

My baby has a...

# Critical Congenital Heart Defect

**You and your baby are not alone.** Each year, about 105 babies in Kentucky and about 7,200 babies in the United States are born with Critical Congenital Heart Defects.

## What are Critical Congenital Heart Defects?

A Critical Congenital Heart Defect is a birth defect that affects the structure of your baby's heart and the way it works. Critical Congenital Heart Defects cause serious, life-threatening symptoms. Sometimes, you will see these types of heart defects referred to as "CCHD".

## How did this happen?

Scientists think that a mix of genetic and environmental factors cause heart defects. Remember, your baby's birth defect is **not** your fault. There is no known way to prevent heart defects. For future pregnancies, doctors recommend having a healthy weight, eating well, taking prenatal vitamins, and not smoking or drinking, to have the best chance of a healthy pregnancy and baby.

## What's next for my baby?

Critical Congenital Heart Defects are very serious, but they are often treatable if caught early. Your baby's heart defect is **critical**, which means your baby will need surgery or other treatment before his or her first birthday. Ask your doctor about the treatment plan for your baby.

## How can I help my baby?

It is important that you speak to a heart doctor regularly throughout your baby's childhood. The doctor will help you make the best decisions about your child's health care. With love and support from their families, many children born with Critical Congenital Heart Defects are able to live long and happy lives.

### Talk to a healthcare provider if your baby has one of these CCHDs:

- *Hypoplastic Left Heart Syndrome*
- *Dextro-Transposition of the Great Arteries*
- *Pulmonary Atresia*
- *Truncus Arteriosus*
- *Total Anomalous Pulmonary Venous Return*
- *Tricuspid Atresia*
- *Tetralogy of Fallot*
- *Aortic Interruption/Atresia/Hypoplasia*
- *Coarctation/Hypoplasia of Aortic Arch*
- *Double-Outlet Right Ventricle*
- *Ebstein Anomaly*
- *Single Ventricle*



### Nick's Story—Written by his mom, Susan

As Susan welcomed the birth of her son Nick, she thought everything seemed normal. However, as she asked, "Is my baby fine?" the initial smiles surrounding her quickly changed to whispers and concerned looks. Soon, Nick was whisked away to specialists in a large children's hospital while Susan was left behind. Shortly afterward, she was released, leaving with a balloon that read "It's a boy!" but she held no baby boy in her arms. Susan did not realize

then that the adventure had only begun as tests soon revealed that her baby had a congenital heart defect. After Nick had three difficult open heart surgeries, his doctors decided that he could survive only with a heart transplant. Just before his second birthday, Nick received his new heart. Although Nick is 23 years old now and doing well, he and his parents still worry about transplant rejection and the future. "I think about the pain and frustration we have been through, and my hope for other families is that we can find out what causes congenital heart defects so that we can prevent them," added Susan.

To read more stories about families like yours, go to: <https://www.cdc.gov/ncbddd/birthdefects/stories/heartdefects.html>

## Available Resources

**The Commission for Children with Special Health Care Needs** has a mission to enhance the quality of life for Kentucky's children with special health care needs through quality service, leadership, advocacy, education and collaboration. Eleven offices and seven satellite clinic locations serve children across the state. Commission staff work with families to help them get the care their children need. Nurse care coordinators assist families with medical needs and Family to Family mentors are able to guide families seeking answers to educational, social, and emotional concerns. <http://chfs.ky.gov/ccshcn/>

**Little Hearts, Inc.** is a national organization providing support, education, resources, networking, and hope to families affected by congenital heart defects. Membership consists of families nationwide who have or are expecting a child with a congenital heart defect. <https://www.littlehearts.org/Default.asp>

## Additional Information

The Kentucky Birth Surveillance Registry (KBSR) is dedicated to preventing birth defects through ensuring timely, complete, and accurate birth defects surveillance; referring children with birth defects to appropriate services; providing data for research studies after appropriate review; and implementing birth defects prevention programs in Kentucky. You can contact Kentucky's Birth Surveillance Registry at [kbsr@ky.gov](mailto:kbsr@ky.gov).

For more information about critical congenital heart defects, visit:  
<https://www.cdc.gov/ncbddd/heartdefects/cchd-facts.html>

Information adapted from: <https://www.cdc.gov/ncbddd/birthdefects/types.html>

