

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.

Winter 1998

Volume 6, Number 3

No Tears Past the Gate

by Barbara Starr, Donor Mother

 I have a small collection of "Precious Moments" figurines. After my son, David, died in January 1991, I added another piece that held a lot of meaning for me. It was titled, "No Tears Past the Gate." It has a child at the gate of Heaven, and beside the gate is a bucket for "old hankies" that won't be needed for tears on the "other side." Timmy, the angel, is there to welcome the child to her new home.

One day a shelf fell off the wall, breaking all the pieces of

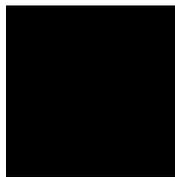
my collection. I was able to glue this treasured figurine back together, but it was evident that it had been broken. Although it looked almost whole from the front side, two fragments were missing in the back.

Because the message of this particular figurine had meant so much to me, I considered replacing it. But as I looked at it, I realized it was like me in many ways, and I wanted to keep it as it was. If any one meets me, I look as "whole" as

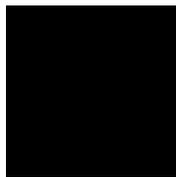
anyone else. No one would know I am a bereaved parent. However, if I share myself with them, they can see the scars that have been left by the death of my son. They'll see that there will always be a hole in my heart and life because of that terrible tragedy.

So, even though I have experienced a lot of healing since David's death, I will never be the same as I was before—a condition I share with my special figurine. 

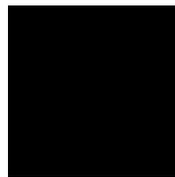
We Fondly Remember



*Nathan Charles
Hodkin
January 10, 1976-
February 24, 1993*



*Wayne A. Greenhaw
November 19, 1932-
February 27, 1996*



*Gerry Potter
February 9, 1956-
June 20, 1997*



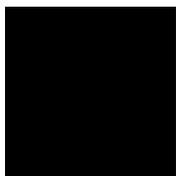
*Kenneth Bowles
June 7, 1961-
April 17, 1995*



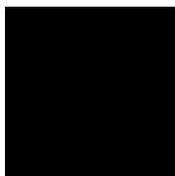
*Luigi Ortega Rodriguez
January 26, 1963-
June 5, 1986*



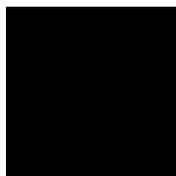
*Leila P. Burnworth
February 14, 1905-
May 31, 1994*



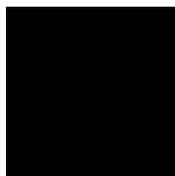
*Jamaroe Chrisstel Salley
February 16, 1976-
December 3, 1995*



*Diana Sharon Stepan
March 14, 1972-
March 5, 1995*



*Tiffany Amelia Hess
March 6, 1985-
October 16, 1996*



*Ronald Batterbee
March 10, 1940-
March 26, 1997*



*Sara Jean Fletcher
March 28, 1977-
May 8, 1994*



*Dennis Mlynec
April 20, 1963-
September 5, 1995*



THOUGHTS FROM

Dear Families and Friends,

Thank you for all your wonderful letters and poems. They are priceless treasures of memories of your loved ones. I want to share all of these with you, but there have been so many wonderful contributions. In this issue, "Thoughts from Donor Families" is a collection of excerpts of your heartfelt poetry, words of tribute and love letters. May the wondrous parts of these memories fill you with hope and peace and continue to bring comfort as we journey together. 🍂

Warmest Regards,
Mary Ann Carpenter, Volunteer Editor-in-Chief

In Memory of Christopher

March 16, 1978 - December 11, 1994

He was a very kind and loving person who told us only a few months before his death that if he were ever in an accident he would want us to donate his organs.

The love never dies, nor does the pride we have in him because of his courageous decision.

Gala Vess, Donor Mom

In Memory of Eric J. Foster

December 27, 1971 - March 7, 1996

"When someone you love becomes a memory, that memory becomes a treasure."

Our prayer is that through your precious gift of giving, someone else can benefit. That they can now go on and fulfill their life's goals.

We Love You Son,
Mom and Dad

Will There Be Life Without Stephen?

Organ donation was not something we ever really discussed, but considering the giving man that Stephen was, I didn't hesitate when I was asked to donate. It gives me great comfort to know that he was able to help someone else after he died; he always went out of his way to help those in need while he was alive.

If you're ever asked to donate, do it. You will feel better knowing you've helped, and you'll feel the love of God and your departed loved one shining down on you each and every day. That alone is enough to give us the strength to face each day without Stephen. We know we'll see him again one day and the first thing he'll tell us is that we did the right thing.

Patricia Porter-Johndro and Merry Johndro

The Gift of Sight

My husband, Michael, died suddenly in June 1996 and I donated his corneas. At first, I felt Michael's donation was not as significant and important as something like a kidney or heart. The letter I received thanking me for the sight of two men and how his other donations helped many people really comforted me. It is so easy to isolate yourself in grief. The newsletter makes me feel connected to people going through similar circumstances.

Christine Vachula



DONOR FAMILIES



"If Chris doesn't make it, could we donate his organs?"

I heard Maurice say that and it just seemed so right. To this day, we don't know what prompted Maurice to say that. Organ donation had never been discussed in our home. It had to have been Divine Inspiration.

Chris had given the ultimate gift, the Gift of Life. We feel there is a special place in Heaven for anyone who has given this gift.

Our lives have changed forever. We will always speak out about organ donation and how important it is. We are so thankful that Chris was able to be an organ donor, and we will never let him be forgotten.

Maurice and Dianne Dalton

Beautiful Love

Our love grows as we grow.
We may be far apart, but I still love you with all my heart.

Megan Radel
For her dad Curtis W. Radel

In Loving Memory of Justin Bobholz

I thank thee Father for my son
you placed within my care.
The memories that still live on
with others I will share.

Though my heart seems heavy,
and often filled with pain.
The joy, the love, the memories
forever shall remain.

So Father now I call to You,
please mend my hurting heart.
And with Thy grace and mercy
Your strength to me impart.

Cathy Zeller, for Kay Bandle
Justin's Mom

And Daniel Was His Name

In Memory of Richard Daniel Whitten
April 9, 1974 - July 26, 1989

Although his breath on Earth is gone,
in our hearts his memory will live forever on.
Many lives were spared, for so
unselfishly his loved ones cared.
And Daniel was his name.

A sudden tragedy became our loss,
and our lives will never be the same.
But by the Grace of God above,
because of Daniel another's life was gained.

Alissa Poole Dyson

When sunset comes and darkness falls, just look up toward the sky.
The brightest, twinkling light I see is my dad's shining star.

Kathie Lynn Carr
Daughter of James E. Funde
July 26, 1934 - June 1, 1994

Dreams

Still

Come

True

by Willa Pilcher,
Donor Wife



Before going to the XI World Transplant Games as a donor family member of Team USA, I dreamed of attending the Olympic Games. Now I dream of the 1998 U.S. Transplant Games in Columbus, Ohio, and the XII World Transplant Games in Tilburg, The Netherlands, in 1999.

Team USA was represented by 150 athletes (each of whom had received a life-saving organ or bone marrow transplant), team officials, a World Games Committee member, many family members and friends, living donors and two of us whose loved ones had died and donated. For most of us, it meant a once-in-a-lifetime trip, both to the Games and to Sydney, Australia.

For me, a donor family member since my husband died in 1994, it was a time of renewal, hope, joy and sadness, and it was a balm to the soul. Witnessing the health, vigor, joy, courage and refusal to give up that was displayed by the transplant recipients thrilled me and reinforced my heartfelt commitment to organ and tissue donation. Meeting the warm and loving donor family members from Australia and other countries reminded me that support, caring and sharing know no boundaries. Hugging my Australian friend from an e-mail widow(er) support group, hearing her tell of her

husband who died while waiting for a bone marrow transplant and being beside her as she so bravely participated in the Closing Ceremonies of the Games returned pieces of my own heart.

Every moment was special, but some are engraved in my memory. Clapping for the last athlete in a race until he or she had won an extraordinary personal victory, watching donor family children presenting medals to young athletes, receiving the honor of awarding medals to the athletes and placing the medal around the neck and receiving a precious hug from a young woman who had won my respect and love at the 1996 U.S. Transplant Games—these memories are mine forever.

For you, I brought home so much love and so many personal stories of hardship, illness and pain overcome and turned into treasured new life. And I brought home so much deep and tender gratitude from recipients of the Gift of Life. I received the thanks, hugs and love for you. Please share these medals of the heart from our transplant athletes.

And, oh yes, Australia was really great.

See page 7 for information about how to participate in the 1998 U.S. Transplant Games this summer!



PERSPECTIVES

To the Editor:

Georgina Roberts, the author of "Your Gift Is Heroic" (volume 6, number 1), mentioned that recipient families are torn between telling the truth to donor families and struggling with a deep emotional bond. As a donor family member, I am struggling, too. My son, Kyle, died a year and a half ago. He is no longer here on Earth, but his heart beats for another man. I need that connection with this man who is

alive because of my son's heart. I want to be able to touch his chest and feel that heart beating. I need to know how his heart is doing. But I don't know! And if the man should die, I would want to be at his funeral—after all, it would be my son's heart that would have died, too. Georgina said that she wouldn't "want to make a donor family grieve a second time." I may need to grieve that loss, too. I am also torn: I am so glad that if a death has to occur, a precious gift can be passed on to continue another life. But I would give anything to have my loved one with me still.

Susan Sippy, Donor Parent

WHAT HELPS WHEN IT HURTS

Simple Relaxation and Breathing Techniques to Help You Through the Grieving Process

by Pilar Kimbrell, Donor Family Editor

 I developed the following exercises to release some of the grief experienced when my husband died. They are easy and helpful physical activities to cope with the tension and stress of the grieving process. Do a little every day, and don't feel discouraged if you cry or get emotional while performing these exercises. After all, that is the whole point—to get it out, so you can continue to cope.

The Breath of Life

Sit in a chair. Take off your shoes and sit back. Close your eyes. Put your hands on your abdomen to remind yourself that this is where you breathe from. This is the center of your breath, not your chest or your shoulders. Inhale slowly and deeply. Always breathe through your nose, in and out.

Try to feel a rhythm in your inhaling and exhaling. Use the image of a balloon being slowly blown up, or of waves coming

in and out, like a slow tide. Develop your own image, but keep your breaths long and steady. In and out. You'd be surprised how grief and sorrow keep us from breathing correctly. This is the Breath of Life. Let it flow in and out of you, and don't be afraid if emotions well up—crying and breathing can happen at the same time.

You may choose to try your own variations, like letting out some kind of sound as you exhale, or lying down instead of sitting. All variations are acceptable as long as you are breathing deeply and from your abdomen.

Shoulder Roll

Sit in a chair or cross-legged on the floor. Slowly roll your shoulders forward. Try to get them up by your ears and then feel the release as they come down. Do this ten times, then roll them backward. Feel as though you are rolling all the

tension, fear and unhappiness away from you, releasing it. Breathe slowly and deeply as you do your shoulder rolls. Then, lift your shoulders up by your ears and hold for a count of ten. Release them with a deep sigh. Do this five times.

Arm Lifts: Oh to Fly Again

Sit in a chair. Make sure you have adequate space along your sides. Close your eyes. Breathe deeply until you have a nice and steady rhythm. Breathe in and slowly raise your arms out to your sides, palms facing down. As they reach shoulder height, breathe out and turn your palms up, and continue reaching above your head until they meet. Hold here for a complete breath, then release down, palms facing out. Do this at least 10 times. Use the image of a flying bird for a model. 



To the Editor:

I've been on both sides. My son's life was sustained through dedicated pheresis

donation (a type of blood donation) when he was five. When he died at 13, he then became a donor.

As the mother of a recipient, my gratitude is indescribable. My son's donors gave him seven more years of life, full of joy, adventure and accomplishment. I cherish those years, even though there were seven rather than 70, more than I can say.

As the mother of a donor, I am there with you, just as my loved one was there with you. I know the pain of loss, the value of hope and having tried everything. I want to be there for you now, to share your pain as I shared your hope. The shared grief is not a burden, but a gift. Together, we, the living, can heal and reach out and touch someone who neither one of us could have touched alone. 

Carol A. Ranney

Please send your questions and comments to the National Donor Family Council.

THOUGHTS FROM RECIPIENTS

by Glen Finland, Tissue Recipient

I'm 44 and the mother of three boys. I was never critically ill. I am not the recipient of a heart, lung or kidney, only a piece of tissue about the size of my finger.

I have been told that donated tissues—ligaments and tendons—are the most commonly used body parts from a donor, but also the least celebrated. In May 1996, I received an anterior cruciate ligament for my left knee, which allows me to pivot to the right and left and come to a quick halt. I want to assure you that every gift from a donor has value; each piece is precious to its recipient.

After my injury, my husband said I was like a bird with a broken wing. I want to tell you how a gift from a family like yours lifted me up and helped me fly once again. Movement is my profession. As a fitness practitioner, I teach people of all ages how to balance their bodies and move in their natural rhythm. I use a lot of dance in my work.

While the doctor fired off the many advantages of using a donor graft, I was thinking: Whose ligament was it? Will I wake up from surgery feeling differently or craving different foods? Was she an athlete? Hey, was she even a SHE?

I decided to name my ligament Mary Margaret, as in, "How's Mary Margaret doing

today?" The response, of course was, "Thank you, we're fine." I needed this kind of humor because deep inside I was scared.

I woke up from the operation feeling fine but aware that a change had occurred, one I hadn't counted on. The Mary Margaret jokes weren't funny anymore. During the course of the transplant Mary Margaret had become a real person to me. She gave me back my quality of life. I could pick up my boys or slow dance with my husband. In time, I would leap again.

In rehab, I looked around at other patients and wondered who else received donated tissue. I met a 76-year-old woman, a self-proclaimed "Polka Queen," who had received a knee ligament, and a former college football player who had received a shoulder ligament.

I am now a trainer at a sports injury rehab center. I'm good at what I do because I've been there. I am able to do what I do because of Mary Margaret. She gave my life balance again and taught me to give back the good things that life brings—to recycle energy, hope and love.

It gives me great joy to thank you for sharing your own beloved Mary Margarets with people like me, the Polka Queen and the old football player. I promise to take good care of her. Thank you. 🍁

- **THE ORGAN AND TISSUE DONATION Stamp** was unveiled on November 6. The U.S. Postal Service will print 25 million Organ Donor Stamps next year to help spread the message about organ and tissue donation and transplantation. It will be available in the summer.
- **THE NATIONAL DONOR FAMILY COUNCIL** would like to thank the Musculoskeletal Transplant Foundation for its continued and generous donation in support of our newsletter and our other activities.

In Remembrance

Memorial contributions made in memory of our readers' loved ones are channeled directly into programs and educational resources for donor families and the professionals who support them.

In memory of: **Frank Sharpe**—from Bette Rarick

Our beloved **Dee**—from Robert and Shelia Boudreau

We welcome tributes for any occasion:

In honor of: **Bruce Smith** (a living donor)—Bowling Green Plant Employees
Happy Birthday, **Barbara!** From Jan and Michael Schichtel (for Barbara Musto)

DONOR FAMILY FRIENDS

DF 79: In April 1997, my husband hung himself in our garage. I found him and am always thinking, "What if?"

DF 80: I lost my 22-year-old son to suicide last year. Therapy hasn't helped the pain, and the recipients haven't responded to my letters. I don't know how to cope.

DF 81: A 30-year-old mother of four, I lost my 11-year-old son in a car accident. I would like to hear from others who experienced the same.

DF 82: The departure of our 17-year-old son has affected the entire family, leaving us in deep sorrow. Let's share this difficult time. Contact me in English or Spanish.

DF 83: I'm a 22-year-old who came across a car accident in which my 19-year-old sister/ best friend/roommate died. I miss her terribly and wish I could've been stronger at the scene of the accident.

DF 84: My 12-year-old son was hit by a car while riding his bike in August 1997. The loss I feel is unbearable.

DF 85: The youngest of six children, our 21-year-old son was killed in August 1996 in a car accident. We also lost our seven-year-old daughter in July 1957 due to birth complications.

DF 86: I am 49 years old. My 23-year-old twin daughter was in a car accident October 1996. Her daughters are seven years and two months old.

My other daughter and four grandchildren survived the accident. There are days I don't feel like I can go on.

DF 87: In September 1996, my 27-year-old son and his friend were killed in a boating accident. The rescue was botched up; they say he could have been saved. I didn't get the chance to say "goodbye" or "I love you." I find it hard to get out of bed each day.

DF 88: My husband/best friend/soul mate died in July 1996, in an on-the-job accident. I am 38, and our sons are 16 and 13.

DF 89: My youngest son, who was 18, was in a car accident. He would have graduated from high school last spring. How do we go on without our precious children?

DF 90: I am a 46-year-old divorced woman. My 18-year-old daughter was murdered in April 1996. My two sons (25 and 21) live out of state. I would love to hear from other moms.

DF 91: My athletic, 31-year-old bachelor son had a fatal mountain biking accident. We lived 2,000 miles away, which added many problems. I would like to hear from someone with similar circumstances.

To submit or re-run a Donor Family Friend ad or to respond to a family, send all correspondence to Donor Family Friends, c/o The National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016.

FOR THOSE WHO GIVE AND GRIEVE

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National Donor Recognition Ceremony & Workshop

 **PLAN NOW** for the National Donor Recognition Ceremony and Workshop. This year, the ceremony will be featured at the Opening Ceremonies of the 1998 U.S. Transplant Games, August 5-9, 1998, in Columbus, Ohio. Join other donor families and friends as we come together in celebration of our loved ones and transplant athletes. Support and education sessions will be offered—including workshops for teenagers!

If you've been thinking about attending a national gathering—this is the one you should make! Come spend your summer vacation celebrating the "Gift of Life" and sharing the warmth of remembrance. For registration information, contact the National Kidney Foundation at (800) 622-9010.

The National Donor Recognition Ceremony and Workshop is sponsored by the Division of Transplantation, Health Resources and Services Administration, U.S. Department of Health and Human Services in collaboration with the NKF's National Donor Family Council, and cosponsored by many transplant organizations. 

The Quilt on Tour

March 5	NKF of South Texas	San Antonio, TX
March 6-18	NKF of Wisconsin	Brookfield, WI
March 8*	TRIO of El Paso	El Paso, TX
March 14	NKF of Nebraska	Omaha, NE
April 18	Midwest Organ Bank	Wichita, KS
April 18	Golden State Donor Services	Sacramento, CA
April 18	NKF of East Tennessee	Knoxville, TN
April 19	Donor Alliance, Inc.	Denver, CO
April 19-26	Texas Medical Association	Austin, TX
April 20	Alabama Organ Center	Birmingham, AL
April 21-23	MidAmerica Transplant	Springfield, MO
April 22-26	TRIO-Pittsburgh	N. Versailles, PA
April 22	LifeGift	Ft. Worth, TX
April 25	NKF of Nebraska	Omaha, NE
April 27- May 4	Nevada Donor Network	Las Vegas, NV
April 28-30	Long Island ANET	Long Island, NY
May 2	California Donor Network	Modesto, CA

*Indicates event not yet confirmed.

The quilt is created from squares submitted 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. Since it may not be displayed in its entirety, please call if you plan on seeing the quilt. For information on how to contribute a square, to request a panel of the quilt for an event in your area, or for up-to-date information, please contact the NKF at (800) 622-9010.

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. The National Donor Family Council is a Gift of Life Initiative of the National Kidney Foundation. 

Organ & Tissue
DONATION
Share your life. Share your decision.

— Visit our Web site at www.kidney.org.

NKF National Donor Family Council c/o
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