

Leila Smith

Leila was born with a severe and often times fatal congenital heart defect called Hypoplastic Left Heart Syndrome (HLHS) in which the left side of the heart is severely underdeveloped. Without treatment HLHS is uniformly fatal - and treatment options include a heart transplant or several stages of open heart surgery. Due to the lack of infant hearts available and the risks and additional illnesses associated with transplant , we chose the surgical route for Leila's treatment.

At 1 day old Leila was life-flighted to Omaha Children's Hospital from our home town of Grand Island, NE. We were so lucky to have a Children's Miracle Network hospital right within our state with qualified doctors and facilities to handle her rare defect. At 5 days old Leila underwent her first open heart surgery - I massive and difficult replumbing of her circulatory system call the Norwood Procedure. She remained in the hospital for 9 weeks. We were then discharged to an Omaha hotel for 6 weeks to await her second operation. At 3 1/2 months old Leila underwent her second open heart surgery - the Bi-Directional Glen. And at 4 months old we finally were able to bring Leila home for the first time.

The next two years were spent on growing and learning. In addition to Leila's heart defect, she had been diagnosed with Partial Tetrasomy 8 - an extremely rare chromosome defect. Also, an ischemic event during her first open heart surgery had left her blind in her right eye. She also had very low muscle tone, physical delays and a severe speech delay. Most of her first three years of life were spent working on overcoming all of her developmental delays in the midst of her fragile health due to her heart defect.

At 3 years old, Leila re-entered Omaha Children's Hospital for her third open heart surgery - the Extracardiac Fontan. Because of recovery problems our stay lasted almost three months - but she had made it through the 3 planned surgeries.

Since then Leila has progressed by leaps and bounds. At 4 she started a Special Needs Preschool in our new town of Fremont, NE, and this fall Leila will be in Kindergarten full time! She continues to work on her developmental delays, participating in Resource class, physical therapy and speech therapy at school. Leila continually amazes us with her resilience and strength - she has been through so much, but she manages to keep a smile on her face every day! We thank God for the wonderful doctors and nurses at Omaha Children's Hospital for the care and love they gave Leila throughout her stays. And we look at every day as a blessing with Leila in our lives - each day is a gift!