Renal Agenesis UK

What is Bilateral Renal Agenesis?

What does a diagnosis of Bilateral Renal Agenesis mean for our baby?



Bilateral Renal Agenesis is a condition where both kidneys fail to develop during the early weeks of pregnancy.

There is no known cause as to why the kidneys fail to develop but in some instances there may be a genetic reason if there is a family history of unilateral renal agenesis (one kidney missing) or bilateral renal agenesis (both kidneys missing).

The absence of kidneys will result in oligohydramnios (low amniotic fluid volume) or anhydramnios (no amniotic fluid).

Amniotic fluid is important because it helps to grow and mature your baby's lungs therefore, if there is very little or no amniotic fluid, this will result in your baby having underdeveloped lungs called pulmonary hypoplasia.

We are so sorry that you have been given the news that your baby has not developed their kidneys.

We are here for you, along side your fetal medicine team, to provide any information we can to support you and your baby.

Bilateral Renal Agenesis is a condition termed 'Incompatible with life'.
This, sadly, means that the condition is fatal and your baby will not survive.

At present, in the UK, there are no recognised treatment options for babies diagnosed with Bilateral Renal Agenesis therefore you will be asked to make a decision about how your pregnancy will progress.

This is an extremely heartbreaking and difficult time for parents. There is much information to be processed and many questions to be asked.

Here to provide support and information to parents and families who have been affected by a Bilateral Renal Agenesis diagnosis



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Potter's Syndrome

Where to find us

Bilateral Renal Agenesis may also be referred to as Potter's Syndrome.

Potter's Syndrome refers to a group of distinct facial features which are associated with a reduction of amniotic fluid.

Bilateral Renal Agenesis is one of a number of reason's as to why amniotic fluid levels may be low or absent.

Others include underdeveloped or diseased kidneys.



Renal Agenesis UK is a UK based charity run by parents and families who have lost a child following a diagnosis of Bilateral Renal Agenesis.

We aim to provide support and information to parents and families during this difficult time and beyond.



support@renalagenesis.org.uk info@renalagenesis.org.uk

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