

# Bilateral Renal Agenesis

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

## **What is a Bilateral Renal Agenesis?**

Bilateral Renal Agenesis is the absence of both kidneys in a baby. It occurs in 1 or 2 out of 10 000 babies. With a very few exceptions, it is not considered compatible with life after birth. It is suspected on ultrasound when the person doing the ultrasound cannot see kidneys, or can only see a small amount of tissue where the kidneys should be. When the scan is performed after 18 weeks, there will usually be a lack of water around the baby (amniotic fluid) and the bladder of the baby may not be seen or appear very small. The lack of amniotic fluid is called Oligohydramnios. This lack can cause malformation in the baby due to lack of space. The most frequent malformations are lungs that are too small and joints that are too stiff.

## **How does a Bilateral Renal Agenesis happen?**

Why kidneys do not develop in some fetuses is unknown. Most cases happen only by chance. However, some cases are caused by genetic diseases. These are problems in the genes (which are in each of our body's living cells), which are passed on by the parents or happen for the first time in the baby.

Occasionally, the renal agenesis is part of a syndrome, a more complex type of genetic disease where many parts of the baby are affected. These children also have other problems, such as with the gut, the brain, the heart, the muscles, the bones, or other parts of the urinary system. These may be caused by genetic changes or the cause may still be unknown.

Should I have more tests done?

If your doctor thinks your baby has a problem that is caused by genetic change, you may be referred for genetic testing and counselling. Genetic testing usually involves getting a sample of fluid or blood, which can be checked for a specific gene. Genetic counselling is a service that can give you information and guidance about conditions caused by genetic cause for the problems seen.

In addition, your doctor may refer you to specialists. You may need more ultrasound scans during the pregnancy to help find out whether it is bilateral renal agenesis. Some women will be offered an amnioinfusion (an injection of fluid around the baby) to improve the visualisation. Others will be offered a MRI (a different way to get images of the baby) to confirm the diagnosis, if the images on ultrasound are not clear.

## **What are the things to watch for during the pregnancy?**

The inability to see the kidneys and the bladder, associated with lack of fluid around the baby after the 16th week of pregnancy should prompt further investigation for bilateral renal agenesis. A thorough examination by a specialist is usually recommended.

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You should receive counseling from a specialist to best plan the rest of your pregnancy, if the problem is confirmed.

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

Babies missing both kidneys cannot survive, even with dialysis or kidney transplant due to the associated lack of lung development. No treatment has yet been shown effective to treat this condition: one-third of babies will die during the pregnancy, and the others die soon after birth.

In such situations, some people decide to terminate (stop) a pregnancy. This is a very personal decision. A healthcare professional will speak with you and support whatever decision you make.

## Will it happen again?

It is unlikely that a future baby will have bilateral renal agenesis. There is a higher risk of having a child with another kind of kidney problem. This risk is estimated at around 10%. If a genetic cause was found to explain the condition, the risk might be much higher. Your doctor will be able to give you more information about this.

## What other questions should I ask?

- How often will I have ultrasound examinations done?
- Should I have genetic counseling? What genetic testing should we consider?
- 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 of my delivery?

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