

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 1999

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The Crystal Tree


*I*n December of 1990, even though it had been only three months after the death of my only child, I still desperately wanted to have a Christmas tree. I remembered decorating the trees of Christmases past with my son, Shawn. I joked that my 16-year-old son would be quite upset and come back and haunt me if I did not have a tree. I put up a tree that year, but it only saddened me and reminded me of my loss.

The next year was better, probably due to the ornaments that I had stumbled upon. In early September, we visited Shawn's grave. On the way home, I had this overwhelming need to stop at the Brooksville Christmas Cottage that I saw advertised on a billboard. I entered the first of five cottages and my heart filled with wonder as I was immersed in a breath-taking world of Christmas. My eyes fell upon a delicately painted sand dollar with a little boy angel and the words "The Lord is watching over thee." It was as if Shawn was telling me something. In the last cottage, I could not believe it when I found black and white soccer ball Christmas ornaments and a soccer player. Shawn loved soccer, and I had to have them.

That year, I pulled out the ornaments filled with memories of Shawn. The soccer balls could be seen, but still sadness surrounded the tree. I am a member of the Compassionate Friends support group, and at Christmastime we gather at the home of one of our members. I was mesmerized with their tree. It was

filled with tiny lights that made each delicate crystal ornament dance in merriment and celebration. They, too, had lost their only child, yet their tree brought me a peacefulness that I longed for during the holiday season.

I started collecting crystal ornaments, especially angels—they made me think of Shawn. It was not my intention, but year by year more and more of the homemade ornaments were not placed on the tree. Oh, I would caress each of the homemade ornaments and relive the memory, but then I would place it carefully back into the box. My Christmas tree slowly transformed from a tree filled with memories of the past to a Christmas tree that brings me hope for the future. In 1998, I again visited our friends and told them of the impact their Christmas tree had on my life. It was then that I learned that their tree, too, came about after their son's death.

This year, my Christmas tree will twinkle with white bell lights that softly fill the air with songs of the season. Silver and white bows from my 25th wedding vow renewal have found a place on the tree. An angel rests on top, her wings fluttering gently as she guides you with a lighted candle. Delicate ornaments of crystal grace the branches, catching specks of light. I only wish Shawn could see our crystal tree. 

*Mary Carpenter
Co-editor in Chief*

Faith in Love

by Jennifer Locken

The wind of change has passed on by
The dust of grief has yet to dry
The love I knew
The pain so deep
Words of love unsaid - unheard
When I wake will my
heart still ache
For one last smile,
one last hug before you go
Before you leave this world I know
Faith in love
Faith in you.

In Memory of Tina

by Grandma Baker

An angel came to our home
To stay a little while
We never will forget her
Or her loving smile
Now she's gone there is nothing we can say
Except if we could be more like her
We will meet again someday
She lost her life trying to protect Rossie her pal
She didn't get to say goodbye to us
But we know she's in heaven now.



In Memory of Jade

There's a big Christmas tree in one of the medical buildings here in Spokane. It's decorated with lights and picture ornaments of organ donors and recipients. The pictures of the organ donors have green ribbons on them with information about the donor on the back.

My daughter, Jade Moore, was murdered in April of 1996. I've lived for two years without her and I honestly wonder if I can really go on for one more

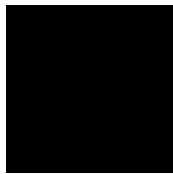
day. I would give my life to hug her just one more time, to see her cute little smile, hear her silly little laugh or to worry about her. It's funny, the things I miss. I will love her and miss her and ache until I die. Knowing that she has helped to save lives is one of the things that keeps me going. A mother's love is forever.

Terri Moore
Jade's Mama
Always and Forever

We Fondly Remember



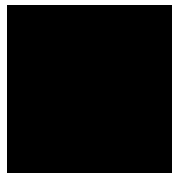
Austin H. Sealock
September 12, 1997-
June 11, 1998



Jon Janzen
January 24, 1978-
March 31, 1996



Nina Ilene Bearth
July 11, 1981-
May 29, 1998



Paul Coulson
May 2, 1979-
August 6, 1995



Lori Frey-Melbourne
November 26, 1958-
September 15, 1998



Jasper Wayne Burns
March 16, 1983-
February 11, 1999



Angela

by Suzie Marine

*I*t's been almost a year since my younger sister was killed in a car accident, but the pain of her death is still fresh. Since memories have no time or space, each time I remember that she's gone, the grief comes back again.


Things I took for granted when she was alive, I would give anything to have now—to hold her hand and feel her soft warm skin, to hear her giggle when she thought something was funny and to look right into her dark blue eyes.

Sometimes, if I'm quiet, I can close my eyes and see her. She smiles so sweetly and her eyes are bright. She isn't sad or broken, like she was before we lost

her, but she looks healthy and strong. She is beautiful.

I can't touch her anymore, or talk to her, but somehow I know she lives. She exists in a better form, a better place, and she's safe now. Nothing can ever hurt her again. Though we're separated right now, the love we gave each other as sisters isn't gone. She's still my sister, and I am still hers.

But I miss her.

Angela Louise Jenkins was killed in a car accident on February 18, 1996. She was 20 years old. 



The Quilt on Tour

Please note: This schedule is subject to change.

Oct. 28-Nov2 & 9-15	Midwest Organ Bank, <i>Donor Awareness Activities</i> ; Westwood, KS. Contact: Marcia Schoenfeld, 913/262-1698.
November 3	Vanderbilt Transplant Center, <i>Vanderbilt Transplant Center 10-Year Anniversary Celebration</i> ; Nashville, TN. Contact: Yvonne A. Money Penny, 615/936-0388.
November 4-7	<i>Giving, Grieving, Growing: An Educational and Support Program for Donor Families at the National Kidney Foundation Annual Meeting</i> ; Miami, FL. Contact: Sarah Acosta, 800/622-9010.
November 9-18	Donor Network of Arizona, <i>Donor Sabbath Events</i> ; Phoenix, AZ. Contact: Sara Pace Jones, 602/222-2200.
November 12-20*	NKF of Hawaii, <i>National Donor Sabbath Weekend; Miss Saigon cast fund raisers</i> ; Honolulu, HI. Contact: Sharon Arneson, 808/593-1515.
November 14*	Golden State Donor Services, <i>Donor Family Recognition Ceremony</i> ; Sacramento, CA. Contact: Tracy Bryan, 916/567-1600.
November 14*	LifeLink of Georgia; Atlanta, Georgia. Contact: Linda Ickes 800/544-6667 (or Skip Wisenbaker)
Thanksgiving/Christmas*	NKF of the Delaware Valley; Philadelphia, PA. Contact: Karen McGrath, 215/923-8611.

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 individual listed above.** 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 (800) 622-9010 for up-to-date information. Information about the quilt can also be viewed on our website at

www.kidney.org

* Not yet confirmed.

REACHING OUT IN YOUR COMMUNITY


A Special Bond

by Darlene Woldt

When my 18-year-old son, Derek, died in 1990 by suicide, our family was faced with the decision to donate his organs. Although my first inclination was to say no, my daughter convinced me this was the right thing to do. Since that cold day in November, we have met all four recipients and their families. What a special bond between strangers!

Three months after Derek's death, it was his birthday. How could I get through his birthday? I decided to write a letter to the recipients and enclose a picture of my son. I sent these letters to the hospital where the transplant took place and asked that they be forwarded to the recipients.

Within three years, we had met all of the recipients. Although the heart recipient only lived five years, the others are doing well and we keep in touch with them throughout the year.


My son's death has taught me a lot about death and grief, but also a lot about life. Derek was a special son and had many friends, and now strangers know about a special 18-year-old from Wisconsin. In memory of my son, I now speak to community organizations on the importance of organ donation. Several years ago, after speaking to more than 300 high school students, I saw many of them wait in line to get the orange donor sticker to attach to their driver's license. Awareness does make a difference. Derek would be proud. 



Suicide: Breaking Through the Silence *continued from page 4*

Each one of us copes with death in a different way. Communication is extremely important to the way a family deals with suicide's aftermath. This tragedy will affect the foundation of a family and can bring family members closer together or tear them apart. Support among family members is a crucial part of the grief process.

Allowing yourself to fully grieve and be as aware as possible of what you feel will help to open the channels of communication. Let others know you need help or need to talk. While it is understandable that the unique pain of a suicide often makes it extremely difficult to share this grief with others, it is precisely this sharing and communication that makes it possible for a survivor to continue on the grief journey and cope with the pain.

Lynn Phillips is a dialysis social worker at Mt. Sinai Medical Center in New York City and a psychotherapist in private practice. 

Reaching Out Through Internet Chatting

Join us on the third Tuesday of each month from 9:00-10:00 pm ET for a supportive and educational chat with donor families and bereavement and medical professionals!

- 11/16/99** Helping Children Grieve
- 12/21/99** Bereavement and Coping
Techniques for Families
- 1/18/00** The Coalition on Donation:
Awareness Initiatives
- 2/15/00** Cultural Aspects in Dealing
with Death
- 3/21/00** Tissue and Eye Donation
- 4/18/00** Communication with Recipients

Visit
**[www.kidney.org/recips/donor/
chatinfo.cfm](http://www.kidney.org/recips/donor/chatinfo.cfm)**
or call 800/622-9010
for more information.



1999 National Donor Recognition Ceremony and Workshop

We Are Not Alone

by Pat Rush

The weekend of April 16, my husband and I attended the National Donor Recognition Ceremony and Workshop in Washington, D.C. This was the first time we ventured into such a large and diverse group as donor parents. It was a remarkable and compelling time for us. It was an emotional time—painful, yet joyful. There was a great sense of compassion, empathy and comfort offered during both the workshops and social times, in the hospitality suite and registration and welcome area, and at the larger get-togethers.


We attended the workshop for parents whose children had died. NDFC Chair Vicki Crosier and Margaret Syret were the presenters, and it was the most practical, realistic and loving approach I've heard. There were no platitudes or catch phrases. Tears were shed, but there was also a great deal of laughter and empathy as these two women helped many folks to continue their journey to healing.



At the Recognition Ceremony on Sunday, Surgeon General David Satcher, MD, PhD, and Deputy Surgeon General Ken Moritsugu, MD, MPS, a donor husband and donor father, spoke very respectfully of donors and their families, but the important thanks came from the people who had received these wondrous gifts. One young woman spoke so lovingly of her twin sister who had given her a kidney and part of her pancreas. It was a moving testimony in honor of living donors, the sometimes forgotten members of the donor family.



Transplant recipients lit candles to pay tribute to donors.

Bob and I learned a great deal at this gathering. It was a special weekend for both of us. One of the most comforting feelings I came home with is that I am not alone in this place. 

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 memory of:

Mathew Zajack - by Beverly Z. Shepherd

David Franklin Garris - by Franklin and Frances Garris

THOUGHTS FROM RECIPIENTS

Dear Donor Family,

I am writing you this letter because I want you to know how grateful I am for each day of my life since receiving the kidney. I am saddened by your loss. I know it was and still is extremely difficult.

I want you to know that I take care of your gift by doing my best to stay healthy and enjoy the many pleasures in my life. I think of my donor every day of my life and I have prayed for your family many times. I also want you to know that I work full time in a doctor's office of 10 cardiologists. It is sometimes hectic but a really nice place to work.

Because of you, I was able to help take care of my father as long as he lived. He passed away three years ago, but had lived to be 103 years old. Also because of your generous gift to me, my family has specified that they wish to donate their organs and tissue at the time of their deaths. As a part of your family lives in me, so will a part of my family live on in others.

Thank you again and again for all you have given me. May God Bless You!

*Love,
Juanita Chick*

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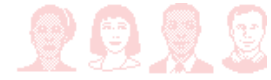
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Donor Family Friends



DF 122 My brother and best friend passed away last year because of a gun accident. I am 17 and it took a toll on me. I would like to correspond with someone who understands what would really help me deal with my grief.

DF 123 My sister died from a sudden stroke/aneurysm. She was only 35. After she died, all my brothers and sisters stopped talking to each other. Not only have I lost my sister, but my entire family. I would like to hear from someone who had a similar experience.

DF 124 I lost my 14-year-old son to meningitis three years ago. I have since had another child—a beautiful baby boy. I also have a 19-year old beautiful young lady. But I still have a very hard time with the loss of my first son. I would like to hear from others.

DF 125 My mom died in April 1999. I never told her goodbye, just that I would see her in Heaven some day. My mom was a friend to me. I still think to myself, “How am I going to cope with this pain?” She will always be in my heart. I would like to hear from those who have lost a parent.

DF 126 My husband passed away awaiting a donor heart, and instead gave a gift of his eyes and tissue. I am 53 years old and would like to share feelings and thoughts with others in a similar situation.

DF 127 My 13-year-old son was killed by a drunk driver in September 1997. It seems like yesterday. I receive comfort from religion. I would like to hear from other parents.

To submit or repeat a Donor Family Friend ad or to respond to a family, send all correspondence to Donor Family Friends, The National Kidney Foundation, 30 East 33rd Street, New York, NY 10016. Please include the number of the DF you are responding to in your letter. Do you have a child who wants a pen pal? Encourage young ones to write us for a Donor Family Friend!

Organ & Tissue
DONATION
Share your life. Share your decision.™

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
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Please help us “Cut Down” by notifying us when your address changes. It costs 33 cents if you forget.