



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.

Spring 2010

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

Volume 18, Number 4

EXPECTATIONS OF SPRING: *a message of hope*

By Rebecca Simon, NDFC Executive Committee Member
Family Services Coordinator, Pacific Northwest Transplant Bank

ONE DAY SEVERAL SPRINGS AGO, I met my friend Sarah for brunch. I greeted her with, "What a happy day! The sun is out!" My friend looked up at me and said, "I'm not so happy that the sun's shining." Sarah's father had died in October.

"You're right," I said quickly. "You don't have to be happy that the sun's out." Sarah smiled at me, shaking her head, "I'm not unhappy that *you're* happy." She paused. "It's just hard."

I asked if she wanted to cancel our brunch date and meet another time. She said no.

We talked mostly about her dad. Sarah had gone through his estate with her sister and had found all kinds of books and artwork she didn't know he had. There was a lot of laughter (her father had a collection of miniature wooden

clogs!) and some tears (their childhood artwork had been lovingly stored in cabinets around the house).

Sarah had spent the past winter sitting by the fireplace, watching movies and grieving the loss of her father. The dark winter skies and Pacific Northwest rain had acted as a shield from the hustle and bustle of the world around her. And then came spring with its flowers, sunshine and brunch dates. "I'm just not ready to have that shield go," she said softly.

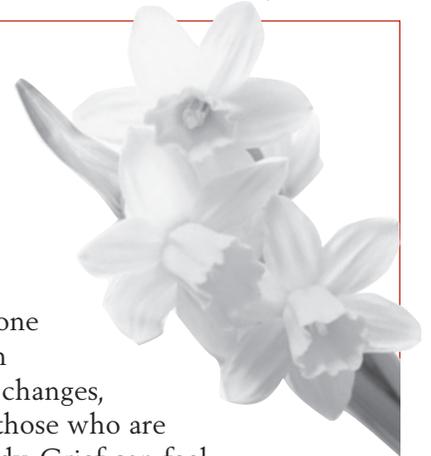
"With the change of seasons comes change in the way the rest of the world continues its day-to-day life."

Sarah reminded me of an often-unspoken addendum to grief — expectation. With the change of seasons comes change in the way the rest of the world continues its day-to-day life. There can be an unspoken expectation that

everyone join in those changes, even those who are unready. Grief can feel overwhelming, frustrating, and so often, isolating. Sarah, like many bereaved people, found that a change of season brought up emotions others might not be facing.

When we left the restaurant, I was heading out to a dog park with another friend and her new puppy. Sarah declined to join me.

She wanted to go to the movies. "It's a PERFECT movie day!" she said as she put on her sunglasses. I hugged Sarah and watched her walk down the street. Her spring season had not begun yet, and that was perfectly okay.



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WE FONDLY *remember...*



Brian Scott Arellano
February 6, 1981 –
March 1, 2003



Geoffrey Todd Corbin
April 8, 1979 –
September 19, 2002



Jennifer Megan Gryzinski
April 7, 1985 –
August 21, 2003



John Henry Massic
March 16, 1966 –
February 13, 2005



Christine "Chris" Owens
June 1, 1929 –
July 8, 2008



Jason J. Strongman
May 4, 1975 –
January 21, 2000



Christine Anne Sutter
July 3, 1973 –
October 21, 2002



Robert K. Taylor
May 21, 1946 –
March 7, 2005



Caitlin M. Thomas
July 25, 1988 –
March 28, 2009



Jemal Wilson Trotter
June 8, 1969 –
November 9, 2008



James Riley Williams
December 25, 1977 –
April 14, 2009



James C. Wilson
October 17, 1978 –
February 3, 2008

For Those Who Give and Grieve

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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 Email: donorfamily@kidney.org

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CARRYING *their spirit*

By Deena Benjamin

Organ Recovery Coordinator, LifeCenter Northwest

IT ALL BEGAN WHEN MY HUSBAND JASON LOST HIS MOTHER to colon and liver cancer.

Jason and I decided to run a half-marathon for colon cancer awareness in honor of his mother. We began training and dare we say, even *enjoyed* running. During the run, we pinned a great photo of his mom to the back of our shirts, along with the phrase “Cancer took her, Love surrounded her, Memories keep her.” I felt like I could do anything with her there. It was a very emotional run, including great laughs when I thought of her and tears when someone would tap me on the shoulder to give me the thumbs up. Crying as I crossed the finish line, I was already thinking of my next race.

My thoughts drifted to the true heroes that I work with—organ and tissue donors and their families. Jason and I both work for LifeCenter Northwest. He is a Surgical Recovery Coordinator and I’m an Organ Recovery Coordinator. After that first half-marathon, I told Jason about my idea of honoring donors and their surviving families whenever we ran a race. I felt it was the least we could do to honor their unselfish act and gift of life.

Our next race was in Vancouver. With the help of our Family

Services staff, we found a donor family willing to participate. They gave us pictures of their loved one, and we symbolically carried them on our backs. It was an awesome feeling, and the support from others we met along the course was tremendous. We have since run another half-marathon in California in honor of a donor.

We planned to run another half-marathon in honor of a tissue donor until appendicitis got in the way. I couldn’t compete, but our coworker Nicole jumped right in and completed the race! Nicole said, “It was a great honor being able to share the donor’s



Deena and Jason Benjamin

“It is both therapeutic and humbling for us to run in honor of donors.”

story with others and carry their spirit with me. I felt pain around mile 9 or 10, but it was easy to push that aside as I was running to honor the donor and their family.” Nicole had a gentleman approach her after the race. “I finally caught up with you!” he said. “I wanted to read your sign...”

It is both therapeutic and humbling for us to run in honor of donors. We hope through our efforts, someone along the race may decide to become an organ

and tissue donor, just like the heroes we are recognizing. Our other hope is that the families that allow us this honor will recognize how much we respect and admire the strength and compassion they were able to show at one of the toughest moments they may ever experience. It is their actions that motivate us to run and their gift that allows us to work in the most amazing career possible. We are now planning our first full marathon in honor of another very special donor.

DONOR FAMILY *voices* *finding comfort*

MANY GRIEVERS GAIN COMFORT by surrounding themselves with special things that remind them of their loved one. It could be an object, such as something they owned, or a souvenir bought together during a vacation. It could be something sensory, such as a piece of clothing that still has their scent, or a song that has special meaning, maybe even a special food that you enjoyed together. When your loved one died, what did you find reminded you of them? What was it about that particular item that comforted you the most? How did you use the item—did you wear it, carry it with you, leave it in a special place, or use it in some other way?

We asked families on our donor family e-mail list these questions; 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.”

My mom Umawatee used to wake me up to see the sunrise or the moonlit sky and one day she roused me up to see this gorgeous yellow full moon. I took out a sketch pad and right at her bedside I started to sketch the scene and she smiled. I continued after her death and now have a beautiful pad of some of the most gorgeous sunrises and moon nights. I've printed these professionally and have hung them around my apartment so each time I see one I can remember her smiling at me drawing the scene.

— Leni Singh

My son Jacob died on 12/1/98. Three months before he died, he had wanted a special jacket, which I now wear whenever it is cold. It makes me feel close to him.

— Phyllis

After my wife Pearl's death, I kept everything the way it was. Six years later, I am still not able to discard most of her clothing and other possessions. I found it very important to keep as many of the belongings of my loved one as possible, because I find the sense of my loved one's presence—especially her scent and her voice—the most difficult memories for me to retain. The keepsake I came to treasure most was her voice on the recorded message on our telephone voicemail. I took comfort in hearing it for more than five years after her death, despite expressions of concern from friends. I only erased it after copying the greeting to a tape that I plan to keep and play for myself when I want to recall her voice.

— George A. Dalley

I lost my husband David three years and three months ago, and I never take off the 20-year eternity band he got me. He was a hunter, and I carry his backpack with all his hunting items in it whenever I go to our camp in South Carolina, even the bottle of water he put in the last time he used the pack. I will love him and miss him forever.

— Sherry Bowen

Judee bought me a gold chain and nugget in 1981, which I still wear today. I never take it off.

— Franklin D. White

I wanted Terry to be close to me at all times and when I felt the need to be close to him. Terry was cremated. I found a special jeweler and a special locket that they put his ashes in, and sealed the locket so he would never get out and get lost. It will be 12 years in March, and I still wear him when I need to be close. Later in life, when the time is right, I will pass this locket on to his sister for her to wear.

— Kathy Snow

As I sit here at my computer, across the room is a chair with my husband's sweater on it. It has been there for 11 years and I see no reason to move it. His presence is felt everywhere in my house, but especially in this office where he conducted business for many years. It's still his room, and I like being in it with that gentle reminder of him. Another special thing I have is a gold bracelet, which I wear every day. When he died, I had our wedding rings melted together and made into a gold cuff bracelet with a symbol we both loved engraved on it. This way I can wear the rings in a way more suited to my life now.

— Terry Murray

For the first three months after my husband's death, I slept with a tee-shirt that he had worn over my pillowcase. It brought me great comfort.

— Darlene Andolsek

When my husband of 25 years died, I put his pillow in the vertical position and sprayed it with his cologne. Then, I would hug the pillow and smell his scent.

— Mrs. Leah Zenker

Nikki was 19 when she went to live in heaven. She had this stuffed puppy called Scamps since she was about 5. Since the first day she left us, I have kept it on my bed every morning. I kiss it and say good morning. On bad days it gives me comfort to hold it. I miss her with all my heart. I know she is pain free and is waiting until we can all be together again.

— Tina Ronning

FROM SON *to mother*

By Delores Benton Evans
Donor Mom and Kidney Recipient

MILLIONS OF PEOPLE have children they are proud of for different reasons. What makes our story unique is the *timing* of when my son did the greatest things.

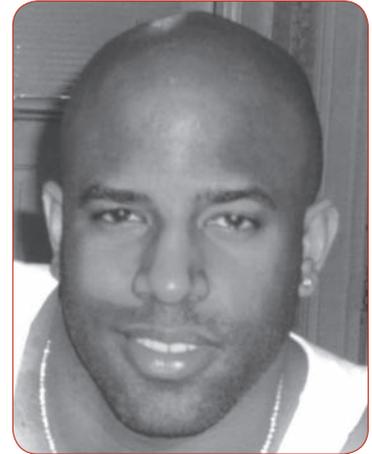
My son's name is Ryan Benton Evans, a very special young man. He was tall, handsome, loving, generous and gregarious.

In high school, Ryan was a star football and basketball player. During a game, he broke the basketball's backboard and years later held his 1½-pound nephew in those same big strong hands. He kept his head shaved like Michael Jordan, had a body like a tight-end football player, and was a kind spirit with the demeanor of a big teddy bear.

Ryan was a doting son, protective of his mother and sister. He fished and

hunted with his father, and he never missed birthdays or spending holidays with his family. He provided shelter for the homeless, sponsored athletic teams and supported charities that help children. He did not accept a college scholarship, opting instead to work with his father and manage the family's food mart business. His proudest time was when he assumed ownership and his father worked for him.

I had been living with kidney disease since the 1970s, but somehow we were able to have three lovely, healthy children. When it was time to get on the transplant list, Ryan and my sister Carol were the first people to volunteer to become donors, but because of a family blood trait they could not. I chose nocturnal hemodialysis, eight



Ryan Benton

hours a day, three days a week. I were asked about donation, we reverted back to how Ryan lived his life—he was gregarious and generous, always willing to help others. We had no idea that I could become the recipient of his kidney, because he was denied earlier as a living donor for me.

“He was gregarious and generous, always willing to help others.”



Delores Benton Evans

hours a day, three days a week. This was preferable because I was not emaciated after treatments and was able to lead a more normal life. I was able to travel and resume some of my hobbies.

Then one day, the unthinkable happened. I am unable to articulate how I felt when I heard what no parent wants to hear: “Your child will not survive.” When we

I still remember Ryan's facial expression when he learned that he could not donate a kidney to me. But I was able to receive his kidney after he passed on, and now I can envision his handsome face with that beautiful infectious smile, pleased that his mother finally received his kidney. Thanks to my son's awesome generosity, many people's lives have been improved and saved, and his mother is strong again.

SPRING *without Jon*

By Christine McGowan

MY SON JONATHAN was killed in October 1995. It was a very long winter, both outside and in my soul.

I was certain I would get some relief when the nicer weather arrived, but that wasn't to be. Spring was an affront to my senses back then, and this poem was one of the first things I wrote during that time.

Over the years, I have written many things about my sweet boy, both poems and prose, and while the actual writing is painful, I always feel better when I'm done. It's my way of keeping his memory and spirit alive. Rereading things from the early years also shows me how far I've come.

Why has Spring come?
Plants are blooming so new.
They insist upon growing
In a world without you.

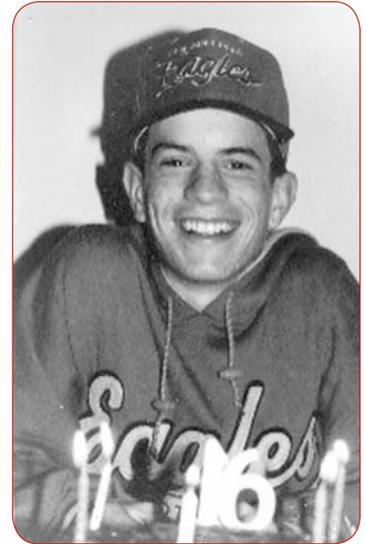
It should still be winter
When the cold winds blow.
With the sky black and gloomy,
My heart tells me so.

I lost my Spring fever
And most of my joy.
I hear no birds singing,
Since I lost my sweet boy.

The clouds aren't as fluffy,
The sky not as blue.
Even the grass
Has a somber hue.

My perception of nature
Is not what it should be.
Colors aren't as vivid,
Flowers have little beauty.

We shared the joy of nineteen springs.
I struggle to remember each one.
Back when life was normal,
With little league baseball and fun.



Jonathan McGowan

Perhaps in time I'll change,
And the world won't seem so bleak.
My coping skills will improve
With the peace of mind I seek.

My heart will never heal
This fact I know is true.
But I'll learn to go on living
In a world where there is no you.

OUR *Revelry*

By Jeff Dauber, Donor Father



Miranda Grace

**LAST YEAR,
MY WIFE
AND I
designed an
outdoor garden
in front of our
home** to honor

the legacy of our daughter Miranda Grace, who died in 1998 at two months old. She was a heart valve donor.

The garden contains flowers,
hanging antiques, wind chimes

and old items like a wagon wheel from the family farm. We have a fountain that depicts a small girl crouching by a pond with her hands cupped, catching a stream of water flowing from a fish's mouth.

At night, white strands of lights and tiki torches illuminate the garden. The bench area is pointed like an arrow and faces north (as though it were pointing to heaven). We also use the area to feed the many wild birds that live in our woods. Miranda's "zen" garden is a very special place for us.

Inspired by the garden, I wrote the following lyrics last summer:

"OUR REVELRY"
I can hear the deep of the wood
I can hear the highway rolling on
I can hear church bells, solemn in the rain
And I can hear every word that you will say
I can see the sky after the sun
And I rely on the coming up
I concede all further battles tonight
I can see your shadows in the light
And by the full of the moon, the fish and the girl
Share secrets
Of certain revelry, our revelry
Our revelries.

WRITING AS A WAY OF DEALING *with grief and loss*

By Claude Sampson, Donor Father

IN 2005 WHEN MY SON JEFF, aged 19, was killed in a traffic collision, his death was so sudden and unexpected that in addition to the shock and grief one normally associates with the death of a loved one, I felt a huge void over no longer being able to simply talk with him. He was a college student who still lived at home, and like most college students, he worked afternoons and into the evening. We found time to talk every day and when our time was taken away, I felt the need to “get it out.” Writing seemed the most logical way. I began writing within days of Jeff’s death.

Writing has allowed me to communicate with Jeff, albeit a one-way conversation. I can express my feelings (ie “get it out”). I use a journal and write in freeform style; sometimes I write to Jeff, other times I express anger, shock, dismay, regret—the things one feels after the death of a loved one, often without an outlet to express them safely.

I started writing out of a strong personal need without the benefit of a class, seminar, workshop or even suggestions. Over time I became exposed to things concerning writing through grief. I attended the National Donor Recognition Ceremony in 2007, where I signed up for a writing workshop. Through several websites I learned more.

The most helpful resource has been a book I purchased from Willowgreen.com entitled *The Rewarding Practice of Journal Writing* by James E. Miller. Here are some suggestions for journaling from the book that I found helpful:

Develop your own routine.

- Morning? Evening? Daily? Weekly?
- Find the rhythm that works for you.

Make it easy to express yourself in writing.

- Write in your own natural, genuine way.
- Give yourself permission, if you can, to forget about misspellings, grammatical mistakes, etc.
- Guard the privacy of your journal.

As much as possible, express whatever is within you.

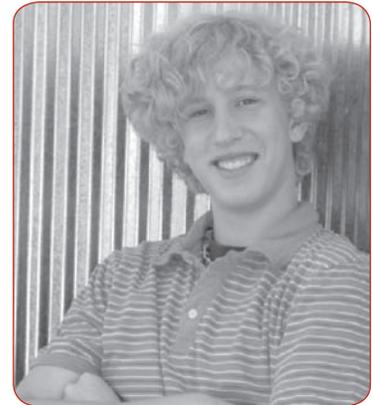
- Don’t hold back. Write what you think and feel; be whoever you are.
- Be reflective if you wish; contemplate.
- This is the place to express your feelings about anything and everything.
- You have suffered a loss; this is your place to verbalize anger, sadness, etc.

Allow your journaling to lead you.

- Follow your inner urgings as you write, whether you understand them at the moment or not.
- Listen to your inner voice; meditate or pray before you begin.

Write honestly.

- It may be hard to write what’s true.
- Some feelings are painful to acknowledge.



Jeff Sampson

Give pen to your soul.

- A journal allows you to write from yourself to yourself and that can be the first step in communicating beyond yourself.

Experiment.

- It is okay and even good to “color outside the lines” in your journal.
- If you are a freeform writer, try writing poetry.

Go back through your journal from time to time.

- Reviewing your past writings will reveal much about how far you have come.

Writing can be very therapeutic. It provides an outlet. Anger, kept inside, becomes stress.

Writing can also keep us close to our loved one. Later we can go back and see how our grief (and our writing) evolved.

After four plus years, I no longer write every day. I don’t feel guilty about not writing daily any longer; I take it as a sign my grief is changing.



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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.

2010

- April 24** Hayward, CA, California Transplant Donor Network, 2010 Honor & Remembrance Ceremony, Trace'e L. Harris, 209.613.7266
- May 1 – 5** Mt. Laurel, NJ, American Society of Transplant Surgeons and American Society of Transplantation, *American Transplant Congress*, Caitlin Dougherty, 856.380.6820
- May 15** Nine Mile Falls, WA, SightLife, *Donor Family Celebration*, Mike Meyer at 509.999.3279 or Lois Parker at 206.838.4625
- July 30 – August 4** Madison, WI, National Kidney Foundation, *2010 U.S. Transplant Games*, Marilyn Jones, 800.622.9010

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.

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.