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Photo courtesy of Lexiam Heart Foundation

## Dedicated To Families Affected By Congenital Heart Defects

By Journal Marketing Department

**W**rapped in a web of medical devices and uncertainty at a hospital in Colorado, newborn Lexi Schneider fought for life. Beside her minutes-old body, her parents watching, hoping and praying for the best for their newborn daughter who was born with a Congenital Heart Defect called Hypoplastic Left Heart Syndrome in 2013.

Then there is Liam, the son of Brittany Behenna Griffith. Liam, born in May 2015 also with Congenital Heart Defects including Transposition of Great Arteries, Double Outlet Right Ventricle, Ventricular septal defect, and Pulmonary Stenosis.

Liam and Lexi's stories and battles brought each of these newborn's parents together. The parents who welcomed their newborns into a world that was filled with uncertainty and plenty of unknowns; but they knew about hope.

Brittany and Leslee, Lexi's mom, were able to connect based on one life changing moment; they both had children born with a congenital heart defect. But little did they know at

that time in the fall of 2015, that their connection would lead to more.

They knew how to connect because each of them has walked the painful explosion of emotions upon finding out their child had a congenital heart defect. But there is one thing that held them together hours after their children were born as they dealt with the fear their child's life.

Through the hours of uncertainty, fear and unknowns after their children were welcomed into this world, they clung to hope. Hope that eventually their dreams of bringing their newborn children back home. But for now, home was a hospital.

Lexi would eventually return home to Bosque Farms after undergoing three open heart surgeries. But for Liam, his battle was lost at 21 hours old, after enduring open heart surgery. His memory lives on in the work his mother continues to do.

This is their story and what brought Leslee and Brittany together. They knew that they to band together to support other families who were given that emotional battle. They created a non-profit to help other New Mexico

families. And in February 2018, they co-founded Lexiam Heart Foundation to help support other families who are affected by congenital heart defects. The name Lexiam shows both sides of congenital heart defect battle, as it empowers Lexi's story and honors Liam.

Then along came Theo and the Mikelson family. Theo who's beginning in this world was also uncertain as he was also born to Zack and Schlræe in 2017 with a major heart defect.

Lexi, Liam and Theo's families all have different backgrounds, but there is one thing that connects them, they are all parents to children born with congenital heart defects. Each of these parents knows the terminology when it comes to dealing with a child born with a congenital heart defect. They also know that their stories can help others when it comes to dealing the emotions, decisions and concerns with this hard battle. They may not be blood-related, but they have become a family whose varied life stories have the same foundation, each of them has someone they love born with a congenital heart defect.

They want to use their stories to support other families affected by congenital heart defects whether financially, emotionally or physically. Congenital heart defects are the number one birth defect in nation, as one in every 100 babies are born with it.

"Congenital Heart Defects changes each of our lives and we want to help others," Leslee said. "Their stories are as important as ours and we want to offer support in any way we possibly can."

The volunteer-run nonprofit raises funds through an annual 5K run and generous donations. It helps families with financial assistance, community resources and emotional wellness.

For more information or to donate, visit [lexiamheartfoundation.org](http://lexiamheartfoundation.org).

"Whether it is taking meals to the hospital or helping with gas cards, we want to ensure that every family has the support they need," Schlræe said. "I remember the time after Theo was born how lonely and hard it was. I want other parents to know that we are here to help and offer support."