

# FOR THOSE WHO GIVE AND GRIEVE



A quarterly newsletter for donor families, published by the National Donor Family Council of the National Kidney Foundation, Inc., to offer information about grief and support.

*For Those Who Give and Grieve* is provided to all families at no cost and is supported entirely by voluntary donations.

Fall 1997

Volume 6, Number 2

## *The Snowflake: An Act of Faith and Confidence*

by Sue, Kerri, Hollie, Heather and David Marron

Even-year-old David was going to accompany us to Justin's wake for his final goodbye. He brought with him a wooden acrobatic toy from the collection Justin had given him a few years earlier, to leave with his brother.

David insisted on having a piece of white paper and scissors to take along in the car. He went about the business of creating a pure white paper snowflake, which he placed beside Justin along with his wooden toy. On the snowflake he had written, "To Justin. Love from David." David said his goodbye and left after a short while.

The following day, David explained to me why he had placed the snowflake beside Justin in his "cradle." "Every winter, Justin always played in the snow with Casey and me," he said. We reminisced about how his brother loved winter weather and never complained of being cold. "Well, I know that

next winter Justin will drop that snowflake down on us," David added. Such unquestionable faith and confidence David has in his big brother.

As the holidays approached, I began to anticipate how difficult this first holiday season since Justin's suicide would be. My whole being was consumed by profound sadness and grief. I thought about all the traditions and preparations that I had always enjoyed. How could I possibly bring myself to celebrate in a way that would give meaning and purpose to this holiday season?

One practice I had adopted many years ago was my annual letter—a family photo and the latest update on the whereabouts and activities of each Marron. I considered a simple card for this year, or no card at all, but was not comfortable with either choice.

In mid-November, my choice was made easier. As I discarded some catalogs that had been accumulating, I gave one a frisbee-style toss toward the basket, but it fell to the floor, opening to an entire page of hand-crocheted, individually created snowflakes. Without a moment's thought or hesitation, it became perfectly clear what I would do about the holiday card: I would send a copy of David's snowflake story and one of the snowflakes to our treasured friends and family. It made perfect sense to me; David and Justin had the connection of the snowflake, and we could share this bond with others. We asked everyone to hang the snowflake in a special place in their home. A snowflake is so much like a person—totally unique and special and here on Earth for such a limited time. That was what Justin was to our family. Just as a snowflake floats down from the sky and touches the Earth, we remember how Justin touched our lives, and we cherish that memory.



# THOUGHTS FROM

## Home for Christmas

by Carol A. Ranney, Donor Family  
Member and Contributing Editor

For Calvin Paul Ranney: Nov. 10, 1982 - June 27, 1996

**H**anukkah is the Festival of Lights. It is marked by the lighting of candles in the home, beginning with one candle on the first night and adding one each following night of the holiday.

One legend tells of how Judah and his brothers came to Jerusalem, only to find the temple desolate and desecrated. They cleansed it and rededicated it on the 25th day in the winter month of Kislev in 165 B.C.E. With a little flask of holy oil expected to last only one day, they relit the great menorah. Miraculously, the oil lasted eight days, and over the years, the custom of lighting Hanukkah lights developed into the festival we celebrate today.

Because Hanukkah is a happy holiday, we do things that give happiness. We light candles, sing songs, play games (especially with a

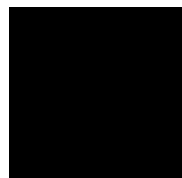
*dreidel*—a four-sided top), eat *latkes* (potato pancakes), visit with family and friends and give gifts. It is considered a *mitzvah* (good deed) to give to those in need. Originally, *gelt* (coins) constituted gifts, and they were given on one night. Today, gifts are often given each of the eight nights, and have become more elaborate.

The candles have not been lit, nor have holiday songs been sung at my house since 1988. That year, Karyn was a senior in high school, and Adam was on leave from the U.S. Army. We shared many happy times that week. Our lives were busy, our hearts full of joy at being able to spend the holiday with our family members and friends.

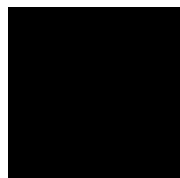
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This year, I feel like relighting my spirit and rededicating my life. I am going to celebrate Hanukkah. I have traveled a road of grief for years. I am making progress slowly but steadily, I think. Every so often, I feel myself slipping and sliding a bit, but each time I do, I find it is a little easier to get back on track. I can reach out to my friends on the road ahead of me. I am encouraged by their progress. I can lean on them and regain my strength. Some are behind me just starting their long journey. I can give them hope and tell them to take their time. We are all together. United we stand. I wish you all love and peace for the holidays. I wish you hope in the new year ahead.

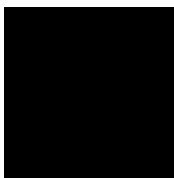
Adapted with permission from the November-December 1996 issue of the Bereaved Parents of the USA's newsletter. For information on local chapters, call (708) 748-9184.



Justin Bobholz  
June 20, 1981-  
July 4, 1996



Angela Louise Jenkins  
May 28, 1975  
February 18, 1996



Hank Bedford  
December 6, 1949-  
August 2, 1995



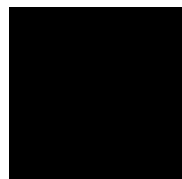
Newell Charles Brooner  
December 16, 1935-  
April 2, 1995



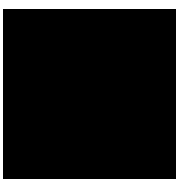
Matthew Stuart  
Steggall  
January 12, 1996-  
January 30, 1997



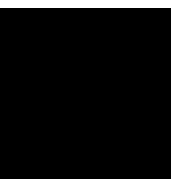
Casey Fisher  
May 21, 1976-  
December 9, 1996



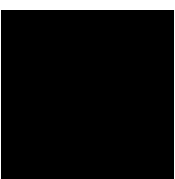
Eric J. Foster  
December 27, 1971-  
March 7, 1996



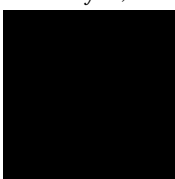
Eric L. Gautney  
September 15, 1976-  
October 11, 1995



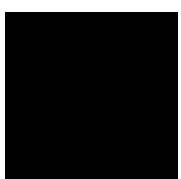
Larry R. Williams  
June 28, 1959-  
November 6, 1995



Nicholas Ryan Bock  
July 12, 1984-  
October 6, 1992



Bethia Kay "Beth"  
Combs  
July 12, 1982-  
August 28, 1996



Lucas Ryan Emsley  
November 17, 1980-  
July 24, 1995

We Fondly Remember



## Hanukkah: The Festival of Lights

by Carol Cole

**H**anukkah is the Festival of Lights. It is marked by the lighting of candles in the home, beginning with one candle on the first night and adding one each following night of the holiday.

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## Gifts that Keep Giving

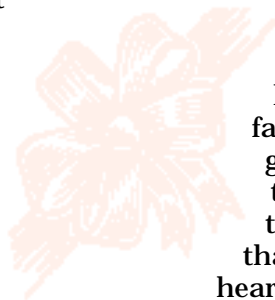
by Jannett Stout

*In loving memory of Billy Joe Stout Sr.: Oct. 1, 1935 - Dec. 31, 1994*

On New Year's Eve, 1994, Bill Stout left this world at 11:56 p.m. Although he had gone for a medical checkup only a short time before, his family had a history of heart disease. Before a New Year's kiss, a sudden heart attack claimed his life.

Bill was a giving person all his life, even as a young man. He served his country with pride as a Marine,

returning home only a short time before his father died, to help fill in the loss of his father's income. A loving and dependable father and faithful husband, he always tried to give gifts that kept giving long after the occasion had passed. I'm sure that, as a donor, his only regret was that he couldn't give someone his heart, too.



# FOR THE NEWLY BEREAVED

## First Christmas in Heaven

by Nan Lang

In memory of Joe Don Lang: June 16, 1980 - Sept. 30, 1995

*I see all the hustle and bustle below,  
as people carry packages with faces aglow.  
The jingle of bells, the honk of the cars,  
everyone with so many earthly cares.  
The turkey being cooked, the tree being trimmed,  
if only they would take a minute for Him.*

*The bells on Heaven's Gate ring boldly,  
all the angels sing, "Holy, Holy, Holy,"  
and as I come before the throne,  
I have but one wish—one wish alone.  
That all could know the baby in the manger  
is now the King, the risen savior.*

*There are no stores in Heaven  
where presents can be bought.  
So, as I watch from up above,  
I come up with this thought.*

*I cannot be with you this year,  
to share your joys, your cares your tears,  
for I will celebrate the birth of our King*

*in the holy city where mighty bells ring,  
where the trumpets play boldly and all Heaven's choir sing,  
here, where praising God is our thing.*

*No trees to be trimmed, no turkey to be cooked,  
but still as I sit up here and look,  
I have four wishes come over me,  
four wishes I want to give thee.  
A wish for peace that has no earthly measure.  
A wish for joy that gives you great pleasure.  
A wish for love that flows like the river.  
A wish for happiness that lasts now and forever.*

*One last thing I want you to know.  
I will stand at Heaven's Gate and watch below,  
so when God is ready to bring you home,  
you won't have to enter the gate alone.  
All our family with me will be waiting  
to welcome you with no hesitating.  
First Christmas in Heaven is special, you see,  
for I am with the King for now and eternity.*



## To Bereaved Grandparents Concerning the Holidays

by Margaret Gerner, MSW, Grandparent

*Y*our grief over the loss of your grandchild is legitimate. You have the need and right to grieve. Learn about the grief process, not only so you will know that what you are experiencing is normal, but to help you know that your grieving child is not "going crazy."

Find someone with whom you can share your thoughts and feelings about your grandchild's death. Know that the holidays will be difficult for you, as well as for your child. Don't expect too much of yourself in the first year after your grandchild's death. Your son or daughter will especially need you this year. Find ways to include memories and/or memorabilia of the dead child in your family holiday ritual. You may even want to change some of your traditional holiday plans this year.

You should keep in mind that your children who have not lost a child may be uncomfortable with whatever you do, but explain to them how necessary it is for your grieving child. Also, understand that however you plan this year's holiday arrangements, they will not be as they have been in the past. The holidays will never be the same because your grandchild will never be there again. It does get easier as the years go by.

Take this opportunity to cement a very special relationship with your child by being sensitive to his or her needs during the holiday season.

Adapted with permission from the November-December 1996 issue of the Bereaved Parents of the USA's newsletter.





## WHAT HELPS WHEN IT HURTS

### Remembering with Love

by Denise Stone, RN, MS, Certified Grief Counselor

How do we remember our loved one during the holidays after his or her death? How do we find comfort, and what is helpful? For each of us, the answer comes from within. Some of us will embrace the familiar holiday traditions, and others will find new ones that pay tribute to the memory of our loved one. However you celebrate, we hope the holidays are filled with love, happy memories and renewal for the new year.

It may be hard to be in the same place that you spent holidays together with your loved one. You may opt for a change of scene and go away, or you may stay home with the family members and friends whom you find most comforting.

Here are some suggestions other families have found helpful during the holiday season:

- ❖ Seek to share some of the season with those whose company you enjoy.
- ❖ Have a living Christmas tree, which you later plant, as part of your holiday remembrance.
- ❖ Buy a gift for a needy child or adult.
- ❖ Decorate the outside of a photo album with holiday trimmings, fill the album with past pictures of the holidays with your loved one and leave it out for others to look at. Include empty pages for people to write about their own memories or attach their favorite photos.
- ❖ Attend a candlelight religious service and light a candle in memory of your loved one.
- ❖ Make ornaments in memory of the loved one, and encourage grieving children to do the same.
- ❖ Share anecdotes and favorite stories. Sometimes, others need permission from you to talk about your loved one. Let them know you would rather keep their memory alive than pretend nothing has changed.



The National Donor Sabbath will take place November 14-16. During this event, religious communities across the country will remember our loved ones in their prayers. For more information, you may call Jennifer Grant at the Division of Transplantation, at (301) 447-7577.

## Reaching Out in Your Community

by John Landers, Heart Recipient, Donor Family Member



On September 6, 1991, I was diagnosed with irreversible congestive heart failure. I needed a heart transplant, and was blessed with a healthy donated heart two months later. I owe my life to that special donor family.

Three years later, my older brother died. Having already witnessed the miracle of transplantation, my family made the decision to donate his organs.

In August 1996, I participated in the NKF's National Donor Family Council (NDFC) program at the U.S. Transplant Games. It was an incredible opportunity to share with other donor families what it meant to be among them as a member of a donor family and as a transplant recipient. I made a commitment to give all donor families in my state the opportunity to also be involved in the "Home for Donor Families," the NDFC.

Over the next few months, I worked with the NKF of Arizona, and in April 1997, with the cooperation of the Donor Network of Arizona (DNA), information and membership forms were distributed to more than 1,200 Arizona donor families so that they might share in the benefits and programs of the NDFC. In addition, the DNA and the NKF of Arizona have pledged to support a local NDFC chapter, which is now in the preliminary stages of organization. Soon, we will offer a service program to donor families who wish to become involved.

*Editor's note: This is an example of what one family did to support other families in its local area. If you would like to become involved in your community, contact the NDFC at (800) 622-9010.*

# THE PRIVILEGE OF CARING

## *The Family Wants to Talk*

by Mark Strong, RN, TransLife Organ, Tissue and Transplantation Services

It's a common phrase for a recovery coordinator to hear. Along with the hospital staff, we make the assumption that the family wants to talk about donation, but this may only be partially true. More often, we find family members who are just beginning to face the reality of a sudden loss. It is often apparent that many families who agree to speak with a coordinator have not yet been able to refer to their loved one in the past tense, and acknowledge that he or she has died.

Discussing organ and/or tissue donation may help families acknowledge death or acknowledge the loss. Questions about a loved one may help family members celebrate that

person's life. These recollections may sometimes raise a tearful smile or paint a colorful portrait. Time spent together may help families begin the healing process.

As a recovery coordinator, I feel very privileged to be invited to share these memories with you, the donor family, and friends. Some of you are unable to speak more than just a few words. Others, who have endured their loved one's long and emotional hospitalization, can finally let the brave face slip and expose your feelings.

The outcomes are often different, and the faces represent many races and cultures, but the common factor is always the loss of someone dear. It is always my hope that when I say goodbye to a group of family and friends that I have given them the time and emotional environment to begin their journey of grief. 🍁

## THOUGHTS FROM RECIPIENTS

### *My Mom Had a ♥ Transplant*

by Alisa Meyer, 11 years old

I remember everything. One Sunday, at about 6:00 a.m., I heard Dad leave. When I woke up, he was back, so I asked him, "Where's Mom?" Then I remembered—Mom was in the hospital. When I had visited her, we drew colored pictures on her curtain so she could look at them from the bed.

About five weeks later, my brother Michael had his birthday. Mom was still in the hospital, so we had Michael's birthday party in the hospital. He got a pair of roller skates, and he roller-skated down the hall. It was so much fun, and none of the doctors cared! The next day, we visited Mom again, and we ate in the hospital cafeteria.

I was sad and curious because I didn't know what was happening. I felt mad, too, because I thought her condition might have been someone's fault. Now I know these things can just happen. But when Mom received the news that there was a heart for her, I was happy because she had been in the hospital from the end of May until the end of September 1992. It was great news!

The day Mom came home from the hospital, all the people in our town waved "Welcome Home" signs and were happy to see her. I am happy now that Mom is home. I know that if she hadn't received a heart she would have died. Thanks to a donor family, she's still alive and she's home. 🍁

## *In Remembrance*

Memorial contributions made in memory of our readers' loved ones are channeled directly into programs and educational resources for donor families and the professionals who support them.

In memory of: **David Oiland**—Love, Donna Oiland  
**Justin D. Bobholz**—Love, Kay Bandle

Happy 5th Anniversary

## Council News



Guess who is celebrating an anniversary?

We are! The National Donor Family Council was formed five years ago by the National Kidney Foundation. To date, we have more than 2,100 donor family members and 275 professional liaisons. Thanks to your support, we have accomplished so much.



Plan now for the U.S. Transplant Games. The Games will be held in

Columbus, Ohio, from August 5-8, 1998. The Opening Ceremonies will feature the National Donor Recognition Ceremony, cosponsored by the Division of Transplantation. Educational and support sessions will be offered throughout the week, along with all the fun and celebration of the athletic events. All donor families and friends are warmly invited to this spectacular event. This will make a great summer vacation, so start planning now!



Visit our Web site at [www.kidney.org](http://www.kidney.org).

If you don't have a computer, you may be able to access our site at your local library.

## Dear Teenagers

NEW COLUMN

Hi, my name is Valerie, and I'm 18 years old. The worst day of my life was in March 1996, when my brother was taken. I just want to say that you are not alone. I hope to hear from any teenagers or younger kids.

*Editor's note: We are starting a new column for kids and teenagers, to allow them to share their experiences with the death of a loved one. Please forward your stories to Teen Sharing, For Those Who Give and Grieve, National Kidney Foundation, 30 East 33rd Street, New York, NY 10016.*

## The Quilt on Tour

Oct. 13-17	Heartline	Kansas City, MO
Oct. 22-26	TRIO Annual Meeting	Washington, DC
Oct. 28-Nov.2	NKF Annual Meeting	San Antonio, TX
Nov. 7-14	South Carolina OPO and NKF of South Carolina	Columbia, SC
Nov. 8	NKF of Illinois	Chicago, IL
Nov. 10-16	Center for Donation and Transplant	Albany, NY
Nov. 13	NKF of the Coastal Bend	Corpus Christi, TX
Nov. 16 & 19	LifeLink of Georgia, Service of Remembrance	Atlanta, GA
Nov. 16-23	Tennessee Donor Services	Knoxville, TN
Nov. 24-26	University of Wisconsin at Whitewater, Awareness Activities	Whitewater, WI
Nov. 25-Dec. 2	NKF of Delaware Valley	Philadelphia, PA
Dec. 6-8	Southwest Organ Bank	Dallas, TX
Dec. 7	Tennessee Donor Services	Nashville, TN
Dec. 7	Life Link Foundation	Tampa, FL
Dec. 14	Midwest Organ Bank	Westwood, KS

Schedules are subject to change. The entire quilt may not be available at all locations. Please call the National Donor Family Council at (800) 622-9010 for more details.

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## **DONOR FAMILY FRIENDS**

by *Cindy Jo Greever, Donor Family Member and Donor Family Editor*

I have participated as a Donor Family Friend, and I have been very pleased with this special outreach.

Through Donor Family Friends, I have experienced comfort and support. Nearly three years ago, my ad was included in this section of *For Those Who Give and Grieve*. I wanted to correspond with others who donated their child's organs. As I received each letter, I felt a positive experience taking place. We shared our grief and pain and how we were dealing with this tragic loss.

I continued to receive letters for about two and a half years, though they came months apart, at times. I treasure them to this day as a very important part of my healing. I encourage those of you who haven't written (and those of you who already have) to print (or reprint) your ad so that you can receive the support of others who have experienced a similar loss. Hope and healing are an immeasurable comfort!

*To become a Donor Family Friend, re-run an ad, respond to a family or write to someone who is promoting organ donation, send all correspondence to Donor Family Friends, c/o The National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016.*

**DF 70:** I am a 37-year-old widow. My husband, 39, died suddenly on December 26, 1996. I have two boys, who are 14 and 10.

**DF 71:** I lost my 15-year-old son, Ken, to suicide. A bright, popular boy with no symptoms of depression, he was my best friend. Every day is a constant struggle.

**DF 72:** I am a 38-year-old mother of five. My 19-year-old son was killed at work, three years ago. The loss has left me very lonely.

**DF 73:** I lost my 44-year-old mother one year ago to suicide, due to alcoholism and depression. I have two children who do not have a grandmother.

**DF 74:** I am a 44-year-old widower. My wife died during childbirth from severe complications of placenta accreta. I would like to hear from others who lost a dear one to pregnancy-related complications.

**DF 75:** My 17-year-old daughter was killed in an automobile accident almost a year ago. She was my only child, and would have graduated recently. My whole life has changed.

**DF 76:** I am a 31-year-old mother of a four-year-old child. My two-year-old child drowned last January. I would like to hear from anyone who has lost a child.

**DF 77:** My son and only child committed suicide in July 1995 at the age of 14. I am still suffering every day. Can anyone share with me how they have survived the death of a teenager by suicide or the death of an only child?

**DF 78:** My two-year-old son, Zachariah, died in March. I don't know how he died; he just stopped breathing in his sleep. He was an organ donor.



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



Please help us "Cut Down" by notifying us when your address changes. It costs 32 cents if you forget.