



**Summary of the Audits Carried out in Our Lady's Children's Hospital, Crumlin, St James Hospital and Cork University Hospital in September 2008**

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**Auditors:**

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Sheffield Haemophilia and Thrombosis Centre, Sheffield, UK.
- b) Christine Harrington, Nurse Consultant in Haemophilia.
- c) Katharine Dormandy, Haemophilia Centre and Thrombosis Unit  
Royal Free Hospital, London, UK.
- d) David Page CEO Canadian Haemophilia Society.

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

**Date of Audit:** 23<sup>rd</sup> September 2008

## **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. There have been significant improvements since the last audit in 2006 with the opening of the new Haematology day unit. The new consultant post to lead on haemophilia issues has been advertised and is due to be interviewed for shortly.

With the appointment of the new consultant, the auditors feel that this centre will be able to provide a high level of local haemophilia care. In view of the role of the centre as a national centre, the auditors recommend a closer working relationship with the adult haemophilia centre at St James's Hospital and the appointment of posts to overlook national haemophilia issues.

## **Recommendations:**

### **Major:**

- a) The new consultant haematologist post to lead on paediatric haemophilia and thrombosis services that has been advertised should be appointed to.
- b) The coagulation laboratory should offer von Willebrand factor activity levels on a 24 hour basis on a formalised on call rota.
- c) The centre's national status should be clarified. If the decision is for this centre to have a national responsibility for children with haemophilia, then the centre should work more closely with St James's Hospital for the delivery of the national haemophilia agenda. In particular there should be appointments of single individuals with national responsibility for:
  - i – Quality Management
  - ii – Data Management
  - iii – Haemovigilance

These 3 individuals should have responsibilities for all 3 haemophilia centres in Ireland and should be answerable to the Irish National Haemophilia Council. Local delivery could be devolved but the local individuals will be answerable to the national leads.

### **Non-major**

a) If during cutbacks, the hospital decides to close the haematology ward (St Michael's ward) at weekends, then the nursing staff from this unit should be deployed on a single new ward, so there is continuous availability of nursing care by individuals with haemophilia training.

b) A community liaison nurse should be appointed and funded to a level that will allow coordination of the delivery of national as well as local requirements of community haemophilia nursing.

c) The medical staff should re-examine their policy of annual testing for HIV, hepatitis C and immunity to hepatitis A and B.

## **2. Report of Haemophilia Audit, National Centre for Hereditary Coagulation Disorders (NCHCD) St. James's Hospital, Dublin**

**Date of Audit:** 22<sup>nd</sup> September 2008

### **Summary:**

This is a high quality haemophilia centre providing all the services expected from a Comprehensive Care Haemophilia Centre. The level and quality of the outpatient service delivered from the Haemophilia Centre is as good as can be found anywhere in the world. The centre is an exemplar site for the outpatient management of any chronic disease.

A problem that was identified in the last two audits 5 and 2 years ago continues and potentially compromises the otherwise excellent service. This is the poor inpatient facility for patients with haemophilia and related inherited bleeding disorders.

Although the centre is the national centre, its role in this respect should be clarified and expanded. There should be closer working relationships with the other haemophilia centres in the Republic and staff within the centre should take national leadership roles on which they should be reporting to the Haemophilia Council.

### **Recommendations:**

#### **Major**

a) Improved and preferably centralized and protected beds for inpatients with haemophilia should be identified. The nurses covering these beds will need to be competent to care for patients with haemophilia and related inherited bleeding disorders and this will require appropriate supervision and training.

b) The role of the centre as a national centre should be clarified and expanded. It is recommended that the quality manager, haemovigilance officer and data manager be given national responsibilities.

#### **Other recommendations**

- a) A psychologist or a social worker should be invited to sit on the National Haemophilia Council.
- b) Services for women and patients with mild haemophilia could be further developed and focused by designating one of the clinical nurse specialists to take a lead responsibility for these areas.
- c) The vacant nursing post, currently frozen, is required to meet the needs of the home treatment programme and community liaison work and should be recruited to. Whether this should be a full or part-time post should be reviewed.
- d) Consideration should be given to the availability of an oral hygienist when patients attend for their reviews.

- e) The ClinTech system should be made available to on-call consultants so they can access it from home.
- f) The centre should be more proactive in publicizing, both at home and abroad, their model of care and excellent services.
- g) Consideration should be given to improving the *clinical* research and development program. In contrast to the excellent basic science research program this is much less well developed.
- h) Von Willebrand factor activity testing must be available on a 24 hour basis via a formalized on call system.

### **3. Summary of the report of Audit of the Cork Haemophilia Centre – Cork University Hospital**

**Date of Audit:** 25<sup>th</sup> September 2008

#### **Summary:**

Overall the quality of haemophilia care in Cork is satisfactory but the infrastructure remains grossly inadequate and is in stark contrast to the facilities available in Dublin.

Because of the gross deficiencies in infrastructure, the last audit in 2006 made 4 critical recommendations which have yet to be acted upon.

The Cork Haemophilia Centre has sufficient patient numbers and covers such a wide geographical area that it should be a Level 1 / Comprehensive Care Haemophilia Centre. The infrastructure is however so poor that it would struggle to qualify as a basic / Level 2 Haemophilia Centre.

During the audit visit, the auditors met with the CEO, and the Deputy CEO, who indicated that the Hospital Board has now approved:

- a) Up to €650,000 to build a new haemophilia centre either by reconfiguring part of C2 ward or as a stand alone building.
- b) The appointment of a new consultant haematologist with responsibility for haemophilia. A locum post can be advertised immediately.
- c) 0.5 WTE haemophilia secretary
- d) 0.5 WTE data manager for haemophilia
- e) 0.5 WTE haemophilia physiotherapist
- f) 0.5 WTE haemophilia social worker
- g) 1.0 WTE MLSO

Provided the above are funded, the haemophilia care delivered in Cork will be transformed for the better and will approach the level of haemophilia care Irish patients get in Dublin.

Since none of the above have actually been built or appointed, it is recommended that the hospital reports to the National Haemophilia Council every 6 months outlining the progress on the critical recommendations arising from this audit.

#### **2008 Recommendations**

##### **Critical**

- Dedicated haemophilia space should be identified within the hospital to form a physical space for the “haemophilia centre”. This should include office space for the haemophilia nurses.
- A haemophilia secretary should be employed.
- A consultant in Haemostasis and Thrombosis to take overall responsibility for the haemophilia centre should be employed.

## Other

- The medical records of patients with inherited bleeding disorders should be kept on site.
- A data manager should be employed on at least a part time basis to provide support for the service, especially when the new Clintech national haemophilia system is introduced.
- The haemophilia physiotherapist should be attending adult review clinics as well as paediatric ones.
- An audit of patients attending outside routine clinics should be carried out every 6 months to document the time between arrival in the hospital and actual treatment with clotting factor concentrate or DDAVP.
- The haemophilia nurses must undergo performance review.
- Once the new consultant is in post, the nursing establishment should be reviewed for fitness to deliver the developing service, including the implementation of other recommendations such as nursing involvement in reviews and genetic counselling and testing.
- Once the new consultant is in post haemophilia reviews should be consultant-led and not conducted by SHOs. A needs assessment should be carried out to determine the number of adult and paediatric review sessions that will be needed for the patient numbers and severity of condition. Dental reviews should be conducted at the same appointment. The specialist nurses should also have the time to play an active role in reviews. The impact of these measures on review DNAs, currently at 50%, should be monitored.
- More space and more dedicated staff need to be identified for the coagulation laboratory.
- A normal range for von Willebrand factor activity should be performed by the coagulation laboratory.
- The platelet aggregation methodology should be reviewed.
- DNA testing for haemophilia should be offered much more readily and widely. The way this is currently done should be revised.
- A standard operating procedure of how urgent and out of hours requests for FVIII and IX level estimations are performed should be in place.
- Protocols should be entered on the Q Pulse system.
- There should be closer working relationships with the data manager, quality manager and haemovigilance officers in Dublin.