

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.

A new year. A graduation. A job change. These are common transitions we encounter as we go through life. But transitions, even positive ones, include loss. And after our child's death, transitions can feel harder; not only because we may feel less equipped to manage change, but because a transition can echo that greatest loss we have experienced, the loss of our child.

Changes to the landscape of the world we knew when our child was alive can also be quite painful: a local playground that was updated, painting a room in your home, or when a sibling enters a new school. Again, changes that are positive, but that can hold deep emotion for bereaved parents.

As we enter a new year, remember that grief is emotional heavy lifting, and transitions can be too. This is a time to treat yourself gently, and to check in with expectations that you should be able to handle something better than you are. Transitions, like grief, do not have a set timeline, they have *your* timeline. As you meet life's changes and transitions, big and small, we wish you a spirit of gentleness and compassion.

Warmly,

The Family Partners

Family Memory Making Day April 22, 2017

A special day for bereaved siblings and their parents 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 attend Family Memory Making Day, email bereavement@stanfordchildrens.org or call (650) 497-8175. Please include your name, address, email, and sibling age(s) and gender(s).



We hope you will join us for a fun and meaningful afternoon with horses and other animals, memory-making activities and ice cream sundaes!

Our Mission Statement

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

Lament, Gratitude and Hope

This talk was presented by Mathai Mammen at the 2015 Day of Remembrance.

These three emotions Lament, Gratitude and Hope swirl, churn and whirl in the days, weeks, months and years following the loss of one's child. As you all know so well. One emotion can dominate for some time, morph into another and surge back at unexpected times. What I have to say to you today is structured similarly – a swirl of emotions – it's messy, but it's what you all and my wife and I feel. It's our reality.

Two of my three children have died. Each one is and was precious to me:

Mathew is now 14 and is currently in the 9th grade. Mia died 5 years ago at six years old, and Laine died last February also aged six. The life, well being and happiness of each one of them was and is more important than my own life, well being and happiness. My wife and I had expected, somewhat naively in retrospect, a more idyllic life. We had wanted several children, boys and girls. We imagined teaching them well so that they would be strong and kind and happy adults with their own families in time.

Mathew was born on a special day – the first Christmas in the new millennium, December 25, 2000. He was also born in the year of the gold dragon, which happens once every 60 years. And he was born with such intelligent eyes and an engaging face. Then came Mia on July 11, 2004. She too had a kind face. But we imagined she had more trouble engaging with us even as an infant. It was our imaginations, we were sure. We spoke of how Mia was probably going to go through a tough period – when we said tough, we meant door slamming, eye rolling, talking back and

the craziness of the teenage years. We did not imagine the storm that was coming.

Lament:

It turned out that Mia was sick. Quite sick, and became especially sick every time we fed her. We worked with the good doctors at Lucile Packard to try and figure out food for poor Mia, but ultimately failed. We set up a make-shift ICU of sorts in her bedroom. Anna and I, Anna more than I, handled all her medical needs 24 hours a day. It was very tough and involved not sleeping very much. But we loved her more than life itself and wanted to do our best for her. We managed to take Mia and Mathew to Disneyland with all her medicines and pumps. Mia loved Mr. Toad's Wild Ride and Dumbo the best. While Mia never spoke, she laughed out loud on Dumbo while Anna held her. Although we did not realize it at the time, we were mourning Mia's death every day, a little at a time, because she was so sick.



Gratitude:

From deep within the chaos at home, new life was sparked and Laine was born on August 17, 2007, three years after Mia was born. Laine was literally like an angel on a mission. She slept with Mia, as we had no

choice. She hugged Mia at night. And her presence during Mia's painful and nauseating TPN infusion was more helpful to Mia than was her morphine. Laine grew closer and closer to Mia. She was deeply empathetic, knowing Mia and knowing all the people around her. We were grateful for our angel Laine.

Lament:

Mia died on June 24, 2010 at nearly six years old. Why did this have to be? This was not fair, we thought. We were not supposed to be burying a daughter. We fought hard to not turn bitter. It would have been easy to just get angrier and angrier, with ourselves, with each other, with family and friends, with God, and with life. Young Laine was a very important part of why we did not spiral. Her empathy was tremendously valuable, therapeutic even. She helped us as she had helped Mia.

Gratitude:

Laine was a special little girl. She loved people, and people loved her. She prioritized connections with others more than anything else. Deep connections. She could look into someone's eyes, and truly see their souls. Her singing filled our house every day. And she was funny. Laine told us that she got married when she was four years old. Her husband was called Prince...of course. Prince was 8 years old. She had nine (imaginary) children, and she kept a calendar on which she recorded their birthdays and various scheduled activities. One day when I was driving with her down El Camino near Café Barrone, Laine was making strange noises in her car seat. Ooh...Ahh. I said "Laine, what is wrong?" She replied, "Daddy, I just had a baby!" Now she had 10 children.

Laine demonstrated profound warmth for someone so young, perhaps because of her sister Mia. For example, during the first day of kindergarten, Laine

knew that anyone new would be nervous and even scared. There were new girls entering her class. As each one came in, she left her friends, went to them, gave each a hug, took them warmly by their hands, and led them to her friends. We felt gratitude for having a girl that had so much empathy and warmth. She never denied her sister Mia, constantly talking about her to friends and strangers. She would introduce the topic of Mia to everyone – the baristas at Starbucks knew all about Mia through Laine. When with Mathew at the park, Laine would jump into conversations with adult strangers, starting with the line "Hi! My name is Laine. I have a sister. Her name is Mia. She died and she's in heaven. I have a brother named Mathew. He's twelve. I don't have any other brothers or sisters because my mommy doesn't like to wipe butts any more." She certainly managed to get across a lot of information in one go. The adult strangers would not know how to respond, and would often just back away, very slowly.

Lament:

But then things went badly. In the middle of February last year, Laine had a stomach ache. It became worse with time and we were in and out of the PAMF and Stanford emergency rooms three times. Almost unbelievably, Laine died on Feb 24th of appendicitis. It was as if space just shimmered, and she was not there. The angel that had saved us from so much had died. We were devoid of bodies. We were empty. This made absolutely no sense and was highly unfair. We were made of stone. Once was bad enough. We had somehow survived Mia's death. Laine was life. She was life in its fullest. She picked the flowers that we took every week to where Mia was buried at our church, St Bede's. We buried Laine next to Mia. And we were not sure who was supposed to pick the flowers now. Swirl, churn and whirl.

Hope:

Now it has been 19 months and 3 days since Laine died. We try hard to understand why God would want our daughters back so soon. Perhaps their souls were intertwined. Perhaps they were part of the same being somehow. They could not be apart. Mathew did say after Laine died that it was quite miraculous that God was able to take Laine with such precision. If she had something more readily diagnosed, she would have been saved by those around her. If she had something protracted, she would have suffered for a long time. If she had been killed when hit by a car when biking, then the person that hit her would have felt guilty for a lifetime. So — it must therefore be the Hand of God. Personally, I honestly don't know.



Lament:

But these feelings of hope are often short lived. We then cry and are angry again. Then we are sad. Profoundly sad. A sadness that you all know — where the primary characteristic is emptiness, a quiet, hollow sadness. Our son Mathew is now an only child. This was not supposed to be. We miss the noise at home, the laughter, the singing and the crying. We miss what would have been the future. Mia should have lived a full life. But that was not to be. Laine was going to be a very special adult. But that is not to be.

Gratitude:

We are grateful that we were able to give our daughters everything it was in our power to give during the six years we had with each. We have no regrets, and for that we are grateful. We saw the impact they had on us and on many around them, and we feel a gratitude, strangely, that we were witnesses to two such miraculous girls. We feel gratitude for Mathew. I feel the depth of the connections with other human beings in a way I have not felt before. I sense a story that has not ended. And for all that, I feel gratitude.



Grandparents' Brunch



This year's brunch honoring bereaved grandparents will be held on Saturday, February 11, 2017.

If you know a grandparent who would like to attend the brunch, receive the *Connections* newsletter or be invited to future events, please send their name, address and email to bereavement@stanfordchildrens.org or call the office at 650-497-8175.

Upcoming Programs and Events

Yoga & Mindfulness for Bereaved Parents

8 Week Series, starting in Spring 2017

Tuesdays 6:30-8:00pm

Grief is a universal human experience that profoundly affects the body, mind, and spirit. In this 8-week series, participants will practice yoga and mindfulness exercises to ease the physical and emotional symptoms of grief within the context of a supportive group.

During each session, participants will be guided through a series of yoga postures followed by relaxation practices, breathwork, and mindfulness exercises (including meditation). All levels of yoga and mindfulness experience are welcome.

If you are interested in participating or have questions, please call the office at (650) 497-8175 or email us at bereavement@stanfordchildrens.org.



*Grief is like the ocean; it comes on waves ebbing and flowing.
Sometimes the water is calm, and sometimes it is overwhelming.*

All we can do is learn to swim.

-Vicki Harrison

7TH ANNUAL summer scamper



Summer Scamper

Sunday, June 25, 2017

8:00-11:00AM

Support the Family Guidance and Bereavement Program and help us to be the top fundraiser for the 4th year in a row! Registration begins in March: please visit www.summerscamper.org. Join the Family Guidance and Bereavement Program team, come walk or run with us, and then participate in fun memory making activities at our booth at the Family Festival. Even if you cannot attend the event, you can join our team as a "virtual runner." We hope you can be a part of this supportive community!

www.summerscamper.org

Calendar of Events

April 22, 2017	Family Memory Making Day, 1:00-4:00pm (See page 1 for details.)
May 5, 2017	Circle of Care Walk to Remember Come join us at our 8 th annual event in support of families coping with illness and bereavement. Walk in honor or memory of your loved on Saturday, May 5 th , 2017. More information on how to register for and be a part of this supportive and healing event at www.ebac.org/walk . Circle of Care - East Bay Agency for Children provides individual and family counseling and peer support groups for the whole family. We also provide consultation and supports to schools and community organizations after a death in the community. Fees are set on a moderate sliding scale, and no one is turned away for inability to pay. If you have any questions please call us at 510-531-7551 x3115, or email us at circleofcare@ebac.org .
June 25, 2017	7th Annual Summer Scamper, 8:00-11:00am (See page 5 for details.)
July 28-30, 2017	Camp Erin: Grief Camp for Children and Teens Kara will be holding its 10th Camp Erin in July of 2017 for bereaved children and teens ages 6-18. Camp is a weekend-long experience filled with fun and traditional camp activities combined with grief education and emotional support -- led by grief professionals and trained volunteers. Camp Erin is the largest bereavement camp network in the country, and provides a unique opportunity for peer bonding between children and teens facing a similar life circumstance. Applications will be available through Kara starting in January. Please visit www.kara-grief.org for more information.

Would you like to receive the *Connections* newsletter by email?
If so, please send your name and email to bereavement@stanfordchildrens.org.
Thank you!

Contact Us

Family Guidance and Bereavement 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

