Information for Fetal Medicine Doctors Considering Referral for Fetal Repair of MMC – FAQs

Inclusion Criteria (as per MOMs criteria[1])

- Maternal age ≥18 years
- Gestational age <26+0 weeks' gestation
- Normal genetic testing (conventional karyotype and microarray)
- Spinal lesion T1-S1
- Confirmed Chiari type II malformation on prenatal ultrasound and magnetic resonance imaging (UCLH will perform MRI if not already done so)

Exclusion Criteria (as per MOMs criteria[1])

- Multiple pregnancy
- Poorly controlled insulin-dependent pre-existing diabetes
- Additional fetal anomalies unrelated to MMC
- Fetal kyphosis ≥30 degrees
- History of incompetent cervix and/or short cervix <20mm by ultrasound scan in index pregnancy
- Placenta praevia
- Other serious maternal medical conditions
- Obesity defined by body mass index of ≥40
- Previous spontaneous singleton delivery <37wks' gestation
- Maternal–fetal Rh iso-immunization
- Positive maternal human immunodeficiency virus or hepatitis B or known hepatitis C positivity
- Uterine anomalies and previous uterine surgery other than lower segment caesarean section
- Psychosocial limitations

Optimal Timing for Referral

Initial notification of a case from 20 weeks onwards is helpful to provide sufficient time to counsel families and to plan the assessment and surgery. If planned in advance we may be able to provide a single visit to London for the whole assessment (fetal ultrasound, fetal MRI if needed and counselling from fetal surgery team).

Optimal Timing for Surgery

23+0 to 25+6 weeks, as earlier surgery is associated with increased risks of chorioamniotic membrane separation/ PPROM, and outcomes from later surgeries have not been shown to be as good.

Prenatal assessment at the referring centre and at UCLH:

- Referral PowerPoint form: to facilitate referrals and prevent needless travel of patients who are unsuitable, we have made a PowerPoint referral template, which we request you to fill out and return.
- Counselling: Please document all counselling that has been performed locally (e.g. paediatric neurologist, neurosurgeon, neonatologist etc.) and forward them to us, or give them to the patient in her handheld notes to bring to UCLH.
- Initial patient discussion: we will call the patient initially to briefly explain the surgery and the process of further review at UCLH to assess if they are suitable; we will emphasise that it is their choice whether to proceed at all points and we have written a patient information leaflet which we will signpost them to if they do not already have it.

- First assessment at UCLH: we will do a complete independent assessment including ultrasound, MRI and fetal medicine consultation. When proceeding to surgery there is an anaesthetic consultation as well.
- Time point: patients can be assessed either at a time point remote from the ideal surgery time point, or in the days before the surgery would be planned. That is dependent on patient preferences and practicalities such as travel, gestational age etc.

Financial aspects

- Fetal MMC repair is currently funded by a charitable grant and so neither the patient nor the referring institution/ local health authority will be charged for the surgery.
- Travel for initial assessment in London will not be funded by the charitable grant.

Stay in London

- Patients are admitted to UCLH the night before surgery. The typical stay is 5-7 postoperative days, initially in the close observation unit on labour ward and then on the antenatal ward.
- Accommodation will be provided nearby for family members if needed, funded by a charitable grant.

Postoperative care and long term follow up

- Following fetal MMC repair, the delivery of this pregnancy and future pregnancies must be by Caesarean section.
- Patients who have had fetal surgery repair at UCLH will be able return to their home hospital for antenatal care and delivery. Patients choosing to return to their home unit must have a local FMU willing to provide antenatal care according to our protocol (including frequent ultrasound scans) and plan delivery by CS by 37 weeks at the latest. In this option we will be in close contact with the local unit to provide advice and to receive details on the patient's progress.
- If the local unit is unable to provide ongoing antenatal care as above, the patient may be able to stay in London until delivery in accommodation provided by charitable funding.
- Babies will be offered long-term follow up at the Great Ormond Street Hospital Spina Bifida clinic. If the patient prefers local follow up, we recommend that this is done at a tertiary centre with experience caring for patients with spina bifida, and that the follow up centre keeps us informed of all follow up consultations (send copies) and provide us feedback when requested.
- We adhere to the recommendations made by IFMSS[2] to keep a register of all patients.

Contacts for further information:

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References

[1] Adzick NS, Thom EA, Spong CY, Brock JW, 3rd, Burrows PK, Johnson MP, et al. A randomized trial of prenatal versus postnatal repair of myelomeningocele. N Engl J Med. 2011; 364(11):993-1004

[2] Cohen AR, Couto J, Cummings JJ, Johnson A, Joseph G, Kaufman BA, et al. Position statement on fetal myelomeningocele repair. Am J Obstet Gynecol. 2014; 210(2):107-11. 3