

Solace

Spring 2013
Volume 9, Number 1

A Newsletter for Organ and Tissue Donor Families

My Loved One was a Tissue Donor... *What Does that Mean?*

The idea that tissue donation is life-enhancing and can be life-saving is difficult for most people to understand. While information regarding tissue donation is provided in the MTS tissue packet, MTS recognizes having the information provided in a variety of ways with the opportunity to ask questions can be helpful. Therefore, MTS will be hosting two tissue donation informational workshops in 2013. Specific topics regarding the tissue donation process and recipient information will be reviewed. Families will also have the opportunity to ask questions. A spring workshop will be hosted in St. Louis and a fall workshop will be hosted in Springfield, Missouri. We hope the workshop will provide you with a better understanding of how important your loved one's gifts are and how they will impact lives for years to come.



Angelo - Tissue Recipient

Our guest speaker for the workshop will be Heather Lueders. Heather is a representative from AlloSource, a key MTS partner, responsible for the processing and distribution of donated tissue. MTS staff will also be available to share specific donor family stories and answer questions.

During the workshop we will cover specific tissue donation information and answer questions including:

- **How are tissue grafts distributed?**
- **What are the typical uses of tissue grafts?**
- **How long can tissue grafts be stored?**
- **How long does it take to get tissue recipient information?**
- **Why isn't recipient information available right away?**
- **Why recipient information is not always available?**

WHEN: Friday, April 19 7:00 p.m. – 9:00 p.m.

WHERE: Mid-America Transplant Services
1110 Highlands Plaza Dr. E. Suite 100 • St. Louis, MO 63110

If you would like to attend please RSVP by calling **314-735-8218** or **800-925-3666** by April 17. Light snacks will be provided. If you have any questions contact **Julie Walton** at **314-735-8450** or by email at **jwalton@mts-stl.org**. The Springfield date and location will be announced in the July edition of Solace.

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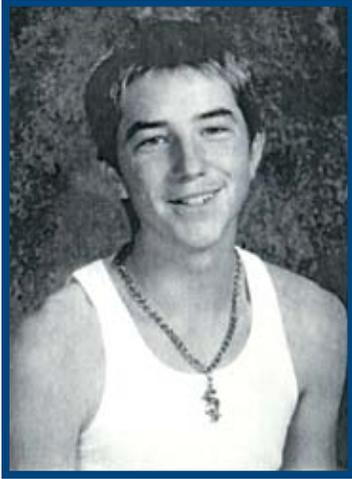
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My Broken Heart Speaks

Jennifer Sanders – book of Poems



Michael Sanders

*That is what I want to do.
I want to be an organ donor.*

“My Broken Heart Speaks”, a book of poems written by donor mom, Jennifer Sanders. It is the result of her honest struggle to cope following the loss of her son on June 24, 2005. Jennifer tells the story of her son and provides insight into a world that felt as if it had been turned upside down. During this time of deep sorrow emerged an amazing gift of poetry writing that became a way to uplift Michael’s (“Mikee” as Jennifer affectionately calls him) family and friends. In “My Broken

Motor Vehicles so he could get his permit to drive. As they waited in line Jennifer remembers the boy in front of them being asked if he would like to become an organ donor and the boy’s mom immediately said “NO!” Mikee turned to his mom and said “That is what I want to do. I want to be an organ donor.” Jennifer remembers the moment clearly, pleased her fifteen year old son, at that moment, had the forethought to sign up to be a donor. Jennifer said, “I do believe everyone

Solace:

comfort,
give moral
or emotional
strength to

“I do believe everyone has choices. He made the right choice. He has made our family look at things in a different way.”

Heart Speaks” Jennifer writes about having the feeling she could not talk to anyone else and get them to understand the sorrow and pain she was experiencing. So, to keep anyone from being hurt or upset, she put her thoughts on paper. When she started to write, the words always came in the form of a poem. She writes in the book, “Although, some of my writings may be a little metaphoric, they were definitely helping us. Each time I finished one, I would read it to my family, and it seemed to bring comfort to them as well.” Through the support of her family and her faith she was able to see that the poems were a gift from God. Jennifer wrote “My Broken Heart Speaks” with a desire to give other families hope after the loss of a loved one and to encourage others to become organ and tissue donors.

Jennifer proudly writes about the day Mikee made the decision to become a donor. She and Mikee were at the Department of

has choices. He made the right choice. He has made our family look at things in a different way.” She wants Mikee’s story to encourage others to become organ and tissue donors.

The day the Sanders lost Mikee they prayed for a miracle. The miracle did not come in the form they were hoping for. Even though Mikee’s life could not be saved he was able to save the lives of four other people that day through organ donation. He was able to donate his kidneys, lungs, and liver. One of Jennifer’s favorite poems is, “The Angels that Came to Town.” We have featured the poem in this edition of Solace.

If you would like to purchase “My Broken Heart Speaks,” by Jennifer Sanders it is available online only at amazon.com and barnesandnoble.com.



com

The Angels that Came to Town

By Jennifer Sanders

The angels came from way up high
And they knew just where to go
God told them to go to you
And they did as he said so

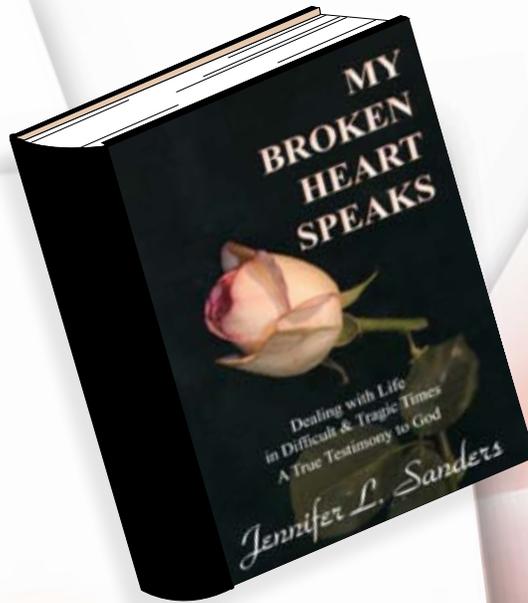
They told you of your new home
Waiting up in the sky
They came to take you away from me
And I was asking why

They said to me these things happen
Even we do not understand
But God saw Mikee was truly hurting
So he's removing him from this land

God said, "Bring him up here to live with me
And I will take his hurt away"
He said, "For you not to worry
You'll see him again someday"

They circled around you and spread their wings
And I knew your were heaven bound
They left this earth without a trace
And left silence all around

So anytime I'm feeling blue
Or perhaps just feeling down
I vision you being lifted up
By the angels that came to town



Beautiful Soul

Your shining spirit lifted into the afterlife that one dark morning.

You knew your time was short, yet you weren't afraid.

Such strength I find myself touched by, I wish I was brave.

Even on your deathbed you told us not to be sad.

Although I must confess I was, and still am.

Your love was more than I have ever seen.

You seemed to have great love for all humanity.

Always giving; your soul was so beautiful.

Now it is somewhere touching someone else up above.

*In Loving Memory of
Renee Haven
Double Lung Recipient*

fort

The Chase Reid Story

A Recipient Thank You

Before Chase Reid was born, his mother Na'Tasha knew her little boy had a long road ahead of him. At 24 weeks gestation, Chase was diagnosed with Tricuspid Atresia, a heart defect present at birth in which one of the valves doesn't form between the two chambers in the heart. After many surgeries, a new heart gave Chase the Gift of Life and a second chance.

“Transplant has changed our lives tremendously, because without it Chase would not be here today.”

Chase's surgeries began at 8 days old. He had five heart procedures, and was added to the transplant list in January of 2010. Five months later, his family received a call about his new heart on June 17, 2010. “Transplant has changed our lives tremendously, because without it Chase would not be here today,” Na'Tasha says.

Chase had a setback two months after he received his transplant when he suffered from a bleed on the brain, also known as a wet stroke. He shows signs of residual side effects from the stroke with slight paralysis on the right side of his face and limited use of his right arm and hand. “Because of



Chase Reid - Heart Recipient and his mom Na'Tasha

his year-long stay in the hospital, Chase is not yet walking or crawling,” Na'Tasha says. “Nonetheless, he is a thriving two year-old child.”

Chase enjoys music and therapy sessions. He went to the zoo recently and especially liked the penguins. “Without a transplant, he would have been very limited with outdoor activities,” Na'Tasha says. “After the transplant, he has no limits. He has a full range of activities like every other child.”

Today, Na'Tasha volunteers for MTS with Chase in spreading the message of organ and tissue donation.

Your Feedback is Important!

Mid-America Transplant Services is committed to providing quality care for Donor Families. To share your donation experience you can contact an MTS staff member by calling the Donor Family priority line or utilizing the Donor Family email address – donorfamily@mts-stl.org. Other ways to provide feedback are completing the Donor Family Satisfaction Survey or Aftercare Satisfaction Survey. Our goal is to make the donation experience a positive one for all families and meet needs as expressed by Donor Families. Donor family feedback is very important because it gives MTS the opportunity to improve our services.

Some changes made following feedback provided by Donor Families include:

- Calls are made to families when the donation is complete
- Option to have donor medals available at the memorial service
- More information provided regarding organs and tissues transplanted and recipient information if available
- Donor photos included in memorial ceremonies

When you receive a survey we encourage you to take a few minutes to provide feedback on the MTS services we provided to your family.

Two Companies Band Together To Save Lives Through Allografts

Reprinted with permission from AlloSource.

Selfless Donors

Through the gift of donation, lives are saved. Though this is widely believed with organ donation, tissue donation is less understood. Yet, when a donor chooses to donate tissue, they are often saving lives as well. In this case, those lives were a world away.

AlloSource, a nonprofit tissue bank, donated allografts to The Foundation of Orthopedics and Complex Spine (FOCOS) to help provide life-saving and life-enhancing tissue to the children of The Republic of Ghana and West Africa.

As a result, lives were saved. Two of those lives belonged to 11-year-old Vivian and 7-year-old Julius.

Vivian: At age two, Vivian was paralyzed with early-onset scoliosis. After being told for nearly a decade that nothing could be done, Vivian's mother located a doctor and FOCOS volunteer who thought otherwise. Six surgeries and one allograft later, Vivian is an active and carefree 11-year-old girl.



Vivian before

Vivian after

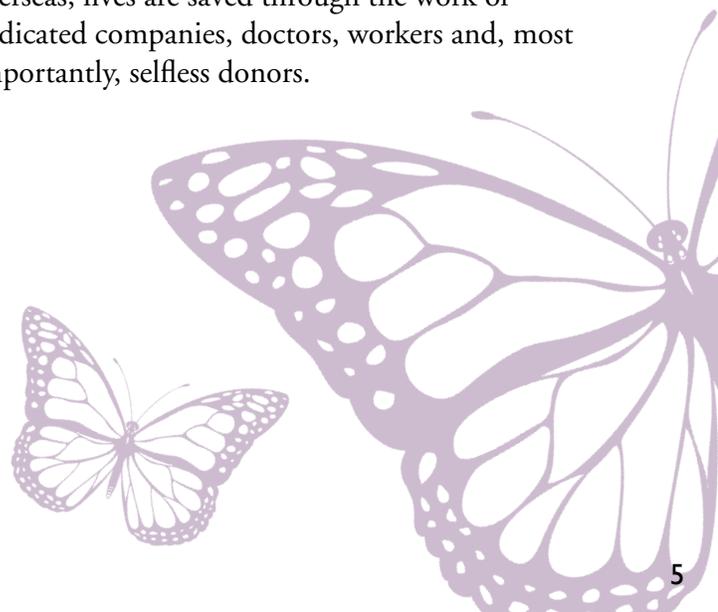
Julius: Seven-year-old Julius suffered from Potts Disease and tuberculosis. These diseases quickly damaged his spine, leaving Julius paralyzed. After a life-saving surgery in November, Julius returned to his village a happy, active and healthy boy.



Julius before

Julius after

Because these two organizations focus on impacting their communities both at home and overseas, lives are saved through the work of dedicated companies, doctors, workers and, most importantly, selfless donors.



Recognize You Are Not Crazy

Excerpt from the book **Understanding Your Grief: Ten Essential Touchstones for Finding Hope and Healing Your Heart** by Dr. Alan D. Wolfelt, Ph.D.

“If you are sure you understand everything that is going on, you are hopelessly confused.” by Walter Mondale

In all my years as a grief counselor, the most common question mourners have asked me is, “Am I going crazy?” The second most common question is, “Am I normal?” The journey through grief can be so radically different from our everyday

“Am I going crazy?”

realities that sometimes it feels more like being picked up and dropped onto the surface of the moon than it does a trek through the wilderness. The terrain is so very foreign and disorienting, and our behaviors in that terrain seem so out of whack, that we feel like we’re going crazy.

I once counseled an older man whose wife had died. Before his wife’s death, they frequently ran errands and drove places together in their car, he at the wheel and she in the passenger seat. Each time they parked outside their destination, the man would turn to his wife and ask, “Do you think we should lock the car?” and his wife would answer, “What’s the point? We don’t have anything worth stealing.” Then, without further ado, they would get out of the car, lock it, and go into wherever they were going. This ritual had started early in their 50-year marriage and had continued until she died.

After her death, the husband continued to drive and do his errands. When he stopped and parked, his body would instinctively pivot to the right and he would start to say aloud, “Do you think we should...” Then he would cry and feel the pain

of his loss. He would also wonder if he was going crazy.

In keeping with the principles of this book, the widower told his friends about his ongoing compulsion to turn to his wife and ask her if he should lock the car. He was expressing a part of his grief outside of himself and he was reaching out for help. But as too often happens in our mourning-avoidant society, instead of affirming that his searching and yearning were normal and that they were helping him encounter his grief and acknowledge the reality of the death, his friends told him he was crazy and that he should see a grief counselor.

And so it was that he came to me. Rest assured that I helped this confused widower talk out his grief. I also normalized his car-locking ritual by helping him understand that it was helping him integrate the death. He wasn’t crazy! His instinct to continue to turn to his wife was very normal, and in grief, learning to follow your instincts is more than half the battle. This man wasn’t crazy, and you’re not either. You may be experiencing thoughts and feelings that seem crazy because they are so unusual to you, but what is unusual in life is often usual in grief.

“Am I normal?”

If you are interested in reading more of Dr. Wolfelt’s writings, you can visit the MTS website at www.mts-stl.org/support/bereavement-resources/griefwords/ for a library of Dr. Wolfelt’s articles or the Center for Loss and Life Transition website at www.centerforloss.com for a complete listing of his books.

Donor Families are the Focus of MTS Center for Life

The focus of the MTS Center for Life is to provide bereavement services to our donor families. The Center for Life serves as a source of information and provides tools for Donor Families throughout their grief journey. Some of the bereavement tools provided by the Center for Life are:

- Books on grief and loss
- Articles for specific relationship loss
- Pamphlets addressing many types of losses
- Grief companion program (donor families helping donor families)
- Donor family private Facebook group (informal online support group)
- Donor family informational workshops
- Donor family memorial events
- Referrals to support groups in your community
- Referrals to professional counselors in your community
- Specific donation information



You can reach the MTS Center for Life by calling the Donor Family Priority Line **800-925-3666** or by email at donorfamily@mts-stl.org. The services and programs provided by the Center for Life are available to you at no cost.

April is National Donate Life Month

National Donate Life Month, established by Donate Life America in 2003, grew out of the federally proclaimed National Organ, Eye, and Tissue Donation Awareness Week, and features an entire month of local, regional, and national activities to show Americans the vital need to join their state organ and tissue donor registry. Because of your family member's generous gift, you already know the importance of organ and tissue donation not only for waiting recipients, but for the human spirit save it brings to Donor Families as well. But, did you know that nine out of 10 Americans support organ and tissue donation, yet only one in three know the essential steps to take to be a donor?

Consider these facts:

- More than 117,000 men, women, and children currently need life-saving organ and tissue transplants
- Every 11 minutes another name is added to the national organ transplant waiting list
- An average of 18 people die each day from the lack of available organs for transplant

This April, celebrate the generosity of your loved one's donation by joining your state organ and tissue donor registry. This gracious act in memory of your loved one will encourage your friends and family to follow your example.

Many donor family members have expressed the healing experienced in their grief journey when participating as a donation advocate, not just in April, but all year long. MTS can help you take some of the following actions:

- Ask your company, association, union, area schools, or other organizations to which you may belong, to hold a donation registry drive
- Become an MTS Passion Panel member and share your story
- Share your loved one's story and picture on the MTS website for Memories and Miracles. You may submit your story along with a photo by email to info@mts-stl.org; Or mail to: Mid-America Transplant Services, 1110 Highlands Plaza Drive East, Suite 100, St. Louis, MO 63110, ATTN: Web Site Testimony
- Tell people you signed up to be a donor

In memory of your loved one, encourage someone you know to join your state donor registry today.

MISSOURI RESIDENTS:

Enroll online at www.DonateLifeMissouri.com or sign up through the Department of Revenue when applying for or renewing your driver's license or non-driver's identification card.

ARKANSAS RESIDENTS:

Indicate your wishes on your driver's license or state ID during the application or renewal process. Register online at: www.DonateLifeArkansas.org

ILLINOIS RESIDENTS:

Sign up online with the Illinois Organ/Tissue Donor Registry at www.DonateLifeIllinois.org or register at any Illinois Secretary of State driver services facility or by phone at **800-210-2106**.

With the first-person consent registry in Missouri, Arkansas, and Illinois, family consent is not required before donation can occur. The documented decision will be honored.

For more information and resources on how you can help become a donor advocate, please contact MTS at **800-925-3666**.

APRIL 2013

April 13 – 4th Annual Life Saving 5k Run/walk

*Hosted by the Celebrate Life Foundation
Raising Awareness towards the miracle of organ & tissue donation
Saturday, April 13, 2013
Registration begins at 8 am
Run/Walk begins at 9 am
Creve Coeur Park • Tremayne Shelter
2348 Creve Coeur Mill Road, St. Louis, MO 63146*

You may register through either of the following links.
www.celebratelife.org/ or
www.events.bigriverrunning.com/celebratelife

April 13 – 2nd Annual Run for Hope

*Healing Grief One Step at a Time
Hosted by Annie's Hope
Saturday, April 13, 2013, 8 am
Queeny Park, 550 Weidman Road,
St. Louis, MO 63011*

For registration: www.annieshope.org

April 19 – St. Louis Donor Family Informational Workshop

*My Loved One was a Tissue Donor...
What Does that Mean?
Friday, April 19, 2013, 7 pm - 9 pm
Mid-America Transplant Services
1110 Highlands Plaza Drive East, Suite 100
St. Louis, MO 63110
Please RSVP by April 17 by calling 314-735-8218*

April 20 – Labyrinth

*Saturday, April 20, 2013
A one-day grief retreat for teens who have experienced the death of a loved one.
Labyrinth is held at Camp Wyman in Eureka, MO.
Offered at no charge to the participants.
Labyrinth is made possible through the support of Magellan Health Services, Friends of Wings, and BJC Hospice.*

For more information, call **314-953-1676** or email griefsupport@bjc.org

April 27 – Springfield Candlelight Memorial

Mid-America Transplant Services invites you and your family to an interfaith ceremony honoring the Organ, Tissue, and Eye Donors who have passed on the Gift of Life.

*Saturday, April 27, 2013
Please join us at 10 am to decorate a special candle to be included in the ceremony
Ceremony will begin at 10:30 am
Campbell United Methodist Church
1747 East Republic Road, Springfield, MO 65804
Please RSVP by Tuesday, April 16, 2013
by calling 314-735-8218*

For more information on any of the events listed above, please visit the MTS website at www.mts-stl.org or call the Donor Family Priority Line at 800-925-3666.



MID-AMERICA TRANSPLANT SERVICES

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Comments or article ideas?

Email us at donorfamily@mts-stl.org

Address Correction?

Address Correction or to be removed
from the active MTS Mailing List
please call us at **800-925-3666** or
email donorfamily@mts-stl.org



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Join Us on Facebook

It is estimated that 50% of Americans today participate in Facebook. As a popular location for family members and friends to reconnect, Facebook provides the opportunity for social interaction at any time of the day or night. Through the new MTS Private Donor Family Facebook Group, the opportunity is provided for Donor Families to connect with others who have experienced similar losses. It is an easily accessible place for individuals to build relationships with other family members who have traveled the grief journey. Started in November of 2012, the MTS Donor Family Group has quickly grown to more than 65 active members.

The MTS Donor Family Facebook Group is a secret/closed/private group. To become a member, you must complete the application for membership located on the MTS website at www.mts-stl.org/support/donor-family-facebook/. Individuals interested in becoming members will be required to read and agree to a disclaimer statement outlining the purpose and guidelines of the Group. The MTS Donor Family Facebook Group has become a place of healing and encouragement for many Donor Families. If you have any questions regarding the MTS Donor Family Facebook Group please contact Sandra Jones at 800-925-3666 or via email at sjones@mts-stl.org.

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