

# *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.

Spring 2000

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## *Thoughts From the Heart*



by Patricia Brown

*In loving memory of Michael Robert*

*I*t has been six long years since the death of our firstborn son, Michael Robert. He was 7-weeks-old and was napping at the baby-sitter's house when he never woke up again. I am not an expert in SIDS (sudden infant death syndrome) but am unfortunately now labeled an SIDS parent. It is the loneliest title I hope I ever have to hold. About two weeks after Michael died, two people said two different things to me that I used to re-build my shattered world.

First, my sister-in-law said to me that she tried to focus on Michael's life rather than his death. I thought that it was odd because all I could think of was that he was dead and how he died. It struck me several days later that if I could focus on his life, I could keep him alive in my heart and in the memories I relayed to other people. I discovered few people want to hear about death, but they are always willing to listen to memories of life.

Next, my husband told me that the death of our son could ruin the rest of our lives or we could use it to begin building a better life. My husband, Mike, felt that Michael, as innocent and precious as he was (giving us his first smile the night before he died), would have wanted us to have a happy and long life. He was right. We deserved to

continue with life and make it a happy and productive one. The only problem was that I was waiting for someone to do it for me. It dawned on me that I was the one who would have to search for the strength to build my life again. Once I realized it was me who would have to do the building (along with precious help from my husband, family and friends), I started to build. I could only do one brick at a time, but that is all it takes.



**Michael Robert**

Today, life is not bad. My heart is not healed, but I have more love in it today. Subsequently, we had two beautiful children, Laura (age 5) and Ryan (age 1). They give us so much joy. We realize each day is a gift of life and cherish the moments we have. We've spent the past few years healing and re-building. I often give speeches for our local transplant agency about how our 7-week-old Michael donated his heart, liver and corneas (what a little hero!). I work as a volunteer peer contact for the Florida SIDS Alliance and counsel newly bereaved parents. I also enjoy a part-time job with the Disney

Cruise Line. I keep busy but, I also give myself time to rebuild. I am pretty confident that my life's building will never be complete until I see my precious little boy in heaven. 

# THOUGHTS FROM DONOR FAMILIES



## Sonnet 697

by Amber Stump

*In memory of her brother, Michael*

**I** wish I could see your face one more time,  
To remember is all I can do now.  
Taking you away was the biggest crime  
If only I could touch your face, but how...

I wish there were some way you could stay  
Your memories are all I have to find.  
That will never be happening, no way,  
You're always in my heart, and on my mind.

You will always have a place in my heart,  
I wish you could be with me, by my side.  
To help me when everything falls apart,  
Sometimes I feel like I just want to hide.

I'll always miss you and always love you.  
One day very soon, I will be with you, too. 

## I'll Meet You Son

by Gayle Shephard, donor mom

*In memory of her son Mathew*

**I**'ll meet you in the lily fields,  
where pollen shines like gold.  
We'll laugh amongst the fragrance,  
at our memories of old.  
I'll meet you 'neath the treetops,  
where the shade is cool and clean.



We'll sit in peaceful silence,  
while we watch the birds take wing.

I'll meet you by the gurgling brook,  
where rocks and water play.  
We'll dip our toes and talk some more,  
there's so much left to say.

I'll meet you on the mountain top,  
where angels softly sing.  
We'll meet where departed children  
visit mothers in their dreams. 

## For Our Loved One KC Boy

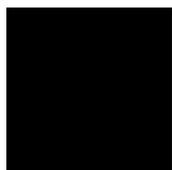
**I** think of you every day.  
My little baby brother, what can I say...  
I remember those times we shared,  
Sometimes just letting you know I cared.  
Special you are,  
Yet you are so far.  
Every day, I cry and that's all I do,  
Understand that we love you. 



*Love always.*

*Shyann, Kuulei & Mom*

## We Fondly Remember



*James Harter  
April 28, 1965 -  
August 3, 1986*



*Bradley Stephen Underwood  
May 4, 1982 -  
November 16, 1998*



*Marie Lynn Albert  
June 14, 1978 -  
April 6, 1997*

# FOR THE NEWLY BEREAVED

## Victims' Rights

by Chari Anhouse, JD

**I**t is the nature of unforeseen tragedy: A loved one dies suddenly, without warning, due to the fault of another. Whether an accident or a crime, the legal system becomes a part of personal tragedy because public servants and private representatives have a duty to determine what happened to your spouse, child, parent, relative or friend, and how society should deal with those responsible.

Every state has laws protecting victims' rights. Most of these contain basic provisions for victims and survivors to:

- be treated with dignity and compassion,
- be informed of the status of their case,
- be notified of trials and hearing dates,
- be heard at sentencing and parole through victim impact statements, and
- receive restitution from convicted offenders.

It is the job of victims' assistance programs to help you enforce these rights.

The victims' assistance program should let you know about changes in scheduled hearings and often can assist in making arrangements for overnight stays if necessary. Be aware, however, that times and dates of proceedings are frequently changed or postponed, even at the last moment. Sometimes family members are not allowed in the courtroom during hearings or the trial itself because they will be witnesses or because the offenders are underage. If this occurs, transcripts of the proceedings may be available. Be aware, however, that court reporters charge for this service and it may take a while to get the transcript.

If the defendant is found guilty, a victim impact statement can be presented by the family as part of the sentencing procedure. This statement is a description of how the crime has impacted every area of the survivors' lives. The impact statement is taken into consideration when the judge—and sometimes the jury—is making a determination about the sentence to be imposed.

Family members can also ask to be notified and to be present when the convicted felon comes up for parole or release. Procedures for requesting notification vary from state to state. Additionally, family members can usually request that their addresses not be given to the defendant or the defendant's attorney and can request that the parole board require that the assailant not contact the family in any way. Then, if contact is made, the felon will be in violation of parole and he or she may be sent back to prison.

There are more than 10,000 programs in all 50 states to help crime victims and survivors, and services are usually provided at no charge. Trained advocates may be available to accompany you to proceedings such as hearings, trial proceedings and meetings with the coroner, as well as to provide emotional support and information about the process.

National organizations can also provide referrals for other cities, which is especially useful in cases where the death of a loved one took place in a different state or community.

For information on available resources, contact us at 1-800-622-9010. 

*Chari Anhouse, JD, is a lawyer working in New York City.*

**The NKF Website got a facelift—  
www.kidney.org is now easier to navigate  
and offers you more!**

**VISIT THE NATIONAL DONOR FAMILY  
COUNCIL WEBPAGE.**

Click on "Organ and tissue donors and recipients" and then "National Donor Family Council." Click on "Donor Family Message Board" to post your thoughts or memorials and respond to other donor families.

# WHAT HELPS WHEN IT HURTS

## *Grief: An Uncertain Time*

by Elissa Kaplan, MSW

**T**he grief journey—the learning to live with grief—is a difficult one. Bereaved family members have described grief as “a constant wave of shock throughout my body,” “a black cloud following me day and night” and “indescribable emptiness.” Extended family members and supportive friends have described their grieving loved ones as “numb, angry, sad: all at the same time!” They sometimes feel as if the grieving person died along with the deceased.

Individual ways to cope with grief are as unique as the relationship you had with your loved one. You must grieve your own way, recognizing that grief is a staggering weight to bear.

A significant grief response which goes unresolved can lead to mental, physical and sociological problems and contribute to family dysfunction across generations. Take small steps with the people who love and need you. A walk, a conversation with a friend, listening to music or quietly looking at photographs: these small steps are important. You may want to write a letter to your loved one, or about your loved one.

TEAR is an acronym used by some to describe the beginning stage of grief work:

- T** → to accept the reality of the loss
- E** → experience the pain
- A** → adjust to the new environment without the person
- R** → reinvent in the new reality

According to this idea, grief work begins when the initial grieving period is over, the friends have stopped calling, everyone thinks you should be over it, everything is supposed to be back to normal. It's at this point that real grieving begins. As you are able, reach out to the people who care about you; find new friends in a support group.

Grief is a time when uncertainty is present more than usual. People who are actively grieving speak of waves of grief spurred by simple influences such as hearing a particular song or seeing a sign, piece of clothing or movie scene that reminds them of their loved one. It is natural for people to alternate from stability to instability as changes occur. It is a normal life event that makes us feel uncertain. Perhaps Helen Keller was referring to grief when she said, “We could never learn to be brave and patient, if there were only joy in the world.”

*Elissa is a social worker working with infants and families in New York City.* 

### *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:**

**William M. Kovacic** - by Mr. and Mrs. Rudolf Orisek and Mr. and Mrs. Thomas G. Lyons

**Shawn Carpenter** - by Bill and Mary Carpenter and LifeLink Foundation

**Donor Families** - by North American Transplant Coordinators Organization (NATCO)

## *Coalition's Donate Life Campaign Set for NOTDAW 2000 Release*

**Everybody knows donating is a good thing**

**Dying, everybody's got to do it but nobody wants to talk about it**

**But, if you don't talk to your family about donating, it won't happen.**

**So really, organ donation is not about dying, it's about living**

**Talk to your family about donating...Life.**

**T**hese were the findings from research conducted by the Coalition on Donation through its ad agency, Arnold Communications, in May 1999. Focus group participants, including members of donor families, who had discussed donation with family members focused more on the "light side" of donation; the ripple effect of the lives and families they would help; and the simple joy of giving. They were adamant about becoming donors and wanted to unburden their families from making the decision. Truly committed donors approached donation and talking with family members as a simple act of compassion, much like how a child would approach the subject—with honesty and simplicity. They talked to their family about donating...*Life*.

The life giving aspect of donation will be used as the foundation for the next phase of the Coalition on

Donation's campaign to increase donation.

Television, radio, newspaper, outdoor and Internet advertisements will be distributed to more than 30,000 media outlets across the U.S. in time for NOTDAW 2000. Common myths, which can deter people from committing to donation, will also be dispelled through a parallel public relations effort. The focus of all efforts will be to motivate the public to commit to donation and to tell their family their wishes.

To get involved in campaign efforts in your community, contact the local coalition in your area. Information about local coalitions and activities of the Coalition on Donation is available at [www.shareyourlife.org](http://www.shareyourlife.org).

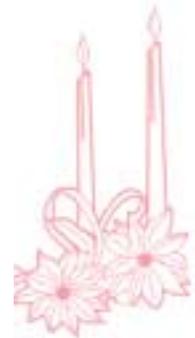


## *The Donor Recognition Ceremony June 22, 2000*

**T**he National Donor Family Council Donor Recognition Ceremony will be held on Thursday, June 22, 2000 from 4:00 to 6:00 pm at the Hyatt Hotel in Orlando. This event takes place every other year in conjunction with the U.S. Transplant Games. This year the Games, which feature transplant athletes competing in Olympic style events, are being held at *Disney's Wide World of Sports™* complex from June 21-24. The Donor Recognition Ceremony will feature tributes in prose, song and verse to donor families and living donors from the transplant community, as well as a memorial ballet, a video tribute to donors and a candle-lighting ceremony. In conjunction with the Donor Recognition Ceremony, the National Donor Family Council (NDFC) invites

you to participate in the Giving, Grieving, Growing™ program to be held Thursday, June 22, and Friday, June 23, from 9:00 am to 12:15 pm and from 8:00 pm to 11:00 pm. The program will feature sharing sessions and educational workshops about topics such as "Death of a Child," "Suicide," "Teenagers Grieve Too," "Helping Children Grieve," "What ifs?", "Finding Support on the Internet" and more. The middle of the day has been left free for participants to observe the U.S. Transplant Games and mingle with other participants and the recipients.

We hope you can join us! Call (800) 622-9010 for more information.



# TEENAGERS SHARING

The following article, originally printed in TransLife newsletter, was the winning entry in the Holmes Regional Medical Center's donor awareness competition for teens. It was submitted to us by Judi Cavazos, RN, CCRN, who reports that the competition will become an annual event.

## Organ and Tissue Donation

by Jesse Payne-Johnson

Imagine being blind, seeing nothing but darkness for all of your life with hardly any hope of ever having normal vision. Then imagine suddenly being able to see, anything and everything, from the pale blue sky to the deep, burning red of rose petals.

It's not impossible. In fact, three years ago, when my mother died and her organs were donated to those in need, it actually happened. I didn't think much of the decision to donate her organs at the time but later that year, when I received a kind and heartfelt card saying that because of donation, a

blind person was given the gift of sight, I was overcome with emotion.

It filled me with an overwhelming sense of charity that I don't believe I've ever felt before or will again. I cannot put into words how wonderful it is to know that because of kind actions, someone else's life has been completely and drastically improved.

In this day and age, when it seems that disease and disabilities are more prominent than ever, the benefits of organ and tissue donation are immeasurable. From giving someone sight, to saving a life, donation is an effective and generous way to help society.

Jesse Payne-Johnson, Melbourne, FL is a freshman at Johnson Jr. High School. 

## The Quilt on Tour

Please note: This schedule is subject to change.

- |              |  |
|--------------|--|
| April 23     | Roxbury, MA, Walter & Loretta Bell Lewis, <i>Amin T. Bell Memorial Birthday Celebration</i> . Contact: Walter & Loretta Bell Lewis, (617) 442-3579               |
| April 29*    | San Francisco, CA, California, <i>Transplant Donor Network, Annual Donor Recognition Ceremony</i> . Contact: Tracee L. Harris, (209) 527-6178                    |
| April 29*    | Nashville, TN, Tennessee Donor Services, <i>Celebration of Life Donor Family Program</i> . Contact: Kathy Prescott, (615) 234-5265                               |
| April 30     | Albany, NY, NKF of Northeast New York, <i>Gift of Life Celebration</i> . Contact: Maegan Frantz, (518) 458-9697  |
| May 6* & 20* | Dayton, OH, Gift of Life Fund, <i>Gift of Life Walk</i> . Contact: Lynn Zimmer, (937) 258-0740   |
| May 8-10*    | NKF of Oklahoma, <i>American Indian Kidney Health Conference</i> . Contact: Jeff Tallent, (405) 947-6405   |
| May 11-17*   | Chicago, IL, <i>American Society of Transplantation and American Society of Transplant Surgeons Meeting</i> . Entire Quilt on Display!                           |
| May 21       | Indianapolis, IN, NKF of Indiana, <i>Gift of Life Run/Walk</i> . Contact: Marilyn Winn, (317) 722-5640   |
| May 21       | Newton, MA, New England Organ Bank, <i>Connecticut Donor Family Ceremony</i> . Contact: Pamela Albert, (617) 244-8000  |
| June 2       | Portland, OR, NKF Oregon/Washington, <i>National Funeral Directors Convention</i> . Contact: Fred Bachofner, (503) 282-0990.                                     |
| June 11      | Concord, NH, New England Organ Bank, <i>NH/VT Donor Family Ceremony</i> . Contact: Pamela Albert, (617) 244-8000   |
| June 21-24   | National Kidney Foundation, <i>2000 U.S. Transplant Games and Donor Recognition Ceremony</i> . Contact: Sarah L. Ockler, (800) 622-9010 Entire Quilt on Display! |

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 Sarah Ockler.** 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 Sarah Ockler at 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/recipes/donor](http://www.kidney.org/recipes/donor).

\* Not yet confirmed.

# THOUGHTS FROM RECIPIENTS

Dear Donor Family:

I was given the honor of presiding at the funeral of my sister who, at the age of 71, experienced the failure of her 22-year-old transplanted kidney.

At the funeral, we were giving thanks to God for what our sister had brought to us over the years, when it occurred to me, how wonderful it would be for the donor family to be thanked as well. Her daughters and I attempted to find the identity of the family, but were unable to.

If I could not thank them personally, I wish to say to all donor families:

Remember our family and what the gift of life meant to us. We had a gift of 22 additional years with my sister, due to the generosity of an unknown family who had lost a young son in a car accident.

We thank you, whoever you are, and give thanks to you and God for the additional years we had with her due to your generosity. Our prayer is that others will consider this option and will be able to receive the thanks they so deserve. 

Jack

## FOR THOSE WHO GIVE AND GRIEVE

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# Donor Family Friends



**DF 135** My brother, best friend, and only sibling died 2 1/2 years ago from a mountain biking accident. He was 31 and I was 29 at the time. There is not a day that goes by that I don't miss him. What makes it worse for me is the fact that there is very little support out there for siblings. I would like to correspond with anyone that has lost an only sibling.

**DF 136** I recently lost my wife after a six-week illness. I would like to hear from others who have gone through a similar situation. I badly need support from other people, as I feel so alone and helpless. Her death has devastated me and left such an empty spot in my life.

**DF 137** My brother was killed in a car accident. Drunk driving was not an issue—the driver of the car was speeding and showing off. My sister, mom, stepdad and I will never be the same, because every day the same question is in our heads: Why?! I hope someone will respond.

**DF 138** I lost my two-year-old son to asthma in July of 1999. He was my only child and I have a very hard time coping. I feel no one understands. I would love to hear from other parents.

**DF 139** My twin sister and best friend passed away in December of 1999 three days before Christmas from breast cancer. She was only 37 years old. I am having a difficult time dealing with her loss. I would like to hear from others who have lost a twin sister.

**DF 140** My husband died in September of 1999 of a massive heart attack at the age of 51. Now, at 40, I am the widowed mother of two teenage daughters. Are there any younger widows out there willing to share experiences and ideas on how to cope?

**To submit or repeat a Donor Family Friend ad or to respond to a family, send 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  
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 33 cents if you forget.