Adeline's Story

When Adeline was born, her heart experienced arrhythmias. Her doctors weren't overly concerned, but as a precaution, they sent Adeline for additional screenings at Duke Children's. At Duke, Adeline's family received a staggering diagnosis.

Dr. Salim Idriss, a Duke pediatric electrophysiologist, diagnosed Adeline with Long QT Syndrome (LQTS), a rare and sudden arrhythmic death syndrome that is difficult to detect because the first symptom is usually death.

LQTS isn't curable, but it can be managed. Dr. Idriss put Adeline on a strict medication regimen. She also had open heart surgery when she was seven days old to implant a therapeutic pacemaker.

LQTS is a genetic disease, and because Adeline had it, it meant one of her parents did too. Dr. Idriss determined that Adeline's father, Aaron, was the carrier. It was a miracle that he was still alive, and he was quickly connected with a Duke cardiologist to manage his LQTS.

Aaron had unknowingly been living with LQTS his entire life. He realized that LQTS had been silently killing people in his family for generations. If not for Adeline, the same fate likely would have happened to him. Adeline wasn't only Aaron's first child, she ended up being his guardian angel.

Today, Adeline is nine and is happy and energetic. She enjoys arts and crafts, her favorite subject is science, and she loves musical theater. Despite facing this difficult disease daily, Adeline and her family stay positive and enjoy life to the fullest.

While Adeline's LQTS will never go away, her family has the tools, knowledge, and access to medical treatments that will keep her on track for a long, happy, and healthy life, thanks to Duke Children's.

Each year, Children's Miracle Network (CMN) Hospitals selects ten patients to represent the impact of its 170 member hospitals. Adeline has been serving in this role in 2024. Adeline and her family have attended special events throughout the country representing CMN Hospitals, like Duke Children's, meeting with corporate partners and sharing her personal story. We are so proud of Adeline and how wonderfully she has represented Duke Children's and kids like her!

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