

We ♥ Harlie
For the Month of
February

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Harlie's Story



At 16 weeks pregnant, the Holtons found out that their baby was different. She had a mass growing in her chest. Then, at each of the rest of their pregnancy check ins, more and more news was thrown their way. After an emotionally draining few months, Harlie was born with just a 5% chance of survival.

Eventually she was diagnosed with Goldenhar Syndrome (a craniofacial syndrome), VACTERAL Association, and Congenital Lobar Emphysema. There are no known causes of these defects - it's just "luck". In fact, Goldenhar and VACTERAL are both a matter of opinion based on a collection of abnormalities - no two cases are the same.

Because of this, life since Harlie has been quite the adventure for the Holtons. 11 years and 60+ surgeries later, they have spent countless hours in hospitals, doctor's appointments and therapy. But, they've also been able to keep their home, travel across the country to see the best doctors and have managed to stay positive. Their attitude and story is the constant flame that lights this organization. Harlie is at the heart of this community that has bonded together to make the lives of all our families a little bit easier. We are so grateful for the lessons Harlie has taught us and we can't wait to see where she takes us next!