Obstetric pathway

Once a woman is referred to the Adult Haemophilia service in pregnancy via a referral form emailed to haemophilia.reception@ouh.nhs.uk and silverstar.midwives@oxnet.nhs.uk, the following should occur during clinic visits to the Centre alongside regular antenatal bloods, reviews and urine tests.

Women should be seen at least twice during pregnancy and ideally post-partum

There should be clear communication between the maternal medicine centre (Silver Star at the John Radcliffe Hospital) as well as the patient's local obstetrician, local shared care haematologist, Adult haemophilia centre and Paediatric haemophilia team.

We strongly encourage that all babies who are confirmed to be affected by a bleeding disorder or who potentially have a bleeding disorder are delivered in Oxford under the Silverstar Unit where the Adult, Paediatric Haemophilia Team and Specialist Haemostasis lab are available 24/7.

<12 weeks gestation

- Clinic review of diagnosis/genetics
- Initial counselling about management in pregnancy, prenatal diagnostics, delivery plans ideally by both haematology and obstetrics
- Factor level check
- FBC/film
- Iron profile check
- Genetic testing if status unknown
- Referral to Silver Star if not yet done
- Blood group RH D confirmation
- Dating scan if termination considered urgently to confirm intrauterine pregnancy
- Free fetal DNA sexing (ffDNA) if termination considered (9 weeks by scan)
    - If ffDNA confirms male fetus and termination being considered, refer for CVS
        - If CVS confirms affected male: arrange termination at maternal request
            - Ensure blood group RHD status and factor levels and haemostatic plan provided

12-32 weeks gestation

Usually seen after 20 week US scan to confirm fetal sex if ffDNA not done previously and relevant to the case.

Women who are already iron deficient in their first trimester, or have multiple comorbidities or are at risk of delivering prematurely or who may proceed to a late amniocentesis are usually offered this appointment

- Clinic review of diagnosis/genetics
- Counselling about management in pregnancy, prenatal diagnostics, delivery plans
- Factor level check
- FBC
- Iron profile check
- Blood group RH D confirmation
- Referral to Silver Star if needed
- Referral to Feto-Maternal unit for late amniocentesis after counselling if appropriate.
    - patient signs genetics consent form and has genetics sample request form given to her.
    - Haemostatic plan made for the procedure if factor or TXA required

32 weeks+ gestation

- Late amniocentesis if requested
- Finalize obstetric haemostasis plan and send to patient and DGH teams, CHOX and complete maternity situational awareness alert
- Ensure factor/haemostatic medication available in blood banks and maternity units
- Factor level check
- FBC
- Iron profile check: arrange IV iron if inadequate response to PO iron (ID without anaemia and IDA)
- Ensure supply of TXA
- Cord pack given with forms and consent taken for cord genetics if appropriate
- Book day 10 and week 6 follow up with OHTC

Labour, Delivery, post natal period

When a woman presents in labour or is admitted INFORM HAEMOPHILIA TEAM OF ADMISSION AS PER PLAN

- **Call if excess bleeding, unexpected bleeding, protracted bleeding**
- If baby might be affected by Haemophilia: await cranial US
- DO NOT DISCHARGE BABY AND MOTHER until
    - haemophilia team review
    - cord levels/ peripheral blood levels/FBC back if taken and discussed
    - paediatric haemophilia review has taken place for possible affected babies
    - Provision for further doses of PO vitamin K made if required

- OHTC will call women day 10 postnatal and review week 6 post natal: review lochia, iron profile, wound healing

- OHTC Consultant will chase cord blood genetics and contact mother with results

- Confirmed bleeding disorders on cord genetics patients will be registered by paediatrics when reviewed in clinic

- Possible carriers will be registered locally at the 6 week check by the adult OHTC team

Acronyms

CHOX: Children's Hospital Oxford

CVS: Chorionic Villus Sampling FBC: Full Blood Count

DGH: District General Hospital

EDD: Estimated Date of Delivery

OHTC: Oxford Haemophilia and Thrombosis Centre

IBDs: Inherited Bleeding Disorders

ID: Iron deficiency

IDA: Iron Deficiency Anaemia

ISTH BAT score: International Society for Thrombosis and Haemostasis Bleeding Assessment Tool score

LMP: Last Menstrual Period

TXA: Tranexamic Acid

EDI statement

This guideline recognises diversity in diagnosis and management of inherited bleeding disorders. Whilst the common hereditary bleeding disorders (haemophilia A and B, and Von Willebrand disease) do not show a predilection for a particular ethnicity, international data suggest that outcomes for these patients do vary with ethnicity and socioeconomic deprivation. Ethnic variation in von Willebrand factor levels can also affect diagnosis. Achieving equality of health outcomes requires identification of barriers, and biases. It needs targeted action to overcome specific inequalities, discrimination, and marginalisation experienced by certain groups and individuals as highlighted in the Equality Act 2010.

Many sources highlight the consequences of complex pregnancy and potential morbidity and mortality. Women and birthing people from Black and minority ethnic backgrounds (BME), along with those with severe and multiple disadvantages are more likely to die in pregnancy compared to white women or those who do not have a disadvantage.

We aim to provide equal and accessible care to all service users with a focus on underrepresented groups or those with multiple disadvantages. This can be achieved with collaborative, specialist, multi-agency input and support. This includes early intervention and effective communication between services. The vision is to ensure exceptional quality care for all through equitable access, experience, and optimal outcomes.