

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.

Winter 2006

Visit our home for donor families at [www.donorfamily.org](http://www.donorfamily.org)

Volume 14, Number 3

## OVERSPENDING, SHOPPING... *an escape from hurt?*

By Lisa Kaplan, MSW

**IF YOU ARE GRIEVING, SHOPPING MAY TAKE YOUR MIND OFF PROBLEMS AND HEARTACHE.** Attentive sales professionals can make you feel important and worthy. Spending and the handling of money can bring you a feeling of power and control. A store may provide beautiful scenery with color, texture and the excitement of music and people talking. For some people, shopping is an enjoyable pastime, complete with the excitement of having a “Eureka” moment, or finding a good buy.

However, like other releases and escapes, if a person is feeling vulnerable emotionally, shopping (along with other seemingly harmless pastimes) may change from an acceptable hobby to an addiction. A person who is feeling down, sad, unworthy or guilty is vulnerable to the “high” shopping can bring, with the excitement of a good fit, find or purchase. However, like other addictions, excess may result in a cycle of guilt and blame once the credit card payments are due, or the spouse gets angry or a necessary bill cannot be paid because you overspent.

If you recognize this need to lift your spirits and feel good about yourself by shopping, or if you or those you love are worried about your spending, it may be time to pay attention to the feelings driving you to do this. First, recognize that you are emotionally fragile and that you have the right instincts to find a hobby to cheer yourself up. Your attraction to activity, scenery, distraction, attention and bargains are perfectly understandable. Next, you will need to acknowledge that though it seems reasonable, using shopping to ease your pain is not working—but at least you can understand why it seemed like it might!

Talk to a friend, a counselor or a grief support group about your concerns about your spending. It

takes time to develop other interests, and ridding yourself of the distraction of shopping and spending can leave an emptiness in your life that can be very painful.

You may need supportive people and professionals to help you through this. If you want to truly understand your shopping behavior, you might want to consider joining an organization such as Debtors Anonymous, based on the principles of fighting addiction set by Alcoholics Anonymous.

Know that you are not alone. There are shopaholic self-help groups and therapy groups.

Most Americans, at one time or another, have been seduced by shopping and overspending. It is very much in our media messaging. However, when faced with a life crisis such as the unexpected and untimely death of a loved one, we are often faced with the truth of what is and is not important in life. Addictions can be a way to avoid the pain, the emptiness. When you are ready, you can work to overcome addictions and proceed upon the grief journey.



*“Most Americans, at one time or another, have been seduced by shopping and overspending.”*

*Lisa Kaplan is a social worker in New York City.*

# The Unfortunate Journey

By Hope R. Gardner, Donor Mother

We do not have a choice,  
we must go on.  
Oh to hear the voice of  
my beloved son.  
On a bright shiny day,  
he left in an instant.  
Now he sits  
at the right hand of God.  
I know that he is  
marching with Lord Baden-Powell,  
in the heavenly troop in the sky.  
Oh, for the day I too leave  
this place.  
I know that Christopher's arms  
will be open for me.  
I will once again be with him on the day  
my unfortunate journey comes to an end.



*Christopher Mitchell Gardner*  
Irondale, AL  
August 20, 1981– July 15, 1995



## FOR THOSE WHO GIVE AND GRIEVE

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# DOES MONEY *matter?*

By Catherine Paykin, MSSW



**MONEY MAY BE THE LAST THING ON YOUR MIND.** A wise man once said, “If a problem can be solved with money, it is an easy problem.” For example, money cannot bring back a lost love or prevent death. When we are financially secure, money does not seem to be important because we do not have to stress about it. However, the death of a loved one, especially an unexpected death, be it of a spouse, a parent or a child, can greatly influence you and your family’s financial well-being in the present and in the future.

In the United States it can seem like there is wealth all around us for the taking. However, as we grow up, we find that we must plan for our

need or that no longer make sense. There may be expenses and responsibilities around money we never expected. A loved one’s death may leave us in the new role of managing the family expenses, savings and investments or settling an estate. Perhaps we now must earn a living or raise a child or children. Do we need to move? Do we need to liquidate a trust for a child we had planned to see graduate high school, college or get married? The ways our loved one’s death impact us financially are huge, yet we may not realize it until we are ready emotionally to tackle these financial unknowns. Some people start a fund in a loved one’s name as a way of keeping them alive.

*“Our needs regarding money change as we pursue education, have children, get married, get divorced, face illnesses and cope with a loved one’s death.”*

financial health, our education, our medical needs, our housing and all other necessities. All the great opportunities we see around us are not ours for the taking—they need to be earned. As we move through life we must continually reroute and rework our financial strategies to fit our needs. Our needs regarding money change as we pursue education, have children, get married, get divorced, face illnesses and cope with a loved one’s death.

What can be a bigger life change than a death within our family or circle of friends? So often, death hurts our future plans. When dreams are dashed, there may be financial strategies that we no longer

What can we do to regain our equilibrium or our financial health after our loved one dies? We can ask trusted friends, family or bereavement support group members about their experiences. Ask what they have learned, who they might recommend as consultants or advisors with our financial decision-making. Often, people who can give us the most help are people who have been through this. People who are financially smart with their own money may also be able to help.

If you are vulnerable and unsure, even suddenly having extra money due to a bequest in a will or fund can be emotionally stressful. You

may have different demands being made on you by different people—loved ones and strangers.

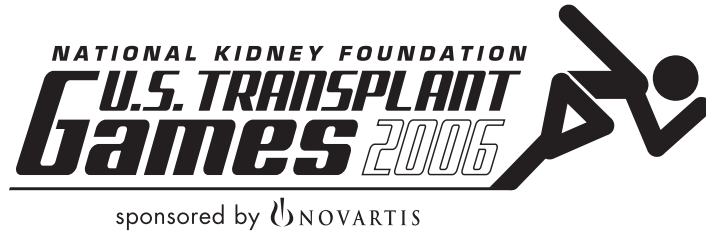
Money has a huge emotional significance to most of us. Money can be confused with love, worth and value. As you continue upon your grief journey, take things little by little. Allow yourself to learn and decide gradually. Recognize that you are vulnerable and, if possible, put off making any major financial decisions until you have had a chance to gain some perspective and access your situation. Progressively you will learn.

You might want to take some classes in financial management or enlist a family member’s help. There are lawyers, accountants and financial counselors who specialize in money management. A librarian can help you locate books, journals and other tools that can help you. Everyone has different needs regarding income and savings and when you have the energy, you will discover you have the ability to find an individual plan that is right for you.

**Editor’s Note:** *The National Kidney Foundation is grateful for the many donations to the National Donor Family Council (NDFC) that we have received from you, our readers, given to us in the name of your loved ones to bring programs of comfort and care to other donor families.*

# A Special Invitation

Please join us for the 2006 U.S. Transplant Games!  
Friday, June 16-Wednesday, June 21, 2006  
Louisville, Kentucky



The U.S. Transplant Games offers four days of inspiring events to highlight the successes of organ and tissue transplantation. Organ transplant recipients participate in athletic competitions, share their stories and honor donors and donor families for their life-changing gifts. All donor families are invited to join us to remember your loved one, support one another and cheer on the transplant athletes. Following are some of our many activities for donor families.

## Donor Recognition Ceremony

The Donor Recognition Ceremony is a special tribute to those who gave the gift of life and to their families. Featuring a video tribute to our loved ones, music and readings to honor organ and tissue donors and reflections from transplant recipients whose lives were changed dramatically from the gift of life.

## Quilt Pinning Ceremony



Donor families will have an opportunity to pin a "patch of love" to the National Donor Family Quilt in honor of their loved one. The entire Quilt will be on display during the Games.

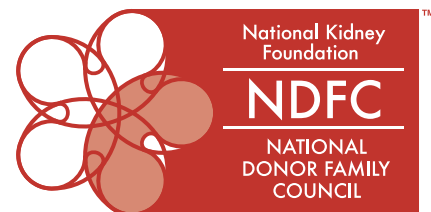
## Giving, Grieving, Growing™ Workshops

Workshops and sharing sessions will be presented on a variety of topics related to bereavement, donation and self-care. The workshops are safe places to share with other families.

## And much more!

Be sure to also look for the Coffee House, opportunities to submit tributes to donors, the Things with Wings gift shop and the donor family processional at Opening Ceremonies.

For more information or to register online, please visit [www.transplantgames.org](http://www.transplantgames.org) or contact the National Kidney Foundation by emailing [donorfamily@kidney.org](mailto:donorfamily@kidney.org) or calling 800.622.9010.



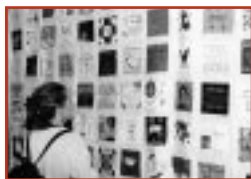
## TOP TEN Reasons Donor Families Should Attend the Games

Here's what donor families tell us about their experience at the Games:

10. The Games are a very "safe" place for all donor families. Everyone understands the road we have taken. While our story is individual, our pain and outcome is the same. It really helped me to have that understanding from others. Some of us do not have family and friends that understand the donation process—at the Games we are understood.
9. Attending the Games reassures you that your loved one/s gift of life was indeed a gift of love and honor.
8. The Games provides a chance for giving, grieving, growing and knowing you are not alone.
7. The experience alone validated the decision-making process we went through and that it WAS the right thing for us.
6. It is an opportunity for tears, laughter and many hugs!
5. It is an opportunity for you to be yourself among people who know and understand.
4. You can meet recipients in action—on the courts, on the track, in the pool—and see and experience their renewed quality of life as a result of your very generous gift.
3. To see, firsthand, the miracle of donation...it is very emotional, but healing to see the impact of the decision to donate your loved one's organs or tissues.
2. To meet and share stories with other donor families...it is so healing to realize that you are not alone.
1. The Games help remind us: What brings us together gives us hope!

We hope that all donor families will consider joining us for the 2006 U.S. Transplant Games! If you have been to the Games, what did the experience mean to you? Do you plan to go to the Games again?

Please visit [www.donorfamilyforums.org](http://www.donorfamilyforums.org) to share your answers and read other responses. Let us know what the Games mean to you and your loved ones.



## 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

April 5

St. Louis, MO, NKF of Eastern Missouri and Metro East, *Team St. Louis Organ Donor Awareness*, Nancy Buck, 314.961.2828

April 21

Fort Collins, CO, Poudre Valley Hospital, *Donor Open House*, Phil Koster/Robin Peterson, 970.231.4240

April 30

Sacramento, CA, Golden State Donor Services, *Donor Family Recognition Ceremony*, Brenda Owen, 916.567.1600

June 16-June 21

Louisville, KY, National Kidney Foundation National Office, *2006 US Transplant Games*, Marilyn Jones, 212.889.2210

September 17

Rochester, NY, Finger Lakes Donor Recovery Network, *Donor Family Celebration*, Roxanne Morsch, 585.272.4934

\* 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.

# AM I LOSING *my mind*

By Charles A. Corr, PhD, CT



**AFTER HER SON DIED IN AN AUTO ACCIDENT, JOAN AND HER HUSBAND AGREED TO FOLLOW THE WISHES THAT HE HAD PREVIOUSLY SHARED WITH THEM ABOUT DONATING HIS ORGANS AND TISSUES.** Joan felt good about that decision.

Just a few weeks later, however, Joan told her sister, Janet, that she felt like she was losing her mind. She said it was almost as if she could not recognize herself or her life anymore. So many of the things that she had taken for granted, like being a mother and raising her children, now seemed different and strange to her.

Like some other donor family members, Joan was unsure if she had done the right thing in agreeing to donation. She knew she had only carried out her son's wishes. Still, the shock of his death still seemed to throw Joan off balance and she could not help but wonder if she had made the right decision.

Joan had always had faith in her own abilities, but now she wondered if she could trust her own judgment. Sometimes when she set out to do things she could not remember what it was she wanted to accomplish. On occasion, she would go off on shopping trips only to return home wondering why she had bought so many items she did not need. These days, it was often difficult for Joan to concentrate on simple tasks or things people talked about. Frequently, she became angry over

trivial matters or started to cry for what seemed like no reason at all. Joan also found it hard to be with other people, especially at family gatherings when everyone wanted to be happy, but she knew she couldn't just stay home, sitting and staring at the television set all day without even realizing what was on.

Finally, she summoned up her courage and asked Janet: "Am I losing my mind?"

Janet knew that these were not her sister's typical behaviors and she realized that Joan was very troubled by what was happening to her. So Janet helped Joan make an appointment with the family services coordinator at the organ procurement organization that had helped to arrange the donation.

*"She explained that many people who have encountered a major loss in their lives experience some type of disorientation."*

Katherine, the coordinator, assured Joan that she was not losing her mind or going crazy. She explained that many people who have encountered a major loss in their lives experience some type of disorientation. They often find it is difficult for them to cope with things that had previously posed no problems at all. Everyday affairs might seem unfamiliar and alien to them. They might even begin to mistrust their own abilities and behaviors.

Coping with a loss like the death of a son, dealing with one's grief reactions to that loss and finding

ways to go forward with healthy living can be quite difficult. That may be especially challenging when the death occurred suddenly and unexpectedly, and when one must quickly make important decisions like those related to organ and tissue donation.

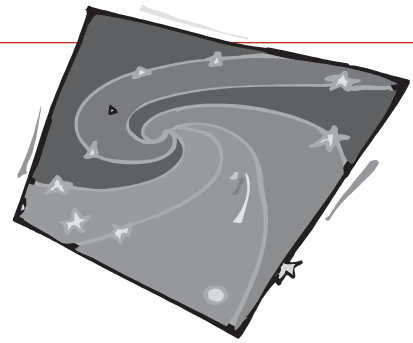
Katherine encouraged Joan to be patient with herself and to accept the help that was available to her. She praised Janet for being available to her sister and showing how concerned she was about her. Katherine also offered Joan the possibility of joining a support group for donor family members or of trying out individual counseling if she preferred that alternative.

Above all, Katherine reported that from her experience in working

with many donor family members, she could assure Joan that very few people really do lose their minds from bereavement. They certainly do encounter challenges and difficulties, but that is only to be expected when one is confronted with a major, life-changing event. In fact, Katherine told Joan that she had been impressed by the courage and strength shown by so many donor family members over the years who have learned that they can rise above those challenges and find ways to honor their loved one's legacy by not giving up on their own lives.

# CROSSES BY *the way*

By Roberta Wilson, Donor Mother



**SIX YEARS AGO THIS JULY, OUR SON NICK WAS KILLED IN A TRAGIC MOTORCYCLE ACCIDENT.** Just writing these words stirs the depth of our family's sorrow. Forever we were changed and a new door in each of our lifetimes was opened so that the walk after death lay before us.

Our oldest son was the last to arrive at the hospital that Friday evening. From his home it was a three-hour drive through the mountains. We embraced and our sorrowful emotions bound us together as we walked the hallway to "Nick's Rotunda" and touched and hugged, sobbing with grief, our disbelieving farewells.

Dazed and lost in numbness, we drove home with the heavy cloak of death. For each of us the world had stopped and even our home seemed to sag with sorrow. The dogs knew, and lay quietly watching as we moved through the house. Words were hushed and the phone's constant ringing was a

comfort through the night as family and friends reached to comfort our hearts.

Somewhere in the night my boys, Nick's three brothers, young and restless, needing to make it better, to fix the pain, gathered up wood, nails and hammers, and set off to build their monument, to mark the place—a sign for all to know that Nick had died right here and do not forget! This was his place now and everyone would know. This tomato-stake cross engraved with magic marker—Nick Wilson July 23, 1999—would be a sign to all.

People came to the cross almost daily, week after week, month after month, leaving tokens: Bouquets, letters, cards and ribbons. Almost like a ritual, they cared for and nurtured this site by the road. Even the property landscapers trimmed and edged around it so as not to disturb the site. Somehow we all found a comfort and strength from Nick's "Cross by the Way."

Since that night, I see other markers by the side of the road, reminding us that there, too, is a "forget me not" plea to us all from someone's loved one. Riding along the highways and seeing them pulls at my heart. I know their feelings and cannot pass without a prayer for both family members and loved ones.

Though we are all strangers, this is a bond, we share an understanding, we know. Recently I decided to make a photo journal of these "Crosses By the Way" and collect stories of other families' loved ones. Perhaps you or someone you know has a "Cross By the Way." I want to share our stories, our love, our need and our understanding.

*If you have a story you would like to share about your "Cross By the Way," please e-mail it to [donorfamily@kidney.org](mailto:donorfamily@kidney.org) to be posted on the [donorfamily.org](http://donorfamily.org) Web site.*



## *Thank YOU for Giving Life*

By Tamra Lewis, kidney recipient

Thank you for giving life,  
To those of us who needed a second chance.

Thank you for the gift,  
That we can open every day and get excited.

Thank you for passing on your love,  
That will live in us forever.

And thank you for giving us life so that we may LIVE again,  
For having life is precious, but giving life is priceless.

# Continuing the National Donor Family Quilt

By Robin Peterson, Donor Mother

**IT IS SUCH AN HONOR FOR MY FAMILY AND ME TO HAVE STARTED ASSEMBLING THE PANELS FOR THE NATIONAL DONOR FAMILY QUILT.** I know from personal experience all the love and thought that go with each square, and I also know the overwhelming gratitude that the recipient's family feels when they receive an organ or tissue. When I pieced together the panel that my son's square is on, I was so moved, and became emotional, in a good way. I always think about each square and wonder about the life of

that individual. But with my son Matt's square, my family and I remembered the times at the hospital, the waiting and praying for a liver, the unbelievable euphoria when he got one and the prayers for the donor we did not know. Later, when Matt himself became a donor, we remembered the part of him that now lives on in another man and the hope that his recipient can see the world as Matt did. When we lost Matt, the grief was unimaginable, but now we see that we are not alone and every single day, lives are saved and/or enhanced because of the unbelievable generosity of strangers. What a wonderful thing.

As I now piece the panels together, my daughter, Matt's sister, and their grandparents gather the backing to

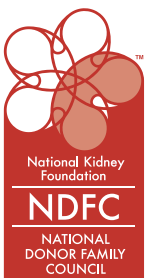
*Charles Pratt, Robin Peterson, Wendy Sedey and Lois Pratt with Panel 27. August 2005.*

attach to the quilts. When working on the panel with my son's square, my mother suddenly became ill and was hospitalized. She insisted on having the quilt brought to the hospital so she could do the handiwork. My daughter and I would go into the hospital early and help her until we had to go to work. As we sewed in the hospital and visited with people, we remembered all the things we loved about Matt, the good memories that are part of us and always will be. It was so nice. We finished the panel at the hospital. Everyone who came into contact with my mother there saw the quilt and learned about organ and tissue donation and the story of Matt. Matt is still making me so very proud to be his mother.

*The National Donor Family Council would like to introduce the new volunteer quilters for "Patches of Love," Robin Peterson and her family. Robin's son, Matt, was a donor in 2003 at the age of 23. We look forward to working with Robin and her family. Together we will be able to carry on the legacies of our loved ones. Their memories will live on.*



*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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