Renal agenesis

What is renal agenesis?
Renal agenesis is the absence of one or both kidneys. It can be unilateral (one kidney absent) or bilateral (both kidneys absent). Normally, the kidneys filter and remove waste from the blood, form urine, and maintain blood pressure.

Approximately 1 out of every 550 babies born each year have unilateral renal agenesis. Babies with unilateral renal agenesis may have other associated birth defects (most commonly, involving the urinary system or genitals). If your child has unilateral renal agenesis, his or her doctor(s) will perform a thorough examination to identify any other birth defects which may be present. Most babies with unilateral renal agenesis lead normal lives; however, these individuals have an increased risk of kidney infections, kidney stones, hypertension (high blood pressure), and/or kidney failure.

Approximately 1 out of every 4,000 babies born each year have bilateral renal agenesis. Babies with bilateral renal agenesis often have additional birth defects, including abnormalities of the urinary system, genitals, limbs (arms and legs), heart, and/or lungs. If both kidneys are absent, the baby cannot produce urine, which is necessary to form amniotic fluid (the fluid surrounding the baby in the womb). Amniotic fluid is needed for proper development of the baby’s lungs; if amniotic fluid is not present, the baby’s lungs cannot grow and mature properly. Since babies with bilateral renal agenesis have immature lungs, they have a higher risk of stillbirth and early death. Most babies with bilateral renal agenesis have a poor prognosis.

What causes renal agenesis?
Currently, the exact cause of renal agenesis is not known. Renal agenesis is thought to be a “multifactorial” condition, meaning that multiple factors (including genetics and the environment) are necessary for renal agenesis to occur. There have also been reports of families with hereditary renal agenesis (multiple family members have renal agenesis).

How is renal agenesis treated?
For babies with bilateral renal agenesis, there is no treatment to help produce amniotic fluid, but there are experimental treatments to replace fluid in the amniotic sac by a technique called amnioinfusion. During amnioinfusion, a replacement fluid is injected directly into the amniotic sac every week, allowing the fetal lungs to develop normally. Risks of amnioinfusion include pain, infection, preterm labor, and premature birth. This experimental procedure is not yet available in Indiana. Most babies with unilateral renal agenesis lead normal lives; any necessary treatment will depend on other birth defects that may be present. Your child’s doctor(s) will discuss appropriate treatment options with you.

For more information

Sources: March of Dimes, NIDDK