



# Faces of Mito

## Genevieve's Journey: As told by her mother, Angela Tomasone



On a Sunday morning in early December 2021, the pregnancy test read positive. I went into our bedroom, and my husband, Michael and our dog, Timmy, started jumping in the bed out of excitement when I shared the news. I was blessed to have an easy pregnancy—she treated me so well.

Michael and I spent the months leading up to August guessing what the gender would be, researching baby items, rearranging furniture, picturing how our lives would change, and imagining life with a baby. On July 31st, 2022, we got the call that we needed to head to the hospital, and I needed to be induced. Two weeks ahead of our due date, Genevieve knew we needed more time with her.

With music playing and labouring through the night, our baby arrived at 7:43 am on August 1st, 2022, to which Michael announced, "It's a girl!" We named her Genevieve, a name we had agreed upon since before we were married, meaning "of the race of women" and "guardian goddess."

Genevieve was the sweetest newborn baby, with a full head of hair and long eyelashes. Her eyes at birth and onward were always wide open, always so intrigued by the world around her. She quickly grew and changed, and her big expressive eyes would make for the best faces. She loved to be held by mommy, in a position where she could look at her daddy, who was undoubtedly her favourite person in the world. Part of him may have hoped for a boy during pregnancy, but Genevieve had her daddy wrapped around his finger in no time. We were blessed to celebrate Thanksgiving, Halloween, Christmas, and Valentine's Day with Genevieve. The turkey was bigger than her, and we were especially grateful.



continued...

Mommy made her Halloween costume an arts and crafts project—spaghetti and meatballs will never be the same. This Christmas was magical, decorating the tree with new ornaments for her, reading her the Christmas story, photos with Santa, all her Christmas outfits, and sharing the joy with our families and friends.

On January 1st, Genevieve saw a New Year, and a few days later, she went on her first plane ride to Florida! There, we began to experience bottle refusal and some other signs that were concerning, such as vomiting and her overall muscle tone becoming weaker.

We'd return from our trip and make appointments to see a physiotherapist, occupational therapist, and optometrist and went in for a weight check, all anxiously awaiting our six-month visit with our pediatrician.

Genevieve was baptized and celebrated by her immediate family on Sunday, February 5th, two days before the most difficult month of our lives began. The signs that our pediatrician saw led her to believe that something was wrong.

Genevieve  
at her  
baptism on  
February  
5th



We made our way directly to SickKids, receiving the best care by the nurses and doctors, and became quite popular on the seventh floor as the “cutest baby with the long eyelashes.” In this month, she demonstrated bravery and strength through numerous tests all with a smile on her face, charming each person she encountered.

“She demonstrated bravery and strength through numerous tests with a smile on her face”

After a barrage of tests—being moved from neurology to metabolics—the doctors told us that they unfortunately suspected Genevieve had Leigh syndrome. We were given so much information and medical vocabulary that overwhelmed us. The only things that stood out to us from that initial conversation were that there was no cure, and that it could be fatal.

That day, our families rushed to our sides as we processed what this would all mean. Genevieve received an NG feeding tube that day as well, which in turn allowed her energy to perk up, and we focused on being as present as possible with our baby girl who was still smiling at her mommy and daddy, unknowing of the anxiety and fear we were experiencing for her.

We were discharged for Family Day weekend, as if she knew we needed one last weekend as a family at home, only to return the Tuesday after. Genevieve caught a virus that would lead to a “Code Blue - Respiratory Arrest.” Once more, our families rushed to our sides as we'd experience the terrifying world of the ICU. By God's grace, she was awake and able to be extubated 48 hours later.

continued...

We cautiously enjoyed another week with our baby girl back up on the seventh floor, anxiously watching her vitals on the monitor. She smiled with us for a few days longer, but inevitably had a repeat Code Blue event leading us back to the ICU, and unfortunately, this time with not much promise that she'd wake again.

On March 8th, 2023 at 11:44 am, we held our daughter in our arms as she took her last breath. It was a bright and sunny day, which was also International Women's Day. Each of her pediatricians, specialists, ICU doctor, and nurses were women. Our brave girl lives up to her name "of the race of women" and is now our "guardian goddess."

Her seven months on earth with us were too short, but as you can see it was filled with memories, love, and laughter. Do not feel sad for us, because although this grief is immensely heavy and always will be, it is all because of the immense love we have and always will have for our baby girl, Genevieve.



We are now focusing our deep love for Genevieve into carrying on her journey and honouring her memory, so that her legacy can live forever. We're looking forward to participating in the Walk N' Roll 4 Mito, and we're overwhelmed with gratitude that we've been able to fundraise over \$22,000. It is our hope that we can increase awareness of mitochondrial disease and connect with families who have experienced a similar loss.

"We are now focusing our deep love for Genevieve into carrying on her journey and honouring her memory"

If you're a patient, parent, or loved one seeking support, MitoCanada can help.

Visit [www.mitocanada.org/support](http://www.mitocanada.org/support) to access a variety of support resources. Or, reach out to us at: [info@mitocanada.org](mailto:info@mitocanada.org)

**MitoCanada** focuses its energy on creating a world where all lives are powered by healthy mitochondria. We use our collective energy to reduce the devastating impact of mitochondrial disease by creating MitoCommunities that are empowered, inspired and connected.

[MitoCanada.org](http://MitoCanada.org).