

**National Kidney
Foundation™**

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.

Spring 2006

Visit our home for donor families at www.donorfamily.org

Volume 14, Number 4

FOREVER *linked*

By Jack Fassnacht, Kidney Recipient

FIFTEEN YEARS AGO I RECEIVED A KIDNEY FROM SOMEONE I WILL NEVER KNOW, AT LEAST BY NAME.

For 15 years that kidney kept me alive, kept me feeling good enough to live, to work and to play. I know almost nothing about my donor, except that his or her family possessed the generosity and humanity to think of helping someone else at a very difficult and sorrowful time. And although that kidney has now worn out and no longer helps keep my blood clean as it did for so many years, the person who gave it to me will stay with me until the day I, too, pass on, the two of us forever linked by that act of generosity.

“Undoubtedly, my greatest joy since that first transplant has been my daughter Claire. I was unable to have children before the transplant, but afterwards that changed for the better.”

I hope that my life these last 15 years has proven me worthy of such a priceless gift. Since that day in December 1989 when I walked out of the University of Chicago hospital, free from dialysis for the first time in nine months, I have become a father, graduated from law school, helped raise money to

build a new church, won a silver medal at the U.S.

Transplant Games and given numerous talks about the critical importance of organ and tissue donation.

Sometimes during those talks I would compare organ and tissue donation to saving a drowning person. No one has to do it by law, but we do it anyway because it is the right thing to do. People and families who donate to strangers are just as heroic as someone who

rescues a drowning person, perhaps more so because they do it at a time of indescribable grief and often anonymously.

In the first year after my transplant I wrote two “anonymous” thank you letters to my donor family and, to be honest, I had hoped to



Jack stops to take in the view during a recent vacation to the Grand Canyon.

receive a letter in return. I did not receive any letters, but that is alright. My donor family had done enough already. They owed me nothing; I owed them my new life. I continue to pray that they have found peace with their loss and perhaps found some small consolation in their decision to donate.

Undoubtedly, my greatest joy since that first transplant has been my daughter Claire. I was unable to have children before the transplant, but afterwards that changed for the better, along with the rest of my life. Claire was born 18 months after my transplant and is now a beautiful 14 year old. She is honest and kind. She plays percussion in her high school band and loves sleeping with her cat, Nellie. She is another happy result of my donor family’s decision to donate.

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National Kidney Foundation

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As I said, that first transplanted kidney wore out in 2005. I guess all things wear out eventually. Nothing is permanent. I have lost my dad and, most heart-breakingly, Claire's mom since 1989. But I still live as good and full a life as I can. Claire, and my first donor, deserve that

families to be "mine." If you are a donor family that has never heard from your recipient(s), rest assured that the community of recipients will never forget your kindness, nor the memory of your loved one. When we attend local tree planting ceremonies in our

"...the community of recipients will never forget your kindness, nor the memory of your loved one."

I was fortunate to receive a second gift of life in 2005 from my youngest sister, Paula, who showed a special courage and love in becoming my living donor.

communities in remembrance of our donors, we remember your loved one too. When we applaud the donor families who march with us at the Transplant Games, we applaud you. When we read the names of donors at church services during National Organ Donation Month each April, we pray for donors and



Jack poses with his new sports car.

So I have four kidneys now. Three people are now permanently and profoundly joined in this 50 year old body of mine. I am lucky beyond words— not only to be alive and dialysis free, but to have experienced firsthand such tremendous kindness and generosity.

donor families everywhere. When we visit the National Donor Memorial in Richmond, Virginia, we pay tribute to the miraculous legacy left by all organ and tissue donors. You and your loved one are never far from our thoughts. From all of us in the transplant recipient community, thank you for your decision. Thank you for our lives.

Since I never knew my first donor family, I consider all donor

THE OTHER SIDE *of the story*

By Sue Dillon, Donor Mother

I REMEMBER WHEN WE DECIDED TO DONATE MY SON MICHAEL'S ORGANS. On one side of the line was the fact that Michael was not going to recover, not come home. On the other side of that line was the hope we had given to another family that their loved one would come home.

In the days leading up to Michael's funeral, I wondered who those families were and if everything had gone well. Was a husband speaking to his wife, a child being hugged by his

On the night of the visitation service, we received word that the liver and both kidneys had been successfully transplanted—perfect matches! At a time of great sorrow, we were given joyous words. Our decision was right: people were healing; mothers were crying tears of joy. I did not need a lot of information, I just needed to know that the transplants had taken place and Michael was helping.

Later on I learned more about the recipients. Nothing was identifiable information: first name only, male or

and that they were well. The rest was up to them. I cannot imagine that there are families that do not know the outcome of their beautiful gift. I do know that there are many emotions wrapped around those gifts, but those emotions need closure. I have spoken with many donor families and they feel, as much as I do, that their gift was a Gift of Life.

I hope for the day when all recovery organizations share recipient information with donor families who want it. Sometimes you need to hear the other side of the story.

“I hope for the day when all recovery organizations share recipient information with donor families who want it. Sometimes you need to hear the other side of the story.”

mother? I hoped with every bit of hope I had left that they were on the surviving side of their ordeal.

female, age, what state they lived in, what organ they received and how they were recovering. I really did not need to know any more. I knew that they had been given a second chance

Editor's Note: For information about writing to donor families and recipients, please contact the NDFC at donorfamily@kidney.org by phone at 800.622.9010, or visit www.donorfamily.org

Grandma's Hands

By Tammy Anderson, Donor Granddaughter

GRANDMA'S HANDS WIPED TEARS, kneaded bread, and planted gardens. They made Sunday supper, held storybooks and scrubbed floors until they shined. They were rough with age and told of the hard years they had endured. Told of the love they had shared, the other hands they had held. Grandma's hands reached out when it was time to have tears wiped, to pass the recipes and the old potato masher—the only thing she had from her own mom.

My own hands love harder, hug tighter and embrace life all the more...because of Grandma's hands.



Does Time Heal—All by Itself?

By Charles A. Corr, PhD, CT

THE DEATH OF THEIR OLDEST DAUGHTER, BRITTANY, WAS A TERRIBLE EVENT IN THE LIVES OF CAROL AND MAX.

It was not easy for them to acknowledge what had happened but they agreed to donate her organs and tissues. They found some comfort in knowing that doing so had helped a number of people who were desperately waiting for transplants. They even felt some reassurance when they eventually received letters of thanks through their transplant coordinator from some—but not all—of their daughter's transplant recipients.

Still, Carol felt that, for the most part, Max had pulled back into himself, withdrawing from her need to talk and share feelings about their daughter, her death and her donations. Finally, she said to him one day, "Max, you just have to tell me what's going on!"

"I'm waiting," he said.

"What do you mean?" she replied.

"Well, everyone has been telling me that 'time heals.' So I'm waiting for that to happen."

"Oh, Max," she said. "That doesn't take place all by itself automatically."

"Why not?" Max asked. "If it isn't true, why do people say it so often? I'm finding it harder and harder, but I'm still willing to be patient until time passes and whatever this 'healing' means, happens."

"Max," said Carol, "it's not enough for you to allow time to pass while

you are sitting around waiting for healing to accomplish itself on its own. You have to take an active part in the process.

"I was talking about this the other day with one of the facilitators in the support group for donor family members. He said, 'It's not the time you have to use in coping with loss and grief that is so important. What really counts is the use you make of the time you have.'"

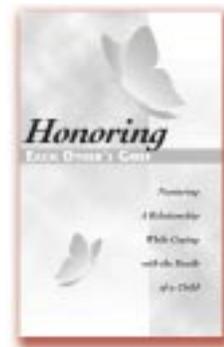
"You know that after your mother died, your father wouldn't let us even mention her name. He was trying to distance himself from the pain of her loss. And then he turned to alcohol. But none of that really worked for him. In the long run, it takes a lot of energy and constant vigilance to keep up a strategy of denial and avoidance. And in the end, strategies like these don't really work because they aren't a good use of the time we have to cope with Brittany's death."

"There are lots of things we could do that would be better than just waiting for time to somehow magically heal us. You could come with me to the support group meetings. Also, our church has a program of bereavement visitors and I know there are experienced grief counselors in our community."

"Above all, we could work together on this just as we have done since we got married when we faced all of our problems."

"What we have to do is find effective ways to cope with Brittany's death and with the fact that she is no longer present to us as she was before. For me, Brittany is still here in my thoughts and in my heart every day. I want her to be here for you in the same way. And I want us to live healthy lives with each other and with our other children. I don't want our marriage and our lives to die just because Brittany did. It's not easy and it won't be painless, but we can't expect time or anything else to do the job for us."

"I know we can do this if we make good use of the time that we have. Let's work together and try, okay?"



Editor's Note: *Everyone grieves in their own way. If you would like to learn more about grief and honoring the loss of a child, the NKCF offers a booklet entitled "Honoring Each Other's Grief: Nurturing a Relationship While Coping with the Death of a Child." Call 800.622.9010 or visit www.donorfamily.org for more information.*

What is Grief Work?

By Catherine Paykin, MSSW

WHAT IS GRIEF WORK? GRIEF WORK TAKES TIME, BUT IT IS NOT JUST TIME. *Grief work is our ability to look inward and examine how our experiences, culture, belief systems, family and choices influence our emotional well-being in light of the loss of our loved one.*

Understanding the impact our life experiences have on shaping the essence of our being can help us to first reveal the underlying dimensions of our own pain, and find emotions to temper the pain through feelings such as forgiveness, tolerance and understanding. At its best, our journey of grief may lead us to a place where we can say “yes” to life and to find meaning and beauty and joy in it, despite a loss for which we cannot be consoled. Grief work is not a one time

endeavor. It is an ongoing journey throughout the span of our lives. People experience grief in response to all kinds of complicated life events: divorce, critical or chronic illness, the loss of a job, a home, a lifestyle and savings. Life affords us with many opportunities to experiment with coping mechanisms and to develop the inner resolve and strength to move forward. One of my favorite books is *Necessary Losses* by Judith Viorst,

which is study of how various losses in life cannot be avoided and can make us stronger. This is because life is riddled with loss, each with its own impact. Our emotions after the death of a child, grand-parent, parent, a friend, a relative, or a colleague all affect us differently depending on where we are on our life’s journey and our relationship with the deceased. Each experience, regardless of how painful, will reveal different things about us to ourselves. Each is a chance to look within ourselves and come out more whole. Each brings us a little closer to understanding the meaning of life.

“Life affords us with many opportunities to experiment with coping mechanisms and to develop the inner resolve and strength to move forward.”

we fondly REMEMBER...

Thomas (Tommy) Odean Overton

Thank you God for sharing Tommy with all of us who knew him in his 16 years among us. He loved all he met. We love him still and will never forget him.

Love, Barbara Leonard, Shaper and the Overton Family and Friends

JUNE 16-21
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MY DARLING JESSICA: *A Letter to My Daughter*

By Josefa Castillo, Donor Mother



IT SEEMS SURREAL THAT ON APRIL 26, 2006, IT WAS 12 YEARS THAT YOU HAVE BEEN GONE FROM MY LIFE. I miss you, your beautiful smile and I will always long for you. Twelve years ago, when the accident happened, I wished you had never been born. That way, I would not have felt the pain and anguish of losing you, of your absence from my life. Someone told me that someday I would be glad to have had the 19 years we spent together, as mother and daughter and as best friends. I did not believe it and I was very wrong!

Today I consider it an honor and a privilege to have known you, to have you as my child. It has taken a long time but I am now really trying to bounce back from the shock and void your departure left me with. I allow myself to experience pleasure, laughter

and joy. I know you would be happy and proud of me. Your gift of love helped others. Someone, somewhere, sees through your eyes. You were a wonderful human being, one of a kind and the angel in my life. You still are! I carry you in my heart, with the deepest, tender love a mother can have for her child.

Be at peace “my little buddy” until we meet again. You are remembered, missed and loved beyond words.

Love,
Your Mom

Letter to Mom

By Joy Curnutt, Donor Mother

Mom, please don't feel guilty,
It was just my time to go.
I see you are still feeling sad,
And the tears just seem to flow.

We all come to earth for our lifetime,
And for some it's not many years
I don't want you to keep crying
You are shedding so many tears.

I haven't really left you
Even though it may seem so.



*Jason Curnutt at work on
his computer*

I have just gone to my heavenly home,
And I'm closer to you than you know.

Just believe that when you say my name,
I'm standing next to you.
I know you long to see me,
But there's nothing I can do.

But I'll still send you messages
And hope you understand,
That when your time comes to “cross over,”
I'll be there to take your hand.



THE PRIVILEGE *of caring*

By Tomoko Asai, Japan Organ Transplant Network

TOMOKO ASAI IS AN ORGAN TRANSPLANT COORDINATOR WORKING FOR THE JAPAN ORGAN TRANSPLANT NETWORK.

She traveled to the United States to research how donor families are supported. Each family goes through the process of considering donation in the midst of the sorrow of losing a loved one. Asai had a desire to study what issues made the U.S. different in terms of the entire organ donation process and the involvement of families.

I have worked as an organ transplant coordinator in Japan for eight years. In the United States, the number of organ donations is 70 times higher than in Japan, while the population is only twice as large.

“In the United States the number of organ donations is 70 times higher than in Japan, while the population is only twice as large.”

Despite such a significant difference in the number of donors, feelings of donor families are the same. Organ and tissue donation is an act of self-sacrifice on the part of a donor's family, who are in the midst of their deepest grief at the time a decision is made. The family members who choose to donate their loved ones' organs or tissues approve the donation based on the intention of the donors themselves or their sympathy with the patients who suffer from organ failure. Donated organs are transplanted into the patients with organ failure and serve once again to sustain life. For the families who consented to donation, this means creating something positive from death through fulfilling the donors' will of helping others.

In the region where I work, donor recognition ceremonies are planned every four years. The ceremony held last November was attended by 53 donor families and 28 recipients. The recipients were volunteers and not directly related

to the donor families. At the gathering, donor families and recipients talked with each other in a friendly atmosphere and seemed to share their feelings. The donor families seemed to empathize with the hardship involved in organ failure and appreciate the tremendous benefit of organ transplantation. Some recipients were happy to finally have a chance to thank donor families, even though they were not the family of the actual donor of the organ they received. This is not a direct personal interaction between the donor family and actual recipient of the organ, but I think it is important for donor families and recipients to have the opportunity to interact with each other.



Tomoko Asai, Japan Organ Transplant Network

As a coordinator, I am respectful and empathetic when I encounter donor families. It is the coordinator's role to provide the support that helps the families who chose donation to feel "it was a good thing that we decided to donate." I would like to make use of what I have learned during my research trip in the U.S. for the progress of the donor family support in Japan.

Donor Family VOICES

What are some things you have done to help yourself along your grief journey? What has given you comfort or hope?

Let us know your thoughts at www.donorfamilyforums.org Any responses received may be published in the Summer issue of *For Those Who Give and Grieve*.



The Quilt on Tour

Please note: This schedule is subject to change. Call the National Donor Family Council at 800.622.9010 for the most up-to-date information. The entire quilt is not on display at these events, and not all events are open to the public. Please call the contact person for more information.

2006

- June 16-June 21** Louisville, KY, National Kidney Foundation National Office, 2006 US Transplant Games, Marilyn Jones, 800.622.9010
- July 22 - July 27** Boston, MA, World Transplant Congress, *World Transplant Congress*, Shannon Fagan, 856.439.0500
- September 17** Rochester, NY, Finger Lakes Donor Recovery Network, *Donor Family Celebration*, Roxanne Morsch, 585.272.4934
- September 30** Seattle, WA, Northwest Lions Eye Bank, *2006 Donor Family Gathering*, Lois Parker, 206.682.8504
- October 6** Indialantic, FL, Associates and Nurses Endorsing Transplantation, *Like Keep It Going Conference*, Judi Cavazos, 321.698.9117

* One panel of the National Donor Family Quilt is displayed year-round at the National Donor Memorial in Richmond, VA. (This Quilt panel will sometimes be moved for display at other national events.) For more information, contact Marilyn Jones at 800.622.9010.

The mission of the National Donor Family Council is to enhance the sensitivity and effectiveness of the organ and tissue recovery 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.



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