

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.

At our first Family Memory Making Day in April, we ended the day by watching two very special horses run off into the hills. These horses were so special because they were carrying precious messages and wishes we had written to our children who have died.

After writing our loving thoughts on colorful papers, each family member - parents, siblings and grandparents - had the opportunity to tie their message to the horse's mane or tail. As we watched each other take turns carefully tying each message, we were quiet, contemplative and, of course, excited.

With great anticipation, the moment came to let the horses go, and off they went!...for about twenty feet, when they stopped for a snack of fresh grass. But then they continued up the hill, finally disappearing from our sight after passing a large oak tree. It was a beautiful end to a very meaningful day.

Whether traveling by horse or the invisible ties that forever bind us to our children, may the messages of your heart reach your child every day.

Warmly,
The Family Partners

Save the Date

*The Tenth Annual
Day of Remembrance and Rededication*



Sunday, September 27th, 2015

1:00-4:00pm

Arrillaga Alumni Center, Stanford University

Invitation to be sent this summer

Contents

Family Perspectives	2, 4
Events and Programs	3, 5
Calendar	6
Contact Us	6

Our Mission Statement

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

This Is My Tribute

Jennifer Massoni Pardini has written extensively about loving and losing her first child, Lorenzo, when she was 24 weeks pregnant. Two years later, she is raising her daughter, Hazel, and writing a memoir about her son. You can learn more about her journey at www.jennifermassoni.com.

Writing *this* is all I do. Writing *this* is everything I do.

I journey here and I journey to my parallel, private writings about my son, and those are my main avenues to any real sense of "arrival"- that feeling that you are interacting with a larger aspect of the world. I no longer get that feeling from teaching an English class, say, or interviewing someone for an article. I'm (not) sure I will again, but for now I arrive right here, at a writing table that has traveled from New York City to San Francisco to Santiago.

I have to come to it, sit at it, open the pages that talk about Lorenzo, and circle back over the week where we had an ultrasound in Santiago on a Monday afternoon and I delivered him on a Saturday morning back home in California. I have to go over it to understand and come to terms with the information we gathered, the impossible decisions we made as parents, the expressions on the faces of the doctors and the nurses as they told us we were still good parents, the sense of how grave everything really was because of the kindness that was extended to us from all sides, and the once unfathomed emotions that are now part of the rest of everything. I have to go over it because it's impossible to accept what happened on a Friday afternoon into Saturday morning without first understanding what happened on Monday and Tuesday and Wednesday and Thursday. For now, those days are still very private.

I reach out from that privacy as I can. I write *this*. I access a compassionate community I never knew existed: a series of beautiful people I have sought and found through a process that began

with a hospital-appointed social worker in a delivery room and continued through calls to three grief counselors who all got back to me immediately. The process included somewhat desperate emails to two other mothers like me who I hoped might help me deal with the impossible emotions that come tethered to the decisions Ryan and I had to make as parents. The process led to adopting our dog, Ruby. The process then hit a wall, as I gathered contact information for some dozen professional therapists, only to never reach out. Really, *I*, no longer sure of where to turn to get the emotions out, hit the wall. I found an acupuncturist instead. He told me to drink grapefruit juice to help my liver, which I've learned is also responsible for filtering our strong emotions - our extreme sadness or fear or happiness.

Like that week from diagnosis to decision, the process also circles. I email the other baby loss moms, I walk Ruby, I go to the acupuncturist, and I sit down here. A few circles ago, one of those moms asked what we were planning to do in tribute to our son. Very early on, before we returned to Chile, I thought we would hold some sort of ceremony in California, where Lorenzo was conceived on our first wedding anniversary in Carmel (it always seemed very meant to be that way) and where he came to rest in my arms in the hospital where I was born (as it never seemed meant to be). But it would have been lodged forever in the still raw wound of *this*. Since then Ryan and I have not been in a rush to figure it out. Lorenzo lives in our hearts always. He taught us that our life here together is but a nanosecond, but that that doesn't mean we don't have to be patient.

Recently, the same mom suggested that perhaps my writing *this* is my tribute. I love her for saying so, and I think she's right. I think it's always been about that, consciously and not so consciously. In writing about Lorenzo, he somehow travels out of that anguished week and through me and into your minds, however you picture him or gain meaning from his life.

I'm learning that there are many ways to tell the story of grief, of losing, of who the person who changed you so categorically really was. I don't know who Lorenzo was going to be. He was not going to be the healthy-hearted boy I keep dreaming about when my mind ventures too far from the realities of that week. That would be as much a fantasy had he lived outside of me as it is to me now. But I still wonder what he would have been like or the funny things he might have said if he lived long enough to see humor in the world or all the terrible pain that would have led up to then because we decided to bestow it upon him. I can only tell you that he and babies like him are so loved, so missed, so whole in our minds it's as if they grew and ran and laughed. It's as if they lived entire lives before they spiraled back down into the moments when we lost them. They did live their entire lives.

I don't expect you to relate. Sometimes I can't even relate to other parents like us because I catch one different detail and spin out from there... Oh, but she didn't deliver. Oh, but he wasn't her first child. Oh, but she didn't have to make that choice. I'm sure the delicate bridge we're walking across teeters when others arrive at the differences in our story. It makes us ask: How do I live through *this* exactly if no one else did exactly? These bereaved journeys are terribly unique. But as much as I search for our story out there, I don't wish for anyone else to know exactly what Ryan and I know exactly. I only wish that we continue to see one another across our respective fields of adversity. That is what compassion is. That is why we try to share. That is me writing *this* to you.



Sometimes love lasts a moment.

Sometimes love lasts a lifetime.

Sometimes a moment is a lifetime.

~ Author Unknown

Annual Bereaved Grandparents' Brunch

After receiving feedback from grandparents about summer scheduling, we have decided to move our annual Grandparents' Brunch to February. Please check the December newsletter for the new date. If you know of a grandparent who would like to receive an invitation, please send their contact information to bereavement@stanfordchildrens.org.



The Driving Power of Hope

by Matthew, brother of Mia and Laine

Over the past eight months, the very foundation of my life and my views on what is necessary to live have been shaken. I now feel enlightened on the meaning and importance of hope relative to my days as a nine-year-old. Five years ago, I thought of hope as nothing more than a superficial attribute that some people possess. Hope did not give anything real or lasting. All it would do is fill people with an empty and temporary happiness that would soon fade away. Now, I feel like hope is fundamental to all humans, and it is the driving force for why we live our lives in a world that can often be quite unfair. My thoughts and beliefs all started to change about four years ago.

Being nine years old, I had nothing to fear, nothing to bring me down, and no responsibilities to burden my shoulders. I was the happiest boy to ever live, possessing two loving parents and two wonderful younger sisters. However, my entire life was about to change that year. On June 24, 2010, my six-year-old sister Mia died. My mother and father were horrified. My littlest sister Laine, who was almost three then, had a vague idea about the circumstance, only partially understanding what was happening. For me, it was the most devastating experience in my life. However, as a nine-year-old, I was not old enough to take the full force of a tragedy like this. This shock and despair was a new and horrible feeling to me, lasting for months upon months. I could not figure out why I was so upset and distraught even when I was not thinking about Mia. Not wanting to do anything, I just couldn't see that tomorrow would be any better, because the fact was that my sister Mia would always be dead.

Gradually, as years passed, I began to accept Mia's death and moved forward. After all, I had my littlest sister Laine, right? Well at the time, the answer was yes. Playing with and caring for my sister, we shared many great times together. I felt like I had been blessed with a companion that

would be with me through my entire life. Possessing genuine happiness, I could almost forget the pain of losing Mia.

That is, until I had to experience the horror of losing a family member for the second time, and this time, unlike my experience as a nine-year-old, I took the full force of tragedy. Eight months ago, on February 24, 2014, Laine died from appendicitis. She died when she was six years old, just like Mia. I could not comprehend the overwhelming grief and sadness. Life had dropped not one, but two atomic bombs. Gradually, my senses came back, but that sense of life being pointless would not cease. I could not see the light at the end of the tunnel, and I started questioning life altogether. *Is life worth living? Why should I live just to go through all of this? What has happened to me as to even be asking these questions?*

Slowly, but surely, some answers came. I could never change the fact that I lost both of my sisters at such young ages. However, I realized that all I needed was simply one thing: hope. Hope was a trait I had seriously devalued, and I realized I needed it in order to keep going on in life.

Everyone has hope. They just don't realize that. If a student has a very stressful day, there is a hope that tomorrow will be better. Hope gives people the power to push on even when times are dark. Life for most people in this modern world is filled with more negative times than positive times. Combined with school, work, relations, death, and much more, many people would find it hard to live without hope that good times will soon come around. As for me, I hope that my future will be brighter, I hope that I will be happier, and most of all, I hope that I will see my sisters again.





*Moments from
Family Memory
Making Day 2015*



Calendar of Community Events

<p>Summer 2015</p>	<p>Pathways Hospice Summer Workshops Various workshops that will be available in Sunnyvale, Oakland and South San Francisco include: Moving through Grief with Writing, Memorial Garden Creation, and Meditation and Grief. For dates of upcoming workshops, please go to www.pathwayshealth.org. For more information and to RSVP, email bereavement@pathwayshealth.org or call (408) 773-4241 (South Bay), (650) 808-4603 (South San Francisco) or (510) 613-2092 (East Bay). Pathways bereavement services are open to the community and free of charge.</p>
<p>Sept. 27, 2015</p>	<p>LPCH Annual Day of Remembrance and Rededication, 1:00-4:00pm Invitations will be mailed this summer.</p>
<p>October 10, 2015</p>	<p>Kara 2015 Walk 'n Run to Remember, 10:00am This annual event is a unique opportunity for individuals and organizations to walk or run in memory of a loved one and support grieving friends, family and community members. For more details, visit www.kara-grief.org.</p>
<p>October 11, 2015</p>	<p>Healing After Neonatal Death (HAND) Annual Service of Remembrance, 1:00pm An event for families to celebrate the memories of their babies. Features music, poetry, readings and a potluck meal. Family members and friends are welcome. Contact Janice Kelley for location, janice.kelley1@juno.com, or visit www.handonline.org.</p>
<p>October 11, 2015</p>	<p>HAND of the Peninsula – Annual Service of Remembrance, 10:00am Miwok Shelter, Huddart Park, Woodside CA. All parents, relatives and friends are invited to join others to remember their babies. Breakfast, beverages and snacks will be served. Contact: sor@handsupport.org.</p>
<p>October 23-25, 2015</p>	<p>Meadowlark Father's Grief Retreat Meadowlark was created to give grieving parents a place to share their stories and feelings with others who had been through the same kind of loss. This retreat is designed for fathers who have lost a child. Interested fathers should contact either: Debbie Lee, Executive Director, Tim Griffith Foundation at debbielee@timgriffithfoundation.org/(408) 386-6446 or Leslie Chin, Facilitator, Meadowlark Retreats, leslie_chin@msn.com. Meadowlark Retreats are presented by the Tim Griffith Foundation. For more details about the retreat: www.timgriffithfoundation.org.</p>

Contact Us

Bereavement and Family Guidance Program • Family Partners Program

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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