

# Connections

A Newsletter from the Family Partners Program, an Initiative of the LPCH Palliative Care Program

*The Family Partners Program at Lucile Packard Children's Hospital Stanford is a group of bereaved family members who work on a variety of initiatives designed to improve aspects of care for families facing the death of a child.*

Crying. Sometimes you cry when you least expect it. At other times, you wait but your eyes remain dry. Like grief itself, our tears are not always under our control.

In the presence of others, we often reach for a tissue and apologize when we start to cry. It is a reaction we have learned, but what are we apologizing for? Yes, our sadness may be uncomfortable for others - few of us were ever taught how to respond to sadness with anything other than a tissue - but our grief does not require an apology. Feeling the depth of our love for our child and our loss is a fact of our lives. It is ok to reveal our loss through our tears. We need to allow that flow of emotion - it is part of our healing.

The next time you feel yourself on the verge of tears, try to not hold back. However inconvenient, accept that this is where you are right now. If you need to find a private space, that is ok. But don't apologize. We ache that our children are missed, but we are not sorry for our love.

We wish you a meaningful and peaceful holiday season.  
The Family Partners



## Some ideas to make the holidays easier

Holidays remind us of family and of traditions. Familiar reminders, but nothing is as it used to be after the loss of your child. Some ideas that may help:

- ◆ Grief can take a lot of energy, so try to balance social time with alone time to recharge yourself.
- ◆ It is ok to change traditions. If you need to do things differently to help you through this time, that is ok.
- ◆ Share memories and remind others that it is ok to talk about your child. Family and friends sometimes think that talking about your child will make you feel worse, but many parents find that sharing memories can be affirming and comforting.
- ◆ It is ok to laugh and have a good time. Pleasurable experiences don't diminish the love you have for your child.
- ◆ Allow yourself to express your feelings.
- ◆ Consider creating a special holiday ritual to remember your child: for instance, light a candle or have a special memory time.

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### Our Mission Statement

The Family Partners Program supports families and their communities facing the death of a child.

### I am Happy Again

*Leilani Schweitzer, member of the Family Partners Program, shared these words about her grief journey at the Annual Day of Remembrance and Rededication in October.*

I don't want to be here. I wish none of you were here either. I want us to be celebrating graduations, or cheering together at a soccer game or meeting at a school picnic. I don't want us to share the bond that we share, but we do.

My son Gabriel died at Lucile Packard Children's Hospital, nine years ago. I think it was nine years, I am always amazed and a bit dazed by that number. How can that number be growing, but he is not? How can it be nine years ago, and also yesterday? This wrinkle in time is something few understand, those few of us who have lost our children. We understand time cannot be measured. We know there are two times now, "The Before" and "The After."

He died when he was 20 months old. There was a long series of medical errors that added up to him dying. Many, many hearts were broken, mine, my family, his nurses, his doctors, the devastation was vast and complete. This happened in the same days Hurricane Katrina crashed into the Gulf. In those days everything was a swirl of disaster, after Gabriel died anything seemed possible—every terrible, awful, horrible nightmare felt completely real.

And people would say to me, "This is the worst thing that could ever happen to you." I really hated hearing that, it was the exact opposite of helpful. I did not want that doom of darkness, I

did not want the worst thing that could happen to anyone to have happened to me. I wondered if I would ever feel happy again. I doubted it.

I lived in a state of grace for a couple years. Somehow avoiding grief, staying busy, never sitting still long enough to feel what had happened to me. Then, I could not avoid it any longer, and the grief hit me. Like a big truck. I didn't understand why I had to lose my son and have my heart ripped open. Now I know the restorative power of grief, but I didn't then.

Now his death is part of me, not all or most of me, but part. Possibly the best part. That is how we should leave our marks on this planet, not with big gravestones, or complicated wills and testaments. When we die, the people we leave behind should be so greatly touched by our existence, that they become better—stronger and smarter, more beautiful and less serious. I hope that is what Gabriel did for me. His death broke me, cracked me open and nearly destroyed me, but I did not die along with him. I will never 'get over it,' and I don't want to. Because he is in my cells.

It took a long time to learn this, but this is my truth. His life was his, and it was exactly as it was supposed to be. As parents, we are possessive of our children, they are our most precious property—we guard, nurture, do our best to prepare them, but they do not belong to us. We are simply witnesses to their participation in the world, and lucky, lucky us, we have VIP seating with backstage passes to watch the amazing show.

I must be clear. I do not like what happened to Gabriel. If I could, I would rewind all of that avalanche of catastrophe. But I can't. It is a horrible, horrible thing, but it happened. It just is. I will never stop wondering what he would look like, how tall would he be? What color would he prefer, what foods, what music? Who would he be?

And I want to hear his voice, and learn his thoughts. When he died he was not yet talking. I am so disappointed he left before he told me his secrets. I wish he would have stayed, I would be so much smarter now. But he didn't stay, he wasn't supposed to. He taught me all he could and left me to figure out the rest. That is the only way it could be.

This is my advice to you, though you probably already know it. Losing your children will make you will lose your minds (for a while, not forever), the pain will be crushing but not deadly. Please be kind to yourselves. Death is really, really hard, and there is no work-around for the pain. I tried that, but the power and importance of it is too remarkable. It cannot be ignored. Pain and pressure is what our spirits require to recover, it is like setting a broken bone in a cast, we have to hold still and sit with it—be careful about how much weight we put on it. But no matter how hard we try, we cannot force the bone, or our spirits, to heal.

Now I work for Stanford. I work to help people after they have experienced a medical error. I take what I have learned from Gabriel's death and try to use it to help other people. And that makes his life bigger. And it heals me.

I still have dark days. The cloudy, overcast days that do nothing good for my mood. I am sad and I am lonely, but I am also completely fine. I know the heaviness will not last, it will lift. The waves of grief lap at my knees and splash up to my hands. But I am no longer afraid of drowning, my head may dip under the surface for a while, but I am familiar with the cold, murky water, and it does not scare me to a panic. I know to hold my breath and wait for the current to push me back to the surface.

And I am happy again.



*The morning glory blooms but for an hour  
And yet it differs not at heart  
From the giant pine  
That lives for a thousand years.*

*- Teitoku Matsunaga*

*For more information or to sign up for any of the following events or programs, please email [bereavement@stanfordchildrens.org](mailto:bereavement@stanfordchildrens.org) or call the office at (650) 497-8175.*

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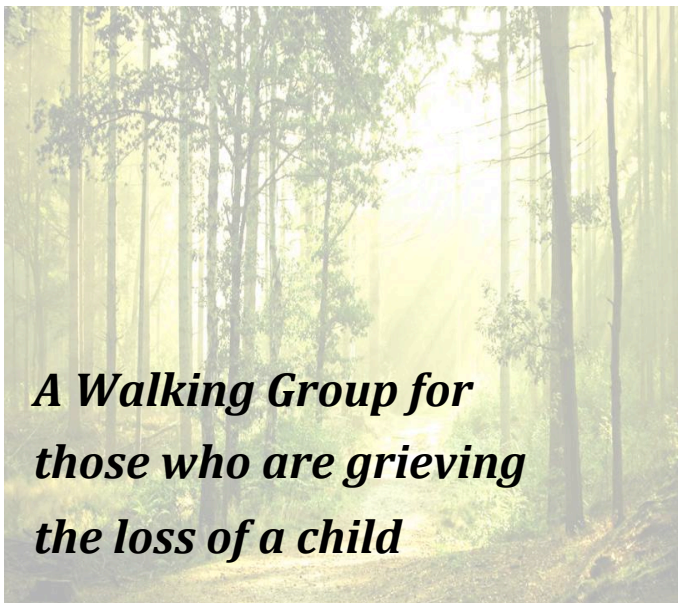
## **Family Memory Making Day**

### **April 18, 2015**

A special day for bereaved parents and siblings at the National Center for Equine Facilitated Therapy in Woodside, CA. This event will give siblings a chance to share stories and engage in fun activities, including guided horseback riding. Parents will also have the opportunity to connect with other parents and engage in a meaningful memory making activity.

If you would like to receive an invitation to Family Memory Making Day, email [bereavement@stanfordchildrens.org](mailto:bereavement@stanfordchildrens.org) or call (650) 497-8175. Please include: your name, address, email, and sibling age(s) and gender(s).

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The Walking Group is an opportunity for bereaved parents to socialize and share experiences. Please join us as we walk in lovely areas near or on the Stanford campus.

We are planning to meet for a weekly, hour long walk. If you are interested in joining us, please let us know if you prefer a weekday or weekend time. The group will start when we have a minimum number of participants.

### Memory Bear Project

A memory bear is a unique way to honor and remember your child. Sewn from your child's clothing or other fabric, this bear can be a source of comfort and treasured memories.

We would like to offer families the opportunity to have a bear made free of charge. If you have questions or are interested in having a memory bear made, please contact our office at (650) 497-8175 or [bereavement@stanfordchildrens.org](mailto:bereavement@stanfordchildrens.org).



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The heart that truly loved never forgets.

-Thomas Moore



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### For Grandparents

If you know a grandparent who would like to receive our newsletter, be invited to our annual Grandparents' Brunch or participate in other special events, please send their contact information to [bereavement@stanfordchildrens.org](mailto:bereavement@stanfordchildrens.org) or call the office at (650) 497-8175. Please include their name, address, email and the name of your child.

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### Family Partners Bereavement Library

#### **A source of information and support for child loss**

The Family Partners Bereavement Library has a growing collection of books on child loss for all ages. Categories include books for parents, siblings, grandparents, caregivers, schools and the community. The library also includes Spanish language sections for children and adults.

If you would like to donate a book in memory of your child, we offer bookplates that can be dedicated with a beautiful personal note.

#### **Library hours and location**

Monday-Friday 9:00am-5:00pm

The Barn at 700 Welch Road, Suite 114A, Palo Alto (*across the street from LPCH*)

## Calendar of Community Events

<p><b>December 4, 2014</b></p>	<p><b>Kara Annual Gathering of Remembrance, 7:00pm</b>            Each year Kara invites the community to join together to remember loved ones and significant others who have died. This is a non-denominational service open to all. Held at First Presbyterian Church, 1140 Cowper Street, Palo Alto (directly behind the Kara office on Kingsley). For more information, please call (650) 321-5272.</p>
<p><b>December 7, 2014</b></p>	<p><b>Annual Winter Memorial Service, 2:00-4:00pm</b>            Wings of Remembrance on Sunday, December 7 from 2:00-4:00pm at Hospice of the Valley 4850 Union Avenue, San Jose. (408) 559-5600.</p>
<p><b>December 7, 2014</b></p>	<p><b>Pathways Hospice Celebration of Light Memorial Service, 2:00-3:30pm</b>            Attendees of all ages are invited to the Celebration of Light Memorial where they will light a candle of remembrance, hear inspirational readings and join others who are grieving in a place of quiet and warmth. The service will be held on Sunday, December 7th from 2:00-3:30pm at Skylawn Memorial Park, Highway 92 at Skyline Blvd, San Mateo. Open to the public, free of charge and light refreshments will be served after the service. RSVP's are encouraged but not required to (888) 905-2800 ext. 4241 or bereavement@pathwayshealth.org.</p>
<p><b>April 18, 2015</b></p>	<p><b>LPCH Family Memory Making Day</b>            Please see details on page 4.</p>
<p><b>May 3, 2015</b>  <b>May 17, 2015</b></p>	<p><b>Pathways Hospice Evening of Remembrance Memorial Service, 3:00-4:00pm</b>            This memorial service includes music, moments of reflection, readings, and the creation of a remembrance flower bouquet. Pathways Hospice is offering two Evening of Remembrance Memorial Services. One on Sunday, May 3, 2015 from 3:00-4:00pm at Chapel of the Chimes, 4499 Piedmont Avenue, Oakland and another on Sunday, May 17, 2015 from 3:00-4:00pm at Skylawn Memorial Park, Highway 92 at Skyline Boulevard, San Mateo. Open to the public, free of charge and light refreshments will be served after the service. RSVP's are encouraged but not required to (888) 905-2800, ext. 4241 or bereavement@pathwayshealth.org.</p>

## Contact Us

**For more information and other resources available from the Family Partners Program at Lucile Packard Children's Hospital Stanford, please contact: Nancy Contro, LCSW, Director of the Bereavement and Family Guidance Program and the Family Partners Program, ncontro@stanfordchildrens.org, (650) 497-8304.**

### Additional Hospital Support Services

Social Services: (650) 497-8303      Chaplaincy: (650) 497-8538 or (650) 723-6661, pager #27729  
 Child Life: (650) 497-8336      Palliative Care: (650) 497-8963 or (650) 723-6661, pager #19474