

# 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.*

## Family Memory Making Day



**April 14, 2018**

A special day for bereaved siblings and their parents at the National Center for Equine Facilitated Therapy in Woodside, California. 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, please 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).



## ••• Sibling Group •••

This group is an opportunity for brothers and sisters grieving the loss of a sibling to share stories, meet others with similar experiences, and express their feelings related to grief. We will incorporate creative and educational activities into each session. We are currently offering this group for siblings ages 8-11, but there may be future opportunities for other age ranges.

For interest and inquiries, please contact Kendall Bozzello at (650) 497-8175 or [kbozzello@stanfordchildrens.org](mailto:kbozzello@stanfordchildrens.org). The group will be held in the Lucile Packard Suite at Ronald McDonald House: 520 Sand Hill Road, Palo Alto.

### Our Mission Statement

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

### Parent Reflection

*This talk was presented by Mike Mendez at the 2017 Day of Remembrance.*

It is a real honor to be here on this special day. I know that no one really expects to be part of these families but as I stand here before you I am both humbled and proud to be a part of this group. I struggle to find the words that describe my feelings after losing a child and the only thing that comes to mind is fallout – walking on a scorched planet in shock. Everything around me is meaningless and different from what it once was. And yet this is a day of remembrance and while thinking about those that we have lost brings great sadness, I wish for there to be a moment when we can all smile as we honor those that are no longer here.

Some of us lose children when they are very young and the only memory we have of them is perhaps an ultrasound, feeling their tiny heart beats or movement within their mother's womb. Some of us lose children shortly after birth and we are left with memories of our children struggling to survive, perhaps a picture or perhaps some newborn footprints. Some children are a bit older, before they can articulate and speak and so all we can do is to look into their eyes with hope to soothe their pain as they struggle to understand. Still a bit older, when our children become little grown-ups we are faced with tough questions, like "am I going to die?" And then our children become young adults and perhaps because of their journey they are wise beyond their age. That was our son Nick.

Nick was diagnosed with retinoblastoma, at age 2. He had his left eye removed. His first cancer was in remission when he was diagnosed with rhabdomyosarcoma at age 8. He underwent 42 weeks of chemotherapy and 6 weeks of radiation therapy.

With his first and second cancers in remission, he was diagnosed with a non-differentiated sarcoma in his maxillary sinus at 14. The tumor was surgically removed and treated with 6 weeks of radiation therapy. With his first, second, and third cancers in remission, he was diagnosed with osteosarcoma at age 20. He underwent 45 weeks of chemotherapy, multiple surgeries and six weeks of radiation therapy. Nick died at age 21. Our older son, Joey, writes "He fought many battles against cancer, sacrificing so much to stay alive, and he did it all with a smile on his face. He is my hero, and the strength of his heart beats within my chest. His compassion was great, and his patience endless."



When I spoke at Nick's celebration of life I talked about breadcrumbs. Breadcrumbs are little bits of information that he left behind for others to find. These breadcrumbs can help other people find their way if they are lost or nurture their souls if needed. So perhaps all our children leave breadcrumbs behind and perhaps it is our life

journey to find them. I wanted to share a few of Nick's breadcrumbs.

A few months before Nick died, I had a chance to ask him "how do you go through all of this, four cancers, chemo, radiation therapy, practically living in the hospital and still keep a smile on your face?" Nick said to me, "I go to sleep at night and wake up in the morning knowing it will be a better day." A breadcrumb – attitude. Recently an 85-year old friend of mine was in a car accident. He was rear ended and went from being a very independent to a person that was a phone call away from a nursing home. It was complicated, he had multiple chronic diseases – heart, gout, rheumatoid arthritis, weight loss, etc. These conditions were controlled but got worse after the accident. I was able to help him get back to health because I knew about being a patient advocate. Something I had learned from being at Nick's side for 19 years. A breadcrumb - advocacy. Things do not

always go right when you are battling 4 types of cancer. As a parent, when your child is fighting for their life, patience is not always easy and small things always seem bigger. I know we had one event when we were in the hospital that did not go as we expected. I was frustrated. Since Nick was older I asked him what he thought about it. Nick asked me, "Dad, if you get angry, will it make me better?" And then he said, you can't wash blood away with blood." A breadcrumb - patience. When Nick was 8, he went trick-or-treating and when he got to people's doors, and they asked for a trick, he would take out his prosthetic eye – he called it his fake eye. When he was a freshman in high school, his fake eye was bothering him and would bleed and cause irritation so he took his eye out. Now most kids at that age would be worried about how they look and what they are wearing. Nick said to me "I only have one eye and if I can handle it, they should also be able to handle it too." A breadcrumb - be proud of who you are. So, as we remember our children, perhaps we can honor them by picking up the wonderful things they left for us to find and make the world a better place – our breadcrumbs.

After losing Nick, I did what I think most parents might think of doing – trying to find their way back to what was before. I read books, looked for answers on the internet and made my way to a grief counselor. Then I got an invitation from Krista Reuther at the Bereavement department here at the LPCH. A bereavement and yoga class. Well to begin with, I am a dad and like many dads I know, I am not great at talking about feelings. Then after that was yoga. Just what I needed. Take a class with a bunch of people wearing yoga pants and doing weird poses. Yoga was not my thing. Well as much as Krista promised that there would be other dads in the class, somehow when I showed up, it was all moms! It was a bit awkward at first but good things came out of it. The experience was humbling in that I realized that I had much in common with this very special group of people. Like many of you. The most important thing I learned was that yoga was not so much about getting

fit, but it was more about tuning the body to open the mind. My journey took me to meet an amazing human being named Nirmala Ma. I went to see her for some grief counseling. We covered a lot of ground and I wanted to share three things that I learned. The first thing she asked me to consider was to imagine that while my son was not here physically, that perhaps his spirit was still with me. That was not hard to do since I think about Nick every day. Songs remind me of him, when I see a family with children I think of him, rainbows, the moon, good food and a million other things remind me of Nick. It sounds a lot easier than it is but perhaps some of us can take comfort in understanding that the children we have lost are always with us. This thought gave me great peace. The second thing that she asked me to consider was to set aside a place in my home for Nick – an altar. I suppose that we all have many altars in our homes with things that remind us of someone we have lost. But this altar is special – it has a picture, flowers, a stuffed animal – a hedgehog, a lamp, some dried flower buds and a tiny urn with some of his ashes. The altar is a place of honor and a place of reflection. When Nick died, the whole house was filled with grief. But as soon as the altar was complete, we had a space of joy. I find that as we move farther away from loss, grief no longer takes up every space in the house and the joy and energy from the altar fills our home with light. The third thing learned was to look within myself for answers. I know that the loss of a child is unbearable and no one would fault any of us if we didn't care about our jobs, or ate or drank too much, or were angry, or were sad or if we physically ran ourselves into the ground. But I also believe that the children that we lost would want us to have joy and prosper. I don't really have a formula but I know I must be gentle on myself and make time for myself. I still don't wear brightly colored yoga pants, and I struggle with faith. But I also meditate every day for 30 minutes. I miss a few days here and there and don't beat myself up about anything that I think I should be doing. Something for all of us to think about.

The last thing I want to talk about is family. I was



married to Nick's mom for 20 years. She is a great mom. We got a divorce and things were tough but the one thing that we did well was to put our children before ourselves. We learned this first hand because we saw children in the hospital that had no family, had no visitors and had no one to stay with them at night. We realized that every ounce of strength that our son had, he needed to dedicate to fighting his disease. Kids love their parents and want them to be happy. And yet we knew that if our son focused his energy on our battles that he would not have enough left to battle the cancers. New physicians used to have to swear to a Hippocratic Oath which was to uphold specific ethical standards mostly directed and caring for patients. As parents, I believe that we have a 'parentcratic oath' which is to put our children before ourselves until they are old enough to stand on their own. When Nick died, we were at my ex-wife's house, with her fiancé in the other room and yet we were blessed because as Nick journeyed to

heaven, his mom, his brother and I were holding his hand together. I think this was possible because we remembered our family. What remains after we lose someone is and will always be our family. We should celebrate our children that are here with us for they are heroes. I always struggle when people that ask me if I have kids. I mean, do I have one son or two sons or do I go into the details. I like to think that I will always have two boys. One on earth and one in heaven. We should celebrate ourselves because we have been down the road less travelled.

We lose our children and this is very sad. But I cherish the short time that I had. One day I hope to be able to look at a picture of Nick and really smile. A thought best described by Dr. Seuss and Gabriel Garcia Marquez. "Don't Cry because it's over, smile because it happened. No llores porque ya se terminó, sonrío porque sucedió.

Thank you.



*"The best and most beautiful  
things in the world cannot be seen  
nor even touched,  
but just felt in the heart."*

*- Helen Keller*

## Family Memory Making Day 2017

Our daughter, Olivia has been anticipating the Family Memory Making Day for over 1 year now. When the day finally arrived, she had the biggest smile possible on her face. We did not know much about the Family Memory Making day and thought this day was a day for our daughter to participate in activities in remembrance of our son, Christian. But when we arrived at the National Center for Equine Facilitated Therapy (NCEFT) center at Woodside, CA, the wonderful staff at the Bereavement and Family Guidance Program shared with us what everyone would be doing during the special day. The day was designed for siblings and family members to come together and reflect and remember their departed loved ones. We thought it was a day for Olivia to be herself and enjoy the many wonderful activities with others who have gone through similar experiences. But the staff at the Bereavement and Family Guidance Program also shared with us that this day was for the entire family, meaning for the parents as well. My husband and I were very touched by this news because since Christian's passing, our main focus has been our daughter's well being. We appreciated the opportunity to share in this experience together as a family.



Our family got a chance to participate in all of the activities that the staff had set out for us. Each activity was designed to help us reflect on our loved ones and to help lessen the pain of our loss even for just a moment in time. We got to watch Olivia ride on a horse named Cody and take silly pictures in a photo booth. Olivia made a sand layer bottle where each of the colors represented a member of our family. She drew a sun rising from the horizon and pressed the picture into a button, which she really loved making. We also made a keychain with 5 glass charms that represent each of the 5 years that our son was here with us and a picture frame to put a picture of our family. Aside from making special keepsakes, this was a day where we can put everything behind us and remember our loved ones and to make wonderful

new memories with our family. This was also a day where we shared and met with other families that have gone through similar experiences and just be ourselves.

Before the end of the day, each family member including the director of the NCEFT wrote special messages and tied the messages onto two Norwegian Fjord horses. Afterwards, Scott from the Bereavement and Family Guidance Program gave a special message about this day and read each of our loved ones' names. The two horses then ran up the hill into the horizon carrying our special messages. Everything about the Family Memory Making day was special. It was a day where we can feel our loved ones' presence, a day to tell them they are always in our hearts, a day to let them know that we will never forget them and a day to simply let go of the pain and cherish the precious moments of our loved ones.

Thank you to the wonderful staff at the Bereavement and Family Guidance Program and the National Center for Equine Facilitated Therapy (NCEFT) center for making the Family Memory Making day full of precious memories. We are also very grateful for the staff at both Bereavement and Family Guidance Program and Lucile Packard Children's hospital for always keeping us in their hearts and for helping us make new memories.



In loving memory of our angel, Christian M. Wong.

Darryl, Eugenia & Olivia Wong

# summer scamper

sunday, june 24, 2018, 8:00-11:00am



Support the Family Guidance and Bereavement Program and help us to be the top fundraiser for the 5th year in a row! Registration begins in March: please visit [www.summerscamper.org](http://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!



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

## Contact Us

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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