NHS

Screening Programmes

Fetal Anomaly

Alobar holoprosencephaly (HPE) information for parents

Information sheet to
help pregnant women
understand more about alobar
holoprosencephaly (HPE).

What is alobar holoprosencephaly (HPE)?

HPE is a birth abnormality that occurs during the very early stages of the baby's developing in the womb. The front part of the baby's brain fails to develop into clearly separate right and left halves. This severely affects the function of the brain.

Babies diagnosed with this condition usually have a small head, excessive fluid in the brain, cleft lip, varying degrees of learning difficulties, epilepsy, hormonal problems, or problems with the heart, bones, bowel or bladder.

Babies with HPE may also have other chromosome problems including Edwards' syndrome, Patau's syndrome or Down's syndrome.

The cause of HPE is unknown.

How is it confirmed?

Diagnosis of HPE is usually made during the 18^{+0} – 20^{+6} weeks' fetal anomaly ultrasound scan but is occasionally diagnosed as early in pregnancy as week 12. It is unlikely to be seen on a scan before week 12 of pregnancy.

Is there any treatment?

Unfortunately there is no treatment for this condition. HPE is a severe condition and treatment is based on improving symptoms and appropriate support to improve all aspects of the baby's quality of life. However, due to the severity of the condition, some women choose to not continue with the pregnancy after discussing their options fully with a specialist doctor, midwife and their families.

What is the outlook for the baby?

Sadly, current studies indicate that only 3% of all babies diagnosed with this condition in pregnancy survive to birth. Those that do survive until birth usually do not survive past the first six months of life. Survival rates depend on how severe the brain abnormality is, as well as other health complications that may be present.

How common is it?

It is estimated that HPE affects 1 in 7,500 births.

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 affected with HPE. However, there is a small risk of this happening again and you may wish to talk to a genetic specialist about future pregnancies.

What happens next?

You will be given the chance to talk to specialists about what having a baby with this condition might mean to you and your family. After having time to think about it, some women choose to continue with their pregnancy and do all they can to prepare for having a baby with this condition. Others may choose not to continue with the pregnancy. You will be offered a termination of pregnancy. Whatever you decide, your decision will be respected and you will be supported by your midwife and doctor.

Where can I get more information and support?

You may feel you only want to talk to your partner, family members or a particular doctor or midwife from the hospital. However, there are a lot of other people and organisations that can provide information, help you make your decisions and support you in your pregnancy and after it. Some are listed below. You can also talk things through with the hospital chaplain or your own faith leader.

Useful websites

Antenatal Results and Choices (ARC)
73 Charlotte Street
London
W1T 4PN

Tel: 0207 631 0285
Email: info@arc-uk.org
Website: www.arc-uk.org

Antenatal Results and Choices (ARC) provides impartial information and individual support to parents whether they are going through antenatal screening or whose unborn baby has been diagnosed with an abnormality.

Contact a Family (CAFAMILY)
209 to 211 City Road
London
EC1V 1JN

Tel: 0808 808 3555
Email: info@cafamily.org.uk
Website: www.cafamily.org.uk

Contact a Family is a charity which provides support, advice and information for families with disabled children, no matter what their condition or disability.

DIPEx
PO Box 428
Witney
Oxon
OX28 9EU

Email: info@healthtalkonline.org
Website: www.healthtalkonline.org &
www.youthhealthtalk.org

DIPEx has created a unique database of personal and patient experiences through in-depth qualitative research into over 40 different illnesses and health conditions. The results of their research are published on two websites which are aimed at patients, their carers, family and friends, doctors, nurses and other health professionals. Their target is to complete at least 100 conditions within the next 5–10 years.

The Miscarriage Association
c/o Clayton Hospital
Northgate
Wakefield
West Yorkshire
WF1 3JS

Tel: 01924 200799
Email: info@miscarriageassociation.org.uk
Website: www.miscarriageassociation.org.uk

Miscarriage can be a very distressing, frightening and lonely experience. The Miscarriage Association provides support and information.

Stillbirth and Neonatal Death Society (SANDS)
28 Portland Place
London
W1B 1LY

Tel: 0207 436 5881
Email: helpline@uk-sands.org
Website: www.uk-sands.org

SANDS support anyone affected by the death of a baby and promotes research to reduce the loss of babies' lives.

This information has been produced on behalf of the NHS Fetal Anomaly Screening Programme. The leaflets have 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

If you have any comments on this booklet or enquiries for the Programme please contact us at the address below:

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