

# Bilateral renal agenesis (BRA)

Information for health professionals

WITHDRAWN April 2020



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## Information for health professionals

The aim of this information sheet is to support staff involved in counselling pregnant women and their partners when a suspected or confirmed diagnosis of bilateral renal agenesis (BRA) has been made following an ultrasound scan.

All diagnoses of the conditions must be recorded and audited to ensure the effectiveness of the screening programme.

### 1. Definition

Bilateral renal agenesis (BRA) is a congenital malformation characterised by absence of both kidneys. This results in anhydramnios which has severe consequences for the development of the fetus.

The compression of the fetus by the uterine wall and the lack of liquor results in a sequence of abnormalities including pulmonary hypoplasia, severe talipes and limb contractures, non-reduced movement, typical facies (beaked nose, low-set ears, prominent epicanthic folds, hypertelorism) and growth restriction.

The cause of BRA is unknown.

### 2. Prevalence

BRA occurs in approximately 1 per 10,000 births (Boyd et al. 2011). It is more common in males.

### 3. Screening and diagnosis

BRA is usually detected at the 18<sup>+0</sup>–20<sup>+6</sup> weeks Fetal Anomaly ultrasound scan. An absence of amniotic fluid, bladder and kidney will be noted. Renal agenesis may not be immediately apparent on ultrasound, but the bladder is never seen and from 16 weeks gestation there is little or no liquor around the fetus.

A repeat scan may be offered to confirm the diagnosis.

### 4. Treatment

There is no treatment or cure for BRA.

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## 5. Prognosis

A small number of cases will miscarry or be stillborn. Neonatal death as a result of pulmonary hypoplasia is inevitable. The vast majority of babies that are born alive do not live beyond a few hours.

## 6. Recurrence

BRA is usually an isolated sporadic abnormality but in up to 36% of cases there is a family history of renal agenesis.

In non-syndromic cases, the risk of recurrence is approximately 3% unless one parent has unilateral renal agenesis, in which case the risk may be higher.

Where BRA is part of a recognised syndrome, recurrence risks may also be higher.

## 7. Prevention

There is no known way of preventing this condition.

## 8. Referral pathway

Following diagnosis of BRA, a second medical opinion should be sought from a specialist in fetal medicine.

After confirmation of the diagnosis, the woman should be informed that this is a lethal abnormality.

A termination of pregnancy should be offered to allow women the option of not continuing with their pregnancy following appropriate counselling.

Some women choose to continue the pregnancy and these parents will need ongoing care and support.

Liaison with the bereavement service may help the family prepare for a stillbirth or early neonatal death. Women may be referred to their local bereavement service. Palliative care should be discussed and women may be referred to the children's palliative care team.

Renal agenesis is known to recur in families and therefore referral to clinical genetics is recommended. This will inform counselling regarding future recurrence rates.

## 9. Further information, charities and support organisations

### Antenatal Results and Choices (ARC)

Email: [info@arc-uk.org](mailto:info@arc-uk.org)

Helpline: 0845 077 2290

Website: [www.arc-uk.org](http://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.

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## References

Boyd PA, Tonks AM, Rankin J, Rounding C, Wellesley D, Draper CS. Monitoring the prenatal detection of structural fetal congenital anomalies in England and Wales: register-based study. *Journal of Medical Screening* 2011; 18(1): 2.

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This information has been produced on behalf of the NHS Fetal Anomaly Screening Programme for the NHS in England. There may be differences in clinical practice in other UK countries. The leaflets have been developed through consultation with the NHS Fetal Anomaly Screening Programme expert groups.

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