

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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Fall, Volume 4, Number 2

The Healing Tree

by Pamela Dulude

From the Editors:

The following story embodies the courage, grace and creativity that can be experienced along the grief journey. Profound grief can become a catalyst for great growth...the human spirit can embrace something as painful as grief and loss and find personal enrichment and bittersweet joy.

We wish you these gifts along your grief journey during this holiday season. Peace!

Maggie & Jayne

After the loss of our 13 year old daughter, Jennifer, and our son James, age 12, we found ourselves unable to face Christmas. With just a few short days until Christmas and after three attempts to buy a Christmas tree, we found ourselves at a loss as to what to do. We had a very impatient 11 year old, named Sara, who still wanted and needed some traditions to stay the same. As if inspired from above, we decided that this tradition had to change. Life is not about having the best of everything; it is about taking what you have left and working with it to make it better. So we decided to use the last Christmas tree we shared with our lovely children, to celebrate this tradition. So out to the woods we went, hoping

to find the old tree. My husband and I hauled the tree out of the woods. We had to clean out an old mouse house and a bunch of dried leaves, but other than that it was in pretty good shape. By this time our Sara was totally convinced that her father and I had gone mad. She cried that this was going to be the worst Christmas of her life. We comforted her and told her to have faith, and that everything would work out. Jim brought the tree into the garage and stood it up in the stand. Jim sprayed the tree using his compressor with white paint. Sara and I stood in amazement, as this old Christmas tree, with no needles left on it, began to take shape. As the paint dried, Sara began to smile. She could see this ugly old tree with no needles was becoming a beautiful white sentimental work of art. We brought it into the house and Sara, Jim, and I decorated it. When it was totally decorated, the tree was beautiful. The lack of needles represented our loss, and the droopy branches represented the weight and pain that we carried from the loss of our children. We all stood back and smiled. We had overcome this problem and found a way not to forget but to live with this tradition. 

For Those Who Give and Grieve is supported in part by



a full service tissue organization



THOUGHTS FROM DONOR FAMILIES

Just Let Me Say Goodbye

by a Donor Family Sister

fter supper on Christmas Eve, I stood with my parents, husband, and daughters in a semi-circle around my brother Michael's grave and held hands. No words were spoken, just a few silent tears. We came to wish Michael a Merry Christmas. On the big evergreen wreath which decorated his headstone, a lone Santa ornament mingled with the red bows. It was still hard to believe he had been gone for two years. We said a quiet prayer, then returned to the warmth of our car. Christmas just wasn't the same. Why did he have to die so senselessly? He was only 37 years old...

October 1, 1991, I received a phone call from my mother, her voice a stranger's voice. It certainly didn't dawn on me that something tragic had happened. Something that would change our lives forever. It was hard for her to tell me that my brother Michael had been shot and was brain dead. All I kept thinking was please God just let me say goodbye, just let me tell him that I love him. Somehow I couldn't comprehend that "brain dead" meant he was already gone. I simply felt that as long as his body was still in the hospital bed, he was still with us. I stood by Michael's bedside with my

dad. I said a silent prayer, then kissed Michael's forehead. My dad's words still echo in the back of my mind: "There was just so much left unsaid," he spoke, trying so hard to be strong, "but I guess the good Lord wanted to talk with Michael more than I, guess you can't argue with such a high honor." I realized at that moment Michael was truly gone. Our small family was smaller. My parents who had two children, now had one. To lose a child, my mother said, is a parent's worst nightmare. The pain of never seeing their smiling face or hearing their voice is something no one can imagine.

Later that tragic day, I found out about the difficult yet courageous decision my parents made. They donated Michael's organs. It brought my parents comfort to know a part of Michael lives on.

Two and a half years have passed since Michael died. We have heard from several of the organ recipients, and they are all doing well. We still miss Mike, but we are a family of survivors. We will hold hands, and cross whatever bridge life has in store for us...together. Michael showed us just how precious life is. How wonderful it is to wake up each morning. How important it is to tell your family you love them. 

How Many Times Does a Once in a Lifetime Opportunity Present Itself?

by Henry Kreis

ome years ago, when my 16 year old son, Steve, was pronounced "brain dead," we as a family made what we believed was the proper decision—to donate his organs. We did this with the feeling that, Steve would have joined with us in wanting to help others survive and live to enjoy a future of service, that would not otherwise for them be possible.

Little did I know then as a *donor parent* that I would later in my life experience the other side of the fence as a *recipient parent*.

I just thought that as a *donor parent* I could feel or know the gratitude, the respect, the love, the appreciation, and the relief that a *recipient parent* experiences. But I did not really feel these things until three days before I was to drive my wife Bonni to Florida to give a kidney to her daughter, Dawn. It was then that the call came to tell us there was a donor. Dawn's brother, Brad, was taking her from Stuart to Jackson Memorial Hospital in Miami for the transplant operation.

2

We made this decision, as I am sure all donor families do, with the conviction that what they were doing was right. That if not already jointly agreed to, their loved one would have been proud to have helped those in need of their organs and be confident of the recipient's warm feelings and appreciation. Even though we would personally not see or hear of their feelings.

continued on next page

THOUGHTS FROM DONOR FAMILIES



The Last Christmas by Shirley Gosney

*We didn't know it was the last Christmas,
That last Christmas with you.
You came striding off the plane,
Hugged your sisters and me,
Got your picture taken in front of the hula girl poster,
And we all trooped happily home from the airport.
The house came to life; the telephone began to ring,
There was a reason to cook,
The dog raced joyously up and down the stairs just to
be near you.
Your friends came by at all hours;
Tall young men on the same journey to manhood,
And together you shared your plans and dreams.
Buying Gina a promise ring for Christmas left you
financially depleted.
So I made you a small loan and you dashed off to finish
your shopping.
Christmas Eve found us in the candle-lit church
of your childhood.
You were touched by the minor song of the guitar
playing singer,
And remarked on the medieval sound.
We didn't know we were sharing the last Christmas
Eve.
Christmas morning was full of joy and clutter of
packages.*



*One married sister, one out-of-state sister,
All together with "little brother" in his proper place;
A family again.*

*We didn't know it was the last Christmas morning.
Later we traveled to the family farm where
Grandparents, aunts, uncles, cousins, food, gifts,
games, wood piles, snow boots, long walks and
winter sunsets waited.*

*We didn't know it was your last Christmas at the
farm.*

*All too soon, we stood watching your plane pull
away,*

And never dreamed that before the next

Christmas you would be

*With your Heavenly Father and would celebrate the
divine birthday*

With God's Own Son.

But, because you lived,

*Somewhere in the Christmas candle glow, three families
are Saying,*

*"We thought it would be our loved one's last Christmas,
We didn't know there would be more."*

And for them every Christmas will be so special—

*Because you lived—and died. Merry Christmas,
Brian.*

*(Brian was 19 years, 3 months, and 7 days old when
he was killed in a motorcycle accident. He was a multiple
organ donor in 1988.)*



HOW MANY TIMES...continued

Our excitement was unbelievable as we drove from Knoxville to Miami so we could be with Dawn. During our drive we were able to talk to and share the enthusiasm with Dawn by phone as she was being prepared for surgery.

Due to the gracious generosity of the donor's family Dawn, now 29, has a chance for a new life to make of it what she will. How many times does a *once in a lifetime opportunity* present itself?

Since receiving the pancreas and kidney, Dawn no longer is diabetic or on dialysis and as a nurse she can continue to professionally serve others. I feel that due to the experience that she has gone through she will have an

insight that will be invaluable to many patients and their families in the future.

Words cannot express our thanks to the donor, her family, and Dr. George Burke, a highly competent, generous and dedicated physician, his fantastic supportive staff—and our Lord.

No matter which side of the fence you are on, *donor or recipient*, the need or challenge is for all of us to help more people to declare themselves by making a positive decision—*now*—to become a donor.



We Fondly



Teresa Maitland Tokar
November 22, 1960-
June 5, 1994



Chris Rahman
April 17, 1969-
March 18, 1994



Julia Ehnatko
February 9, 1984-
November 29, 1994



William D. Bidlack
April 25, 1973-
January 9, 1991



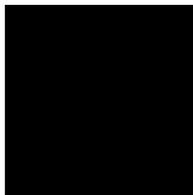
Christopher Michael Lingenfelt
June 24, 1977-
April 18, 1994



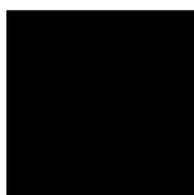
*Sherry Christina
Goodall Huggins*
November 12, 1942-
September 26, 1993



Richard Lee Tillapaugh
November 17, 1944-
March 15, 1995



Lezley Ann Yarger
November 7, 1973-
November 6, 1994



Anita Donelle Shanks
May 17, 1971-
March 1, 1994



Melinda Carole Payne
February 12, 1976-
October 22, 1993

1996 U.S. Transplant Games

Sponsored by:  **SANDOZ**

Partners in Transplant Health

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

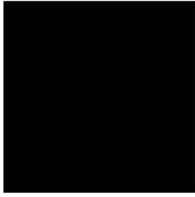


Donor Family Council Memorials

 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*

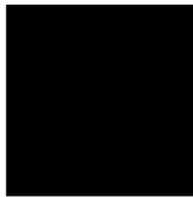
Remember...



Robert Daniel Herrera
April 24, 1973-
February 17, 1995



Tony Hyde
January 1, 1977-
April 27, 1992



Robert E. Dean, III
January 9, 1978-
January 20, 1995



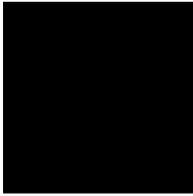
Christian Herrera
January 24, 1978-
December 10, 1994



Paul Dean Braggs
September 13, 1936-
July 6, 1994



Sharissa Lew Tews (left)
December 4, 1969-
August 19, 1989



George Wright
November 15, 1941-
July 6, 1994



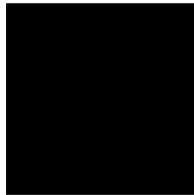
Donald D. Butson
January 31, 1992-
August 2, 1994



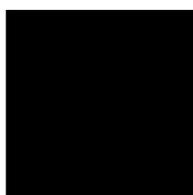
Andrea Clark
January 8, 1973-
November 3, 1991



Timothy James Hochstetler
February 14, 1979-
December 28, 1994



David D. Bratton
February 25, 1954-
October 26, 1993



Kristie Heuing
April 9, 1975-
April 25, 1992



Ken Ulibarri
April 28, 1964-
July 28, 1994



James Edward Price

Sobrevivir en Días Especiales

Las fiestas, cumpleaños y aniversarios pueden resultar especialmente difíciles. Es posible que los días que preceden al día señalado en cuestión sean más difíciles incluso que el día en sí. Una parte de ustedes desea celebrar la fiesta con su familia y amigos. Por otra parte, una celebración de este tipo puede resultar dolorosa, especialmente si tiene lugar durante las etapas iniciales de su duelo. Puede decir que no, o cambiar sus costumbres, si es que esto sirve de ayuda. Algunos de nosotros tenemos la costumbre de hacer algo especial en

recuerdo de nuestros seres queridos: encender una vela especial, hacer una tarta, plantar una flor. De este modo logramos que nuestros seres queridos sigan siendo parte de la celebración. 🕯️

Esto es una selección de libro "Para Los Que Dan Y Sufren" que sera disponible en el año 1996.

Ledeseamos un FELIZ AÑO NUEVO!

WHAT HELPS WHEN IT HURTS

How to Reinvest Yourself in Living When a Loved One Dies

Permission to adapt by Alexis Stein and Howard Winokuer

☞ Feel the pain

Allow yourself to really feel what you are feeling—the whole range of emotions—whether it's sadness, anger, guilt, etc. Denying the feelings may only intensify and prolong the pain.

☞ Cry

Tears may be the most therapeutic tool you have—let them cleanse you and relieve your pain inside.

☞ Talk, talk, talk

Share the pain. Sharing grief diminishes it. You *must* talk about your feelings, even when you feel you “can't go on,” or that “life will never have meaning again.” It helps you when someone responds by their presence to your pain.

Talk, too, to the loved one who died. Even though you may feel uncomfortable, this will give you the opportunity to finish your thoughts and feelings you've wished to express. Use statements such as: “When you died, I wanted to...”, “I miss...”, “How could you leave me...”, “It was a relief when you died: the ordeal and pain were over...”

Let the words flow. You *can* do it. You have already been through the worst.

☞ Keep a journal

Your journal is a private place where you can write anything. Here, write about unfulfilled wishes, guilts, angers, and other thoughts and feelings. Again, fill in unfinished sentences:

“If only...”, “I wish we had...”, “I'm furious with...”, “I'll never forgive...”, “I'll never see you...”, “I remember...”

☞ Let go

Don't let bitterness engulf you. Resentment is a heavy load and it only hurts *you*. Find the source of your anger and do everything you can to resolve it—whether you actually clear the matter up with the hurtful person or you resolve the problem in a symbolic way with a friend.

☞ Find your own comfort

Create rituals that feel right to you and give you comfort. Whether it's prayer, meditation or other activities, rituals can be a source of strength.

☞ Hold off

Tread lightly when making decisions. Mull over, thoroughly explore your options before

making a major step. You may still be too vulnerable to make a life-changing decision.

☞ Be kind to yourself

Be patient with the conflict inside you. Find a balance between the happy person and sad person, the angry self and peaceful self, the guilty you and the glad you—all feelings which may be raging inside your mind. Have patience with yourself. Life is too short for you to be the villain in your life.

☞ Learn to laugh again

Rediscover your sense of humor. Remember: disloyalty to your loved one is not in finding joy again but in giving up on living when you still have life.

☞ Nurture your body

Be good to yourself! Exercise. Your body can't revitalize without good nutrition and physical activity.

☞ Hug

Take pleasure from physically sharing with others. We *all* suffer from skin hunger. So reach out and hug someone—and yourself.

☞ Don't be hesitant

If you need outside help, admit it. You want to be willing to be helped and healed. An outside resource may be just the salve you're searching for.

☞ Become a wounded healer

Reach out and help others. It just may help you too.

☞ Let life grow

Develop new interests, skills and friends. Focus your energy away from the past and toward the future. Take small steps and enjoy the small victories. You are a changed person seeking a new life.

You *can* be stronger after grief, the choice is yours. You may have been powerless to help your loved one, *but you are not powerless to help yourself*.

Seize the power right now that abides within you and begin again the journey that is your own life. Grief is the price we pay for love—but we do not have to go on paying forever.

Reprint from: *ToLife*, Volume 4, Summer 1986.



DONOR FAMILY FRIENDS



I am a 57 year old mom whose 25 year old daughter died in a tragic accident on July 6 of this year. She has a three year old daughter. They lived with me. How do I keep her memory alive for her daughter. I need help so desperately.

DF57

Widow, 40 years old loves to make friends and help people who suffer from the loss of a loved one or a friend.

DF58

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. DF57).



Christmas Bear

by Kayla Renee Reichert, December 1993

*For days all she could hear was,
"Christmas is coming!"
"Christmas is coming!"*

*There was so much excitement in the forest!
Little Bear didn't know what Christmas was,
so she went around the woods asking the other animals.*

*"It's presents!"
"It's sweets!"
"It's games!"*

*She heard so many answers but none seemed to be
the right one.*

*Finally, she went back to her home and saw her mother,
her father and her big brother bear and she smiled!*

*"Now I know what Christmas is!
It's not presents, or sweets, or games!
It's being together! It's a family!"*

(Kayla was an organ donor.)

FOR THOSE WHO GIVE



AND GRIEVE

*For Those Who Give and Grieve is published quarterly by
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The Quilt on Tour

☛ The National Donor Family Quilt will be coming soon to a town near you, as many individuals and organizations have requested the quilt to display to recognize donors and increase awareness about donation. Here's a schedule of where it's been and where it's going:

1995

September 8-9	TRIO	Boston, MA
September 9-13	AATB	Atlanta, GA
September 23	The Tree of Life Ceremony	Wisconsin
September 24	Wisconsin Donor Network	Wisconsin
September 25-27	St. Luke's Medical Center	Wisconsin
September 29	Translife in Florida	Orlando, FL
October 5	South Texas Organ Bank	Dallas, TX
October 13	CT Donor Family Ceremony	Hartford, CT
October 19-21	Univ. of NE "Final Gifts"	Omaha, NE
November 1-5	NKF Annual Meeting	San Diego, CA
December 3	Midwest Organ Bank	Westwood, KS
December 8,9	Southwest Organ Bank	Dallas, TX

1996

February	DOT/UNOS Annual Meeting	
March 24	CT Donor Family Ceremony	Hartford, CT
April 13-14	National Donor Recognition Ceremony	Washington, DC
August 22-26	1996 U.S. Transplant Games	Salt Lake City, UT

If you would like to view the quilt at any of these meetings, please contact the NKF for information.

1996 National Donor Recognition Ceremony

April 13-14, 1996
Washington, DC

Bonor families from across the country come together for this annual gathering to share, to remember, and to honor their loved ones who gave the Gift of Life. For more information, contact Kathleen Casey at the NKF at 1-800-622-9010.



PERSPECTIVES

Some responses to the questions posed in the summer issue included:

Why aren't transplant recipients encouraged to acknowledge donor families?

Three years ago, we donated our daughter's organs and tissues and were frustrated as letters we wrote to the recipients went unanswered.

After a year, we learned that our letters had not been forwarded! Fortunately, a caring coordinator sent them. The heart recipient responded immediately, and we now enjoy a wonderful friendship. Had this not been the result, we could have all bid farewell. We still hope to hear from the other recipients and wish them good health and happiness. Also, do remember that many recipients write letters to donor families that also go unanswered.

WE hope that others realize that as we donor families find a piece of our lives, we come to have more peace in our lives.

Why don't hospitals allow donor families to speak with prospective donor families?

Amen, Jackie! Our family was in agreement about donation, but facing this decision was traumatic. How comforting it could have been to have someone speak with us. Yes, the coordinators, doctors and staff were kind, but what did they know about losing an adult child? Reassurance from donor family members who have experienced this could help ease the doubts and concerns. Someone to listen who has nothing to gain would be valuable. It would not usurp the authority of any staff member or procurement person in the hospital setting. Worth a try? Why not? This could help turn the tide of reluctant donor families.

We thank the Colants for their responses. Please send your questions and comments to the National Kidney Foundation.



30 East 33rd Street
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