

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 2006

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

Volume 15, Number 2

EVERY DAY IS A *celebration*

By Rebekah Arsenault, LifeLink Foundation

THE HOLIDAYS ARE APPRECIATED TO A MUCH GREATER EXTENT THESE DAYS BY THE VILA FAMILY. Marcelino—Marc to his friends and loved ones—underwent a liver transplant in 2004. The day has become a holiday in its own right for the Vilas. “My transplant date is my second birthday,” says Marc, “and my holiday celebrations now include prayers of thanks. Gratitude has become a huge part of my life.”

The owner of a radio station, Marc devotes daily airtime to educating the public about organ and tissue donation. He recognizes that he received a gift two years ago, and began commemorating the generosity of donors and donor families just days after his surgery.

“I received my new liver on a Saturday, and Monday morning, the first phone call I made was to the radio station. I said I wanted information on donation and transplantation played on the air every half hour.”

died waiting for transplants.” The chance to share winter celebrations with his family, Marc notes, “is cause for immediate thanks.”

Hoping it would brighten the holidays of donor families, Marc shared the following insights.

How do you celebrate your transplant date?

We make it a point to go away. My wife and I take several days off and celebrate life. We don't let the day pass by, because we want to use it as a way to say thanks.

Have your personal spiritual beliefs been affected by your transplant?

Yes. I was feeling so bad...not just having no energy, but I couldn't remember things...now my mind is sharp again and it's something to be thankful for. It's a miracle made possible by my donor and their family. When I see people who only saw me before my transplant, and I hear how good I look and

"The fact that I am here to be with my family is because of someone else... and I feel grateful."



The father of a young transplant recipient lights candles in gratitude at the Donor Recognition Ceremony at the 2006 U.S. Transplant Games in Louisville, Kentucky.

Photo by Erica Berger

After Marc's transplant, he welcomed his granddaughter into the world and attended his son's wedding. Neither of these celebratory events would have been possible for him had he not received the gift of life. Marc acknowledges that he is one of the lucky ones. “Everything has more meaning, and the holidays are more special now. I know two people who have

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Every Day is a Celebration Continued from page 1

how well I'm doing, I remind them it's due to someone else. Someone truly saved my life.

How do you think your donor family would react to the passion you now have regarding donation?

I think they would be appreciative. I do it out of happiness; I do it because I want to do it. I want to help others now, so I give support to people on the waiting list. I want to give hope and inspiration. I'm committed to doing it. It's become my cause. Before, it was a public service when I shared information. Now it's a personal commitment.

How have holidays changed for you since your transplant?

The fact that I am here to be with my family is because of someone else. And not just on the holidays but every day, simple things during my daily routine make me stop and reflect on the chance I was given. And I feel grateful. Every day is a celebration, made possible by donors and their families.

The Day After

By Douglas Harrell, Donor Husband

I stumbled over your shoes today
They were in the middle of the floor
Right where you always left them
For a moment the world was right again
Until I remembered
I started to put them away
But then I put them back
So I can stumble again tomorrow

DEAR
fellow donor family members,

Along with family, I helped make the decision of donating my sister's organs. Vickie and I were very close and had talked about organ donation. We both thought it was a good thing to do, but I didn't take it into serious consideration until our family was faced with it in September 2003.

Vickie was my only sister, and she passed away of a brain aneurysm at the age of 38, on her only daughter's eighth birthday. She also left four sons behind. It has been a rough road with many angry, lonely and sad times. Lots of questions of *why?* and *how can this be happening to our family?*

Now, I am proud to be part of a donor family. It has brought our family comfort knowing that Vickie is still with us through somebody who is full of life and enjoys every minute of it, just as my sister did.

She won't be here for her five children. She held the family together even through tough times. This was the first real tragedy for us with somebody so young in our family. We were all lost and in disbelief.

My family and I had spent that day with Vickie and her family. It was my last day with her and I thank God for the time we had. I never want to forget that day. I hang on to every memory I can. The first six months I had a hard time remembering because I was trying too hard. Now I remember many fun times with her; they come back with the littlest



*In memory of
Vickie I. Dirkschneider*

reminders. These are so precious to me and now I write them down in a journal.

I decided to contact the recipient of one of her kidneys and pancreas. She shares the same first name and spelling as my sister. It amazed me that they are very close in age and share similar interests.

I got to speak with her after a year. She was very gracious and excited to have a second chance at life. She had severe diabetes from childhood and had been in a coma for five days before receiving her transplant. There were many ups and downs in her life associated with her health. She has two children and family members that are so grateful for the organ donation. I have heard from her sisters and mother and she has wonderful support. I enjoy speaking with her and seeing the results of what an organ donation can bring.

Now, I am proud to be part of a donor family. It has brought our family comfort knowing that Vickie is still with us through somebody who is full of life and enjoys every minute of it, just as my sister did. I consider Vickie to be a true miracle to help continue the life of somebody she didn't know. My husband, 16-year-old son and I are registered organ donors and our family knows what our wishes are. We want to leave this world knowing we could help someone continue their life as my sister did.

*Sincerely,
Cindy Albus, Donor Sister
North Bend, NE*

"ATTENTION ALL YOU UNDER USED CARS!"

"IF YOU'RE HANGING OUT BY THE GARAGE, JUST RUSTING, CALL KIDNEY CARS AND DONATE YOURSELF TO HELP FIGHT KIDNEY DISEASE AND SAVE LIVES."

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"SO DON'T JUST PARK THERE LEAKING OIL, PUT IT IN GEAR AND CALL THE NATIONAL KIDNEY FOUNDATION... BECAUSE IT'S DONATE OR OXIDATE!"

1-800-488-CARS
www.kidneycars.org

FINDING MEANING *in rituals*

By Charles A. Corr, PhD, CT

AFTER THE DEATH OF A LOVED ONE, DONOR FAMILY MEMBERS FACE MANY CHALLENGES. Not least among these may be challenges associated with rituals of various types.

Long-established rituals are well known at birthdays, anniversaries, holidays and other special times. For example, we may light candles on birthday cakes and

When a person whom we love dies, however, that event may impact these time-worn rituals in unfamiliar ways. Some bereaved people cling tightly to old rituals as ways of finding solace and security in a time of confusion and pain.

Other donor family members may find now that old rituals are hurtful when many people appear to be so blissfully happy, but the bereaved can

Explain what you are doing so that others may understand.

You may also want to develop new rituals that can become sources of strength and gratification. When a ritual is “broken,” it no longer works effectively for you. In those circumstances, it is perfectly appropriate to develop new rituals whether on a temporary or a permanent basis.

What you do in a ritual isn't always the most important thing. What is important is that the new ritual serves your needs at a difficult time in your life.

make wishes; share a glass of champagne at weddings and other anniversaries; give gifts at Christmas, Hanukah, or Kwanzaa; or have a special meal at Thanksgiving.

The purpose of ritual activities is to bring us together with those we love, either physically or psychologically, in order to act in ways we recognize, know and cherish. Rituals guide us as individuals, members of families and participants in larger communities. They involve us in activities that provide comfort and meaning.

only think of the absence of their loved one. Some of these families may want to create new rituals to honor their deceased loved one. Each individual and family can decide what feels right to them.

It is important to set boundaries for yourself when you are bereaved. Do not allow even the well-intended wishes of others to draw you into activities that require too much of you. Take part in old rituals as you are able, but feel free to withdraw or hold back when you need to do so.

What you do in a ritual isn't always the most important thing. What is important is that the new ritual serves your needs at a difficult time in your life. You may only need the new ritual for a little while or it may come to replace an old ritual for the remainder of your life.

What is most significant for you now about any old or new ritual is that it should affirm the life and legacy of your loved one, express the joy and happiness you were privileged to share together, maintain a new, ongoing connection with your special person, and bring some measure of consolation to you in your bereavement.

DONOR FAMILY *voices*

DOES YOUR FAMILY HAVE ANY SPECIAL RITUALS TO HONOR YOUR LOVED ONE during the holidays? Do you do anything special to remember their life and gifts? Have you changed any old family rituals or added new ones? Selected responses from our e-mail list follow. To join the e-mail list, write to donorfamily@kidney.org and ask to be added to the NDFC e-mail list. To read the full responses, please visit www.donorfamilyforums.org



A special ritual is planting a tree in honor of a loved one.

On TJ's birthday, we buy a small cake and talk about the silly things he did and the things we loved about him most.

—Terry Blinkenberg

On Valentine's Day, we meet at the cemetery with red and white balloons, and with our Valentines tied to the strings we let the balloons go up to heaven. On Father's Day we send Father's Day balloons, along with cards. Sometimes we include pictures of my kids.

—Laura Winterton

In August, we have a memorial picnic, and in September, we have a memorial walk. We started a scholarship fund at the high school where my daughter taught music.

—Patricia Oines

A friend made my son a blanket out of my husband's old shirts. Someone else is making my daughter a pillow from a dress my husband bought for her on Christmas the year he died.

—Helen Gregory

The year after my sister died, we sent out a Christmas letter and asked that people e-mail us or send us a letter of memories they had of my sister. Then, as they would come in we put them in a stocking and on Christmas we read them. Now, we have put them in a memory book. This really helped the grieving process and helped us to honor her in a special way.

—Raenelle Finney

Every year, my Aunt Pat gets out a white teddy bear with Beth's name on it. She announces to everyone that Beth

is still part of the ceremony as we call out names for gifts.

—Teresa Colburn Bird

We now had one less birthday to celebrate in our family, but his birthday could not be forgotten. So we changed the date to "Parents' Day" to commemorate that our first-born son made us parents for the first time. Our remaining six children do not forget and send us Happy Parents' Day greetings on November 22.

—Kevin and Phyllis Cogan

For Thanksgiving, we left Derrick's place at the table vacant and had a plate there turned over with a candle lit in his honor.

—Sherry Ellis-Freeman

Over the years we have implemented several "quiet rituals" to remember him during special times. I bake his favorite cake on his birthday and share it with family, friends and co-workers. For both his birthday and Christmas, I donate the money that I would have spent on his gift to a charitable organization or participate in the local "angel tree" program.

—Diedra (Dee) Thompson

For many years, my extended family gathered at our grandparents' home, with the last child to arrive placing a little blue bell on the Christmas tree. Grace used to complain because we always got there early to help, so she never got to put the bell on the tree. Last year my mother put the bell on the tree, saying the tradition has changed. The bell will always be the

first ornament on the tree, Grace's bell, because she was the first to arrive at our eternal home and will be there to greet us.

—Lisa Lovegrove

We began a tradition of having an "Anniversary Mass" said in the small chapel at our parish on a Saturday morning in December. This allowed us a more private, quiet time to pray and remember Michael.

—Donna Geffen

I started a butterfly garden that has butterfly bushes, beautiful flowers, and a solar light to see at night. For Mother's Day this year, my daughters gave me things to add to my garden. Our butterfly visitors have been everything from a tiny white, simple butterfly, to a three inch monarch. These butterflies actually land on us, and just give us a comforting feeling! Chris, we miss you tremendously, and hope that you will keep sending your butterflies, because like you, they are a true work of art!

—Julie Walker

Every anniversary day of the death we do good deeds in Chad's name. Last year we walked a neighbor's dog because Chad loved animals. We took flowers to an elderly neighbor because Chad loved his grandparents. We played video games and laughed because Chad loved doing that. Each year we come up with creative ways to implement the good things he gave to the world when he was alive. We carry on those "good things" for him.

—Carolyn Moor

Continued on page 6

We put flowers on Amanda's grave for holidays and on her birthday. Just making sure her grave is marked with flowers during a time that we are especially missing her gives comfort. Our faith in God continues to sustain us and give us hope even in the darkest days. Our church family is especially supportive.

—Cheryl Manley

When my daughter died, her cousin wrote a poem called "She Shines." We started collecting stars and angels and have a Christmas tree with that theme. Wherever we celebrate the holiday, our family includes a centerpiece or garland with stars as a quiet reminder that they remember.

—Patti Norquist

Stephanie was born on Thanksgiving Eve in 1986. After she died, I decided that the only way to get through the day was to be together, so I invited everyone to our house and we celebrated Thanksgiving in Stephanie's memory.

—Patty Smith

I buy special ornaments for the Christmas tree for him. I buy extra food and gifts for the needy. I try to

buy everything on their list. This is my gift to my son or from my son. The best is just to follow your heart. Your heart will guide you to what you need to do to help you heal.

—D. Sue Logan

On the anniversary of Jacob's death, I shoot fireworks off on his grave. (He died July 6th.) I take the day off from work. I put a memorial in our local newspaper. I spend the day with my mother and a quiet evening with my spouse.

—Kelly DeLine

My daughter Kelly died on December 23rd. Christmas is quite different now in my family's lives. We have learned how to be sad when we need to and joyful when we can. It is a reality that we are not the same people anymore so we don't try to pretend for the world that the holidays are the same. Ten years later we put our daughter's portrait on the fireplace mantle and decorate around her. Her stocking hangs with the rest of ours and every Christmas St. Nick leaves a teddy bear in her stocking. My other kids love to see what she gets every year!

—Patricia Morrison

Noah's birthday is on October 30. On Halloween, we decorate the front of our house as Noah's Pumpkin Patch. It is a very kid-friendly display since Noah was only 2 1/2 years old when he died. On Hanukkah, we light a separate Menorah for Noah.

—Gabi Tidhar

We have memory meals on Jennifer's birthday, preparing her favorite foods even if it results in a "different" combination. There is no rule against waffles and clam chowder for dinner! Jennifer loved coffee and one year I asked everyone to think of her as they had their morning cup of coffee. On the second anniversary of Jenn's death we started a tradition of volunteering at a soup kitchen, because Jennifer had always wanted to serve a meal there.

Just because something felt right one holiday or birthday, it may not be the right plan the next year. Take time each year to decide what will bring you comfort and then try to make it happen. You've grown and changed and so has your grief. Take inventory with yourself and develop a new plan to care for yourself.

—Lorraine Tierney

WE FONDLY *remember...*



Delaney Elizabeth Shelton
January 14, 2000 –
May 12, 2004



Gary Paul Tillman
April 2, 1976 –
May 6, 1996



Jaime Foust
May 18, 1979 –
May 24, 2004

MY BROTHER *Robbie*

By Mia Lester, Donor Sister, age 14
For Those Who Give and Grieve *Teen Editor*

I was living the life any typical 5-year-old would, a life full of fun and no responsibilities. Until, in September 1996, one day changed my average life forever. I lost my 16-year-old brother Robbie because of stupidity; a mistake someone else made took his life. Of course accidents happen, but the consequences my family would suffer were beyond small.

Because of this unexplainable event, my family seemed to be lost. My mom stayed distant, blaming herself for everything. This had to be instinct. What's a mother to do when she loses a son? Your children are supposed to bury you, not the other way around. I knew this wasn't her fault, even though she thought she could have prevented it. In life you don't know what to expect. She couldn't go through life holding his hand; eventually she had to let go, and she knew it as well as anyone.

My other brother Alex was 14 at the time and had no idea what to do. Nothing he did would bring Robbie back. Most people understand the relationships between brothers. Fighting, disagreeing, but no matter how harsh of an argument they had, they knew they loved each other. But something troubled Alex and his pain was clear: regret, something that many

people suffer with. He regretted the fights, the words, and the tears. I hardly understood it all; I wanted to do so much, but what? I just wanted him back. I didn't have memories to hold on to, at least not any I could remember. I may not have memories but others did and this unknown figure I couldn't imagine came back to me. The gentle, caring, loving young man that everyone loved. The boy who would never judge you or hurt a soul. He was always there whether you needed just a hug, or shoulder to cry on. I knew from these memories that he would never be forgotten, by friends, by family, by me.

Life continued to feel empty for the longest time. We all felt shut out. But eventually life took a turn. Things actually started to feel okay. My mom and a friend of hers both had devastating stories of losing their children. So through this rough time, they decided to start the Donor



Robbie Sisemore

Family Network. This made a change in not only my life, but also in the lives of others. My mother finally came out of the depression that we all knew she'd disappeared into since the day of Robbie's death. She now was able to tell her story.

My brother saved the lives of many people. He may not be able to see how much of a hero he was, but we all do, and we'll never forget.

My brother saved the lives of many people. He may not be able to see how much of a hero he was, but we all do, and we'll never forget.



The *Quilt* on Tour

Since 1995, over 2,000 families have created Quilt squares for Patches of Love, the National Donor Family Quilt. The Quilt is an ever growing memorial created by donor families in honor of our loved ones.

The Quilt travels to events throughout the world to pay special tribute to our loved ones while raising awareness about donation. Donor families, professionals, and organizations may reserve one or two panels of the Quilt for display. There is a small fee to cover shipping and maintenance of the Quilt.

Donor families can request their loved one's Quilt panel for display at local events, special occasions or holidays. Some families reserve a Quilt panel for family reunions, memorial services, weddings, birthdays, or anniversaries.

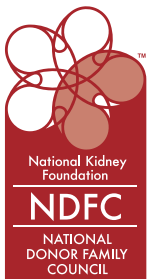
Where Can the Quilt Be Displayed?

Families and organizations can display the Quilt almost anywhere, at both public and private events including:

- Local events honoring donors, such as donor recognition ceremonies, memorial events, dinners, brunches, picnics
- Family gatherings or milestone events, such as reunions, memorial services, weddings, anniversaries, birthdays or holidays
- Donor awareness activities (April is National Donate Life Month, but the Quilt can be reserved for a donor awareness campaign at any time)
- Educational workshops, support groups
- Shopping malls, holiday gift fairs
- Universities, schools, lecture halls, libraries
- Places of employment
- Places of worship: local churches, synagogues, mosques, or other places
- Arts and crafts shows, art classes, quilt making workshops
- Health fairs, health screenings, hospitals, nursing homes

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.



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