

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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Connecting at the U.S. Transplant Games

By Sue Capps

While we were stationed at Davis-Moahan AFB in Tucson, Arizona, in 1993, my husband and I lost our first-born son, Corey, in a tragic accident. About a year after his death, I wanted to find out about Corey's donations. I wrote letters and slowly, one by one, I was able to make contact with three of the four main recipients of Corey's organs.

One of Corey's kidney recipients, Michael Scazzaro, is a swimmer in the U.S. Transplant Games. In 1998,

Mike and his wife Sharon convinced me to go to the Games in Columbus, Ohio. Wow!

Some things about the Transplant Games cannot be illustrated with simple words. I cannot express how Mike and I felt meeting in the airport after I flew into Ohio. How do you describe the feeling of hugging a man who carries a part of your baby inside his body? How do you describe looking into the faces of his wife and children, knowing that had we not given Corey's organs, Mike might not be alive today to be a husband and father to his family? How do you describe the motherly emotions expressed when Mike's mother approached me with her gratitude for donating my son's organs so that her son might live?

While Mike and I were at the Games, *Life* magazine did an interview with us. As we stood on a bridge overlooking the Potomac River waiting for the photographer, I was overwhelmed by all that was happening. As I bowed my head, Mike came over and asked if I was all right. In the moment that I said yes, Mike hugged me, placed my hand on his



Donor mom, Sue Capps, and kidney recipient, Mike Scazzaro, share a special moment.

body where Corey's kidney was, and said, "Your baby is right here." I cried even harder!

While the Giving, Grieving, Growing workshops are wonderful, the only place I wanted to be while at the '98 Games was by Mike and Sharon's sides while Mike was competing, cheering him on as any mother would do.

One can feel the emotions I've shared from meeting Mike's family—donor and recipient making contact—only at the U.S. Transplant Games. In attending the event, you can experience the full and powerful effect that organ and tissue donation has on the human soul and spirit. I hope that you and your family will consider joining us at the Games this summer.

Sue Capps is a donor mom from Pollock, LA. She is the volunteer donor family liaison to the National Donor Family Council and U.S. Transplant Games for Team Louisiana.

Join Us at
the Games



In addition to athletic competitions for transplant recipients, the 2002 U.S. Transplant Games will comprise the Giving, Grieving, Growing Program for donor families, including the memorable Donor Recognition Ceremony, Quilt Pinning, Coffee House, educational workshops, open sharing sessions and more. The Games will be held at *Disney's Wide World of Sports*™ Complex in Orlando, Florida, June 25-29, 2002. If you would like more information about the Games or the volunteer donor family liaison in your area, please contact the National Kidney Foundation at (800) 622-9010 or visit www.transplantgames.org



National Kidney Foundation Seeks Nominations for 2002 U.S. Transplant Games Awards

The National Kidney Foundation is currently seeking nominations for three awards to be presented at the 2002 U.S. Transplant Games to be held June 25-29 at Disney's Wide World of Sports™ Complex.



The American Society of Transplantation (AST) Award

is presented to two athletes who have furthered the cause of donation in their return to health and productivity by raising awareness about the critical need for organ and tissue donation in their communities. The two categories are for athletes under and over the age of 18.



The Mickey Mantle Courage Award


recognizes a transplant athlete who has overcome great challenges to participate in the U.S. Transplant Games. For more information on the AST and Mickey Mantle Courage Award or to request a nomination form, please contact the National Kidney Foundation Transplant Athletics department at (800) 622-9010. All nominations must be received by May 10, 2002.



The Musculoskeletal Transplant Foundation (MTF) DonorCARE Award

will be presented to an individual or group that has

provided consistent and comprehensive care to donor families. To receive more information on the MTF DonorCare Award or to request a nomination form, contact the MTF at (800) 946-9008. Deadline for nominations is April 22, 2002.

The U.S. Transplant Games is a biennial, Olympic-style event open to recipients of every type of life saving organ transplant, including kidney, liver, heart, lung, pancreas and bone marrow. With an anticipated 2,000 athletes participating, the 2002 U.S. Transplant Games promise to be the largest-ever gathering of transplant recipients. 

Melody of Love

A Donor Mom Meets her Son's Heart Recipient

Meeting you and hearing the beating of your heart
Brings melodies to my soul that
I could never imagine.

As streams of tears well up in my eyes,
I'm reminded of songs in a minor key
That have played in my heart in recent
bygone days.

Songs of shock, denial, disbelief and sadness
Emanated from my heart like staccato notes.
Struggling to find a major key seemed
unreachable

As the process of grief prevented a key change.

Keenly listening to your heartbeat, the beautiful
harmony
Blended smoothly as it reflected love, joy, purpose
and hope.

It was the playing of these notes that I long for and
never tire of.

The time is here where the melody in a major key

Of the joy of your second chance at life, helps
diminish

The minor key of the grief of the loss of a son.

Thank you for sharing your heart, as it's rhythm
and notes

Combine to complete the melody that will
play on in your soul forever.

Each heartbeat reminds me of melodies of
love for Tom,

As memories of him will be indelibly etched
in my heart.

It is the void of his loss linked with your
gratitude overflowing

That helps to heal the emptiness without my son,
And serves a purpose beyond the tragedy itself.

Thank you for helping me change the key in this
melody of love!

Your "Donor Mom" Jan

For Thomas Mauk

Janet Mauk



For the Newly Bereaved

By Mary Ann Carpenter

Crying is natural and if you feel like crying, then cry. It can be a great emotional release. Do not be overly concerned if you find that you are not crying, as it may not be how you express your grief.

Honor the memory of your loved one

Make a donation to your local church, favorite charity or shelter. Donate books to a childcare center or senior center. Plant something in memory of the one who died. Create a memory book filling it with photographs, awards, notes and reminders of special occasions. Name a star in memory of your loved one.

Find a good listener

Talking can be therapeutic. Talk about what is on your mind. Talk about your feelings.

Write

Keep a journal. Try to write out what you are feeling or thinking. Don't worry about spelling or punctuation. Just write. Let your thoughts and feelings flow from you to the pen. Occasionally read what you write and then write about how you felt when you read your thoughts and feelings.

Exercise

Your muscles need movement and your body wants to stretch. Pick something you enjoy. Try walking; it is simple, needs no special equipment and is easy on the body. You can walk alone or find a companion.

Eat your Vegetables

Grieving is hard work and your body needs to be nourished. Eat healthy, as your diet will affect how you feel. You may not be hungry, but try to eat regular well-balanced meals.

Dreams

Dreams may be scary at first. They may not make any sense. You may wonder why your loved one does not appear in your dreams. You may be comforted when your loved one does appear in your dreams. Dreaming is healthy and is as natural as sleeping.

Music can be relaxing

Listen to music. Select music you like. Let the sound carry you to a peaceful place. You may want to stretch or dance to the music. You may want to listen to the music while relaxing in a warm bath.

Tell people what you need

People want to help, but they don't know how. If they could read your mind they would know that you love to hear your loved one's name spoken out loud. They would know when you need to be alone or when you need a hug.

Since people can't read minds, you will have to tell them what you need.


It is ok to laugh

The first laugh is the hardest. You will wonder how you can laugh when you are grieving. Laughter is the natural response to something funny just as grieving is a natural response to death. Enjoy the moment of laughter to its fullest.

Be good to yourself

Treat yourself to a massage. Buy some flowers. Rent your favorite movie. Do something that makes you feel good. Find an open field and watch the clouds dance across the sky. Visit a planetarium and revel in the stars.

Try a new hobby, sport or activity

What have you always wanted to do but keep putting off? Whatever it is, do it. Take a trip. Learn a new craft. Explore a new state or country. 

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 Honor of:

Brock "Rascal" Reimath - by Kia Reimath

Diane Wilson - by Carol Kennedy

Walter Kubistal - by Marie Kubistal

Cecil Thompson - by Peggy Thompson


Larry L. Walker - by Harry & Laura Greene

Jason Scott Wilson - by Charlotte Johnson

All donor families - by the Moser Family, Amy Derasmo, Jonathan and Jennifer Gordon, Mrs. Sterling Jones, Judith Baxter

The Special Gift

By Lorraine Remillard

My little girl gave you a gift today
We thought she'd never give.
She gave it to you my son
Just so you could live.
Treasure it with love and kindness
This gift she gave to thee
Shower her with lots of prayers,
And laughter full of glee.
You were the little one picked
From God,
That we surely see
So take good care of my little
Girl's treasure,
It's also a gift from me. 

Love from Ellen's Mom

Ellen M. Remillard December 15, 1968—
May 5, 1999




Remembering My Dad

By Christina Langowski (aged 10)

There were so many fun times, when you were in
my life, like sledding, skating, shows and shopping.
Oh, how nobody knows.

I wish you were still here to do these things with
me. But, God has taken you so far away, that I
can't even see.

I never will forget you. You are going to always be
in my heart. I only had six years with you, but, they
were the best start.

I hope that you are happy. I miss you so much! If
only you could see me, I'd love to feel your touch. 



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Complicated Versus Uncomplicated Bereavement: What is Good Grieving?

By Kathleen MacNaughton, PhD and Jim Rodriguez, PhD

Perhaps one of life's most difficult and, for some, most unforeseen challenges is coping with the death of a loved one. Indeed, grief is a process that we must all endure at one or more points in our lives. Some may wonder, "How do I grieve? Is my grief experience normal or typical?" Some may even look for guides or books on how to get through this emotionally and physically challenging experience.

While information about the grieving process is most certainly helpful, it is critical to remember that there is no right way to grieve. The way that a neighbor dealt with the untimely death of her 15-year-old son may barely resemble the way that you are coping with the tragic and sudden loss of your teenager or spouse. Throughout the grieving process it is essential that people resist judging themselves harshly or comparing their experience to that of others. It is rarely beneficial, and often painful, to measure one's own experiences against what we think we "should" feel or what we believe others may expect of us.

Complicated grief occurs when we remain stuck in an unresolved and long-lasting grief state. This is an extreme version of the typical feelings experienced during grief. While we all feel emotionally overwhelmed and forever altered in the first few months following a loss, people who are experiencing complicated grief may never truly move beyond this state. Those

with complicated grief reactions have extreme difficulty making sense of the loss over an extended period of time. Also common are recurrent and intrusive (unwanted) thoughts and images, extreme agitation, survivor guilt and difficulty talking about the deceased loved one without experiencing renewed and intense grief. Noticing a lack of basic self-care activities, a change in usual behavior patterns, suicidal talk or actions, severe withdrawal, and substance abuse may be further cause for concern that a complicated grief reaction is present.

It is important to recognize that complicated grief is not a result of inadequate or "poor" grieving. Rather, it results from a variety of factors, including the nature of the relationship with the deceased loved one, the manner of death, concurrent life stressors, the availability and stability of support systems and other related factors. Also, it is not necessarily a permanent or an unavoidable state.

So-called "good grieving" can help prevent or turn around a complicated bereavement response. Good grieving is characterized by a willingness to acknowledge and experience a range of painful and, at times, frightening emotional states. It also involves making self-care a priority. The manner in which this is done may vary widely from person to person. For example, one person may find that talking with family and friends or regular sessions

with a psychologist allows them to experience, acknowledge and heal their emotions. Someone else may find that solitary pursuits like journaling or creating a memory book gives them the time to recognize their emotions and make sense of their loss. People must find for themselves how they can best observe, acknowledge and appreciate their emotional responses. Often this means considering one's relationship with the deceased and coming to terms with things left unsaid or issues left unresolved.

Good grieving may also involve exploration of one's identity. Often when we lose a loved one, it seems that we also lose part of our personal identity (for example, the loss of a parent, spouse or child). It is important that we make some sense of who we are in relation to the deceased, the living and, most important, ourselves. Each person in the family will grieve differently and in a different timeframe. Remember that the work of grief is a gradual process, requiring, above all, patience and time.

Kathleen MacNaughton, PhD, is a licensed psychologist and Director, Haile Behavioral Health Services, Gainesville, Florida.

Jim Rodriguez, PhD, is an associate professor and Director, Center for Behavioral Health Research on Organ Transplantation and Donation, University of Florida, Gainesville, Florida.



The Chain—My Son Lives On

By a Donor Mom

On July 21, 1999, my 23-year-old son passed away as a result of a tragic accident. He had informed his father and me several years prior of his decision to be an organ donor. Frankly, we didn't know too much about organ and tissue donation, and we were not in favor of his decision. Never in my wildest imagination did I ever think that I would have to carry out his wish. I am ashamed that I had initially felt as I did. Now, as a result of Jason's Gift of Life, three men are alive today. They are now able to live healthy, productive lives. What a wonderful gift — "The Gift of Life."

Jason started the chain by donating the first link. Now, I too have decided to be an organ and tissue donor, as have at least 20 others in our family. This is just the beginning, as my daughter and I are committed to making people aware of the gifts they have to give, and share with their fellow man. It is so important to tell your family your wishes, as my son did. He is truly my hero, and I know that as a result of his decision the "Chain of Life" will have many links added to it.

My son, Jason Bradley Segarra, was a special young man—full of life and compassion. I would like to share some writings from two of his friends.

Very few times in someone's lifetime does he meet a friend with a life force or personality as strong as Jay's. If the measure of a man is the lives he touched, and the memories he left, then Jason lived a life to envy. His spirit will live forever.

Like A Ship

By Yvette Segarra



Like a ship that's left its mooring and sailed bravely out to sea—So, Jason has sailed away in calm serenity. But, there are promises of greater joy than Earth could have in store—for God, has planned a richer life for my friend Jason beyond the unseen shore.

Jason lives on, and the chain will grow as a result of his donating the first link—Our community has become aware and involved in promoting awareness. I am proud of the legacy my son has left.

Why?

By Leah Lorene Butts, Donor Nanny

Why did you have to leave us?

We all loved you so.

When death came knocking at your door,

Why did you have to go?

Some days we find it hard to cope.

We feel so very sad.

Some days we just can't stand the pain.

It makes us feel so bad.

There's pain deep in our hearts,

No doctor could ever heal.

'Cause of the love we feel for you

And I know we always will.

They say that time will heal all wounds,

Someday we'll feel okay.

But, the pain we felt the day you left,

Is just as real today.

Sometimes we feel you've gone away,

And soon you will be back.

Then reality hits us once again,

And we must face the facts.

Your leaving left an awesome void

That nothing else can fill.

Our lives go on, but not the same,

And we know they never will.

We'll keep our faith and trust in God.

We know He has it planned.

Some day we'll see your smiling face.

And then we'll understand.

In Loving Memory

Rickey Anderson, July 5

By David Anderson



I'll be there when you hear the singing of the birds in springtime and the hollering of the frogs. *I'll be there* when you see the flowers blooming and the grass growing under your feet.

I'll be there when you feel the warmth of the sun upon your face.

I'll be there when summer arrives and you laze under the shade tree, just look in the shadow,

I'll be there when you feel the cool winds blow in the fall and see the colored leaves.

I'll be there when you see the frost kissing the grass and the snowflakes fall from heaven.

I'll be there.

THOUGHTS FROM RECIPIENTS

Dear Donor Families,

"Give my kidneys to one who depends on a machine to exist from week to week."

That was me six years ago. I depended on a machine to live, love, hope and care for family and friends. I was young, life was young, but then: kidney failure. All of my hopes and dreams were pushed aside by this terrible disease. I couldn't understand why this horrible disease had entered my life. I only knew it was there, and prohibited me from living life to the fullest. All of a sudden I was faced with sodium restrictions, fluid restrictions and the surgeries that it would take before I had good access, so that I could endure the pain of 14 gauge needles in my arm three days a week.

Then on September 4, 1990, a 16-year-old boy, Shawn, died of a brain aneurysm. His parents, Mary and Bill, decided to give the gift of life. When the call came that I was to receive a kidney, I was overjoyed. But when I learned of this young man, my joy faded. The self pity I felt disappeared, and all I could think of was the boy who would never know the joy of dating, borrowing the car or one day having a family of his own. Life was unfair to both him and me. Now I make the best of each new day. I'm studying to be a nurse. Shawn's parents and I talk on the phone often and my family and his have both benefited from the tragedies of our lives. Through all the sadness and pain, we found each other.

So please remember, all donor families are forever in the thoughts and prayers of each and every recipient. Your gift of love will forever be remembered.

*In my heart,
Shirley M. Parks
Mary Carpenter's Son's Recipient
Shirley passed away on October 12, 1998*

The Quilt on Tour

Please note: This schedule is subject to change.

- April 13-27 Chicago, IL, National Kidney Foundation of IL, Hilary Cichosz, *Living With Transplantation & NOTDAW*. (312) 321-1500.
- April 14 Team Connecticut, Ken Harrington, Tip Team Connecticut.
- April 14 Riverside, CA, OneLegacy, Susan Prairie, Hawthorne. *2nd Annual Inland Empire Donor Recognition Ceremony*, (800) 338-6112.
- April 22 Portland, ME, National Kidney Foundation of ME, Tammy Atwood, *Great Chefs Event*, (207) 772-7270.
- April 23-25 Westwood, KS, Health Care Finance Administration (HCFA), Venus Bucker, *NOTDAW*, (913) 262-1668.
- April 27 Oakland, CA, California Transplant Donor Network, Tracee Harris, *Annual Donor Recognition Ceremony*, (209) 527-6178
- April 29 Honolulu, HI, National Kidney Foundation of HI, Harriet Kaimimoka-Wong, *Gift of Life Walk*, (808) 589-5928.
- May 19 NY, National Kidney Foundation of NENY, April, *Gift of Life Walk*, (518) 458-9697.
- June 10-15 IN, National Kidney Foundation of IN, Marilyn Winn, *Annual Meeting & Run / Walk*.
- June 25-29 Orlando, FL, National Kidney Foundation, Sarah Ockler, *2002 US Transplant Games & Donor Recognition*, (800) 622-9010. *ENTIRE QUILT*

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 John Paul Ried 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

TEEN SHARING



In Loving Memory of My Best and Most Loving Grandfather


Donald L. Edmisten (died May 3, 1998)

He was an organ donor who gave two blind people the ability to see again. Two people who were depending on dialysis to survive are now living a comfortable life, and someone who desperately needed a liver has one so he could be happy and live to see his family grow. In addition, bone marrow, tissue and other parts of my grandpa were used to help many others. Thus, even after he left he continued to help others. That is no surprise because that is how he was, always helping people. He helped the older neighbors whose bones were aching more than his, helping them with yard work that they were no longer able to do.

It has been three years without my grandpa, but I still remember the fun things I did with him. We went

on bike rides and he, as a 64-year-old man, could even ride backwards and could run while pulling my brother and me in a wagon. I miss those things a lot. Now I am older and I have learned to handle things better. But some days, things I think about really hit me hard and I can't hold it in. It is okay to cry or get mad, but do me a favor — don't take anyone for granted because one day he will be gone when you least expect it.

I grew up with one grandma and one grandpa because my Mom's side died before I was old enough to remember. The ones I did have have been the greatest, and now I have only my grandma. I love her and hope she will live to see my children.

Please remember don't take anyone for granted because they will be gone when you least expect it. Please remember also that the life of the person you love can live on with the precious gift of organ and tissue donation. It is possible to give the gift of life. 

Kelley Edmisten
Tavares, FL

Donor Family Friends

DF 158 My 22-year-old son Jason was pronounced brain dead from an automobile accident August 4, 2000. He was my only son. I would like to correspond with other families who have lost.

DF 159 Three years ago my 17-year-old sister died unexpectedly of a brain aneurysm. She was an organ donor and since her death, we have met recipients

who have gotten another chance at life. I am now 22 and would love writing to someone who has lost a sibling.

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!

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 34 cents if you forget.