



**Bright Light Foundation**

**Bright Light Foundation Mission:**  
 Inspired by the faith and courage of Tammy Bright and her family, the mission of the Bright Light Foundation is to raise funds, in the spirit of compassion and fun, to assist with the medical needs of those within the oilfield community stricken by catastrophic illness.

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### **Ella Elizabeth Rhodes (3 years-old)**

#### **Daughter of Jeff Rhodes/Schlumberger**

Hi my name is Ella Elizabeth Rhodes and this is my story as told by my mommy and daddy because I cannot talk yet. I have a twin brother named Ethan and an older sister named Payton. My daddy works offshore so mommy can stay home with me because I am sick.

It all started on May 10, 2002, when my mommy got very sick and had to be rushed to the hospital.

You see, my mommy was pregnant with my brother and I when she developed Eclampsia (*Eclampsia is the occurrence of seizures not attributed to another cause during pregnancy, usually after the 20th week*).

On May 13, 2002, she had to have an emergency C-section and my twin brother and I had to be born three months early. I was born first, and weighed only 2 lbs. 4 oz. One minute later, my brother was born and weighed 2 lbs. 6 oz. We were rushed to the NICU and my mommy had to be admitted to the AICU. My daddy was very scared. Ethan and I were very sick and required the help of breathing machines and oxygen. Our bodies were not able to produce enough blood, so we had to get new blood too. My mommy was very sick too and had to get blood also. My mommy was not able to see us for several days but my daddy, our big sister and our grandparents would come see us a lot. They could not hold us but they would talk to us and tell us how much they loved us. My mommy finally got better and was able to come visit us. She cried a lot, and I think she was really scared too. It was very hard for my mommy and daddy to leave us at the hospital, but my daddy had to go back to work soon and my mommy had to go home and take care of Payton.

Ethan had some troubles in the beginning but was able to go home after two months in the NICU. I was not so lucky. I was really sick, became dependent on a breathing machine and oxygen, and developed a bad lung disease called Bronchial Pulmonary Displacia. My family would come to visit me as much as they could. The hospital was far away from our house.

At the age of six months, I required a tracheotomy, nessen wrap, and the placement of a feeding tube. My parents had to come to the hospital and learn how to take care of me. When I was eight months old, the doctors tried to send me home without my breathing machine, and two days later I went into respiratory distress. I had to be admitted to the PICU of another hospital, also far from my home. Along with my breathing problems I was also very malnourished. I had to be put back on a breathing machine and a special high calorie diet. My family would come to see me every weekend, but they could not hold me much because

I was so sick. It was at this hospital that I spent my first birthday. I continued to require a ventilator and oxygen to breathe. It was there that the doctors finally discovered that I had a hole in my heart that had been there since I was born. One month after my first birthday, I went to another hospital where a nice cardiologist was able to patch the holes in my heart. I went back to the PICU to recover and try to get better so I could go home to be with my family.

In July of 2003, after 14 months of my life, several machines, many operations, and three hospitals, my family was finally able to bring me home again. I still had to come home with my trach, breathing machine, oxygen, and the feeding tube. Due to my condition and the amount of medical equipment I required, I had to stay in my parents' room instead of with my twin brother. It was very hard on everyone, trying to take care of me, my twin brother, my older sister, Payton, and on top of everything my daddy was gone a lot for work. I started getting therapy daily to try to learn how to walk, talk, and eat. I was still very sick and severely delayed and had to see numerous doctors and therapists.

My first winter home, only five months after being released from the hospital, I got really sick with pneumonia, and had to go back to the PICU. To make matters worse, my twin brother also had pneumonia and had to be hospitalized at a different hospital locally. After two long weeks of being in the hospital, my brother and I were able to come home. Soon after that, I was able to breathe without the breathing machine but still required the trach, oxygen and feeding tube. At this time, I was well enough to move out of my parents' room. We live in only a three-bedroom house, so they tried to have my twin and I share a room. This did not work out due to my condition (I cough a lot), sleeping habits, and my feeding and therapy schedules. So, my daddy cleaned out our laundry room, which is rather big, and added a door. I now have my own room, although I share it with the washer and dryer.

On May 13, 2004, my brother and I celebrated our second birthday at home with our family and friends. I wouldn't eat any birthday cake and still couldn't walk or talk. August 2004 was a good month for us. I finally started walking and my lung doctor took my trach out. I still required oxygen, so I had to start wearing a nasal cannula in my nose and I still would not eat anything by mouth, so I still required the feeding tube in my stomach. I continued seeing my doctors and therapists and was making a little progress. Then, once again, my second winter home my brother and I both got sick. This time it was RSV (respiratory stress virus). I had to go back to the PICU at Tulane and Ethan went to a local hospital. After another week we were better and went home. I then lost my Medicaid and, of course, I had already spent most of my insurance coverage through my daddy. This was also hard on my parents. They had to start paying for a lot of my medical expenses, including my special formula.

On May 13, 2005, my brother and I turned three and I still would not eat any of our birthday cake. We got a swing set from our mommy, daddy, gammy, and paw-paw. I like to play on it even though I can't climb or swing by myself, or that my lung condition causes me to lose my breath fast, and that I have to take a lot of breaks. After my third birthday, I lost all of my therapy I had been getting since I was fourteen months old through a state program. This was also hard because I am still very behind and require a lot of therapy. My family starting paying for what therapy they could afford, and enrolled me in a special program in the public school system. I am three but developmentally I am only about half my age, and still not talking much. I will require an extensive amount of speech and occupational therapy in order to learn how to eat, talk, and developmentally catch up with my peers. I still need my oxygen through my nasal cannula 24 hours a day, and require breathing treatments on a daily basis. A feeding tube feeds me four times a day because I still will not eat anything by mouth.

I guess I can say that I am lucky to be here, as well as my brother. I know that my family loves me and wants the best for me. I also know that my daddy works a lot so my mommy can stay home and take care of my brother, my sister and me. It has been hard and we still have our bumps in the road. My doctors are hopeful that my lung condition will improve with age, but have no idea how long that may be.

The Bright Light Foundation was kind enough to choose me for their benefit this year. I am very thankful for this, and know that it will help my family to provide for me more of the special nutrition and therapies that I so desperately need.

