

**Report of Haemophilia Audit
Our Lady's Children's Hospital
Crumlin, Dublin**

Date of Audit: 14th November 2006

Auditors:

- a) Dr Mike Makris,
Haemophilia Director
Sheffield Haemophilia and Thrombosis Centre, Sheffield, UK
- b) Christine Harrington,
Nurse Consultant in haemophilia,
Katharine Dormandy Haemophilia Centre and Haemostasis Unit
Royal Free Hospital, London, UK

Summary:

The Haemophilia service at the Our Lady's Children's Hospital (OLCH) is a high quality national paediatric service. All services expected from a Comprehensive Care / Level 1 Haemophilia Centre service are provided and user questionnaires indicate satisfaction with the service they receive. Despite this, one major issue was identified during the audit which is the fragmentation of the inpatient and outpatient care and the need for a clinician to lead the haemophilia service.

Recommendations:

Major:

- a) A new consultant haematologist to lead on paediatric haemophilia and thrombosis services is urgently required
- b) Specialised coagulation laboratory tests including FVIII should be available on a 24hr basis on a formalized rota.

Non-major

- a) Data management support is required especially with the introduction of the Clintech system. One option may be for the Data manager from the National Haemophilia Centre at St James's Hospital to spend time at the Crumlin site.
- b) The haemophilia nurse specialists should incorporate peripheral venepuncture into their repertoire in order to provide continuity of care and fulfill their role in home treatment training.
- c) The nurses should also be supported in assessing the need and appropriateness of school and home visits, taking account of the wide catchment

area of the Centre. Community visits and liaison should be incorporated into their role.

d) Results of investigations should be filed more promptly and the process should be formally audited

e) The physiotherapist should be encouraged and enabled to attend conferences and visit another paediatric centre as part of his continuous professional development

f) Improved facilities and space for the coagulation section of the haematology laboratory are required

Background to the audit:

The UK Haemophilia Centre Doctors organisation (UKHCDO) conducts 3 yearly audits of Comprehensive Care Haemophilia Centres. There are agreed national standards of what a Comprehensive Care Haemophilia Centre and a Haemophilia Centre should provide. A pro-forma is provided for the audit and the auditors complete this on the day. The auditors are a haemophilia centre director and a haemophilia nurse specialist from another centre.

The intention was to have a patient representative on the audit panel. However, there are as yet unresolved issues in the UK including the selection, recruitment and training of patient auditors, revision of the audit tool and clarification of the role of the patient auditor. Because of these issues, patient representatives are not a requirement of the 2006 audit. It is the view of the auditors that future audits should incorporate an independent patient perspective.

Until an independent local audit tool is developed, the Irish National Haemophilia Council has agreed to use the audit tool and format of the UKHCDO to conduct the audits of the Irish Haemophilia centres.

This is the first ever audit of the OLCH Haemophilia Centre.

Patients registered:

Total patients registered	480	
Haemophilia A	92	(61 severe)
Haemophilia B	52	(9 severe)
Von Willebrand's Disease	155	

Haemophilia Centre Staff

Consultants

Dr Corrine McMahon (Haemophilia lead)

Professor Owen Smith

Haemophilia nurses

2 whole time clinical nurse specialists:

Mary Kavanagh and Imelda Kelly

1 Transfusion Surveillance Officer (based in blood transfusion and covering all blood and blood products)

Social worker

Physiotherapist

Comment on staffing levels:

Dr Corrine McMahon has significant haemophilia experience and has been the haemophilia lead. The dramatic increase in the number of sickle cell disease patients attending the OLCCH over the last 5 years has resulted in Dr McMahon devoting all her time to this aspect of the service at the expense of the haemophilia service. Due to lack of time Dr McMahon only provides care to patients attending with bleeding episodes and the outpatient reviews are carried out by a doctor who comes from St James Hospital. This fragmentation of service and lack of clear leadership hinders development and continuity of haemophilia care. There is a clear need for another paediatric haematology consultant to take over the haemophilia service and look after inpatient and outpatient children with bleeding disorders.

Nurse staffing appears to be adequate for current practice but may need to be reviewed in the light of recommendations for extension of the community liaison role.

Patient services at the Centre

A new haematology oncology day unit is due to open early in 2007 and patients with haemophilia should benefit from these additional facilities. Children over the age of one year are admitted to St Michaels ward, a 22 bedded medical ward. There is a full time clinical facilitator/nurse educator on this ward. Ward and A&E nursing staff are trained to administer factor concentrates and are educated to care for this group of patients. The ward, emergency department and outpatient department have designated play areas.

The auditors were informed that there is funding for a full-time physiotherapist and a psychologist through the National Haemophilia Council. Once these posts are in place, the Centre will have a fully comprehensive service.

Coagulation factor stock control, storage and issue

There are adequate procedures for factor concentrate ordering, storage, stock control and recording of issue to patients. The home delivery service by TCP has helped the quality of care delivered to the patients and is generally well appreciated. Parents requested that TCP should take away waste and the auditors have been informed that this is likely to commence shortly.

Treatment delivery

The delivery of care is adequate and fulfils all the standards required for a Comprehensive Care Haemophilia Centre. Protocols are in place for all main areas of practice,

Availability of comprehensive care services

All services/personnel required for qualification as a Comprehensive Care Haemophilia Centre are provided with the exception of a Data Manager. This is an essential post for a haemophilia centre as large as this.

A good data management service is provided at the St James Hospital Haemophilia centre and the possibility of getting some support from there on a long term basis should be explored.

Patient medical records review

Eight sets of notes were selected at random for review.

The quality of the medical charts is high and no significant problems were identified. A family tree was included in all 8 sets of notes reviewed.

Consideration should be given to adding the date of clinic attendance to the top of the front page of the Haemophilia review clinic forms (currently the only date is on page 2 after the signature).

Clinical Governance, Audit, Teaching, CPD and Research

There is adequate participation in clinical governance, audit, teaching and clinical professional development. The auditors would encourage the audit of adolescent transition to adult services to be ongoing.

No active research is currently taking place at the centre.

The Haemostasis Laboratory facilities

The laboratory has full Clinical Pathology Accreditation (CPA) but the last inspection was in 2003 which is prior to the move of the haemophilia service to the site. The laboratory takes part in 3 external quality assessment schemes and performs satisfactorily.

The laboratory space dedicated to coagulation is small and the bench surface area not occupied by equipment is tiny and by far the smallest the auditor has seen in a Comprehensive Care Haemophilia Centre. In comparison to the coagulation laboratory space at St James Hospital this is possibly up to two orders of magnitude smaller!! The available space is inadequate to deal with the volume of specialised coagulation work going through the laboratory.

Most coagulation tests are performed on site with the exceptions of:

VWF activity - sent to the Royal Free Hospital in London

VWF multimers – sent to the Royal Free Hospital

Platelet aggregometry – sent to St James Hospital

PFA 100 – sent to St James Hospital

Platelet granular constituents – sent to St James Hospital

There is an unacceptable wait for platelet function results but this will shortly be resolved since the laboratory have purchased the equipment and will start to do their own testing.

Standard 8.9 states that “Coagulation factor assays are always available throughout the 24hour period”. Although coagulation factors can be performed on a 24 hour basis, this is on an ad hoc basis and depends on the good will of the medical laboratory scientific officers MLSOs. This is an unacceptable risk and a formal on call arrangement for the 24hour availability of these assays should be in place.

Paediatric care

All the standards are fulfilled and satisfactory. The staff met by the auditors all seemed to be very enthusiastic and committed to delivering high standards of care for children and families.

Patient Questionnaires

The auditors selected at random from an anonymised list 30 patients to receive questionnaires. Completed questionnaires were to be completed and posted to Dr Makris in Sheffield.

11 of 30 (37%) completed questionnaires were returned.

The comments about the service were very positive especially about the nursing staff. By far the most frequent negative comment is the lack of adequate and available parking facilities.

Patients were asked to specifically comment on what is particularly good about the center.

The staff at the haemophilia center, especially the nurses, were felt to be particularly good. Some of the comments include: “Everybody is always helpful and understanding and nothing seems to be a problem for them”. “The nurses become friends and make you feel very relaxed. I always come away thinking that things are nowhere as bad as I think they are”. “Everybody is treated with dignity and respect and not made to feel like just another number in the health system.”

Patients were also asked to comment on what they felt was most in need of improvement at the haemophilia center. Comments received were:

- Car parking (repeatedly)
- Play room and play therapist
- Better facilities for parents eg eating areas
- Shorter waiting times to see a dentist
- Increased efficiency at the blood taking facility (often forms are not available and there is a lot of unnecessary waiting which is stressful to children with needle phobia)
- Better facilities at the medical day unit

Signed

Mike Makris

Date

Christine Harrington

Date