

**Dylynn Renee Watterson**  
**February 16<sup>th</sup>, 2009 – October 21<sup>st</sup>, 2013**

**Why we Donate to Ronald McDonald House and Charities of Kansas City**

Many of you know that David and I lost our first child to a chronic illness at the age of 4. What many of you may not know is why we have chosen to donate to Ronald McDonald House and Charities of Kansas City in her honor of her birthday year after year.

To give you a little back ground on Miss D, she was born 9 weeks premature at 31 weeks total gestation. Due to being so early she required extensive medical intervention and support when she was first born. She spent a total of 43 days in the NICU at Overland Park Regional. Prior to her birth – Dave and I were already aware that Dylynn would have club foot. This was determined at one of our routine sonograms. During her stay in the NICU and due to routine exams and testing, several other medical issues were brought to our attention. Not only did she have club foot but she had an undiagnosed tumor on her spine (binding her spinal cord to her spinal column), low muscle tone, one functioning kidney, and multiple skeletal abnormalities. Her heart and lungs, however, checked out great. Each day in the NICU felt as though we were taking 10 steps forward and 20 steps back.

Finally, on day 43, we were discharged from NICU. We left with a list of multiple specialists to follow up with and several tests and diagnostic images that needed to be completed.

In March of 2010 at the age of 1, during an MRI scan on her liver (which turned out to be nothing), Dylynn aspirated contrast fluid which caused us to stay at Children's Mercy for what we thought was the night. The night turned into a week and a week turned into a month. During that stay it was determined that Dylynn had failure to thrive due to the inability to eat or drink as she was silently aspirating what she was putting in her mouth. It was determined that she needed the support of a feeding tube. During the hospital stay, she was also requiring minimal oxygen support which was slowly increasing the longer she was in the hospital. At that time the Dr.'s thought this was due to the rhino virus (common cold) which she had tested positive for. The weeks turned to months and her need for oxygen kept increasing. Dylynn's need for oxygen became so great that she was transferred to the PICU. At that time Dylynn was diagnosed with Idiopathic Pulmonary Hypertension. Idiopathic, meaning they do not have an answer as to what caused her medical condition. **Pulmonary hypertension** is a type of high blood pressure that affects the arteries in your lungs and the right side of your heart. In one form of **pulmonary hypertension**, tiny arteries in your lungs, called **pulmonary** arterioles, and capillaries become narrowed, blocked or destroyed. The very same day she was diagnosed – she went into cardiac arrest and needed extreme medical intervention to save her life. PICU attending that night decided to place her on a life support machine called ECMO. ECMO is a heart and lung bypass machine that did the work for her body while she was in a medically induced coma. Dylynn remained on ECMO for over a week all while requiring 24-hour around the clock care of 2 nurses.

During this time, even though we lived close enough to not qualify, Dave and I were able to stay at the Ronald McDonald House across from the hospital. We were able to take advantage of the comforts of home (as close as it could be). A bed to sleep in, a bathroom to shower, donated food to eat, washing machines to do our laundry all while being within walking distance from our very fragile little girl.

After a total of 93 days in the hospital Dylynn was finally able to come home. She came home with new belongings, as in, 24-hour supply of oxygen, a feeding tube and pump, suction, oximeter, etc. She was also suffering from severe withdraw from the narcotics that were used to keep her sedated. Our world had completely changed and it literally took hours to prepare to leave the house but we did it. We never once limited her. We took her

everywhere! Disney World, Arkansas, Branson, swimming, petting zoo, movies, etc. We were aware that Dylenn's time was limited and we were going to make the best of it!

Over the course of the next 3 years Dylenn would have several hospital stays that would last anywhere from a few days to a month or more. Each time Dylenn ended up in the hospital we were comforted by the convenience and accommodations of the Ronald McDonald House Family Room within Children's Mercy hospital as well as the actual Ronald McDonald House within walking distance from the hospital. We were able to cash in our "McBucks" at RMHC for toys and games to bring to Dylenn while she stayed in the hospital. She thought this was the greatest thing and brought so much joy to her even though she did not feel well.

In October of 2013 we took a family vacation to Seattle to celebrate my aunt and uncle's 50<sup>th</sup> wedding anniversary. The week-long trip was amazing and we were able to spend uninterrupted time together as a family. During our last few days in Seattle, Dylenn caught a cold. Dave and I knew that this required medical intervention and a stay at the hospital. Dylenn was admitted to Seattle Children's hospital on October 14<sup>th</sup>, 2013. They placed her in the NICU, as they normally did, due to increased oxygen support and the support of nitrous. This protocol was normal when it came to Dylenn catching a common illness.

As the Seattle hospital staff and Children's Mercy hospital staff were in the midst of planning her a medical flight back to Kansas City to be with her own team of Dr.'s, she passed away suddenly on October 21<sup>st</sup>, 2013.

During our stay in Seattle, Dave and I were once again comforted as much as we could be by the generosity and comfort of the Ronald McDonald House and Charities of Seattle. We stayed a total of 7 days while Dylenn was in the hospital. They also set up transportation for us to the airport as well as took care of returning our rental vehicle so we could get home to be close to our family and friends.

In regards to Dylenn's previous medical diagnosis – Pulmonary Hypertension ultimately became the main focus for treating. The tumor on her spine was diagnosed as a benign Sacrococcygeal teratoma (basically a tumor made up of all types of tissue). She did have surgery to help untether it from her spinal cord at 10 months of age. She also had her right kidney removed due to it being non-functioning. Her club feet were treated with casting and by age 3 you could not tell she was even born with the issue.

Many people who had the opportunity to meet Dylenn would describe her as being wiser beyond her years. Dylenn loved hard. She loved her pets, she loved her friends, she loved her family but most of all she loved life. Her demeanor and love for life is something I have never come across in anyone else. Dylenn knew her time was limited and she always, no matter what, always made the best of each day. She always said "Live life the Dylenn way, today is a good day." I believe that she was a gift to David and I to teach us how precious life can be. She would be thrilled to know that we honor her with this great tradition year after year as RMHC did so much for her family during many times of need.

We thank you for your continued support and will continue to enjoy celebrating this tradition year after year.