

Family Education Sheet

Cardiac Rhabdomyoma



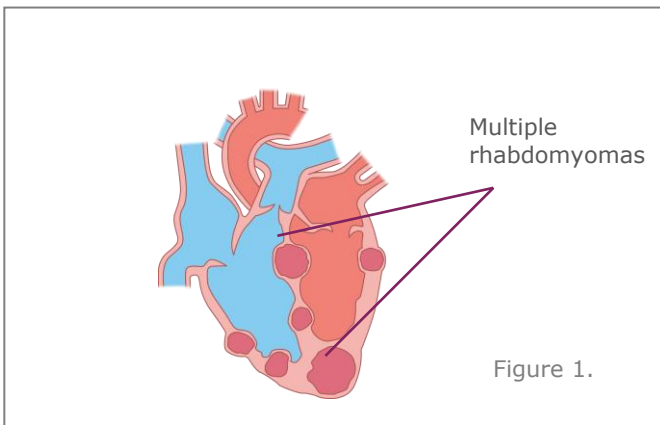
This sheet explains what a cardiac rhabdomyoma is and how Boston Children's Hospital approaches treatment.

Key points

- A cardiac rhabdomyoma is a non-cancerous tumor.
- A tumor can interfere with the way the heart works, blocking blood flow to vital organs and causing an abnormal heart rhythm (arrhythmia).
- Cardiac rhabdomyomas naturally shrink during childhood.
- In rare cases where treatment is necessary, medications called mTOR inhibitors can shrink the tumors.

What is a cardiac rhabdomyoma?

- Cardiac rhabdomyoma is a kind of benign (non-cancerous) heart tumor and is the most common type of heart tumor in children (Figure 1).
- It is usually found during pregnancy or when the baby is an infant.
- When they are found in a fetus, the tumors tend to grow during the later stages of development until about 30-32 weeks gestation. Then, they may slowly shrink during the first few years of the child's life.



Is it associated with other conditions?

- Most babies with cardiac rhabdomyomas have a condition called the tuberous sclerosis complex (TSC).
- TSC can affect other systems in the body, such as the brain, skin, kidneys and other organs. It can cause epilepsy, seizures and developmental delay. MRI and ultrasound can be considered to screen for other associated findings.
- TSC is a genetic syndrome caused by a mutation in the TSC1 or TSC2 gene. We recommend a genetics evaluation to see if genetic testing is indicated. This can be done prenatally or after the baby is born. Learn more about this condition at <http://www.tsclinic.org>.

- Cardiac rhabdomyoma may be associated with arrhythmias (irregular heartbeats), which can potentially be life threatening. The kinds of arrhythmias associated with cardiac rhabdomyomas include supraventricular tachycardia and ventricular tachycardia.
 - Supraventricular tachycardia is when the heart beats very quickly and involves the upper chambers (atria) of the heart.
 - Ventricular tachycardia is an abnormal heart rhythm that starts in the ventricles.

How can you tell if my child has a cardiac rhabdomyoma?

- An ultrasound test can tell if there are one or more tumors. It also looks at blood flow through the heart and how the heart muscle is working. If more than one tumor is found, there is a higher likelihood that they are cardiac rhabdomyomas.
- If a different diagnosis is possible, your doctors might suggest other kinds of imaging tests, such as an MRI of the heart. Sometimes, a biopsy (small piece of tissue) is taken from the tumor and studied by a pathologist to make a diagnosis.

What problems does it cause?

In fetuses and infants, these tumors can sometimes grow and block blood flow through the heart.

- When the blood flow is blocked in a fetus, it can cause fetal hydrops (fluid that collects around the heart or body). In rare cases, the blood flow is seriously blocked and the fetus may not survive.
- If a baby is born with circulatory problems from the tumor, the baby may need to be hospitalized in the intensive care unit.
- In most babies and children with rhabdomyomas, the tumors do not cause blockage of flow and shrink during childhood, to the point where they may become undetectable.

What is the treatment?

In the past, surgery was recommended for babies who had symptoms related to the tumor. Now, we often use a medication called an mTOR inhibitor to shrink the tumor. This allows some babies to avoid surgery.

Contact us

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