## **Ectopic kidneys**

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

### What are Ectopic Kidneys?

We call a kidney ectopic when it is not located in its usual site, the posterior upper part of the abdominal cavity, but can be found elsewhere in the abdomen, such as the pelvis, or very rarely, in the thorax. Most ectopic kidneys are found in the pelvis ("pelvic kidney"). The other kidney is usually located in the correct position.

Another type of ectopic kidney occurs when both kidneys are found on the same side of the abdomen, usually stuck together with the upper pole of the inferior one fused with the lower pole of the superior one. This is called "crossed renal ectopy". Usually, this is seen in antenatal ultrasound as a large kidney of abnormal shape associated with the absence of its pair.

The most common type of fusion anomaly is the "horseshoe kidney". This happens when kidneys are stuck together with their bottom poles fused, losing their "bean" shape, and resembling a horseshoe. It presents with two separate ureters that connect the kidneys to the bladder. Ureters are ducts linking the kidney to the bladder in which the urine flows.

#### How do Ectopic Kidneys happen?

It is not clear why renal ectopy occurs. Kidney formation happens at five to nine weeks of gestation, when tiny renal buds migrate from the bottom to the midportion of the embryo. They reach their final place at the level of the lumbar ribs. Anything that affects this migration process could prevent kidneys from getting to their definitive site, originating ectopic kidneys, either fused or not.

Ectopic kidneys are not rare, described as an incidental finding in 1 in 1000 people. However, diagnosis before the baby is born is still rare as ectopic kidneys can easily be missed during antenatal ultrasound.

### How are chromosomes relevant to Ectopic Kidneys?

Genes are pieces of DNA in our cells that contain our genetic information on how our body will be formed and how our organs will function. For example, a group of genes linked to CAKUT (Congenital Anomalies of Kidneys and Urinary Tract) has been described; however, a single gene has not been linked to ectopic kidneys. This means that when a kidney disease runs in the family, it is easier to find genes associated with it. Otherwise, finding a gene linked to the disease may be more challenging when it happens isolated and sporadically.

When one or more anomalies happen at the same time because of the same genetic abnormality, we call it a genetic syndrome. For example, horseshoe kidney may be a part of a syndrome.



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#### Should I have more tests done?

If renal ectopy is suspected, a detailed anatomy ultrasound should be performed by a fetal medicine specialist. If no other anatomic anomalies are identified, no further investigation is necessary. Invasive diagnosis after genetic counseling (consult with a geneticist), is only recommended if a genetic syndrome is suspected.

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

Babies with ectopic kidneys are not at risk of complications during pregnancy, so intensive follow up is not needed. In some cases, there may be dilatation of the renal pelvis or the ureter (the duct linking the kidney to the bladder in which the urine flows). In these cases, monthly scans are recommended.

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

Once the baby is born, consultation with the Pediatric Urologist or Nephrologist will define the need for follow-up. Usually, an ultrasound is done to reassess kidneys, ureters, and bladder in the first days of life. This scan will confirm diagnosis and screen for additional problems with ureters or bladder, like dilatation of the ureters and kidneys.

The most common complication seen is vesicoureteral reflux. Reflux means the urine flows down from the ureters into the bladder, but a small amount can go back up into the ureters towards the kidneys. The severity of reflux can vary and will guide management and follow-up. In such cases, antibiotics are usually administered to the baby to prevent urine infection. Eventually, after the first month of life, additional tests will be performed to check the function of the ectopic kidney.

Girls can present uterine or vaginal anomalies and should be screened for them. Boys should have their testicles checked if they are in the correct place and screened for any anatomical problems with the penis and urethra. If no other anomalies are seen, the prognosis of renal ectopy is excellent.

### Will it happen again?

Ectopic kidneys and especially horseshoe kidney can run in the family. Chances of this happening again are higher than in the general population, mainly if renal anomalies are found in first-degree relatives. Screening mother, father and siblings for renal disease with ultrasound is recommended. In the rest of the cases (which is the common scenario), the chance of recurrence is minimum.



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#### How can I prevent this?

Taking folic acid before and during early pregnancy can prevent kidney anomalies. The recommended dose is 1mg per day, started at least 3 months before conception.

### What other questions should I ask?

- Can I meet the team of doctors that will be assisting my baby when it is born during prenatal care?
- What happens if the ectopic kidney does not function well?
- What happens if a genetic condition is found?
- Will my baby need surgery?

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