success. "My spine is what holds me up. It would be like my son supporting me through all this. It seemed meant to be."

Often, these special requests from families for specific donated tissue can be fulfilled. Sometimes, however, the patient's surgeon

determines that the donor's tissue is not suitable for the needed surgery. When tissue cannot be used for a requested tissue recipient, the donated tissue is processed and distributed, as in any donation. And while that can be a disappointment for the donor family, there still is comfort in knowing that their loved one's donation changed someone's life for the better. 🌸

## we fondly *remember*



*Don Hartwell*

**D**on was a cornea donor to a woman in Germany. Ironically, 50 years earlier, he was stationed as a helicopter technician near her hometown.

**J**ackie was killed by a drunk driver on Long Island, New York, in March 1992 at age 14. She gave the gift of life to three people.

*Jaclyn Ann Shutowich*



**J**onDavid passed away 14 years ago, at 15 months of age, from liver disease. He received a kidney transplant from his mother, Dana, but passed away before he could receive his liver transplant.

*JonDavid Penn*



# this little light of mine, *I'm gonna let it shine!*

By Karen Kennedy, M.A.

**GRIEVING IS A COMBINATION OF PHYSICAL, EMOTIONAL, COGNITIVE** and social processes that requires the patience of yourself and those around you. Studies have found that people grieve differently. A person may experience many emotions or just a few. Some common feelings include shock, anger, guilt, depression, loneliness and hope.


As a person who donated a kidney to her mother and then had to deal with the grief of losing her, I can relate on a personal level. Ten years ago, I successfully donated a kidney to my mother. Last year, she passed away in her sleep and my grieving process began. She could not be a donor herself, but believed in organ and tissue donation. After the initial shock, I began the process of grieving and growing. Initially, I felt guilty that there was not more that I could have done to prolong her life. Friends and family provided some solace as they reminded me that my donation 10 years earlier allowed my mother to continue living. I have found that the grieving process has given me the knowledge and power to honor my mother in many ways.

For those of you who are not where you wish to be along the grief journey, please don't despair. As you work through your grief, you can gain new coping skills that will help. While experiencing your grief, it may help to think of ways to honor your loved one.

One of the most helpful things for me, after my mother died, was to do something that would honor her. Just as donating your loved ones' organs can help you through the grieving process because you have helped other people, continuing to honor your loved one may also comfort you. For some, honoring their loved one is a way to stay connected to them. There are so many ways to honor your loved one and each person has his or her own ideas. It is important to know that no matter how small or how big your ideas are, they are achievable. And in honoring your loved one, you could also make a difference for others by raising awareness about organ and tissue donation. One little person in one little town can make a difference.

When my mother was alive we had discussed the idea of having the Empire State Building's tower lights illuminated to raise awareness about organ and tissue donation. My mother thought it was a great idea. After she died, I knew it would be a great way to honor her. It was a daunting task for one person, and there were

many obstacles to overcome—lighting the Empire State Building took time, patience and perseverance. Fortunately, those were things that I had learned throughout the grieving process. After two years of hard work, with the support of the National Kidney Foundation, I was able to achieve my goal.

The world-famous tower lights of the Empire State Building will be illuminated green and white on April 19, 20 and 21 in a groundbreaking event to honor you, your loved one and all who have donated for National Donate Life Month. I see myself as one little person from one little town honoring another little person with little lights that can be seen from miles away. In your own way, in your own time, I hope you will let your own little light shine to honor your loved one. 

*Karen Kennedy is a living donor who is a Ph.D. candidate in psychology at Fordham University.*



# a quilt patch story:

## *Kristy's wedding dance*

By Steve Kaplan, Donor Father



I want to take this opportunity to thank you and the Donor Family Council for allowing us to have panel 8 of the Donor Quilt on display at my daughter Kristy's wedding. It was a most treasured item and brought joyful tears to many of the guests, especially our son David's heart recipient, Jim Kane.

Everyone at the wedding saw the quilt and knew about Jim, but only a few family members had ever met him. Jim sat at my table with his wife. During dinner, the conversation would come around to David and the work David's mother, Faith, did with NKF and how she met Jim.


During the reception, a special announcement was made about

our son and Jim, followed by a special dance with Jim and my daughter to the song "Wind Beneath My Wings." After the dance, Jim presented Faith with the jersey he wore as a participant at the U.S. Transplant Games in Orlando.

Prior to the wedding, I contacted all the Massachusetts residents on panel 8. Twenty-five family members were invited to my home to see the quilt and their loved one's panel. Tears were abundant as they touched their loved one's living memorial. Everyone had a story, and each was heartwarming. Hundreds of pictures were taken. Two daughters who lost their father at the ages of seven and nine (they

are now 21 and 23) felt their father's love on a panel they had only seen previously on the Internet.

One donor father made the profound statement that the quilt really felt like it was "ours," in front of us and tangible, and not just something to read about or see on a computer screen. We could read of the lives of every person on the panel. Each square on the quilt makes them a family. The legacy of our loved ones will survive—even after we are gone.

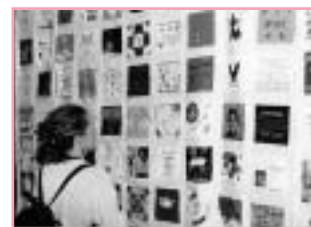
Again, thank you and God bless all who gave the gift of life. 

## *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.

### 2004

- |                  |   |
|------------------|---|
| April 15         | Sacramento, CA, <i>UCDavis Transplant Center</i> , Living Donor Recognition Reception, Lisa Rodriguez (916) 734-4916                  |
| April 17         | Fullerton, CA, <i>Gift of Life</i> , Gift of Life Run/Walk, Kathleen Hostert (714) 526-0181   |
| April 18 – 25    | Chicago, IL, <i>National Kidney Foundation of Illinois</i> , Organ Donor Recognition Reception, Hilary Winkelhake (312) 321-1500 x233 |
| April 23         | San Jose, CA, <i>Donor Appreciation Ceremony</i> , UCSF Tissue Bank, Maddie Belles (408) 345-3516                                     |
| April 24         | Modesto, CA, <i>Celebration &amp; Remembrance 2004</i> , California Transplant Donor Network, Trace L. Harris (209) 545-8400          |
| April 25         | Sacramento, CA, <i>Donor Family Recognition Ceremony</i> , Golden State Donor Services, Tracy Bryan (916) 567-1600                    |
| April 25         | Honolulu, HI, <i>Gift of Life Race &amp; Fun Walk</i> , National Kidney Foundation of Hawaii, Sharon Arneson (808) 589-5922           |
| April 29         | Mobile, AL, <i>Donor Family Recognition Ceremony</i> , USAMC Golf Coast Regional Transplant Center, Helen Huppertz (251) 471-7107     |
| May 14-19        | Boston, MA, <i>ATC Annual Meeting</i> , American Transplant Congress, Shannon Fagan (856) 439-0500                                    |
| May 16           | Rochester, NY, <i>Donor Family Celebration</i> , Finger Lakes Donor Recovery Network, Roxanne Morsch (585) 272-4934                   |
| July 27-August 1 | Minneapolis, MN, 2004 U.S. Transplant Games, National Kidney Foundation, Marilyn Jones (800) 622-9010                                 |



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 your 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)

# thoughts from *donor families*

## Richard's Garden

By Sue Begin, Donor Wife

*I HAD BEEN DOING A LOT OF "SELF" WORK TO DEAL WITH THE LOSS OF MY HUSBAND, Richard, including a grief support group and a class on "rebuilding your life after a major loss," but I still felt there was something else I needed to do for Rich. Because he had a love for the land, the idea for a memorial garden was born. I called a dear friend, ran the idea by her and got started. It was a lot of work, but it helped me more than I could have ever imagined.*

Cultivating the land for the garden helped me deal with a lot of my frustration. I found myself talking to Rich while I worked. Each day I was eager to get home from work so I could work in the garden. Shopping for the flowers was fun and I grew very excited. This garden of love gave me a purpose and it got me motivated.

I shared my plan for a garden with my family and friends. Soon afterward they were stopping by with surprise gifts of flowers, clippings from their own gardens, a garden fairy and angels. My parents brought over a cherry blossom tree. Richard's brother Tom and his wife learned of my plan to purchase a memorial stone and they bought it for me.



Richard's garden of love helped me and so many others who share my loss. I know that I have been very blessed, not only to have the love of a wonderful man for 25 years, but also to have the love and support of a wonderful family and friends. 🌸

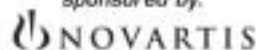


National Kidney Foundation's

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*With a special Donor Recognition Ceremony honoring donors,  
recipients and donor families.*

*July 27-August 1 in Minneapolis - St. Paul, MN*

## WINNING "Gift of Life" MUG DESIGN!

In our Fall 2003 issue, we challenged our readers to create and submit a mug design for our "Gift of Life" mug design contest. Congratulations to **JANET JAMERSON** of Lapeer, MI! Her winning design will be available on mugs for sale at the upcoming 2004 U.S. Transplant Games this July.

Janet is the donor mom of Deena Jamerson (1970-2001). Janet shared the message behind her design: "The heart represents the grief, mixed feelings and broken hearts of donor families, while the rainbow colors of the 'Gift of Life' slogan represent the darkness of the recipients' lives and a movement into the light of life after transplant."

The NDFC would like to thank everyone who submitted designs for the mug. The decision was not easy due to all the outstanding entries that were received. We hope all donor families will connect with Janet's thoughtful design. 🦋



*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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