

# *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 2000

Volume 9, Number 1

## *Charlie Loved Fireworks*

by Virginia Peddicord

**E**very year, since he was little, my son Charles McElderry loved the Fourth of July holiday the best. At this time of year the carnival came to town, and Charlie would volunteer to do all sorts of chores around the house. I knew all along why he was suddenly so helpful, and I can summarize it in one word...fireworks.

The year Charlie was 10 years old, he was especially diligent in saving his nickels and dimes. He kept his stash in a tin can under his bed and emptied its contents daily to count it. His goal was to save \$24.95. I came to understand that this was the cost of the super-duper deluxe box of fireworks at a particular fireworks stand in our little town.

When Charlie had reached his goal, we loaded everyone into the car for the big purchase. He was so excited! From then on, instead of pulling his tin can out from under his bed for the daily money count, he pulled out his box of fireworks and counted each piece. He would arrange them according to size, and then rearrange them according to power. He read each package as though it would be his life's vocation. He made lists of the order in which he would launch each rocket or fire cracker. Oh, how he loved his box of fireworks. The wait for darkness on the Fourth of July seemed like an awfully long time away.

When the big day arrived, Charlie insisted that everyone be present. When it was finally dark, he positioned the spectators for the best view. He put his precious container by the mailbox and lined his first



*Charlie, as a young boy, was the spark of his family's life.*


bottle rocket on the side of the road, so it would land in the open field by our house. He had everything planned.

Then with lighted punk in hand, Charlie lit the first rocket. But something misfired. The rocket fizzled, growled and spurted, then headed directly for Charlie's box as though it had a mind of its own. Soon the box was on fire with a single amazing display of snaps, crackles, and pops. The spectators headed for shelter, but Charlie stood his ground, his mouth open in utter amazement. All of his counting, and all his dreams were banished in less than one

minute. Even though his brothers shared their fireworks with him, it wasn't the same. The spark was gone for this year. Poor Charlie.

Today, the carnival is pulling into town with even bigger and better rides. The fireworks stands are still there, too. But Charlie is no longer here to enjoy the excitement. On March 12, 1995, at the age of 20, he was killed on his way to work by a drunk driver.

The spark has gone out of our lives.

We donated all of Charlie's usable organs. He had signed his driver's license at the age of 18 for organ donation. Today, there is a tiny square on a national quilt to symbolize his contribution. I think of Charlie often, particularly on his birthday and the day he died, but none puts a smile on my face, as the day the carnival comes to town. 

# THOUGHTS FROM DONOR FAMILIES



## Why?

by Christie Mason (Aunt)

*In memory of Rick & David Keeseker*

**W**hy did they have to leave us?  
The ones that we loved so.  
When death came knocking at their door,  
Why did they have to go?


Some days I find it hard to cope...  
I feel so very sad.  
Some days I just can't stand the pain  
It makes me feel so bad.

There's pain deep in my heart  
No doctor could ever heal,  
Cause the love I felt for them,  
I know I'll always feel.

They say that time will  
    heal all wounds...  
Someday I'll feel okay,  
But the pain I felt the day they left  
Is just as real today.

Sometimes I feel they've gone away  
And soon they will be back,  
Then reality hits me once again  
And I must face the facts.

Their leaving left a void  
That nothing else can fill.  
My life goes on, but not the same;  
I know it never will.

I'll keep my faith and trust in God;  
I know He has it planned,  
Someday we'll see their smiling faces,  
And then we'll understand. 

## The Decision Wasn't Questioned

by The Buckalew and Boehm Families

**M**onday morning, July 6, we received a phone call that changed our lives forever. While preparing for a meeting, our son Christopher collapsed and never regained consciousness. His co-workers performed CPR to restart his heart and he was taken to the hospital. A CAT scan revealed he had suffered a cerebral hemorrhage due to a congenital brain aneurysm. It took his life instantly. We can be grateful that he never suffered a minute of pain.




Christopher R. Boehm

We're still trying to believe our youngest son, so happy and healthy, is really gone. He was such a pleasant young man, always a source of pride to our whole family. Arriving years after the rest of our children, he was the family's baby and was a gift to us all.

When it became apparent that Christopher was not going to survive, our family made the decision to donate his organs. Although the questions designating which organs they could recover were difficult to answer, the decision wasn't questioned. We knew it was what he would want.

We have learned that his organs have given a second chance at life to five adults, who are all recovering nicely. And the tissue and bone donations may help as many as 50 to 100 patients.

Our hearts are broken and we're trying to face the future without Chris, but we are grateful for the too short time we had him. 

## In Memory of Todd D. Schumacher

by Peggy Sue Rayn, (Sister)

**I**m writing in memory of my youngest brother, Todd D. Schumacher, who passed away suddenly, on July 18, 1993, of a brain aneurysm. When the hospital asked about organ donation, our family didn't know what to think. It was a very difficult time for us, but we all decided to donate his organs. Because of this decision, Todd saved five lives. We still miss him terribly, but thinking of the lives he saved is a great comfort to us.

I will always miss Todd. Some days are harder than others but, believe it or not, life does go on. Todd is always in our hearts and loved.

# FOR THE NEWLY BEREAVED

## *When Death is Unexpected and Sudden*

The following was written by National Donor Family Council Internet chat moderator Daniel K. Festa, (D) Min., Chaplain, Assistant Professor, Patient Counselor at Virginia Commonwealth University.

One of the things that we as human beings crave in our lives is a sense of evenness. We seek to achieve this order in many ways. We live by alarm clocks and schedules. This sense of order helps us to feel safe and secure in an otherwise chaotic and turbulent world. Within that ordered environment, we can move along doing fine as long as our life stressors and our coping mechanisms remain balanced.


When traumatic death happens, survivors struggle with many issues. When someone dies a sudden death, there is no time for the family and loved ones to prepare for one of the most awful events in their lives. With a sudden, traumatic death survivors are caught off guard and initially have a very difficult time believing what has happened.

As families and loved ones survive a traumatic death, they begin to share difficult moments, struggling to make sense of what happened. Some become fixated on the specifics of the death. Others suffer from survivor's guilt and ask why they didn't die instead. Another issue survivors deal with is trying to cope with the belief that their loved one may have died alone. They may also struggle with "what if" and "if only" questions. Seeking answers to these difficult questions is an attempt to understand

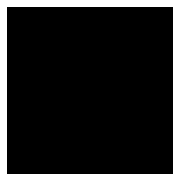
and lay to rest some of the plaguing problems survivors face.

For survivors to begin to heal and move on, it is important for them to find out all they can about the death of their loved one. This reconstruction of events seems to help recreate the conditions before death and produces a false sense of a pre-grieving period.

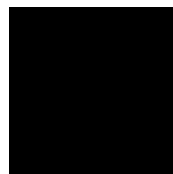
Because traumatic deaths make up such a small percentage of the deaths in any given year, this group of grievors may feel isolated from other grievors. Very few other people will have survived a similar kind of death, and a survivor can begin to feel alone and different from others. It is important to allow survivors of traumatic death to tell their story, probably many times. Depending upon the nature and the level of support available in their community, it may be important for survivors to attend support groups, which are specific to traumatic deaths.

You can read more on this and other bereavement topics on our web site:  
<http://www.kidney.org/recips/chatsched.cfm> 

## *We Fondly Remember*



*Renato C. Keith*  
*April 4, 1989 -*  
*January 8, 1999*



*Catherine H. Ruessler*  
*June 14, 1940 -*  
*September 3, 1993*



*Charles E. McElderry*  
*October 8, 1974 -*  
*March 12, 1995*  
*\* See cover story*

# ANET

## (Association of Nurses Endorsing Transplantation)

by Mary Gainey, RNC

As the professional liaison to your newsletter, I would like to share with you what my organization is about. I represent ANET (Association of Nurses Endorsing Transplantation) as the national executive director. We were originally called CORNEA (Consortium of Registered Nurses for Eye Acquisition) when we first formed in 1983, by a group of nurses in Kansas City, Missouri.


Our purpose is to create awareness and avidly endorse transplantation of all organs and tissues.

With nearly 70,000 people on the waiting list for life-saving organs (according to UNOS, United Network for Organ Sharing), and many more waiting for tissue and corneal donations, we need to reduce the waiting time for them. We support and work with organ procurement agencies, tissue banks and eye banks. Our members consists not only of nurses, but

also social workers, chaplains, hospital personnel and people from the community who share an interest in our mission. Members are also from eye banks, tissue banks and organ procurement agencies.

We are a non-profit organization based in Merritt Island, Florida. Each September we sponsor a National Conference for networking. Last year the conference was in San Antonio, Texas, and in 2000 we will be in Cocoa Beach, Florida.

ANET is meeting the challenge and responding to the national need for organ and tissue donation. It is devoted to restoring health and hope.

I am honored to be a part of your newsletter, which reaches the hearts of so many. The stories you share are an inspiration to us all. Having a part of the Donor Quilt at our conference was wonderful. 

### The Quilt on Tour

|                  |  |
|------------------|--|
| July 13-16*      | National Kidney Foundation of IN. Contact: Marylin Winn, (800) 382-9971  |
| July 15-16*      | Medway, MA, Pow Wow. Contact: Lynn Puishys, (508) 533-4392   |
| July 20-21*      | Las Vegas, NV, Nevada Donor Network, <i>Conditions of Participation Technical Assistance Workshop</i> . Contact: Ginny McBride, (301) 443-5464                     |
| July 29          | Omaha, NE, NKF of Nebraska, <i>Donor Family Reception</i> . Contact: Karen Englesman, (402) 572-3180   |
| Aug. 23-Sept. 6* | Rome, Italy, Novartis. Contact: Entire Quilt on Display!   |
| Sept. 9-17       | Denver, CO, Donor Alliance, <i>Donor Family Tribute 2000</i> . Contact: Patricia Taylor, (303) 329-4747  |
| Sept. 10         | Sebasco Harbor Resort, ME, New England Organ Bank, <i>Maine Donor Family Ceremony</i> . Contact: Pamela Albert, (617) 244-8000                                     |
| Sept. 10-14*     | Dorchester, MA, American Society of Minority Health & Transplant Professionals, <i>ASMHTP National Conference</i> . Contact: Brenda Butler Hamlett, (617) 427-2600 |
| Sept. 15-Oct. 1* | Granby, CT, North East Organ Procurement Organization, <i>Big E Health and Argo Fair</i> . Contact: Ginger Van Nostrand, (860) 545-6104                            |
| Sept. 17         | Albany, NY, Center For Donation and Transplantation, <i>Donor Family Memorial Service</i> . Contact: Richard Dalaba, RN, (518) 262-5853                            |
| Sept. 23         | Las Vegas, NV, National Donor Family Council, <i>Giving, Grieving, Growing Program</i> . Contact: Sarah L. Ockler, (800) 622-9010                                  |
| Sept. 24*        | National Kidney Foundation of Northern CA, Contact: Adelle,  |
| Sept. 27-29*     | Chicago, IL, Personal Communications Industry Association, <i>PCIA Foundation - Wireless Partnership for Donor Awareness</i> . Contact: Anne Riser/Bob Hughes,     |
| Oct. 7           | Riverside, CA, SCOPC, <i>Inland Empire Donor Recognition Ceremony</i> . Contact: Susan Prairie Hawthorne, (800) 338-6112   |

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/recips/donor](http://www.kidney.org/recips/donor).

\* Not yet confirmed.



# THOUGHTS FROM RECIPIENTS

## *A Chance to Be Normal*

by Jessica Harder and her mother, Debbie Harder-Thorpe

**O**n January 22, 2000, Jessica Harder, a 12-year-old Brevard County girl received a kidney transplant. This kidney had been a long time coming. When she received her kidney, she was in desperate need of a transplant.

Jessica would spend nine to thirteen hours a day hooked up to a peritoneal dialysis machine. She received her treatment through a catheter in her abdomen.

This did not keep her down. She filled the rest of her day with surfing and softball. Besides sports, Jessica is a good student. She maintains an A/B average in school.

While surfing, she gained notoriety because she was the only female surfer in the world on peritoneal dialysis. Now that she has her transplant, when she is up and surfing again, she will be the only female with a transplant to surf competitively.

Jessica will be doing this in good company. Rich

Salick, a fellow surfer and best "bud" is a three-time transplant recipient. Rich is the senior regional director of the Florida Affiliate of the National Kidney Foundation.



*Jessica: Determined to keep on surfing.*

Jessica will be dealing with a lifetime of health concerns, medications, blood draws and worrying if rejection will come. It is the support of her family and her love of life that continues to make Jessica thrive. She uses every opportunity she can to talk to people about the need for organ donation.

In June, she will attend the 2000 U.S. Transplant Games in Lake Buena Vista, Florida. She hopes to win as many competitions as she can. Jessica will be doing a surfing demonstration in the Typhoon Lagoon with Rich Salick.

Jessica is determined to be normal and show people that just because you are stricken with an illness, doesn't mean you have to give up on life. She hasn't. Just watch for her at the games! She will be the one out ahead of the rest.

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

**VISIT THE NATIONAL DONOR  
FAMILY COUNCIL WEB PAGE.**

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.

## *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:**

**Dennis J. Drahmman** - by Ruth W. Drahmman

**Rick and David Keeseker** - by Christie Mason

**Todd D. Schumacher** - by Peggy Sue Ryan

**Christopher R. Boehm** - by Buckalew and Boehm Families

# PRIVILEGE OF CARING

## James

by Wilma Walker, Mother of James McNair, RN, CPTC

**H**e talks with gentle compassion and skill  
to families of the very ill  
Discussing with them should their loved  
one die

If he, with help for God on high  
Might have the gift of life to give  
To someone else that they might live

He shares their grief and dreadful fears  
And helps to wipe away their tears  
Their bravery he knows so well  
They're going through a private hell  
Yet still have time to think of others

Mothers, fathers, sons or brothers  
And agree that the greatest gift to give  
That others may go on to live

He is blessed to share in all these things  
So when my telephone bell rings  
And he talks to me about his day  
I too feel blessed in some small way

To know that he's my firstborn son  
Giving love and hope to everyone.

*James McNair, RN, CPTC is a Translife Organ  
Procurement Coordinator.*

## Where to Go for Help

The National Organization of Parents of Murdered  
Children (POMC)  
100 East Street, B-41  
Cincinnati, OH 45202  
(513) 721-5683

The Compassionate Friends (TCF) - National Office  
P.O. Box 3696  
Oak Brook, IL 60522  
(708) 990-0010 or fax (708) 990-0246

The Sudden Infant Death Syndrome Alliance  
(SIDS Alliance)  
1314 Bedford Avenue, Suite 210  
Baltimore, MD 21208  
(410) 653-8826 or (800) 221-SIDS  
or fax (410) 659-9709

The International THEOS Foundation (THEOS)  
322 Boulevard of the Allies, Suite 105  
Pittsburgh, PA 15222  
(412) 471-7779 or fax (412) 471-7782

National SHARE Office  
(Pregnancy and Infant Loss Support, Inc.)  
St. Joseph's Heath Center  
300 Capitol Drive  
St. Charles, MO 63301  
(800) 821-6819 or fax (314) 947-7486  
Web site: [www.NationalSHAREoffice.com](http://www.NationalSHAREoffice.com)

Ray of Hope, Inc.  
Po.O. Box 2323  
Iowa City, IA 52244  
(319) 337-9890

TAPS (Tragedy Assistance Program for Survivors, Inc.)  
2001 S Street, NW, Suite 300  
Washington, DC, 20009  
(800) 959-TAPS or fax (907) 274-8277  
e-mail: [tapsk@aol.com](mailto:tapsk@aol.com)

The Dougy Center  
3903 S.E. 52nd Street, P.O. Box 86582  
Portland, OR 97286  
(503) 775-5683

In Loving Memory  
1416 Green Run Lake  
Reston, VA 22090  
(703) 435-0608

GriefNet  
Rivendell Resources, P.O. Box 3272  
Ann Arbor, MI 48106  
e-mail: [riverdell@falcon.ic.net](mailto:riverdell@falcon.ic.net)  
Web site: [www.riverdell.com](http://www.riverdell.com)


American Self-Help Clearinghouse  
Northwest Covenant Medical Center  
Denville, NJ 07834  
(201) 625-9565 or fax (201) 625-8848  
e-mail: [asch@buttercup.cybernex.net](mailto:asch@buttercup.cybernex.net)  
Web site: [www.cmhc.com/self help/](http://www.cmhc.com/self help/)

**DISCLAIMER:** The above is a partial listing of no-fee  
support groups and services in the loss and grief area.  
This information in no way constitutes endorsement  
by the National Kidney Foundation.

# THOUGHTS FROM RECIPIENTS

## My Angel

by Terri Willis

When I was sick and in need, you gave me life.  
Now you're forever a part of me.  
For what ever I do, you're only a thought away.  
For wherever I go, you'll be there.  
When I'm scared and alone, you're there to chase my fears away.  
When I'm down and out, you're there to cheer me up.  
When I use poor judgment, you're there to let me know about it.  
When you visit me in my dreams, I wake with a smile upon my face.  
Life doesn't go by without you in it.  
God only knows what you do for me.  
You were there for me, now I must be there for you  
And live this beautiful life that you've given me.  
Though I only hope you'll know how much you mean to me.  
For I am not me without you.  
For all that you give me, I thank you heavenly angel. 



## FOR THOSE WHO GIVE AND GRIEVE

For Those Who Give and Grieve is published quarterly by the National Donor Family Council of the National Kidney Foundation (NKF). Opinions expressed in this newsletter do not necessarily represent the position of the National Kidney Foundation. The NKF reserves the right to edit all submissions. Please contact the NKF for article submission guidelines.

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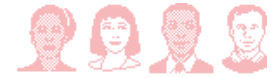
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# Donor Family Friends



**DF 141** I have lost many dear ones in my life and I feel as though I am always in a state of grief. The hardest loss was my nephew, Justin. Since his death our whole family has been shattered—our only comfort is knowing that through his death, 17 families are rejoicing instead of grieving. I would love to correspond with others.

**DF 142** My husband of 32 years died suddenly a year ago. His organ donation has brought me great peace and comfort. I would like to correspond with other widows and widowers to share our experiences and coping techniques.

**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.*



Mary Ann Carpenter

## JOIN US!

*Are you interested  
in volunteering for  
the National Donor Family  
Council ?*

**Call 1-800-622-9010 to find  
out how you can get involved.**

*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.