# 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 2000

Volume 9, Number 2

little cowboy was and didn't he look cute as he shook his bag and said thank you over and over again?"

Mom was so thrilled about the little boy's response

to her pennies that she told my dad and everyone who

visited that day. The beauty of simplicity and the joy of

Who would have thought that the very next day my

This is not the end of the story or the end

of this beautiful, unique life. My mother was

when she left this earth. She gave her liver

My mother assisted God in the miracle

of giving birth to 12 healthy children. Now

she was assisting God in prolonging lives

Through organ donation, Mom was giving pennies

that it is not the cost or the size of the gift that

behind the gift that brings the joy.

provides the joy felt by the giver. It is the feeling

from heaven. Yes, I know a liver, two kidneys and life

are worth more than pennies. But my mom taught me

If my mom found great joy in giving pennies to the

children who came to her door, can you imagine the joy she is feeling as she sees three lives physically

could no longer use? The beauty of simplicity and the

restored because she was willing to give what she

through the miracle of organ transplantation.

and kidneys to individuals who otherwise

an organ donor. She was 71 years of age

giving are part of what made my mother's life so

mom would go for her daily 10-mile bike ride and

pronounced dead that evening.

would have died.

never return. She suffered a brain aneurysm and was

# Pennies from Heaven

#### by Anne Phillips

wonderful.

t was October 31, 1998, and my mom was equipped with her basket of coins for the children who came to her door trick-or-treating. This Halloween she was giving out pennies. She had always given pennies, dimes or nickels; but never candy. I always wondered what her reasoning was behind this choice of treats. Was she giving them money to help pay for the dental work that would be needed from all of the candy they will eat? Or was she giving money so the children could buy candy of their choice? I should have asked her.

My mom loved to give. She found her greatest pleasure in giving to others. With 12 children of her own, she became quite skilled at generosity. Whether she was giving three jellybeans to each of her grandchildren or \$100.00 to a neighbor in need, she found real joy in giving.

The children never had time to knock. As soon as my mom saw them coming, she was at the door eager to give away her pennies. The children held open their bags and one by one my mom dropped 25 pennies into each bag. She even counted as she dropped each penny. One little boy, dressed as a cowboy, was so thrilled that he kept shaking his bag to hear his new fortune jingle. As he shook his bag he exclaimed, "Thank you, thank you," all the way down the sidewalk. My mom had a huge grin on her face as she realized how delighted the little cowboy was with his new treasure.

"Mom, don't you think you ought to give more than twenty-five pennies, especially with inflation?" my brother questioned.

"That is true Damian, but you saw how happy that



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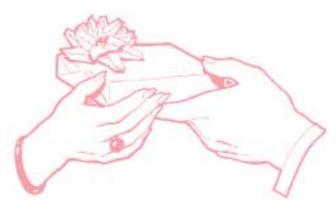
joy of giving.

### THOUGHTS FROM

### Gifts

#### by Dave Stanton

A ch person mourns the loss of his or her loved one differently. Over time, we all ask pretty much the same questions at varying stages of our grief. For instance, after our daughter's death, I lost much of my faith in God. I have struggled mightily with it since, but my wife's faith remained the same and quite possibly has grown stronger. We both asked similar questions, but came to very different conclusions.



As time goes by, we, the grief-stricken, are occasionally treated to a gift of compassion that the giver is not even aware they have given. These gifts tend to hold greater value to us as the actual trauma of the event becomes a more distant memory. Consider, if you will, how much the gift of remembrance can mean on our emotional trigger day, and how an unknown innocent's mournful cry can encourage warm thoughts to arise from the catacombs of the past. A gift of remembrance holds greater value than we know.

## We Fondly Remember





Joseph W. Davis September 29, 1986 — August 5, 1999 Ryan M. Boyd February 9, 1978 — February 3, 1993



by Dorothy Marlene Reed

He counts the tears as they fall because they have a special part As he gathers them, one and all And puts them deep within his heart

He feels the pain that's oh so deep He hears the cries of "why" He knows this is a time to weep He'll calm the storm as time goes by

He knows there is an empty place He sees the void that's there this day He'll send the comfort to fill the space Along with strength to find the way

He'll be right there beside you You won't walk this road alone And he'll put around you too His arms as a loving dome

Yes, now is a time that you will cry And this burden you don't understand But if you'll give it to God on high He'll tenderly hold it in his hands

The Lord led Dorothy to write this poem after Jeffrey Payne passed on.

### 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 memory of:

**Raymond A. Bobiak, Jr.** - by Anna E. Gray Joseph J. Billicki - by Debra and Joseph Adamski

Sonia - by Nancy Gilliland-SeymourMerideth - by Anita MugraveShirley Nathan - by Margaret B. Coolican

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### DONOR FAMILIES



I'm Spending Christmas with Jesus Christ this Year

see the countless Christmas trees Around the world below With tiny lights, like heaven's stars Reflecting on the snow.

The sight is so spectacular Please wipe away that tear For I am spending Christmas With Jesus Christ this year.

I hear the many Christmas songs That people hold so dear, But the sounds of music can't compare With the Christmas choir up here.

I have no words to tell you The joy their voices bring It is beyond description To hear as angels sing. I know how much you miss me I see inside your heart We're not that far apart this Christmas

With Jesus Christ this year.

I can't tell you of the splendor Or the peace here in this place Can you just imagine Christmas With our Savoir, face to face.

I'll ask Him to light your spirit As I tell Him of your love Please pray one for another As you lift your eyes above.

Please let your hearts be joyful And do not have a fear For I am spending Christmas With Jesus Christ this year.

# The Grave Site Vigil

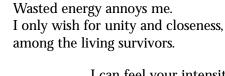
#### by Terry Jean Ratner

I know you are standing there, somber and teary, thinking of my persona, and what I used to be.

But I am somewhat altered now, in a different dimension. and wish you could understand, but it is too simple for the living.

Don't set down those pictures, For I no longer have vision, and put your notes away, For my eyes are helping others now.

Those flowers are for the living, For I can no longer smell, and put those beer bottles away, For no longer do I have the thirst.



Don't dwell on what could have been,

I can feel your intensity, both positive and negative, Not hear your words, which are merely letters put together.

Please use this serene place of mine, to contemplate your life, and focus on good deeds of man, to better remember me.

This poem was written to the many people that visit my son's grave site. He was killed in a motorcycle accident in March of 1999. I hope they can read this and understand the meaning by applying it to their personal lives.

### WHAT HELPS WHEN IT HURTS

# Healing Holiday Rituals for Grieving Children

#### by Denise Stone RN, MS Certified Grief Counselor

Holidays can be very difficult for a grieving family. Images of family togetherness and often unrealistic expectations of the holiday season are everywhere; in the malls, on television and on the fronts of greeting cards. So how does a family celebrate the holidays when a loved one is so sorely missed? Creating new therapeutic rituals and new family traditions is a good start and can be very healing.

# Here are some suggestions that might help the family get started.

- Buy a strand of (battery powered) miniature lights, string them on a miniature tree, decorate it, and place at the grave. Family and friends can bring miniature ornaments to trim the tree.
- Meet at the grave site, light a candle, and sing a favorite holiday carol.
- Plant a living thing to commemorate your loved one. Make the planting a ritual with invited family and friends. Serve punch and cookies after the planting.
- If your loved one loved animals, make a donation to the Humane Society in his or her name or take the children to the Humane Society with a gift of dog or cat food. Write a gift card: Happy Holidays! (sign with your loved one's name). Have the children use the money they would have spent on gifts to purchase the cat or dog food.

- Purchase or make a Memorial Candle. Light it each evening and place it by a picture of your loved one. Also, light it beside the dinner table on Christmas Day.
- Take time to have family members share their favorite stories about your loved one on Thanksgiving, Christmas Day, Hanukkah or other holidays.
  - Set a place for your loved one at the holiday dinner table. Place a candle or flower on the plate in his or her honor.
  - For the Thanksgiving Holiday blessing, write your own. A good start would be: Lord, we miss and remember \_\_\_\_\_, but we are thankful for \_\_\_\_\_.

Set aside some time before opening gifts to discuss the non-material gifts that your loved one gave the family: Family values, morals and/or beliefs.

 Instead of signing his or her name on your holiday cards, add a symbol of your loved one: a butterfly, an angel, a bird, the sun, a star, a heart, a flower, balloons or a rainbow.
Purchase a special stamp and pad with this logo on it and use it often.

For the New Year: Make a resolution to your loved one that you will work on your healing in the new year.



### THOUGHTS FROM RECIPIENTS

#### Donor Family:

Your daughter lives in the hearts, souls and body of our family. As a mother of five children, I have often thought of love as a rubber band...It always stretches to hold more.

"Awesome" is our word of choice to describe our gratitude. We may not have known your daughter, but now we feel her presence and love in our lives. There are no words I know of to tell you "thanks" for the life you have given my daughter, Lisa.

Lisa's story is filled with courage, faith and hope. She is a single mom with a two-year-old daughter named Taylor Rose. Her story is lengthy and I hope some day to share it with you, our donor family.

Your daughter's kidney adds so much to Lisa's life, especially the hours spent with her young daughter. You have made this possible.

Above all, in our joy, we share so deeply in your loss. Not a day goes by that my heart, as a mother, doesn't feel such pain as I think of walking in your shoes. As our Taylor Rose opens her gifts this holiday season, little does she know that the greatest gift was received in December 1997, by her young mom. You wrapped it so beautiful with all of your love.

We wish to share our lives with you as a living testimony to your daughter, if it is your choice. Most of all, we wish you peace, love and serenity.

Sincerely,

Joan Reardon Mother of Kidney Recipient, Lisa Reardon Rouillard



# The Quilt on Tour

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

	Riverside, CA, <i>SCOPC, Inland Empire Donor Recognition Ceremony</i> . Contact: Susan Prairie Hawthorne (800) 338-6112
October 11 Le	exington, KY, Kentucky Organ Donor Affiliates. Contact: Jenny Miller, (606) 278-3492
October 16/20* Fe	ernley, NV, Contact: Alice McKinney, (775) 575-1257
October 22 Pr	rovidence, RI, <i>New England Organ Bank, Rhode Island Donor Family Ceremony.</i> Contact: Pamela Albert, (617) 244-8000
October 28* N	Vational Kidney Foundation of Middle TN, Gift of Life Walk. Contact: Lu, (615) 383-3887
	Cennessee Donor Services, <i>Donor Family Ceremony and Hospital Displays</i> . Contact: Whitney Webb, 615) 234-5265.
November 10-13* Li	ifeLink of GA, Contact: Skip Wiesenbakerm, (404) 266-8884.
November 12* G	Golden State Donor Services, Contact: Debbie Drennin, (916) 567-1600
December 13* Ta	Campa, FL, LifeLink Foundation of Tampa, Contact: Mary McClintock, (813) 253-2640 ext 187

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 Sarah Ockler** at the National Kidney Foundation at (800) 622-9010. 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 Sarah Ockler for up-to-date information. Information about the quilt can also be viewed on our web site at www.kidney.org/recips/donor. \* Not yet confirmed.

### When a Spouse Dies Suddenly

#### by Sandra Helene Straub, EdD Certified Grief Counselor and Death Educator

No one ever expects to grow up and be widowed. We assume that our family will always be intact, that no one important to us will die, that living a good life will be rewarded and that life is fair. Then, a sudden death occurs and changes the way we view our world. We lose our spouse, our mate and our partner in life. The surviving spouse must now stop including his or her loved one in future plans, thoughts and conversations. The task is not simple.

Being widowed is not easy. It is probably one of the most difficult changes in a person's life. Being alone with a slew of additional responsibilities can become frustrating and overwhelming. All you may want to do is run from the pain and avoid the grief of your situation. You may want to bury your feelings rather than have others see you crying or depressed. These actions may lead to prolonged grief, as well as physical and emotional illness. Working through your grief can help you find a new beginning in life. On your journey, there are several things you can do to help yourself accept reality, express your emotions and find support in others.

Facing the finality of death brings on an emotional tidal wave. You have never been more alone than at the announcement of your spouse's death. The news hits you like a ton of bricks. Although you try to fight the finality of death's call, the funeral arrangements need to be made and the reality of your unwelcome situation settles in. You finally realize this is not a bad dream. It is *your new* reality. Your spouse is gone.

Everyone expresses emotions differently. Some cry uncontrollably, while others become extremely sullen. You may constantly question "why?" or you may totally withdraw from others. You are emotionally wounded. It is natural to feel this way, but you must express your emotions in order to begin to heal. Where, when and how often is up to you. Everyone is different and there are no set rules in dealing with death. Don't feel you always have to be strong. It is fine to depend on others for help. Cry when you need to cry. Don't be afraid to mourn openly. Many times there will be no one around with whom to share your feelings. And when there is, you may not feel like talking. Keep a journal of your feelings. Try to record significant events of the day and how you felt about each one. Write about the good times, such as a good night's sleep, a weekend getaway, your first day back to work, or your first outing with a friend. You need to keep in touch with who you are throughout this traumatic experience. Keeping in touch with your feelings is very important. It allows you to begin your healing process.

> You need to reach out. This might be difficult, but stoicism will not help. You may never have had to depend on others as much as you do now. Never consider yourself a burden. The outpouring of love you receive can be a tremendous source of comfort. It can help you to keep perspective in your life. Try to be with those who can accept and understand your emotions, not those who say, "Don't worry, you will be all right." There is nothing all right about how you are feeling. Some people will not know what to say and may

even avoid you entirely. Do not allow this to hurt you. Expect changes in your relationships.

You will have days when it seems that such a big piece of you has been ripped away and that only a gaping hole is left. You will also have days of celebrating new beginnings in life. After my spouse died, I experienced many positive changes, along with the not-so-positive ones, and I trust that you will too! Good luck in your new journey!

Sandra Helene Straub, Ed.D., is the author of Death Without Notice.

#### THE HOME FOR DONOR FAMILIES ONLINE

When was your last visit to the NDFC web site? We've just completed two new sections and we want to know what you think! Stop by **www.kidney.org/recips/donor** to explore "What Helps When it Hurts: A Collection of Resources" and "A Safe Place to Ask—Questions & Answers." While you're there, check out the message board, view patches and stories from the Quilt, read *Connections* and the featured *For Those Who Give and Grieve* article and more! We appreciate your suggestions and comments about our web site. If you would like to share your thoughts, please e-mail us at donorfamily@kidney.org. *The Donor Family Home Page is supported in part by the Division of Transplantation, Health Resources and Services Administration, U.S. Department of Health and Human Services.* 



If you would like to submit a letter or story to Teenagers Sharing, a section devoted to teens who wish to express their emotions in writing, please direct all correspondence to:

FTWGG Teenagers Sharing, c/o National Kidney Foundation, 30 East 33rd Street, New York, NY, 10016 or e-mail donorfamily@kidney.org.

#### 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. **Editor-in-Chief** A Organizational Liaisons Mary Ann Carpenter, Merritt Island, FL AATB Sandie Henderson-Bancore **Assistant Editor AOPO** Margie Fischer Steve Gardner, Hueytown, AL ARCTS Chyrrel Mock **Donor Family Editors** DoT Mary Ganikos, PhD Brenda Ashton, Sandy, UT Janet Davison, Moline, IL EBAA Rachel Syska David Stanton, Mesa, AZ MTF Martha Anderson **Contributing Donor Family Editors** ANET Mary Gainey, RNC Bridgette Begley, Brownwood, TX **UNOS** Fred Geiger Steve Gardner, Irondale, AL NATCO Laurel Williams Todd, RN, MSN, CCTC Patricia Rush, Nutley, NJ Pam Stivers, Melbourne, FL **Editorial Office Professional Editors** National Donor Family Council Patti Baller, Reading, PA NKF, 30 East 33rd Street Lisa A. Colaianni, Falls Church, VA New York, NY 10016 Margaret B. Coolican, RN, MS, CDE, East Hampton, CT (800) 622-9010 George Herrera, San Antonio, TX (212) 889-2210 Mark Jones, San Antonio, TX Jayne Miller, Redlands. CA FAX: (212) 689-9261 www.kidney.org Denise Stone, Merritt Island, FL Ivy Vincent, Houston, TX Executive Editor Managing Editor **Production Manager Editorial Director** Editorial Manager **Design Director** Gigi Politoski Sara Kosowsky Marilyn Lara Catherine Paykin Sarah Ockler Oumaya Abi-Saab

### Donor Family Friends 🔵 👰 🧕 🤶

DF 143 I am a 21-year-old mother of two beautiful boys. My husband and I lost our 22-month-old son in August 1999. Our 3-year-old was there when they took him in the ambulance and that was the last time he saw him, unconscious. Now I am lost trying to explain to my son why he can't play with his brother. I would love to correspond with anyone who has been in this situation.

DF 144 Less than one year after my mother, aunt and father died, my husband passed away suddenly. He was our life—a loving and devoted father, husband and grandfather. I would love to hear from others. I also have a six-year-old grandson and 28year-old granddaughter who could use a friend.

DF 145 I am a widow, age 65. My husband of 43 vears died suddenly and I miss him so much. He was my best friend. I would like to correspond with someone who has lost a spouse.

To submit or repeat a Donor Family Friend ad or to respond to a family, send correspondence to Donor Family Friends, The National Kidney Foundation, 30 East 33rd Street, New York, NY 10016. Please include the number of the DF you are responding to in your letter. Do you have a child who wants a pen pal? Encourage young ones to write us for a Donor Family Friend!

#### Are you a Member?

The National Donor Family Council is home to over 8,000 donor families, but thousands more receive the newsletter. If you have not filled out the enclosed member reply card or signed up online, you may not be a member of the NDFC. Membership is free and includes access to resources and a free Gift of Life butterfly pin. Please fill out the enclosed card or visit www.kidney.org/recips/donor to join.

#### Moving?

If you are planning to move, please notify us of your change of address so you can continue to receive For Those Who Give and Grieve and other NDFC mailings.



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.



National Donor Family Council National Kidney Foundation 30 East 33rd Street New York, NY 10016





Please help us "Cut Down" by notifying us when your address changes. It costs 33 cents if you forget.