

Healthy Baby?



This is Taryn (she is 1 day old in this picture).

Taryn's heart defect was found after she stopped breathing when she was 27 days old. Taryn passed away when she was 29 days old.

*A baby makes footprints in our hearts
that never dim or fade.*



Visit www.blessherheart.org for the Spanish and Vietnamese version of this pamphlet.

DISCLAIMER: ALWAYS check with your doctor if you have any questions or concerns about a condition. This material is for informational purposes only and should not be interpreted as medical advice for any specific facts or circumstances.

Contact sources for permission to reprint original materials.

This pamphlet is written by Taryn's mom:
Vi Kennedy, RN, BSN, MBA

Congenital Heart Defects Summary

Information for Parents



Congenital heart defects are the most common birth defect (1/115 live births ⁽¹⁾) and are the # 1 cause of death from birth defects during the 1st year of life. ⁽³⁾

Get Smart About the Heart
www.blessherheart.org

Congenital Heart Defect (CHD) Facts

- A congenital heart defect is an abnormality in the heart that is present at birth. ⁽¹⁾
- Heart defects start in the early weeks of pregnancy when the heart is forming. ⁽¹⁾
- Defects range in severity from simple to life-threatening. ⁽³⁾
- **Congenital heart defects are the most common birth defect (1/115 live births ⁽¹⁾) and are the # 1 cause of death from birth defects during the 1st year of life.** ⁽³⁾
- Nearly twice as many children die from congenital heart disease in the U.S. each year as from all forms of childhood cancers combined. ⁽³⁾
- Some babies will be diagnosed at birth, sometimes the diagnosis is not made until days, weeks, months, or even years after. In some cases, CHDs are not detected until adolescence or adulthood. ⁽²⁾

What causes CHDs?

In most cases, scientists do not know what makes a baby's heart develop abnormally. Genetic and environmental (e.g., exposure to chemicals or certain medications) factors possibly play a role in CHDs. ⁽¹⁾

At least 30% of children with chromosomal abnormalities have heart defects. ⁽¹⁾

Who is at risk?

Anyone can have a child with a congenital heart defect. ⁽³⁾ You may have an increased risk if you have a chronic illness such as diabetes or if you have a family history of a CHD.

What signs / symptoms should I report to my doctor?

Infants ⁽²⁾

- Tires easily during feeding (i.e. falls asleep before feeding finishes)
- Sweating around the head, especially during feeding
- Fast breathing when at rest or sleeping
- Pale or bluish skin color
- Poor weight gain
- Sleeps a lot - not playful or curious for any length of time
- Puffy face, hands, and/or feet
- Often irritable, difficult to console

Children ⁽²⁾

- Gets out of breath during play
- Difficulty "keeping up" with playmates
- Tires easily/sleeps a lot
- Change in color during active play or sports (looks pale or has a bluish tint around mouth and nose)
- Frequent colds and respiratory illnesses
- Slow growth and weight gain/poor appetite
- Complains of chest pain and/or heart pounding

Talk to your doctor about any questions or concerns



Sources:

(1) March of Dimes

(2) The Congenital Heart Information Network

(3) American Heart Association

Is there a standard test to find out if my child has a CHD?

Pre-natal ultrasounds can detect some birth defects, but it does not pick up all CHDs.

After birth, there is not a standard test/screening at this time. The current screening method is to look for symptoms and listen for murmurs.

Pulse oximetry, a non-invasive test that can measure the oxygen level in the blood, may be useful in screening newborn babies for CHDs. Ask your pediatrician about doing pulse oximetry after the birth of your baby.

How are CHDs diagnosed?

Babies and children who are suspected of having a heart defect are usually referred to a pediatric cardiologist (children's heart disease specialist). This doctor can do a physical exam and often recommends one or more of the following tests:

- Chest X-ray
- Electrocardiogram, a test that records heart rate patterns
- Echocardiogram, a special form of ultrasound that uses sound waves to take pictures of the heart. *This test can be performed before birth (during pregnancy) and / or after birth.*

All of these tests are painless and noninvasive (nothing enters the child's body). ⁽¹⁾

Some children may undergo a procedure called a cardiac catheterization. ⁽¹⁾

Is there treatment for CHDs?

Treatment ranges from medicines to surgical intervention with visits to a pediatric cardiologist.

Visit www.blessherheart.org for links to additional information