

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 2005

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

Volume 13, Number 4

shattered *glass*

By Ben Wolfe, MEd, LICSW

You've probably heard the story of the shattered glass: A window is broken and no matter how hard one tries, the glass, after being glued back together, will never be the same again. When significant events take place in our lives, we will never be who we were before. Significant transition points shatter the glass. Some individuals think they can find all the pieces and glue them back together. Others learn that some of the glass will always be blurred.

Transitions are not always negative, but are instead "windows in time." They remind us that although we want predictability and control in our lives, neither is guaranteed. Life-changing events challenge our coping skills. They force us to re-examine our priorities.

Individuals and families who have experienced the death of a loved one have an entirely different perspective on what the glass looks like today compared to families who have not experienced a death in the family. In addition, for organ and tissue donor families it is often a traumatic death and one that did not allow for the "good-byes" we often think of in a "perfect, good death." Those affected by a traumatic death are reminded at

the time of the death that nothing is for sure. Hopes, dreams and fantasies are all affected. In the future, when new information surfaces about any traumatic death, those who have experienced this trauma before look through the new "window in time" and view the old window as we thought it was. Anyone who is affected by a loved one's death looks back through the old window and asks if they did the right thing. *What could we have done differently? How could this have happened and why?* Everyone looks for answers.

Traumatic deaths are extremely hard to accept due to the shock and suddenness of the death.

Traumatic deaths are extremely hard to accept due to the shock and suddenness of the death. They do not make sense and cannot be understood. We try to reconstruct the events and, as a result, try to change the outcome. There is clearly a sense of loss of security and a feeling that nothing can be trusted again.

At some point in our lives, we go beyond "just coping" with the death to being transformed by the death. At some point, we stop focusing on *What*

I have lost, and focus more on What do I have left and what can I now do about it?



Ben Wolfe

Shortly after a death, however, is the time to share with others our concerns and feelings, to acknowledge our pain and sorrow and to allow ourselves to know we have been changed. There are no time lines for grief.

Many of life's events and transitions are beyond our understanding and certainly beyond our control. Sometimes life, or at least the transition points in our life that shatter the glass, are not only

beyond our understanding—they alter who we are forever. Each new "window in time" will be different for everyone, but at some point in the future, may what you see through it be bright and hopeful.

Ben Wolfe is Program Manager/Grief Counselor for St. Mary's Grief Support Center in Duluth, Minnesota. He is also an Executive Committee Member of the National Donor Family Council.

letter from *the editor*

Ben Wolfe's article about shattered glass reminds me of how I felt when my husband died. As a young married couple, Tony and I dreamed of buying our first home, having children and growing old together. In one swift day, those dreams—like a beautiful stained glass window—were smashed into a million little pieces.

After years of wondering what to do with my shattered dreams, I had a vision. I decided that, metaphorically, I'd gather up the pieces and put them in a new form, one that is fluid and has no predetermined outcome: just like life, a kaleidoscope of possibilities. The dreams Tony and I shared are still a part of the picture; they simply have taken a new shape.



My hope for the future is like a kaleidoscope. It's always moving. It's always changing. I may not know what will come next, but that's what is exciting: knowing that my life holds more possibilities than I ever could have imagined.

Sincerely,
Rose D'Acquisto, Donor Wife
Volunteer Editor

we fondly *remember*

Daddy was very special. He was a good man and loving father. I love him and miss him very much. He is in heaven with others we love.



*William E. Young
March 29, 1937 to
August 23, 2004*

My husband was a very gentle, sincere, caring man. He appreciated being able to volunteer for many causes. For over 48 years he especially enjoyed being Santa Claus and bringing pleasure to people of all ages. William was a wonderful husband and pal, father and grandfather and cared so much for our families. William (Papaw) worshipped our grandson, Jaycob William Young, and loved holding, sharing, and teaching him new things, including catching his first fish. We miss William so very much; his smile, his hearty laugh, his caring words and actions and his hugs and kisses. We love William and are always so proud of him for the precious life he gave to us, and he has given to help others.

*Submitted by Tara Marie Young (daughter)
and Judy C. Young (wife)*

FOR THOSE WHO GIVE AND GRIEVE

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Annie's legacy

oasis of love

By Jill Halimi, Family Services Coordinator, LifeSource

In March 2004, mother and daughter Evie and Jennifer Komarek traveled to Honduras to dedicate a library in memory of Jennifer's daughter, Antoinette, at the Oasis de Amor—or "Oasis of Love"—orphanage. For Jennifer, this was her first trip to Honduras—a land frequented by Evie, who returns each year because she is drawn to the people, especially the children. Antoinette, or "Annie" as her family lovingly refers to her, was also drawn to the children. At the age of 16, after a three-week trip to Honduras with her grandmother, Annie knew what she wanted to do with her life: graduate from high school, major in Spanish, receive a degree in education and work with underprivileged children in Honduras.

Unfortunately, those dreams would never be. Annie died in a car accident on January 20, 2003. Her family, knowing her giving nature, lovingly donated her organs and heart valves, saving the lives of seven individuals. She is deeply missed by her family, as well as the



Jennifer poses with the orphanage children as they display book plates with her daughter's picture.

children of Honduras, who remember her vividly. With the dedication of the one-room library, she will always be remembered. A plaque hanging over the library door reads in Spanish: "Library Dedicated in Memory of Annie Komarek." Bookplates with Annie's picture are inside each book cover. For the children who live in the orphanage, the books are a glimpse into the outside world. According to Evie, the donated books are "healing, allowing the children to dream and explore, taking them to other parts of the world and serving as a friend when needed."

The children of Oasis de Amor have very little. Each child is a victim of circumstance. For various reasons, they have been left to survive in this world alone. Annie's library provides them with an escape, a hope for a better tomorrow. It's a wonderful legacy dedicated to the memory of a very special young lady. For Jennifer, who hopes to return to Honduras again, it was very special to meet the

children whose lives had been touched by Annie. She knows now why her daughter was drawn to this special place.

Evie returns to Honduras as often as possible, each time taking the allowed 70-pound suitcase filled with as many items as possible for the children. At last year's LifeSource Hope for the Holiday event, Evie shared her experience and travels to Honduras with the attendees and what Honduras meant to her granddaughter. After the event, a donor mother named



Annie, center, with the children of Oasis de Amor.

Margaret approached Evie and asked if she could contribute books to the orphanage in memory of her son, Isaac, as books were so important to their family. To Evie's surprise and delight, Margaret, along with the help of family and friends, donated nearly 400 books, and they plan to send more in the future!

Jill Halimi is the Family Services Coordinator for LifeSource, the Upper Midwest Organ Procurement Agency, Inc.

To learn more about Annie's library or how to help the children of Honduras, please contact Evie Komarek at 651-646-5278 or via e-mail at evie@stribmail.com

A Gift of Love: Ten Years Later

The National Donor Family Council (NDFC) would like to thank Maggie Coolican for her passion and dedication in creating, designing and sewing the National Donor Family Quilt for the past 10 years.

Since 1995, thousands of families have created patches in honor of their loved ones for the National Donor Family Quilt, an ever-growing memorial to those who gave the gift of life through donation.



Photo: Jason Arnold

Maggie helps a donor family pin their quilt square.

traditional quilt patches, some made from baby blankets or the donor's favorite clothes, some with photos, patches or embroidery."

Over the past 10 years, the Quilt has grown to more than 2,000 patches, making up 27 separate panels. Today the Quilt travels to events all over the world to raise awareness about donation while paying special tribute to loved ones. "All donor families will be forever grateful to Maggie for this beautiful quilt," says donor mom Barbara Musto. "Because of Maggie's love and dedication, 'Patches of Love' enables our loved ones' legacies to continue and they will never be forgotten. They will always be in memory."

As she retires from her work on the Quilt this year, we wish to thank Maggie for her work over the years in helping to create so many resources and programs to support donor families across the country.



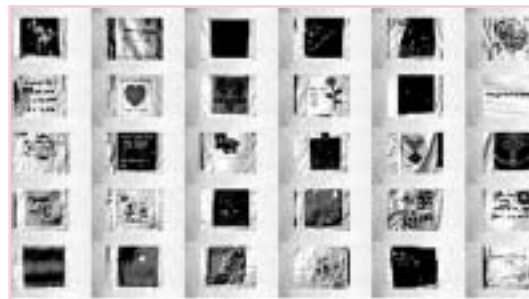
Photo: Jason Arnold

Maggie shares a laugh with the audience at the 2004 Transplant Games Quilt Pinning Ceremony.

The founder of the Quilt and founding chair of NDFC, Maggie is the mother of six children. When her daughter Katie died at the age of six and became a donor, Maggie got the idea to create a national quilt to remember all organ and tissue donors and to promote the power of donation in changing lives.

With support from the NDFC, the quilt quickly became a reality. As patches came in from all over the country, Maggie began sewing. "As I sewed," says

Maggie, "I wondered about the donor, feeling that I knew each one in a special way through the life presented on his or her patch. There were



The first panel of the National Donor Family Quilt is displayed.

Make a Quilt Patch for the National Donor Quilt

The National Donor Family Council invites all organ and tissue donor families to participate in the Quilt Project. Dedicated to the memory of your loved ones who gave the gift of life, each quilt patch is a symbol of love. There is no deadline for your patch, as the Quilt is never finished. One panel is always left open to allow new families to remember loved ones through this very special project. Please note that we can accept only one patch per family.

Size

YOUR QUILT PATCH MUST BE AN EIGHT-INCH SQUARE, allowing for a half-inch seam on all four sides (design should be within seven inches). It's very important that your patch meets the size guidelines, or it will be very difficult to include in the Quilt and may be returned.

Fabric And Sewing

- **THE QUILT TRAVELS** frequently. Please sew everything securely and avoid using glue, as it may dry out over time. If you are including a photograph on the patch, it should be laminated or transferred directly onto the fabric.
- **YOU MAY USE ANY FABRIC** color or type, including sentimental materials such as your loved one's baby blanket, high school jacket, tie or favorite sweater.
- **YOU MAY USE CRAYONS**, paint, permanent markers, glitter, thread or any other medium to design the patch.
- **FEEL FREE TO INCLUDE** your loved one's name and dates of birth and death, if desired.
- **DO NOT "FINISH"** the patch with quilting or backing.
- **IF YOU'RE UNSURE** about what to do, ask a friend or relative to help, or look through other donor family quilt patches on our Web site at www.donorfamily.org
- **PLEASE SEND IN ONLY** one patch for each donor. You may want to ask other family members for their input when designing the patch.

Story

WE INVITE YOU TO SHARE a 100-word story for online publication about your loved one, the patch design or what this project means to you. The story will accompany your patch. You may send your story with your quilt patch, or wait and send it at a later time. A story is not required to submit a patch.

Release Form

PLEASE DOWNLOAD THE QUILT release form at www.donorfamily.org and mail it in with your patch. If you are not able to print the form from our Web site, we can mail you a copy when we receive your patch. The release form grants us permission to publish your patch and story online and gives you the option of including or removing your name, city and state.

Mailing Your Patch

ENCLOSE THE PATCH in a resealable plastic bag to ensure safe arrival. Include the release form and story, if you choose, and send by registered mail or insured carrier to:

*National Donor Family Quilt
c/o National Kidney Foundation
30 East 33rd Street
New York, NY 10016*

Confirmation of Received Patches

WE WILL SEND YOU a letter within six to eight weeks confirming receipt of your patch. We will also notify you when your patch has been sewn into the Quilt. Please note that it may take up to one year to add your patch to the Quilt and Web site.



thoughts *from donor families*

Gracias! Thanks!

By Pat Brown, Donor Mom

(Thoughts while viewing the
National Donor Family Quilt on Tour)

Whatever language we speak, Thanks is but a small word compared to what the **Heroes** on this Quilt have accomplished. Each square of this quilt tells the story of a Loved One that is larger than life. These people, young and old, are **Heroes**. Sure we have everyday heroes such as policemen and firemen, But the heroes of this quilt are **Our Heroes**. These **Heroes** gave of themselves to people they would never meet.

They gave the precious gift of life to people who could never pay them back.

It was not their job to donate organs like it is a policeman's job to protect us.

It was not their time to die.

It was not their wish to leave their families.

BUT in all of this sorrow and tragedy, came **Life**.

The **Life** that was saved, the sight that was restored, the heart that is beating came from

Our Heroes.

Rest always in our memories, **Our Precious Loved Ones.**

Remembered always in the simple beauty of the Quilt Square.

You are the **Heroes** that Life can no longer take away.

Remembered always in our Hearts and in the Lives of the people you helped the day you died.

May the Love built into these squares

Be a Lasting Tribute to

Our Heroes.

Single, Married, Separated, Other?

By Lynn Marie Steinmayer, Donor Wife

Have you ever had to fill out one of those forms that ask if you are "single," "married" or "divorced/separated?" I recently had to put a check in one of those boxes. I turned to a friend who has been widowed for 11 years; we looked at each other and wrote in a fourth category: "widowed."

I suppose, technically, I am single, but I could also be classified as separated (be it against our wills). I know that for each and every divorce or separation there is a reason or story behind it. I know many couples that have gone through counseling and then still divorce, learning that it is the healthiest course for all involved. Yet even

knowing this, I want it known that I am not divorced nor separated nor single nor married. I am widowed. If given my druthers I would prefer to still be married. We laughed, we cried, we ate chocolate and drank champagne. We had two kids and a house we couldn't decide to sell or renovate. We were happy.

As I contemplate returning to school to continue my education, I fear that prospective professors may see that I am a single mother and think that I "gave up" on a marriage because my husband wouldn't pick up his socks or because he cared more for football than for me. I acknowledge that this is nonsense, but it seems very real to me at the moment.



I'm not looking for sympathy when I get on my soapbox, but I *am* looking for an accurate representation. I know—or maybe

I should say, I hope—that there aren't that many widowed people. There are far more divorced or separated individuals, but if space is an issue on a form why not ask "single," "married" or "other?"

"Other" could be a very interesting category that encompasses so much: divorced, separated, widowed, gay civil union or common law spouse, to name a few. If I can't be a "widow" then I choose to be "other"—they may have more fun.

Surrounded by Butterflies



By Gloria F. Villareal, donor wife

I felt so alone as I walked toward my car without him. I was not ready to let him go. Tears blurred my vision as shock and disbelief traveled through my body. My husband, Tony, had always been healthy. So his unexpected death took us all by surprise.

“If this is a dream, please God, make me wake up.”

I rushed Tony to the emergency room that early morning of June 2003. Some discomfort in his chest and a little pain in his left arm was the only sign: a heart attack. Trembling after the diagnosis, I went to the nearest phone to call my four daughters.

Panic with a mixture of thoughts and memories flashed through my head.

I was 15 when I met Tony. We attended the same high school. After graduation, he left on a tour of duty with the U.S. Army. We loved and missed each other so much that he came down on furlough to marry me. I was 19 and he was 21.

After our daughters graduated from college and left the nest, we traveled more and enjoyed our dream vacation to Hawaii. Soon our grandchildren were filling our lives with joy and laughter.

My husband went into cardiac arrest and died that morning. My daughters and I surrounded him while we cried a million tears. We just couldn't understand why he was taken from us so soon. He was only 59 years old.

I opened the box and there was a card with a picture of a butterfly that read “A Symbol of Life Renewed.”

How could I live the rest of my life without him? What about our trips? My daughters still needed his wise advice. He wanted to see his grandchildren grow up. Thirty-eight years of marriage seems like a lot, but not to me. I was not ready to let him go.

I was so glad that Tony's mother, whom he had not seen for eight years, was staying with us for a few days. He was so happy to

see her. My daughter and her family, who live hours away, were also visiting. I was so glad we were all by his side.

Words of consolation meant nothing to me at that time. I felt numb all over, I blocked out everyone and everything. It was a feeling that only persons who have lost a loved one can understand.

After the funeral, my little granddaughter sat by my side and said, “Grandma, I wish I could turn into a butterfly, so I can fly to heaven and visit Grandpa.”

Since her beautiful thought, butterflies have surrounded me. I had donated my husband's corneas, and weeks later I was given a medal in his honor for The Gift of Sight. I opened the box and there was a card with a picture of a butterfly that read “A Symbol of Life Renewed.” Driving home that day, a beautiful butterfly landed on the side mirror of my car. As I arrived at my house, which was several miles away, I noticed that the butterfly

was still on the mirror. I touched it and it flew away. Was this a sign from Tony? Is he looking after me? I have a feeling that he is.

I am still grieving and I know that my life will never be the same. But with the donation of my husband's corneas, I know that part of him still lives. As long as there are butterflies—those symbols of love and re-birth—I will always feel that he is close by and looking over me.





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.

2005

March 1- 31	Philadelphia, PA, National Kidney Foundation of the Delaware Valley, <i>March Madness</i> , Alysia Bruno, 215-923-8611
March 13	Windsor, CT, LifeChoice Donor Services, <i>Gift of Life Gathering</i> , Margaret Coolican, 860-286-3120
April 18 - April 22	Chicago, IL, National Kidney Foundation of Illinois, <i>Donate Life Month</i> , Kate O'Connor, 312-321-1500
April 22	Ft. Collins, CO, Poudre Valley Hospital, <i>Donor Awareness Open House</i> , Robin Peterson 970-495-7500
April 22	San Jose, CA, UCSF Tissue Bank, <i>Donor Appreciation Ceremony</i> , Patricia Black, 408-345-3516
April 23	Fullerton, CA, One Legacy/Orange County, <i>Donate Life Walk/Run</i> , Katnleen Hostert 714-264-5030
April 23	Modesto, CA, California Transplant Donor Network, <i>Ceremony of Recognition</i> , Trace'e L. Harris 209-545-8000
April 24	Sacramento, CA, Golden State Donor Services, <i>Donor Family Recognition Ceremony</i> , Jennifer Ivery Johnson, 916-567-1600
August 6-August 7	Oklahoma City, OK, LifeShare Transplant Donor Services, <i>Donor Family Recognition Ceremony</i> , Julie Avants, 405-840-5680
September 17	Louisville, KY, National Kidney Foundation of Kentucky, <i>Kidney Walk</i> , Lisa Allgood, 502-585-5433
September 24	Newcastle, WA, Northwest Lions Eye Bank, <i>Donor Family Recognition Ceremony</i> , Lois Parker, 206-656-8500

* 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.

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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New York, NY 10016

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