

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.

Even when it is the worst year of our lives, sometimes it is hard to leave a year behind. We hear calls of "Happy New Year!" but all we can think about is the fact that our child will never see this new year. We hear resolutions made, but all that we feel resolved to is missing our child. How can we look to the future when we don't want to leave the past?

After the death of a child, the future can be scary (and unwelcome). And yet, it comes. So we think of the ways that we would like to carry our children forward with us: through the personal relationship we continue with them, the stories we share with their siblings, family and friends, and the things that we do in their honor and their memory.

We wish you the warmth of memory, the strength of love, and a quiet and peaceful entry to this new year.

Warmly,

The Family Partners

Family Memory Making Day

April 30, 2016

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

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 receive an invitation to 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).



Our Mission Statement

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

Fifteen Years Later...

by Family Partners member, Sylvia Constantz

A life that still matters. A life that continues to have meaning for all those who loved him. He is still with us.

After a courageous and hard fought two-year battle with cancer, our precious son Ryan died on June 13, 2000. He was twelve years old. Aside from his parents, he left behind three siblings. Daniel was ten years old, Andreas was eight, and his beloved little sister, Annalise, was five years old. In 2002 our fourth son, Dominic, was born. Even though he never met Ryan, he deeply felt the loss of never having met his brother. Ryan was, indeed, their hero and big brother. He was our perfect first-born son.

As I dig deep into the crevices of my memory, I can still vividly recall the utter despair that I felt those first few days, months and years after our Ryan died. I have a recurring memory of driving into my garage after taking my children to school, closing the garage door, and then proceeding to wail at the top of my lungs. The pain in my heart was palpable and truly unbearable. I am weeping now as I recall those moments. I honestly thought that I would never again truly feel any joy in my life. All of my hopes and dreams seemed to vanish. I mourned so much for all of those milestones in life that Ryan would never get to experience. The graduations, the thrill of driving his first car, the excitement of going off to college, the giddiness of falling passionately in love...

Aside from my own grief, there were the feelings of helplessness in knowing that I could do nothing to alleviate my husband's or my children's grief. Watching my family suffer was heartbreaking. I forced myself to get up every morning. I had no other choice. I still had a family to care for. I had birthdays and Christmases that needed to be celebrated. I didn't have a choice then, or now, about when the waves of sadness and longing would hit me. I remember running away crying from that first Thanksgiving table set without Ryan.

It took every bit of my strength to get through those first few Christmases, birthdays and Mother's Days.

Every April as Ryan's birthday approached I would brace myself for a renewed sense of loss and grief. As every year passed I was reminded of the fact that I would never see my boy grow into that handsome young man that I had always envisioned. Nevertheless, we celebrated Ryan's birthday. For fifteen years, without fail, our family and friends have gathered to take our annual "Ryan Hike." We hike along a challenging, but beautiful, forest trail that ends at the most serene little spring, where we set up our family picnic. It amazes me that in fifteen years there have never been other hikers picnicking at that spot. It has become our special place. A place where we can take time to celebrate and remember Ryan.

As the years passed, the only way that I found I could survive my grief was to focus on the many joyful moments of Ryan's life. I forced myself to push away the painful memories. I refused to let my mind wander toward those dark times...the day we first heard the words "Osteogenic Sarcoma," the nightmare of our first night spent in the hospital, the chemotherapy, the surgeries, the recurrences, and the utter fear we experienced. Instead, I willed myself to visualize Ryan's warm smile. I recalled his sweet boy smell and his peach fuzz against my cheek as I held him close. I remembered his big appetite for his Mom's cooking and his love of the big redwood trees that surrounded his boyhood home. I thought about his shared enjoyment with his dad and brothers of the ocean and High Sierras. I remembered the delight in his face as he held his newborn sister for the very first time. But most of all, I thought about how much Ryan loved his family. His biggest concern was not for his impending death. Instead, he worried about how his family would manage to survive without him. He wanted reassurances that we would be OK. I tried to reassure him as best I could, even if I had my doubts.

Every person's journey through loss and grief is so unique. As for me, I found strength in the love of my family and friends, as well as in my personal Faith.

The one thing that I know for certain is that we are all gifted with amazing resilience, grace and hope. Whether these come to us by way of our personal religious beliefs, or by some other means, they are surely present to lift us through the dark times. Like most families, we have faced our share of life's struggles and challenges along the way. But now, fifteen years later, I can reassure you that our family did eventually find a renewed sense of joyfulness, as well as many reasons to celebrate again.

On August 8, 2015, under the majestic trees overlooking the lake at Camp Okizu, Daniel and Erin recited their marriage vows. The same lake where, fifteen years ago, Daniel had come to as a little boy a week after his brother's death. It was here that he and his siblings came to year after year to mourn, to remember, and to begin to heal. Camp

Okizu became a safe place to grieve. A place where others really understood what it felt like to face the illness and death of a sibling. Daniel first came as a camper and later as a camp counselor. It was at Camp Okizu that he first laid eyes on the pretty young lifeguard who would one day become his wife. As our family and friends stood witness with us on this joyous occasion of Daniel and Erin's wedding, one could not help but to feel Ryan's presence. I imagined him smiling broadly, as he watched over his family. My sweet boy...he truly has never left us.

I will love you forever...I will love you for always.

For more information about Camp Okizu please visit their website at www.okizu.org.

SUMMER SCAMPER!

Our participation in the 5th Annual Summer Scamper was a great success! The Bereavement and Family Guidance Program was the top fundraising team, collecting \$44,360 in donations. We wore team t-shirts that included our child's name and completed the 5K walk and the 5K and 10K runs as a community. At our team booth at the Family Festival, many people enjoyed a dress up polaroid photo booth, making origami cranes and beading memory bracelets. In fact we were so popular, kids were folding and beading while everyone was packing up! It was a wonderful experience to spend time with other bereaved families and to feel the support of the LPCH community.

**We hope you will join us for the
6th Annual Summer Scamper
on June 19, 2016!**



Dear Ryan

by Annalise Constantz

I never quite know how to put into words my experiences with losing my brother Ryan. In truth, I don't often talk about it so the words don't come as easily. Throughout my childhood, I gave up confiding in many of my peers. Friends have said to me "Wasn't his death ages ago? And you're *still* not over it?!" as if speaking about my brother indicated weakness or a desire for sympathy and attention. Just recently, a friend stopped me mid-sentence while I was sharing a memory about my brother just to clarify that I was, in fact, "a child" when he passed and to ask why I "still feel sad about it." These responses always used to undermine my loss and make me feel as though I wasn't allowed to feel sad, angry, or confused about missing him, let alone to even bring him up at all.

I did, however, find solace and support within an organization called Camp Okizu, a summer camp for children with cancer and their siblings. There, I find common-ground with most everyone and am able to talk about my experiences. I am eternally grateful for the love and support Okizu has given me and my family and try to give back each summer by volunteering as staff. (To learn more about Okizu, check out okizu.org).

Anyhow, what I have learned in my short twenty years of life is that the opinions of others in regards to *your* grief are to be acknowledged respectfully, but not taken to heart. Not even the closest of friends can dictate to you how long you should grieve because grieving is personal. Personally, my grief has evolved as the years since his death passed by. My definition of grief has changed. Grief is remembering and cherishing and dedicating time to be with Ryan. I think of him when I hear the song "Someday" by Sugar Ray, when I see kayakers floating on the sparkling Pacific, and when I'm enjoying the sun in our backyard. He's on my mind when I watch "The Simpsons" (I can almost hear his laughter) and I feel safe and secure

when I sport his old O'neil t-shirt. All of these day-to-day experiences make my heart ache but heal me at the same time. I'm not quite sure of my spirituality just yet, but I feel him with me at all times as a guardian angel of sorts. With all that said, I decided to finish out my thoughts with a letter to my brother.

Dear Ryan,

It's been a little more than 15 years since you went to heaven and I still miss you. I miss how you would play the "Dopey" to my "Snow White" every night when you were home from the hospital. I miss your huge grin and how you would get *so* excited to see me when I visited you in your hospital room. Just so you know, I was (and am) unbelievably proud to be your little sister and to have you as my big brother because to me, you were amazing and invincible. I remember bragging about you to my friends. I would tell them about all of your operations and chemotherapy, and how you were pretty much a super-hero. And you were *my big brother*. You made me feel so special and important.

While you were sick, the gravity of the situation didn't quite register in my head. Some of my earliest memories involve your hospital room which, at my young age, didn't seem out of the ordinary because it was all that I knew. I feel so lucky that I was old enough to remember my time spent with you. Similarly, I feel lucky that I was left out of the difficulties of your experiences with cancer. In hindsight, what I really remember from our time together was not your illness, but you. I remember thinking how cool it was that you wore that Yankees cap everyday (almost as cool as how soft and fuzzy your bald head was beneath it).

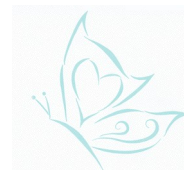
I also remember feeling helpless once you had passed away. I watched our parents and brothers experience unfathomable amounts of pain and I just didn't know what to do. I remember crying in my bed for you and for our parents and for our brothers. Everything felt different and wrong and I missed you.

Now that I am older, not only do I miss the memories that we shared, but also the things that never happened. Graduating from middle school, senior prom, going to college... all things that I have now experienced that you never will. I miss the advice you could have given me and the support you could have offered me. But, I take comfort in the fact that I know you are with me everyday. I used to feel as though family gatherings, birthdays, and holidays were incomplete because you weren't physically there. But just recently, on the day of our brother's wedding, I didn't feel as though there was something missing. The ceremony was held at Camp Okizu, where I always feel intensely close to you. And I felt your presence in the wind through the redwoods and the birds in the sky- our family felt complete. Thank you for making me feel loved

and showing me how to love and care for others. I try to channel your kindness to me, especially in being a great older sister to our little brother. I often lose my way and take the wrong turns; however, your memory always leads me in the right direction and reminds me of what is important (tell your loved ones that you love them as often as you can!!). As I wander aimlessly into my future, confused as hell, I feel your footprints on my heart, which helps me to put one foot in front of the other, because in the end that's all you can really do.



Love,
Leesee



“Some people come into our lives and quickly go. Some stay for a while, leave footprints on our hearts, and we are never, ever the same.” - Flavia Weedn



Kara's 9th Annual Camp Erin: Grief Support Camp for Children and Teens

Camp Erin is a free, weekend grief camp designed for children ages 6-18 who have experienced the death of a family member or friend. The 2 days and 2 nights at camp are filled with traditional fun camp activities combined with grief education and emotional support, facilitated by grief professionals and trained volunteers. Applications are available January 11th and are due by March 25th. Applications are reviewed in the order received and priority is given to new campers. Space is limited so apply early.

“At Camp Erin, I feel safe, not different.” -13 year old participant

Applications can be found at www.kara-grief.org/camperin. For information or specific questions regarding the application, please contact us at camperin@kara-grief.org or (650) 321-5272.

Calendar of Events

<p>April 1-3, 2016</p>	<p>Meadowlark Retreat for Mothers Grieving the Loss of a Child</p> <p>Meadowlark was created to give grieving mothers a place to share their stories and feelings with others who have been through the same kind of loss. The retreat is professionally facilitated. Interested mothers please contact Stacey Redman, sredman@timgriffithfoundation.org/(650) 483-9912 or Leslie Chin, leslie_chin@msn.com. Please see www.timgriffithfoundation.org for more details.</p>
<p>April 30, 2016</p>	<p>LPCH Family Memory Making Day, 1:00-4:00pm</p> <p>For more information or to sign up, please call (650) 497-8175 or email bereavement@stanfordchildrens.org. See Page 1 for details.</p>
<p>May 15, 2016 May 22, 2016</p>	<p>Pathways Hospice Afternoon of Remembrance Memorial Service, 3:00-4:30pm</p> <p>Pathways Hospice is offering two Afternoon of Remembrance memorial services in May. One on Sunday, May 15, 2016 at Skylawn Memorial Park in San Mateo and the second on Sunday, May 22, 2016 at Chapel of the Chimes in Oakland. Both services will be held from 3:00-4:30pm with refreshments following. Open to the public and free of charge. For more information, please call (888) 755-7855 or email bereavement@pathwayshealth.org.</p>
<p>June 19, 2016</p>	<p>6th Annual Summer Scamper, 8:00-11:00am</p> <p>Support the Bereavement and Family Guidance Program and help us to be the top fundraiser for the 3rd year in a row! Registration begins in March: summerscamper.org, look for the Bereavement and Family Guidance Program team and come walk or run with us.</p>
<p>July 29-31, 2016</p>	<p>Kara's 9th Annual Camp Erin: Grief Support Camp for Children and Teens</p> <p>Applications available January 11th. See Page 5 for details.</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