Message from Aftercare

Season’s Greetings! Here at Donor Network West, we are putting the finishing touches on our new headquarters in San Ramon, CA. We have experienced many transitions over the last several months, but throughout these changes, our main focus has been to continue serving our donor families. Here is our updated mission statement, which speaks to our commitment to our donor families:

Donor Network West saves and heals lives through organ and tissue donation. We honor and respect the donors and families we serve with compassionate care, and inspire our communities to donate life.

We find ourselves once again with the winter holidays upon us. In this time of celebration and cheer, we recognize that you may not be feeling in the spirit. This happens to all of us from time to time. If you feel that you need support from any of us during this time - resources, referrals, a supportive phone call - please do not hesitate to contact us. We are always here for you, during this season, and any other.

Warmest Regards,
The Aftercare Team
925-480-3159
aftercare@dnwest.org

Holiday Checklist

As we approach the upcoming season, it is important to reflect on the ways you will take care of yourself. One way to do this is through a checklist. Place a CHECK beside the activities that you would traditionally do and then CIRCLE what you might want to do this year. Share this and talk about it with your friends and family.

DECORATIONS
◊ Decorate as usual
◊ Modify your decorations
◊ Ask for help
◊ Let others do it
◊ Have a special decoration for your loved one
◊ Eliminate the tree or other decorations

TRADITIONS
◊ Keep the old traditions
◊ Attend holiday parties
◊ Go to an entirely new place
◊ Prepare the usual holiday foods
◊ Attend religious services
◊ Do not attend religious services
◊ Attend services at a different time
◊ Attend totally different services
◊ Spend some quiet time alone
◊ Visit the cemetery

DINNER
◊ Prepare a meal as usual
◊ Go out for dinner
◊ Invite friends over
◊ Eat alone
◊ Change time of dinner
◊ Change routine of dinner (buffet)
◊ Change location of dinner (different room)
◊ Ask for help
◊ Cook something to honor your loved one

GREETING CARDS
◊ Mail as usual
◊ Shorten your list
◊ Include a letter
◊ Elect to skip this year

THE NEW YEAR
◊ Spend time as you usually would
◊ Remove decorations early
◊ Go out of town
◊ Avoid New Year’s Eve parties
◊ Attend a New Year’s Eve party
◊ Hold a New Year’s Eve party
◊ Spend time with only a few friends
◊ Write down your hopes for the New Year
◊ Go to a movie
◊ Go to bed early

*adapted from Hospice Calgary
Words of Thanks in a Season of Thanks

For our donor families,

Almost eight years ago, I was fortunate enough to become the Chief Executive Officer of Donor Network West. With a lifelong career spent in healthcare, I knew about the value and benefit to patients of life-saving and life-giving organ and tissue transplants. Little did I realize that I, too, would benefit from the work of my organization. I became a tissue recipient. An oral surgeon rebuilt a portion of my jaw for which he used donated bone and gum tissue. Even though it seems like a small item when compared with the use of skin for a massive burn or restored sight from a corneal transplant, I am grateful for the eventual normalcy that allowed me to chew food appropriately.

A few years after this repair, I became a donor family member. Nothing prepared me for this experience. My precious son died at age 34. At his time of death, I told the nurse to call the donor network. It was the right thing to do. However, it was hard to think about. If you really want to know about your company, become a consumer of its services. I got to see our organization in action: to have an experience like our donor families, to receive support after the donation from our staff, and to honor the generosity of my son by attending the Donor Family Gathering.

It’s not easy to be a donor family member. Having an intimate connection with the process from donation to transplantation, I can’t express enough the gratitude I have towards my donor and the admiration I have for donor families.

Thank you,

Cindy

Donor Family Correspondence by Clea Vannet

In this day and age, it has become increasingly easy to make contact with our loved ones, acquaintances, and even strangers. In the donation world, we respect the rights of donor families and recipients to reach out to one another, or to keep to themselves. Many donor families and recipients make the personal choice to write to one another, and just as many choose not to.

Nationwide, organ procurement organizations and transplant centers respect each individual’s decision whether or not they wish to send, receive, or respond to correspondence.

The decision to write a letter to your loved ones’ recipients is a personal one. You may want to send a letter immediately, or perhaps writing is something that feels more appropriate with time. Or, it may be something that you never choose to do. It is important to know that this decision is yours to make and we support whatever feels best for you.

We have heard from many donor families that have chosen to write to their loved ones’ recipients that composing their letter was healing. Creating a space to share memories of their loved ones’ lives, describing special characteristics about them and including their hobbies and pleasures all add to this experience. You can paint a picture for the recipient that highlights the uniqueness of who your loved one was.

After dedicating time and emotional energy to completing such a letter, many families are hopeful that they will hear back from the recipient. Just as your decision to write is a personal one, so is the recipient’s. Some letters will receive a response, while others will not. In past meetings with transplant centers we have found that many recipients are so overwhelmed by the generosity of strangers who give the gift of life, that their own emotion hinders their ability to express their gratitude in writing.

We encourage you to look at this process as something you are doing for yourself, no matter what the outcome. You can visit our website for advice on how to begin your letter, and how to send it to us: dnwest.org/correspondence. Please know that if you have questions as you compose your letter, we are here to help and would be honored to speak with you.

“Dear Wonderful Donor Family,
How does one begin to thank an organ donor or their family for a second chance at life? Words seem inadequate but I and my entire family want you to know how thankful and grateful we are for your generosity through organ donation...

...It is difficult to adequately express my appreciation, but I want you to know that ‘she’ and all of you are always in my prayers. I am ‘living well’ by taking very good care of this tremendous gift given to me.

With deepest sympathy, love, and gratitude.”
Beyond Grief: Understanding Post-Traumatic Stress Disorder by Karen Adler

In the night of death, hope sees a star, and listening love can hear the rustle of a wing.
– Robert Ingersoll

In my role as a Donor Family Advocate with Donor Network West, I was recently asked by one of my donor families if the grief and loss experience is different when the death of a loved one is traumatic and witnessed. This led me to reflect on how a trauma can in fact impact the experience of loss, and how for some it can present another layer of challenge.

Grief is a normal reaction to loss. When we lose someone close to our hearts, we can feel broken open, wandering a path we have not chosen, deep in a forest of uncertainty and pain. How we experience our own individual grief is personal and unique, and may not fall into a set structure of a given timeline or direction. In other words, our paths may vary and our individual experiences may not look the same.

When a loved one dies, the circumstances of that death may contribute to the responses of grief those left behind may feel. For example, when a loved one dies suddenly and unexpectedly, we may feel that this loss is premature, unjust, and wrong. We may be more inclined to wonder if the death could have been prevented, if we could have done something, anything. The way our loved one dies may shape our response to the loss we are experiencing.

Furthermore, if our loved one’s death has been traumatic, and witnessed, the person or people who witness the death may experience symptoms that are confusing and overwhelming, and can ultimately be debilitating. These feelings and the effects of what we have witnessed can sometimes result in a medical condition called Post Traumatic Stress Disorder (PTSD). PTSD is a mental health condition triggered by experiencing or seeing a terrifying event. This condition is significant and may require professional help.

How do you know if you have PTSD? Your doctor can help you find out by providing an assessment of what you are experiencing. The following is a list of criteria that can help you understand what PTSD looks like:

**Criterion A: Traumatic Event**
There is exposure to an actual or threatened traumatic event, such as death (exposure can be direct, witnessed or indirect, by hearing of a relative or close friend who has experienced the event):

- Symptoms we may experience after witnessing the death of a loved one fit into a criteria and are seen as a significant medical condition, sometimes requiring professional help. The symptoms can include one or more of the following:

**Criterion B: Intrusion or Re-experiencing**
- Recurrent, involuntary and intrusive memories. Note: Children older than six may express this symptom in repetitive play.
- Traumatic nightmares. Note: Children may have frightening dreams without content related to the trauma.
- Dissociative reactions (e.g. flashbacks) which may occur on a continuum from brief episodes to complete loss of consciousness. Note: Children may reenact the observed death in play.
- Intense or prolonged distress after exposure to traumatic reminders.
- Marked physiologic reactivity after exposure to trauma-related stimuli.

**Criterion C: Avoidant symptoms**
- Avoiding thoughts or feeling connected to the traumatic event
- Avoiding people or situations connected to the traumatic event

**Criterion D: Decline in mood or cognitions**
- Memory problems that are exclusive to the event
- Negative thoughts or beliefs about one’s self or the world
- Distorted sense of blame toward self or others, related to the event
- Being stuck in severe emotions related to the trauma
- Severely reduced interest in activities that have been important before the trauma
- Feeling detached, isolated or disconnected from other people

**Criterion E: Increased arousal symptoms**
- Difficulty concentrating
- Irritability
- Difficulty falling or staying asleep
- Hypervigilance (exaggerated behaviors with the purpose of detecting threats – often leads to anxiety and exhaustion)
- Being easily startled

While you may notice symptoms in this list that are similar to experiences you may be having, it is important to mention that having symptoms of PTSD does not mean you have PTSD, and symptoms of PTSD can be similar to what we experience when grieving the loss of a loved one.

This information is not provided to help people diagnose themselves, or to offer medical advice, but rather to provide an understanding of the impact of how witnessing a traumatic event may affect someone. If you are concerned you may have symptoms of PTSD, please contact a professional who can discuss your experiences with you directly. Thank you to the National Center for PTSD, [www.ptsd.va.gov](http://www.ptsd.va.gov) for providing the diagnostic criteria in this piece.

The death of someone you love deeply will always have a profound impact on you, and if the death has been traumatic, you may be affected in ways that are overwhelming and may require support. My involvement in the journey is to offer a direction to that support when needed, and my hope is that every donor family will find a path toward healing, no matter how long and winding the path may be.
D.I.Y. Memory Candles

Here is a fun, simple art project to enjoy with adults and kids alike. We encourage you to be as creative as you would like by adding your own words and memories, pictures, and/or photos. Then, enjoy these memory candles all year long, or bring them out on special occasions.

Materials:
- Glass Jar
- Tissue Paper (the light will shine brighter with lighter colors)
- Scissors
- Glue
- Paintbrush
- Marker

Directions:
1. Cut or tear tissue paper into pieces of different sizes and shapes
2. Use the paintbrush to brush glue onto the jar, then place a piece of tissue paper onto the jar
3. Brush a light coat of glue on top of the tissue paper (it will dry clear)
4. Continue gluing tissue paper onto the jar until it is completely covered
5. Write a memory, poem, or quote, or draw a picture on a piece of tissue paper and glue onto the jar. You can also wait until your jar is dry and write directly onto the jar.
6. When the jar is completely dry, place a candle or an LED candle inside the jar and enjoy!

Would you like to see more ideas for memorial activities to do with your children? Please let us know by emailing us at aftercare@dnwest.org.

Resource Corner: Aftercare Website

Have you visited our website recently? Over the last several months, we have updated and added information that is pertinent and useful to our donor families. Check it out at dnwest.org/donorfamilyaftercare to see what you may be missing!

- Contact information for everyone in our department
- An extensive resource page with a list of grief literature, websites, and links to local support resources
- In-depth information including how to write to transplant recipients, and how to make a quilt square for a memorial quilt
- A change of address form so you can easily let us know when you have moved
- And of course, an archive of past issues of Life Ties

Still haven’t found what you are looking for? Call or email us: 925.480.3159 / aftercare@dnwest.org
The Power of Research by Michael Salvatore

Organ donors can help save and improve lives in many ways beyond direct organ and tissue transplantation – with the power of research donations. Without research donations, transplantation would never have been possible. At Donor Network West, we maximize every gift by contributing to this body of knowledge to continually improve transplant outcomes, in addition to partnering with scientists who work to cure diseases and improve health outcomes. Thanks to the generosity of donors and donor families, we may be able to find better ways to diagnose, treat, and prevent many diseases in the future. Below are a few examples of how research samples may impact the future of healthcare and medicine.

Livers:
Unfortunately, newborns and children die prematurely from complications caused by rare liver diseases. Our partner Cytonet is exploring treatment options for children affected by a rare disease. Cytonet is infusing liver cells into these children with hope to restore their liver to normal function.

Lungs:
Idiopathic pulmonary fibrosis is a fatal lung disease without a known cause. On average, patients diagnosed with this disease die within three years. By comparing diseased samples to donor lung samples, researchers at UCSF are closer to finding potential treatment options and hope to reverse the effects of this fatal disease in the near future.

Pancreas Islet Cells:
Type 1 diabetes affects many people globally; however, scientists don't fully understand what happens in the pancreas to cause this disease. By comparing diseased samples to donor pancreas samples, researchers at UCSF are closer to addressing many unanswered questions and achieving their goal of restoring the body's ability to produce insulin.

Mark Your Calendars!

2016 Rose Parade: January 1, 2016
The 13th Donate Life Rose Parade float, “Treasure Life’s Journey,” will be a part of the Rose Parade on January 1st in Pasadena, CA.
The float features a colorful caravan with sixty donor medal-inspired floragrams that honor the invaluable treasure of the gift of life. Twenty-four float riders continue to share in life’s adventures through the gift of organ donation. Sixteen living donors will walk beside the float carrying provisions of fruit accented with flowers, symbolizing the life-sustaining gifts that have been given. And, Dedicated Roses placed by families create floral jewels that ornament the base of the float.

The Rose Dedication Garden is an opportunity to honor donors, families, recipients and candidates waiting for transplant with a personalized rose placed on the Donate Life Rose Parade Float inspiring tens of millions of people nationwide to save lives as donors.

Visit donatelifefloat.org/wp/ to find out how to dedicate a rose.

2016 Donate Life Run/Walk: September 10, 2016
The 2015 Donate Life Run/Walk was a huge success. Hundreds joined us to walk, run, and dash our way to increasing awareness about the importance of organ and tissue donation. Donor families, recipients, concerned citizens, and even local politicians brought their spirit to Heather Farm in Walnut Creek, CA, and their energy was palpable.
The 2016 event will be held again at Heather Farm on Saturday, September 10. Mark your calendars now – it’s never too early to start planning your teams and your training schedule for this fun, supportive event!
Want to receive future issues of *Life Ties*? If you haven't already, email aftercare@dnwest.org or call 925-480-3161 to be added to our mailing list.

And remember to visit donornetworkwest.org/donorfamilyaftercare for further information and resources.