

Bilateral renal agenesis (BRA)

Information for parents



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Information to help you understand more about bilateral renal agenesis.

1. What is bilateral renal agenesis?

Bilateral renal agenesis means that your baby does not have kidneys.

Kidneys filter waste products from the blood, so they can be passed out of the body as urine. The urine normally produced by a baby's kidneys after around 12 weeks of pregnancy creates the amniotic fluid (the liquid that surrounds the unborn baby). As babies with bilateral renal agenesis do not have kidneys, they have very little or no amniotic fluid. This means that your baby's lungs will not develop properly.

2. How common is it?

Bilateral renal agenesis occurs in about 1 of every 10,000 births.

3. How is it diagnosed and confirmed?

Bilateral renal agenesis is usually noticed at the Fetal Anomaly ultrasound scan carried out between 18 weeks and 21 weeks of pregnancy. The doctors will suspect this because there will be little or no amniotic fluid around the baby and they won't see the baby's kidneys or bladder on the scan.

You may need a second scan to confirm the diagnosis.

4. Is there any treatment?

Unfortunately, there is no treatment for bilateral renal agenesis.

5. What is the outlook for the baby?

Sadly, babies with bilateral renal agenesis die before they are born, at birth or very soon after birth as they cannot live without kidneys and fully developed lungs.

6. What happens next?

You will be given the chance to talk to specialists about your options. You will have the opportunity to discuss the possible implications of ending or continuing your pregnancy.

You will be offered a termination to end the pregnancy. If you choose to have a termination, your health professional will talk to you about the procedure and support you through the process.

If you choose to continue your pregnancy, your healthcare team will help you plan how your care, including delivery, is managed. As there is no cure for bilateral renal agenesis, doctors will discuss palliative care with you. Palliative care is care aimed at relieving the symptoms of a condition rather than treating or providing a cure. You may be referred to the children's palliative care team and the local bereavement service.

Whatever you decide, your decision will be respected and you will be supported by your midwife and doctor.

7. How likely is it to happen in a future pregnancy?

You are much more likely to have a normal, healthy baby in your next pregnancy than to have another baby with bilateral renal agenesis.

There is no way to prevent this condition. It is not due to something you have done or not done. Some kidney problems may run in families. Doctors may suggest that you, your partner and any other children you have, are offered an ultrasound scan of your kidneys. If this shows an abnormality, the implications of this will be discussed with you. You may also be offered extra scans during your next pregnancy.

8. Where can I get more information and support?

You may feel that you only want to talk to your family and friends, or a particular doctor or midwife from the hospital. However, there are other people and organisations that can provide information, help you make your decisions and support you in your pregnancy and afterwards. You may also want to talk things through with the hospital chaplain or your own minister or faith leader.

9. Further information, charities and support organisations

The following organisation can offer you support. There are details of other support organisations on our website at www.fetalanomaly.screening.nhs.uk. If you have any questions about the information in this leaflet or where the information came from, email us at enquiries@ansnsc.co.uk.

Antenatal Results and Choices (ARC)

Email: info@arc-uk.org

Helpline: 0845 077 2290

Website: www.arc-uk.org

Antenatal Results and Choices (ARC) provides information and support to parents before, during and after antenatal screening and diagnostic tests, especially those parents making difficult decisions about testing, or about continuing or ending a pregnancy after a diagnosis. ARC offers ongoing support whatever decisions are made.

This information has been produced on behalf of the NHS Fetal Anomaly Screening Programme for the NHS in England. In other countries, check with a health professional to find out whether there are any differences in approaches to screening.

This leaflet has been developed through consultation with the NHS Fetal Anomaly Screening Programme expert groups. All of our publications can be found online at www.fetalanomaly.screening.nhs.uk.

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