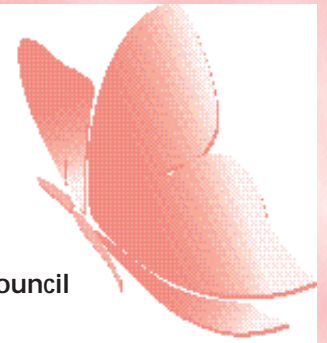


# *For Those Who Give and Grieve*



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 2002

You can visit us on the Web at: [www.donorfamily.org](http://www.donorfamily.org)

Volume 11, Number 2

## *Some Days Will Be Easier Than Others*

By Arlene Barnett

Clinical AfterCare Manager, New York Organ Donor Network

**T**he journey through grief is unique to each person, and although you may share the pain of loss with others, each of you is traveling your own difficult path. Neither time nor circumstances can prevent the sadness from breaking through unexpectedly. Even when it is anticipated, as a birthday, anniversary or holiday approaches, it can be surprising in its intensity. It can feel like a physical blow. Often, the days or weeks leading up to a significant event are harder than the day itself. Sometimes the pain is overwhelming for an hour, a day, a week or longer. Sometimes it is so fleeting, that with a pause and a sigh, it has passed. The real problem is that it is so unpredictable that we cannot prepare ourselves, and some days will be easier than others.

As this season of food, family, hubbub and holidays approaches, it may be a good time to take your emotional temperature. Depending on where you are in your grief journey on any given day, you may find the whole idea of a "celebration" impossible. Or, you may find the idea of not celebrating the holidays unimaginable. Do you think you can prepare a big holiday dinner or even

attend one this year? Are you able to shop for presents, decorate the house, send out cards or do any of the other usual holiday preparations? Is it important to you to do any of these?

Here are a few questions to help you take your emotional temperature:

1. What do you think you are ready for?
2. What do others expect of you?
3. What are your own expectations of yourself?
4. What is your energy level?

You may want to ask yourself these questions several times over a few weeks before you commit yourself to anything. Give yourself permission to sit down with your family and/or friends and let them know what you think you can and cannot do this year. Well-meaning folks may try to convince you to continue all the past traditions and preparations you have "always done." If you find comfort in your family traditions, and think you will have the energy to carry them out—great. If you cannot face the preparation and festivities this year, say so and remember, some days will be easier than others.

It can be helpful to sit down and make a list of all the "usual" things you have done for this season in years past. You may be surprised at how much you have "always done." Many people may expect you to perform as usual and others may think you cannot do anything. Neither is likely to be accurate. Look over your list, either alone or with your family, and mark those items that are too precious to change or give up. Now remake the list in order of your priorities. It will probably be a great deal shorter than the first list. If even making a list is too much for you to do, then this year may be the year you let others do it all.

Too often, family traditions are thought of as unalterable and this can put a lot of pressure on you. The purpose of a tradition is to create comfort and signify a special event. All traditions had a start somewhere, sometime, so why not create new ones, modify old ones, or just drop some temporarily or permanently? Unfortunately, there will be resistance from some people at the mere idea of changing traditions and you may even find

*continued on page 4*

# TEEN SHARING

## *A Valuable Gift*

By Erin Stierwalt

*Dedicated to Tim Boyle of Toledo, Ohio*




**W**hen I was in second grade, my seven-week-old cousin died of SIDS (Sudden Infant Death Syndrome). At a time of such shock, pain, and confusion my aunt and uncle were hardly worried about organ donation. However, after countless conversations with family and close friends they made a significant decision to donate some of Baby Michael's vital organs so that other children might benefit. At such a young age, I hardly knew anything about organ and tissue donation. But I did know that my cousin was a hero because he was giving something of himself so that other "Baby Michaels" could live.

As I grew older, I learned more about organ and tissue donation, but I was never really aware that donating organs could be so crucial to someone's life. Then I met Tim. Tim transferred to my school in the fifth grade, and we instantly became good friends. Tim enjoyed performing on stage, making music videos and having fun, just as I did. Tim and I did have one significant difference though; I was perfectly healthy and Tim suffered from kidney failure.

Throughout fifth grade, our class prayed with him as he struggled through his sickness and hoped to receive a kidney. Tim fought his sickness with courage and strength; his cup was always half full, never half-empty. He missed multiple school days and even more social events. But God was watching out for Tim and everyone's' prayers were answered. Tim received a kidney and his life was saved. An anonymous person saved Tim's life by being an organ donor. Tim was able to enjoy the rest of grade school, have a lead role in his eighth-grade musical, attend homecomings, his cousin's high school football games, watch his brother graduate and enjoy life to the fullest—all because of the kidney someone donated. The kidney unfortunately only postponed the inevitable; Tim passed away in his sleep during his last night of spring break 2002. He was 16 years old.

Now I am a senior in high school without one of my best friends. I realize the immense impact that donating your organs can have on someone's life. Many may think that because Tim died just six years after receiving his organ donation that donation isn't worth it. The people who may believe that obviously never saw Tim during his six extra years. Those years were his happiest because he knew he was very lucky.

"Baby Michael" will always be my hero and I know that someone out there feels that he is their hero too! Organ and tissue donation is a priceless gift. As the holidays approach, I can think of no other gift quite as valuable. 

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## Stories from the 2002 U.S. Transplant Games

By Darlene Aymerich, Donor Mom

**T**he day finally arrived. It was time to leave Buffalo, NY, for the 2002 U.S. Transplant Games in sunny Florida. All the fund-raising had been done, reservations were made and we were ready to go. I went to the Games in Orlando in 2000 for the first time. I was truly amazed to see what the Games were really all about and to meet so many caring, giving people all in one place at one time. I cried tears of emotion at each of the events, and knew that I would return again to the Games.

In February of 2002 I was asked to be the Donor Family Liaison for Team Western New York (Team WNY). I was flattered and excited; I would actually be walking out on the field with all those athletes. How proud my daughter Shannon would be of her Mom. It would be such a remembrance of her, too. I wanted the whole world to know what a wonderful, giving young woman she was and will always be, even after her death.

The other thing that made the 2002 U.S. Transplant Games even more special was that one of the athletes walking onto the field with me was Vickie, the recipient of Shannon's kidney. It couldn't have been more perfect. Vickie is a very special person, not only because she has one of Shannon's kidneys, but also because of all the dedication and hard work she does everyday with the National Kidney Foundation of Western New York and transplant community. She is so vibrant, energetic and full of life. Everyone that knows her loves her, just like my Shannon.

At the Opening Ceremonies our team stood waiting to go out on the field in upper 90 degree temperatures with our long-sleeve, nylon wind suits on that at that time felt more like sauna suits. Other teams, dressed in shorts and tee shirts while waiting and exchanging pins would say to us, "Those suits are really nice but aren't you hot?" And yes, we were

very hot, but we were from Buffalo, so you wouldn't hear us complain about the heat! It was fun mingling with the other teams as we were waiting.

Finally it was time to go onto the field. We all moved towards the gate. As we walked through those gates onto the field, I carried the Team WNY sign with Vickie beside me and all the other excited recipients/athletes behind us, proudly waving the Team WNY yellow foam noodles high in the air. As they announced our team, we looked up into the stands and saw several other yellow foam noodles waving high and proudly too. Oh—what a feeling!

After we got to our seats, I returned to where the donor families were waiting to walk in after all the teams had been introduced and seated in the stands. The "Patches of Love" quilt was being carried in first by some of the donor family members. The rest of us



*Darlene (left, donor mom) and Vickie (Shannon's kidney recipient)*

followed. This time when we walked through the gates onto the field, I felt like I had walked through the "Golden Gates" of Heaven. When they announced us coming onto the field, 8,000 people in the stands stood and cheered for 10 solid minutes. They referred to us as the "heroes" of this event. They said without donor families there would

be no Transplant Games. As we entered the stands, thousands of people still standing and cheering, walked up to our seats and people reached out to touch and thank us for our Gifts of Life. One little boy reached out and said, "Without people like you, my brother wouldn't be alive today, thank you!" Tears filled our eyes, but they were mostly tears of pride; our loved ones had been able to give the precious Gift of Life. My heart was so touched by it all. That was just the beginning of four event-filled days just as moving as the first. It's an experience I will always treasure and never forget. I am eagerly looking forward to attending the next Games in 2004. 🍷

## More Stories from the 2002 U.S. Transplant Games

**B**efore I even got to Orlando, I had a wonderful time on the plane with my flight attendant and a couple of ladies seated by me. We all shared where we were traveling to and why. The attendant asked me what the Transplant Games were, what a donor mom was, and how my Corey died. I shared all this information with her and the other ladies and really enjoyed my flight. I had also told the attendant that I liked the bracelet she was wearing, and that I thought it looked good on her. When we got off the little puddle hopper from Alexandria, Louisiana, to Memphis, Tennessee, the stewardess walked us over to the airport terminal. As we started to walk into the building, she pulled me to the side and told me to open my hand. She placed her bracelet in my hand and said, "This is for Corey's mom." I tried to refuse her kind gift, but she would not allow me. I hugged her and told her to go home and hug her babies.

**By Sue Capps**  
Donor Mom and Donor Family Liaison,  
Team Louisiana.



*Recipients stand and cheer to welcome donor families to the Games.*

Attending the 2002 U.S. Transplant Games and Donor Recognition Ceremony in Orlando, Florida, was a very heart-warming experience. As a donor mom, the Games are the one place I feel I can relate to just about everyone who attends. Sharing stories about our loved ones and listening to others talk of their loved ones is very healing. The hugs from recipients and the understanding from fellow donor families can help you feel that you are not dealing with the death all alone. It's felt with every donor family you meet. I walked away with wonderful memories. All I can say about connecting with some of the recipients who competed is—WOW!

They live life to the fullest and are eager to meet donor families. All of the recipients I had the pleasure of meeting are grateful for the Gift of Life that was given to them and look up to their donors as heroes. Our heroes will be cherished forever.

**By Lisa Groft**  
Donor Mom and Donor Family Liaison,  
Team Maryland.

### *Some Days Will Be Easier Than Others*

*Continued from page 1*

that you are one of them. But, you know that some days will be easier than others and it may be unrealistic to think you can do everything you have done in the past. That is where your list of priorities can help. Enlist the support of those family members or friends who are likely to back you up and be firm with yourself and others.

If some traditional preparations or events are more important to others than they are to you, ask them to take charge of those this year. On the other hand, if something is very meaningful to you and high on your priority list, don't let it go. Be clear about what events you think you can participate in and which ones you know you cannot face. Remember, that even though you think you can do something, when the

time comes, you may find you are not up to it. Grief's unpredictability can make it difficult to know what your emotional temperature will be at any given time. Do not feel guilty about this. State the fact that you are having a more difficult time than you anticipated and cannot participate in or prepare whatever you thought you could.

It can be difficult for some of you to ask for help or admit that you are not able to do everything you used to do. It can be even more difficult for others to offer help, for fear of offending you or just because they don't know what to say or do. If you are able to tell them what you need, you allow them to give you meaningful help. In this season of giving, this is a precious gift to give and to receive. With the love and support of those near and dear to you, this holiday season can be meaningful and comforting, even though some days will be easier than others.

# THOUGHTS FROM DONOR FAMILIES

*Here are some ideas and traditions that some donor families do to remember their loved ones during the holidays..*

**W**hen the holidays come around at our home we often remember our little guy by taking him balloons or something to match the theme of the holiday.

For instance, at Christmas time we take him a little tree with battery-operated lights. Our son's grave is about a 30-minute drive so we don't always make it over there to change the batteries, but he had such a love for Christmas lights. He was two and a half and his last Christmas was the best Christmas we ever had. I can still hear his voice saying, "pity lights mommy, wook it, pity lights," when we would drive by Christmas displays. We also have a garland that has foil cuts of light bulbs that we string on his wrought iron heart that is constantly at his grave. We still hang up his special Christmas ornaments that were either bought for him or have his name on them.

For Halloween, we bring orange and black balloons. These are tied to a weighted Halloween bucket which is decorated with a ghost coming out of a jack-o-lantern.

On his birthday, we take him the number of balloons which coincide with his birthday—last year we took him six purple balloons. (He was also a very big fan of Teletubbies Tinky and Winky, and we therefore give him purple balloons. We usually try to get him a mylar Teletubby balloon as well.) Next year we will take him balloons with notes in them, let them go in the air and try to trace the notes. I hope this helps.

**By Lori & Chad Elness**

**W**e started new traditions for the holidays to honor our daughter Elizabeth (Beth). We bought a Christmas ornament for us and each one of Beth's recipients. It gives me comfort to see them on our tree and to know that Beth gave others the Gift of Life.

**By Sheila Pund**

**O**ur daughter, Elena Hovander, was three and a half years old when she died of a brain tumor in 1996. Since that time we have created these holiday traditions in her honor.

Each year we place a small, artificial tree decorated with ribbons and miniature ornaments on her grave at the same time that we put up the tree in our home. All of us, Elena's father, her older brother Ian and I, also write a letter to Elena sharing our memories and how much we miss her. In the craft store we found clear plastic ornaments that consisted of two semicircles that could be opened and closed. We decorated the outside with glitter and paint and then put our letters inside. We now have six such ornaments to mark the six holidays which she has missed.

I hope this is helpful to those who have to endure the pain each holiday (and each day) of not being able to see the joy and love on the face of their loved ones during family occasions such as Christmas and Chanukah.

**By Patricia Oppenheim Hovander**

## *In Remembrance*

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

### ***In Honor of:***

***Mathew Alburn Woockman*** -  
by Rita and Otto Woockman

***Betty Hart*** -  
by Gwen Hart

## *Donation in the Spirit of the Festival of Lights*

By Elaine R. Berg

**I**n this season, as many faiths celebrate some of their most cherished religious holidays, I cannot help but make the connection between the miracle of Chanukah, the Jewish Festival of Lights, and the miracle of organ and tissue donation.

The Chanukah story involves the desecration of the Jewish temple in a war in the year 165 B.C. When the Jews came back to rededicate their house of worship by rekindling their Menorah (candelabra), there was only enough oil for one day, and the trip to get more was an eight-day trip. The miracle was that the candle burned for eight days, until more oil was obtained. In celebration of this, Jews all over the world light Chanukah candles for eight days. The word "Chanukah" incidentally, means "dedication."



The analogy to organ and tissue donation is clear to me. A candle, or a life, which is about to end, is miraculously transformed into saving the lives of up to eight people. The light continues through others' lives and is carried forward to brighten the world with its life-affirming strength.

Eight lives saved by an organ donor—eight Chanukah candles. Transforming darkness to light. Dedication.

Happy Chanukah to all of our Donor Families. Thank you for bringing more light into our world. 🕯️

*Elaine R. Berg is the president and CEO of the New York Organ Donor Network, New York.*

## *The Quilt on Tour*

*Please note: This schedule is subject to change.*

### **2002**

- Oct. 31-Nov. 5 Denver, CO, Donor Alliance, *Donor Family Tribute*, Carla Talevi, (303) 329-4747
- November 1-11 Atlanta, GA, Life Link of Georgia, Chaplain C.H. (Skip) Wisenbaker, (404) 266-8884
- November 16 Honolulu, HI, National Kidney Foundation of HI, Ken Higa, (803) 373-4125

### **2003**

- March & April Los Angeles, CA, OneLegacy, *Various Events*, Bryan Steward, (213) 401-1226
- April 1-May 1 Alabama Organ Center, Jane B. Geloneck, (334) 271-1690
- April 26 Fullerton, CA, National Kidney Foundation of Southern CA, *Celebrate Life Walk/Run*, Amy Young, (714) 447-7725
- April 26 Riverside, CA, California Transplant Donor network, *Annual Donor Recognition Ceremony*, Tracee L. Harris, (209) 527-6178
- April 26-27 Honolulu, HI, National Kidney Foundation of HI, *Donor Family Recognition and Gift of Life Walk*, Ken Higa, (808) 373-4125
- May 30-June 4 American Transplant Congress, *American Transplant Congress Annual Convention*, Lisa Wagenseller, (856) 642-4401

The quilt is created from squares made by donor families in honor of their loved ones. It travels in sections around the country to pay tribute to loved ones and to raise awareness of organ and tissue donation. **The quilt is not displayed in its entirety, and some events may be closed to the general public. If you plan to attend one of the displays, please contact the 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](http://www.donorfamily.org)

## THOUGHTS FROM RECIPIENTS

### Awakening

By Stephen Blanton, Transplant Recipient  
March 1999-May 2002



*Steve Blanton winning the bronze in the 100-Meter Dash this summer.*

The precious moments of my life  
Like most of us I did not see  
Until I finally realized  
That time was running out for me

A transplant was my only hope  
But donors few and far between  
And twenty dying every day  
While on a waiting list like me

Could not accept the truth at first  
Then anger stole my mind until  
Resigned and sad I set about  
To make amends and write my will

Then I couldn't bear the thought  
For me to live someone must die  
But we can't choose when  
we'll pass on  
Or how or where or reason why

A family I may never know  
Courage breaking through their tears  
Made the choice to follow through  
For someone that they loved so dear

Now every day I live my life  
To try and help my fellow man  
Showing that I really care  
And giving all the love I can.

### Things with Wings for Holiday Shoppers



This summer, the 2002 U.S. Transplant Games saw the first ever "Things with Wings" gift shop operating at the donor family headquarters hotel. Items included a variety of butterfly- and angel-themed gifts for families, friends and professionals.

"Wings" items like the "Kelly" donor bear and National Donor Family Council mugs featured at right make great holiday gifts and stocking stuffers! If you would like to purchase an item, please contact us at (800) 622-9010 or [donorfamily@kidney.org](mailto:donorfamily@kidney.org). Proceeds from all sales help support programs for donor families.

Items for sale include the following (prices do not include shipping):

- "Kelly" donor bear - \$10
- National Donor Family Council mug - \$6
- Bear and mug together - \$15
- Sequined butterfly ornaments - \$5

### FOR THOSE WHO GIVE AND GRIEVE

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# 2002 U.S. Transplant Games Memories

All photos by Sarah Ockler



Donor families receive an endless standing ovation as they enter the field during Opening Ceremonies.



Donor families and living donors march across the field during Opening Ceremonies in honor of those who have given the Gift of Life.



Rain doesn't stop this Team Philadelphia member from cheering on the donor families during Opening Ceremonies.



Donor families decorated paper hearts displayed during the Donor Recognition Ceremony to honor their loved ones.



Donor families carefully guard the National Donor Family Quilt as they prepare to enter the field during Opening Ceremonies.

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



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