

## **TODAY 5 BABIES WILL BE DIAGNOSED**



Today almost 5 families in the United States alone will receive the devastating news that their unborn child will have to fight for its life. They have been diagnosed with a potentially fatal birth defect called a congenital diaphragmatic hernia. A congenital diaphragmatic hernia is where the diaphragm in development does not completely close in an unborn baby and organs migrate to the thorax which under normal circumstances is where the heart and developing lungs are located. This defect has a profound impact on lung function.

Thirty-five (35) families a week. One hundred fifty (150) families a month. 1800 families a year. Congenital diaphragmatic hernia occurs just as often as spina bificia and cystic fibrosis and more often than muscular dystrophy, yet most do not hear of it until their child is diagnosed.

It doesn't just affect the baby, the mother and the father – it affects the whole family and the entire community. This baby will need Intensive Medical Care at a level three NICU with ECMO. The medical bills will total hundreds of thousands and quite often, millions of dollars. These are million dollar babies. The care to save their lives depletes blood supplies at local blood banks – one infant required 6 gallons of blood and blood product in 38 days. Some families will be financially depleted due to the long term care of these children or other costs associated with one or both parents without a job. Without benefits, Medicaid takes over and covers costs. Some families require state and government assistance for short periods of time. This has an effect on communities. Some insurance companies have "Lifetime Caps" and these children reach them very quickly. These children require insurance to provide the therapy they need so that they can accelerate and thrive.

What can you do to help save these babies? What will help these families? What can you do to make a difference?

1. Learn about congenital diaphragmatic hernias.
2. Donate blood regularly, if you can, to your local blood centers to help ensure all patients receive the blood they need.
3. If you know a family affected by CDH, tell them of Breath of Hope –we are here if they need us.
4. If you are looking for a cause to help with – we would welcome your assistance!
5. Wear turquoise on March 31 for Congenital Diaphragmatic Hernia Awareness Day! When someone asks what it's for – tell them!

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