



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 2008

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

Volume 16, Number 3

SEEING *life anew*

By Patrick Pruitt

THE MICHIGAN STATE UNIVERSITY CAMPUS is often described as one of the most beautiful in the country, and as a recent graduate, I have to agree. I've seen the landscape draped in a pristine, unbroken layer of sparkling snow on frosty winter mornings. I've seen the green buds break through the layer of white as the arrival of spring was heralded. In summer, I've seen the sun rise over the horizon as the sky turned from black to purple to a breathtaking blue. And in the fall, I've seen the campus turn a thousand shades of red, orange and yellow as the trees prepared once again for winter.

As I experienced this beauty from season to season, I was always cognizant of the fact that I am extremely fortunate. To have seen those wonderful images is a blessing I don't take for granted. At the age of five, my vision began to deteriorate due to a scar on my left cornea. Suddenly, I was no longer able to play outside with my friends, to read or play with Legos®, to see the concerned faces of my family and friends. A slow shift occurred from a five-year-old's bright mysterious world of endless



Patrick Pruitt

possibilities to a world of blurred shapes and colors. I was headed toward partial blindness, a condition that was averted by the decision of a couple who had lost their son in

an auto accident.

Their decision to donate led to my cornea transplant at the age of six. Their decision changed my life.

The transplant has affected just about every facet of my life. Thanks to the transplant, as captain of the cross-country team I could see the pride in my teammates' faces when we won the conference championship. Thanks to the transplant, I could be awestruck when I picked up a young woman for our first date and saw how stunning she looked. (It's funny that sometimes what your eyes see can make your heart beat faster.) And thanks to the transplant, I could see the tears in my mom's eyes when I hugged her on my graduation day.

I feel a responsibility to use this phenomenal gift to its fullest—to use it not only to benefit my own life, but the lives of others.

I've worked in childcare for a domestic violence shelter and as a youth mentor in the juvenile justice system. I studied hard and graduated with Honors with a degree in psychology. I tell you these things not to brag about individual achievement—quite the contrary. Everything I've done is the product of inspiration from many different sources: parents, friends, mentors and, though they may never know it, my donor family.

I wish I were eloquent enough to express the gratitude I feel toward my donor and his family. I've never met them, as they wished to remain anonymous. I still don't know what words to use to describe my awe, respect and appreciation for the decision they made—a decision that was courageous and selfless and made at an incredibly difficult time. Everything I've seen over the past 16 years is a gift. I've seen things both happy and sad, beautiful and frightening, and I wouldn't give up any of it. On behalf of all recipients who have been touched by your loved one's gift and your decision to donate, all I can say is thank you. It doesn't begin to cover it. Nothing ever could.

Editor's Note: *Adapted from a speech given at the National Donor Recognition Ceremony in July 2007, in Washington D.C., hosted by the United States Department of Health and Human Services. Used with permission.*

New eye transplant procedure revolutionizes the GIFT OF SIGHT

By Rusty Kelly
Eye Bank Association of America

DID YOU KNOW that new technology has revolutionized the way surgeons are performing cornea transplants and the way that eye banks are preparing these precious gifts for the operating room?

The new technology allows technicians to prepare corneal grafts in a way that surgeons can insert the cornea into the recipient's eye with only small incisions. The donor cornea is inserted into the eye and floated to stick into place. This new surgical technique, called endothelial keratoplasty

(EK), replaces the innermost layers of the recipient's cornea, rather than replacing the entire cornea. The new procedure provides the corneal transplant recipient with a rapid recovery time, as no stitches are necessary in most cases.

This is a very exciting time for corneal transplantation and eye banking. In 2006, the Eye Bank Association of America (EBAA) reported a 300 percent increase in the number of EK procedures being performed versus the typical procedure.

WE FONDLY remember...



Tommy Coles
August 22, 1997 –
September 11, 2000



Duawonna Untoee Dawson
December 8, 1976 –
February 26, 1999



David James Demattio
September 7, 1968 –
January 27, 2004



Rebecca S. Gabbard
March 3, 1961 –
October 30, 2001



Robert Howze
March 15, 1983 –
September 14, 2005



For Those Who Give and Grieve

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CORNEA DONATION— *truly unique*

By Lois Parker, Family Services Coordinator, SightLife

I CANNOT COUNT THE NUMBER OF TIMES I've heard families lament that their loved one could "only give corneas." Some families consider corneas to be somehow "less than" organ donations, since they aren't life-saving. Well, that all depends on how you look at it. (No pun intended.) Here are a few facts about cornea donation and what makes it so unique.

The cornea is the clear disc in the front of the eye, much like the crystal on a watch. Vision is dramatically reduced when the cornea becomes cloudy or damaged from disease, injury or infection, which can result in corneal blindness. A cornea transplant can remedy this condition. (Only the cornea is transplanted, not the entire eye.) This is one of the most frequently performed types of transplants, with more than 46,000 surgeries in the U.S. last year and a success rate of over 90 percent. Recipients range in age from nine days old to 103 years!

One donor mother said that her son had always wanted to visit Japan. As it happened, his left cornea was sent to Japan. The recipient was a college student who'd been waiting several months for a new cornea.

It's very clear that corneas DO save lives.



The donor mother said, "William got his wish. I know we did the right thing. He was able to help two people to see and now his eyes are taking in all the amazing sights of Japan. I miss him, but I know he'd be happy knowing he made a difference in somebody's life."

Next time you look at the intricate design of a snowflake or contemplate the colors of a winter sunset, remember that somewhere, someone else is enjoying them with a new depth of appreciation and gratitude all because of your loved one's precious final gift. Still think that corneas aren't that important? Just ask the young man who now has a bright future ahead, the grandmother who sees her grandson's face for the first time or the surgeon who can continue his life-saving work through skillful heart surgery.

It's very clear that corneas DO save lives. Thank you for helping others to see the world in a different light.

For additional information about cornea donation and transplantation, visit the Eye Bank Association of America Web site at www.restoresight.org

MORE WE FONDLY *remember...*



Richard I. Leavell, Jr.
November 24, 1980 –
September 6, 1997



Andrew Marlatt
August 3, 1981 –
July 4, 2005



Jim E. Riffel
October 31, 1952 – April 18, 2001
and
Ethelyn "Grams" Weldy
March 12, 1900 – June 1, 2001



Kerri Lynn Saxton
August 17, 1975 –
June 30, 1998



Greg Toland
July 19, 1951 –
July 22, 2005

LAUGHTER *lightens the heart*

By Rose D'Acquisto, Donor Wife

WHEN MY HUSBAND TONY DIED, my heart was so heavy it sometimes hurt to breathe. My co-workers, who saw my pain every day, did whatever they could to make me smile. One day, Cathy, a graphic designer I worked with, placed a whoopee cushion on her chair. As she sat down, she proceeded to make faces to match the noisy, embarrassing sounds that came from her seat. I felt like a seventh-grader laughing during a sex-ed class. If I'd been drinking milk, it would have spurted out of my nose. At that moment, my heart felt 10 pounds lighter. Laughter can do a lot.

Laughter is good for health.

Research shows there's a strong connection between stress and illness. Laughter can lower blood levels of cortisol and epinephrine, "stress hormones," which can have a damaging effect on the body if they remain elevated over an

Laughter is just another release, a "heart vacation" that lightens our grief journey for a moment.

extended period of time. The immune system benefits because laughter stimulates the increase of natural "killer cells" that attack abnormal cells. And, the mood lift we feel after laughing comes from the release of endorphins,

powerful "pain blocking" molecules that come from the brain's dopamine reward centers.

Laughter is good for healing.

When I was a kid, I never understood why sometimes I'd have the impulse to laugh when I saw a friend get hurt from taking a spill on a bike. I certainly didn't think it was funny. I've since discovered that there's a fine line between tears and laughter. Both serve as a release of emotions. After someone we loved has died, we can sometimes feel guilty about enjoying ourselves and laughing, but laughter is just another release, a "heart vacation" that lightens our grief journey for a moment.

Laughter is happiness.

At the 2007 National Donor Recognition Ceremony, I had the privilege of hearing laugh-out-loud funny stories from donor

families about their loved ones in the "Laughter Lightens the Heart" sharing session. It confirmed something I've come to believe: with the shock of sudden death, it's as though our grief takes on a circular pattern. We go over and over

details that will never make sense in our minds. I think laughter helps break that pattern and allows all the sweet, funny, joyful and happy memories to come back into our minds. These are our treasures—our most precious memories of all.



"People Like Us" today!

"People Like Us" members are:

- Educating elected officials and government about chronic kidney disease and the unique needs of patients, organ and tissue donors, and transplant recipients.
- Encouraged to participate in the public policy process at the federal, state and local levels.
- Engaging the media by putting a face on chronic kidney disease, donation and transplantation.

Join "People Like Us" today—it's free! Visit www.nkfpeoplelikeus.org or call the National Kidney Foundation toll-free at 800.622.9010.

DONOR FAMILY *voices* *Laughter and memories*

BOTH TEARS AND LAUGHTER ARE HEALING. Are there happy memories of your loved one that make you smile? Do you have any funny stories you like to share? When you're feeling especially blue, what cheers you up?

Editor's Note: We asked families these questions on our donor family e-mail list; some of their responses follow. Please visit www.donorfamilyforums.org to read the full responses or to share your own experience. To join the e-mail list, write to donorfamily@kidney.org and ask to "Join the NDFC e-mail list."

When my daughter played basketball, she was always looking for a team member to throw the ball to; she was a team player. When she died on her 16th birthday, her death brought a second chance to many others. Even in her death, she was willing to pass the ball (her life) to others.

— *Larry McMillin*



I think about my handsome Eric every day! He was so funny and paid the price for making everyone laugh. The grade school he attended called us on a regular basis to come and get him. The final straw was when he and a friend put a frozen hamburger patty in a classmate's locker over Easter break. The smell was awful. His friends still talk about how he always made them laugh.

— *Diane M. Knotts*



Tommy had a dry sense of humor and most of the time he didn't know he was funny. Once he told his friends, "I have to watch what I do because my mother is on a first name basis with God." Until we are together again, I will always smile when I think of him.

— *Anna Parham*



One day, Jason visited his grandmother at the senior home when they were playing Bingo. From the rear of the room he yelled out "Bingo" and everyone threw in their cards, thinking there was a winner. His friends continue to tell funny stories about the crazy things he did. I know he's hanging out with the angels and filling heaven with laughter.

— *Yvette Segarra*



At age 20, Aimee was a total coordinated fashion pack-age. She never walked out the door without her hair, make-up and clothes completely perfect. We would giggle because even when going to the pool, her earrings, necklace, eye shadow, lipstick, bathing suit, sandals, beach towel and beach bag were all the same color! It has been 14 years, but we miss our perfectly coiffed blonde so much. We still laugh and cry at the same time.

— *Steve and Leanne Doud*

Julian's daughter Tatiana is his legacy. She is so much like him with a quick wit and ready smile. I am comforted whenever I am around her. She still has conversations with her father and tells me that he tells her things. I don't doubt it and am comforted because she remembers him and he lives in her.

— *Barbara Weston*



Remembering Bob's Big Fish Smile... One afternoon many years ago, we went fishing with Bob, my godson. "Oh! Bite on the line." It was a big one, 22 lb., 7 oz. As it came into the boat we all cheered and laughed. We had all caught fish before, but none with as much fanfare. I can still feel Bob's smile today.

— *Katherine Golden*



When I'm missing Josh, I listen for his laugh, envision his smile, and think about him instigating food fights and wrestling matches. When he was 18 he went to visit his brother and it was traumatic for me to have him leave home, even temporarily. As was tradition, I gave him a copy of Robert Munsch's book *Love You Forever*. He said "No, mom, you have to sing it to me like you did for everyone else." So reluctantly (because I knew I would lose my composure), I did. As I read and sobbed, he laughed and held me close. By the time I was finished, everyone was laughing, including me—in between sobs of course. When I'm feeling blue, we go to the waterfall where he died and have a picnic with the family, play in the mountain stream, climb the falls and write him love letters. Then, we either burn them and watch the smoke rise toward heaven or inscribe them on helium balloons and let them go.

— *Mary Tate Elbell*



I think back to our first date and first kiss. We were both so shy. It took three months of dating before we finally kissed. It was magical; I saw fireworks. We were married 21½ years before he was taken from me by a heart attack. People said that we acted like teenagers in love, no matter how long we had been married. He was my one true love.

— *Michele Simmons*

THE U.S. TRANSPLANT GAMES *isn't just for transplant recipients*

THE U.S. TRANSPLANT GAMES is the only national athletic competition for recipients of solid organ transplants.

Transplant recipients compete in events like basketball, swimming, cycling, track and field, volleyball, bowling and tennis during the four-day event.

The Games is the largest gathering of transplant recipients in the world. It showcases the success of transplantation, highlights the importance of donation and honors the thousands of selfless acts of love from donors and their families all over the world.



The Games give transplant recipients an opportunity to thank donors for their gifts.

But the Games isn't just for transplant recipients. Hundreds of donor families also attend the Games to cheer on the transplant athletes and see first-hand how their loved one's donation has changed lives. There are many special activities and events for families to share with one another to find support and understanding, and honor their loved one in creative ways. The highlight for many families is the Donor

Recognition Ceremony, a chance to honor loved ones and remember their life and legacy. The Ceremony includes a video tribute to all donors whose families are in attendance. Families will have an opportunity to write a tribute to their loved one and view *Patches of Love, the National Donor Family Quilt* in its entirety.

The Games will also feature a hospitality suite for donor families, educational and supportive workshops, a coffeehouse for families who want to share their story and a Quilt Pinning Ceremony. Workshops and sharing sessions for donor families will include: Making a Quilt Square; Understanding Brain Death; What to Do with Our Memories (a creative art session); The Power of One; Finding Good Along the Grief Journey; Movement for Mind, Body and Spirit; Grief, Loss and Spirituality; Writing Your Way through Grief and Loss; Laughter Lightens Your Heart; and more.

Donor families will march into the Opening Ceremonies together, after the transplant athletes and living donors. There are no words to describe the impact of seeing hundreds of donor family members enter the arena and hearing the applause from all the transplant recipients, family members and friends in the audience. Donors and their families are, after all, the ones who make the Transplant Games possible.



From left to right: Erin Brenner (liver recipient) and Bailey McCullough (heart recipient), both age 6, celebrate their successes in the 25-meter dash at the 2006 Games. Erin won a silver medal and Bailey won a bronze medal.

Photos: Eric Miller



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Please join us for the
2008 U.S. TRANSPLANT GAMES
July 11–16, 2008
Pittsburgh, PA

For more information about the Games,
visit www.transplantgames.org
or call
800.622.9010

THE DAY *that changed my life*

By Chandler England, Donor Brother

Note: Chandler wrote the following when he was 16 years old. Today, at age 22, he says, "After six years, I still think about what happened every day, some days more than others. My faith helps, along with knowing that though my brother is no longer with us, someone else has the chance to live because he donated. My approach to life has changed in a positive way. I try to think, how would I want to be remembered if I passed away suddenly? Would my loved ones know I really do care about them? This has helped me to set the important things first: family and friends."

"TURN OFF THE TV," my Dad said in a voice full of shock and disbelief. "There has been an accident. Riley's been killed."

The whole world stopped. I stared at the wood floor for what seemed like days. I was trying to comprehend what he had just told me, but the words did not make sense. This sort of thing didn't really happen to people like us. It only happened to people on the news, and the news wasn't real life, was it?

"I have to see my Riley," my mother said. She could barely get the words out. I still hear those words echo in my heart to this day. We rushed to the hospital. The ride there was cold and dark with few words spoken, but with many tears shed. When I saw my dad begin to cry, it was really hard for me to hold back my tears. He was the strong one, stern and confident. I began to worry a bit then.

We arrived at the hospital and were led down endless hallways. I was scared. "When will we get to see Riley?" my mom asked the nurse. "Just around the corner," she replied. It felt like we were in a labyrinth of hallways.

I began to think about how my older brother Riley would look

when I saw him. He was 21 years old. I didn't know what to expect. Riley was my idol; the one I aspired to be like. The nurse finally revealed our Riley to us. No tubes, not mangled, just cut and bruised a little. I will never forget the feeling I had when I touched his hand. He was no longer in his body; he had moved on to something better.

That night after everyone had gone home, I couldn't sleep. I was scared of death. It just took my brother. I became increasingly frightened of it. It can happen to anyone, anytime. I realized life is fragile; it is given and taken very easily. You are never guaranteed a tomorrow.

I began to think—what if everything I had been taught my whole life was wrong? My whole life I had proclaimed that there is life after death. Did I really believe that after this incident had happened? Did I believe in heaven, in hell, in God, in Jesus? I was terrified that my whole belief system could be proven wrong. Then what would I do with myself?

I was scared this event might have a bad effect on my family and our relationships. Maybe this would push us apart, make us despise one

another. I was scared this could cause tension between my parents and they would get divorced. I didn't want these types of changes in my life. I liked my life as it was. I liked how I interacted with my family and friends. I liked how I lived every day knowing I had a tomorrow, but then I realized this philosophy was not true.

That night was the scariest of my life. I tossed and turned to try to fall asleep. I eventually did, but it seemed like I was awake for months. In the days and months to follow, I was confronted with all these fears. The funny thing about the whole situation is I thought death would

*Riley was my idol;
the one I aspired to be like.*

change my life for the worse. I thought it would ruin my family. The truth is it did change my life, but for the better. It brought my whole family closer, it showed me what true friends really are, it reassured my faith and I am as happy as I have ever been in my life.

Death causes you to think you are alone or will become alone in this life, but in reality, you become closer to others.



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.

2008

April 26 Modesto, CA, California Transplant Donor Network, *Celebration & Remembrance Ceremony*, Trace'e L. Harris, 209.613.7266

July 11-16 Pittsburgh, PA, National Kidney Foundation, *2008 U.S. Transplant Games*, Marilyn Jones, 212.889.2210

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.

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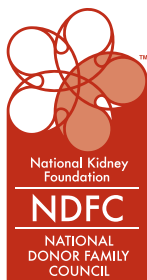
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The mission of the National Donor Family Council is to enhance the sensitivity and effectiveness of the organ and tissue recovery process, to provide opportunities for families to grieve and grow, and to utilize the unique perspective and experiences of these families to increase organ and tissue donation.



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