

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.

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We May Be Heroes

By Aracely "Shirley" Garcia, donor mom

It brings great comfort to my family to know that our loved one's organs go on living in someone else's body.


In the summer of 1997, eight-year-old Christopher Michael Garcia, my first-born son, was pronounced brain dead. He died of a rare genetic disorder called Ornithine Trans-carbamylase Deficiency (OTC), caused by a deficiency of one of the enzymes in the urea cycle. At the time, my husband, Ruben and I were asked if we would consider donating Michael's organs. We agreed without a second thought, even though we had never thought anything like this could ever happen to us.

Michael was the kind of child who knew no strangers. He once told me he wanted to give his new

toy to a friend so that they could play together.



(Left to Right) Butch, Anita (recipient) with Shirley and Ruben Garcia (donor parents)

A year after Michael's death we received a call from Anita Hood, one of Michael's kidney recipients and we spoke to her for over an hour. We agreed to talk more and planned to meet in the future. It was October of 1998 when we gathered at Anita's home in Texas. The meeting was angel sent. It was as if we had always known each other. Anita's family members warmly welcomed us into their family. To this day we speak practically every week and our families have forged an incredible bond and a dear friendship. 



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 NOVARTIS

SAVE THE DATES! The National Donor Family Council invites you to the 2002 U.S. Transplant Games at *Disney's Wide World of Sports™* Complex in Lake Buena Vista, Florida June 25-29. Come see transplant recipients compete in Olympic-style events and participate in the Donor Recognition Ceremony, educational workshops and sharing sessions, a special quilt pinning and more. For more information, e-mail donorfamily@kidney.org or call (800) 622-9010.

Taking Care of Your Physical Needs in Bereavement

By Charles A. Corr, PhD, and Donna M. Corr, RN, MSN

What should you do to take care of your physical needs when you are bereaved? Here are some simple suggestions that some bereaved people have found useful in taking caring of their needs for hydration, nutrition, rest, and exercise when they found themselves encountering difficulties in focusing on such needs.

HYDRATION. Living creatures need fluids to sustain life and health. Dehydration is a real danger when a profound loss leaves



you stunned. The best way to rehydrate yourself is to drink water. Keep cold water in a jug or bottle in the refrigerator and try to drink eight glasses every day.

Avoid excessive amounts of tea, coffee, caffeinated/non-diet soda, and alcoholic beverages. They will bog you down with calories, caffeine, and sugar. They will also dehydrate you and contribute to insomnia and nervousness.

NUTRITION. Food may not seem very appealing, especially in large amounts. Don't settle for poor eating habits, such as grazing



on whatever is available or turning to unhealthy comfort foods.


Seek out a well-balanced diet of nutritious foods such as seafood, fruits and vegetables that require little preparation. Eat six small servings each day, instead of three large meals.

Allow close friends to invite you over for an occasional meal. Let them help you prepare wholesome meals or bring over foods that are attractive, easy to fix, and not hard to reheat. Real friends will be glad to be shown how to help you in these practical ways.

REST. Restful sleep will recharge your batteries and help you cope with the challenges of bereavement. If you can't fall asleep or often wake up during the night, try sharing your feelings with someone else to release tensions. Plan enjoyable activities for periods of nighttime wakefulness, like reading, listening to music, keeping a journal, writing to a friend, or just soaking in a tub of warm water.

If you are simply unable to sleep or get the rest you need, try one of the non-addictive nighttime preparations that are now available over the counter in your pharmacy. But don't overmedicate yourself. Always check with your physician before starting a new medication, even a nonprescription one.

EXERCISE. A modest exercise program can help you feel better physically and psychologically. Try walking around the block or strolling through a park, either on your own or with a friend. Or choose simple activities that you like, such as jogging, riding a bicycle, swimming, or playing tennis or golf.

Whatever you do to take care of your physical needs for hydration, nutrition, rest, and exercise, keep in mind that bereavement is a difficult time (as you well know). You should not feel guilty about finding ways to take care of yourself or about indulging yourself in an occasional special treat. 



Losing Peter

By Judi Cavazos, RN, CCRN, donor mom

I've been a nurse for over 20 years and always thought I could understand grief. I've seen the effects of long-term illnesses and devastating trauma. I've cried with the families of my patients. I've given care, counsel and support to grieving families and have been a proponent of organ and tissue donation for many years. In fact, I chair a committee for that cause at the hospital where I work.

I've lost friends and members of my family during my lifetime, including my father. However, nothing could prepare me for the day in December of 2000, when a Florida highway patrol officer knocked on my door at 5:30 in the morning to tell me that my oldest son had been killed in an automobile accident. It was a mistake. How could it be true? Peter was an excellent driver. He was always the "designated driver" when he and his friends went out. He couldn't have had an accident. Peter couldn't possibly be dead.

I was heartbroken; I still am and probably always will be. Nothing

"Perhaps it will get better some day, but for now it helps to write it down and to know that Peter has given the gift of life"

on earth can surpass the grief of losing a child. I still live my life and manage to function, but there is never a day that goes by in which I don't feel the loss of Peter.

I was faced with many decisions over the coming hours and days, but there was one decision that needed no deliberation. My family and I had already discussed our wishes about organ and tissue donation in great detail. We would donate Peter's corneas and tissues.

Peter always set an example for his six brothers and sisters. He was an unselfish and giving person. As the single parent of two lovely children, he did everything in his adult life for his kids. Even before Peter was an adult, he was a giving soul. At 14, he worked a part-time job while going to school and contributed almost his entire paycheck to help support our large family. He used to tell me, "I don't mind, Mom. I don't need money. Helping the family makes me feel good." Well, he can still feel good because he continues helping people. Two people in West Palm Beach, Florida now have sight because of his gift and his strong bones and other tissues will be used to help many more.


I used to tell my patients' families that organ and tissue

donation would be a source of consolation to them in their grief. I said it like a robot reading a script because it was what I was supposed to say, no matter how trite it sounded. Now I say it with my whole heart because I know it's true. I'm on the other side of the fence and it offers some comfort to my patients' families, as well as my own.



I am extremely proud of the life Peter led, the kind of person he was, and the examples he set. Every time I see the sun glitter on the ocean, or hear his favorite song, or cook his favorite meal, I think of him. It can make me smile, cry, or both.

He loved simple things in life. He enjoyed surfing, fishing, and being with his family. He never cared about money or prestige. He knew what was really important – love and giving. I still love Peter and Peter is still giving.

I am lucky to have my husband, my other children, friends and family to support me. Still, there are times when I feel like no one can understand my grief, except another mother who has lost a child. Even now, I can't talk about it without breaking down. Perhaps it will get better some day, but for now it helps to write it down and to know that Peter has given the gift of life. 




A Special Message from Mary Ann Carpenter

For Those Who Give and Grieve editor-in-chief

Five years ago, Maggie Coolican, the driving force behind the NDFC and a donor mom, asked if I would serve as co-editor of this newsletter. I was sure she had me confused with someone else. I soon discovered that she believed I was the right person and, as I could not say "no" to a woman I admired, I accepted. Shortly thereafter, I became the volunteer editor-in-chief.

It has been an interesting journey, and all of the memories readers have shared of their loved ones will not be forgotten. I have been told that the newsletter has given hope to donor families when there was none. I have been told that it has stood beside the families so that they would not be alone in their grief.

The journey does not end here. The path is merely merging with another. We will continue to share what we have learned through our newsletter with our new editor, Steve Gardner. Steve is a donor dad and has served as our assistant editor.

Each one of you is special and I am grateful to have had the honor and privilege of serving as the editor of "your" newsletter. Thank you for all of your support. 

Mary Ann Carpenter

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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 or permission to reprint articles.

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You Do Not Walk Alone: Tissue Donor Families Are in Good Company

By Daris Langham

Many people have heard about organ donation, but tissue donation is not as commonly discussed. Although the quest to increase public awareness of tissue donation continues until they are faced with the decision at the hospital, many are unaware that they can donate tissues for transplant.

Skin grafts, for instance, can be used to help people who suffer severe burns over large portions of their body.

When you work in the field of transplantation, you tend to believe that you know what donor families go through when making the decision to donate. However, unless you have experienced the death of someone dear to your heart, you can't be sure that you do. I never quite understood until my mother suffered a traumatic intercranial hemorrhage (bleeding around the brain).

I headed out on my five-hour journey to the hospital in Athens, Georgia where she was undergoing emergency brain surgery. A million things were running through my mind: She was fine just a few days ago. How could this have happened? Is my father alone at the hospital waiting for us to arrive?

When I spoke briefly with my father, he was confused about my mother's prognosis, but knew it wasn't good.

Clinging to every bit of hope, I joined my dad and my siblings at the hospital. I suddenly realized that we had never discussed our own wishes regarding donation. Would she want to be an organ or tissue donor if our family was faced with this decision? Despite my experience with donation and transplantation, I did not have the answers.

I have been involved with tissue donation since 1994. The donor families have touched my life immensely. The strength and courage the families show at times of such despair fills me with hope. I deeply admire the willingness to give so much to help others.

By donating tissues, one family's loved one may be able to help as many as 75 people who face crippling or debilitating injuries or diseases. Skin grafts, for instance, can be used to help people who suffer severe burns over large portions of their body. Other transplantable tissues include corneas, for sight restoration, and heart valves, to replace those that are damaged or deformed.

Thanks to medical advances, tissue transplantation has profoundly affected the lives of many recipients. I'm sure no one knows this better than seven-year-old Lane and 13-year-old Joanne. When aggressively cancerous bone tumors threatened to destroy their legs, donated allograft bone from the Musculoskeletal Transplant Foundation allowed them to recover. To Lane and Joanne, who would have lost their limbs without the transplants, bone donations were blessings.

Your decisions to donate the organs or tissues of your loved ones can give others hope for the future and for a better life.

I am pleased to say that my mother survived her traumatic event and my family considers every new day brighter than the last. We now discuss our own feelings regarding donation so that, when the time comes, we can find peace in our decisions. I have my donor families to thank for this; they touch my life deeply and provide me with great inspiration.

Darice Langham is the president and CEO of Florida Tissue Services, Inc.



The Giving Soul of Ana

By Sharon Crain



Rarely in life do you meet someone and sense an immediate kinship. But that is exactly the way I felt when I first met Ana. A mutual friend introduced us at an exhibition in New York and Ana was bubbling, smiling and talking as if we'd known each other for years. Though I would only have the opportunity to visit with Ana once or twice a year, I knew I would always share her enveloping warmth when we were together.

Ana's family was first in her heart. Thoughts of her husband, Pete, and her sons, Peter and Luis, were always woven throughout her conversations. She always said that marrying Pete was the "best thing that ever happened" to her. Her beloved sons were her pride and joy.

Ana's love was generous, spilling over to embrace countless stray dogs, cats and other animals. Abandoned or homeless animals

often found shelter in Ana's home, as well as her heart. Even a local duck found protection in Ana's giving nature.


Ana was a giver, in life and in death. In the truest sense of the word, which is often overused, Ana was one who gave not simply for the sake of giving, but because she truly cared. There are people who give only to tell others that they are "givers," but that was not Ana. She was real. She gave quietly with her heart and soul. She didn't need to talk about it and she sought nothing in return.

Four years ago, I was mourning the loss of my dear college roommate, Donna. I promised her parents that I would give them a doll in remembrance of her. Ana made the dress for the doll. I will never forget sitting next to her while she created, in precise detail, a dress Donna had worn years before. Ana asked me about

Donna's life and about her two sons.

As I spoke about Donna and her family, Ana's eyes filled with tears. She wanted so much for the dress to be perfect for the parents she had never met who had lost their daughter, and she made sure that it was.

The dolls Ana created, those beautiful and soulful children, will always touch my heart. They are an enduring reminder of the bright light she cast around her and a testament to her talent.

When Ana died, she continued to bestow her gifts on others. I was privileged and honored to have known her. If you were blessed with a gift from Ana, you received it with her love. I take solace in the knowledge that so many have been the recipients of the bounty of her goodness, her loving heart, and for some — the very gift of life itself. 

The Quilt on Tour

Please note: This schedule is subject to change.

March 1	Southington, CT, National Kidney Foundation of CT, <i>Moonlight & Magic Gift of Life Gala</i> , Marcia Hilditch, (860) 232-6054
April 6-14	Birmingham, AL, Alabama Organ Center, Jane Geloneck, (800) 252-3677
April 12-26	Westwood, KS, Midwest Transplant Network, Marcia Schoenfeld, (913) 262-1668
April 14	Riverside, CA, Southern California Organ Procurement Center, CA, Susan Prairie Hawthorne, <i>2nd Annual Donor Recognition Ceremony</i> , (800) 338-6112
April 23-25	HCFA, Centers for Medicare and Medicaid Services, contact information not yet available
April 27	Oakland, CA, California Transplant Donor Network, Tracee Harris, <i>Annual Donor Recognition Ceremony</i> , (209) 527-6178
June 25-29	Orlando, FL, National Donor Family Council, Sarah Ockler, (800) 622-9010, <i>2002 U.S. Transplant Games and Donor Recognition Ceremony</i> , ENTIRE QUILT ON DISPLAY.

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 the person hosting the event.** 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 (800) 622-9010 for up-to-date information. Information about the quilt can also be viewed on our Web site at www.donorfamily.org.

Holiday Donations

The National Kidney Foundation would like to thank the following organizations for their ongoing support through holiday donations to the National Donor Family Council. We are forever grateful for your generosity! Donations can be sent to National Donor Family Council, c/o National Kidney Foundation, 30 East 33rd Street, New York, NY 10016.

Arkansas Regional Organ Recovery Agency
Blood and Tissue Center of Central Texas
Center for Donation and Transplant, Albany, NY
Cleveland Clinic Foundation Tissue Program
California Transplant Donor Network
Carolina Donor Services
Case Western Reserve University Tissue Program
Donor Network of Arizona
Finger Lakes Donor Recovery Network
Florida Tissue Services
Gift of Life Donor Program, Pennsylvania
Inland Eye and Tissue Program, California
Intermountain Donor Services, Utah
LifeBanc, Ohio
LifeGift Organ Donation Center, Texas
Medical College of Georgia Tissue Services
Mississippi Lions Eye and Tissue Bank

Mississippi Organ Recovery Agency
Midwest Transplant Network
Northeast Organ Procurement Agency
NJ Organ and Tissue Sharing Network
Nebraska Organ Retrieval System
New York Organ Donor Network
OneLegacy, Los Angeles, California
Organ Donor Center of Hawaii
Rochester Eye and Human Parts Bank
MTF/TranSource of Wisconsin
Texas Organ Sharing Alliance
Transplant Resource Center of Maryland
Transplant Services Center, Dallas, Texas
Transplantation Society of Michigan
UC San Francisco Tissue Bank
Wisconsin Donor Network
Wisconsin Tissue Bank

THOUGHTS FROM DONOR FAMILIES




In Loving Memory



Michael T. Abbenante

By Sharon Nichols

You never said, "I'm leaving"
You never said "good-bye."
You were gone before we knew it,
And only God knows why.
A million times we cried.
If love alone could have saved you,
You never would have died.
In life we loved you dearly,
In death we love you still,
In our hearts you have a special place,
That no one else could fill.
It broke our hearts to lose you,
But you didn't go alone,
For part of us went with you,
The day God took you home. 

Love you forever!
Your cousin, Sharon

For My Brother, Jeff

By John Banks

Although he had his [human] faults his soul touched us
In so many ways.

His fierce drive for what is right
And his strong will, helped shape who I am today.
I miss you Jeff, you are in God's hands now.

I realize I will see you again,
In Heaven

For now it is time for me to let go of your body
And embrace your joyful spirit.

I love you Jeff, you are in the hands of God.

I see you in my actions,
Feel you in my dreams
And love you with all my heart.

No one can take away this joy and comfort I have.

Armed with the knowledge
Of God's love for us,
I will remain strong

And when I am weak I will pray.


Not for the solution,
But for God's will.

This sometimes is not easy.

So I look up to you, Jeff.

Your soul shines so bright

In my heart.

I miss you, Jeff. 

Love, John

Donor Family Friends

DF 156 My son passed away on May 7, 1999 — three weeks short of his 16th birthday — from injuries sustained in a car accident. His high school graduation would have been June 8, 2001. I am divorced and have another son, age 15. I would like to correspond with others.

DF 157 My daughter Vanessa died on December 5, 1999 and donated her heart, eyes and kidneys. She was 17 years old and left behind a 16-month old daughter. I would like to correspond with others.

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!


An Open Letter to a Donor Family

**By Mary Penza, daughter of Carole
Custis, a liver/kidney recipient**

In your time of loss and true sorrow,
You set your loved one free to live on.
What grace and kindness of human spirit to share a
precious part of you and your love.

We don't know you in person,
but we know you in spirit.
We remember and honor your gift,
As we take joy in the sunlight, a smile,
and our loved ones.

The words "thank you" are a mere uttering,
For the depth of feelings cannot be known
by speaking.
It can only be felt from the language of the heart.

You are a true giver of light and love.
Our spirits soar with your selfless act.
Blessings of peace and joy to you. 

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
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Please help us "Cut Down" by notifying us when your address changes. It costs 34 cents if you forget. 