

# FOR THOSE WHO GIVE AND GRIEVE



A quarterly newsletter for Donor Families published by 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.

National Kidney Foundation, Inc.

30 East 33rd Street, New York, NY 10016 (800) 622-9010

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Summer, Volume 4, Number 1

## National Donor Recognition Ceremony

*This year's ceremony was held in the nation's capital city, Washington, DC, April 1-2, 1995, and consisted of several events that brought together donor families from all over the country. Saturday featured discussion groups, a reception, group dinners, and a bus tour of Washington.*

*The crown jewel of the weekend was the Sunday Ceremony, a tribute to all donors everywhere. The 200 donor family members who participated received special gifts in recognition of their loved ones, including a rose bud bouquet and a donor medal. Also, each participant received a keepsake booklet with a letter from President Clinton and a short paragraph about each donor whose family attended the program. Families admired the National Donor Family Council Quilt which was on display, and will continue on a tour of the country.*

*After two years of increasing success, National Donor Recognition 1995 Ceremony has proven to be one of the most heart-rending ways to say "Thank you for giving the gift of life." The event is spearheaded by the Division of Organ Transplantation, U.S. Department of Health and Human Services, and co-sponsored by numerous national organizations including the National Donor Family Council. The goal of this program is to honor America's organ and tissue donors.*

*Watch for news of the upcoming 1996 Donor Recognition Ceremony and Weekend. We anticipate the weekend will continue to be a very special and memorable occasion. Please try to attend. For information, contact Kathleen Casey at 1-800-622-9010.*

## Thoughts to Ponder

🍂 **Summertime** - a time for vacations, fun in the sun and remembering those we have loved and lost. Take time for memories, share them and do something special for yourself...and for them.

🍂 **Awareness** - each of you who shares your experience about donation, whether to one person or to many, is important. Be proud of what you are doing to increase awareness in your town, state or nation.

🍂 **Communication** - communication between health care professionals, donor families and transplant recipients continues to be a controversial topic. We are collaborating with several organizations to develop national guidelines. Hopefully, these will assist you in obtaining information and communicating with recipients. To review the draft document, please call Kathleen at 800/622-9010.

🍂 **Support** - many organizations offer bereavement literature and support. See page 5 for more information.

🍂 **Articles** - please let us know if there are specific topics you would like to see addressed in the newsletter.

🍂 **Thanks** - many thanks for the special letters, photos, calls and quilt squares, and for your continued support of the National Donor Family Council and our activities. 🍂

*For Those Who Give and Grieve* is supported in part by  
Musculoskeletal Transplant Foundation a full service tissue organization




# THOUGHTS FROM DONOR FAMILIES

 It's never too late to say goodbye to someone we love. Sometimes writing a letter or a poem can be very helpful in our grief.

## **In Memory of Samuel Brian Everage** **10/6/76-9/6/92**


**by Kathy Merix**

 Have you ever had a friend that died?  
All you did was cry  
Sam Everage was really a funny guy  
If you were depressed, Sam would always  
Make you laugh, and once you started  
He wouldn't quit  
If you were upset, he would be there  
To lend a shoulder and an ear  
He was his own kind of guy  
He was very popular and athletic  
He would take his friendliness very seriously  
If you didn't know him, he would walk  
Up and introduce himself  
He would always make a wisecrack  
He loved sports very much  
All I know is Sam is going to be missed  
Very much  
Sam, sorry we didn't get to say goodbye  
Everybody loves you and misses you  
So, Sam, goodbye!!!



## **In Memory of Christopher** **December 19, 1970-May 23, 1994**


**We miss you, Christopher**

 Our Christopher left us May 23, 1994—and did not say goodbye—why did he leave so suddenly. We sit and wonder Why? He's gone away forever now and left us broken hearted. We'll miss him oh so very much—we had so many good times and now the fun's replaced by tears—but the memories live forever—and we'll cherish those special years we shared with you, Christopher.

Memory Eternal

Kathleen Lake  
Virginia Beach, VA

## **My Son...He Was A Champion**

 Like the song goes, "We are the champions my friend and we'll keep on fighting to the end,"

My son was a true champion and he  
Did keep fighting till the end

Only 8 1/2 years old he had a  
Heart made of gold

A beautiful golden haired boy that  
Brought me so much joy

He was a Champion because he  
Fought death till the end

He could not walk  
Nor could he talk

But he and I had a bond  
Stronger than life itself

Though death has taken us apart  
My son lives within me in my heart

My son was filled with Love  
For me as I was for him


He was the apple of my eye  
And the music in my heart


My son was Heaven sent  
And he taught me what Love really meant

Susie, 7-21-92

This is dedicated to my Son...  
Jonathan Matthew Vance  
Sept. 27, 1983 - April 21, 1992


## **What the Angel Said**

 One beautiful fall day a young, harmless angel said: "Come with me and walk my way, sing with me like the echo of the rain, look at me. Do you see pain? No, I am an angel, one from your dream. I help you when you scream. I know what you feel—when you feel it. I know what you say when you say it. Come now, child. It's time. Time to see what you dream." And so sweet Michelle went with the angel to see her life-long dream. God, with all of his team.



Melissa Greever,  
Sister of donor


## PRIVILEGE OF CARING

 became a bereavement volunteer because I needed a way to understand how the families I met, going through terrible tragedies survived. I would think, "how can they stand it?" I saw no difference between their lives and mine except a simple twist of fate.

Over time I realized that no one truly deals with the terrible things that happen. You just get by and do the best you can. You aren't looking for magic words to make you feel better. There aren't any. The only true way to make "it" better is to bring back your loved one. I can't do that, but I can mourn and feel sad and remember your loved one with you. I can remember those first days of school, holidays, wedding dates that never happened, birthdays, and anniversaries. I can go over those last

terrible moments with you. I can reassure you that you aren't going crazy when you still have your loved one's message on the answering machine or their clothes in the closet.

I need families as much as they need me. You help me see that life miraculously goes on and is good. You help me stay focused and look at the positive side of things. I frequently read quotes and poems about the joys of living, of which there are many. I've learned that it sometimes just takes a while to find them.

I would like to thank all of you for allowing me into your lives. It has been a privilege. I stand in awe of your courage and your vast abilities for love and hope. 

*Gina Costello, RN  
Hartford Hospital  
Hartford, CT*

### *1996 U.S. Transplant Games*

*Presented by the National Kidney Foundation  
Salt Lake City, Utah  
August 20-24, 1996*


### **Programs for Donor Families!**

*Join us in celebrating  
the Gift of Life...*

*Contact: Kathleen Casey, 800/622-9010*


 **Congratulations!**  
*to Virginia Villanueva, donor family editor, who has been appointed to represent donor families on the Board of Directors for California Transplant Donor Network in San Francisco.*

### *Donor Family Council Memorials*

 Many of you have asked us to develop a memorial program. Whether you want to remember a loved one's birthday, their death, or a special occasion or accomplishment, we are pleased to announce that families and friends can make contributions to the National Donor Family Council. Special acknowledgement cards will be sent to the family in memory of their loved one. Please include their name and an address where an acknowledgement can be delivered.

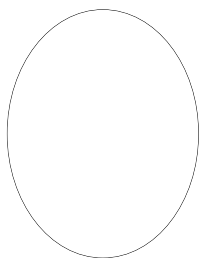
*Memorials  
National Donor Family Council  
c/o National Kidney Foundation  
30 East 33rd Street  
New York, NY 10016*

### *Thanks!*

 o Vickie Crosier from New York, who has represented donor families on the United Network for Organ Sharing Patient Affairs Committee and Board of Directors for the past eight years.

Vickie is a member of the Executive Committee of the National Donor Family Council.

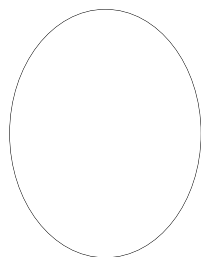
# We Fondly



*Vickie Lynn Thibodeaux*  
January 19, 1963-  
March 7, 1992



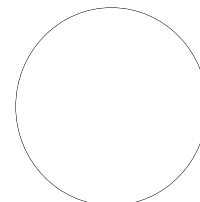
*Kenneth Barnett*  
June 6, 1926-  
May 2, 1992



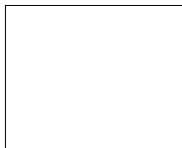
*Joseph P. Bauer*  
January 1, 1959-  
October 3, 1993



*Gregory John Samson*  
January 15, 1970-  
July 18, 1992



*Shawna Marie Bedard (far right)*  
with her sisters Kristi and Cara  
February 4, 1980-  
May 26, 1994



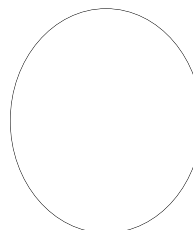
*John Gerard Beata*  
November 9, 1965-  
February 11, 1994



*Anthony W. Tenbusch*  
August 4, 1931-  
February 7, 1994



*Ted Ardary*  
May 9, 1926-  
July 6, 1989

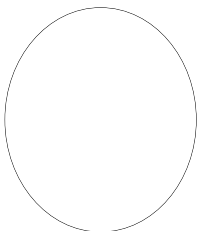


*Tashina R. Ploof*  
August 2, 1981-  
July 23, 1994



*Joey Stricklin*  
May 29, 1975-  
August 28, 1994

*Darrell M. Vorheis*  
February 15, 1937-  
May 14, 1994



*Leo Edward Sikora*  
August 1, 1910-  
October 30, 1992



*Sherrie Cullemore*  
August 1988

## Support For Donor Families



We represent a group of families who have lost loved ones and we recognize the benefit of the donation to the survivors. We have worked with LifeNet in Virginia (an organ procurement organization) in educational seminars, in-service training, public information and wherever our stories can be heard. We recognize that donor families continue to have needs after donation as well as healing benefits from our involvement in spreading the word. The more we speak of our loved one's "gift," the more we receive from that "gift."

LifeNet transplant coordinators are concerned about donor families. They answer questions and lend support, their compassion is heartwarming and you can feel and see their love. The coordinators support families with phone calls, letters and a questionnaire. They have sponsored the donor family committee, support committee and family newsletter; grief seminars, get-togethers and parties.

Donor families participate on LifeNet's Organ Procurement Organization Advisory Board and five families were sponsored to attend the first National Recognition of Donor Families in Washington, D.C. We feel fortunate that our tragedy occurred in an area served by LifeNet. Their progressive thinking and support of donor families should serve as a model to encourage other agencies to continue donor family care after the donation process.

It has been a privilege to work with an organization that is thoroughly professional yet uncommonly compassionate and has dedicated themselves to the caring for the needs of the donor families.

*The Donor Family Committee:  
Darlene Bailey, Don and Linda Chapman,  
Shirley Drye, Chairman, Sue Hilliard, David and  
Joan Kaiser and Ann L. Lange*

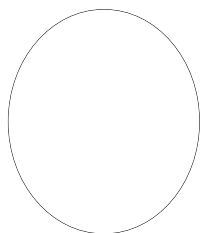
*If you would like to get involved in donation education in your community—call Kathleen at 1-800-622-9010.*



# Remember...



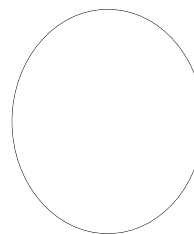
*Timothy James Pfau  
September 17, 1968-  
September 12, 1993*



*Brandy Michelle Beebe  
June 17, 1986-  
May 13, 1994*



*James Sunde  
July 26, 1934-  
June 1, 1994*

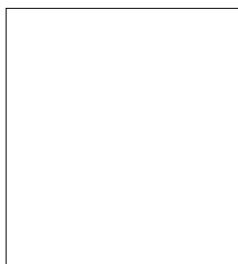


*Kevin Mark Darus  
December 5, 1965-  
March 28, 1994*

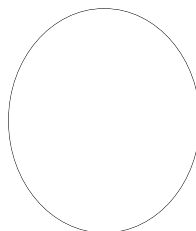


*Brizel James (B.J.) Overturf  
May 24, 1980-  
October 17, 1993*

*Christopher Cabe  
December 19, 1970-  
May 23, 1994*



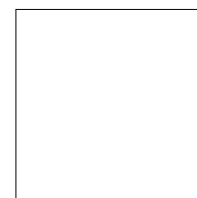
*Russell Brown  
May 9, 1961-  
October 10, 1992*



*Donald L. Martin  
July 4, 1937-  
May 18, 1993*



*Carla J. Palomba  
April 4, 1973-  
September 17, 1994*



*Kelly Joseph Mueller  
October 12, 1965-  
September 6, 1992*



*David Wendell Rye  
March 8, 1973-  
January 8, 1994*

*Travis Justin Wright  
October 27, 1977-  
April 21, 1994*



*Michelle Greever  
August 24, 1984-  
November 5, 1993*



## NATIONAL DONOR FAMILY COUNCIL

### Liaisons from National Support Organizations

The National Donor Family Council has established liaisons with the following national support groups. For more information about their specific programs and meeting dates, call them directly.

► **ANNE STUDNER**

American Association of Retired Persons (AARP)  
(202) 434-2277

► **REV. AL GALLOWAY, JR.**

Association for Clinical Pastoral Education  
(813) 253-2640

► **KEN DOKA, PHD**

Association of Death Education and Counseling  
(ADEC)  
(914) 654-5418

► **SUSAN SALSBUURY-RICHARDS**

Compassionate Friends  
(708) 990-0010

► **SUZIE SAWYER**

Concerns of Police Survivors (COPS)  
(314) 346-4911

► **JAMES O. PINKERTON**

National Funeral Directors Association  
(412) 766-5600

► **NICK PALAZZETTI**

International THEOS Foundation  
(412) 471-7779

► **STEPHANIE FROGGE**

Mothers Against Drunk Driving (MADD)  
(214) 744-MADD

► **DORIS AIKEN**

Rid Intoxicated Drivers (RID)  
(518) 372-0034

► **ELIZABETH ECKL, MS, LS**

Sudden Infant Death Syndrome (SIDS)  
(703) 821-8955

► **MARCIA WILLIAMS**

Survivors Helping Survivors  
(414) 649-6333


► **SKIP WISENBAKER, MAE, FCOC**


College of Chaplains  
(800) 544-6667

# WHAT HELPS WHEN IT HURTS


## The X, WHY, Z's of Grief


by Ellen S. Zinner, Psy.D.

 The WHY question. It seems impossible to avoid it when confronted with significant loss in your life. In the early days of grief, the WHY question may be posed to yourself and others unrelentingly—in the hope, perhaps, that the “right” answer would bring sought-for consolation and decrease the pain. No answer is good enough to warrant the tragedy that has befallen you. How can you best handle the WHYS in your life to support your own grief process and recovery?


 **THE PHYSICAL WHY:** At a very basic and concrete level, we have a need to know WHY a death took place, that is, what injury or illness precipitated physical death. When this basic fact is unknown or indeterminate or questioned by you, the grief process often becomes stuck. We seem to have an urgent need to know what exactly has happened to explain this sudden turn of events, and when circumstances or physicians’ explanations are questionable or inadequate to satisfy that need, the WHYS gnaw at us.


Children, too, need to have a clear and understandable accounting of death, one that they are able to verbalize to others. Otherwise, they will tend to invent answers that are often at odds with reality.

 **THE TEMPORAL WHY:** Especially in sudden deaths, we often are plagued by the thought of how the death might have been avoided if our family member had only lingered longer over coffee or taken an alternate route to his or her destination. Might a phone call from us have altered the fate that befell our loved one? Timing—a minute here or there—might have made such an enormous difference, we think. And we play the game of “what if’s” as if, at least in our fantasies, we might change such a pivotal outcome.

 **THE PERSONAL WHY:** Ultimately, the process of mourning is a lonely, personal one. Others may console you; some share the significance of the loss of your loved one in their own lives. But, your pain, your memories are unique. It is normal and natural to ask the question: Why me? The question may concern

whether your actions or inactions may have contributed to the death or whether the loss is somehow a punishment. Guilt is an omnipresent emotional response in grief. You might wonder what you have ever done to deserve this or cry out against the unfairness of the loss. Anger, too, often dominates our grief, until we no longer have the energy to bear it.

 **THE VICTIM WHY:** Similarly, these same WHY questions are raised about the deceased—why him or her. There really is no good time to die. Yes, release from physical and emotional pain can and often is seen by survivors as a blessing for the deceased; but the survivors still are left to grieve their loss. Our grief is made more difficult to bear when we contemplate all that our loved one might have yet experienced. Our reflection on the unfairness of a life cut short—at any age—adds to our burden of mourning.

 **THE PHILOSOPHIC WHY:** What is the meaning of this loss in our lives and to human existence in general? I find that this WHY question can lead to answers that support the grieving process, if you are willing to search for them. There is no one answer, of course, but I will assert the following: A death not learned from is a death wasted. If you find no growth, no contribution, no positive change in your life from having experienced this loss, then you have gotten little and paid dearly. As donor families, you, of course, have already given to others, and this very significant contribution must never be overlooked in the reckoning of this life event.

Iris Bolton, a survivor of her son’s suicide, confronts these WHY questions bravely and beautifully in the following poem from her book, *My Son, My Son* (Bolton Press, 1984):

*I don't know why...  
I'll never know why...  
I don't like it...  
I don't have to like it...  
What I do have to do is make a choice about  
my living.  
What I do want to do is accept and go on  
living.  
The choice is mine.  
I can go on living, valuing every moment in a  
way I never did before.*

*Continued on page 7*



## DONOR FAMILY FRIENDS



25-year-old younger sister who just lost her big sister a little over four months ago, would like to hear from others who have lost their best friend. I would enjoy sharing thoughts, grief, friendships, or just an ear with someone who is going through some of the same fears as me.

DF54

56-year-old mother who lost a son would like to contact other donor families who lost an adult child.

DF55

I am a 37-year-old mother who has lost an only son in an automobile accident. I would like to correspond with others that have experienced just some of the pain I have.

DF56

Names & addresses of people placing ads will be kept strictly confidential. Responses will be forwarded directly to you. Please send your ad to: *Donor Family Friends*, c/o The National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016. If you are responding to an above ad, please use the above address and include the ad number (ex. DF54).



## WHAT HELPS WHEN IT HURTS

*continued from page 6*

*Or I can be destroyed by it and, in turn,  
destroy others.  
I thought I was immortal, that my children  
and my family were also,  
That tragedy happened only to others...  
But I know that life is tenuous and valuable.  
And I choose to go on living, making the most  
of the time I have,  
Valuing my family and friends in a way I  
never experienced before.*

Dr. Zinner is Co-Director of The Center for Loss and Grief Therapy in Kensington, Maryland.

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Opinions expressed in this newsletter do not necessarily represent the position of the National Kidney Foundation, Inc.

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## PERSPECTIVES

Some of our readers have submitted questions in the hope that other donor families may have thoughts to share. If you would like to respond to one of these questions please write to:


*Perspectives*  
c/o National Kidney Foundation  
30 East 33rd Street  
New York, NY 10016.

### **Donor Family Advocates?**

I wonder if there shouldn't be someone who is a member of a donor family in each hospital to actually talk to the prospective donor family?

*Jackie Christian*

### **Please help me understand**

We donated all organs and tissues of my 18 year old son. What I can't understand is why the recipients don't even try to acknowledge us. With no response from the recipients, I have to wonder if I did the right thing. I know it's better to give than receive but in this case it's so hard to understand. Why don't the agencies encourage the recipients to acknowledge the donor families? 

*Diane Lege*


## THOUGHTS FROM RECIPIENTS

### **I Cannot Express How Thankful I Am**

I do not know anything about your family or the loved one who died when you decided to donate the gift of life that resulted in my receiving a heart transplant in June of 1990. I do know that you cared enough for someone unknown to you that in your own sadness, you were willing to share. That was very courageous of you, and for that I am ever grateful.

I cannot express how thankful I am. Still, whenever I think of you and the loss you faced five years ago, I get sad. I think about you and your loved one all the time. Not a day passes without the thought. Though we have never met and probably never will, except by chance, I feel a nearness to you that is inexpressible.

I am sorry this letter comes five years past my transplant, but please know that all the while I wanted you to know my feelings— but have not had the chance to express them. Even yet, someone else must write this letter for me, but be assured my whole being is wrapped up in the words and pages of this letter.

I would love to hear from you, should you feel that you want to write. In the meantime, I remain lovingly grateful. 

*Yours,  
Brenda*

*This letter was written for a specific donor family. LifeGift in Houston, TX has not been able to locate them.*



**NKF** National Kidney Foundation  
30 East 33rd Street  
New York, NY 10016



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