

# 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.*

## Family Memory Making Day



April 25, 2020

Family Memory Making Day is 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 (age 4-17) 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). **Space is limited** due to the activities planned. Priority will be given to those families who will be attending Family Memory Making Day for the first time.

## Family Perspectives

### Parent Reflection

*This talk was presented by Paul Lorence at the 2019 Day of Remembrance.*

I'd like to thank the Family Guidance and Bereavement Program for inviting me here today. I'm flattered and honored to be speaking with all of you, and, like most of you (I suspect), I never imagined that I would actually be here, with this specific group of people and the common circumstances we share.

Losing a child – of any age – is extremely challenging to

describe, much less process. I have read others' words and listened to their stories and compared them to my own experience. Sometimes it makes me feel better, and sometimes it makes me feel worse. But either way, I always end up appreciating taking the time to read those words and to hear those stories. And so, with that in mind, I'd like to tell you a little bit about my son, Trevor.

In 2003, when he was just over a year old, Trevor was referred to the Neurology department at LPCH by his pediatrician due to delays in his development. Together we set upon the path of understanding why this bright, smiling little boy wasn't able to sit up or form words. After many months of tests – including brain MRIs and

*The Family Guidance and Bereavement Program*

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## Family Perspectives (continued)

a skin biopsy – to get a diagnosis, our neurologist recommended that we have his blood tested for metabolic disorders. That blood test resulted in the definitive answer: Trevor had a rare disease which affected all the mitochondria in his body. The acronym is M.E.L.A.S – which stands for Mitochondrial Encephalomyopathy And Stroke-Like Episodes. You may recall from middle school biology that mitochondria are known as “the powerhouse” of the cell – they have the specific task of generating energy. MELAS is genetic disease that affects all mitochondria and it manifests in a wide variety of symptoms. The diagnosis from the blood test was definitive down to the specific point mutation in Trevor’s genes – and it was fatal; there is no cure.

After the diagnosis, Trevor was followed by several specialties at LPCH. As parents of a child with special needs, we did what most parents do – which is to say: everything that we could. We scheduled a lot of doctor appointments and attended hours of therapies. We read to him, played \*for\* him, worked at feeding him and getting his weight up, adapted toys so he could grasp them, researched for hours after putting the kids to bed. When he reached preschool age, we attended IEP meetings to negotiate the services and equipment he needed. Doing what we had to do mostly involved simply being his working arms, legs, and voice that he needed to engage with the world.

In 2010, around Halloween, at age 8, Trevor began exhibiting a severe form of *dystonia*, which is uncontrolled movement of the arms and legs, including smacking lips and grinding teeth. The movements would go on for hours, causing his heart to race and covering him with sweat. It was clear he was uncomfortable and scared. We rushed him the Stanford emergency room, and he was admitted to the LPCH Pediatric Intensive Care Unit (the “PICU”). Multiple teams worked together to understand and try to control this severe movement disorder. He would end up staying in PICU for the next 6 months.

As many of you know, life becomes very different when you are forced to live in the hospital for any extended length of time. We didn’t plan on spending 6 months in the hospital, but things began to spiral downward, and it seemed that getting better and being discharged was a goal that kept moving just a little further beyond our reach. I spent the overnight hours while my wife took the daytime hours, as we tried to keep a normal routine for our daughter Stella, who was 11 years old at the time.



When you are in the hospital for that long, you learn a lot of names, you learn the rhythms of the place, the sounds, and even the smells. The baseline stress and the constant worry makes your new normal existence intensified, like an exposed nerve. A fresh cup of coffee after a sleepless night can feel like the best gift in the world. An inconsiderate word from a resident can feel like stabbing insult. We saw many other patients enter and exit the PICU while we seemed to be stuck there, including Thanksgiving Day and Christmas morning, unfortunately.

But we finally did manage to escape: our protracted stay included everything from an induced coma to an experimental drug trial, but we nursed Trevor’s health to a point where the movements were under control, and he finally came home in April of 2011.

Through the summer and the fall, we adjusted to our new life. Trevor attended school remotely because of his fragile health. In November, we decided to host Thanksgiving at our house, since we were so thankful to once again be spending the holiday all under the same roof.

Unfortunately, in the late afternoon of Thanksgiving Day, the movements began again. Knowing that the hospital would be short-staffed, we were reluctant to rush him back to the ER, because we knew that it could likely result in yet another prolonged stay. After checking with the on-call neurology resident, we decided to hold out for a few more

hours – hoping this episode would subside by morning. Only we did not make it to the morning: Trevor stopped breathing in our bed while watching TV shortly after midnight. We rushed him to our local emergency room, but it was already too late.

The next few hours and days are very hard for me to recall. I can remember specific moments, as we came home alone and waited for his sister to awaken so we could tell her what had transpired while she slept. Trevor adored his big sister; this was probably the hardest moment. I can remember making phone calls and sending emails and struggling with how to announce our news – how was it possible that everyone, the entire world – didn't already know?

During that painful time, I can remember thinking that I would never really sleep again, or that I would never really be fully awake again, or that I would never really be hungry again. I even thought I might never laugh again. I can remember one of the first times that I laughed out loud after Trevor died; it was strange and shocking to me, as if I were violating his legacy. I hadn't laughed in weeks. But I quickly realized that it meant, perhaps in a small way, I might actually be healing.

I realize now that I've spent much of my time telling you our terrible story, and I want to make it clear: Trevor was a great kid, the absolute best. As I mentioned, he adored his sister, he loved his mom, and he loved to laugh. He loved trains, books, video games, Pikachu playing wiffle ball, "running" in his walker, going fast in his power wheelchair, teasing his teachers at The Bridge School, his Sponge Bob pajamas, soy sauce, Mario Kart, the color yellow... I could go on and on. There is not a day that goes by when I don't think about him and miss him. He was the strongest person I've known.

After Trevor died, my wife and I arrived at a few small strategies that helped us with our grief. I'd like to share three of them with you now.

First – and I know this sounds trite – but we try to make time for the important things, because there are so many things that we thought were important before which are now... just not that important to us. Being there for your children, sharing yourself with family and friends, celebrating milestones... these are the important things. Nearly everything else isn't, so why waste your energy on unimportant things?

Second, we try hard to say "yes" to things, even when we are feeling bad and would rather be alone with our grief. So when we receive invitations from family and friends who care about us, we just force ourselves to say "yes" – even when it makes us a little uncomfortable. Four years ago I said "yes" when the Family Guidance and Bereavement group contacted me and asked if I wanted to join them, and two months ago, I said "yes" to Krista when she asked me to speak here today. I encourage you all to think about things you want to say "yes" to. Are they important things to you? Do they matter?

Third, don't be hard on yourself. There is no "right" way to grieve, there are no checklists or timetables. My grief is extremely personal and private to me; I am careful and selective about when I choose to share it. Being deliberately guarded is my defense mechanism for dealing with "the gut punch" moments: those times when something just triggers you, like an unexpected punch to the gut. It might be an upcoming anniversary, the news about someone else's hospital stay, or even a smell in the air that instantly triggers you and knocks you down. I'm sure you know these moments; I have them all the time. Don't be hard on yourself when they happen. For example, if you don't yet have a standard reply when someone asks you, "So... how many kids do you have?" – it's okay. We are all still learning.

And so there are ups and there are downs. There are times when you smile and say, "Oh my goodness, Trevor would've loved this" and you actually feel better. And there are times when an offhand remark makes you think, "What I wouldn't give to have just had more time with my beautiful kid, I miss him so much" and you actually feel worse. It's okay. I know my life is very different now, and it will continue to be disorienting and confusing – and I have to be okay with that. Doing these small things – focusing on what's important, saying "yes," and not being hard on myself – has really helped me deal with it.

Although I've been invited before, this is my first time attending the Day of Remembrance, and I'm really glad I came. Thank you again for having me, thank you for listening, and I wish you all the best of luck on your journeys.



# Summer Scamper

Sunday, June 21, 2020, 8:00-11:00am



Support the Family Guidance and Bereavement Program and help us to be the top fundraiser for the 7th year in a row! Registration begins in April: 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 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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