

## Words of Remembrance for Juliet Christina

September 11, 2020

From a very early age, we knew that Juliet was not ours to keep forever. Sixteen years later and we are less prepared than we could have ever imagined having to let go. Our identities are so deeply rooted in being her parents and caregivers that it provides an extra level of cruelty to having to let go of a child. Here is my attempt to begin that process of letting go...

Juliet was a very sick little girl from the very first day she was born. However, her illness did not define her. Her story was much, much deeper, layered and filled with LOVE—love of people, love of places and love of activities.

Juliet's most striking physical attribute was her radiant, glorious, gorgeous face! Her plump, ruby-red lips begged to be kissed. Her smile was warm and genuine. Sometimes she made you work for that smile, but it would melt your heart when she gave it to you. She had the most beautiful blue eyes. And lastly, she was blessed with amazingly long, thick, dark hair. Her good looks were perfectly matched by her sassy personality and love of life.

Juliet's first year of life was a glorious but confusing time. We couldn't understand why she missed milestone after milestone and why feeding became increasingly difficult. We started visiting doctors at Plymouth Pediatrics, CHOP, and ultimately found a home away from home at A. I. DuPont Hospital for Children in Wilmington, DE. She was the world's sweetest baby, but something wasn't right, and we were determined to find out what it was so we could give her the best life possible.

One day while going about Juliet's normal routine, Janice received a frantic call from a Geneticist and a Neurologist from DuPont. They wanted to know how Juliet was doing right now. They went on to explain that Juliet's recent bloodwork showed a lactic acid level that was off-the-charts too high. They expected her to be in serious distress. Fortunately, that wasn't the case. It was the first indication that Juliet suffered from what is known as an Inborne Error of Metabolism.

Instead of producing energy in the form of ATP, she was producing excessive amounts of lactic acid, the same thing that makes your muscles sore after strenuous exercise. Her Inborne Error of Metabolism was more specifically known as Mitochondrial Disease. We ended her first year of life traveling to Ohio for a muscle biopsy and a g-tube placement to better meet her nutrition and hydration needs, and to facilitate her ability to receive medications. Juliet didn't do well with the anesthesiology and we almost lost her for the first time out there. These interventions did, however, manage to give Juliet better quality of life.

She continued to slowly progress with continued interventions. Along the way, she developed the sweetest of personalities. She also developed a love of animals. She had two dogs, Hope and Tucker, whom she adored. They have since passed and she has acquired two more dogs,

Cody and Crystal. Crystal is a trained companion dog. What Crystal lacks in obedience, she more than made up for in loyalty to Juliet. Juliet also had a spirit animal—the penguin. She loved watching movies, cartoons, and even documentaries about penguins. There is a certain poetic justice to her loving a bird that doesn't actually fly but swims and waddles instead of walks!

Juliet was a hugger! No one gave better hugs than Juliet. To be on the receiving end of a Juliet hug was to experience a small slice of heaven on earth! It usually started with you sitting next to her. She would take the arm closest to you and summon you closer as she put her arm around your neck. Once she had you in position, she would reach her other arm around you and squeeze you into submission. A lot of times she also found this incredibly funny, so she would belly laugh in a way that would make you and everyone around belly laugh too.

At the very end of her life, Juliet was very weak. However, about four days before she passed, while we laid in bed together, out of nowhere, Juliet gave me a bear hug that I will never forget. I don't know how she was able to do it, but I honestly believe it was her way of saying, "Thanks for all the good times, Daddy."

Over the years we've been fortunate to have many great nurses who Juliet has adored. Our first nurse was Liz L. She enabled our family to earn our paychecks, occasionally decompress, and even pursue some degree of normalcy in our lives. Juliet learned about relationships and people by interacting with her nurses and therapists! Liz we are eternally grateful to you and value you and Jim's continued friendship.

Many nurses followed and became part of our staff. I would like to thank Nurse Beth G who became Juliet's longest tenured nurse. Beth spent eleven years as a valued member of our family working twelve hour shifts three, four, sometimes five days a week. Beth gave Juliet DIGNITY, which isn't an easy thing for kids with severe disabilities, like Juliet. For all of Juliet's nurses, please know that you held a special place in her heart and in her life.

At the age of eight, Jules underwent spinal fusion surgery that lasted thirteen hours. She had a titanium rod installed that extended from the base of her skull to her tailbone. The surgery provided her lungs and vital organs the space they needed to function properly. It was a quality of life improvement that also gave her many additional years of life on the back end. The weeks that followed the surgery were painful and difficult. She never allowed it to get her down. Her recovery took months of intense therapy, but in the end, she came out stronger and better. I learned a lot about bravery watching Juliet.

When Juliet was nine doctors at the Children's Hospital of Philadelphia made a discovery about the origin of her disease. Jules was the first person in the world to be identified with a mutation of the FBXL4 nuclear gene. Since the discovery 7 years ago, more than 100 people have been identified with the same gene being improperly coded. Now, testing is available for people with profiles similar to Juliet's. And someday, her cells, which are still being used in studies around the globe, will lead to a cure.

Her impact has been felt around the world. She has been written about in just about every local paper, The Philadelphia Inquirer, and Time Magazine. She's been on ABC News with her dog Crystal, NBC News, and Fox News. She was prominently featured on CHOP's website when the Mitochondrial Medicine Frontier Program was started. Her story was used to drive traffic to the site and ultimately help connect suffering patients with CHOP's care.

Janice and I would like to thank Dr. Christopher Raab from A.I. Dupont. Dr. Raab was Juliet's Primary Care Physician for the last fourteen years. Without him, Juliet would not have lived and thrived for as long as she did. His rapid responses to our questions, willingness to consider our input about the course of Juliet's care, and his warm relationship with our daughter will never be forgotten.

Juliet would grab all kinds of dangling items. Stethoscopes were her favorite thing to grab, usually as Dr. Raab or one of her nurses were trying to listen to her heart and lungs. She loved beads and crinkle paper. She was always up to something with her hands. She was known to steal watches off of peoples' wrists and loved to get her hands tangled up in her female caregivers' long hair.

Jules loved going to school. She Skyped into Kindergarten and 1<sup>st</sup> Grade—way before Virtual Learning was even a thing. By 2<sup>nd</sup> grade Juliet was taking a bus to Swarthmore five days a week to an amazing school called CADES. It was there that she truly blossomed. Her education was tailored precisely to her ability, but more importantly, Juliet spent the day with other kids, which she adored. She received physical therapy, speech, and occupational therapy while at CADES.

Sadly, she only attended for six years because the travel and her illness became too much as her disease progressed. We are very grateful to the amazing staff of CADES that helped her along the way. The work that these women do with the most special-of-needs students is extraordinary. The peak of Juliet's life was spent at this very special place and Janice and I intend to support their mission in the future.

Juliet's "happy place" was her lake house in the Poconos. There she was able to experience being outdoors in the summer with less oppressive heat and humidity. She was able to swim with the assistance of a special life preserver. She sat by our dock, under the shade of the trees and watched the world go by. She got to take many boat rides and to go tubing. One of her favorite things to do was to go for walks around the lake in her wheelchair and listen to her parent's conversations about everyday life. They were simple pleasures that we never took for granted.

Jules started off this Summer surprisingly strong despite being home on hospice care since November of 2019. But then something changed. She couldn't stay up past 5 pm. She was getting physically weaker. Her labs were becoming increasingly concerning. Doctors suspect

that she suffered a metabolic stroke sometime in early July, the third in her lifetime. Janice and I knew that this one was different and that our beautiful girl wasn't going to come back to us.

Our Juliet was such a dear, special girl. Her ability to form relationships was impressive. But the one relationship that I was so privileged to witness firsthand was with her mother. Janice, I am so ever grateful that you are my wife and that you were the mother of our precious daughter. I am convinced that it was your intelligence, compassion, and tenacity that enabled Juliet to live her best life for the past 16 years. You taught me how to be a good parent. You made her feel like every day was a celebration. Juliet loved you so much. And I know how much you loved her. I'm proud to be your husband because I've seen firsthand what an incredible mother and woman you are.

And so, this it. Juliet, I hope you are happy and pain free. I hope you are smiling and enjoying heaven right now. Mostly, I hope that you know you were loved while you were here with us and that your Mommy and Daddy miss you so very much.

Goodbye sweet girl, I love you.

