

## **Report of Audit of the Cork Haemophilia Centre**

**Date of Audit:** 15<sup>th</sup> November 2006

### **Auditors:**

Dr Mike Makris,  
Haemophilia Director  
Sheffield Haemophilia and Thrombosis Centre, Sheffield, UK

Christine Harrington,  
Nurse Consultant in Haemophilia,  
Katharine Dormandy Haemophilia Centre and Haemostasis Unit  
Royal Free Hospital, London, UK

### **Summary:**

Overall there is evidence that the haemophilia service in Cork has improved significantly in the last 5 years from a very low base, largely due to the efforts of Dr Oonagh Gilligan and the appointments of the Haemophilia nurse specialists in 2001 and 2005. Clearly the staff are hard-working and enthusiastic but the infrastructure remains very poor and grossly inadequate. The facilities significantly hamper the delivery of effective and efficient care for patients with inherited bleeding disorders. The Cork Haemophilia centre has the 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. The “cuckoo” model of haemophilia centre (ie lack of a physical centre but borrowing space from many other areas if they are free) practiced in Cork is unacceptable and patients with haemophilia and their families deserve and should expect better facilities. The poor infrastructure at the Cork Haemophilia Centre is in stark contrast to the excellent haemophilia facilities the auditors inspected in Dublin.

### **Recommendations:**

#### **Critical:**

- a) 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
- b) A haemophilia secretary should be employed
- c) A consultant in Haemostasis and Thrombosis to take overall responsibility for the haemophilia centre should be employed
- d) The medical records of patients with inherited bleeding disorders should be kept on site and be readily available on a 24hr basis.

Although haemophilia centres are audited on a 3-year cycle the auditors consider the above four issues to be so important that they recommend that Cork University Hospital should formally provide a progress report to the National Haemophilia Council in 12 months from the date of this report.

## **2. Other recommendations**

- a) More space and more dedicated staff need to be identified for the coagulation laboratory
- b) A dental surgeon should be available in the clinics when children attend for their 6 monthly reviews
- b) The haemophilia on-call service should be provided, at middle grade, by a haematology doctor on all days rather than at weekends as now
- c) 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
- d) the Social worker and Physiotherapist should be attending adult review clinics as well as paediatric ones
- e) Subcutaneous high concentration DDAVP should be introduced to replace the intravenous formulation currently used
- f) An ansaphone should be provided for the haemophilia nurses
- g) Standard operating procedures for patients attending the A&E department should be reviewed and revised.
- h) The new card registration system due to be introduced in Dublin should also be introduced in Cork at the same time
- i) An audit of patients attending outside routine clinics should be carried out to document the time between arrival in the hospital and actual treatment with clotting factor concentrate or DDAVP
- j) The haemophilia nurses should undergo performance review
- k) The Q-Pulse system currently developed at St James Hospital should be introduced as most of the shared protocols are already used.

**Background to the audit:**

The UK Haemophilia Centre Doctors organisation 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 were not a requirement of the 2006 audit. It is the view of the auditors that future audits should incorporate an independent patient perspective.

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

**Patients registered:**

Total patients registered	255	
Haemophilia A	71	(26 severe)
Haemophilia B	18	(9 severe)
Von Willebrand's Disease	123	(8 severe)
Hepatitis C positive	28	
HIV positive	8	

**Haemophilia centre staff:**

## Haematology consultants:

Oonagh Gilligan	[7 sessions at CUH]	Haemophilia lead
Mary Cahill	[9 sessions at CUH]	
M. Madden	[4 sessions at CUH]	only malignant haematology]
C. Ryan	[2 sessions at CUH]	

## Haemophilia nurses (2 whole time equivalents):

Helen Browne  
Brid Booth-Flemming  
Norma Collins  
Annmarie Ryan

## Haematology registrars: 2

SHO: 1  
Intern: 1

### **Patient services at the Centre**

The central issue in the provision of comprehensive care is that there is a physical space called the haemophilia centre. There is no such centre in Cork.

### **Coagulation factor stock control, storage and issue**

Increasingly these are delivered to the patients' homes by the TCP home delivery company. This is working well.

A small number of patients continue to obtain their concentrates from the hospital and the arrangements for storing and issuing of the product are satisfactory.

### **Treatment delivery**

Although treatment is delivered, this can be in a number of places. The standard relating to this part of the audit is that "There is a designated treatment area that provides privacy and comfort"

### **Availability of comprehensive care services**

There are standards for comprehensive haemophilia care laid down in the Haemophilia Alliance Service Specification (2006) and in the UK Department of Health document HSG93.

The Cork centre fails to provide a comprehensive service in the following respects:

There is no dedicated day care/outpatient area

When patients telephone and need to be seen urgently because of bleeding, the haemophilia nurses ask them to come to the hospital main entrance and then try and identify a free area which they can use to assess and treat the patient.

Possible areas they can use if these are free are:

- a) an one-bed plasmapheresis room that is rarely available but is the only dedicated outpatient haematology space
- b) the recovery area in radiotherapy outpatient department on Tuesdays and Wednesdays
- c) the radiotherapy outpatient suite
- d) the accident and emergency department

Staff are restricted in the times that they can book in elective patients e.g. for DDAVP trial, because of lack of availability of free space in these areas. At times patients have to be moved from one space to another in the middle of a consultation or procedures cancelled at short notice due to lack of a place.

The haemophilia nurses currently work from a small office in the former Doctor's residence well away from the main hospital. As it is currently laid out, the office is only suitable for one occupant. Its distance from the hospital and any area that a patient may need to go for treatment, adds to the fragmentation of care and wastes nursing time.

The auditors consider this "Cuckoo model" of delivery of haemophilia care unacceptable and dedicated space should be identified as soon as possible. **This is the most important and critical failing of the Cork Haemophilia Centre.**

The Centre lacks the following staff:  
Haemophilia centre receptionist  
Haemophilia secretary  
Dedicated social worker  
Dedicated physiotherapist  
Dentist

The lack of clerical support to the haemophilia service means that the haemophilia nurse specialists have to perform many of these functions such as:

- setting up clinic lists
- following up patients who fail to attend
- typing patient letters
- sending out appointments
- typing protocols
- collecting medical charts etc.

#### ***Inpatient haemophilia service***

This is not an area that is heavily used by the haemophilia service but the number of dedicated haematology beds is inadequately small. The problem is part of the wider issue of inadequate inpatient haematology facilities in general. Incredibly for a hospital this size, serving such a large population there are only 8 inpatient haematology beds.

#### ***Out of hours service***

Patients attend the A&E department. The patient questionnaires identify this as an area where unacceptably long delays occur. Although patients are seen by the triage nurses fairly quickly, they can wait for hours to see a doctor, even though they have attended with acute bleeding into a joint. The auditors recommend that the time between presentation A&E and completion of factor concentrate/DDAVP infusion is recorded for every attendance and is audited on a regular basis.

#### ***Obstetric service***

This is likely to improve with the opening of a single obstetric unit at the CUH site in early 2007

#### ***Patient medical records review***

During the audit, eight sets of medical charts were reviewed.

The quality of the information in the charts is satisfactory. Only one of 8 charts had a family tree however and it would be useful to include this and consider if any female relatives could be carriers.

During the audit we requested 3 random additional charts that were not physically in the medical notes trolley. Of these 2 were with other secretaries and the third was in "Record Data". The response to our request to see this chart was that it would be available the following day. Apparently Record Data is an off-site store room for medical notes that is not open at night or weekends and notes are usually only made available the following day. All notes of patients not seen in a 12 month period are sent to Record Data.

This unavailability of medical notes of patients with bleeding disorders on a 24hr basis is unacceptable and is a major risk issue. It should be rectified as soon as possible.

### **Clinical Governance, Audit, Teaching, CPD and Research**

We saw no evidence of research activity.

There is evidence of teaching of other medical, nursing staff as well as a commendable amount of both formal and informal education for patients and families

The Haemophilia Nurses recently embarked upon a vaccination audit, however there should be more audit activity in a centre of this size. Staff have conducted an impressive number of assessments of individual's suitability for DDAVP treatment and this work could be retrospectively audited. Another area highlighted during the audit visit was a perceived reluctance on the part of patients to consider orthopaedic procedures. It would be useful and interesting to investigate what this is about, perhaps by questionnaire.

Nursing staff do not appear to have had recent performance and development reviews and this should be rectified. They do have records of appropriate training and education for continuing development in their specialist role. This should continue to be supported.

### **The Haemostasis Laboratory facilities**

The coagulation section of the haematology laboratory performs the following number of tests annually

INR	93,000
APTT	58,000
D-Dimer	6,000
FVIII	643
Thrombophilia	1,300

Despite the high volume and complexity of the coagulation tests performed the dedicated coagulation laboratory space is tiny and only 2 medical laboratory scientific officers (MLSOs) are dedicated to coagulation.

There is an urgent need for expansion of the coagulation laboratory space as well as the number of coagulation MLSOs.

The laboratory takes part in external quality assessment and performs satisfactorily.

All specialized coagulation tests with the exception of VWF multimers and platelet granule assessment (which are sent to St James's Hospital who then transfer them to the Royal Free Hospital in London) are performed locally.

A basic requirement of all coagulation laboratories attached to comprehensive care haemophilia centres is that they are accredited by Clinical Pathology Accreditation (CPA). No such accreditation has taken place. The Cork laboratories need to be inspected and to pass CPA accreditation as soon as possible.

Although FVIII measurements can be performed out of hours this is done by the laboratory staff who are not on call and are prepared to come in and do the test. A comprehensive care centre needs to have a robust on call system that will be able to cope with the measurement of specialized coagulation tests (such as FVIII) on a 24 hour basis.

### **Paediatric care**

The paediatric services have recently improved with the appointment of Dr Ryan but as she is only at the Cork University Hospital on 2 days a week this is far from ideal. The lack of a dedicated Haemophilia centre significantly hinders the delivery of haemophilia care to children.

A further problem is that Dr Ryan does not have a secretary at CUH.

### **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.

9 of 30 (30%) completed questionnaires were returned.

The returns from patients were very mixed with some being grateful for the facility and others very critical of the poor infrastructure. Some of the questionnaires were very comprehensive in their comments and advice on how to improve the service. Most of the comments and solutions suggested by the patient questionnaires closely match what was identified by the auditors during their visit.

Patients were specifically asked what was particularly good about the center.

The mixed comments generally identified the medical and nursing staff as being helpful and recognized the improvements over the last few years. Several patients commented on the improvements in home delivery, but also indicated that this is not fully sorted yet as only the concentrate (ie not sterile packs, needles etc) is delivered

Patients were also asked what was most in need of improvement at the haemophilia center. Many comments were provided including:

- a full service at CUH
- dental support
- orthopedic care
- social work support
- car parking
- permanent physical space to see patients
- haemophilia secretary
- better cover out of hours
- annual and biannual reviews to be done in Cork rather than Dublin
- Long waits in A&E
- Need to provide patients with details of support groups including the Irish Haemophilia Society
- Better communication with the Dublin centers in terms of data on factor usage and results of blood tests
- Psychologist support
- More privacy when seen on the ward

Signed

Mike Makris

Date

Christine Harrington

Date