



National Kidney
Foundation®

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/Holiday 2009

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

Volume 18, Number 2

the DAD tree *By Ida Kelleher, Donor Wife*

My husband Mark died suddenly a few weeks before Christmas in 2008 and became an organ and tissue donor. After his death, a close friend was looking for a way to help, found our artificial tree in the attic and set it up. But as the days passed, no one had the energy to decorate it.

When I thought about what a loving husband and father Mark was, it seemed more relevant to decorate the tree in honor of him. I told my kids, Michael, 20, and Marci, 12, "You know what, let's skip the Christmas decorations. Go around the house and find things that you gave dad or dad gave you, and things that remind you of him or things that were important to all of us. It doesn't have to be a regular Christmas tree; let's make it a dad tree."

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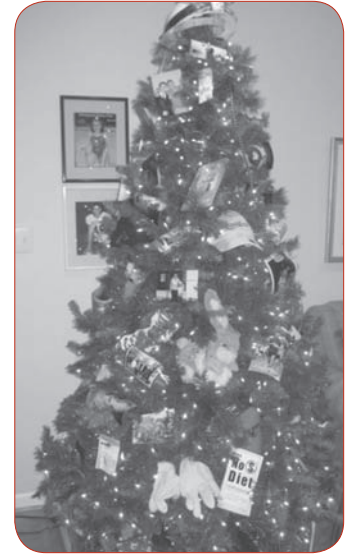
It was really amazing watching them. We were all saying, "Remember this" and laughing and carrying on and crying. It was cathartic.

My daughter Marci swam, so she hung a team shirt on the tree. My

son Michael hung t-shirts from football, wrestling and crew. We put an old dog leash on it because Mark walked the dog every day. Every now and then Mark would have a Michelob Ultra-light, so we washed out a can and put it on there. The sunglasses Mark wore were on there. We're also big Seinfeld fans so we added a Seinfeld puffy shirt. We included pictures of friends and kids and family.

We included his work boots and a few of his guitar picks. We hung a picture of Mark when he ran the marathon and one of the sneakers he ran in. We put a little stuffed animal on it that he had given Marci—one she carried everywhere and had sent to him in the hospital. We were always finding his socks everywhere, so we put one of his socks on there—it was funny. We

hung up his safety glasses. There were a million things on this tree. Then we said, "What are we going to put on top?" We decided to take the hard hat he wore to work every day. It had electrical tape wrapped around it and a light on top for working at night. We placed it on top of the tree.



After the holidays, we didn't want to take it apart, because we really loved it. So we moved it from the den to a corner of the living room, and on special occasions, we turn on the lights and sit there and really feel his presence. It just keeps him so much a part of us. It's welcoming and very comforting. The neat thing is we can still add to it. Anytime we go on a long day trip or do something special, we buy a little something for Mark and put it on the tree. I plan to write letters to his recipients, and when I do, I'll put a copy of those on the tree, too. The tree is our place to remember Mark; it's full of life and in his home, which he took so much pride in, and it's with his family, which he also took so much pride in. It might not be right for everyone, but it sure is right for us.



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*For Those Who
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WE FONDLY *remember...*



Danielle "Dee" Carman
April 13, 1986 – June 7, 2007



Christopher Hutchinson
February 2, 1985 – April 23, 2005



Ricky Lavell Dalton
August 18, 1966 – April 13, 2006



William Anthony Devon Lacy
March 13, 2007 – December 13, 2007



Thomas G. Donovan
September 5, 1934 – August 14, 2001



Mark David Le Blanc
January 18, 1971 – September 25, 2007



Kathryn Elizabeth Gardia
August 12, 1988 – February 25, 2007



Charles Lee Markham
October 3, 1965 – June 28, 2005



Jennifer Anne Hornstra
June 20, 1980 – March 9, 2003



Shannon Lea Petersen
May 30, 1967 – September 20, 2008

If you'd like to share a photo of your loved one for this newsletter's We Fondly Remember section, please e-mail it to



donorfamily@kidney.org

or mail it to:

National Donor Family Council
National Kidney Foundation
30 East 33rd Street
New York, NY 10016

Please indicate that it's for the *FTWGG* newsletter and include your name and contact information, along with your loved one's name, date of birth and date of death.

DONOR FAMILY *voices*



FOR THOSE OF US WHO'VE LOST A LOVED ONE, holidays can be exhausting. Amidst the hustle and bustle of the season, it's important to give ourselves "permission" to do what's necessary to help us cope. What helps you get through the holidays?

Editor's Note: We asked families these questions on our donor family e-mail list; some of their responses follow. Please visit www.donorfamilyforums.org to read the full responses or to share your own experience. To join the e-mail list, write to donorfamily@kidney.org and ask to "Join the NDFC e-mail list."

Since I lost my son Justin close to Christmas, it was especially painful to celebrate my favorite holiday without him. My family and I decided to travel to a new, sunnier destination over the holiday rather than spend it at home. We invite other family members to join us. Each family member chooses one activity they want to do there. It could be stargazing or snorkeling or just trying a local restaurant. We started a new tradition that helped us start living again.

– Pamela White



Our 17-year-old daughter died right before Christmas. Sarah loved Christmas and had just decorated our home for the holidays. Every year on the anniversary of her death, we decorate the house as a way of remembering her. Our family has always attempted to avoid "hustle and bustle" around the holiday and focus on the meaning of giving. We honor Sarah and her passion for teaching preschool by carrying that passion on. Every year, we adopt several preschoolers who are in need of gifts and provide them with toys and clothing. This helps to focus on what brings hope rather than on what we are missing.

– Sue Wintz



I lost my 16-year-old daughter, Tiffany Taylor, on December 24, 1996. Christmas had always been my favorite time of year, and I was determined that in memory of my daughter, I would not let that change. Every Christmas Eve, I light a candle and burn it all day in her memory. I know she would want me to continue to love Christmas and to be thankful for the time we had together.

– Linda Brown



My son Terry died March 11, 1998 at age 19 and gave the gift of life to seven people. Christmas was his favorite holiday. I buy a special ornament each year in his honor. When I have grandchildren, I will pass these ornaments onto them and tell them of the uncle they never met. I also buy gifts for less fortunate families and children in Terry's honor. He was always a giving person and this way he still gives on long after death.

– Kathy Snow

My 19-year-old son died in 2003, right before Thanksgiving. Needless to say, that holiday and Christmas just really didn't happen for me. The first few years, I didn't even do any decorating, except at my son's grave. Now, I put up the tree and get into the spirit, but perhaps not in the same way. I always buy special ornaments for my daughter and myself in remembrance. I also like to donate to charity in memory of my son. Knowing that he was an organ donor and helped so many is also a comfort. But the holidays will never be what they used to be, and I have accepted that new reality.

– Stephanie Willis



We have a special ornament for Mac on our Christmas tree. We have a wreath that I made and a special poem that we read as we light candles in remembrance of him. This is always a part of our holiday to keep his memory alive. We talk and remember stories of our fun times. He is always with us.

– Linda Winkle



I am organizing a candle lighting ceremony in our community. I got involved with the Boys & Girls Club, which my daughter liked, and brought the "Festival of Trees" to our town. This is my way of keeping her spirit alive. Christmas was always her favorite holiday, and she was always about giving to others.

– Linda Johnson



This is our fourth holiday season since my husband, Ron, passed. What helps me through the holidays is respecting and honoring the traditions of the past that were important to us as a family, but also realizing that we need to establish new traditions that reflect who we are in the here and now. We still have the traditional Christmas Eve dinner, but instead of another big meal at home on Christmas, we go to a very exclusive inn, and let ourselves be pampered by the very attentive staff. On the way home, we get a movie, and enjoy family quiet time at home with the "Yule Log" ablaze in the family room fireplace. This is our time to talk about Christmas Past and keep Ron's memory a part of our celebration.

– Mary Schuler



GIVING YOURSELF *permission this holiday season*

By Rebecca Simon, Family Services Coordinator, Pacific Northwest Transplant Bank

THE HOLIDAY SEASON CAN BE A DRAINING TIME. For those who have lost a loved one, it can sometimes feel almost unbearable. Expectations of family, friends and colleagues to celebrate, “be over it by now,” and “move on” can cause those who are grieving to feel isolated, exhausted and overwhelmed.

This holiday season I ask that you give yourself permission to:

- SURROUND yourself with those you love.
- GIVE yourself time alone as you want or need it.
- DECLINE events that you do not feel up to attending.
- TAKE care of yourself physically and mentally.
- ASK for help.
- MOURN.
- CRY.

I also ask that you give yourself permission to:

- REMEMBER your loved one who has died: mention his or her name.
- HUG, and let yourself be hugged.
- SHARE stories with friends and family.
- REST.
- LAUGH.
- BE KIND to yourself.

Ultimately, you are the best judge of your own needs. On the days, in the hours, when you are feeling lost and/or alone, remember that you are not.

“May every sunrise hold more promise, every moonrise hold more peace.”

—Anonymous

Donor family voices (Continued from page 4)

For the first four years after my son Nick died in a bicycle accident, I couldn't bear to put up a Christmas tree, so we hung favorite ornaments from our living room archways. Since I had given both of my children a special ornament at each Christmas, I had 24 wonderful, memory-making ornaments to hang for Nick. In the past few years, we again began putting up a tree, but we put all of Nick's ornaments on the mantle in a special place of honor. As I look at each one I remember why he received each ornament (a soccer-playing Santa for the high school soccer days, a hot-air balloon for his trip to England) and I smile at those cherished memories. I have found that creating a ritual involving the life of Nick, rather than just his death, has helped me heal. I do sometimes look at the ornaments and feel sad for a moment, but I think that is just part of the “healing, but not forgetting” part of losing a child.

—Peggy Lehr

For the first three years after my husband's death, I didn't decorate for any holidays. Then, the next year my seven-year-old granddaughter asked me why I didn't have a tree “like grampa used to put up.” Since then, I have a tree, and our family spends a little time talking about our memories

of Christmases when he was alive. I realized that not keeping rituals was stealing from those of us still alive.

—Peggy Salters

It seems like only yesterday since I lost the love of my life—my husband Cliff Echols. He was only 36. Even though it's been eight years, my heart still feels the love deep inside and that helps keep his spirit alive within me. One of my favorite movie quotes of all times sums it up. “If the people we love are taken from us, the way they live on is to never stop loving them. Buildings burn, people die, but real love is forever.”

—Robin Cote

Holidays can be a very emotional time after losing a loved one. We lost our daughter Kacy on July 29, 2007 in an auto accident. We have not yet put up a tree in our home for Christmas, as it just has not felt right. However, I purchased a small tree in a basket, decorated it all in hot pink (Kacy's favorite and signature color) and placed it at the cemetery. Additionally others will bring a new ornament and place it on her tree; we call it Kacy's Place.

—Theresa Wagner

GRIEF *and unfinished business*

By Kathleen Braza, M.A.

If only I'd said "I love you" before he died.

If only we had taken that trip to Hawaii.

If only Mother had received flowers while she was alive.

DO ANY OF THESE EXPRESSIONS SOUND FAMILIAR TO YOU?

Have you heard these words of regret and frustration from others? All too often, these expressions of "unfinished business" can become obstacles to the mourning process.

Unfinished business has been defined as "something that is incomplete in our lives and deprives us of a sense of peace." It is almost always about relationships and includes things said or unsaid, done or not done. It is often reflected in statements preceded by the words, "if only."

Unfinished business might be expressed with comments, such as, "Why was I so concerned about being a perfect housekeeper? Why didn't I play more with my children instead?" Or, "Why didn't I just get him to the doctor for a complete physical?" and, "Why didn't we go to Disneyland with the kids instead of recarpeting the house this year?"

These expressions of guilt, remorse and resentment can prolong or delay a healthy grief and mourning process. They can make you feel "stuck" in your grief. Unfinished business can continue long after a death and make healthy reconciliation of grief difficult.

You may have also "collected" unfinished business by not expressing your honest feelings when they were appropriate and timely. How many of us are carrying around old hurts and resentments from someone who offended or disappointed us in some way? How many of us have hearts that are weary from holding on to hurt or fear? Perhaps the concept of "letting go," so often used in grief work, also relates to letting go of the pain of unfinished business that can wear heavily on our hearts and, perhaps, even our souls.

Some unfinished business is centered around painful physical and emotional trauma, such as child abuse and incest. These issues usually require professional intervention to help in the healing process.

However, in many cases, we can take care of our unfinished business – even with someone who has died. One profound way is to write a letter (or many letters) to the deceased and express all that is in your heart, painful as well as wonderful. Then, write a letter from the deceased person back to you and listen for the messages you need to hear. You may want to read the letters out loud to yourself or a trusted friend.

Daily journaling, making an audio or video tape, or mentally putting the

deceased in a chair across from you and just talking things out are also healing strategies for dealing with unfinished business. Take a walk and

Daily journaling, making an audio or video tape, or mentally putting the deceased in a chair across from you and just talking things out are also healing strategies for dealing with unfinished business.

mentally have the individual you need to talk to join you. Share what you feel. The walk can also release the energy and anxiety that builds up in the process.

Grief needs expression in healing ways. You may have heard the expression, "What we resist, persists." The more we resist our grief and the painful process of completing our unfinished business, the more it will persist in our lives. But if we can find ways to work through our "unfinished business," it can help us live more fully, love more completely and experience peace.

after the SHARK bite

An Interview with Tyler Gray, Bone Recipient

AT THE 2007 NATIONAL DONOR RECOGNITION CEREMONY IN WASHINGTON DC, donor families watched a Donate Life campaign featuring organ and tissue recipients. Particularly memorable was Tyler Gray, a teenage recipient of donor bone, who said, "Sometimes I like to tell people that I got my scars from a shark bite – girls love it when I tell them that."

For Those Who Give and Grieve recently had an opportunity to talk with Tyler Gray, who is now 21 years old and a student at Western Carolina University:

When donor families saw the ad campaign you were featured in, you made us laugh and we were charmed. You received a bone graft in your leg as the result of having bone cancer (and not really from a shark bite). How old were you when all this happened? Why was the bone graft important to your recovery?

I was diagnosed with Ewing's Sarcoma nine years ago, which is a rare type of bone cancer. I was a research patient for a new type of chemotherapy that was given to me every other week for a year and a half. I also went through a ten-hour surgery to remove a portion of my right femur and replace it with new bone from a donor, along with two titanium plates and about 25 screws. The bone graft saved my right leg from being amputated.

Since that surgery, what have you gone on to do that you hoped and dreamed you'd be able to do?

Today I am living life just like a normal college student, and most people never guess that I went through what I did. I love the outdoors, especially since my college is located in the perfect spot for hiking, backpacking, and all other types of activities in the Appalachian Mountains.

What are you studying in college?

I am going into my senior year at Western Carolina University with a major in Natural Resource Conservation Management with a concentration in soil and water. I am trying to make it into Graduate School for Forestry.

Having such a serious, life-changing experience at a young age, do you believe it's shaped the way you live your life?

It seems like forever since I was lying in a hospital bed with chemotherapy being pumped into my body. Some people say that I am a miracle, but I just think that I was put on this world for a purpose. A saying that I go by is "Live for the day, but always hope for tomorrow." I can't be thankful enough that someone was willing to donate a loved one's tissue (bone), so that I could have a second chance at life.

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The **Quilt** on Tour

Please note: This schedule is subject to change. Call the National Donor Family Council at 800.622.9010 for the most up-to-date information. The entire Quilt is not on display at these events, and not all events are open to the public. Please call the contact person for more information.

2010

July 30–
August 4

Madison, WI, National Kidney Foundation, *2010 U.S. Transplant Games*, Marilyn Jones, 800.622.9010

April 24

Modesto, CA, California Transplant Donor Network, *2010 Honor & Remembrance Ceremony*, Trace'e L. Harris, 209.613.7266

One panel of the National Donor Family Quilt is displayed year-round at the National Donor Memorial in Richmond, VA. (This Quilt panel will sometimes be moved for display at other national events.) For more information, contact Marilyn Jones at 800.622.9010.

For information about reserving a Quilt panel, please contact the NDFC for updated information and pricing. The NDFC can be reached by e-mail at **donorfamily@kidney.org** or by phone toll-free at 800.622.9010. Please notify the NDFC of any special requests, including requests for a specific panel of the Quilt. Arrangements will need to be made to display the Quilt properly and obtain permission from the venue where the Quilt will be displayed.

The mission of the National Donor Family Council is to enhance the sensitivity and effectiveness of the organ and tissue recovery process, to provide opportunities for families to grieve and grow, and to utilize the unique perspective and experiences of these families to increase organ and tissue donation.