

# BILATERAL RENAL AGENESIS

## OVERVIEW

Bilateral renal agenesis (BRA) is a rare and fatal condition in which the baby's kidneys never develop.

The role of the kidneys is to clean waste out of the body and control fluid balance. During the later parts of pregnancy, the baby's kidneys also produce amniotic fluid (the liquid around the baby) that is needed to help the lungs grow. Without enough amniotic fluid, the lungs of babies with BRA do not fully develop, and are not strong enough at birth to sustain life.

BRA can be associated with other physical defects and chromosomal disorders. Women pregnant with a child who has BRA will often miscarry.

Unfortunately, there are currently no good treatments for babies with bilateral renal agenesis. A baby with BRA usually only lives for a few hours or days after birth.

BRA is usually diagnosed during pregnancy. After diagnosis, parents are offered support to help cope with the difficulty of expecting a child with a life-limiting condition. A prenatal consultation with the palliative care team will be arranged. They will help you make plans for your baby's care at birth.

## HOW BILATERAL RENAL AGENESIS IS FOUND

Bilateral renal agenesis is usually found between 18 and 22 weeks of pregnancy, during routine prenatal ultrasounds. A doctor may notice that you have very little amniotic fluid and that the baby's kidneys are missing. Your doctor may recommend additional tests, such as an MRI (magnetic resonance imaging) done to confirm the diagnosis. Your doctor may also recommend genetic testing (blood tests or amniocentesis), to look for genetic or chromosomal disorders that can go along with BRA.

## SYMPTOMS AND CAUSES OF BILATERAL RENAL AGENESIS

Normally, the kidneys develop in the few weeks of pregnancy. Over time they will produce a liquid that becomes the amniotic fluid surrounding the baby. In fetuses with BRA, the kidneys never develop, and too little amniotic fluid is produced. Without enough amniotic fluid, the baby's lungs are not able to develop normally, and are not strong enough at birth to sustain life.

The lack of fluid can cause other problems as well, including defects in the nervous system, the stomach and intestines, the eyes and ears, and the limbs--such as *clubfoot*. The combination of organ and physical defects caused by a lack of amniotic fluid is called "Potter Syndrome." Potter Syndrome can be caused by BRA alone, or by another chromosomal disorder that triggers BRA.

Scientists do not know what causes BRA, but they believe there is a genetic component. Other possible risk factors include:

- Having diabetes
- Exposure to toxins or chemicals

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## **BETWEEN DIAGNOSIS AND DELIVERY**

Following a diagnosis of bilateral renal agenesis, you will continue to receive care from your obstetrician, who will discuss the different options available to you for managing your pregnancy. You may be referred to the Ohio Fetal Medicine Collaborative (OFMC) for additional information and help.

Through the OFMC, you can see a doctor who specializes in the care of high-risk patients. You may also meet with specialists from Nationwide Children's Hospital to learn more about how your baby will be cared for when he or she is born. A fetal nurse coordinator can also help answer your questions and concerns, guide you through your pregnancy and prepare you for what to expect



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**“Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.**

**It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.”**

*– World Health Organization*

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## **PERINATAL PALLIATIVE CARE**

When prenatal testing shows that a baby has a life-threatening or life-limiting condition, many parents feel overwhelmed at the thought of preparing for the possible death of their child

Perinatal palliative care is designed to help families through an often confusing and heartbreaking diagnosis, and to help them cope with the challenges of expecting a newborn with a potentially fatal illness.

You will be faced with many difficult decisions following your baby’s diagnosis. The goal of Perinatal Palliative Care is to provide compassionate and expert care starting from the time of diagnosis. While there are not cures for many of the conditions commonly referred for palliative care, there are many things the team can do to help support you, your baby, and your family.

### **Who is part of a Perinatal Palliative Care Team?**

Perinatal palliative care is provided by a multi-disciplinary team of specialists including doctors, nurse practitioners, nurses, social workers, and clergy. The team is committed to supporting you and your family.

You and your family will meet with members of the palliative care team before delivery, and have additional visits as needed during your pregnancy and after delivery.

Palliative Care is highly individual and there is no one right path for every family. We will help guide you through making decisions about how to best care for your baby, decisions that fit with your goals and values. We will explain the different medical treatments that may be chosen, with a focus on keeping your baby comfortable, and allowing you to spend quality time together.

Many families find the time between diagnosis and delivery very emotionally difficult. A fetal nurse coordinator can help connect you with counseling services and support groups.

## **WHAT HAPPENS WHEN YOUR BABY IS BORN**

You should discuss your plans for labor and delivery with your obstetrician. The specifics of the care your baby receives after birth will depend on what you and the team have discussed during your Perinatal Palliative Care consults. Depending on your wishes, the neonatal team can be present at delivery. There are a variety of treatments and medicines that can be provided for comfort and support. The plan for how to care for your baby can evolve over time, as well.

## **LOOKING AHEAD**

### **Future Pregnancies**

Most parents who have one child with BRA do not have another with the condition. However, your doctor may recommend genetic counseling to discuss risks for a future pregnancy because bilateral renal agenesis can be related to inherited disorders. Your doctor may also recommend that you and your family members be screened for renal problems.

## **ADDITIONAL RESOURCES**

- March of Dimes — <http://www.marchofdimes.com/genital-and-urinary-tract-defects.aspx>
- You may be able to find online support groups created by parents who have had a baby diagnosed with bilateral renal agenesis or Potter Syndrome.