

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.

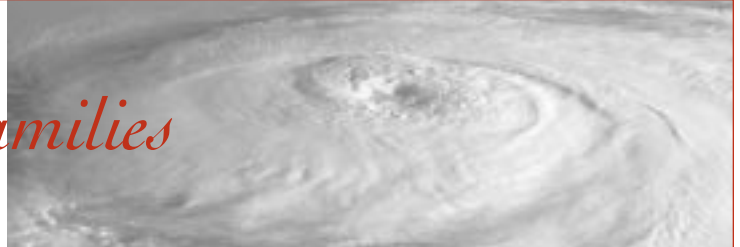
Fall 2005

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

Volume 14, Number 2

HURRICANE KATRINA *and donor families*

By Charles A. Corr, PhD, CT



AMERICANS ARE WELL AWARE OF THE UPHEAVAL AND DEVASTATION WROUGHT BY HURRICANES KATRINA, RITA AND OTHERS THAT HAVE HIT OUR NATION.

Wind, rain and a huge surge of water struck the coastal areas of Louisiana, Mississippi and Alabama. The storm also caused major damage as it moved inland. Additional destruction occurred as water was pushed into Lake Pontchartrain and back over the levees intended to protect the city of New Orleans and surrounding areas. Sadly, some of those levees gave way and flooded the city.

What does this have to do with donor families? As fellow Americans we all were witnesses to the shock and horror of these events. We also experienced our own grief and other reactions of varying intensity at the many examples of trauma and loss that followed this extraordinary storm.

More importantly, donor families have already experienced their own trauma and losses in connection with the deaths of their loved ones. Those who have offered a pure gift of love by giving the gift of life know all too well how difficult it is to cope with

the many implications of just a single death. Now we witness and perhaps share in multiple losses on a very broad scale from a very special perspective.

Even those of us who do not live in storm-ravaged areas and do not have direct contact with individuals displaced from those areas can be affected in many ways. As Shakespeare wrote in *Hamlet*, "When sorrows come, they come not like single spies, but in battalions." In other words, "When it rains, it pours."

Whether we were the immediate victims of this storm or witnesses from afar, we can experience losses from it. Donor families, in particular, may find that these new losses may trigger unresolved grief from their donation experiences. One loss recalls another; one grief stimulates another.

In these circumstances, Shakespeare also reminded us that bereaved persons need to "give sorrow words" (*Macbeth*, IV, iii: 209). His advice is to recognize and acknowledge our sense of loss and the full range of our grief reactions. He tells us to express our grief in constructive ways, to cope as best we can and to take care

of ourselves as we do so. We also need to care for others who are tender and vulnerable to these new encounters with grief. Donor family members are affected both by Hurricane Katrina and by the losses associated with the death of their loved ones.

The death and loss of a loved one is a hard thing to bear and its implications are likely to remain with us for a long time—perhaps for the rest of our lives. Still, donation is the right thing to do. It was a gift to our community and our fellow citizens. And, for most, it brought a small measure of solace.

Hurricane Katrina has also been a hard thing to bear, and will continue to be so for a long time—especially as more bodies are recovered and the tally of deaths rises. As this is written, however, just over one week after Katrina struck, it appears that Americans are already reaching out in many ways to those most directly affected by this storm. Together we will help to rebuild the new lives and new communities that will follow this huge natural disaster. Together we will give witness to the compassion, care and unconquerable spirit that make this a great country.

we fondly
REMEMBER...



Kimberly Creel Perruchon

April 8, 1969 –

December 18, 2003

(Correction in dates from Summer 2005 issue)



Light Your Way My Son

By Kim Miller, Donor Mom

I put a light up on your grave.
The place where in peaceful sleep...your body lay.
For so many reasons I just have to say.

To light your way as you walk alone.
So you can see as you make your way home,
To your father above.

To represent all the lives you affected
in your lifetime on this earth.

By giving the gift of life and saving those
four people.

For being the person you were.
And for so many more reasons I would
need an eternity to say.

And to remind you always of my everlasting
and undying love.
Light your way my son!

I love you always and forever!

FOR THOSE WHO GIVE AND GRIEVE

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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2005 National Donor Recognition Ceremony and Workshop In the Words of a Recipient

The National Donor Recognition Ceremony and Workshop (NDRCW) is sponsored by the Division of Transplantation, Health Resources and Services Administration, U.S. Department of Health and Human Services, with the assistance of the National Donor Family Council of the National Kidney Foundation.

The 2005 event was held in Washington, DC from July 22–24.

By Jim Gleason

UNOS Tour

The weekend began with a bus tour to Richmond, VA, to see the United Network for Organ Sharing (UNOS) headquarters. UNOS is the national organization that assists with transporting and placing donated organs and tissues for transplantation. The UNOS staff welcomed donor families and their friends with enthusiastic open hearts and arms. In many cases, they had never met donor families before, working as they do in the middle of the donation process with the transplant waiting list database.

The Donor Memorial Gardens were beautiful (see their virtual tour online at www.donormemorial.org/garden.asp) with each “room” of the garden designed to offer its very special message and meaning. I was struck by something said during our welcome there. The focus has been on “raising awareness” and polls now show that this has been very successful, with over 90 percent responding about how they now

know about organ donation. The shift is now on “commitment”—getting people, now that they are aware, to commit to being organ donors.

Another interesting thought was shared on the bus while returning from Richmond. A father was having difficulty with the idea of donating his sons' organs, despite strong advocacy from his wife and daughters supporting the gift. An orderly in the hospital cafeteria overheard the conversation and came over to point out that there

was no question that he would be an organ donor, but the real question was whether the sons' organs would be donated “to the ground or to save a life.” When that orderly left, the father asked for the papers to be signed. Wow, what a simple concept: Organs are wasted in burial, but I’ve never heard it put quite that way before.

If you will be traveling near Richmond, consider adding a visit to the Memorial Gardens to your trip.



Home page for the Donor Memorial Garden's online virtual tour.



*“we fondly
remember...”*

wall of
remembrance.

Photo by Rich Mullane

2005 National Donor Recognition Ceremony and Workshop

The following workshops focused on topics of particular interest to the intended participants. They were facilitated by experts in the fields of bereavement, donation and transplantation.

Moderated by a donor family member, the sharing sessions offered an opportunity for donor families who have experienced a similar loss to gather informally and share stories about themselves and their family experiences in coping since the death of their loved one.

Grief and Bereavement Workshops

Jim Gleason

The grief and bereavement workshops were both varied and well done. Families that have attended such events before were heard praising the keynote speaker, Darcie Sims of Grief Inc., with her very different and thoughtful remarks on the grieving process.

Friday night's workshop was on communication between donors and recipients, with a special sharing session by a 26-year-old heart recipient who received a transplant in 1998 as well as a corresponding donor family experience of finding their recipients. The overall message from those attending was a very strong desire to hear from recipients.

Donor Recognition Ceremony

Jim Gleason

On Sunday the ballroom filled with families and friends—led by the All Services Color Guard—to share stories and receive recognition. The Marine Band played and gave everyone chills with its bright tones and vibrant beat. Officials and dignitaries spoke of the gifts of life and the new breakthrough initiatives currently in the works, with dramatic results in increasing both donation and the number of life saving transplants. Emotions ran deep as both deceased and living donation stories were presented. One five-year-old girl hugged her father, her bone marrow donor, as he tried to talk around her in his arms. Naturally, she stole the show as living evidence of that gift of a life-saving bone marrow transplant.

Another individual shared a beautiful story with a twist. A woman's young husband died a few years ago, and when her own life was threatened, her bone transplant was made possible by her husband's gift. She discovered that such a donation takes a long time, as the bone is prepared into whatever form is needed by the recipient; in her husband's case, the bone was just entering that particular phase, and was able to be processed to provide her with the needed transplant.

The ceremony—with beautiful song and music, candle-lighting, medal presentations and a video montage presentation—left everyone in attendance filled with a sadness over loss but it was tempered with joy at the life saving options that had come out of their donation decisions.

A final surprise was a group of donor family children who sang "This Little Light of Mine."



Donor families pin their quilt square to the National Donor Family Quilt during the Quilt Pinning Ceremony.

Photo by Rich Mullane

As a heart recipient who was in attendance, I felt privileged to be there and to offer special thanks for their donation gifts—not only for myself, but on behalf of recipients everywhere.

Grief and Bereavement Workshops and Sharing Sessions

UNDERSTANDING BRAIN DEATH

Dorian Wilson, MD, Assistant Professor of Surgery
UMDNJ—New Jersey Medical School

THE SESSION ON “UNDERSTANDING ORGAN DONATION AND BRAIN DEATH” was well attended. The presentation opened with a description of the evolution of organ donation, as well as federal laws that were landmarks in the development of the organ donation system as it is known today in the United States.

TWO OF THE KEY CONCEPTS presented during this portion of the talk were: 1) **Required Request**—a law mandating the legal requirement of hospitals to offer the option of organ donation in the appropriate setting of brain death, and 2) **Decoupling**—the concept of ensuring that families understand that brain death, and thus death, has occurred (and its declaration) *first* followed by an interval of time, *then* the presentation of the offer for organ donation.

WE ALSO DISCUSSED the specific criteria that must be met, including absence of brain function of the entire brain, *including* the brainstem, before the diagnosis of brain death is rendered. The lack of oxygen to the brain was carefully demonstrated to be the culprit, using a number of pictures and illustrations that made the concept concrete and tangible. Based on comments made during the sharing session that followed each presentation, it became clear that brain death remains a difficult topic for donor families to completely understand.

For a free brochure on brain death, please contact the NDFC at donorfamily@kidney.org or (800) 622-9010.



A donor father pins his son's quilt square to the National Donor Quilt.
Photo by Rich Mullane

FINDING GOOD ALONG THE GRIEF JOURNEY

Ben Wolfe, Program Manager/Grief Counselor,
St. Mary's Medical Center's
Grief Support Center, Duluth, MN

THE GOAL OF THE WORKSHOP was to remind those who donated that “finding good” means being active and not passive in one’s grief, and “not letting anyone SHOULD on you!” Ben emphasized that, for example, tents in northern Minnesota are wonderful for keeping mosquitoes and rain out, but when one is grieving, “although the tent (whether it is our home,

apartment or some other safe place) may be ‘safe,’ we need to get out of the tent! We need to remind ourselves that it is not through time that one heals, but rather what we do with the time.”

BEN WENT ON TO DISCUSS grief as not only an individual process, but also a process that a family experiences as they grieve. He emphasized the concept of “getting lost” by stating, “Getting lost means exploring ourselves, not from the outside, but from within. [It means] taking chances, being vulnerable with ourselves and, in turn, pushing buttons, thoughts and feelings we usually do not explore.”

THE WORKSHOP ENDED with Ben talking about the need to care for ourselves before we can care for others, and to find, even for a short while at different times, somewhere to “rest, to renew the job of being and to gather strength for the journey.”

Continued on page 6

2005 National Donor Recognition Ceremony and Workshop

BARRIERS TO RECIPIENT/DONOR FAMILY COMMUNICATION

Jane Harrison, LCSW, CCM

Heart and Lung Transplant Social Worker, Inova Fairfax Hospital

IN MY 18 YEARS OF WORKING in organ transplantation, I often feel that I have come across every imaginable scenario and then, on any given day, I find that there is something new under the sun! Over the years, I have had numerous conversations with recipients and their families about taking that first step and writing to their donor family. There are a few themes that I see over and over again that I would like to share with donor families.

FIRST, I HAVE YET TO SEE a patient who was not extremely grateful for “the gift of life”—so much so that often the recipient is overwhelmed by the enormity of the gift and the generous spirit which these families possess at such a tragic moment in their lives. The recipient is always aware of the fact that while he or she is always elated at beating death, there is a family out there somewhere planning a funeral. This naturally leads to a sense of “survivor guilt” that often causes him or her to question his or her own worthiness of this precious gift. Frequently, the recipient has also come to know fellow transplant candidates from education classes, support groups and clinic waiting rooms. Candidates often ask about one another when they have not seen someone for a period of time.



Shadow boxes made by donor families in the “What to do with our Memories” Workshop.

Photo by Rich Mullane

AFTER A CANDIDATE IS TRANSPLANTED, you will hear questions like “Joe seemed very sick last time I saw him. Was he a different blood type than me?” You can tell that candidates are measuring their “worthiness” for the precious gift and wondering why they received an organ and another candidate did not.

SELF-ESTEEM HAS LITTLE BEARING on a candidate’s sense of worthiness in these cases. He or she is often afraid of not measuring up and fears that the donor family could judge him or her unworthy of the loved one’s organ(s). This reason alone often causes a recipient to delay taking that first step in writing. He or she wants to be able to tell their donor family of their accomplishments after their transplant.

Whether it is returning to work or seeing a milestone in life, such as the birth of a grandchild, a graduation, or a fulfilled dream, the recipient wants to reinforce the donor family’s decision and provide some comfort to them that their donation made a difference in this world. I often see the recipient set the first anniversary of his or her transplant as the time to contact the donor family. He or she has had time to fully heal from the procedure; in addition, the donor family’s grief may also have healed a bit. The recipient also hopes that the donor family would welcome hearing from someone who shares that date as a significant one.

BECAUSE I HAVE SEEN these recurring themes over the years, I have made “Communicating with your Donor Family” a regular education group topic. It always helps to know how others have approached the issue. Listening to experiences of communicating with and sometimes meeting donor families dispels some of the concerns that many fear. They become a great resource for one another and everyone benefits from learning about others’ experiences. Fortunately, there is an excellent article that is often used in working with this group. The September 2001 issue of *Washingtonian Magazine* published “Two Hearts Beat As One,” by Drew Lindsay, about a heart transplant recipient meeting his donor family, forming a relationship and jointly becoming part of a speaker’s bureau and speaking publicly about organ donation and transplantation. Although it is made

Grief and Bereavement Workshops and Sharing Sessions (cont'd)

BARRIERS TO RECIPIENT/DONOR

FAMILY COMMUNICATION (cont'd)

very clear that this is not everyone's scenario, nor does everyone seek this experience, it demonstrates the power of communication and the ability to promote organ donation through the donor/recipient bond. The bond that these families share is unique. The strong desire that many recipients feel "to give back" begins when they reach out to donor families. They often view their second chance at life as an opportunity to make the world a better place and they are acutely aware that it begins with that precious gift of life.

For a free brochure on writing to recipients, please contact the NDFC at donorfamily@kidney.org or (800) 622 9010.

SUDDEN AND ACCIDENTAL DEATH

Jan Frye Hill, BSN, RN, CCM

Wake Forest University Baptist Medical Center

IT WAS AN HONOR TO ASSIST IN THE SHARING SESSION on "Sudden and Accidental Death."

There were approximately 35 or more participants present and the session was very rewarding. Most individuals stayed long after the session ended to continue to share and learn ways of coping with their grief. I shared part of my journey, and then we broke into smaller groups, allowing others to tell their stories.

I SHARED THE STORY OF MY MOTHER'S liver transplant in 1994, followed by a call from a former family friend, who called to check on her status.

Two years later that friend became my husband. My mother loved the fact that her transplant brought us back together. Unfortunately, my husband was killed three months after our wedding, five days before Christmas. Despite my grief and disbelief, I honored his desire to be an organ donor. I have been fortunate in meeting one of the recipients, who has been blessed with two children since receiving my husband's kidney. Thus, I was able to share the joy of a recipient family and the grief associated with a donor family.

The stage is set for the 2005 National Donor Recognition Ceremony. Photo by Rich Mullane



FOLLOWING THIS STORY, WE DISCUSSED the importance of finding ways to cope with the loss. One of the most profound ways in which I have coped is through working with organizations such as the National Kidney Foundation and my local procurement agency, Carolina Donor Services. Everyone who was present agreed with me that service is a wonderful way to do something positive and productive with what has happened in our lives. We spent time discussing ways to cope with loss. Most importantly, we found the importance of sharing our grief and seeking assistance if the loss interferes with daily functioning. Many noted how difficult it was to recognize they had to reach out for help, but how rewarding was the outcome when they did so.

I WAS TOUCHED BY THE STORIES and was saddened to know others had experienced loss as well. There was a closeness among the participants, who had formed a bond by sharing and were encouraged by their gifts of life, recognizing their unselfishness during such a difficult time in their lives. I encouraged the group by noting they were part of a special group in which, despite what had happened to them, they honored their loved ones, thought of others and would always be comforted for having offered gifts of life.

IN CLOSING, WE EXPRESSED OUR GRATITUDE to the federal government for providing such a special venue for allowing us to begin the journey toward healing.



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.

- November 15-16 Eau Claire, IL, Musculoskeletal Transplant Foundation, *Linking Tissue Donation & Transplantation: The Gift of Tissue Donation*, Maggie Coolican, (860) 267-5749
- November 20 El Paso, TX, Musculoskeletal Transplant Foundation, *Linking Tissue Donation & Transplantation: The Gift of Tissue Donation*, Maggie Coolican, (860) 267-5749

* 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.

Katrina and Rita Relief Aid



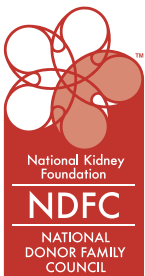
THOUSANDS OF VICTIMS OF HURRICANES KATRINA AND RITA face homelessness and devastation, but kidney patients without access to dialysis treatment face life-threatening danger in addition to loss of property.

To help patients in the affected areas get the services they need, the NKF has created a relief resource network posted on www.kidney.org, offering dialysis locations and treatment information, other direct patient assistance and information for health care professionals interested in volunteering for the effort.

"We are very gratified by the terrific cooperation we have seen by everyone involved in helping our patients deal with this disaster. National Kidney Foundation Affiliates, other kidney organizations, the large dialysis organizations and the kidney-related industries have all worked hard and closely together on behalf of the people who are suffering," stated John Davis, CEO of the NKF.

To contribute to the Foundation's Patients Hurricane Relief Fund, visit www.kidney.org or mail checks to the National Kidney Foundation Patients' Hurricane Relief Fund, 30 E. 33rd Street, New York, NY 10016. One hundred percent of funds contributed to the Relief Fund will go directly towards patient assistance.

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.



National Donor Family Council
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