

# Unilateral Renal Agenesis (URA)

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

## **What is a Unilateral Renal Agenesis (URA)?**

Unilateral renal agenesis (URA) is the complete absence of the kidney on one side, with compensatory hypertrophy (overgrowth) on the contralateral (opposite) side. One to two out of every 1000 births have URA. The diagnosis is often made at the time of the 18-23 week antenatal ultrasound scan, done to examine the fetal growth. Unilateral renal agenesis may be suspected if one of the kidneys cannot be seen.

Babies born with URA can show signs and symptoms at birth, in childhood, or, in some cases, only show the symptoms later in life. Symptoms can include: high blood pressure, poorly working kidney, urine with protein or blood, swelling in the face, hands, or legs. Babies born with URA may also have associated genital anomalies.

## **How does a Unilateral Renal Agenesis (URA) happen?**

The cause of URA is currently not known. Most cases are not inherited from mother or father. However, some cases are caused by genetic mutations. These are problems in the genes (which are in each of our body's living cells), which are passed on by the parents.

Occasionally, the renal agenesis is part of a syndrome, which is a collection of symptoms and signs. These children may also have other problems, such as with the digestive system, nervous system, heart and blood vessels, muscles and skeleton, or other parts of the urinary system. These may be caused by genetic mutations.

## **Should I have more tests done?**

If your doctor thinks your baby has a problem that is caused by genetic mutations, you may be referred for genetic testing and counselling. Genetic testing usually involves getting a sample of body tissue, 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 mutations. In addition, your obstetrician may refer you to a pediatrician, or a paediatric nephrologist, a doctor who treats babies, children and young people with kidney problems.

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

Since contralateral (on the opposite side to which the conditions occurs) renal abnormalities are common in fetuses with unilateral agenesis, you may need more ultrasound scans during the pregnancy to look at the shape and size of the fetus's remaining kidney and other parts of the urinary system, the amount of amniotic fluid (or liquor), and the growth of the baby.

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

Many children URA will not have long-term problems. The other kidney usually grows larger to

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help do the work of two kidneys. A small number of children may be at higher risk of problems later in life. These include vesicoureteric reflux (a condition in which urine flows backward from the bladder into the ureters and sometimes to the kidneys), hypertension (high blood pressure) and proteinuria (protein in the urine). Your baby will need a follow-up renal scan in the neonatal period to exclude any abnormality of the contralateral kidney. The baby should be able to do all the things other children their age do. He or she can go to nursery and school, play with other children and stay active.

## Will it happen again?

Unless your baby's renal agenesis was caused by a genetic mutation, it is unlikely that a unilateral renal agenesis will recur in a subsequent pregnancy.

## What other questions should I ask?

- Does this look like a severe condition?
- Is treatment during the pregnancy available?
- Is my baby one that could benefit from treatment inside the womb?
- How often will I have the ultrasound examinations done?
- Should I have genetic counselling? 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 prior to the delivery?

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