

My name is Sheridan Gluff, and my husband is Wayne Gluff. We are parents of two wonderful little boys, and yet, we are only raising one. Ryan Wesley Gluff, came into our life on April 22, 2010 at 8:36 p.m. He was named after my father and after Wayne. My entire pregnancy was a breeze. And though labor was difficult on me, there were no complications. He passed away suddenly on April 24, 2010, just two days after he was born. According to all of the standard newborn screenings, he was happy and healthy. We were discharged less than 24 hrs after he was born. We never dreamed we would be rushing our newborn son to the Emergency Room that same night, where they would eventually tell us there was nothing more that they could do. It was the worst day of our lives. The ER doctor had explained to us that it was a heart murmur. However 3 days later, we received a phone call from the Medical Examiner's Office in Albuquerque. The doctor explained to us that he actually had a birth defect of the heart, more commonly known as a CCHD (Critical Congenital Heart Defect), which is a structural defect of the heart that often are associated with hypoxemia among infants during the newborn period and typically require some type of intervention, usually surgical and often fatal. Ryan's particular defect was Hypoplastic Left Heart Syndrom (HLHS).

Through the encouragement from my family, we were introduced to the March of Dimes not long after we had Ryan. I knew it was meant to be when the very first walk we'd participate in would be exactly year after his due date. The decision to be a part of March of Dimes has significantly changed our lives. I love to advocate for babies and I now have an outlet now to "take care of Ryan" without being able to physically take care of Ryan. I have also made great friends, Kim Huett and Becky Horner who have helped us and supported us in this journey.

Kim asked us in January if we knew of the new screening for newborns that could detect CCHD. We had not heard of this screening so I instantly started my research.

I found that this screening can detect 7 primary CCHD's:

- Hypoplastic Left Heart Syndrome
- Pulmonary Atresia with Intact Septum,
- Tetralogy of Fallot,
- Total Anomalous Venous Return,
- Transposition of the Great Arteries,
- Tricuspid Atresia, and
- Truncus Arteriosus.

It can also detect 5 secondary CCHD's,

- Coarctation of the Aorta,
- Ebstein Anomaly,

- Double Outlet Right Ventricle,
- Interrupted Aortic Arch, Single Ventricle.

Kim then asked if we would like to be spokespersons for the legislation if she could get it on the agenda at Lobby Day. Of course, we said yes. Since then, I have searched, and searched and got as much information as I can. I am currently in contact with 11 other states spokespersons for the same or similar legislation. I also have been working closely with the Save Babies Through Screening Foundation, that help provide me with statistical information throughout the states. I since have been in contact with Dr. Ron Reid as well who has been so helpful in letting me know if I am going about it in the right steps or not. Dr. Reid and I have discussed being able to pass this legislation as "Ryan's Law", as it is so close to my heart and my family.

We realize that get this law passed will not bring our son back, but we would do anything to keep another mother and father from going through this tragedy. A friend of mine once said, "No parent should find out about their child's birth defect from the coroner's office." Being one of the many parent's who have lived through this situation, I cannot imagine knowing of a screening that could prevent this and not implementing it in our everyday here in New Mexico. We keep this issue close to our hearts. We would like to ask for your support as well.