

# Congenital heart block

Patient Information Series – What you should know, what you should ask.

## What is heart block?

Heart block is a fetal heart condition that causes an abnormally slow heartbeat in the fetus. The first symptom detected in utero is usually an incidental finding of abnormally low fetal heart rate during prenatal visits. There are three types of heart block: first degree, second degree, and third degree. Third degree is the most severe form. The highest risk for this to occur is between 18 to 25 weeks. The most common cause of congenital heart block is due to trans-placental passage of certain antibodies, known as SSA and SSB antibodies. These antibodies are most associated with mothers with medical conditions such as Lupus or Sjogren syndrome. Not everyone with these conditions has these antibodies.

## Should I have more tests done?

If you have Lupus or Sjogren syndrome, your physician should order tests to identify presence of SSA and/or SSB antibodies. Early identification of these antibodies and increased surveillance of the fetus have been shown to improve outcome.

## What monitoring should I have?

Experts recommend patients at risk to have close monitoring of their fetus with weekly fetal echocardiogram, which is a special ultrasound of the fetus' heart, weekly from 18 to 26 weeks. This allows for diagnosis of first and second degree block and to allow for consideration for intervention before progression to irreversible third degree heart block. Referral to a Maternal Fetal Medicine specialist, Pediatric Cardiologist and Neonatologist should be made to assist in monitoring and management.

## What treatment is available if congenital heart block is diagnosed?

There are not many options for treatment of congenital heart block in utero. If a decision to treat is made, it will involve a type of steroid, taken orally by the mother, which can cross the placenta to reach the fetus. Ongoing close follow up with weekly fetal echocardiogram should be planned to identify signs of fetal distress, which may necessitate urgent delivery.

## What does it mean for my baby after it is born?

Newborns with congenital heart block will be monitored closely in the neonatal ICU after birth. The main treatment is placement of a temporary or permanent pacemaker. The type of pacemaker required will be dependent on severity of heart block and presence or absence of co-existing heart defects.

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## What is the prognosis?

Complete heart block is associated with intrauterine fetal demise in 5 to 20 percent of cases. Once delivered, the prognosis is generally favorable following pacemaker implantation. These children should have follow up with a Pediatric Cardiologist in the long term to monitor for heart dysfunction.

## Will it happen again?

Recurrence of congenital heart block occurs in approximately 18 percent in those with a history of congenital heart block in a previous fetus. Treatment is available to decrease the risk of recurrence in future pregnancies. Patients should have pre-conceptual counselling with a Maternal Fetal Medicine specialist prior to planning future pregnancies.

## What other questions should I ask?

- When should I delivery?
- Where should I deliver?
- Where will the baby receive the best care after it is born?
- Can I meet the team of doctors that will be assisting my baby when it is born in advance?

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