

Fact Sheet

Division of Child and Adolescent Health
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Renal Agenesis

What is renal agenesis?

Renal agenesis is the absence or improper development of the kidneys. When one kidney is missing, it is called unilateral renal agenesis. When both kidneys are missing, it is called bilateral renal agenesis. Each kidney may not have developed at all, or it may be damaged or have cysts (sacs of fluid).

What types of problems occur with renal agenesis?

Children with unilateral renal agenesis may have no symptoms or health problems. Some may have urinary tract infections or other problems urinating.

Unfortunately, children with bilateral renal agenesis do not typically survive because of kidney and lung problems. These children do not have any kidney function. The kidneys produce the fluid that surrounds a developing fetus and helps the lungs develop. Infants with no fluid have severe lung problems at birth. Babies may have other birth defects, like clubfoot or malformed ears, because of the lack of fluid (called Potter's syndrome or Potter's sequence). About half of infants with renal agenesis have other birth defects.

How common is renal agenesis?

Unilateral renal agenesis occurs in about 4,000 births each year in the United States. Bilateral renal agenesis occurs in about 400 births each year in the United States. In Virginia, approximately 30 children are born with renal agenesis each year.

What causes renal agenesis?

Renal agenesis can occur as the only birth defect a child has. It can also occur in combination with other features as part of a syndrome (combination of findings). The way in which a syndrome is passed through a family is specific to the given syndrome. A genetic counselor or geneticist can help you determine the risks for your family and situation. Parents and siblings of infants born with renal agenesis may have ultrasounds to look at their kidneys for any minor changes. Mothers who take insulin for diabetes may have a higher chance of having a child with renal agenesis.

How is renal agenesis treated?

Unfortunately, bilateral renal agenesis has no available treatment. Some children with unilateral renal agenesis may need surgery to remove the damaged kidney. Other children will not need any treatment.

Where can I go for more information about renal agenesis?

March of Dimes Birth Defects Foundation
www.modimes.org
1-888-MODIMES (1-888-663-4637)

** This publication was supported by grant number U50/CCU321127-02 from the Centers for Disease Control (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.*