Renal agenesis
(Overview)

Most people are born with two kidneys. Renal agenesis (or kidney agenesis) means one or both kidneys do not develop while a baby is growing in the womb. Renal agenesis may be picked up before birth on the 20 week antenatal ultrasound scan, or soon after birth. It may also be picked up in an older child who has certain symptoms.

- If one kidney has not developed, this is called unilateral renal agenesis. Many children and adults live with one kidney with no serious problems. They may need to go to follow-up appointments to check for any possible long-term effects.

- If both kidneys have not developed, this is called bilateral renal agenesis. If this is suspected on your antenatal scan, you will need to go back to the hospital for more scans to confirm the problem. Sadly, babies with no kidneys are unable to survive.

About the urinary system

The urinary system gets rid of things that the body no longer needs, so that we can grow and stay healthy.

The kidneys are bean-shaped organs. They filter blood to remove extra water, salt and waste in urine (wee). Most of us have two kidneys. They are at the back on either side of our spine (backbone), near the bottom edge of our ribs.

The two ureters are long tubes that carry urine from the kidneys to the bladder.

The bladder is a bag that stores urine until we are ready to urinate (have a wee). It sits low down in the tummy area.

The urethra is a tube that carries urine from the bladder to the outside of the body.

» More about the urinary system and kidneys
Causes
Renal agenesis happens in the womb when one or both kidneys do not develop. It is estimated that one baby in a thousand is born with only one kidney. However, it is very rare that both kidneys do not develop.

It is not always possible to know why renal agenesis happens. In the majority of cases, it is not caused by anything that the mother does during her pregnancy, and it is unlikely that a future pregnancy will result in renal agenesis or other problems with the kidneys.

Occasionally a specific cause is found.

Tests and diagnosis

During pregnancy
The 20 week antenatal ultrasound scan looks at your baby growing in the womb. Renal agenesis may be suspected if one or both kidneys cannot be seen on this scan. You may need to go back to the hospital for more scans or other tests to check whether this is affecting your baby.

Your obstetrician may refer you to a paediatrician, a doctor who treats babies, children and young people, or a paediatric nephrologist, a doctor who treats babies, children and young people with kidney problems.

After your baby is born, he or she may need an ultrasound scan or other tests to confirm whether there is renal agenesis.

Unilateral renal agenesis

In unilateral renal agenesis, one kidney has not developed. (‘Unilateral’ means one side.) Many children with only one kidney have no symptoms or complications and do not need treatment. Sometimes the other kidney grows larger than normal to make up for the missing kidney. However, children may be at risk of urinary tract infections (UTIs) and/or hypertension (high blood pressure) later in life.

Your child may need to visit your family doctor for urine tests and blood pressure measurements.

Bilateral renal agenesis

In bilateral renal agenesis, both kidneys have not developed. (‘Bilateral’ means two sides.) If this is suspected, you will need to go back to the hospital for more scans to confirm the problem. Sadly, babies with no kidneys are unable to survive.

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.

More information on renal agenesis on www.infoKID.org.uk