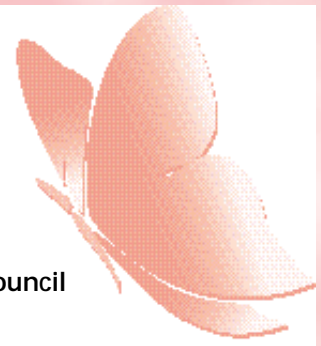


For Those Who Give and Grieve



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 1999

Volume 7, Number 4

The Story of Two Donor Moms

by Jayne Miller

This is a true story about two moms. They are both health care professionals who had life-altering experiences in 1985. One welcomed her oldest child into her life with great joy. The other, a mother of six, watched her pigtailed, freckle-faced daughter skip down the driveway to her school bus one morning. But within hours, this little girl was stricken suddenly with a cerebral hemorrhage on the play yard at school. This courageous mom, together with her husband, Don, would make a generous decision to donate young Katie's organs and give others a chance at restored and extended life.

Katie's legacy became her mom's new path—challenging the transplant community to provide comprehensive care for the donor families it had the privilege of caring for. She taught the professionals that grief is a journey that lasts a very long time and that for some, donation can be a perspective-point along that journey. It allows families to have their loved ones matter to others at the time of death, as they mattered to so many during their lives. This mother, Maggie Coolican, wrote an article 12 years ago titled "Katie's Legacy," chronicling her young daughter's life, sudden death and donation.

I am the other mom in this story, and I read "Katie's Legacy" one year after my son became a donor. The brown-eyed toddler had suddenly rejected his newly transplanted heart and died. My husband, Thomas, and I very much wanted to return the generosity that Nicholas' donor family had exemplified. **WE CHOSE DONATION!**


In 1986, donation wasn't rare exactly; however, it also wasn't as common as it is today. I read Maggie's article with great interest. Her poignant words captured the humility of the moment when parents are confronted with the decision to consider donation on behalf of their beloved children. After reading this article, I telephoned Maggie in Connecticut from my home office in California. We chatted openly and quickly became friends, agreeing to work together on some donor family support ideas. We began to work creatively and collaboratively on projects like the creation of the *For Those Who Give and Grieve* newsletter.



L-R: Bruce Stroeever (MTF), Maggie Coolican, Martha Anderson (MTF) and Jayne Miller (MTF).

Maggie is an example of creativity, strength, courage and volunteer spirit in a world where many people have forgotten how much one person can accomplish. She is a quiet dynamo who is a hero to so many her life has touched. She is legendary for notes of support and remembrance to those of us who also have lost loved ones. Maggie chaired the National Donor Family Council for seven years, and has singlehandedly stitched over

1,000 "patches of love" into the National Donor Family Quilt.

It was my personal honor to present the Musculoskeletal Transplant Foundation 1998 Nicholas Miller Award for excellence in support of donor families to my friend, my colleague and the hero of many donor families, including my own—Margaret Beatty Coolican. 



In Memoriam to Our Brother, Craig McGilton

Ride in peace our brother, our friend.
Ride in peace
For now all your troubles have finally come
to an end.
Even though we miss you so, the one thing
that makes us go,
is to know we'll ride in peace together, brother
So gallop through every sunset,
But slow down enough to watch it rise.
Fulfill your wildest dreams and whatever
may cross your mind.
And now may all your journeys have a happy,
happy end
cause one day we'll be together again
May the moonbeams be your highway,
let the sun be your guiding light.
The stars they are your road map as you
travel through the night
And may the comet be someone your dreams would
simply like to chase through your new land,
your new world, your new place.
So ride in peace brother, go ride in peace.
For now you hold the key to unlock any door
and even though you're gone
that's what keeps us drifting on
to know we'll ride in peace, together,
once more.


We miss you so much, Craig, and we know you're
with us now.

*All of our love,
Kim, Joe, Kelly, Dawn and Stacie*



A Year Later

The day before last Mother's Day he died.
The day after that, we said goodbye—a suicide.
So deep the pain, so far, so wide, and yet so near—
And Mother's Day is here, again.


The tears are fire and ice,
Yet, warm with love
That only reaffirms, in joy, the bond
Between this mother and her son
On Mother's Day. 

Pamela Johnson



Afterglow

*For my son, Aaron Cockran
April 29, 1978-February 2, 1995*

Id like the memory of me
to be a happy one.
I'd like to leave an afterglow
of smiles when life is done.
I'd like to leave an echo
whispering softly down the ways,
Of happy times and laughing times
and bright and sunny days.
I'd like the tears of those
who grieve to dry before the sun
Of happy memories that I leave
When life is done. 

Geneva Comeaux

**Visit the National Donor Family Council
Webpage at www.kidney.org.**



Post your thoughts or memorials on our
message board and respond
to other donor families.

WHAT HELPS WHEN IT HURTS

The Grief of Siblings ... The Forgotten Mourners

by Elizabeth Turner Haase, PhD

The death of a brother or sister can be an extremely devastating event in our lives. However, sibling death is not always acknowledged as the intensely painful and difficult loss it is for some people. While society recognizes the depth of grief after the death of a child, parent or spouse, sibling grief is less understood. The bonds of siblings are forged early and are expected to last throughout our lifetimes. Siblings are most often the people we know the longest in our lives, and they know how we have changed over a lifetime.

During childhood and adolescence, siblings are a large part of each others' lives, whether they spend a great deal of time together or not. During young adulthood, as they establish careers and families, some siblings may see less of each other, while others continue to be very close. Many siblings become dear and trusted friends as they grow older and rely on each other for many needs, on physical, emotional and spiritual levels. The depth of investment and attachment siblings feel is often a predictor of the intensity of their grief.

The grief of siblings at any age or under any circumstances can feel overwhelming, and surviving siblings need outlets to express themselves. Surviving siblings frequently talk about the need to protect their parents or their sibling's family members after the death, which may lead them to neglect their own needs. Because their own grief is intense, they may feel angry at their sibling's family or their parents for not paying attention to their needs.

In addition, siblings of all ages often feel survivor guilt—that somehow they should have died instead of their brother or sister. One sibling's comment after his brother's death from cancer was, "How is it that I seem to have all the good genes and my brother had all the bad ones! Why am I alive and he is not?"

When a sibling dies suddenly, grief is often more intense. It may be difficult to believe the death has actually occurred. Many brothers and sisters have questions about how their sibling actually died. These are not unusual questions and learning more often

helps with the grieving process. Many times, too, brothers or sisters die before we've had a chance to tell them how much we loved them or before we have cleared up a misunderstanding. Talking about these feelings and about a brother or sister's life and death is important to our own healing.

During the grieving period, siblings may feel such intense emotions as deep sadness, depression, anger, anxiety or fear. In addition to these normal grief reactions, surviving siblings have expressed feeling many of the following: a need to carry on their brother or sister's work in the world, a need to carry on his or her name, a fear of growing old without the sibling, a sense of lost history, and a feeling of being alone in the world without a sibling's support.

When a surviving sibling is the only child or family member left in the family of origin, the grief and sense of being alone may be even more intense.

It is important to respect and honor the sibling's feelings and allow time to grieve and heal. If surviving siblings' family or extended family cannot help deal with the grief, they may need to talk to friends or a grief counselor, or join a support group. Oftentimes during grief, families have difficulty supporting each other and need to seek outside assistance.

Whether we love our brothers and sisters and enjoy them in our adult years or see very little of them, they provide a frame of reference and a sense of family. They share secrets, memories and understandings from years past and are partly responsible for making us into the people we are later in life. Clearly, the death of a sibling has strong meaning in the lives of surviving brothers or sisters. If that grief is acknowledged, supported and allowed to take its natural course, most siblings will move through their grief despite the pain and upheaval.

Elizabeth Turner Haase, PhD, is a psychotherapist in Washington, D.C.

For more resources on grieving for a sibling, call the NDFC at (800) 622-9010.

REACHING OUT IN YOUR COMMUNITY

Betty's Story

by Forest Hamlin


February 24, 1975. That's the day I'll remember for the rest of my life. You see, that is the day I met my wife. Each of us has our own story about how our lives were changed by death. My story begins with the first meeting of the woman who was a victim, became my friend, my wife and the mother of our daughter.

In 1975, I was a police detective with the Metropolitan Police Department in Washington, D.C., and I monitored a call to respond to a robbery. It was late, I had been in court all day and was moments from the end of my shift. Something told me to take the call and I did. It was on this call that I first met a lady named Betty Morgan. She was upset but composed, shaken but not hysterical. And even with my professional approach to this case, I could tell she was pleasant and very attractive. I liked her. That did not stop me from doing my job, and I assisted in identifying the suspect. But Betty and I later started to date and she proposed to me; we were married two years later.

In 1979, I transferred to the homicide branch. Betty was always there for me and very supportive during the long hours and stressful cases. We talked about everything as friends and as family—everything, that is, except death. And why should

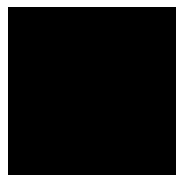
we have? She was 41 and I was 40. We all know that 41-year-old people who have never been sick do not just get sick and die without warning.

On April 28, 1988, my unthinkable fears became reality. Betty complained of headaches and before the night was over, she was in a coma. She never regained consciousness and was declared brain dead days later. It was then that I made the decision to donate Betty's organs—a decision which has given me and our six-year-old daughter comfort, support and pride. Even in the grief of the moment I knew that this was the only way that I could ensure that Betty would live on in others. I would like to believe that whomever received her organs may inherit some of her habits and her love of life and family.

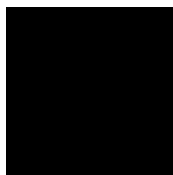
Today I work at the Washington Hospital Center as a Family Advocate. I approach families and give them the option to donate organs and tissue for transplant. This office was formed in September 1994 by the Washington Hospital Center to assist and support families and patients, particularly in cases that apply to organ and tissue donation. I have always been one to believe that things happen in our lives for a reason. I am now retired from the police department and have accepted my new role in life as an advocate for patients, families and organ donation. 



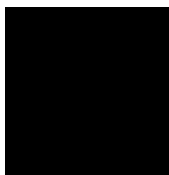
We Fondly Remember



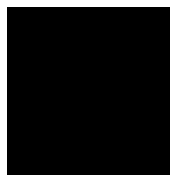
*Amy Lynn Marie
Cathey
August 19, 1980 -
January 23, 1997*



*Brian Brustowicz
December 30, 1974-
January 13, 1992*



*William Hearn
October 29, 1980-
April 4, 1996*



*Holly Lea Nelson
October 30, 1982-
February 20, 1998*



*Jeffrey Lee Payne
January 27, 1986-
March 7, 1997*



*J.R. Lamb
May 18, 1977-
October 12, 1996*

In Remembrance

Memorial contributions and other public donations to the NDFC are channeled directly into programs and educational resources for donor families and the professionals who support them.

In memory of:

Our son - by Cathy and Dave Nonnemaker

Aurora Sass - by Marilyn McGuire

Florence M. Landry - by Doris R. Pitcher

Terry Rhoades - by his parents and sisters

George Lewis - by Ruby Lewis

Teri Lohr - by Julie Daly

Karen Musto - by Jan Schichtel

Keith Eric Friedman - by Pam and
David Friedman

To the National Donor Family Council -

From Cynthia Coleman

From Paul and Catherine Brustowicz

From Carolyn O. Wetherhold

How Does the Organ Sharing (Allocation) System Work: Matching Donors with Recipients

by Fred Geiger, regional administrator,

United Network For Organ Sharing (UNOS), and liaison to the National Donor Family Council

As promised in the last issue of For Those Who Give & Grieve, this article will explain how recipients are matched with donors after the decision to donate has been made.

All candidates for transplant are accepted onto a transplant program's waiting list and are registered with UNOS. UNOS maintains a centralized computer network linking all organ procurement organizations and transplant centers. When a donor then becomes available, the transplant center or organ procurement organization will access the UNOS computer, which generates a list of candidates ranked according to the UNOS policies on organ allocation.

When a candidate's name is added to the list, his or her medical profile is entered and stored in the UNOS computer. When an organ donor becomes available, each candidate in the pool is matched by the computer against the donor characteristics. The computer then generates a list of candidates ranked in order, based on medical and scientific criteria comparing all candidates in the pool to that particular donor. The list is accessed first for potential recipients at centers within the local area

of the donor hospital. If no suitable matches are found, the search is broadened to a larger region of the country and then nationwide if necessary.

After receiving a printout of the waiting list, the transplant coordinator contacts the transplant team of surgeons and physicians for selection of a candidate using the ranking list. Often the top candidate will not get the organ for one of several reasons. When a candidate is selected, he or she must be available, healthy enough to undergo major surgery and willing to be transplanted immediately. Also, a laboratory test to measure compatibility between the donor and recipient may be necessary. Once the right candidate is selected and contacted and all testing is complete, surgery is scheduled and the transplant takes place.

For more information, contact your local procurement organization or call the NKF at (800) 622-9010.

THOUGHTS FROM RECIPIENTS

If Not For You

A Tribute to My Donor

If not for you
There would not be me
That gift of life
You gave to me.


There were tears of joy.
There were tears of sorrow.
You gave me hope,
For a brighter tomorrow.

I wiped away the tears
Tried not to cry
Knew some would live
And others die.

The only way
I could understand
Was to realize this
Was part of God's plan.

If not for you
What would I do?
God chose someone special
He sent you.

Now a part of you
In me has thrived
Thanks to you, donor,
I have survived.

And with each new day,
This thought comes through
I would not be alive,
If not for you. 

Nancy Sinisi Talty

The Quilt on Tour


Please note: This schedule is subject to change.

May 1	Transplant Celebration Picnic, Alabama Organ Center Contact: Margaret Tresler, 205/731-9230	Birmingham, AL
May 1	Donor Recognition Ceremony, California Transplant Donor Network Contact: Tracee Harris, 209/527-6178	Modesto, CA
May 3	Cadillac Golf Invitational, NKF of Connecticut Contact: Jacqui Connoly, 860/232-6054	Fairfield, CT
May 5-10	Donor Awareness, GOLD Family Support Group Contact: Sue Ripp, Luther Hospital, 715/838-3258	Eau Claire, WI
May 16	Donor Recognition, New England Organ Bank Contact: Pam Albert, 800/446-6362	Woodstock, VT
May 17	Nifty Fifty Golf Marathon, NKF of Connecticut Contact: Jacqui Connoly, 860/232-6054	Middlefield, CT
June 4	NKF of Mass. and R.I. Contact: Bridget Foley, 781/326-7225	Boston, MA
June 13	Donor Recognition, New England Organ Bank Contact: Pam Albert, 800/446-6362	Rockport, ME
June 27	Donor Recognition, New England Organ Bank Contact: Pam Albert, 800/446-6362	Framingham, MA
July 24-25	Celebration of Life Weekend/Regional Transplant Games, NKF of Oregon and SW Washington Contact: Fred Bachofner, 503/282-0990	Portland, OR

The quilt is created from squares made by donor families in honor of their loved ones. It travels in sections around the country to pay tribute to loved ones and to raise awareness of organ and tissue donation. **The quilt is not displayed in its entirety, and some events may be closed to the general public. If you plan to attend one of the displays, please contact the individual listed above.** If you are requesting a particular panel or square to be displayed at one of the above events, would like to bring the quilt to your community, or if you would like information on how to contribute a square, please call the National Kidney Foundation at (800) 622-9010 for up-to-date information. Information about the quilt can also be viewed on our website at www.kidney.org.

TEENAGERS SHARING

My name is Heather Davison. I'm 14 years old. My five-year-old sister was tragically killed in March 1997. It had started just like any other day, but then it became a nightmare. I was on my way to pick up my other sister, and on the way home I saw an ambulance turn down my street. My mom said, "Please God, don't let it be one of my babies." But it was just like God wasn't listening.

I started to run. My neighbor told me something had happened to my sister Randi. I completely lost it. Randi died less than an hour later. Because someone chose to drink and drive, my sister had to die. And now, I feel like her friends and family have to pay. Please don't drink and drive. 



If you would like to submit a letter or story to Teenagers Sharing, please direct all correspondence to:

FTWGG Teenagers Sharing, c/o National Kidney Foundation, 30 East 33rd Street, New York, NY, 10016 or e-mail donorfamily@kidney.org.

FOR THOSE WHO GIVE AND GRIEVE

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▲ **Editorial Office:**

National Donor Family Council
c/o NKF, 30 East 33rd Street
New York, NY 10016
(800) 622-9010/
(212) 889-2210
FAX: (212) 689-9261
www.kidney.org

Executive Editor:
Gigi Politoski

Managing Editor:
Sara Kosowsky

Production Manager:
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Editorial Director:
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Donor Family Friends

DF 112 I'm 14 years old. My-five-year-old sister was killed by a drunk driver. My mother and I would like to hear from others.

DF 113 Today my son would have been 25 years old. He was killed in a car accident. There are so many feelings and emotions! My friends do not want to talk about my son, so I've been coping on my own. Please write.

DF 114 I became a first-time mother in November 1997 and now am a single mother after the death of my husband of 14 years. I'd love to hear from other widows ages 30-40 who have lost a husband and are raising a child. How do we survive?

DF 115 Our 18-year-old son was killed in an automobile accident a little over a year ago. It is still very difficult to cope. I am reaching out to others in hopes that sharing this difficult time will help.

DF 116 I'm a mother, age 31, and I lost my 11-year-old son in a car accident. I have four surviving children. I would like to hear from others who have lost a loved one. Writing helps. 

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, 30 East 33rd Street, New York, NY 10016. Please include the number of the DF you are responding to in your letter.

NDFC Upcoming Events

✧ **July 24, Scottsdale, AZ**, "Giving, Grieving, Growing," one-day educational and support workshop for donor families, in conjunction with an educational program for transplant recipients

✧ **November 4-5, Miami, FL**, National Donor Family Council Executive Committee business meeting*

✧ **November 6, Miami, FL**, "Giving, Grieving, Growing," one-day educational and support workshop for donor families in conjunction with an educational program for transplant recipients and kidney patients and families.

✧ **NDFC Internet Chats**—Chats take place on the third Tuesday of each month, 9-10 pm EST. For a complete listing of topics and speakers, call the NKF or log onto our Website at www.kidney.org

* The business meetings of the National Donor Family Council are open to the public. For more information on any of these events, please call the council 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 c/o
National Kidney Foundation
30 East 33rd Street
New York, NY 10016



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