



# BIRTH DEFECTS & DEVELOPMENTAL DISABILITIES

**F**or the millions of Americans with birth defects, disabilities, and blood disorders, a happy, healthy life can be challenging to realize. CDC conducts research and prevention efforts to save babies, researches autism, prevents and manages complications from blood disorders, and makes sure health services and programs work for people with disabilities throughout their lives.



**2 MILLION**

More than 2 million children and adults have severe heart defects.



**900,000**

Up to 900,000 Americans develop blood clots each year.

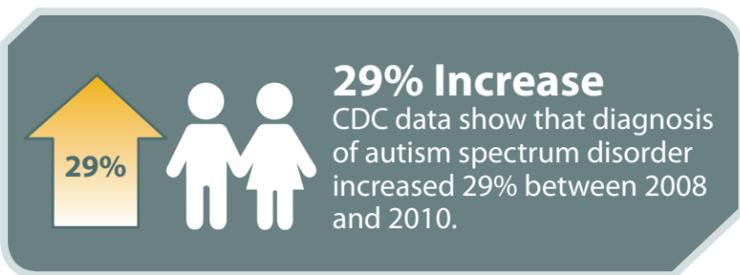


**\$400 BILLION**

Healthcare associated with disabilities costs an estimated \$400 billion a year, or about 25% of all health expenses in the U.S.

## KEY ACCOMPLISHMENTS

- Determined there is not enough evidence to guarantee that medications commonly used by pregnant women do not pose a risk to their unborn babies.
- Expanded the “Learn the Signs. Act Early” program to improve early identification of autism and other developmental disabilities, helping families get the services and support they need as soon as possible.
- Identified more than 2,000 gene mutations reported to cause hemophilia worldwide. The gene mutations can be used for genetic testing of family members of a person with hemophilia and may help predict who will develop a genetic inhibitor (antibody) to treatment.



Baby Cora could have been saved by pulse oximetry screening—a type of newborn screening that can identify congenital heart defects.

## CORA'S STORY: FINDING A BROKEN HEART

After a healthy and normal pregnancy, I gave birth to my daughter, Cora, on November 30, 2009. Two days later we took her home after getting a clean bill of health at the hospital. The next 3 days were spent cuddling, getting to know each other, and waking every few hours to feed her.

One early morning my husband handed Cora to me because she seemed hungry. I started to feed her, and everything was going great. I looked up at my husband to tell him I loved him. When I looked back down, Cora was pale, gray, and not breathing. We raced to the hospital, which was no more than 5 minutes away, but we arrived too late. Cora was gone. We learned from the coroner that she had an undetected congenital heart defect. Neither of us had ever heard the term.

We later learned about a type of screening—pulse oximetry—that might have helped identify Cora's heart defect before it was too late. While we'll never know for sure if it would have made a difference for Cora, we sure wish she'd had the simple screening. Cora's story is extremely sad, but it's also full of hope. In Indiana, where we live, a new law requiring newborn heart screening with pulse oximetry is named after her and is known as Cora's Law.

Now I hope for a day when no mother finds out about her child's heart defect from a coroner. I hope that undetected congenital heart disease becomes a thing of the past. And, ultimately, I hope that one day congenital heart defects can be prevented and that no baby is born with a broken heart.

— Written by Cora's mother, Kristine