

FOR THOSE WHO GIVE

AND GRIEVE



A quarterly newsletter for donor families, published by the National Donor Family Council of the National Kidney Foundation, Inc., to offer information about grief and support.

For Those Who Give and Grieve is provided to all families at no cost and is supported by voluntary donations.

Summer 1998

Volume 7, Number 1

Sara

March 28, 1977 ~ May 8, 1994

It has been three years now,
But it seems as if it has been a day.
Everything about you still reigns in my heart.
I can still see your smile and hear your voice.
I hear your laugh when I listen to the birds,
And see your smile on the bright sunny days.

You had your own special laugh,
And could make some of the funniest faces.
You never tried to be like anyone else,
If anything, you wanted to be different.

You were never afraid of trouble,
And always took on a dare.
You told people what you thought of them,
And there was no one you were afraid of.

You talked to everyone,
No one was a stranger to you.
Even if you didn't know someone,
You pretended they knew you.

I sometimes wonder if you are that dove,
Perching on the branch,
Or that rainbow on the warm sunny days.

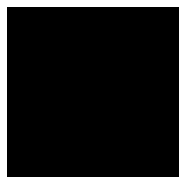
At night I look up into the sky,
There is one special star I always see.
That is the star I believe you have become.

The star symbolizes you so very well.
It is always shining bright, and
Sometimes flickers, as if you are laughing,
Or maybe just winking to say "HI."

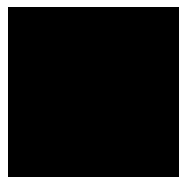
In reality you are so far away,
But your memories are always with me,
And in my heart you are always very near!

From all who love you,
Mom and Dad, Dave, Dawn and Russ

We Fondly Remember



James Bellacosa
June 22, 1971-
June 23, 1997



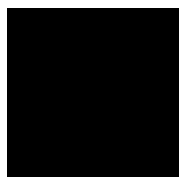
Bryan Edward Breitenbach
August 27, 1969-
August 25, 1997



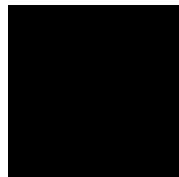
Tristen Todd Nettleton
October 31, 1995-
October 22, 1997



Michael G. Highsmith
January 22, 1966-
June 16, 1997



Laureen Bohr
July 14, 1934-
November 17, 1991



Stephanie Renee Henson
May 4, 1976-
November 28, 1996



George Lewis
February 14, 1933-
July 8, 1996



Roy John Geringer, Jr.
October 2, 1950-
October 15, 1996




THOUGHTS FROM

In Memory of My Devoted Son Alex *En Memoria de mi Adorado Hijo Alex*


(In English)


by Jose Gallego and family

(En Español)


 At the end of the most beautiful summer time, on August 16, when the sunrise is brighter than ever, the flowers show their most beautiful colors, the leaves of the trees are greener and the birds sing their most beautiful melodies, my son was washing cars in a fund raising activity at the church where we belong.

Later that day I went to the airport with my daughter, and my son decided to stay home to rest. Ten minutes later the sky turned from beautiful blue to darkness. A strong wind blew, and I felt very scared. My son went outside to give me a message, but it was too late—we had already left. As he walked back into our building, a big branch of a huge tree stole my son's life. He did not have a chance to do anything. My dear son was at the hospital for three days, but all the medical evaluations showed cerebral death. Our Lord Father God wanted another angel in His kingdom and He took away my Alex.

I want to share my grief with you and the huge emptiness left by the loss of a child. I am imploring God for the strength that only He can give to keep us going on this journey full of happiness and sadness. It has been a great hope to know that part of my son's body contributed to improve the life of a transplant recipient. 

 Ese día sabado 16 de agosto, terminando el tiempo más lindo del verano, cuando el sol sale más brillante y más temprano, las flores se encuentran con sus colores alegres, las hojas de los arboles son más verdes y el cantar de los pajaros resueñan en toda la bella ciudad, mi hijo se encontraba efectuando una actividad del grupo pastoral en la parroquia cercana a mi casa.


Al terminar el día yo tuve que salir al aeropuerto con mi hija, y mi hijo ya estaba en casa descansando. El cielo se puso muy oscuro, el viento soplo con fuerza y yo sentí miedo. Alex bajo a darme un mensaje y como no me vio se regresó, pero cuando caminaba hacia la entrada del eficio, el viento fuerte y un ramal grande y horroroso de un arbol muy alto le quitó la vida a mi hijo sin darle le tiempo de nada. Alex estuvo tres días en el hospital, muy bién atendido, le efectuaron todos los exámenes necesar, pero Dios quería otro angel en el cielo y se llevó a mi niño.

Quiero decirles que de corazon yo comparto con ustedes ese dolor tan grande y ese vacio irreparable que nos deja la perdida de un hijo. En mis oraciones pediré por ustedes también para que El Señor nos de fortaleza y podamos seguir adelante con los que quedamos en este valle de alegrías y tristezas. Estoy muy contenta porque se que hay algo vivo de mi hijo y la persona que obtuvo su riñon se encuentra bién gracias a Dios. 

My Hero

*In memory of Arlie Gene Bray, Jr.
December 29, 1964 ~ August 22, 1995*

There are so many things we forget to say
There are so many things we forget to do
But deep inside, I hope you knew
Just how much I cared about you
You taught me how to run and play ball
But most importantly...how to stand tall
I put a lot of expectations on you
But even with this you always came through

In school, I was nicknamed "Lil Arlie Lou"
Oh how much, I wanted to be like you
You were rough and tough with a heart so true
If only everyone knew the "Big Brother" I knew
You stood for what you believed in,
No matter who looked on
You were you, from morning until the next dawn
Oh...If only they knew
Hardest of all was never telling you 

Love,
"Your favorite sister"
Daryla Morgan

DONOR FAMILIES



A New School Year Begins

Reprinted with permission from the Compassionate Friends Newsletter; article originally appeared in *Saying Olin, To Say Goodbye*, by Dan Hackett of Kingston, Mass.

School opens for another year. There is a flurry of activity to end the summer: clothes to buy; notebooks, pencils and pens to gather; decisions to make on rulers and odd-shaped erasers. The family plans and almost plunges into the final weekend, the Labor Day splurge that ends summer and starts the fall.


For many, there will be no flurry. Clothing, notebooks, erasers, and all those other things become simply another note of hollowness in a fragmented life. For these, the last summer weekend may pass unnoticed. It is a time to consume silence in the land of bereavement.

When the school doors open, when the buses roll once more,

communities across this nation visibly proclaim the hope we all invest in our children. Bereaved parents, having no immunity to these desires and aspirations for our kids, find themselves even more highly sensitized to that never-again kiss of parting, that vigorous waving as the school bus pulls away. Perhaps for some, an empty desk, an unoccupied chair, will form the elements of a new vision that proclaims again an emptiness forever a part of life.

I teach. I know that school's reopening will remind me, even six years into bereavement, of the bittersweet capability of this time. And, I admit with some sorrow, I am never totally free of it, for often do I consciously hope that death will not again shadow a door

that is mine, even the door to a classroom! School is opening. For some among us this is a period of deep, unuttered hurt. Only the pain of the holidays may be deeper.

As these doors open once again, and as the opening weeks pass, let us remember and reach out to those for whom the school bell is no longer calling. For these parents, that bell is an endless tolling. Let us all offer the assuring hope that today's doleful tolling will instead, someday, become an evoker of memories...remembered images that will dance upon the heart, forming an anchor of love on which healing may poise itself to soar, to bring darkness of pain to light. 




DONOR FAMILY FRIENDS



DF 95 I lost my niece in an automobile accident. I feel that I not only lost my niece, but also my sister. I would like to know how other "aunts" helped their siblings through this horrible time.

DF 96 My mother was killed in an automobile accident two months ago. It feels like I am the only one in the world without a mother. I would like to hear from others who have lost a mother to sudden death.

DF 97 My son was murdered in October of 1997. He was only 23 months old. I have an 11-year-old daughter and a nine-year-old son. We are all having a very difficult time dealing with our loss.

DF 98 The departure of our 17-year-old son has affected the entire family, leaving us in deep sorrow. We know that he is our guardian angel. Let's share this difficult time. 

To submit or repeat a Donor Family Friend ad or to respond to a family, send all correspondence to Donor Family Friends, c/o The National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016. Please include the number of the DF you are responding to in your letter.

FOR THE NEWLY BEREAVED

Making Sense of Loss

by Kenneth J. Doka, PhD

We tend to think of grief as an emotional response. But grief also affects us on other levels. We can experience all types of aches and pains. It can influence the way we behave, making us withdrawn, overactive, or short-tempered. We may find it hard to concentrate or to focus. All of these are ways that grief can be expressed.

One of the most difficult issues that we can face is making sense or meaning of our loss. Whenever we ask the question, *Why did this have to happen?*, we are raising the issue of meaning.

Not every loss challenges our sense of meaning. Eleanor's mom died soon after she turned 96 years old. The last years had been tough. Eleanor's mom had gradually lost her mobility, sight and independence. Mom had been ready to die, constantly talking about how tired she was. One night she drifted off to sleep, never to wake again. Eleanor missed her terribly, but she never asked those "Why?" questions. Even in Eleanor's grief, the circumstances of her mother's death comforted her. She had lived a rich and full life. She had not experienced great pain. She seemed ready.

Other losses may challenge our sense of meaning. Doris' husband, Phil, died soon after retiring. "We had all these wonderful plans. He had worked so hard. He never had time to enjoy." Not only does Doris struggle to find meaning in Phil's death, she has yet to find a sense of purpose for her own life now. Paul, too, is troubled by the death of his wife. "She

was such a good woman, constantly volunteering, always helping. Why did she suffer so?" Both Doris and Paul remind us that struggles with meaning are likely to be more difficult when the circumstances of death are troubling or ill-timed.

Whenever we grapple with these questions, it is important to remember a few key points:

Making meaning is an individual process. The meanings that give others comfort may not be helpful to us. That does not mean that we should not discuss these questions with others. Talking with others is essential to helping us find meaning. But we need not be troubled if we cannot find support in the thoughts that comfort them.

Search your own spirituality. Each of us has our own ways of understanding the world. That understanding is the center of our spirituality. We need to ask how our spirituality can help us make sense of the loss.

Focus on the connections and legacies. Anyone we grieve has touched our life in many ways: memories we have shared, things we have learned, new appreciations and skills. These legacies, as well as other connections we find in our own spirituality, reassure us that they still remain a part of our lives. Connections and legacies can help us find meaning even in the most difficult losses.

Reprinted with permission from *Journeys: A Newsletter for the Bereaved*. 

In Remembrance

Memorial contributions are channeled directly into programs and educational resources for donor families and the professionals who support them.

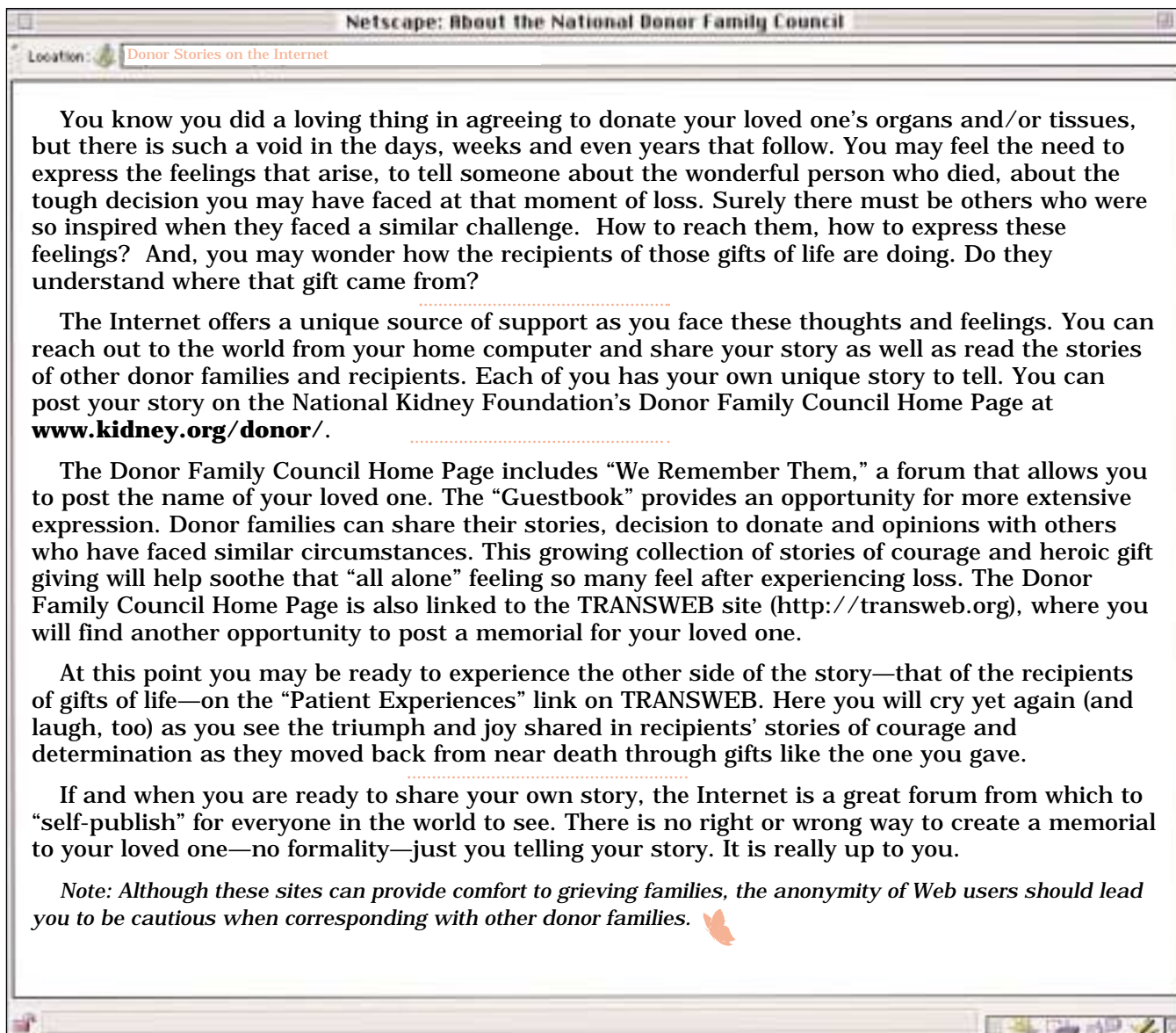
In memory of **Randy Lee Hughes**, from Virginia & Mary Hughes
In memory of **Bryan Edward Breitenbach**, from Mr. & Mrs. William Breitenbach

To the National Donor Family Council, from **Viola De Land**
Special thanks to **Bell South** for their generous gift.

WHAT HELPS WHEN IT HURTS

Donor Stories on the Internet

by Jim Gleason



The screenshot shows a Netscape browser window with the title "Netscape: About the National Donor Family Council". The address bar shows "Location: Donor Stories on the Internet". The main content area contains several paragraphs of text discussing the challenges of organ donation and the support available through the Internet. The text is formatted with horizontal lines separating paragraphs. There is a small orange butterfly icon at the end of a note.

You know you did a loving thing in agreeing to donate your loved one's organs and/or tissues, but there is such a void in the days, weeks and even years that follow. You may feel the need to express the feelings that arise, to tell someone about the wonderful person who died, about the tough decision you may have faced at that moment of loss. Surely there must be others who were so inspired when they faced a similar challenge. How to reach them, how to express these feelings? And, you may wonder how the recipients of those gifts of life are doing. Do they understand where that gift came from?

The Internet offers a unique source of support as you face these thoughts and feelings. You can reach out to the world from your home computer and share your story as well as read the stories of other donor families and recipients. Each of you has your own unique story to tell. You can post your story on the National Kidney Foundation's Donor Family Council Home Page at www.kidney.org/donor/.

The Donor Family Council Home Page includes "We Remember Them," a forum that allows you to post the name of your loved one. The "Guestbook" provides an opportunity for more extensive expression. Donor families can share their stories, decision to donate and opinions with others who have faced similar circumstances. This growing collection of stories of courage and heroic gift giving will help soothe that "all alone" feeling so many feel after experiencing loss. The Donor Family Council Home Page is also linked to the TRANSWEB site (<http://transweb.org>), where you will find another opportunity to post a memorial for your loved one.

At this point you may be ready to experience the other side of the story—that of the recipients of gifts of life—on the "Patient Experiences" link on TRANSWEB. Here you will cry yet again (and laugh, too) as you see the triumph and joy shared in recipients' stories of courage and determination as they moved back from near death through gifts like the one you gave.

If and when you are ready to share your own story, the Internet is a great forum from which to "self-publish" for everyone in the world to see. There is no right or wrong way to create a memorial to your loved one—no formality—just you telling your story. It is really up to you.

Note: Although these sites can provide comfort to grieving families, the anonymity of Web users should lead you to be cautious when corresponding with other donor families.

PERSPECTIVES



Dear People:

My son, Joseph, age 16, passed away in April 1997, from injuries received in an auto accident. I will not tell anyone that he was an organ donor because of the stupid things people say:

- See, God wanted him dead so he could save these four other people.
- You received a miracle by your son's death. Others were able to live.
- It was God's wish for him to pass away and donate

organs. Maybe others will be saved in Jesus.

- Don't you know how many people this has made happy? Four other families are able to enjoy life now.

People think they are saying comforting things, but in reality they are just making things worse. I will not discuss or tell people of the organ donations. At this time in my life I could care less about the recipients. I love my son and always will.

Thanks for listening.

Sincerely,
George D. Durden, Jr.

Please send your questions and comments to the National Donor Family Council.



What is a Non-Heart-Beating Donor?

by Kristine Nelson, RN, MN

Last year there were a number of reports in the media regarding a protocol that was considered by the Cleveland Clinic Foundation but never used, for organ donation from donors after their hearts have stopped beating. These donors are commonly called “non-heart-beating donors.” You may have heard something on television or read an article in the newspaper about this type of donation. There are many organ procurement organizations and transplant centers across the country that recover and transplant organs from non-heart-beating donors. This brief article is intended to provide you with some basic and factual information about donation from donors after their hearts have stopped.

All people who become organ and tissue donors are declared dead before organ and tissue donation takes place. The overwhelming majority (over 98 percent) of organ donors have died from brain death. This means that the entire brain, including the brain stem, has permanently stopped functioning and the individual is declared dead. (For more information on brain death see the NKF-NDFC brochure “Brain Death: A Simple Explanation.”) When the family gives permission for organ donation, oxygen and blood flow to the organs are maintained by a respirator and medications that keep the heart beating until the organs can be removed.

In a few rare situations, severely brain-injured patients, who cannot breathe on their

own and have no chance of recovery, may be considered as organ donors after their hearts have stopped. In these cases, the patient’s family and physician agree that the respirator, other machines and medications should be stopped. Once this decision is made, the family may initiate a discussion or be asked to consider organ donation. The family is given a clear description about the donation process and time to consider this option before making the decision. If consent is obtained, the physician caring for the patient and the family will develop a plan for discontinuing mechanical support systems. Then the patient’s physician, who is not involved in organ donation or transplant, will pronounce the patient dead after the heart has stopped. The donor’s organs (usually the kidney and liver) are immediately removed in the operating room.

Non-heart-beating donor protocols offer the option of organ donation to the families of patients who have fatal brain injury and are being withdrawn from life support, but who will not experience brain death. In some instances, family members will initiate a discussion about organ donation when they learn that their loved one has no chance of recovery. Clearly, the decision to donate rests with the family. The family must ask for and be given clear and accurate information in order to make an informed and appropriate choice regarding organ donation after the heart has stopped.

THE PRIVILEGE OF CARING

Dear Friends:

I have been working for an eye recovery organization for over 25 years. The most rewarding part of my job is my interaction with donor families. I am constantly amazed at the special love and courage families find at such a difficult time in their lives. I attend seminars, read books and talk to “experts” in the field of grief and bereavement. I thought I had a clue.

In June 1997 my husband and best friend for 29 years died of cancer. We had been told over two years before that it could be three months or three years, but the cancer “would cause his death.” Donation was not my first thought as I watched him take his last

breath. It was my thought as I realized that the body lying there was not the person I so adored.

As the reality of my loss sinks in and the wounds become more painful, I realize what the journey of grief is all about. These are lessons I don’t care to learn, and the patience it is going to take seems nowhere to be found.

I am so happy we talked about donation and I could honor the person he was by donating. I have lived, talked and walked donation for 25 years. I know it was the right option for us. The thing that has really hit me is the heroic decision families in total shock make in the midst of total confusion. I am in awe.

Sincerely yours,
Donna Oiland

THOUGHTS FROM RECIPIENTS

Excerpted from a poem by John "Sandy" Naclerio

A short time has passed;
the diagnosis, "sinking in";
the idea of a transplant;
new fears begin.

Out of darkness,
though no time to rejoice,
a glitter of hope;
maybe a choice.

Do I dare take the risk,
What if I don't survive?
Can I spend the time left
being more alive?

The fear of the unknown
had reached a new height;
but my life's partner and I
were up for the fight.

"We're pleased to announce
you have passed the evaluation,
move to our city
while we await a donation."

With beeper in hand and
at the mercy of strangers;
patiently waiting,
denying the dangers.

Will the beeper ever go off?
As the months fade by.
Will the transplant come
before I die?

Moving slower now,
and in an emotional drain.
Life on the edge,
and feeling the strain.

How do you keep going,
pushing to capacity?
Where do you find the
strength and tenacity?

You reach out to God,
seeking courage and grace.
You look deep down within,
looking fear in the face.

The strength of your family,
does a fire ignite;
giving you the will,
to continue the fight.

After four false alarms
this time "It's a go!"
Everything's in a frenzy,
you just go with the flow.

The cycle of donating an organ
has a rhythm all its own.
The drama unfolding
is not really known.

Families elated
in the joy of winning;
waking the next morning,
to a new beginning.

For over a year,
quite a battle we fought.
A second chance was won
with everyone's support.

One must agree,
the true miracle of
transplantation
lies, most certainly,
in the donation.

Unconditionally to give,
in your hour of grief,
takes a whole lot of love
and a strong belief.

To a loving family
a thank you to write;
feeling their loss
while expressing delight.

Your donor is secret
that's the design,
automatically making
all Donor Families mine!

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. NKF reserves the right to edit all submissions. Please contact the NKF for article submission guidelines.

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BOOK NOTES

Swallowed by a Snake The Gift of the Masculine Side of Healing

(Golden Healing Publishing, \$15.95, 888/870-1785)

by David Stanton, Contributing Editor

"When a woman feels lost, she tends to ask for help. When a man feels lost, he'll look for a map." If this sounds like you, Tom Golden says you are not alone. "Men...don't want to be a burden to others, they want to maintain their independence...(and) tend to grieve in a private and quiet manner," he says. His book provides testimony and insight to help you find the route to healing.

Drawing on over 20 years of experience as an author, speaker and psychotherapist, Golden, a licensed certified social worker (LCSW), explores how many men and some women process feelings of grief, likening grief to being swallowed by a huge boa constrictor and having to slowly cut your way out of its belly. Healing from grief can take years, he says, and confronting your own grief (the boa) by enticing it to swallow you is often more difficult than extricating yourself from it. 

The Quilt on Tour

Aug. 5- 8	1998 U.S. Transplant Games	Columbus, OH
Aug. 20-23	San Diego Quilt Show	San Diego, CA
Aug. 21-24	NKF of Hawaii	Honolulu, HI
Aug. 25	Llano Memorial Hospital	Llano, TX
Sept. 11-12	Horse and Buggy Day	Weyauweega, WI
Sept. 13	New England Organ Bank	Bedford, NH
Sept. 18-Oct. 4	"Big E"	West Springfield, MA
Sept. 24	LifeGift	Lubbock, TX
Sept. 25-26	ANET	Cocoa Beach, FL
Oct. 3- 4	NKF of East Tennessee	Knoxville, TN
Oct. 4	New England Organ Bank	Trumbull, CT
Oct. 7*	LifeGift	Houston, TX
Oct. 9*	NKF of Michigan	Romulus, MI
Oct. 11	Pleasant Valley United Methodist Church	Barkhamsted, CT
Oct. 18	New England Organ Bank	Providence, RI
Oct. 22-25	NKF Annual Meeting	Philadelphia, PA
Nov. 2-16	Midwest Organ Bank	The Lake of the Ozarks, MO
Nov. 9	New England Organ Bank	Boston, MA

* Indicates events not yet confirmed.

Information about the quilt can also be viewed on our website: www.kidney.org

The quilt is created from squares submitted 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. Because it may not be displayed in its entirety, please call if you plan on seeing the quilt. For information on how to contribute a square, to request a panel of the quilt for an event in your area, or for up-to-date information, please contact the NKF at (800) 622-9010.

Organ & Tissue
DONATION
Share your life. Share your decision.™

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. The National Donor Family Council is a Gift of Life Initiative of the National Kidney Foundation.

NKF National Donor Family Council
National Kidney Foundation
30 East 33rd Street
New York, NY 10016



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