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 2007 Visit our home for donor families at **www.donorfamily.org** **Volume 15, Number 3**

THE SMILE THAT *love restored*

By Douglas Harrell, Donor Husband

AT THE AWKWARD AGE OF 13, WHEN TEENAGERS ARE ALREADY UNCOMFORTABLE WITH THEIR BODIES, Melissa Nguyen had a bigger worry. A cell bone tumor was taking over the upper right side of her face. It had to be removed, but so did most of the bone and teeth on that side.

As a young girl, Melissa wasn't able to have her own bone used for her transplant. "I actually did all the treatment options that were available before I had my transplant. My age restricted me from having my own bone removed and transplanted into my face. I was still a growing girl, so they didn't have a choice but to use synthetic bone," she says. Although she was given partial prosthetics, they had to be taken out during meals, making Melissa feel self-conscious about her appearance.

Melissa shares a smile with husband Tony at their wedding on June 15, 2006

"I have very few pictures that were taken between the ages of 13 and 21. The prosthetics were good, but there's only so much those can do. I always covered my mouth with my hand when I smiled, and there's nothing like the embarrassment of having to take out your teeth to eat when you're on a date."

> *"A stranger gave me a gift that changed my life forever. I am truly grateful and always will be."*

Although she can now look back on her experiences with a smile, she remembers how often it made her cry. "This may sound ridiculous, but the thing I missed the most was to bite into a homemade caramel apple from Pokey's (a restaurant in my hometown). They only sell them in the fall, and it was something my mom and I did every year together," Melissa says.

Now, after a bone transplant and reconstruction, Melissa has a new smile, a new husband and her life is better than ever. "There is nothing that I can't do. I went back home to visit my family in Iowa, and I had my caramel apple. Also, I got married last June, and there wasn't one picture where I had my hand covering my face."

Touched by her experience, Melissa is now giving back as a transplant coordinator in Hawaii. She sends this message out to her tissue donor and donor family: "The smile I have on my face today is because of you. My confidence and happiness are with me because a stranger gave me a gift that changed my life forever. I am truly grateful and always will be."

For Those Who Give and Grieve is supported by MTF Musculoskeletal Transplant Foundation *Changing Lives Through Tissue Donation*

ISSN# 1524-7600
03-60-1503

National Kidney Foundation

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 NKF The NKF reserves the right to edit all submissions. Please contact the NKF for article submission guidelines or permission to reprint articles.*

EDITORIAL OFFICE
National Donor Family Council
NKF, 30 East 33rd Street
New York, NY 10016
800.622.9010 • 212.889.2210
Fax: 212.689.9261
www.donorfamily.org
E-mail: donorfamily@kidney.org

Remembering TJ

By Terry Blinkenberg, Donor Mother

AFTER MY ONLY SON TJ HAD PASSED AWAY, I suffered through awkward questions as to whether or not I was a mom. Originally I said "no," to avoid further questions, but I felt I was erasing TJ's worth and memory. Then, I just said "yes," so as not to make others feel uncomfortable by mentioning my loss. But that always prompted more questions, like "How old?" Now, I say, "Yes, and my son is in heaven now."

I am very open about TJ's death and life, and I no longer worry about other people's reactions. If they are uncomfortable, they can walk away. It's much more harmful for me to try to ignore his existence. Talking about TJ always makes me smile, and it's a way to keep him alive in my heart and honor his life.

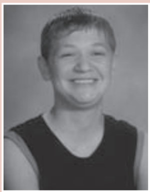
My sons all know about their "big brother," and as they get older, they ask me about him. They see his pictures everywhere and they know it's not an awkward or uncomfortable thing to talk about him. They do so freely. It's wonderful to hear their ideas and thoughts of what he would be like; it makes me feel as though he is alive and well in my heart and our home.

Terry and Travis Blinkenberg with son TJ (Travis Jr.)

WE FONDLY *remember…*

Stormy Sean Beck
April 29, 1975 –
August 10, 1993

Travis Robert "TJ" Blinkenberg
July 6, 1995 –
December 2, 1996



Jarred Dean Fasching
April 12, 1989 –
April 26, 2003

James Stephen Morris
July 1, 1987 –
October 25, 2005

Kirk William Veach
May 6, 1985 –
October 19, 2003

LIGHTING *the way*

By Rev. Sue Wintz, MDiv, BCC, Donor Mother

Sarah Elizabeth Wintz

AS A BOARD-CERTIFIED CHAPLAIN IN A LARGE MEDICAL CENTER, I've worked throughout my career approaching families about donation and supporting them. Every day I see lives saved and enhanced because of organs, tissues and research made possible by those who have given the gift of life.

Through the years, there has often appeared to be a tier or hierarchy of sorts—with organ donation at the top, considered to be the "most important" type of donation, followed by tissue donation and finally, gifts for research. However, I don't think there is one gift of life that is "greater" or "better" than another. The gift, whatever it may be or for whatever use it is given, is wonderful and precious. People who give those gifts are heroes.

> *"Our loved ones who donated…are lighting the way for us and future generations."*

Felix Adler said, "A hero is one who kindles a great light in the world, who sets up blazing torches in the dark streets of life for others to see by." I love that quote. It reminds us that our loved ones who donated, whether for transplantation or research, have kindled torches that light the way for us and future generations.

I learned the true meaning of this quote on December 2, 2003. My beautiful and talented 17-year-old daughter Sarah Elizabeth was killed instantly in a car accident. A senior in high school, Sarah was a passionate, joyful and outspoken young woman. She adored children and planned to become a teacher of developmentally delayed preschoolers.

Sarah was a very spiritual young woman who had no fear of death and believed life's journey would continue beyond this physical world. Donation was one of Sarah's greatest passions and she carried this statement in her wallet: "I am an organ and tissue donor. I do not want to be buried. I want my body donated to science."

Because Sarah was killed instantly, we were unable to donate her organs for transplantation. However, Sarah gave the gift of tissue for transplantation and the gift of her body for research, bringing hope and life to an immeasurable number of persons.

The major recipient of Sarah's gifts was the Barrow Neurological Institute in Phoenix, Arizona. Sarah's gifts have assisted research in the treatment of lower back pain, among other areas.

For our family, being able to honor Sarah's passion for donation allowed us carry on her life in the midst of her death. Sarah wanted to be a powerful changing force for good in the world. She was and continues to be. Many who knew her have made the decision to become donors.

My daughter is one of my heroes. Sarah showed me what it means to be a single light illuminating thousands. All whom we have loved, who have given the gift of life in whatever way, are heroes. You and I have been honored and blessed—we have walked with heroes, and their blazing torches continue to shine with light and life.

Editor's Note: *In some areas, whole body donation may not be done in conjunction with organ or tissue donation. Check with your local organ or tissue recovery agency for information about available giving opportunities in your area.*

WHY SO MANY *questions*?

By Maggie Coolican, RN, MS, CT, Musculoskeletal Transplant Foundation, Donor Mother

FAMILIES OFTEN ASK WHY SO MANY QUESTIONS must be answered when making the decision to donate a loved one's organs or tissues. This part of the donation process can cause much stress, and families may be upset by the personal nature of the questions posed. When asked about drug use or the sexuality of a loved one, for instance, many families become angry or frustrated, especially if their loved one was a young child.

These questions are part of federally regulated donor screening requirements put forth by the Food and Drug Administration, as well as from recommendations made by the Centers for Disease Control and Prevention and the U.S. Public Health Service. Other professional organizations, including those that prepare donated tissue, may also require screening for specific criteria that are used in risk assessment questioning. These questions are similar in nature to those asked when donating blood and are necessary to ensure safety for recipients and recovery and transplant staff. The questions, in addition to the testing performed, help to ensure the gifts donated are suitable for transplantation.

Regardless of age, cause of death, gender or lifestyle of the donor, all families must answer all the questions in the medical/social history form. Sometimes a friend or person who is most knowledgeable about the potential donor may also be encouraged to help answer the questions. The coordinator offering donation to the family is not allowed to edit the questions in any way, regardless of how the family might be feeling.

Although many families would like to reduce the number of questions, each time a new disease appears—such as Asian flu or mad cow disease—additional questions are added.

Some families have suggested that individuals should complete the form when they make a donation decision and update it annually to relieve their family of this responsibility at the time of death. The information obtained, however, must be the most current available, and therefore, the majority of questions require answers at the time of the donor's death. Other families have suggested that individuals should be informed about the number and nature of the questions through a Donor Registry when a donation decision is made. Recovery agencies throughout the country are continually educating the public about the benefits—and process—of organ and tissue donation, and should include information about the medical/social history.

Because of the length of the medical/social history and the nature of the questions, it is the responsibility of the professional interviewing the potential donor family to be skillful and obtain needed answers quickly yet thoroughly.

The Donor Family Advisory Council of one recovery organization, LifeChoice Donor Services, found that a family's experience will be better if the interviewer is compassionate and skilled. For example, it is helpful to inform the family approximately how long the interview will take, and throughout the process (at 25%, 50% and 75% intervals), to provide updates on how much more time will be required.

A sensitive interviewer will also be able to tune to the family's needs, giving families chances to take a break, get water, talk with each other orreturn phone calls. At the beginning of the process, a skilledinterviewer also lets the family know that the questions will be personal, yet are standard and mandated. Compassion is key for the interviewer. Personal questions seem less invasive when a donor family is asked about "your loved one" or "your family member" rather than "the deceased." The skill of the interviewer can make all the difference to the donor family experience.

DONOR FAMILY *voices*

WHEN YOUR FAMILY WAS ASKED ABOUT DONATION, was there anything that helped make the process more comfortable for you? Do you wish that anything had been handled differently? Do you have any suggestions for improving the process for future families—either the consent process or the medical/social history questions?

We asked families these questions on our donor family e-mail list. Some of their responses follow. To join the e-mail list, write to **donorfamily@ kidney.org** and ask to be added to the National Donor Family Council e-mail list. To read the full responses, or share your own ideas, please visit **www.donorfamilyforums.org**

The only thing that was difficult was having to go through questions over the phone, stuff that was in his hospital record already. There should be an easier way to do that.

– Pat

◆

It seemed that some of the questions on the medical/social history were asked over and over. This tried my patience and I really wanted to say "I already answered that." The questions should be more streamlined and direct if possible. The procurement specialist was wonderful, but his job was difficult.

– Mary LeBeau

◆

If I had to go through this again, it would be more comforting to be in a room with warm colors, possibly a candle, and comfortable chairs—sitting together in a close-knit circle, maybe even holding hands. This would ease the interviewing process. I think the interviewer should... get to know the grieving family before asking the questions.

– Charlene Myers

◆

The most important part of this process when my mom died was the patience, courtesy and compassion of the person asking us the questions. She sat with us and allowed us to reminisce and never once made us feel like we were taking up her time. She patiently listened to our stories and remembrances and laughed with us and cried with us. The questionnaire itself offered us a little comic relief when we had to consider if my mother had any tattoos or if she had used any drugs. Anyone who knew her would have chuckled at the thought of her getting a tattoo!

– Leeann Bongiorno

◆

The lady that spoke with us was very kind and soft spoken. She seemed to understand what we were going through. I think that it would probably be easier if the questionnaire was given to the family to fill out and not have to answer those questions out loud.

– Cheryl Stanford

◆

One of our interviewers was himself in a similar position to us when his brother had a fatal accident. His compassion, patience and gentle way made the experience easier.

– Cynthia Thompson

◆

It should be stated upfront what (the Organ Procurement Organization) is and that the hospital is mandated by law to approach family members about donation. In my opinion it would make the conversation move along at a more comfortable pace.

– Mary Schuler

◆

The entire hospital staff and the team involved with the donation process were all very professional and sincere in explaining and keeping us informed of the process. I am thankful for the many questions that were repeated because I believe it helped the donation process to be a success.

– Nancy Wagner

OUR JOURNEY *continues*

By Patti Rivetti

Dennis Rivetti

WHEN MY HUSBAND, DENNIS, DIED ON FEBRUARY 5, 2004 OF A BRAIN ANEURYSM, I thought my world had come to an end. I didn't know what I would do without him. I was scared—and there are moments I still feel afraid.

Our family's lives are still adjusting without Dennis, and perhaps they will for a long time to come. We had dreams of being together forever; we made many plans for the future...and one day I found myself alone with our dreams. However, I am comforted that Dennis was an organ and tissue donor, and I take pride and honor in knowing that in his death something so beautiful came to be...five people were given a chance to continue their own dreams!

At first, it was heart wrenching for me to think of other lives continuing while Dennis' ended; it felt like my life ended too. But I found that it didn't. I found joy in knowing that Dennis is still here with us, in the lives of others, and he truly will always remain in my heart and my thoughts.

My family and I had the privilege of meeting Mark, Dennis' heart recipient, and I am so glad that our families became friends. What an amazing man. He, like Dennis, is full of life and the love for it.

My sons and I went to the U.S. Transplant Games in June 2006. Our journey is still in progress, but part of it came full circle when we had the opportunity to see what organ and tissue transplants do for others. My son, Dylan, had told me the athletes competing have "heart," and we noticed that no matter the outcome of the game, they continued to smile and laugh. How amazing to see that in moments of grief there are others whose lives are celebrated with such joy in being given another chance. We had a chance to share our stories, grief, love and joy in knowing that our loved ones are forever unselfish. I love to speak about Dennis and organ and tissue donation. We support it, knowing it is the right thing to do. If one beautiful life—such as Dennis'—cannot be here anymore, then that life should be passed on.

"I found joy in knowing that Dennis is still here with us, in the lives of others, and he truly will always remain in my heart and my thoughts."

My family and I miss and think about Dennis daily, and about the decision to give of himself in his death. My life is not without Dennis; I have a place for his love and laughter deep within me, and it will remain there.

CORRECTION

An incorrect photo and caption were included with Mia Lester's article in the last issue. The correct photo of Robby Somerville, Jr. is printed here. We regret the error.

A transplant recipient competes at the 2006 U.S. Transplant Games.

photo credit Eric Miller

GO AHEAD, HAVE A GOOD CRY:
how tears help us heal

By Suzy Ball, RN, MHS

CRYING IS A NATURAL RESPONSE TO DEATH OR LOSS and part of the universal human experience. Research shows tears can be a powerful ally in the healing process. Not only is it okay to cry, but it is also a healthy way to cope with loss.

Are all tears the same?

There are three kinds of tears: those that are continually produced to keep the cornea moist, nourished and resistant to infection; reflex tears, which are produced to wash away irritants and foreign particles; and emotional tears from sadness or joy. Humans are the only animals capable of emotional tears.

> ***It is important to acknowledge feelings of loss and sadness. Knowing the value of crying, and the healing power of tears, allow us to express grief in natural and therapeutic ways.***

Why do I feel better after I cry?

Emotional tears actually rid the body of toxins and wastes. Dr. William H. Frey, author of *Crying: The Mystery of Tears*, studied the chemical make-up of tears and found that emotional tears contain protein and high levels of cortisal (the primary hormone released during stressful situations). Emotional tears also release high levels of manganese and prolactin, helping to lower depression. Dr. Frey found people reported feeling less sad and angry after crying. He noted when people talk about "crying it out," they mean it literally.

What causes me to cry?

It is no surprise that emotional tears result from an outside source, such as the death of a loved one. The pain of loss sends a message to the brain, which produces emotional tears. The body relies on tear glands to release the excess chemicals and hormones, helping us to return to a normal state.

Dr. Frey also studied reasons for crying: sadness, happiness, anger, sympathy, anxiety and fear. For those on the grief journey, tears are a normal part of the process and are the result of many emotions.

Researchers found that people who cry frequently feel better and enjoy better overall health.

Can I cry too much?

People who are unable to stop crying should be aware of signs of complicated grief, and may need to seek assistance from a counselor or physician. Seek help if you have:

- difficulty functioning adequately at work or home.
- extreme feelings of guilt or worthlessness.
- unexplained physical symptoms.
- feelings of depression or nervousness that do not improve or that worsen within a month or so.
- persistent and severe trouble sleeping (lasting four to six weeks), particularly if you wake in the early morning and cannot return to sleep.
- unintentionally lost more than 10 to 15 pounds.
- suicidal thoughts.

Will I ever stop crying?

It's hard to believe tears will come to an end. Crying tends to gradually decrease from intense weeping immediately following the death to occasional tears that come with a reminder of the lovedone. Something, such as a song, an anniversary or a favorite place can bring a wave of sadness and tears. It is important to acknowledge feelings of loss and sadness. Knowing the value of crying, and the healing power of tears, allow us to express grief in natural and therapeutic ways. It may help to remember this bit of wisdom from William Shakespeare: **"To weep is to make less the depth of grief."**

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.

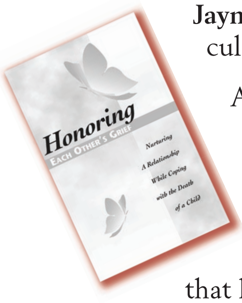
2007

January 25	Norwood, CA, National Kidney Foundation of MA, RI, NH & VT, *Gift of Life Awards Dinner,* Michael Blazek, 781.278.0222
April 18 — 23	Eau Claire, WI, Luther Midelfort, *Public Education and Family Recognition*, Chaplain Aimee Wollman, 715.838.8128
April 28	Modesto, CA, California Transplant Donor Network, *Celebration & Remembrance Ceremony,* Trace'e L. Harris, 209.545.8000

* 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.

For information about reserving a Quilt panel, please contact the NDFC for updated information and pricing. The NDFC can be reached by e-mail at **donorfamily@kidney.org** or by phone toll-free at 800.622.9010. Please notify the NDFC of any special requests, including requests for a specific panel of the Quilt. Arrangements will need to be made to display the Quilt properly and obtain permission from the venue where the Quilt will be displayed.

Congratulations



Honoring
Each Other's Grief
Nurturing
A Relationship
While Coping
with the Death
of a Child

The National Donor Family Council (NDFC) would like to extend our congratulations to **Jayne Miller** on her retirement from the Musculoskeletal Transplant Foundation (MTF).

As a donor mother, Jayne helped to establish the NDFC and its programs and resources for donor families. She authored the NDFC publication, *Honoring Each Other's Grief: Nurturing a Relationship While Coping with the Death of a Child* that has meant so much to other bereaved couples. She helped to establish and support *this* newsletter along with the MTF, and helped establish MTF's Nicholas Miller Award and DonorCARE Award.

Jayne, thank you for your friendship, vision and wisdom over the years, which have meant so much to the donor families and professionals who have worked with you.

Editor's Note: For a free copy of *Honoring Each Other's Grief,* please contact the NDFC.

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 Kidney Foundation
NDFC
NATIONAL DONOR FAMILY COUNCIL

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

NON PROFIT ORG.
U.S. POSTAGE
PAID
New York, NY
Permit No. 5327

Please help us "Cut Down" our costs by notifying us when your address changes. E-mail us directly at **donorfamily@kidney.org** It costs 39 cents if you forget.