

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.

Fall 2004

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

Volume 13, Number 2



helping yourself heal

during the holiday season



By Alan D. Wolfelt, PhD

Holidays are often difficult for anyone who has experienced the death of someone loved. Rather than being times of family togetherness, sharing and thanksgiving, holidays can bring feelings of sadness, loss and emptiness.

* *Love Does Not End With Death*

Since love does not end with death, holidays may result in a renewed sense of personal grief—a feeling of loss unlike that experienced in the routine of daily living. Society encourages you to join in the holiday spirit, but all around you the sounds, sights and smells trigger memories of the one you love who has died.

No simple guidelines exist that will take away the hurt you are feeling. The following suggestions, however, could help you cope with your grief during this joyful, yet painful, time of the year. As you read through this article, remember that by being tolerant and compassionate with yourself, you will continue to heal.

* *Talk About Your Grief*

During the holiday season, don't be afraid to express your feelings of grief. Ignoring your grief won't make the pain go away and talking about it openly often makes you feel better. Find caring friends and relatives who will listen—without judging you. They will help you feel understood.

* *Be Tolerant of Your Physical and Psychological Limits*

Feelings of loss will probably leave you fatigued. Your low energy level may naturally slow you down. Respect what your body and mind are telling you. And lower your own expectations about being at your peak during the holiday season.

* *Eliminate Unnecessary Stress*

You may already feel stressed, so don't overextend yourself. Avoid isolating yourself, but be sure to recognize the need to have special time for yourself. Realize also that merely "keeping busy" won't distract you from your grief, but may actually increase stress and postpone the need to talk out thoughts and feelings related to your grief.

* *Find Supportive, Comforting People*

Identify those friends and relatives who understand that the holiday season can increase your sense of loss and who will allow you to talk openly about your feelings. Find those

persons who encourage you to be yourself and accept your feelings—both happy and sad.

* *Talk About the Person Who Has Died*

Include the person's name in your holiday conversations. If you are able to talk candidly, other people are more likely to recognize your need to remember that special person who was an important part of your life.

* *Do What Is Right for You During the Holidays*

Well-meaning friends and family often try to prescribe what is good for you during the holidays. Instead of going along with their plans, focus on what you want to do. Discuss your wishes with a caring, trusted friend. Talking about these wishes will help you clarify what it is you want to do during the holidays. As you become aware of your needs, share them with your friends and family.

continued on page 3

MTF Dedicates Donor Sculpture Garden



ON MAY 18, THE MUSCULOSKELETAL TRANSPLANT FOUNDATION (MTF) invited donor families, recipients and transplant professionals to attend a dedication ceremony for a new Donor Sculpture Garden at the MTF facility in Edison, New Jersey. Joseph Benevenia, M.D., orthopedic surgeon and MTF board member, created the centerpiece of the garden, a tall, stainless steel sculpture entitled "The Gift: Tears of Joy." It is a tribute to tissue donors and their unselfish gift to countless others.

One of Dr. Benevenia's patients, Gloria Clausen, was also in attendance. Gloria received a tissue transplant after she was diagnosed with cancer. "I was very surprised to learn that it is possible to save a limb through tissue donation. If that tissue was not available, I probably would have to face amputation. I'm very grateful to a donor family that I did have that option," Gloria stated through tears of gratitude.

Butterflies were released during the ceremony, with the hope that they would find a home in the garden, where many butterfly bushes have been planted. 



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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helping yourself heal...

continued from page 1

* Plan Ahead for Family Gatherings

Decide which family traditions you want to continue and which new ones you would like to begin. Structure your holiday time. This will help you anticipate activities, rather than just reacting to whatever happens. Getting caught off guard can create feelings of panic, fear and anxiety during the time of the year when your feelings of grief are already heightened. As you make your plans, however, leave room to change them if you feel it is appropriate.

* Embrace Your Treasure of Memories

Memories are one of the best legacies that exist after the death of someone loved. And holidays always make you think about times past. Instead of ignoring these memories, share them with

your family and friends. Keep in mind that memories are tinged with both happiness and sadness. If your memories bring laughter, smile. If your memories bring sadness, then it's all right to cry. Memories that were made in love—no one can ever take them away from you.

* Renew Your Resources for Living

Spend time thinking about the meaning and purpose of your life. The death of someone loved creates opportunities for taking inventory of your life—past, present and future. The combination of a holiday and a loss naturally results in looking inward and assessing your individual situation. Make the best use of this time to define the positive things in life that surround you.

* Express Your Faith

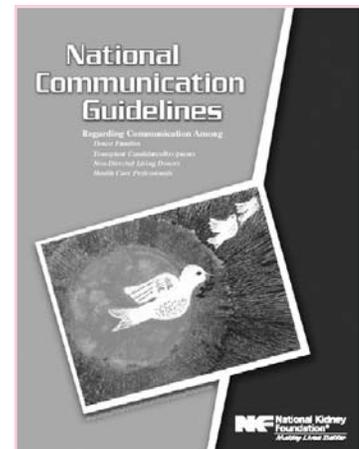
During the holidays, you may find a renewed sense of faith or discov-

er a new set of beliefs. Associate with people who understand and respect your need to talk about these beliefs. If your faith is important, you may want to attend a holiday service or special religious ceremony.

As you approach the holidays, remember: grief is both a necessity and a privilege. It comes as a result of giving and receiving love. Don't let anyone take your grief away. Love yourself. Be patient with yourself. And allow yourself to be surrounded by loving, caring people. 

Alan D. Wolfelt, PhD, is a noted author, educator and practicing grief counselor. He serves as Director of the Center for Loss and Life Transition in Fort Collins, Colorado, and presents more than 100 grief-related workshops each year across North America.

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Writing to Transplant Recipients

A Simple Guide for Donor Families and Living Donors



Writing to Donor Families and Living Donors

A Simple Guide for Organ or Tissue Transplant Recipients



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(800) 622-9010 ext. 175



Tony Riley
10/25/74 – 04/09/96

YOU GAVE ME A BROTHER

by Karen Pooler
in honor of Tony

YOU GAVE ME A BROTHER
YOU TAUGHT ME TO DREAM
YOU GAVE ME A BROTHER
YOU MADE US A TEAM

YOU GAVE ME A BROTHER
YOU TAUGHT ME TO SMILE
YOU GAVE ME A BROTHER
FOR SUCH A SHORT WHILE

YOU GAVE ME A BROTHER
YOU TAUGHT ME TO TREASURE
YOU GAVE ME A BROTHER
WHOSE LOVE YOU COULDN'T MEASURE

YOU GAVE ME A BROTHER
YOU TAUGHT FRIENDSHIP TO GROW
YOU GAVE ME A BROTHER
WHOSE FATE I COULDN'T KNOW

YOU GAVE ME A BROTHER
YOU TAUGHT ME TO LOVE
YOU GAVE ME A BROTHER
WHO IS NOW UP ABOVE

YOU GAVE ME A BROTHER
YOU GAVE ME HOPE
HE TOOK MY BROTHER
TEACH ME TO COPE 

Submitted by Mary Bailey,
sister of Tony and Karen

donor *sisters*

By Julie Alexandrin, Donor Mom



LUCIA AND ELSA ARE TWO SISTERS who do many sisterly things together. They enjoy playing with each other and reading together. They also talk with each other about their brother, Dasan.

He is the middle child and the only boy in the family. He is also a heart valve and cornea donor. Dasan died five years ago from complications of meningitis. Lucia was two and a half at the time of Dasan's death and Elsa was born a year later on the exact day Dasan had been diagnosed with meningitis. When hearing them talk about Dasan, it is not always evident that Dasan is no longer alive, for he is certainly still a part of their lives and our family.

This past December, when getting the house ready for Christmas, we started looking through all the Christmas decorations and the stockings. Elsa found Dasan's stocking and we started talking about how he was alive during Christmas and what Christmas was like for him. Elsa enjoyed hearing about him and put the stocking to the side when the conversation was over. We started decorating the house; soon, we got to hanging up the stockings. We hung up the girls' stockings and our stockings. Then Elsa went over and got Dasan's stocking and asked us to put it up. It was not a request—it was an order. She wanted his stocking up.

At first I hesitated. What would I say to people who

come into our house and see Dasan's stocking hanging with the others and expect an explanation of who Dasan is, or why we have our dead son's stocking up?

I looked at Elsa and asked her why she wanted Dasan's stocking up. She stated, in her own way, that since Dasan is a part of our family he needed a stocking up, just as everyone else had one up, including the pets. After hearing this I lost my hesitation: we found a place to hang Dasan's stocking.

Did people ask when they saw his stocking during the holidays? Yes. When they did I just explained without reservation why Elsa had wanted it up and that seemed to satisfy everyone.

Through experiences like this during the past five years, I have learned even more to follow my heart and instinct when dealing with my daughters and their grieving. I have also learned to bring my daughters into the grieving process instead of pushing them out. This way, we have supported each other and become closer. Therefore, if you ask my daughters to describe themselves, one way they will always do it is to tell you that they are donor sisters. 

letters to the *editors*

Dear Ms. D'Acquisto,

We really enjoy the newsletter that you and the National Kidney Foundation publish. Due to unfortunate circumstances, I had to grieve alone when our granddaughter, Marissa, was killed.

Having your newsletter and articles to read helped me a great deal. Enclosed is a poem I wrote to share with your readers.

Thank you to you and your wonderful crew for all the help you have given me over the years.

Sincerely,

Rebecca Amicoreles
"Marissa's Maw-Maw"

Happy Heavenly Birthday

Color the Heavens with
Bubbles shaped like
Big Red Hearts
Look to the Sky for
Balloons sent with Gifts
while we're apart
While releasing the Balloons
we'll play our song
"The Dance Marissa"
to let you know
We Love You Baby
and We Miss You

Eternal Love
Maw-Maw and Pa-Pa
2-14-03 

more letters to the *editors*

Here's how some other donor families have told us they celebrate their loved one's birthday and/or holidays. If you would like to share the way you remember your loved one's special days, we would love to hear about it! Write to: FTWGG, National Kidney Foundation, 30 East 33rd Street, New York, NY 10016. Or e-mail us: donorfamily@kidney.org

WE STILL CELEBRATE ROBBY'S BIRTHDAY. Even though he is gone, the day he was born was, and still will be, the best day of my life. Everyone does things differently. I receive roses — I get 16 red ones for the years he was with me, and I get white ones for the years he hasn't been. This year it was 8. We have cake and his sister and brother like to let balloons go. 🌸

Michelle Lester
Robby's mom
Central New York

We call Will's birthday and angel day "Family Days." Terry, my husband, takes the day off from work and we spend the entire day together as a family. We do various things, like going to the donut shop, the zoo or Chuck E. Cheese. Our surviving children are so young that it is just a fun day to them. It usually ends with a picnic in the cemetery leaving flowers and balloons. 🌸

Mindy Fischer
Will's Mom
West Tennessee

We celebrate our son's birthday every year (since 2002). Family, friends and Dan's friends. We go out on the front lawn, sing "Happy Birthday" and let balloons go (this year will be 25, for his 25th birthday). Everyone loves Danny's birthday party. Our list grows with each year.

We have a buffet, cake, etc. I would rather celebrate his birthday than the anniversary of his death. On his anniversary day my husband and I spend that day alone, we have a mass said in his honor, go to the cemetery, etc. 🌸

Rosanne Minor
Danny's Mom
New York

One of the things I do that helps me for Shannon's birthday is to buy a board game. Shannon loved to play board games and every year on her birthday or Christmas or Thanksgiving, or any time the family got together for any occasion, she would be the one to initiate or insist that we all play a board game as a family. So every year now, I buy a new board game on Shannon's birthday and we get together and play it in her memory. Sometimes we play some of the old ones too, that we used to play when she was still with us here on earth. That would bring up memories of "Remember when Shannon had to act out that phrase or word and what she did?"

I also always buy myself a birthday gift from Shannon on my birthday, and on her birthday I make a contribution in her memory to the SPCA or sponsor a homeless animal for the year. Because she loved animals so much, I know that would make her happy. They send me a nice little certificate with her name on it for the contribution. And it doesn't have to be a lot of money. On Christmas, I buy a new ornament for the tree in memory of Shannon. It goes on the tree with the ones she made from the time she was in kindergarten. I treasure them dearly and always will. 🌸

Darlene Aymerich
Shannon's Mom
Western New York

privilege of *caring*

SINCE 1998, THE NATIONAL KIDNEY FOUNDATION has displayed as many panels of the National Donor Family Quilt as possible for exhibition at the American Transplant Congress (ATC). Even though the ATC is designated as an American conference, it has an international representation of transplant surgeons and physicians from around the world. At the ATC this year in Boston, transplant physicians and scientists with different backgrounds from many cultures stopped to experience the quilt, despite a hectic meeting schedule. The quilt brought to mind for many of the viewers family interactions that were a positive and moving reflection of organ donation experiences. One transplant physician noted, "I will never forget where the organs came from."

Another surgeon, giving a preliminary presentation at the ATC, dis-

Reflections on the National Donor Family Quilt

By Francis L. Delmonico, MD

played a photograph of a 17 year old boy who, years earlier, became the first non-heart beating donor (donor after cardiac death) in the Philadelphia area. The doctor described how the boy's mother insisted that the doctors honor the boy's wishes to be a donor, even though he did not fulfill the criteria of brain death. The only opportunity for donation was to procure organs after death (determined by the cessation of heartbeat). Non-heart beating donation or donation after cardiac death is an alternative approach to the recovery of organs from someone who has died. The doctor who made the ATC presentation recalled how he still carries this young man's memory in his thoughts.

Transplant surgeons and physicians do not often get an opportunity to thank the families of deceased donors directly because these transplant doctors are ethically removed

from the death and decision-making interaction with families. However, other transplant surgeons mentioned in conversation before the quilt that it was easy for him to remember every single donor, from every single transplant he has ever done. The quilt elicits these reflections that can be shared with physician colleagues and donor families.



Francis L. Delmonico, MD is a Professor of Surgery at Harvard Medical School, Medical Director of the New England Organ Bank and incoming President of the United Network for Organ Sharing. He presided over the Donor Recognition Ceremony at the 2004 U.S. Transplant Games in July.

our privilege *—our work*

By Nancy Senst, NATCO President

IN 1988, WHILE LOOKING THROUGH THE JOB CLASSIFIEDS, I came across a position entitled "Organ Procurement Coordinator." I applied and soon started on the call schedule working with families at perhaps the most difficult moment of their lives. I have to admit, I had no idea what I signed on for. Even now, I struggle to share with new coordinators about what to expect and how to prepare for the patients and families that touch us so deeply.

This past year I had the opportunity to be President of the North American Transplant Coordinators Organization

(NATCO), the organization for transplant professionals. This organization represents health care professionals who encompass the donation process, including procurement coordinators, family support specialists, hospital liaisons, educators, pre- and post-transplant clinical coordinators, transplant social workers and administrators. Our work completes the circle of donation and transplantation through our shared vision: a better quality of life for patients with end stage organ and tissue failure, and a respect for those who shared.

The work we do is unique. NATCO assists its membership through our mission: to support, develop and advance the knowledge and practice of its members and to influence the effectiveness,

quality and integrity of donation and transplantation. We accomplish this mission through educational offerings, including an introductory course, the transplant institute and our annual meeting, which features seven specific educational tracks. NATCO supports and develops its members' research capabilities, publishes the professional journal *Progress in Transplantation*, and advocates in the legislative arena for you, the people whose lives are affected by this remarkable process.

Very few people have the privilege to do what we do. Our work can be physically and emotionally challenging; however, we are honored to have our lives touched by yours and the life of your loved one through the legacy of donation.

thoughts from *a recipient*

Mahalo Nui Lou (Many, Many Thanks)

By Rachael S. Wong, MPH

*WRITING THIS PIECE
FLOWS EASILY BECAUSE
IT COMES DIRECTLY
FROM MY HEART.*

I am a 32 year old kidney transplant recipient, and I received the Gift of Life on April 30, 2002. Soon my husband and I will be celebrating my two-year anniversary of health and new life with Susan, the woman who received our donor's other kidney, and her husband, Morris. We haven't yet met our donor family, but hopefully one day we will be able to thank them in person.

My evolution—from a healthy teenager to a college student living with lupus and compromised kidneys—occurred during the first few weeks of college when I was 18 years old. For the next 12 years, much of my being swayed with the ups and downs and ebbs and flows of living with a chronic illness. When fluids collected in my ankles, I knew I was declining. When I was full of energy and movement, I felt joy for this period of feeling well.

When my husband Brad and I married six years ago, we had already been together for four years. He was going into medical training, and I like to say that he was tested by fire! Our life together has been spiced with hospitalizations and dialysis, along with tremendous growth and a full spectrum of experiences.

In 2000, I started work with a Hawaii coalition to improve end-of-life care, and within months I became their poster child. During this time, many of Brad's and my discussions focused on end-of-life care in a personal context: What would he do if I died? How could we bring a child into our lives if I wasn't going to be around? How should I put my affairs in order?

*With this gift, I
am now able to
contribute to
our shared lives
and to be of
service to
others.*

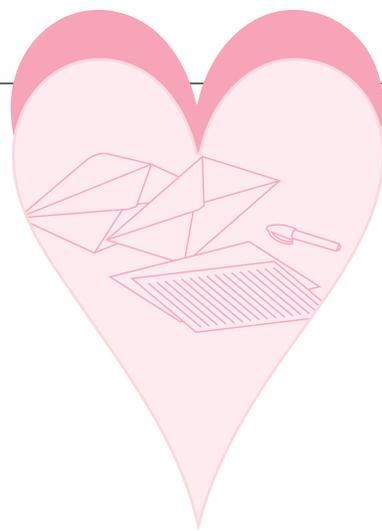
New life entered our lives when the phone rang that April morning in 2002, and I was told that I matched for a kidney transplant. At noon Brad and I went in for testing, I was in the operating room at 8 pm and in the recovery room by 10 pm. The kidney kicked in right away and from that moment on, I have been healthy, well and living every day filled with overflowing gratitude for this second chance at life. And this gift does not just allow me to survive:

I have the opportunity to thrive, to blossom and to be truly well.

With this gift, I am now able to contribute to our shared lives and to be of service to others. I am back to working in end-of-life care, but no longer as the poster child! Now I work on coordinating a project to build our community's capacity for palliative (comfort) care, and I serve as president of our Transplant Association of Hawaii, which provides support to transplant candidates, recipients, donors and their families. I joined a gym for the first time ever (having missed out on physical activity throughout the '90s). I also participated in the U.S. Transplant Games in July and competed in tennis, the sport I love.

Although words will never fully express my feelings, on behalf of organ and tissue transplant recipients everywhere, I thank you. I thank you for giving the gift of life, for giving unconditionally and for sharing that which is part of you.

Rachael Wong is president of the Transplant Association of Hawaii and also volunteers as a member of the transAction Council Executive Committee.





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.

September 11, 12, 14	Dayton, OH, <i>Donor Memorial Service</i> , Life Connection of Ohio, Tracy Williams, (937) 223-8223
September 12 - 13	Minneapolis, MN, United Resource Networks, U.R.N., <i>13th Annual National Clinical Conference</i> , Sharon Dillon, (763) 797-2309
October 2	New Castle, WA, <i>2004 Donor Family Ceremony</i> , Northwest Lions Eye Bank, Lois Parker, (800) 847-5786
October 2, 5	Dayton, OH, <i>Workplace Partnership Event</i> , Life Connection of Ohio, Tracy Williams, (937) 223-8223
November 6 - 7	Norcross, GA, <i>Service of Remembrance</i> , LifeLink of Georgia, Terri Medina, (770) 225-5465

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

* 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.

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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