

# **Reflections & Hope**

A quarterly newsletter honoring organ and tissue donors and their families.

Summer 2014

### **New Aftercare Coordinator and New Newsletter Format**

Hello and thank you for reading this edition of the *Reflections & Hope* newsletter. My name is John Dullard and I have been serving the families of donors as Aftercare Coordinator at Donor Alliance since December 2013. I had worked previously within Donor Alliance as a Tissue Donor Coordinator, and before that I offered care and counseling to hospital patients and their families as a hospital chaplain.

Although I have changed the look and layout, the goal of this quarterly newsletter will continue to be "honoring organ and tissue donors and their families." I plan to do this by having three sections in each publication. The first section will focus on the Aftercare program and how Donor Alliance can offer continued support to donor families. In place of this introductory note, future newsletters will focus on individual aspects of the Donor Alliance Aftercare Program, such as donor memory cards and correspondences between donor families and recipients.

The second section will alternate between topics related to grief and the donation and transplantation field. The third section will vary with every publication, but the theme will be donor families honoring their loved ones. I would welcome submissions of poetry, brief stories, or other ways loved ones of donors have honored the lives and legacies of those who gave the gift of life. It would be my honor to assist you in any way I can. Please do not hesitate to contact me if you have any questions or concerns about donation or the Aftercare program.

Sincerely,

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### The Mourner's Bill of Rights

by Alan D. Wolfelt, Ph.D.

Though you should reach out to others as you do the work of mourning, you should not feel obligated to accept the unhelpful responses you may receive from some people. You are the one who is grieving, and as such, you have certain "rights" no one should try to take away from you.

The following list is intended both to empower you to heal and to decide how others can and cannot help. This is not to discourage you from reaching out to others for help, but rather to assist you in distinguishing useful responses from hurtful ones.

#### 1. You have the right to experience your own unique grief.

No one else will grieve in exactly the same way you do. So, when you turn to others for help, don't allow them to tell what you should or should not be feeling.

#### 2. You have the right to talk about your grief.

Talking about your grief will help you heal. Seek out others who will allow you to talk as much as you want, as often as you want, about your grief. If at times you don't feel like talking, you also have the right to be silent.

#### 3. You have the right to feel a multitude of emotions.

Confusion, disorientation, fear, guilt and relief are just a few of the emotions you might feel as part of your grief journey. Others may try to tell you that feeling angry, for example, is wrong. Don't take these judgmental responses to heart. Instead, find listeners who will accept your feelings without condition.

## 4. You have the right to be tolerant of your physical and emotional limits.

Your feelings of loss and sadness will probably leave you feeling fatigued. Respect what your body and mind are telling you. Get daily rest. Eat balanced meals. And don't allow others to push you into doing things you don't feel ready to do.

#### 5. You have the right to experience "griefbursts."

Sometimes, out of nowhere, a powerful surge of grief may overcome you. This can be frightening, but is normal and natural. Find someone who understands and will let you talk it out.

#### 6. You have the right to make use of ritual.

The funeral ritual does more than acknowledge the death of someone loved. It helps provide you with the support of caring people. More importantly, the funeral is a way for you to mourn. If others tell you the funeral or other healing rituals such as these are silly or unnecessary, don't listen.

#### 7. You have the right to embrace your spirituality.

If faith is a part of your life, express it in ways that seem appropriate to you. Allow yourself to be around people who understand and support your religious beliefs. If you feel angry at God, find someone to talk with who won't be critical of your feelings of hurt and abandonment.

#### 8. You have the right to search for meaning.

You may find yourself asking, "Why did he or she die? Why this way? Why now?" Some of your questions may have answers, but some may not. And watch out for the clichéd responses some people may give you. Comments like, "It was God's will" or "Think of what you have to be thankful for" are not helpful and you do not have to accept them.

#### 9. You have the right to treasure your memories.

Memories are one of the best legacies that exist after the death of someone loved. You will always remember. Instead of ignoring your memories, find others with whom you can share them.

## 10. You have the right to move toward your grief and heal.

Reconciling your grief will not happen quickly. Remember, grief is a process, not an event. Be patient and tolerant with yourself and avoid people who are impatient and intolerant with you. Neither you nor those around you must forget that the death of someone loved changes your life forever.

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### **Family Lives On Foundation**

#### Bringing joy and comfort to children, teens and families by continuing cherished traditions.

"If you can't perform, you provide" is a phrase that is taught to chaplains and grief counselors when they are first beginning to care for others. What this means for those who offer care and counseling in the hours and days after a loss is to be prepared to connect the people in your care with resources outside of your role as a short-term caregiver. I hope to apply this principle in my role Aftercare Coordinator and would like to share some information about an organization that I recently learned about. – *John Dullard, Donor Alliance* 

**Family Lives On Foundation** supports the lifelong emotional well-being of children whose mother or father has died. Our Tradition Program provides opportunities for intentional remembering, creating a safe haven for grief, communication and celebration.



"By still practicing traditions that I did with my mom, it allows me to bond with my sister and my dad, just the three of us. And also with my mom because I know she's always with me." -Alexis, Family Lives On Program Alumni

Parents embrace our Tradition Program because it takes place within the context of family life and promotes healing conversations. Family members participate in the tradition independently of Family Lives On volunteers. Children and teens embrace it because they get to select which tradition they want to continue (and are excited about doing so). And, because we facilitate the tradition until the child turns 18, their traditions continue to support family connection and communication and provide opportunities to celebrate a loved one's life story. We serve all children ages 3-18 regardless of race, gender, religion, socioeconomic status, or the cause of the parent's death or illness.

#### WHY:

There are more than 2 million children and teens in the US grieving the deaths of their moms or dads. 1 in 20 children experience the death of a parent before the age of 16 – that's 1 in every classroom, 2 on every school bus.

Research shows that bereaved children are at 2 to 3 times greater risk for psychological problems than nonbereaved children and are more likely to spend time in jail than their non-bereaved peers. Children with unresolved childhood grief following the death of a father are 5 times more likely to commit suicide, 9 times more likely to drop out of high school and 20 times more likely to have behavioral disorders.

Children who are able to maintain emotional connections with their deceased mothers or fathers are more likely to adapt to their loss and navigate grief in a healthy manner and to avoid emotional, psychological, physical, and behavioral problems.

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### Family Lives On Foundation, continued

While death is a normal part of living, it can be a traumatic experience and have a serious impact on a child or teen's growth and development. Children grieve differently than adults and often their pain is not recognized or understood. Some may develop unhealthy patterns of expressing their grief, and may experience physical complications, depression, anti-social behavior, failure in school, or involvement with the judicial system. (The Center for Grieving Children)

#### HOW:

Family Lives On provides free direct services to children and teens who are grieving the death of a mother or father through the use of our "Tradition Program" - a therapeutic tool that supports the bereavement process and enables children to move from survivors to thrivers, from "at risk" to "at promise."

We help them continue traditions they used to celebrate with their mother or father - but we don't do it with them. We just provide all they need - amusement park tickets, baking ingredients, etc. for a surviving caregiver to do the tradition with them. It promotes intra-family connection and communication, provides ongoing support and helps maintain a healthy connection with their deceased parent.

In our 16 year history, we know what we do works - and it works for many reasons. Not the least of which is that the average child remains in our program for several years. Every child participates until age 18 - we provide the free direct services.

After an extensive preparation and process phase, we are now preparing for accelerated national expansion - please share this information with families who can benefit from our services.

#### For more information about Family Lives On, and to enroll a child in the Tradition Program, please visit: www.familyliveson.org

We welcome stories, poems, pictures or ideas for future editions. It is essential to us that this newsletter grows from the hearts and minds of our donor families. Thank you for your participation. Please submit your input by mail or email to the address listed below.



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Donor Alliance is a non-profit organization dedicated to saving lives through organ and tissue donation and transplantation. Register to be an organ & tissue donor and share your decision with your loved ones. Follow us on the Web: www.donoralliance.org | www.donatelifecolorado.org | www.donatelifewyoming.org