MANAGEMENT OF NEWLY DIAGNOSED HAEMOPHILIA PATIENTS

PURPOSE
This guideline is designed to outline the management of newly diagnosed haemophilia patients at the Royal Children's Hospital.

DEFINITIONS
ABDR: Australian Bleeding Disorder Register
RCH: Royal Children's Hospital

BACKGROUND
In the majority of cases there is a family history of haemophilia. The child is usually diagnosed via prenatal testing or soon after birth when a clotting factor level is taken. Where there is no family history (30%), boys with severe haemophilia are usually diagnosed within the first 12 months of life. Common scenarios for diagnosis in this setting include: intracerebral bleed following traumatic delivery, bleeding post circumcision, bleeding post Guthrie test or venepuncture, excessive bruising, joint bleed, muscle bleed post immunisation. Moderate to mild haemophilia may not be diagnosed until later in childhood after a challenge to haemostasis such as trauma or surgery.

Receiving a diagnosis of haemophilia in their child is a difficult and stressful time for families. Haemophilia is uncommon and families may have misconceptions about the condition and its treatment. It is important families are provided with up to date written information, education and support at and following diagnosis.

PROCEDURE

Clinic appointments
When haemophilia is diagnosed or suspected in a child, an urgent appointment is made for the next haemophilia clinic. A haemophilia information pack is given to the family at the first appointment where there is a confirmed diagnosis. An education session (1-1 ½ hours) with the haemophilia nurse should then take place within 1 to 2 weeks.

Patients with severe haemophilia are reviewed in clinic on a regular basis (e.g. monthly for the first 4 months). Patients with moderate and mild haemophilia may be diagnosed later in childhood and review frequency depends on the presenting issues and family situation.

Haemophilia information pack
At the time of diagnosis families are given a Haemophilia information pack consisting of the following:

- Haemophilia Foundation Australia Folder “Haemophilia. For parents whose child has recently been diagnosed with haemophilia”. This can also be found in electronic form on the Haemophilia Foundation website http://www.haemophilia.org.au/
- “Boys will be boys. A guide to sports participation for people with haemophilia and other bleeding disorders.” This book gives the important message to the family at diagnosis that boys with haemophilia can and in fact are encouraged to play sport.
- Recognizing a bleed, observing your child (laminated page)
- Haemophilia Foundation Victoria membership form
- Haemophilia Treatment Centre fridge magnet (has contact phone numbers)

Social Work
The haematology social worker is an important part of the multidisciplinary team and wherever possible is introduced to the family at the first clinic appointment. Haemophilia patients with a clotting factor less than 10% are eligible for the carer’s allowance. Carer’s allowance is discontinued at the age of 16 years, the family can then apply for an ‘Ex-Carer Allowance (Child) Health Care Card’.

Assigning clotting factor
The haemophilia consultant assigns an appropriate recombinant clotting factor at the first or second clinic visit (unless one has already been assigned to treat a bleeding episode). The haemophilia nurse or data manager registers the patient onto the ABDR noting clotting factor level and assigned clotting factor as soon as this information is available.

Emergency Department Alert
Haemophilia centre staff will establish an Emergency Department Alert that notes the patient’s type of bleeding disorder and assigned clotting factor as outlined in the protocol “Establishing an Emergency Department Alert for patients with a bleeding disorder” HA-P-0010.

Blood Bank Alert
The “Yellow Card” is an electronic screen in the laboratory Medipath database where information relating to blood bank serology is communicated to blood bank staff. This is also utilised to note which clotting factor should be issued to a particular bleeding disorder patient and acts as an extra safeguard to ensure patients receive the correct treatment product. When a diagnosis is made and a clotting factor assigned to the patient, the haemophilia nurse or data manager will notify blood bank and request a yellow card be established.

Haemophilia ID card
When the patient’s clotting factor level has been established and a clotting factor assigned, the haemophilia centre issues an RCH Haemophilia ID card to the family. This card indicates that the child is a patient of the Henry Ekert Haemophilia Treatment Centre and states the patient’s name, date of birth, RCU UR number, assigned clotting factor, emergency guidelines and contact numbers for the RCH haemophilia centre and haematologist on call. Families are asked to present this when attending the RCH emergency department or elsewhere for treatment and when picking up clotting factor from RCH blood bank.

Immunisations

Haemophilia patients should not be given intramuscular injections due to the risk of muscle bleeding. Immunisations should be given deep subcutaneously and the puncture site firmly compressed for at least 10 minutes. The RCH immunisation centre is experienced in giving immunisations to haemophilia patients and many families elect to use the centre for their child's immunisations. For families who are unable or prefer not to attend the centre, a letter should be sent to the GP instructing immunisations to be given as above.

Physiotherapy

For patients with severe haemophilia an appointment with the haemophilia physiotherapist is made within the 12 months for education about joint health and first aid.

ATTACHMENTS

N/A

REFERENCES

HA-P-0010 "Establishing an Emergency Department Alert for patients with a bleeding disorder"

HA-P-0011 "ID Cards for bleeding disorder patients".