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Fetal Abnormality Guideline (including fetal echo referral criteria)

Summary statement: How does the document support patient care?	By providing clear guidance for staff on the process to follow when referral for fetal abnormality is required.
Staff/stakeholders involved in development:	Obstetric Consultants, Antenatal Screening Team and Senior Midwifery Staff
Division:	Women and Children's
Department:	Maternity
Responsible Person:	Chief of Service
Author:	Antenatal Screening Coordinator
For use by:	All Obstetric and Midwifery staff
Purpose:	To ensure early and appropriate referral when a fetal abnormality is detected in pregnancy.
This document supports:	Fetal Anomaly Screening Programme Standards 2015-16 NHS Fetal Anomaly Screening Programme Handbook 2018 (PHE)
Key related documents:	**UH Sussex West:** Antenatal Care and Patient Information, Maternal Antenatal Screening Tests, Intrauterine Death Including Induction of Labour for Fetal Abnormality
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If you require this document in another format such as Braille, large print, audio or another language please contact the Trusts Communications Team	
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Version	Date	Author	Status	Comment
1.0	January 2011	Antenatal Screening Coordinator (ASC)	Archived	New Trustwide guideline
2.0	February 2011	CNST Lead Midwife	Archived	Administrative update
3.0	30/10/12	CNST Midwife	Archived	Minor amendments for CNST 2012-13
3.1	July 2013	Antenatal Screening Coordinator and Fetal Medicine Specialist Midwives	Archived	Anomaly tracker updated
4.0	January 2014	Antenatal Screening Coordinator and Fetal Medicine Specialist Midwives	Archived	3 year review-update to process following chorionic villus sampling / amniocentesis
5.0	August 2016	Antenatal Screening Coordinator and Fetal Medicine Specialist Midwives	Archived	Removal of Anomaly Tracker
6.0	August 2017	Antenatal Screening Coordinator (ASC)	Archived	3 yearly update
7.0	February 2019	ASC	Archived	Referral timelines and process updated in line with national guidance Addition of undetected anomaly process
7.1	September 2019	ASC	Archived	Amendment made to process for an undetected fetal anomaly
8.0	April 2021	ACS and Lead Fetal Medicine Consultant	Archived	Addition of referral criteria for fetal echo and early anomaly scan
8.1	January 2022	R. Mason, Obstetric Consultant	LIVE	Section on polyhydramnios added.

The interpretation and application of clinical guidelines will remain the responsibility of the individual clinician.

If in doubt contact a senior colleague or expert.

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Fetal Abnormality Guideline
(including fetal echo referral criteria)

1.0 Aim

- To ensure effective multi-disciplinary communication and appropriate referral when fetal abnormality has been identified.
- The identification of a fetal anomaly offers the woman choice about whether to continue with the pregnancy or not.
- To act as resource for staff caring for pregnant women/poeople whose needs fall within the scope of this protocol.
- To ensure optimal care for babies diagnosed with an abnormality.
- To ensure mother has optimal care in appropriate setting.
- To ensure arrangements are clear which professional is responsible for the woman/person's care at all times.

2.0 Scope

This guideline applies to all staff caring for antenatal women/people when a fetal abnormality is detected.

3.0 Responsibilities

Midwives, obstetricians, sonographers and paediatricians:

- To access, read, understand and follow this guidance.
- To use their professional judgement in application of this guideline.
- This guidance is for staff employed by University Hospitals Sussex West. The guidance is not rigid and should be tailored to the individual circumstances of each woman/person. If the guidance is not being followed, documentation of the reasoning and/or justification is essential, with clear documentation of alternative plans and discussions.

Management:

- To ensure the guideline is reviewed as required in line with Trust and National recommendations.
- To ensure the guideline is accessible to all relevant staff.

4.0 Abbreviations used within this guideline

MIS - Maternity Information System	**FASP –** Fetal Anomaly Screening Programme
TGA - Transposition of the great arteries	**AVSD -** Atrioventricular septal defect
TOF - Tetralogy of Fallot (TOF)	**HLHS -** Hypoplastic left heart syndrome

NT - Nuchal translucency	**DVP -** Deepest vertical pool
TORCH - Toxoplasmosis, rubella, cytomegalovirus, herpes simplex	**ANC -** Antenatal Clinic
ARC - Antenatal Results and Choices	**FMU -** Fetal Medicine Unit

5.0 Introduction

NHS FASP (2018) recommends the offer of a mid-pregnancy scan which is undertaken between 18+0 to 20+6 weeks of pregnancy to screen for major fetal anomalies. Where the first scan is incomplete, the pregnant woman/person must be offered a second scan to complete the pathway by 23+0 weeks.

Where an adequate assessment of the fetal anatomy remains compromised after the repeat scan, there is no requirement to offer further ultrasound examination for completion of screening. The pregnant woman/person should be informed that the screening is incomplete and this should be recorded on MIS and in the woman/person's handheld notes.

Pregnant women/people who wish to have a fetal anomaly ultrasound scan, but do not wish to be informed if abnormalities are found, should be advised that all significant findings seen on the scan will be reported and therefore they should consider not having fetal anomaly ultrasound screening.

6.0 The Anomaly Scan

There are currently 11 conditions which should be screened for as a minimum during the anomaly scan (FASP 2018). These conditions specified below indicate conditions that may:

- Benefit from treatment before or after birth.
- Require that the birth should be in an appropriate hospital/centre and/or to optimise treatment after the baby is born.
- Cause the baby to die shortly after birth.

Anencephaly
Open spina bifida
Cleft lip
Diaphragmatic hernia
Gastroschisis
Exomphalos
Serious cardiac abnormalities including the following: • Transposition of the great arteries (TGA) • Atrioventricular septal defect (AVSD) • Tetralogy of Fallot (TOF) • Hypoplastic left heart syndrome (HLHS)
Bilateral renal agenesis
Lethal skeletal dysplasia

Edward's syndrome (T18)
Patau's syndrome (T13)

These findings require tertiary appointment within 5 working days.

6.1 Normal variant

The following findings now defined as normal variants (previously termed as 'soft markers') should no longer be referred for further assessment whether one or more are found:

- Choroid plexus cyst(s)
- Dilated cisterna magna
- Echogenic foci in the heart
- Two vessel cord

However, the findings below should be referred for further assessment and treated as for any other suspected fetal abnormality:

- Nuchal fold (equal to or greater than 6mm)
- Ventriculomegaly (atrium equal to or greater than 10mm)
- Echogenic bowel (with density equivalent to bone)
- Renal pelvic dilatation (AP measurement greater than 7 mm)
- Small measurements compared to dating scan (significantly less than 5th centile on Viewpoint chart).

6.2 Polyhydramnios

Polyhydramnios is excess amniotic detected on USS and affects approximately 1 in 100 pregnancies. Amniotic fluid level is measured using a vertical measurement of the deepest vertical pool (DVP) (normal range 2 – 8 cm). In 80% of cases polyhydramnios is mild (DVP 8-12 cm) and the majority of cases idiopathic and do not require any further investigation.

When the DVP is >12cm it is more likely to be associated with maternal or fetal pathology (The Fetal Medicine Foundation). Etiology of polyhydramnios includes:

- Fetal malformations
- Maternal diabetes
- Multiple pregnancy
- Fetal anaemia

When polyhydramnios is isolated - TORCH and Parvovirus screens should not be requested.

If polyhydramnios is detected:

- DVP 8 - 12 cm – advise low GI diet and reassure mother/birthing parent.
- DVP > 12 cm – perform random BM, advise low GI diet, refer to Fetal Medicine Consultant.

7.0 Process following Inconclusive / Abnormal Scan

Pregnant women/people must be informed of a suspected anomaly before they leave the ultrasound appointment.

6.1 Abnormal Scan Result

- Sonographer informs screening team and if necessary accompanies the pregnant woman/person to ANC. It is the responsibility of the screening team to follow up pregnant women/people who fail to attend antenatal clinic.
- Findings discussed and explained to pregnant woman/person by screening team.
- Outcome and statistics should not be discussed at this point or information outside of expertise given to parents.
- If there is written information available for the particular condition then this should be made available for parents.
- For pregnant women/people with poor understanding of English, the telephone interpreting service should be used in the first instance. Ideally this should be backed up by written information in the correct language where available. When ongoing appointments are required, every attempt should be made to arrange a face-to-face interpreter including sign language.

8.0 Fetal medicine referral

Where local referral is required, this should be within 3 working days. Local referral is to an obstetric ultrasound specialist.

Where tertiary level referral is required, this should be within 5 working days

Cases where the referral occurs outside the above timeframes (e.g. maternal/birthing parent request), must be documented on MIS and on the screening scan abnormality database.

The screening team are responsible for ensuring the referral form is emailed to the tertiary centre followed by scan reports and blood results once the referral has been accepted.

8.2 Following appointment at Fetal Medicine Unit (FMU)

- Screening team will liaise with FMU to discuss results/care/follow-up.
- Scan reports and invasive testing results are to be received by screening team prior to contact with pregnant woman/person.
- Any results and subsequent plans will be documented on MIS (with an alert created if abnormal) and in the hospital notes.

- Patient to be telephoned next day to discuss consultation and appropriate follow up appointments made.
- The GP and community midwife should be notified of the referral and outcome.
- If parents opt to discontinue the pregnancy, protocol for termination of pregnancy to be followed following appointment with Consultant Obstetrician (see Intrauterine Death Including Induction of Labour for Fetal Abnormality).

9.0 Continuing with pregnancy

- Follow up appointments should be arranged as per plan of tertiary unit
- Once place of birth is identified - whether locally or at tertiary unit, the screening team are responsible for ensuring the plan is liaised to the local obstetric ultrasound specialist consultant and local lead paediatrician for neonates.
- The postnatal plan will be documented on MIS (with an alert created) and in the maternal/birthing parent notes.
- If necessary an appointment will be made for the parents with Consultant Paediatrician to discuss condition, care at birth and follow-up. Parents should be given the opportunity to visit the Neonatal Unit (as required).
- Screening team to liaise with Labour Ward Manager, Neonatal Unit Manager and Postnatal Ward Manager as required.
- Whenever clinically appropriate, the possibility of organ donation should be discussed with the parents by the Consultant Obstetrician / Paediatrician. Details of the discussion must be documented in the health record as above.
- Letters should contain the names of all health professionals who have received a copy; and a copy should be filed in the hospital record.
- Letters must also be copied to the pregnant woman/person for her information and they should be given a list of contact numbers for any queries, including support groups such as Antenatal Results and Choices (ARC).
- If appropriate a referral can be made to the palliative care team at Chestnut Tree House Hospice.

Pregnancy care should be provided by a designated midwife throughout the antenatal period

10.0 Birth

Labour Ward staff should inform on call paediatric team and obstetric team when the pregnant woman/person is admitted for birth. The neonatal plan will be in the pregnant woman/person's notes and on MIS.

11.0 Postnatal

- The screening team will record the birth outcome on the screening scan abnormality database.
- The health professional performing the NIPE check will ensure follow up appointments are arranged as required.

12.0 Recording of confirmed abnormalities

All confirmed fetal anomalies should be recorded as follows:

- Confirmed fetal anomalies and undiagnosed postnatal anomalies to be presented and discussed on a quarterly basis at departmental meeting.
- Information should be shared with the National Congenital Anomaly and Rare Disease Registration Service for quality and monitoring.

13.0 Referral for fetal echo

Indications for fetal echo at 20- 21 weeks (after the anomaly scan):

- Previous pregnancy (either partner) affected with a significant cardiac abnormality (not patent ductus arteriosus, small VSDs or secundum atrial septal defects).
- One of the parents has had a significant cardiac abnormality that required surgery.
- Nuchal translucency (NT) $\geq$ 3.5 mm.

When a fetal echo is required this can be booked via the screening team midwife. Other referrals for fetal echo should be discussed with the fetal medicine consultant.

Maternal anti-Ro / La antibodies are not an indication for fetal echo. These patients require fetal auscultation every 2 weeks from 16/40 to 30/40. A fetal medicine referral for fetal echo is required when a bradycardia is heard during auscultation.

Pregnant women/people with diabetes do not require a fetal echo. They should be offered a routine anomaly scan at 20 weeks to detect fetal structural abnormalities, including examination of the fetal heart (4 chambers, outflow tracts and 3 vessels).

14.0 Referral for fetal medicine early anomaly scan

Indications for early anomaly scan (16-18/40):

- Previous pregnancy (either partner) affected by a major structural abnormality.
- One of the parents had a major structural abnormality.
- Patient taking teratogenic drugs in current pregnancy e.g. sodium valproate. The UK Teratology Information Service (www.uktis.org) is a good resource. See also The Commission on Human Medicines which has reviewed the available safety data for epilepsy medicines during pregnancy (January, 2021).

An early anomaly scan should be booked via the screening team midwife. Cases which do not fit the above criteria or further advice needed should be discussed with the fetal medicine consultant.

15.0 Monitoring

This guideline is monitored through the annual Key Performance Indicator (KPI) data submitted to Public Health England by the screening team.

References

The Commission on Human Medicines (2021) Public Assessment Report of antiepileptic drugs: review of safety of use during pregnancy.

The Fetal Medicine Foundation

NICE NG3 (2015) Diabetes in pregnancy: management from preconception to the postnatal period. Updated 2020.

NHS Fetal Anomaly Screening Programme Handbook 2018 (PHE)

Organ donation Nice Guidance CG135 (Dec 2011)

Pasquini L et al '*Prevalence of a positive TORCH and parvovirus B19 screening in pregnancies complicated by polyhydramnios*' Prenat Diagn 2016 36(3)

UK Teratology Information Service

Appendix 1: Undetected antenatal Fetal Anomaly Process