

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.

Summer 2001

Volume 10, Number 1

“Just Hold My Hand and Let Me Cry, and Say, My Friend, I Care’.”

by Arlene Barnett, Manager

New York Organ Donor Network AfterCare Program

I have this line from a poem, author unknown, posted in my office. A donor mom gave it to me when I first began the AfterCare Program at the New York Organ Donor Network (NYODN). She told me that it was a rare and special person who could just be there with a grieving person while he or she cried. Someone who would never say that she knew how it felt, or it would be all right, or that crying wouldn't help, or any of the other platitudes that people use to avoid their own unease with grief. I try to remember this whenever a family member begins to cry on the phone or in person. Working with donor families has given me a new perspective on humanity. I believe that the courage and generosity families display through their gifts to others is heroism of the highest order. It is a privilege to walk beside them on their journey through grief.

After more than 20 years of working as a counselor in colleges and high schools, where I developed programs dealing with bereavement, crisis interventions and family counseling, I retired and moved to the New York area. I was retired for six weeks. After I roamed the New Jersey malls, I was itching to find some part-time work. A small miracle occurred. I saw an ad for a part-time bereavement counselor in the *New York Times* and I became involved in the world of transplantation and donation with the New York Organ Donor Network.

The job was to create a program of follow-up services for donor families. I knew next to nothing about organ and tissue donation and transplantation. I sought help in setting up such a program to meet the needs of donor families. I received an education and help from transplant professionals, a few donor moms and some

bereavement specialists already working with donor families. After a few months, it became obvious to NYODN and to me that providing this service was not a part-time job, and so I rejoined the ranks of the fully employed to begin a journey that has taken me to unimaginable emotional highs and lows.

The AfterCare Program of NYODN began in the fall of 1998 as a work in progress. As I learn more from those we strive to serve, I find out how little I really know about the way each person mourns and what kind of support each person may want from us. My teachers are the donor families who share their needs. I have been privileged to share their tears and their laughter. My

heart has been touched, bruised and renewed by listening to their pain and hearing about their "empty places" and small victories. I have been able to see them grow stronger, despite the pain. I have learned from their letters, their phone calls and kind advice, and even their angry words. I have learned that

reaching out to those who grieve is a special gift to the bereaved. I can offer my hand and heart to let them know that someone cares. Many of them call or write to tell us they have been touched by our outreach to them.

When I try to describe my "job" to others, in or out of the transplant community, I find it difficult to refrain from making it sound like a "mission," as a dear Sister of Mercy called it. It has become a challenging, painful, loving and inspiring vocation. This program is still a work in progress, continually modified by what we learn from all those for whom we provide after care. Every day I face different challenges, different families and different emotions. Every day brings an altered understanding of how people give, grieve and grow.



My Brother Bobby

by Karen Ball Hooker

Why did God have to take him?
My brother was still young
He left behind a life of plans
A love he'd just begun
I'll never really understand
How God decides one's fate
Is it based upon your challenges
And how they're handled that He rates
Is it knowledge of this world
That God wants you to learn?
Or the love you give to others
And its effect His main concern?
Or maybe just a bit of both
Knowledge and love combined
That makes the materialistic
Just a waste of earthly time?
My brother had his ups and downs
Preferring to handle them on his own



Himself he did not talk of much
His concern for others he made known
My brother he has always been
And this I took in stride
I wish I had more time
To know the him he was inside
Maybe God took him early
Because the selflessness he displayed
Could no longer help his spirit here
Only harm it if he stayed
Going back home to heaven
Is a destiny we all share
What we do now on earth
May determine our status there
If God is rating accomplishments
On how we treat one another
I know another angel's been made
He found this in my brother. 🦋

In Remembrance

Memorial contributions and other public donations to the National Donor Family Council are channeled directly into programs and educational resources for donor families and the professionals who support them.

To make a donation in memory or in honor of your loved one, simply send your gift to the National Donor Family Council, 30 East 33rd Street, New York, NY 10016.

Be sure to include your loved one's name so that we can acknowledge your special gift in the next issue of *For Those Who Give and Grieve*.

We Fondly Remember



David L. Curry
December 23, 1976 - August 6, 2000



To Comfort You

Written by Sandra M. Schmidt, before her untimely death by stroke, donor wife.
Submitted by her husband, Don Schmidt

*L*ove linger not at this. The home
In which you've laid me down to rest.
Don't weep or scuff the fresh new soil
That presses lightly at my breast.


The heart that danced in time with yours
No longer strains or clings to life.
The pain that tore us both apart
No more can harm your faithful wife.

Come, touch the stone that speaks my
name;
Don't curse the fates that put me here.
The day has passed for fault or blame;
It was my time to leave you dear.

But, though this grave, now hoe-blade new,
Will in good time be overgrown,
My spirit's warmth will follow you,
And see that you are not alone.

One day, I know you'll join me here,
And take my hand in yours once more.
Together, we'll go toward the light
And knock, as one, at Heaven's door

Now, tuck your sorrow far from sight
And kiss the children tenderly.

I'll slumber dreamless, in the night,
Until, at last, you come for me. 



Trevor's Tale




*This letter is written in loving memory of Trevor Nathaniel Melvin by his Mom, Tamra Melvin
[March 10, 1995 - September 26, 1996]*

*I*t's always good to know that there are people out there that care and know what I'm going through. My name is Tamra, and I am grieving over the loss of my child.

On March 10, 1995, at the young age of 16, I gave birth to a healthy baby boy. I named him Trevor Nathaniel. He was, no doubt, the greatest thing I had ever created. With blonde hair and blue eyes, he was a mother's dream come true. I was raising him alone.

In September 1996, my 18-month-old son was found unconscious in his bed. Later that evening I was told he would probably not come out of it. If he did survive, he would never be the same. I was devastated. All the hopes, all the dreams, everything was destroyed. He was a fighter, he held on for eight days. As I found out, there are some prayers that even God can't answer.

When I was first approached about donating Trevor's heart, I wouldn't even consider it. All the praying and begging him to wake up just wasn't enough to pull him through and he was pronounced brain dead. It was after hours of saying goodbye to my little angel that I decided to donate his heart. As it turned out, they were able to use his two heart valves to save two children's lives.

Donating Trevor's heart didn't make his death any easier to accept, but it did help me believe that his life had a purpose. Even though his life was taken much too soon, there was a reason God put him on this earth. There isn't a day that goes by that I don't think of Trevor and what he could have become, had he lived. My goal now is to reach out to other people dealing with the loss of a child. Each and every one of us has something in common; we are each grieving over a terrible loss. 

Tamra Melvin

Mothers Against Drunk Driving's Victim Services

by Stephanie Frogge, MTS, CTS, National Director, Victim Services

In 1999, impaired driving claimed the lives of 15,794 Americans. It is not known how many of the survivor families chose to become donor families or even how many were given the opportunity. However, in my role as a victim advocate for MADD, I speak with many families whose pain and horror of their loved one's death is, while not diminished, tempered by the knowledge that the death meant life to others.

Mothers Against Drunk Driving [MADD] was founded in 1980 out of personal tragedy caused by a repeat offender drunk driver. Frequently touted as the premier example of grassroots activism, MADD has over 600 local entities and is widely credited for changing the nation's drinking and driving habits as reflected in a 36 percent drop in alcohol-related fatalities since 1982, according to MADD's statistics.

MADD's mission is to stop drunk driving and to help victims of this violent crime. When asked, most Americans identify MADD with its legislative efforts, public awareness campaigns, attention to underage drinking and court monitoring programs. However, half of MADD's mission is victim assistance—provided by nearly 1,400 specially trained victim advocates through numerous programs and services. Some of MADD's victim assistance programs, such as Victim Impact Panels and MADD's death notification training, have become widely utilized in areas beyond the victim service arena.

Many victims and helping professionals are surprised to learn of MADD's victim assistance services. Information and referrals, advocacy and accompaniment, connection and compassion are just some of the ways MADD can be of assistance to victims. MADD is there for all those affected by drunk driving including the injured and their families, friends, first responders such as police and medical professionals, and members of the larger community. Whether the incident was the result of alcohol or some other drug and happened last week or 20 years ago, MADD is available to provide assistance to

those affected by the crime, even if no criminal charges were filed. Even in complicated cases such as hit-and-runs, crashes in which the offender was not tested for alcohol, or crashes in which the offender is killed, MADD is ready to provide support.

Currently, MADD's policy prohibits an advocate from initiating first contact with the victim or victim's family following a crash. Above all else, we do not want to intrude where we are not wanted or in any way to re-victimize an already devastated family. However, just as organ donation policies have been refined over the years, efforts are being made to establish guidelines that would make MADD's services known to people who need them as quickly as possible, while remaining respectful of those who don't.

Please let us know how we might assist someone whose life has been forever changed by a drunk driver. We would like you to know about your nearest MADD chapter, providing you with some of MADD's victim assistance materials and add you to the mailing list for MADDVOCATE—MADD's semi-annual publication for crash victims and their advocates, relevant to many kinds of trauma. You can call us at 800-GET-MADD or check out our award-winning Web site at www.madd.org. Many of our victim assistance materials can be downloaded from there.

Finally, numerous opportunities are available for anyone interested in volunteering their time and talent. MADD's ranks are made up of people personally affected by the crime of drunk driving, concerned citizens who care about the issue, and other compassionate individuals who are motivated as a result of some other personal tragedy. Those who fall in the latter category usually find that the shared experiences of trauma and loss with crash victims far outweigh any differences in cause. And in that sharing of experience and healing the profound mystery is revealed: by helping others, we help ourselves. 🌸



THOUGHTS FROM RECIPIENTS


I have been trying for seven years to, hopefully, one day meet Loren's donor family. When that day comes, I have set aside some memorable things for the family to keep. I have made copies or duplicates of pictures, items and different things from the 2000 U.S. Transplant Games at Disney World.

This was Loren's first time participating in the Games. My family has so much to share with this wonderful donor family. There is not a day that goes by that I do not think of them. I know I do not know them personally, but we share a special bond. They are a very special part of our lives.

Hopefully, we will be able to meet and share things. We'd like to know what the person who died was like, because we all know that she and her family made a very unselfish, kind and loving decision by donating.

Paul and Faye Woolery, Parents of Loren Woolery, kidney recipient

The *National Communications Guidelines* were developed by the NDFC and many collaborators, to help donor families and recipients find one another. The NKF has brochures on contacting donor families. You can obtain a brochure by calling (800) 622-9010.

Editor's Note—Recipients are encouraged to write to their donor families and give the letter to their transplant center. Their transplant center can then deliver it to an OPO and to the family, if the family is willing to accept it. 

The Quilt on Tour

Please note: This schedule is subject to change.

- | | |
|--------------|---|
| June 23 | Omaha, NE. National Kidney Foundation of NE. Tim Neal. <i>Annual Donor Recognition Ceremony</i> , (402) 572-3180. |
| June 23 | Orlando, FL. National Kidney Foundation of FL. Melanie Bell. <i>Team Florida Reunion</i> , (407) 894-7325. |
| July 6-8 | Washington, DC. National Donor Family Council. Sarah Ockler. <i>National Donor Recognition Ceremony & Workshops</i> , (800) 622-9010. |
| August 2-5 | New Brunswick, NJ. Phi Sigma Sigma. Sheila Weiner, (800) 622-9010. |
| Sept. 12-30 | Granby, CT. Northeast Organ Procurement Organization. Ginger Van Nostrand. <i>Organ & Tissue Donation Awareness</i> , (860) 545-6104. |
| September 16 | Rochester, NY. Finger Lakes Donor Recovery Network. Laurie Barton. <i>Donor Family Celebration</i> , (716) 272-4954. |
| October 7 | Denver, CO. Donor Alliance. Tammi Backer. <i>Donor Family Ceremony</i> , (303) 329-4747. |
| Nov. 10-11 | FL LifeLink Foundation - Tampa. Charlayne Gray, (800) 262-5775. |

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 person hosting the event.** 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 for up-to-date information. Information about the quilt can also be viewed on our Web site at www.donorfamily.org.

Dedicated to My Brother — Jason Blanco

July 29, 1976-April 3, 1995

by Jennifer Blanco

I saw bright lights beam, that glow "the sun";
I hear Angles whisper,
"Come to me Jason"

I realize that you were gone, "not here";
I laid down to sleep and shivered with fear.

Now I know you're gone forever,
But still I didn't realize God was very clever.

I wonder at times what days will bring...
Summer, Fall Winter or Spring.

But still I have a very important question, and just
then over blue fields and copper roses,
I saw my Master.

So I asked "Why do you put such
innocent people to the test? And He
replied, "Because, my child, I only take
the Very Best."

I love you!

Peace, clouds, fields of blue, we're all
a day closer to being there with you.

To laugh, to cry, to sing, and play; without you
hear my heart breaks day by day.

Your music, your voice, are oh so missed, a
relationship based on a single kiss.

Questions of confusion flow daily through my
mind; but still I truly know you are one of a kind.

Wow! "18" years old is still very young, but you
seemed to live life always on the run.

I guess we'll now realize that life hasn't really
ended, its only just begun!

I miss you!

To laugh, to cry, to work or play, I sometimes
wonder why aren't you here to stay.

You're suppose to be here,
here to see,
see me grow up and be all I can be.

And if I make wrong turns you can spin me back
around;

If I were to trip and fall you would catch me
before hitting the ground.

But nothing has changed, I know
you're still there;

There where you could be around
the clouds, over the rainbows,
mountains, and hills.

Your soul's still with me, your secrets
given through windmills.

Your soul's my air, it flows so quick,
Your blood is my water just a little bit
thick.

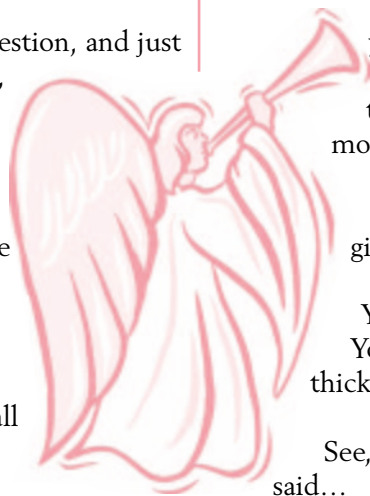
See, there's no need to worry cause it's been
said...

Your watching over me Jason, you're not really
dead!

Love always & forever!

Your sister who misses you dearly, Jennifer

Sent in by Rosa Blanco, West New York, NJ.



Correction: In the Winter 2001 issue, author John Carlsen's name ("Danny's Story") was misspelled. We apologize.

Join Us for the 2002 U.S. Transplant Games

The 2002 U.S. Transplant Games and Donor Recognition Ceremony will return to *Disney's World's Wide World of Sports™ Complex*, June 25-29, 2002. We encourage you to join us in Florida and participate in Games and related events for donor families, including a special recognition ceremony and Giving, Grieving, Growing educational workshops. The entire Patches of Love Quilt will be on display.



Last year, over 1,400 donor squares from every state were displayed. If you would like to learn more about the Games and program planning for donor families, please call (800) 622-9010.

Registration materials will be available in late fall.

Donor Family Liaisons – Local Links to the NDFC

The National Donor Family Council and National Kidney Foundation affiliates have appointed donor families from each state to serve as liaisons to the council and 2002 U.S. Transplant Games. Liaisons will help donor families on a local level learn about NDFC resources, projects and special events like the Games and Donor Recognition Ceremonies. In the coming weeks, liaisons will introduce themselves to NDFC members and area organizations through letters. If you are not a member of the council but would like to learn more about this program, please call (800) 622-9010 and let us know.

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Donor Family Friends

DF 149 I am a 53-year-old widow whose husband died at age 54 in September of 2000. I have two daughters, ages 24 and 30. My husband was my life. We did everything together for nearly 32 years. I do not know anyone who is my age and a widow. I would love to correspond with someone my age who has also lost a husband.


DF 150 I am a single parent with four young children. In 1989, my husband left us. In 1990, my mother died suddenly. In 1998, my youngest brother was killed at the age of 41. My father died accidentally in 1999. In 1991 and 1992, three close friends died. I have one brother left. We are a very close family. I would love to correspond with someone who has had to cope with sudden death.

DF 151 I am 43 years old and divorced. My youngest son is fifteen years old. My oldest son died in 1999 in a car accident. I would like to correspond with others and find a pen pal for my son — a sibling who lost a sibling. My sons were very close — a special bond. My son and I are still trying to work through the grief process.

DF 152 My husband of over 14 years passed away suddenly in September of 1999. He was only 42. Overnight I became a 35-year-old widow with two teenage boys. I would like to correspond with those who have lost a spouse and are dealing with being newly single.

DF 153 It was very hard looking at my oldest son's illness progressing and facing the fact that he was getting ready to leave me. It was like my heart dropped. It is still hard on me now. I can talk about it with others now and want to hear from a donor family.

DF 154 One year ago, after being in a coma for six nights, my 16-year-old daughter died from a head injury. We donated her organs because she had specifically informed me that she had made that decision (proudly) when she received her license. Although we are proud of our daughter, I have no one to talk to about it and would love a pen pal.

DF 155 I am a widow, age 72. I lost my husband in February of 2001. He suffered with cancer. We were going to celebrate our 50th wedding anniversary on July 28. I miss him so. I would like to correspond with someone in the same boat. 

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!

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.



NK 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 34 cents if you forget. 