

Connections

A Newsletter from the Family Guidance and Bereavement Program at LPCH

The Family Guidance and Bereavement Program supports LPCH families and their communities who are facing the death of a child. Our services are offered at no cost in English and Spanish. All are welcome to participate.

Reflecting on a difficult year...



Looking back on this year, I'm struck by what an incredible degree of adaptability and resolve it has required of everyone—and also how stressful it's been. The pandemic, social and political turmoil, and wildfires have been significant ongoing threats to contend with on top of the normal complexities of everyday life.

For families who are grieving, these pressures can make the experience of grief even more overwhelming. With less access to social connection and self-care activities, finding new ways to cope with grief and access support is now more important than ever. We've listed a couple of online community events for grieving families through the end of the year. Also, if you would like to be connected with grief resources specific to your area, please call our bereavement social workers at 650-497-8175.

In these pages, you will find Megan and Brian Favat's reflection from our recent Day of Remembrance ceremony. We hope you find inspiration and some reflection of your own resilience in their story.

Wishing you health and moments of peace,

Krista Reuther

Director, Family Guidance & Bereavement Program

Parent Reflection

This talk was presented by Megan and Brian Favat at the 2020 Day of Remembrance.

Marien's journey

When we were asked to share our story as part of this year's Day of Remembrance and Rededication, we panicked a bit. How do we summarize the story of our daughter Marien, her life, and our journey with her into a short, relatable talk? We quickly realized this is the struggle we've faced every day of the last 2 years since losing her. Each time we meet someone new, or are in a new environment, we grapple with how to share the most wonderful - and the most painful - part of our life.

The wonderful part is talking about Marien, the child; who she was outside of her medical complications. We had her with us for almost 7 beautiful years. She had reddish wavy hair, with random ringlets. Marien's eyes were wide with long eyelashes that always caught

people's attention. She most enjoyed being with her school friends, watching Disney movies after school with her caring nurses, and snuggling with her dog, Flynn. She loved new adventures, whether it was taking family trips to Disneyland or being in nature and the outdoors. Some of our favorite memories with Marien were trips to Yosemite, Hawaii, and the Grand Canyon.



The Family Guidance and Bereavement Program

650-497-8175

Family Perspectives (continued)

The painful part is describing the challenges Marien endured during her life, and the disease that ultimately took her from us. While Marien seemed perfectly healthy when she was born, we gradually started to realize that she was missing milestones. And she kept getting so ill that she needed to be hospitalized. Pretty soon we found ourselves sleeping in the hospital every 3 months. So between the developmental gaps and the medical issues, we knew something wasn't right, but no one could figure it out.

We consulted with every specialist we could and did every workup possible. We would spend any free time Googling her symptoms and reading about other children with mysterious illnesses... but nothing came together. Doctor after doctor couldn't explain what was going on, nor could they predict what would happen in the future. Year after year went by without any answers. Ultimately Marien never spoke, walked, stood, or even sat independently. She was completely dependent on those that loved and cared for her in every aspect of her life.

We never got the miraculous outcome we so desperately wanted. During the last few years of Marien's life, things seemed to deteriorate more quickly. We didn't realize it at the time, or didn't want to. We were so focused on her day to day care, that we couldn't see the bigger picture. Two months before her 7th birthday, Marien was once again admitted to the hospital with breathing difficulties from a virus. Before we knew it, we were having discussions with her care team that we never imagined; those conversations are forever seared into our memory. This time Marien didn't make it home. After so many years of battling respiratory illnesses, her little body couldn't do it anymore...

We didn't know the disease that had taken our daughter from us until 7 months *after* her death. Three years before her passing, we had enrolled Marien in the Undiagnosed Disease Network at Stanford. The intent of the program is to find a diagnosis for particularly complex, mysterious cases that doctors haven't been able to solve. The team regularly revisited Marien's case to see if any new information had emerged. Finally, they discovered a lead. After a lot of detective work, and convening of medical experts across the country, they diagnosed Marien with a very rare disease, POLR3A. In fact, they had never seen anyone with this exact genetic profile, making it even more complicated. We felt relieved to know. It didn't change the fact that she was gone or erase the difficulties she had faced. There was no cure. But we now knew what had prevented Marien from leading a normal, healthy childhood and what had taken our daughter from us.



So that's the painful part. As I'm sure you can all relate, a flood of emotions come as we tell Marien's story - love, pain, hope, anger, regret ... and also a lot of gratitude. We are both so thankful that we got to be Marien's mom and dad. And while we would have done anything for her to be healthy, she taught us so much and showed us a world we had been ignorant of. She showed us what unconditional love is. And there were so many wonderful people that were part of her team - from doctors, nurses, respiratory therapists, teachers, and bus drivers, to name a few - we couldn't have kept her with us for so many years without their selfless help.

We're also so grateful for the people who showed us compassion through everyday gestures - like holding a door for us so we could get Marien's wheelchair through. Or the friends who randomly sent us meals, knowing how chaotic our days were. Or the people at Disneyland who would go out of their way to help Marien get on a ride. Or the coworker that showed compassion and helped with projects while we were at her bedside in the hospital. Through Marien's life and struggles, we saw the best of other people, and ourselves.

We're only 2 years into our life without Marien, and often it feels like a mere 2 hours. The thought that one day we'll be 5 years, 10, years, 20 years out from our time with her seems unfathomable.

What have we learned?

First, we have learned that it is hard for people to know how to support us in our grief. Most people mean well, but fumble through how to respond to someone who is living what would be their own worst nightmare.

We also have learned that support is not limited to those who knew Marien. We have new friends who never met her and yet they embrace our grief, opening a pathway for us to talk about her and about our journey since her death. Their willingness to hear our stories brings them into our longstanding community of family and friends who *did* know Marien and were there for our family throughout her life. Old and new, we are deeply grateful to everyone for their support.

Second, we've learned that we are no longer the same people and can't keep trying to be. The way we process things now is different. Things that we cared about previously, no longer matter, and things we're passionate about now weren't on our radar back then. Our relationships have changed as a result. Things that should be smaller stressors can escalate into triggers that lead us to melt down. And just when we were learning to better manage these stressors, the global pandemic has thrown us *back* into a world of uncertainty and anxiety - and the rest of the world along with us.

Third, the pain hasn't gone away or lessened. Instead, we've learned to process it and function with it every day. We don't think of Marien any less now than we did immediately after she passed. The raw pain is still there. But we've learned how to go through everyday life, bringing both fond memories and the pain of losing her with us. It's as if thoughts of Marien are on a continuous loop that hums in the background of every



day, no matter what we're doing. We like it that way.

We don't know what things will look like or feel like for us down the road, after several years without Marien. For now, we take things day by day, knowing some days are harder than others. We'll keep learning what helps and what hurts in our journey onward. We'll keep adapting.

Thank you for having us and letting us share the story of our beautiful daughter Marien. We wish you all peace on your own personal journey of learning to move forward in life, while continuing to honor the memory and lives of our children.

**The mention of my child's name
May bring tears to my eyes,
But it never fails to bring
Music to my ears.
Let me hear the beautiful music of
his name
It soothes my broken heart
And sings to my soul.
-Author Unknown**

Some Ideas to Help Make the Holidays Easier (reprinted/adapted from 2010 edition)

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

- It is ok to change traditions. If you need to do things differently to help you through this time, that is ok.
- It is ok to laugh and have a good time. Pleasurable experiences don't diminish the love you have for your child.
- 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.
- Consider creating a special holiday ritual to remember your child: for instance, light a candle or have a special memory time.
- Allow yourself to express your feelings.
- Decide what you want to do, what you can handle, and what can be avoided.
- Grief can take a lot of energy, so try to balance family time, time on Zoom, and alone time to recharge yourself.

Community online events to support grieving families

1. Candlelight Service of Remembrance: Thursday, December 3rd

An evening of meaningful remembrance with personal sharing on the themes of love, hope and community. An event to honor loved ones who have died with live music and culminating in a special candle lighting ceremony. This non-denominational service is open to all. <https://kara-grief.org/services/community-events/>



2. Compassionate Friends Worldwide Candle Lighting Memorial Service: Sunday, December 13th

Uniting family and friends around the globe in lighting candles for one hour to honor the memories of the sons, daughters, brothers, sisters, and grandchildren who left too soon. As candles are lit on December 13th, 2020 at 7:00 pm local time, hundreds of thousands of people commemorate and honor the memory of all children who have passed. <https://www.compassionatefriends.org/wcl/>.

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

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Additional Hospital Support Services

Social Services: (650) 497-8303

Chaplaincy: (650) 497-8538 or (650) 723-7288, pager #27729

Child Life: (650) 497-8336

Palliative Care: (650) 497-8963 or (650) 723-7288, pager #19474