

Lila Wolfram's Story



Lila is a beautiful, happy, previously healthy little girl who suffered a cardiac arrest at home on October 3, 2015 when she was 8 months old. We awoke that morning to hear her crying in her crib around 6:30 am. When we went in to check on her we could see that she was having trouble breathing and quickly became unresponsive. We started CPR immediately and called 911. When EMS arrived, she had no pulse and was shocked several times with an AED (Automatic External Defibrillator) in order to restore her heartbeat. She was initially brought to the emergency room at Hunterdon Medical Center where she was put on a ventilator and started on IV medicines in order to control her heartbeat, which was extremely erratic. She was then transferred to the PICU at St. Peter's in New Brunswick where she was further evaluated, stabilized for travel, and transferred to the Cardiac Intensive Care Unit at CHOP. While at CHOP she underwent several electrophysiology tests in order to determine the cause of her arrhythmia - a malfunction of the electrical system of the heart. However, the studies could not determine what part of her heart was causing the arrhythmia. Amazingly, neurological tests showed minimal signs of brain damage, in spite of her having been pulseless for 20-30 minutes. Since the cause of her arrhythmia was unknown, it was recommended that she have surgery to implant an AICD (Automatic Internal Cardioverter Defibrillator). An AICD monitors her heart and can also deliver an electrical shock when it senses a life-threatening change in the heart's rhythm. Lila had this surgery on October 12th, and was sent home a week later on a beta blocking medicine.

November was filled with weekly cardiology appointments at St. Peter's so that she could be monitored closely. There were a few minor irregular beats noted initially, but increasing her dose of medicine seemed to work --- until December 1st. That afternoon Lila was napping when she

suddenly began screaming in pain – I quickly discovered that her AICD was shocking her and called 911. She was again taken to the ER at Hunterdon, where the doctors identified her as being in the midst of a “VT (ventricular tachycardia) storm”. A magnet was eventually placed over her device in order to suspend the shocks, but not before it shocked her so many times that the battery (that was designed to last 5 years) was completely depleted. She was again transferred to CHOP, where she was stabilized and monitored for several days. The doctors at CHOP recommended that Lila be considered for a procedure called a sympathetic denervation, which is an irreversible surgery that severs the connection of the sympathetic nervous system to her heart. This procedure is rarely used on children, and is not something that is done at CHOP, so Lila was transported by plane to the Mayo Clinic in Rochester, Minnesota for the surgery. The battery in her AICD was changed at the same time as her sympathectomy was performed. Lila did well with the surgery, and was at Mayo for 2 weeks before being transferred back to CHOP and released on December 23rd, just in time to be home for Christmas with us and her older brother and sister.

She is home now, and taking medicine 4 times a day in an attempt to control her arrhythmia. The doctors at Mayo are currently running genetic tests in their lab to see if they can determine the root cause of her cardiac issues. Lila is also receiving physical therapy in order to make sure that she continues to hit her milestones.

Because of everything that has happened, we have both been forced to take leaves of absences from our jobs. Thank you to the Shannon Daley Memorial Fund for helping us to ease the financial burden of the past few months. We truly appreciate your support and are grateful to our whole community for rallying around us and our amazing little girl.

