

# Multicystic dysplastic kidney

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

This leaflet is to help you understand what multicystic dysplastic kidney are, what tests you need, and the implication of being diagnosed for you, your baby, and your family.

### What are multicystic dysplastic kidney?

Fetal multicystic dysplastic kidney (MCDK) is a condition characterized by the abnormal development of the kidney during fetal growth. The affected kidney exhibits irregular cysts resembling clusters of grapes. Multicystic dysplastic kidney happens in about 1/1000–5000 live births; unilateral in approximately 75–80% of cases.

MCDK is detected through a routine fetal ultrasound examination at around 20 weeks (5 months) of gestation. The ultrasound reveals multiple fluid-filled cysts, replacing the entire kidney which has no function. Usually, only one kidney is affected, allowing the healthy kidney to compensate by growing larger. In rare cases where both kidneys are affected, it can lead to underdeveloped fetal lungs (pulmonary hypoplasia) and a low chance of survival for the baby.

### How do multicystic dysplastic kidney happen?

The cause of MCDK is not fully understood, but some factors have been identified that may contribute to its development. One of the main causes of MCDK is a blockage in the urinary tract of the kidney, which can lead to the formation of cysts and disrupt normal urine flow. This blockage can occur at various levels, such as the ureteropelvic or ureterovesical junctions.

MCDK may occur as an isolated condition or in association with other urogenital and multi-organ abnormalities. This suggests that genetic and chromosomal abnormalities may also play a role in the development of MCDK during a critical stage of fetal development.

### Should I have more tests done?

In some cases, a genetic counselor or geneticist may recommend meeting with you to discuss your baby's risk for genetic/chromosomal problems. They can also provide information about available tests during pregnancy to identify these issues. One such test is amniocentesis, an invasive procedure performed after the 15th week of pregnancy. It involves removing a small amount of amniotic fluid surrounding the fetus to examine problems with the number of chromosomes and some of the problems within the chromosomes (genetic material). If needed, the genetic testing may also be recommended for the parents.

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

After your baby is born, they may undergo a kidney ultrasound to assess their condition. If the ultrasound reveals excessive fluid in the unaffected kidney, the pediatric kidney specialist may suggest administering antibiotics after the baby is discharged. This aims to prevent infection in the healthy kidney, in the event that urine flows back from the bladder during urination (urinary reflux). When your baby reaches a few weeks old, you might have an appointment at the hospital for a specific test called voiding cystourethrogram (VCUG).

About 50% of MCDK show a natural decrease in size. Most babies with MCDK do not have long-term problems, as long as their unaffected kidney remains healthy. If the MCDK enlarges or if your baby develops high blood pressure, the pediatric kidney specialist may recommend surgical removal of the affected kidney.

### Will it happen again?

In the isolated MCDK, there is a 1-2% risk of recurrence. If there is a genetic reason, this will determine the risk, and a consultation with a specialist may be helpful to help sorting this out.

### What other questions should I ask? Does this look like a severe case of multicystic dysplastic kidney?

- Are there extra signs apart from the affected kidneys?
- Is there a way to be sure of the diagnosis?
- How should the pregnancy be followed-up?
- Is there a treatment available during the pregnancy?
- Where and when should I deliver?
- What care will the baby receive after it is born?
- Can I meet the genetic specialist?
- Can I meet the kidney specialist?
- Can I meet the team of doctors that will be assisting my baby when it is born in advance?

Last updated November 2023