

# 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.

Summer 1996

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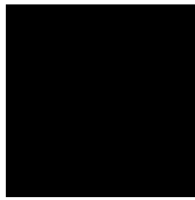
## We Fondly Remember...



*Bobby Berlincourt*  
April 12, 1968 -  
June 10, 1995



*Melissa Julie Schlueter*  
August 30, 1981 -  
August 21, 1992



*Arthur H. Cardy*  
March 18, 1926 -  
July 11, 1992



*Chad R. Jessop*  
August 7, 1975 -  
November 27, 1995



*Craig Doyle*  
July 22, 1973 -  
December 16, 1994



*Charles Allen Colvin*  
August 4, 1976 -  
July 12, 1994

## Life Goes On

*L*ife goes on that's what they say.  
Time heals all wounds, I've been told  
that also today.

You were here, then you weren't.  
Your life was taken just that fast.

Yes, it is true life goes on, God  
has shown me that.


No, time doesn't heal all wounds.  
After losing a child you have no choice.  
You just try to live with that.

God knows man's heart, He knows how  
hard life is without you.

Yes, life goes on, but nothing is the same  
as it was before losing you.  
You're not here with us, still you're everywhere.

I wonder how many times have you driven  
the streets of this town.  
Played on your old high school football field,  
or just hung out with your friends around town.

With your death came the unwanted  
knowledge man cannot understand grief he has  
never known but God understands and He knows...

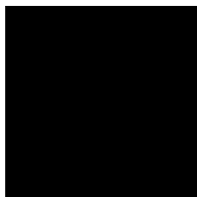
A sunset isn't quite as beautiful,  
A red rose isn't quite as red,  
Birds do not sing quite as sweetly,  
When you awake to face each day  
With the knowledge that your precious  
Child is dead. 

*Virginia Hughes, Randy's mother*

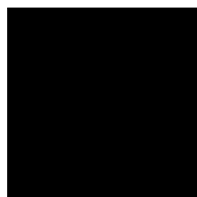
*In Memory of Randy Lee Hughes*  
December 15, 1969-January 10, 1993



*Evelyn I. Hance*  
August 6, 1942 -  
July 7, 1994



*Pearl L. Anderson*  
February 25, 1918 -  
May 9, 1994



*John David Crow*  
May 20, 1983 -  
April 29, 1995



*Timothy Hicks*  
November 6, 1976 -  
October 19, 1995



*Teresa Ann Strickland*  
March 29, 1929 -  
November 26, 1991



*Ricky Dean Cook*  
July 27, 1957 -  
December 9, 1994

# THOUGHTS FROM DONOR FAMILIES



## My Heart Cries

*This is dedicated to my son,  
Johnathan Matthew Vance*

*M*y heart cries day and night  
It's not easy drying the tears inside  
And it's so hard knowing  
You're not here anymore  
My heart cries out for you  
My dear precious child  
I've lost our fight you and I  
But my precious child  
You're in Heaven where you belong  
Mamma loves you so very dear  
The pain of losing you is so severe  
Sometimes my thoughts aren't very clear  
I was always your number one fan  
You were always mamma's little man  
Sweet, sweet child of mine  
If you can hear my cries

They are for you my little man  
Look down from the sky and  
You'll see the tears in my eyes  
My tears are for you  
And the pain is so great  
That sometimes I don't know  
How much more my heart can take  
Your pictures sit upon the TV  
And I think back to the way  
Things used to be  
It was you and I against  
The world but to me that  
Was OK 'cause I had you  
You were always my number one guy  
And within my heart you will  
Always be mamma's little man  
And I believe everyone knows why  
You were the world to me  
And you will always be

*Susie Vance, Donor Mom*

## Héroe Sin Loa

El cornejo está en flor,  
se despereza la maleza trepadora  
y el sol me hace compañía  
hasta la llegada del ocaso.  
Esta es la época más suave  
y sin embargo tiene  
el dejo amargo  
que le imparte el tiempo:  
hace un año te internaste tranquilo  
en un desierto agujereado  
por los estragos de la guerra.  
Un hombre solo,  
una mano que orienta,  
un obrero incansable.  
Empuñando la herramienta,  
otra vez hacia el viento,  
los ojos turbios  
por el humo del petróleo en llamas:  
tu presencia impartía  
razón a la sinrazón  
labrando terrazas en médanos de caos.  
ecuaciones matemáticas,  
trazos rigurosos  
para sopesar linderos y declives.  
Rara vez tienen los ingenieros  
dimensión heroica,  
quizás sean moldeadores  
y hasta curanderos.  
Allá en el desierto  
dejaste tu huella,  
y aquí, tras de las medallas,  
los honores y los retóricos elogios,  
un corazón que muere y se contrae.

## Unsung Hero

*"Unsung Hero" is the English version of "Héroe Sin Loa."*

The dogwood is blooming,  
the kudzu coming back  
to life,  
and the sun keeps me company  
long into my afternoon.  
This is a gentler season  
and yet,  
a bitter mark of time:  
a year ago today  
you drifted quietly away  
into a desert pocked  
with the ravages of war.  
One man,  
one guiding hand,  
one ceaseless laborer.  
With tools in hand,  
back to the wind  
and eyes filmed  
with oil-fumed smoke:  
you made sense of the senseless—  
cutting edges into the chaotic slope.  
Measurements,  
and exacting lines determining  
the edges of borders.  
Engineers are rarely heroes,  
just simply molders  
and sometimes healers.  
There in the desert  
you left your mark,  
and here beyond the medals,  
honors and rhetorical praise,  
a dying, shrinking heart.

# MORE THOUGHTS FROM DONOR FAMILIES

## Moving Forward

Since everyone's emotions are different, dealing with the grieving process is different for each of us that has dealt with the loss of a loved one. There can be extreme emotional highs and lows within hours or even minutes of each other. After all, a part of your life has been torn from you forever.

Family birthdays, holidays, graduations, weddings and many other memorable family events are changed because of the loss. But we cannot stop life, so after the loss of our loved one(s), we go on...somehow we muck through it.

There is no time frame for the grieving process. Being able to turn that grief into "positive" grief is the first step to a healthier grieving process. Let yourself feel emotions as they arise. Talk to the people that have been and are supportive in your life. By allowing yourself to feel and talk about your emotions, you can reach beyond the anger and denial to positive grief, which will enable you to move forward with your life.

Susan Burd Barnes, Donor Family Editor

## Organ Donation Softened Sad Death

On September 6, 1993, my son was suddenly killed when he was hit by a car.

Previously, I had thought about organ donation; never did I dream I would be making the decision about my child. Sean was brain dead. He was warm and breathing artificially, but he was dead when I saw him. If his father and I did not already have a philosophy about organ donation, I do not know if we would have been able to make any decision at a time of such pain.

I am not a baseball fan, but even I know Mickey Mantle was a hero who brought joy to millions of people.

I would have been proud to donate Sean's organs to Mickey Mantle. I am equally proud that one kidney went to a 50-year-old grandmother, another kidney to a 37-year-old housewife, two recipients gained sight through corneal transplantation, and the valves of my son's heart were given to children born with congenital heart defects. My son's utterly meaningless death was softened just a bit.

Barbara Chasen, Ph.D., Donor Mom

## Council News

### 1. Programs for Families

More than 200 family members participated in the following programs for families in Washington, D.C., prior to the National Donor Recognition Ceremony, April 13-14:

- Understanding Brain Death and Donation;
- Male and Female Grief and Marriage;
- Families: Different Roles, Different Grief;
- Communication Between Donor Families and Transplant Recipients; and
- The Legacy Continues: Getting the Word Out.

#### Here's what families thought of the program:

"The weekend gave credence to the legacy of the donors and their families."

"I left with a new view of what it means to be in the donor family—the group of us who experienced a loss and donated."

"The freedom and safety of exchange with other family members was appreciated."

Programs will be offered again at the U.S. Transplant Games in Salt Lake City, August 22-25, 1996.

### 2. "Patches of Love: The National Donor Family Quilt Video,"

describes the meaning of the National Donor Family Quilt. It features parts of the Quilt and the stories of some participants. This eight-minute video can be used for public and professional gatherings, as well as a keepsake for your family. We want to thank the **North Jersey Chapter of the International Television Association** for volunteering its time, energy and services to make such a compelling and provocative piece. To order a VHS copy, please send \$8.00 (check payable to the National Kidney Foundation) for postage and handling to: *National Kidney Foundation, c/o quilt video, 30 East 33rd Street, New York, NY 10016.*

### 3. The Executive Committee of the National Donor Family Council

is comprised of volunteers who donate their time to advocate and support donor families. Donor family representatives include: Maggie Coolican, CT; Vicky Crosier, NY; Jayne Miller, CA; Barbara Musto, NY; Kenneth Moritsugu, MD; Cynthia Rodriguez, CA; and David White, KS. Transplant and other professionals include: Myron Bennett, NY; Charles Corr, MO; Roger Decker, WA; Cindy Huber, WI; and Mark Reiner, FL.

# Disenfranchised Grief

(continued from the Spring issue)

by **Kenneth J. Doka, Ph.D.**

*Part one of this article appeared in the spring issue of For Those Who Give and Grieve. Disenfranchised grief occurs when someone dies and your relationship with that person is not recognized. The loss is not recognized and the grief is not recognized. Disenfranchised grievers may include step-family members, children, the elderly, the mentally challenged and friends.*

**T**he first step is to realize that wherever there has been attachment, grief is a natural and normal response to loss. Simply recognizing your grief can ease some of the isolation of disenfranchised grief.

Talk about the loss. If you are fortunate enough to have empathetic friends, share your feelings and reactions with them. If that is not possible, consider a self-help group or a grief counselor.

Try to find ways to acknowledge the loss. If the funeral ritual was not helpful, you may consider your own private rituals. That is what Bill did. Excluded from any meaningful role in Martin's funeral, he decided to invite some friends to a private memorial service at a sympathetic church. Elizabeth and her friends shared a pizza at what had once been their crowd's favorite restaurant, sharing their memories of Ann.

If you choose to mark the loss with your own

private rituals, remember the feelings of other mourners. Silvia, for example, remembers her long extramarital relationship with Ted by leaving long-stemmed roses on his grave on significant holidays. Unfortunately, her actions have greatly increased Ted's wife's anger and grief. It would be better if Silvia could find ways to express her grief while not intruding on Ted's wife's memories.

If others around you are experiencing disenfranchised grief, listen to them express their feelings about their loss. Respect their grief even if you do not necessarily understand or approve of the relationship. Remember that grievers, such as the very young, the developmentally disabled, the confused, the disoriented, and the distressed, may not always understand or express loss in ways similar to others, but that does not mean that their attachments are not felt, that their losses are not grieved.

We need to remember two key points to enfranchise disenfranchised grief. First, as humans, we have multiple relationships and a tremendous capacity to form meaningful attachments that extend over time and even species. Second, we can reaffirm that whenever these attachments are lost, there is grief. 🍂

*For further reading on such grief, you may see Disenfranchised Grief: Recognizing Hidden Sorrow, by Ken Doka (1989, Lexington Press, Boston, Massachusetts).*

6

**Understanding Brain Death** is a brochure for you and your family. This brochure may help you understand a difficult subject—brain death. Developed by donor families, it defines and explains brain death from a personal perspective.

A complimentary copy may be ordered by calling the NKF's material orders coordinator at (800) 622-9010. Bulk copies are available for \$15 per 100 (plus \$8 for shipping and handling). Please enclose payment with your order. Checks can be made out to the National Kidney Foundation.

## **DONOR FAMILY FRIENDS**

We invite you to submit ads to Donor Family Friends. You may request to correspond with someone whose situation is similar to yours. Many families find comfort in sharing their feelings this way. All correspondence is kept confidential. Please send your ad to:

*Donor Family Friends*  
c/o The National Kidney Foundation, Inc.  
30 East 33rd Street  
New York, NY 10016

### Special Days Special Traditions

For many of us, special times such as the first day of school, graduation and the holiday season may be very difficult because of the loss of our loved one. Some of you have started new family traditions to help you through the special days. Please share these special traditions with us by September 1, 1996, to include in the holiday issue of our newsletter. Send your suggestions, with photos if appropriate, to Editor, *For Those Who Give and Grieve*, NKF, 30 E. 33rd Street, New York, NY

### Community Donor Family Services

Do you participate in programs for donor families in your community? Please share the names and phone numbers of these organizations with us. We will publish them in this column so others who are looking for such organizations may contact them.

Examples of such programs include:

- Toward Tomorrow, Delaware Valley Transplant Program (800) 543-6391
- Northeast Organ Procurement Agency, After Care Program (800) 874-5215
- Donor Family Support Program, Alabama Organ Center (205) 731-9200
- LifeAnew Aftercare Program, Carolina OPA (919) 489-8404
- Lifelink of Georgia (800) 544-6667

## **FOR THOSE WHO GIVE AND GRIEVE**



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## PERSPECTIVES

*This letter is in response to D'Arcy Lovetere's letter in the Perspectives section of the winter issue of For Those Who Give and Grieve.*

I also requested letters from the recipients who received my brother's liver, two eyes and two kidneys. I received no response, briefly felt angry at the recipients' inability to express their thanks. Then it struck me that they were probably so lost in their own worries—"Has my body accepted the organ?" and "Has my turmoil ended?"—that they were too stressed and upset to thank us. But, I know in my soul that it's constantly on their minds, because the gift of life is so remarkable.

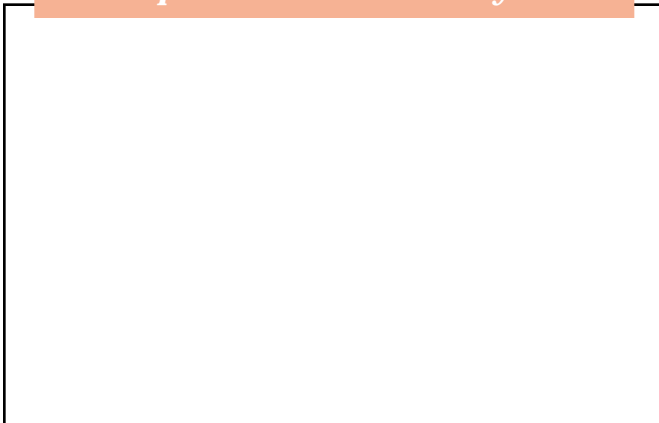
Recently, a client's 13-year-old daughter crossed my path. She needs a kidney donation or she will die. Her strength and courage made me realize how selfish we are when we do not

donate our organs. Why should this child die because somebody failed—for whatever reasons—to properly thank us? Try to forgive. My prayers are with you. I'm so thankful that my brother's death was not useless; five people's lives were dramatically changed in a wonderful way.

*Susan Schappell, Donor Sister*

**Signing an organ donor card, or indicating the wish to be a donor on a driver's license, lets family members and health care professionals know that a person wants to be a donor. In most cases, even if there is a donor card, the next of kin must consent or donation cannot occur. However, some states are testing a program in which consent of the next of kin is not necessary if a donor card, driver's license or other document identifies the patient's wish to be a donor. Please let us know your views on this issue by writing to the National Kidney Foundation.** ✂

### The Spanish Donor Family Book



*The Spanish Donor Family Book has arrived, thanks to Cynthia Rodriguez (pictured second from left), a Donor Mom who led the way to provide this resource to families. A complimentary copy may be ordered by calling the NKF's material orders coordinator at (800) 622-9010. Additional copies are available for \$2.50 each (\$8 for shipping and handling). Please enclose payment with your order. Checks may be made out to the National Kidney Foundation.*

**NKF** 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.