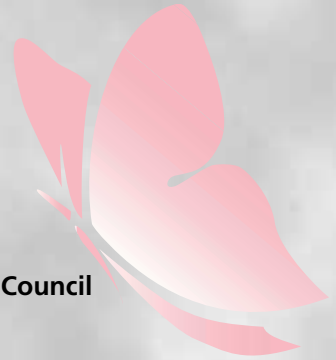


For Those Who Give and Grieve



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

For Those Who Give and Grieve is provided to all families at no cost.

Fall 2003

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

Volume 12, Number 2

mystery: white crows and *extraordinary experiences*

By Ben Wolfe

Have you ever seen a white crow? Crows are large flocking birds recognized by their solid black plumage and their distinctive cawing. If crows are black, how can anyone see a white crow? If you saw a white crow, how would you explain it? Would anyone believe you? Scientifically, it is impossible to see a white crow: Black crows are the only crows in existence.



touch, smelling a fragrance, hearing a voice or seeing the deceased or meeting the loved one in a vision or dream. Messages are also received in symbolic ways, such as finding an object associated with the deceased, unusual appearances of animals or other unexplainable

“Something unexplained, unknown,” is how *Webster’s Dictionary* defines a mystery. Scientists say only what we can *see* and *prove* is real. If what scientists say is true, how do mourners explain, after the death of a loved one, the occurrence of Extraordinary Experiences (EEs)? How do those who have had Near Death Experiences explain to others what happened to them?

What are Extraordinary Experiences (EEs)?

According to Lou LaGrand, PhD, author and professor emeritus at the State University of New York at Albany, “EEs [occur when] a person believes he or she

has been spontaneously contacted by a deceased loved one. It is important to emphasize that the living person is not actively seeking to make contact with the deceased; the experience does not in any way involve a psychic.

“EEs [occur when] a person believes he or she has been spontaneously contacted by a deceased loved one.”

Although a contact experience may occur at any time, it commonly takes place when one is mourning the death of a loved one and [the experience] becomes the basis for the bereaved person to deal with the loss and begin the task of integrating it into his or her life.

“EEs include sensing the presence of the deceased, feeling a

touch, smelling a fragrance, hearing a voice or seeing the deceased or meeting the loved one in a vision or dream. Messages are also received in symbolic ways, such as finding an object associated with the deceased, unusual appearances of animals or other unexplainable happenings that occur at or shortly after the moment of death. Several combinations of the above phenomena may occur within weeks of the death or over a period of years.”

Is this about faith? About spirituality? About a belief system that needs to be proven? Or is it about finding some meaning that comes from having an EE? One’s “grief work” is not complete if the griever has had an EE, and EEs do not take away the pain of the separation between the mourner and the deceased. EEs ask us to revisit what we only have “assumed to be true.” They may reinforce our beliefs, thoughts and assumptions

continued on page 2

mystery: white crows ...

continued from page 1

or they may challenge us to continue asking new questions—questions we once thought unimaginable.

Not everyone has EEs after a loved one's death. Is there something wrong with me if I haven't had an EE? LaGrand says, "Maybe you have had them but did not realize at the time it was an EE! Maybe it is just time to talk about them with others and be willing to share what you feel has taken place. Or, maybe you just don't need them."

We don't know what lies ahead, what mysteries exist, but we have opportunities today to create continued meaning in our lives and to maintain a connection with those we care about.

The original version of this article was published by the SMDC Grief Support Center, Duluth, MN, Grief Notes Volume 18, No. 1 – Winter 2001. Reprinted with permission from the author.

About the Author

Ben Wolfe is the Program Director/Grief Counselor of the St. Mary's/Duluth Clinic Health System's Grief Support Center in Duluth, MN, and a member of the NDFC Executive Committee.

design the new "Gift of Life" mug

WE NEED YOUR HELP!
We want YOU to design the new logo for our "Gift of Life" ceramic coffee mug. The winning design will be printed on the new mugs and sold at the 2004 U.S. Transplant Games in Minneapolis. So let your creativity flow—just make sure your design will fit onto a regular-sized, ceramic coffee mug.

Please submit your mug design to the address below by November 23, 2003:

National Donor Family Council
Mug Design
ATTN: Sarah Revere
30 East 33rd Street
New York, NY 10016

If you have any questions, please call 800-622-9010

or e-mail

donorfamily@kidney.org

The winning design will be unveiled in the Winter 2004 issue of For Those Who Give and Grieve.

FOR THOSE WHO GIVE AND GRIEVE

For Those Who Give and Grieve is published quarterly by the National Donor Family Council of the National Kidney Foundation (NKF). Opinions expressed in this newsletter do not necessarily represent the position of the National Kidney Foundation. The NKF reserves the right to edit all submissions. Please contact the NKF for article submission guidelines or permission to reprint articles.

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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

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what helps *when it hurts*

Rock Therapy

By Rose D'Acquisto, Donor Wife

As the first anniversary of my husband Tony's death approached, I felt a sense of dread. I wanted to be far away from home, my job and mostly my life.

It was my sister's idea that the two of us take a trip. Leanne was living in Europe at the time, while I was living in St. Paul, Minnesota. Later she would confide that my deep sadness worried her. She thought a trip might help. I wasn't sure if I could even pack a suitcase. It meant having to think of details, like remembering toothpaste.

"I think I want to be near an ocean," I told Leanne.

"What about Martha's Vineyard?" she replied.

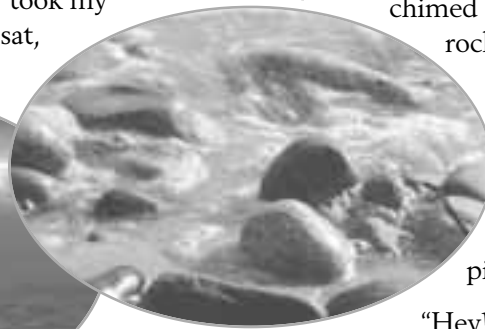
We met in Boston and drove to Martha's Vineyard. On the morning of September 25, Leanne and I packed a bottle of wine and some cheese and crackers and drove around the island until we found ourselves at Gay's Head, now called Aquinnah. Tucked below brilliantly colored cliffs that still belong to the Wampanoag tribe, we found a long stretch of beach. I spied a large hunk of driftwood, which seemed like a good spot to spend the afternoon.

Trudging slowly in the soft sand felt like a fitting metaphor for the past year of my life. Moving forward seemed impossible, like I wasn't getting anywhere for all of

my effort. But before we knew it we were at the driftwood. We stared at the dark blue ocean rolling endlessly in front of us. At that moment, the clouds parted and a beam of light shone on the water. Leanne and I looked at each other.

"It's a God sky," I said in amazement.

My sister took my hand as we sat,



remembering in silence. The sticky, salty air matched the tears that slid down my cheek. I thought about Tony and how we were supposed to grow old together. We were only married for five years. I was cheated.

I stood up and walked to the ocean. Cupping my hands to my mouth, I yelled, "Nooooooo!" into the roar of the waves. It was the "no" I had been holding inside from the moment my world spun out of control at the hospital.

I picked up a rock and whipped it into the water as hard as I could.

"That's for taking Tony too soon!"

Leanne came over and joined in. "This is for Mom and Dad's divorce!" she yelled as she also threw a rock.


We kept up our rock therapy for a while, getting punchy as we went along.

"This is for those dorky gym uniforms we had to wear!" Leanne exclaimed.

Good one, I thought. "Me too!" I chimed in, throwing two rocks.

As we cleared the beach of rocks, a cheeky seagull snatched a stack of crackers from our picnic and ran off.

"Hey!" I yelled. Leanne and I laughed at his boldness. We each kept one eye on the seagull and took turns chasing him when he returned to steal again.

Sitting beneath the red and yellow cliffs, gazing at the sunbeam that still shone on the ocean, I was lulled by the rhythm of the waves crashing against the shore. Suddenly, I understood how I could face a second year without Tony. Just like the ocean, I realized that my grief would continue to come—and go—in waves, sometimes pounding wildly, sometimes slapping faintly against my heart. I knew that as I learned to feel their rhythm, I could also find peace. 

honoring the *Gift of Life*




MORE THAN 500 LIVING DONORS and donor family members turned out on July 12–13 in Washington, D.C., for the eighth National Donor Recognition Ceremony and Workshop. The event was sponsored by the Division of Transplantation, Health Resources and Services Administration, U.S. Department of Health and Human Services, with assistance from the National Donor Family Council of the National Kidney Foundation and other national and local organizations.

The program opened on Saturday with welcoming speeches and guest speaker Darcie Sims, who brought tears and laughter to the audience as she shared her thoughts about honoring grief. During the afternoon, donor families participated in workshops and sharing sessions that included “Communication Between Donor Families and Transplant Recipients,” “Rediscovering Joy,” “What To Do With Our Memories” and many more.

The weekend included a display of the National Donor Family Quilt (see page 6) in its entirety, and families brought photos or poems of their loved one for a large picture board. A hospitality room also was provided to give everyone the opportunity to gather and share stories.

On Sunday morning, families gathered for the quilt pinning ceremony, where two more quilt panels were filled with new patches of love. At noon, the Donor Recognition Ceremony was held in the Grand Ballroom to pay

tribute to our nation’s organ and tissue donors, living donors and marrow donors. The ceremony was moderated by Kenneth P. Moritsugu, MD, MPH, Deputy Surgeon General, who is also a donor husband and donor father. Following the tributes, each donor family and living donor was presented with a white silk rose and a medal of honor while a beautiful video presentation shared photos of loved ones who gave the Gift of Life. Everyone was invited to a reception following the ceremony. 

in remembrance

We would like to thank the following families who have made contributions to the National Donor Family Council in honor of a loved one who gave the Gift of Life.

In Memory of Ronald Wahl:

Nancy Tallo
Sandy and Irv Levy
Teri and Alan Cohen
Linda Dolley
Arleen and Bill McGuire
Paul and Barbie Rothfuss
Susan and Jay Kaplan

Christopher Petrillow—by Laurel
and George Frey

Miriam Gilson—by Joseph and Carolyn Piranio



we fondly *remember*



Melissa Militello
1977–1995

donor families invited to *U.S. Transplant Games*

By Dan Manley



THE U.S. TRANSPLANT GAMES, *presented by the National Kidney Foundation (NKF), is the largest sports event in the world for people who have had life-saving organ transplants. Held every two years, the Olympic-styled 2004 Games will take place at the University of Minnesota campus from July 27 to August 1. The honorary chairman for the 2004 Games is Nobel Prize winner Dr. Joseph Murray, who performed the first successful kidney transplant in 1954.*

Events at the Games range from a ball toss to track and field to golf and team sports, including some pretty intense basketball and volleyball. (Hey, they play to win!) Organ transplant recipients of all ages may participate, so you might see someone's grandmother—or grandchild—on the winners' platform.

While the athletic events are designed to celebrate the recipients' second chance at life, the Games themselves also honor those families whose decisions to donate made that second chance possible.

The Opening Ceremonies for the Games include the athletes' procession, the lighting of the torch and a tribute to donors. After the athletes enter the stadium, donor families enter and march with the National Donor Family Quilt while participants show their respect and recognition to those who made the sacrifice that enabled these athletes to compete.

There are many other events for donor families, including the Quilt Pinning Ceremony for families who want to add a "patch of love" to the National Donor Family Quilt. Giving, Grieving, Growing™ workshops and sharing sessions offer families a safe haven for

sharing and learning. I would never pretend to know how another person feels about his or her loss, because that person does not know how I feel. But just being in the company of others who have shared similar experiences can be more helpful than you can imagine.

Donor families may also wish to participate in the Coffee House, where they can share stories, poems or songs with other Games participants. Families can also participate in the Donor and Recipient Golf Outing and the 5K Race for Organ & Tissue Donation Awareness.


All Games participants are invited to the Donor Recognition Ceremony, a special tribute to individuals who donated organs or tissues at the time of death. The ceremony features reflections from donor families, recipients and professionals, a video tribute to donors and more. There is also a separate event honoring living donors.

The primary focus of the Games, however, is watching the athletes compete and cheering them on. The participants in these Games demonstrate that the gift of life is not merely an extension of a lifetime, but a second chance to

live life. Aside from the events, there are times when donor families and athletes get together for socials and fun—you know, *living*.

So how do you participate? To receive updates on the planning of the U.S. Transplant Games—"The National Celebration of 50 Years of Transplantation"—send an e-mail to transplant@kidney.org or call the National Kidney Foundation at 800-622-9010 to inquire about who is organizing a team from your state or area.

While not everyone can travel to Minneapolis next summer, they can still participate in the organization and fundraising for their area team or help recruit athletes. Believe it or not, many eligible transplant recipients aren't aware of the Games or opportunities for participation in local events.

The U.S. Transplant Games are designed to raise awareness of both sides of organ donation—those who give and those who receive. While it produces somber moments for the donor families at times, it also produces a unique euphoria as you realize the gift given was received and used gratefully. 

About the Author

Dan Manley, donor father and contributing editor, lives in Tulsa, Oklahoma with his wife Cheryl. After the death of their daughter, Amanda, in 1996, they became involved in the U.S. Transplant Games as Donor Family Liaisons for Team Oklahoma.



perspectives

In the Spring 2003 issue, donor mom and contributing editor Pat Brown wrote an article entitled "Why Not A Thank You?" The following letter was written in response to this article.

Dear Pat:

Thank you for your heartfelt message. As the incredibly fortunate recipient of the gift of a liver, and more so because I had acute liver failure and the odds were stacked higher against me than those on the "list," I want to say thank you. A huge thanks to you, your family and your son. You are my donor family, as is every other family out there, regardless if they hear or never hear, or meet or never meet, their recipients.

You covered all the bases in your article. Obviously, you have heard or read the excuses given by many (certainly not all) recipients about not writing that simple note. I hear them all the time.


I tell everyone to write and accept no excuse—it is the duty and obligation of each of us to say "thank you" at least once. If words are too hard to come by, there are

transplant process. Many of us, as you wrote so well, need to hear kind words and be reassured that what we have done is right, that our decisions were worthwhile. I

Many of us, as you wrote so well, need to hear kind words and be reassured that what we have done is right, that our decisions were worthwhile.

very nice cards with thoughtful wording.

Sometimes a transplant center, doctors and coordinators actively discourage letter writing, do not promote it or fail to forward their recipient letters to the local organ procurement organization. The giving of thanks through an anonymous letter should be an integral part of the organ

encourage all medical professionals to counsel their patients on their duty to their donor and that person's family. 

About the Author

Alex Whiteaker received a liver transplant in 1997 and is a member of the National Kidney Foundation's transAction Council Executive Committee. He lives in Brooklyn, N.Y.

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.

2003

- | | |
|------------------|---|
| September 28 | Syracuse, NY, Finger Lakes Donor Recovery Network, Donor Family Celebration, Susan Michaels (315) 425-1569 |
| October 5 | Oklahoma City, OK, Oklahoma Organ Sharing Network, Donor Family Recognition Ceremony, Terry Weir (405) 840-5551 |
| November 2 - 7 | Knoxville, TN, Tennessee Donor Services, Kathy Richards Thanks For Giving Ceremony, (865) 588-1031 |
| November 16 - 22 | Atlanta, GA, LifeLink of Georgia, LifeLink Donor Family Service of Remembrance, Michelle Duke (800) 544-6667 |
| November 23 | San Diego, CA, National Kidney Foundation San Diego, Great Chefs of San Diego, Mary Bauer (619) 521-5878 |
| November 23 | San Antonio, TX, Liz Palmer Donor Awareness Sunday (210) 654-0608 |



The quilt is created from squares made by donor families in honor of their loved ones. It travels in sections 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 person hosting the event.** 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 would like information on how to contribute a square, please call the National Kidney Foundation at our national toll-free number (800) 622-9010. Information about the quilt can also be viewed on our Web site at www.donorfamily.org

angels gain *an all-star*

By Don Huebscher



KRISTI'S SELECTION to the "all-star" softball team was a no-brainer. She could hit, run and throw, but best of all, she loved to play catcher—and she was good at it. We had a pretty good tournament season, winning 10 out of 12 games. One of the games was a 1-0 heartbreaker. Kristi also streamlined the job of recording the team's batting order. We simply marked her in the number 2 spot in the line up and told her to put on her gear. A smile and a nod and she was on her way to the plate.

One thing I could never impress on Kristi was that striking out wasn't the end of the world. She absolutely hated striking out and often took it hard. I could relate. When I was 12, I hated striking out too.

I always meant to tell her that as long as she tried her best and didn't give up, she would never fail. I wanted to tell her that she may not always hit the ball, but people who give it their best shot—as she always did—are never losers.

Painfully, I'll never get to tell her. Kristi was killed in a car accident in 1998 while crossing a busy highway on her bicycle. When I heard the shocking news, I sat back and tried to soften the anguish by thinking about the good times, the laughter on the bench, the celebration after winning two tournaments and about the "hard-nosed" catcher who hated to lose. Mostly, however, I thought about a nice young lady, so full of life, whose smile was infectious. I also pondered why it takes such a

terrible tragedy to realize the insignificance of so many things in life that we spend too much time worrying about—like the outcome of ball games.

This much I do know: Heaven has picked up one heck of a catcher. She bats second for the angels.

This story by Kristi's softball coach was submitted by Caroline Kortness. Kristi Brummond, who died at age 12, was an eye and heart valve donor. In her memory, her classmates wrote grants and worked with the City of Eau Claire to obtain funding for a highway underpass that would provide safe access to school for other students. The WDOT awarded the City \$400,000. Construction for the new underpass began in spring 2003.

thoughts from *donor families*

The Decision

By Joy Cunutt, inspired by son Jason

Thanks Mom for your decision,
I'm really proud of you.
For you did something wonderful,
You knew I'd want you to.

We come to this earth to show love,
And to give as much as we can.



Jason Cunutt
1974–1999

You made the decision to give part of me,
Knowing I'd help my fellow man.

I know that sometimes there's still sadness,
And you really miss seeing me.
Know that I'm always with you,
Just not physically.

You wear the green ribbon pin proudly,
And love for someone to ask.
To tell them your son was a donor
Is part of your work and task.

Mom, where I am now is wonderful,
It's beautiful, I don't have a care.
Remember, don't take your organs and
tissues to heaven.
Cause we don't need them there.

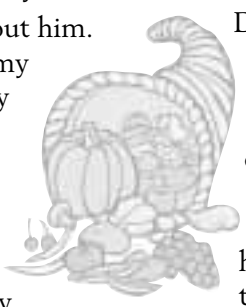


coping through *the holidays*




By Jennifer Cerney, Teen Editor

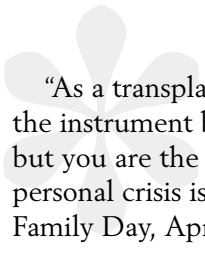
I remember the first Christmas without my dad. I really didn't know what I would do without him. At first I thought that I would just stay in my room and feel sorry for myself, but then my mom came in and talked to me and finally got me to come out. We lit a candle in remembrance of him, and have every year since then. For Thanksgiving, we go to my Grandma Cerney's house for a huge feast. When we sit down to eat, we talk about my dad and how much he loved my Grandma's




famous turkey. My dad's birthday was on Valentine's Day so we usually bring him some really pretty yellow roses (his favorite flower) and also a card for his birthday. On Halloween, we carve pumpkins, bake pumpkin seeds and do a lot of other holiday things that my dad loved to do.

All these things and talking to my family about how I feel have helped me get through the hard times during the holidays. You can try them too—maybe they will help you. 

the privilege *of caring*



"As a transplant surgeon, I see the wonders of your gifts every day; you don't. I am truly humbled to have been the instrument by which your loss has been transformed into new lives for my patients. They call me their hero; but you are the real heroes in this work. The courage you have shown by thinking of donation during your personal crisis is true heroism." —Jimmy Light, MD, at the Washington Regional Transplant Consortium Donor Family Day, April 1, 2001. 


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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