

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.

Winter 2005

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

Volume 13, Number 3

nutrition: the foundation *of self-care*

By Darlene Kvist, MS, CNS, LN

You may ask what your day-to-day nutritional choices have to do with surviving the loss of a loved one. The food that you eat affects your moods, overall health and immune system. When you experience a traumatic loss and ongoing stress, good nutrition becomes critical to maintain your health and well-being.

STRESS AND EATING

Stress of any kind, particularly grief, can change eating patterns. When we grieve, food often becomes a secondary concern, even an afterthought. Some people lose their appetites for a while and eat little or not at all. Others eat almost by default, consuming whatever is handy, including sugary or junk foods that they would not eat under other circumstances. Eating is no longer about self-nurturing or even nutrition. We eat to keep going, to distract us or to dull the pain.

I believe that most of us know intellectually or intuitively that the sugar or junk food is not helping. Many of us realize that our blood sugar will crash after eating sweets, causing us to feel worse. Ironically, those plates of brownies that family and friends bring to comfort you

may actually feed your depression and weaken your immune system.

THE FOOD-MOOD CONNECTION

What is the connection between food and mood? Our cells talk to each other through an elaborate network of chemical communicators called neurotransmitters. Eating foods with sugar or trans fats (margarine or hydrogenated oils) desensitizes or blocks those neurotransmitter receptors. The well-intended "comfort foods" people bring during a time of loss are frequently high in sugar or processed carbohydrates and are the very foods that create heartburn, low moods and depressed immune function. When this happens, you may experience more pain, depression and anxiety. Short term, you can aggravate an already stressful situation; long term, you compound health problems.

STRESS AND YOUR IMMUNE SYSTEM

Have you ever thought how stress affects your immune system? Trauma, stress and grief have a detrimental effect on the immune



Darlene Kvist, MS, CNS, LN

system. When you are grieving, you may experience frequent colds, cold sores or other viral infections. These viruses may seem bothersome, but if you do not eat healthy enough to rebuild your immune system, and the stress continues for months or years, you become more vulnerable to illnesses such as cancer, chronic fatigue or other immune problems.

IMPORTANCE OF NUTRITION

In elementary school, high school, and college we are taught to read, to memorize and to solve problems, but not how to deal with grief or to survive the day-to-day reality of putting one foot in front of the other after a loss. As those years in school did not teach us how to experience and grow from the loss of a loved one, we also did not learn to support the body, mind and spirit nutritionally during this time.

continued on page 3

letter from *the editor*

Of the many great experiences I had at the 2004 U.S. Transplant Games, I believe one of the highlights was meeting Health and Human Services Secretary Tommy Thompson, who made a surprise special guest appearance. A longtime advocate of organ and tissue donation and transplantation, Secretary Thompson generously pulled an all-nighter so he could show his support for the Games. Can you guess his first stop? It was the Radisson Metrodome Hotel to see the Donor Family Quilt. As he looked at some of the individual quilt patches, his eyes filled with tears. He shook hands and embraced donor families who had gathered to meet him. When Secretary Thompson spoke to us, he told us how sorry he was for our loss, and how thankful he was to us for giving others a second chance at life. His faced showed how deeply he cares.

Photo: Jason Arnold



It's understandable. Our stories are heartbreaking and heart-lifting. To all of my courageous donor family friends, I marvel at the strength of your spirit. As Secretary Thompson so aptly put it, "You are truly America's heroes."

Sincerely,
Rose D'Acquisto, Donor Wife
Volunteer Editor

SAVE THE DATES!

JOIN US IN OUR
NATION'S CAPITAL

July 22-24, 2005

for the Federal
Government's ninth
National Donor Recognition
Ceremony and Workshop
(NDRCW).

For NDRCW registration
information, e-mail
donorfamily@kidney.org
with your request, including
your name and
mailing address.

STAY TUNED FOR MORE
INFORMATION!

FOR THOSE WHO GIVE AND GRIEVE

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

Editor-in-Chief

Rose D'Acquisto, St. Paul, MN

Donor Family Editors

Pat Brown, Orlando, FL

Dan Manley, Tulsa, OK

Jan Frye-Hill, Winston Salem, NC

Professional Editors

Penny Colthurst, Ann Arbor, MI

Margaret Coolican, RN, MS, CDE, East Hampton, CT

Charles Corr, PhD, St. Petersburg, FL

Kimberly Kasprovicz, Syracuse, NY

Raelynn Maloney, Iowa City, IA

Teen Editor

Jennifer Cerney

Organizational Liaisons

AATB Sandie Henderson-Bancore

AOPO Lisa Colaianni

ARCTS Chyrrel Mock

DoT Mary Ganikos, PhD

EBAA Jennifer Johnson

MTF Martha Anderson

ANET Mary Gainey, RNC

UNOS Fred Geiger

NATCO Nancy Senst

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

E-mail: donorfamily@kidney.org

Executive Editor
Gigi Politoski

Managing Editor
Sara Kosowsky

Production Director
Sunil Vyas

Production Manager
Helen C. Packard

Editorial Director
Sarah Revere

Design Director
Oumaya Abi Saab

Importance of nutrition...

continued from page 1



Grief counselors, clergy, friends and family all try to help us. Culturally, we are trained to seek emotional support. However, until recently, nutritionists have not been part of the support team. While we may recognize the need for emotional help, what about our physical/mental/spiritual health?

“*The food that you eat affects your moods, overall health and immune system.*”

A time of loss or of extended caregiving often takes a greater toll on our health than we may initially realize. Have you ever thought that good nutrition is more powerful than anything else

you could do for yourself? Eating nutritious, good food is the most basic way to care for your health and well-being.

NUTRITIONAL SELF-CARE PLAN

If you are experiencing intense loss, nutritional guidance may help you feel stronger and keep you healthier. Working with clients who have suffered a loss and are grieving, I have formulated several nutritional steps for self care.

Eat several small meals per day. Five or six may be best.

Include protein, vegetables, and healing fats (olive oil, butter, nuts, olives) at each meal and snack.

Limit consumption of coffee, soda and alcohol.

Drink eight to ten glasses of water per day.

Avoid processed sugar and carbohydrates. When you crave sugar, slice an apple and spread it with healthy peanut butter (no added sugar or fat).

To sleep better, avoid sugar, cookies, chips, popcorn and alcohol at bedtime. Instead, have a handful of nuts and hot herbal tea.

Make sure to eat sufficient animal protein throughout the day to support proper neurotransmitter production.

Encourage yourself to do nurturing things by cooking a meal that includes meat, vegetables and healing oils, such as olive oil.



If you have difficulty sleeping, which is often the case after a loss, taking additional magnesium at bedtime can help you relax and sleep. I recommend taking between 400–600 milligrams of magnesium citrate or glycinate, both of which are readily absorbed.*

Good nutrition is nourishing on every level. Eating healthy will not only help you cope better in the short term, it may also protect you from future health problems.

[*Editor note: If you are taking medications or other supplements, check with your doctor before trying any new nutritional supplements.]

Darlene Kvist, MS, CNS, LN is the founder of Nutritional Weight and Wellness in St. Paul, MN, and co-author of Picture Book for Zone Cooks. She has 30 years of experience as an educator, counselor, psycho-nutritional consultant and licensed nutritionist.

2004 U.S. Transplant Games Highlights

reflections on the games

let the healing begin

While the athletes participating in the 2004 U.S. Transplant Games were hearing "Let the Games begin!" many donor families experienced the joy of the athletic competition while sharing stories of personal loss. There was comfort in knowing their gifts of donation made it possible for these athletes and many others to live their lives to the fullest!

Even though it has been seven and a half years since my husband Jim's death, I felt that through counseling, support groups and work with donor organizations my grief journey was moving in a direction filled with growth and healing. My passion for organ donation has enabled me to do something positive with the loss of my husband, Jim.

Despite years of effort and steps toward healing, participating in the donor family venues at the

Games was still a monumental event in my journey. The Opening Ceremonies were moving, and I was overwhelmed when the athletes and donor families entered the Metrodome. Exchanging stories in the hospitality room was emotional and healing. There were no borders separating each donor families' state or situation. Rather, there was a blending of everyone from different cultures and backgrounds, but with one



Photo: Jason Arnold

Maggie Coolican, founder of the National Donor Family Council, hosts the Quilt Pinning Ceremony at the 2004 U.S. Transplant Games.

common theme—learning the importance of giving in the midst of loss.

The Quilt Pinning Ceremony was impressive as we shared stories about our loved ones. I was deeply touched when a donor family from North Carolina thanked me during the ceremony for helping him and his wife cope with their daughter's death.

We have recognized that the painful journey we are on can be balanced with cherished memories of our loved ones. Above all, we value their gifts of life. My gratitude goes to the many donor families, liaisons, athletes and other contributors who gave their time, support and friendship! From this experience, I am confident many can proclaim, "The healing has begun!"

*Jan Frye-Hill, Donor Wife
Donor Family Liaison,
Team North Carolina*

circle of life

The 2004 U. S. Transplant Games have definitely been the best yet! Without a doubt, the events in Minneapolis personally showed me a complete circle of life. This amazing journey started with the Opening Ceremonies when I was asked to do an interview about a friend I will always remember—Wendy Marx. Saddened by the thought that her physical presence wasn't with us in the stands this year, I then received a phone call from my cousin Katy in Seattle. She had just

given birth to a baby boy named Sean Michael. This made the celebration at Opening Ceremonies even more profound—a life mourned, a life born.

As the week continued, I began to reflect even more on my own personal journey with organ and tissue transplantation. This year I had the privilege of facilitating the Giving, Grieving, Growing programs "Death of a Sibling" workshop. At first I felt nervous; I wanted to make sure I provided as much information and support as possible to the group. Little did I know then that everyone in the group would be teaching me

something on just how far I have come. As I sat in a circle with everyone and listened to their stories, for the first time I had confidence in saying "It will get better." It has, and I was able to provide them comfort in knowing that they are not alone.

*Audrey M. Sasso Stout,
Donor Sibling
Donor Family Liaison,
Team Northern California*



*Sharon Anne Stout,
sister of Audrey,
donated five organs in
March 1999.*



2004 U.S. Transplant Games Highlights

on the road *to healing*

I am a donor spouse. My husband, Bob, died in a work accident in 1997. Maine is a small state and I have had the privilege of being the Donor Family Liaison (and the only donor family) for the past three Games.

This year, I came without a companion (other than my fellow Team Mainiacs) and decided to volunteer with the Donor Family group. I registered donor families and living donors, handed out programs at the Donor Recognition Ceremony and, probably most significant for me, participated in two workshops for donor families. My experience was awesome.

I suffer from anorexia, an eating disorder rooted in a desire to control certain aspects of my life when I could not control my husband's death. It began as a dedication to running, which increasingly became more obsessive. Then I started throwing away food and restricting my food intake. When I entered an outpatient program at a Maine hospital, I weighed 80 pounds.

As I started to come to terms with Bob's death and learn to give up my need to control, the Transplant Games came along. For the first time at the Games, I allowed myself to feel pain and sadness and to share it with others. While it was heartening and life affirming to share this with my teammates, I felt very privileged Friday morning to be in a space with only donor families. In the first workshop, which focused on sudden and accidental death, I was in a room where people cried and laughed—especially when we got onto the “Top 10 Stupid Things That People Say Who Mean Well”—and shared advice and offered support. It was a loving space.

The second workshop was on movement, which turned out to be a yoga exercise. This was an incredible healing exercise for me, the beginning of a path back to feeling not only the loss of my husband, but also a very close friend who died last fall waiting for a lung transplant. When we began meditating, I found myself focusing on my friend, and I



Photo: Jason Arnold

Left: Allison Hepler at the 2004 Donor Recognition Ceremony.

missed her so much. I found myself in tears and heard the soft crying of other members of the group. It reminded me that these deaths have had a profound effect on me. Even more importantly, I was not alone in that grief.

I still have a long way to go in conquering my eating disorder, but I cannot emphasize enough how important these workshops were for me.

*Allison Hepler, Donor Wife
Donor Family Liaison, Team Maine*

abundant *appreciation*

Our family attended the 2004 U.S. Transplant Games and was sponsored by the Louisiana Organ Procurement Agency because we are a donor family of both organs and tissue. My sister, Evelyn Parker Howell Hood, who died at age 47 from a cerebral aneurysm in 1994, was an organ and tissue donor. My dad, Frank Parker, died last year due to cardiac arrest and was a tissue donor.

As a donor family, we participated in Opening and Closing Ceremonies and attended many of the Games events to watch the recipients compete. Each of them was so appreciative for the gift of life. In addition,

donor families and living donors were honored at special ceremonies focusing particularly on the legacy of donation and the life cycle.

Our experience at the Games was absolutely wonderful! It was so inspiring and motivating for us! We were filled with humility and felt honored as the transplant recipients demonstrated so graciously their appreciation to every donor family or living donor for their second chance at life. Everyone we met stated that they knew God had a part in their transplant experience.

*Susie Parker Holton and Family
Shreveport, Louisiana*



the privilege *of caring*

Listening for the Donor's Voice... Hearing their Message of Hope!

By Helen Leslie-Bottenfield, RN, CPTC

I can still remember, some 24 years ago, being clearly instructed that a donor card, driver's license or any other document of gift for organ and tissue donation was a valid and legal document.

I also clearly recall being told that we don't abide by the stated wishes of the donor, only those of the donor's family. The policy sounded reasonable to me at the time and I shared it with several generations of professionals in my own organ procurement organization (OPO).

Imagine my concern when my state legislators took the initiative to strengthen the language in our state's laws making a donor's decision "irrevocable" by anyone upon the donor's death. The administrator in me fully recognized my legal and corporate responsibility, but the nurse in me was waving red flags. How could we follow this mandate, recognizing the inherent right of an individual to make his or her own personal decision about donation, and still provide appropriate, compassionate care for the donor's family?

As I started the process of organizational change, the Donor Family Advisory groups were first on my list for guidance. Listening to their thoughtful discussion reminded me once again how fortunate we are to have families willing to share their time in order

to help assure the best care for another family. Over and over I heard individuals speak about the privilege of being able to honor any request their loved one had made. Donation was no different. But what about the donor family who disagreed with their loved one's decision? How could we serve that family and also honor the donor?

Their response came with clear direction: You must first advocate for the donor!

We gained passion and power through our discussions with donor families and moved through the process of full implementation of policies that would honor a donor rights model. Most families, upon hearing of their loved one's donation decision, were supportive of the decision and grateful that their loved one had chosen to leave such a gift of love. Families rarely were surprised at the gift and found comfort in knowing that the circle of life would continue. On the rare occasion that a donor's family opposed the donation, the donor

family support professionals observed that the opposition appeared to be directed more toward the circumstances around death and death itself rather than on the donation event. In many cases, the family's opposition has been lessened by the mere presence of someone to listen, support and care.

As the list of patients waiting for a transplant continues to grow, we have a responsibility to each other, our loved ones and to those who follow to allow each

“We gained passion and power through our discussions with donor families.”

individual to make a personal donation decision that will be honored. It is in serving each other that we are served. The circle of life is a fragile one, but together, donors, donor families and health care professionals keep the circle strong and growing! We have only to listen to the voice of those we most wish to honor!

Helen W. Leslie-Bottenfield, RN, CPTC, is senior vice president for transplant services and executive director of LifeNet's Organ Procurement Agency.

thoughts *from donor families*

Poem

(from the 2004 U.S. Transplant Games Coffee House)

You're feeling sad, you're feeling lonely
and no one understands.

They think you can get back on track
and do your same old plans.

There's something missing,
something gone and life's just not the same.

You know your friends and family
are really not to blame.

Life without your loved one makes life feel so
dissolved

Everyone does what they can to try to be involved.

Life will carry on, you know, you never will forget.

The way they smiled back at you
the way their goals were set.

You know they saved a life or even more than 1.

You may have lost a mom, a dad, a daughter
or a son.

But if you think about it, they'd want you
to go on.

Go on and meet new people and talk about
your life.

And how your cherished loved one gave
the gift of life.

*By Mia Lester, age 12, Donor Sister, written in
memory of Robbie Lester.*

Ladybug Love

You sang, you danced, you giggled, you glowed.
You sparkled like the morning sun when it snowed.
You glistened with Ladybug Love.

Your eyes shown with compassion and your
smile brought sad people cheer.
You gave your friendship to anyone with a tear.
You hugged with Ladybug Love.

You stretched out your hand placing yours in mine.
We walked together feeling the warmth of
our love shine.
You touched with Ladybug Love.

Your sense of humor saw the funniest things.
You laughed from your heart at the silly things
life brings.
You smiled with Ladybug Love.

You learned with excitement about nature
and caring.
Your passion for people was seen in your
passion for sharing.

You enjoyed with Ladybug Love.

Your family and friends you held very dear.
Your courage and perseverance could be
seen so clear.
You thrived on Ladybug Love.

Because of the way that you lived day to day,
We knew when you died we couldn't keep you
that way.
Following the example of your Ladybug Love,

We donated your organs while your spirit flew
like a dove.
The love that you lived continues to grow
Through your family, your friends and people
we don't know.
Thank you for your Ladybug Love.

*By Susan Adams, Donor Mom
Written in memory of Kimberly Adams*



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 13 Windsor, CT, LifeChoice Donor Services, *Donor Family Gift of Life Gathering*, Maggie Coolican (860) 286-3120
- April 1 Montgomery, AL, Alabama Organ Center, *Transplant Picnic*, Jane B. Geloneck (334) 271-1690
- April 22 Fort Collins, CO, Poudre Valley Health System, *Donor Alliance Open House*, Robin Peterson (970) 495-8362
- April 23 Modesto, CA, California Transplant Donor Network, *Ceremony of Recognition*, Trace'e L. Harris (209) 545-8000

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

* 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.



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

NON-PROFIT ORG.
US POSTAGE
PAID
NEW YORK, NY
PERMIT No. 5327

Please help us "Cut Down" our costs by notifying us when your address changes. E-mail us directly at donorfamily@kidney.org. It costs 37 cents if you forget.