

# **UKHCDO CCC AUDIT 2006**

## **NAME AND ADDRESS OF AUDITED CENTRE**

**Northern Ireland Haemophilia Comprehensive Care Centre**  
***Belfast City Hospital, 1st Floor Tower Block, Belfast BT9 7AB***  
***Royal Belfast Hospital for Sick Children, Belfast BT12 6BE***

## **DIRECTOR(S)**

**Frank Jones – Belfast City (acting)**  
**Sid Dempsey - RBHSC**

## **NURSING STAFF (Grades and WTEs)**

### ***Belfast City***

**Collette McAfee**                      **Band 6 (formerly G grade, prior to AFC) 1WTE**

**Margaret O'Donnell**              **Band 6 (formerly F grade, prior to AFC) 1WTE**

### ***RBHSC***

**Fionnula Diamond**              **1WTE**

## **AUDIT TEAM**

## **MEDICAL AUDITOR**

**John Pasi**

## **ADDRESS**

**Royal London Hospital, Whitechapel London, E1 2BB**

## **NURSING AUDITOR**

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## **ADDRESS**

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## **PATIENT / PARENT AUDITOR**

**-**

## **DATE OF AUDIT VISIT**

**19 November 2007**

## **DATE OF SUBMISSION OF DRAFT AUDIT REPORT TO CENTRE**

**11 August 2008**

## **DATE OF SUBMISSION OF FINALISED REPORT TO AUDIT CO-ORDINATOR**

**24 September 2008**

## 1.1 PREVIOUS UKHCDO AUDIT REPORTS

**Standard** –The 2003 audit report should be available and viewed by the audit team prior to the audit visit.

1.1.1. 2003 audit report reviewed Yes

1.1.2. Other audit report(s) reviewed No  
Year.....

### COMMENTS

## 1.2 UKHCDO ANNUAL RETURNS

**Standard** – Annual returns should have been submitted to the UKHCDO secretariat each year since the 2003 audit and copies should be available for inspection.

1.2.1. 2003 returns submitted and available No

1.2.2. 2004 returns submitted and available No

1.2.3. 2005 returns submitted and available No

### COMMENTS

None of the annual returns were made available for inspection

### **1.3 NUMBER OF REGISTERED PATIENTS**

- 1.3.1.** Total number of patients registered with UKHCDO data base as of 2006 – 170 BCH, 93 RBHSC
- 1.3.2.** Total number of patients treated during 2005 – data not available locally
- 1.3.3.** Total number of patients with severe haemophilia A and B and type 3 von Willebrand disease – 40 BCH, 43 RBHSC
- 1.3.4.** Number of patients with active inhibitors – 3 BCH, 3 RBHSC

These data were taken from figures supplied by Belfast City Hospital and RBHSC

## 2. THE HAEMOPHILIA CENTRE

**The audit team should give a brief description of the centre to include location, layout, adjacencies etc. (Include this description in the audit report).**

The haemophilia service in Belfast is provided on two sites, adults at the Belfast City Hospital (BCH) and the children's service at the Royal Belfast Hospital for Sick Children (RBHSC).

At BCH the centre is sited in a purpose built / refurbished area adjacent to the haematology / oncology unit. It is bright, modern and well fitted with plenty of space and facilities for meetings, offices and consultation rooms with patients. The full facilities of a busy teaching hospital are available on site. The haematology laboratories and blood bank are only a very short distance away on the same level.

The main work of the RBHSC unit is within the paediatric haematology / oncology unit - this is an 8 bedded unit with an associated day care and out patient facility. The full facilities of a dedicated paediatric hospital are on site. Office facilities are at some distance from the clinical facilities.

BCH and RBHSC are just over 1 mile apart.

### 2.1 PATIENT SERVICES AT CENTRE

**Standard** – Patients, family members and carers attending the CCC should have easy access to the centre, adequate facilities whilst waiting, a private counselling area and availability of written information about all aspects of haemophilia and related disorders.

	ADEQUATE	INADEQUATE
Access by car	BCH, RBHSC	
Designated Centre Car Parking	BCH (disabled, not designated)	RBHSC
Access by public transport	Good access to both centres	
Disabled access	Good at both centres	
Direct Emergency Ambulance Access	Via A+E or centre	
Signposting	BCH, RBHSC	
Direct telephone line	BCH, RBHSC	
Answerphone	BCH, RBHSC	

<b>e-mail access</b>	<b>BCH, RBHSC</b>	
<b>Waiting area</b>	<b>BCH, RBHSC</b>	
<b>Toilets</b>	<b>BCH, RBHSC</b>	
<b>Disabled toilets</b>	<b>BCH, RBHSC</b>	

	<b>ADEQUATE</b>	<b>INADEQUATE</b>
<b>Play Area (in centre where children are treated)</b>	<b>RBHSC</b>	
<b>Television</b>	<b>RBHSC</b>	
<b>General reading material</b>	<b>BCH, RBHSC</b>	
<b>Information on haemophilia and related disorders</b>	<b>BCH, RBHSC</b>	

## COMMENTS

The facilities at both sites are generally very good. The purpose build unit at BCH is extremely light, airy and spacious and provides a very pleasant environment. In general the patient survey responses were favourable about the environment and access.

The facilities at RBHSC are all good, with an excellent new OP clinic but they are all fragmented – day care, laboratory, medical and nursing offices and OP clinic all considerable distances apart. Clearly a dedicated centre might be advantageous.

### 3. COAGULATION FACTOR STOCK CONTROL, STORAGE AND ISSUE

**Standard** – CCCs should have in place adequate procedures for factor concentrate ordering, storage, stock control, recording of issue to patients and use by patients.

- 3.1 Procedures for factor ordering

**Satisfactory**

- 3.2 Procedures for storage of concentrate

**Satisfactory**

- 3.3 Procedures for stock control

**Satisfactory**

- 3.4 Procedures for recording of concentrate issues to patients

**Satisfactory**

- 3.5 If home delivery service in place, adequate recording of concentrate issuing by company

**NO SERVICE**

- 3.6 Procedures for recording concentrate usage by patients on home treatment (e.g. home treatment recording system and return of this record to the centre)

**Unsatisfactory**

#### COMMENTS

Concentrate management is largely performed through blood bank. The same blood bank computer system operates throughout the Royal Victoria, BCH and RBHSC. Concentrate is purchased via the Royal Victoria with the major stock held at that site. Stock is then distributed from the Royal Victoria, as required and stock control maintained on the computer, visible at all sites. In both haemophilia centres, an initial paper request for concentrate is made and the concentrate then issued as a component from blood bank.

These requests are then transferred onto the computer system. BCH and RBHSC maintain limited stocks to limit problems with dating product. Audit and stock control takes place each Thursday. There appear to be no issues with accounting, stock distribution or batch traceability from blood bank.

However, at BCH there appears to be a very poor and highly variable system for recording patient home treatment usage and overall a poorly understood, or inaccessible system, to enable individual or aggregated usage data to be drawn together. BCH could not provide a figure for number of patients treated nor annualised use of concentrate, by total or broken down by product for either patients or the centre itself. In addition the annual returns were not available for inspection. No one asked had any clear idea of overall usage of product or patterns of product usage.

In contrast, complete and detailed patient and centre records were available at RBHSC.

Fridges used for storing concentrate at RBHSC in the laboratory should be alarmed.

#### 4. TREATMENT DELIVERY

**Standard** – Patients who are actively bleeding receive prompt and effective treatment according to established protocols throughout the 24 hour period. Appropriate arrangements are in place for routine patient review and liaison with affiliated haemophilia centres for shared care patients. Adequate mechanisms and protocols are in place for home treatment, prophylactic administration of concentrate and management of inhibitor patients where appropriate. General and genetic counselling is readily available for patients and their families.

- 4.1. There is a designated treatment area that provides privacy and comfort

Satisfactory

- 4.2. Universal cross-infection precautions are in place

Satisfactory

- 4.3 There is evidence of appropriate routine review of patients

Satisfactory

- 4.4 There is prompt review by junior medical staff out of hours

Satisfactory

- 4.5 Senior haemophilia medical staff are available 24 hours a day for treatment advice.

Satisfactory – see comment

- 4.6 There is effective community liaison between the unit and the patient in their home and with primary care providers

Satisfactory

4.7. Written protocols / guidelines / procedures and procedural training are available for the following:

	Satisfactory	Unsatisfactory	N/A
1. Management of bleeding episodes	RBHSC	BCH	
2. Commencement of home treatment / Venous access training	BCH, RBHSC		
3. Commencement of prophylaxis in children	RBHSC		
4. Management of inhibitor patients (including immune tolerance)	UKHCDO		
5. Treatment in Accident and Emergency		BCH	
6. Management of pregnancy and childbirth	UKHCDO		
7. Genetic counselling	BCH		

## COMMENTS

Both sites provide appropriate standards of treatment delivery. However, there are issues that arise for the absence of a dedicated consultant haematologist for coagulation at BCH – some of which roll over into provision of out of hours care.

The patient survey highlighted in some responses problems with out of hours care at BCH with regard to A+E attendance and quite junior medical staff. One particular issue was access to the centre and time delays out of hours – hospital security must be contacted out of hours to allow staff to access the haemophilia centre.

At BCH many of the protocols were very out of date and require urgent updating or at the very least dated review, for example management of bleeding episodes.

Much of the service has recently been provided by Dr Orla McNulty (1WTE staff grade). She has essentially held the clinical service together through the absence of a substantive centre director. The auditors are not sure what would have happened to the adult service if she had not been in post.

It would appear that there are some doubts over the funding of her post and that the funding is not secure. It is essential from a service provision and clinical governance perspective, even with the appointment of a centre director, that this post is maintained and appropriately recognised. In the 2003 audit it was highlighted that a second

consultant in haemostasis was essential. The staff grade post partly addresses the clinical governance issues of single handed haemophilia centre directors pending a second post.

#### 4.8 Relationship between Comprehensive Care Centre and neighbouring Haemophilia Centres

##### 4.8.1. List of Haemophilia Centres in locality of CCC

None

##### 4.8.2. There is a formal network arrangement between the CCC and the neighbouring Haemophilia Centres

Yes No

##### 4.8.3. If yes, assess the arrangement with regard to the following:

There is shared patient care Yes No

If so, shared care arrangements are satisfactory Yes No

There is effective liaison between the CCC and the HC for advice/ patient referral over the 24 hour period Yes No

There are shared treatment protocols/ guidelines Yes No

There are adequate arrangements for the supply of factor concentrate to the HC Yes No

#### COMMENTS

There is no home delivery service. All concentrate is distributed through blood bank and the centre direct.

## 5. AVAILABILITY OF COMPREHENSIVE CARE SERVICES

**Standard** – Services required to provide a comprehensive care service are available as detailed in the Haemophilia Alliance National Service Specification.

5.1. The following services / personnel are available;

	AVAILABLE	NOT AVAILABLE	N/A
Centre receptionist / secretary	BCH	RBHSC	
Centre data / business manager		BCH / RBHSC	
Dedicated Social worker		BCH / RBHSC	
Dedicated Physiotherapist	Access at RBHSC	BCH	
Psychologist	BCH		
Dental service / Dentist	Royal Victoria / RBHSC		
Orthopaedic service / Orthopaedic surgeon	Royal Victoria / Musgrove		
General/Specialist surgical services	BCH		
HIV physician	Royal Victoria		
Hepatologist	Royal Victoria		
Obstetric / Gynaecology service / Surgeon	BCH		
Paediatrician (in paediatric or paediatric/adult centre)	RBHSC		
Dietician	Access at required		
Genetic Counselling Services	BCH		
Antenatal diagnosis arrangements	BCH		

**COMMENTS**

(Any contacts made with multidisciplinary staff during the visit should be noted)

None of the associated specialist support staff were meet during the audit visit.

The previous audit in 2003 highlighted the need for hepatology services – this has now been addressed. Dedicated physio services are not available, but a case is being put together.

Most other specialised services are provided by direct referral to the appropriate speciality. Gynae and prenatal diagnostic services are provided by Ann Harper.

## 6. PATIENT MEDICAL RECORDS REVIEW

**Standard-** The following should be present in the patient's medical records:

- clear documentation giving the diagnosis and usual treatment
- genetic mutation or potentially informative polymorphisms
- family pedigree with identification of obligate carriers / confirmed carriers
- appropriate review interval as per National Service Specification recommendation (six monthly for severe and moderate haemophilia, yearly for mild)
- appropriate physiotherapy / orthopaedic referral
- appropriate management of HIV, hepatitis B / hepatitis C infection as per national guidelines where applicable.
- evidence of effective communication with primary and secondary care colleagues and affiliated regional haemophilia centre directors.

It is recommended that a random sample of 8 medical records are reviewed.

6.1. There is documentation giving the patient's diagnosis:

Number of records with this information 8/8 BCH 8/8 RBHSC

6.2. There is documentation giving the patient's usual treatment:

Number of records with this information 5/8 BCH 8/8 RBHSC

6.3. There is documentation of the patient's genetic mutation:

Number of records with this information 5/8 BCH 0/8 RBHSC

6.4. There is documentation of the family pedigree:

Number of records with this information 8/8 BCH 8/8 RBHSC

6.5. There is evidence of appropriate follow up review:

Number of records showing this to be satisfactory 8/8 BCH 8/8 RBHSC

- 6.6. There is evidence of appropriate physiotherapy / orthopaedic referral

Number of records showing this to be satisfactory 2/3 BCH 4/4 RBHSC

- 6.7. There is evidence of regular dental review

Number of records showing this to be satisfactory *no evidence* BCH 8/8 RBHSC

- 6.8. There is evidence of appropriate management of HIV, HBV, HCV infection where applicable

Number of records showing this to be satisfactory 5/5 BCH n/a RBHSC

- 6.9. There is evidence of effective communication with general practitioners and consultant colleagues

Number of records showing this to be satisfactory 8/8 BCH 8/8 RBHSC

- 6.10. Investigation results are readily accessible in the medical records

Number of records showing this to be satisfactory 8/8 BCH 8/8 RBHSC

## COMMENTS

Notes were examined at BCH and RBHSC.

In general the notes were all neat, clearly divided and well kept. Good summary sheets were provided and excellent family trees.

There is no rapid card or other index system for accessing basic / core information out of hours. Finding notes may be difficult out of hours. A card or other rapid index system with core information is recommended to be developed.

## 7. CLINICAL GOVERNANCE, AUDIT, TEACHING, CPD, RESEARCH.

**Standard** – There is evidence that CCC staff participate in clinical governance, audit and teaching activities. There is evidence that unit staff undergo regular personal performance review and participate in CPD schemes. The unit participates in clinical trials and active research.

7.1. CCC staff participate in clinical governance and audit activities:

YES

Give a list of recent audits performed:

BCH  
HCV 2007  
Satisfaction survey 2006  
Relexology survey 2007

RBHSC  
Prophylaxis compliance 2007

7.2. CCC staff participate in teaching activities:

YES

Give examples of teaching activities:

Medical student teaching  
Haematology staff / general / postgraduate

7.3. CCC staff undergo regular performance review:

see comments

7.4. CCC staff participate in continuing professional development:

YES

7.5. The unit participates in clinical trials:

NO

7.6. The unit participates in clinical research:

NO

## COMMENTS

At BCH the haemophilia service falls within the cancer / haematology clinical governance committee.

There have been no meetings with Trust management at BCH for more than 2 years. This must be addressed given other issues that are highlighted in this audit report. Communication between Trust, clinicians and commissioners appears to be very poor.

Staff at BCH have not undergone any appraisal process recently, and certainly not within the last 12 months (lab staff >1 yr, nursing staffing 2-3 years). Within the nursing structure there appears to be no line manager responsible for the haemophilia staff. Medical appraisals also seem to have lapsed, albeit that Dr McNulty has been appraised annually.

Other than the lab staff issue at RBHSC staff appraisal have taken place the last 12 months for both medical and nursing posts.

Although there is no appraisal, CPD and other educational activity is well supported for both medical and nursing staff.

There is no research or R+D activity due to lack of medical staff time at both sites.

## 8. THE HAEMOSTASIS LABORATORY FACILITIES

**Standard** – The haematology laboratory in which the CCC haemostasis laboratory is located should have full CPA accreditation. The haemostasis laboratory should be adequately staffed with an appropriate skill mix and have adequate space and facilities to perform an effective diagnostic and monitoring service. The laboratory should participate in a national quality assurance scheme. Clotting factor assays should be available throughout the 24 hour period.

- 8.1. The haematology laboratory has full CPA accreditation:

YES

If yes, year of last CPA inspection Feb 2007

- 8.2. The staffing levels and skill mix is adequate to provide an effective service:

NO

- 8.3. The laboratory space and facilities are adequate:

YES

- 8.4. The laboratory participates in a national quality assurance scheme in coagulation:

YES

- 8.5. Has there been any persistent poor performance over the previous two years?

NO

If yes, list the problem assays

8.6. The following tests are performed in the haemostasis laboratory:

	YES	NO
All coagulation factors	√	
FVIII Inhibitor screening	√	
FVIII Inhibitor quantification	√	
VWF antigen	√	
VWF activity	√	
VWF multimers		X
Platelet aggregometry	√	
PFA 100 analysis	√	
Platelet granular constituents		X

8.7.If any of the above tests are not performed outline the alternative testing arrangements.

VWF multimers are sent to Edinburgh as are platelet nucleotides

8.8. List any diagnostic tests that are performed not listed above:

HIT /PF4

Thrombophilia tests

8.9. Coagulation factor assays are always available throughout the 24 hour period: (Evidence of this must be provided)

YES

8.10. A diagnostic genetic laboratory service is provided

YES

If yes, has the service been audited as part of the UKHCDO / Haemophilia Clinical Scientists audit scheme and is the audit report available for review?

Audit via UKHCDO genetics working party – report not available for review

If no, what arrangements are in place?

## COMMENTS

The haemostasis component of the laboratory is understaffed – there is only 1WTE BMS3 and 1WTE BMS2 as permanent staff. An additional 1WTE BMS1 is provided but is a rotating post and frequently away from the bench due to days in lieu or on call commitments.

On call services is provided by the general haematology BMS on call and clear competency documentation is available for all individuals on the rota.

Reports are not validated by a medical consultant prior to issue and there is no results or laboratory meeting to discuss abnormal results, further investigations etc on samples in process.

The current VWF RCo assay is an ELISA – this should be swapped to a platelet based RCo as soon as possible and currently work is being undertaken to address this.

Staffing in this section of the lab is a major issue. The very poor establishment provided little if any opportunity to develop assays and laboratory practice, either on a research basis or, more importantly for this centre currently, as a service enhancement. The assay repertoire is acceptable but very basic.

There should be more medical haemostasis involvement in laboratory issues and management develop the service provision above its most basic current level. A programme of service development is required to be drawn up.

As mentioned earlier lab staff appraisal is well overdue. CPD for staff is again very well supported by the Trust.

## 9. PAEDIATRIC CARE IN CENTRES LOOKING AFTER CHILDREN

**Standard** – The care of children with haemophilia and related disorders can be complex and should only be carried out by staff who are experienced and trained in the management of children. Facilities should be adequate for the care of children.

### 9.1. Staff qualifications

<u>Medical staff -</u>	YES	NO
Consultant Haematologist has paediatric training and expertise		n/a
Consultant Paediatric Haematologist	√	
Named Consultant Paediatrician supporting Consultant haematologist (in centres without a Consultant Paediatric Haematologist)	n/a	
Consultant Paediatric Surgeon with experience of implantable venous access devices	√	
<u>Nursing staff -</u>		
Unit nursing staff have appropriate qualification eg Registered Sick Children's Nurse(s) (RSCN) RN Child Branch (Project 2000) BA Nursing (Child)	√	

### COMMENTS

The service is essentially provided with great dedication by Sid Dempsey and Fionnula Diamond. Dr Dempsey provides all paediatric haematology services and shares his clinical duties with a paediatric oncologist. Medical trainees rotate through the service. CNS Diamond is supported by other paediatric nursing staff. The crossover seems to work efficiently and comments from the patient survey were highly complementary about excellent service and the work of Sid Dempsey and Fionnula Diamond.

## 9.2. Treatment facilities and services

	ADEQUATE	INADEQUATE
Child friendly waiting/play area and toys	√	
Child friendly treatment area	√	
Dedicated paediatric in-patient facilities	√	
Out of hours treatment facilities	√	
Paediatric resuscitation facilities	√	
Training in paediatric resuscitation	√	
Use of local anaesthetic creams and distraction techniques	√	
Effective outcome monitoring of patient on prophylaxis	No current planned physio assessments	
Sensitive arrangements for the transfer of adolescents to adult services	√	

### COMMENTS

No comments

### 9.3. \*General paediatric services

	ADEQUATE	INADEQUATE
Availability of trained / experienced physiotherapists	access	
Growth and development assessment programme	√	
Availability of play therapist	√	
Liaison with Health Visitors/School nurses	√	
Liaison with nurseries and schools	√	

*\* See also section 5 Availability of Comprehensive Care Services*

## 10. CLOSING MEETING BETWEEN AUDITORS AND CCC STAFF

10.1. Have all the issues raised in the previous audit been rectified?

YES

10.2. If there are outstanding issues, what are these and what have been the barriers to resolving them?

Although technically the outstanding issues from the 2003 audit have been addressed there remain problems. These primarily focus on the lack of a substantive haemophilia centre director being in post. At the end of the 2003 audit a new consultant had been appointed but the postholder left after being in post less than 12 months. Since then the centre at BCH has been without dedicated leadership.

10.3. Issues identified during this audit meeting and mutually agreed provisional plans to address these.

### ***Royal Belfast Hospital for Sick Children***

There are no notable issues on the RBHSC service. This is an excellent service provided by dedicated staff. The facilities are scattered and it would always be nicer for them to be co-located. That aside the main area that requires attention is the identification of or dedicated administrator / manager to support the service.

### ***Belfast City Hospital***

There are, however, a significant number of issues that focus on the BCH service.

### ***General comments***

Management and direction for the long term plans for the Centre have suffered due to the lack of permanent Centre Director, this has had an impact on all members of the multi-disciplinary team, who at the time of this audit were clearly showing the strain of the situation, and described morale as at an all time low. There has been no programme of development and the service has functioned to 'survive'. There has not really been a Director for more than 5 years and the difficulties that this has imposed on the acting Director, Frank Jones, are clearly showing.

Albeit that morale is very low, all the staff have clearly shown that they are committed, hard working with a patient centred vision, and it is a testament to their strength and dedication that the centre continues and that vast majority the patient comments in the patient survey were very complementary about the staff. However, some comments in the patient survey supported concerns that were noted by the auditors with regard the service *per se*.

Below are itemised specific issues that were discussed

### ***Medical issues***

We understand that a permanent appointment has been made and that Dr Gary Benson is due to start work in January 2008. We hope this is the start of a bright future for the centre. There is a lot of work for Gary to undertake and he requires much support from his colleagues, both medical and managerial throughout the Trust.

Orla McNulty's post needs funding to be clarified and secured, with appropriate recognition of the work undertaken by the postholder.

### ***Nursing issues***

There are 2 WTE nurse in the Adult Centre, one Haemophilia Nurse Specialist and one staff nurse. It was noted that under the Agenda for Change Banding system both nurses (previously G Grade and F grade) have been banded on a Grade 6. The Haemophilia Nurse Specialist is accountable and responsible for the staff nurse, including Annual Staff Development Reviews, despite being on the same grade. This is out of line with practice in the rest of the UK where Haemophilia Nurse Specialists are usually at least a Band 7, and given the size of this Centre and its role in providing care and advice for the whole region this post should be reassessed. Line Management for the Haemophilia Nurse Specialist is provided by the Haematology Nurse Manager, however she has not had a development review for >3 years and has no personal or professional development plan in place, and as a result neither does the staff nurse.

A "link nurse" system has been implemented using at least one of the nurses from the Haematology Unit to cover Sickness and Absence – this link needs to be made more robust with a recognized period of training and assessment, within written guidelines and protocols, and should aim to recruit more nurses able to cover the haemophilia service at short notice in the event of sickness and to enable both nurses to fulfil their own learning needs.

Although the nurses describe the present establishment as "adequate", it is noted that there is not a designated social worker or psychologist at this Centre and this tends to increase demands on the nursing team in terms of practical and psychological support for patients and their families

The lack of direction for the Centre as a whole is reflected in the lack of development of the nursing roles and in other roles within the multi-disciplinary team. The model of care in the Centre has been mainly "Medical" and with support, from the Centre Director and Nurse Managers the Haemophilia Nurse Specialist has the expertise and training to expand her role further. The Haemophilia Nurse Specialist has taken part in an initiative of the Scotland and Northern Ireland Haemophilia Nurses Group, which has produced a "Guideline for Teaching Home Treatment" and this is very comprehensive and user friendly, however no other guidelines were in use at the time of this audit. The Nurse Specialist has taken advice from the Genetics Scientist and has begun to draw "Family Pedigrees" for all the registered patients – these were found in all the records examined and were of a very high standard.

Any community visits tend to happen on an ad-hoc basis. We would suggest that this is reviewed as in a Centre of this size with such a wide catchment area, practice elsewhere would suggest the need to be higher. Home visits can be key in providing Comprehensive Care to both Adults and Children.

### ***Recommendations***

- Nursing establishment needs to be re-assessed, including the further development of the “link nurses” from the Haematology Department
- A training and assessment package for link nurses needs to be established, including relevant evidence based guidelines and protocols
- The Haemophilia Nurse Specialist’s job description should be reviewed and should be recommended as an AFC Band 7 in line with the rest of the UK
- The nurses should be supported to assess the need for Community visits for People with Haemophilia, particularly those who are not proficient in self-treatment, or who are recovering from bleeds or surgery
- The nurses would benefit from visiting other CCC’s where the nurses “extended role” is well established.
- A formal programme for “transitional care” between the Adults and Children’s Centres needs to include the Nurse Specialists from both sites

It is without doubt that the Haemophilia Nurses at this Centre have continued to give a very high standard of care throughout very difficult times without direction or leadership from either their Senior Medical or Nursing Staff.

Time has been taken to develop new skills, such as the drawing of family pedigrees, which contain such vital information for the present and future generations affected by haemophilia.

The nursing team need to work with their newly appointed Centre director to make the Centre truly fit for purpose in line with National Guidelines

### ***Administrative and managerial issues***

There is very little data that seem to be available within the centre on standard metrics of activity. There is no database and we could not be given any idea of product usage or sight of the annual returns. No-one was able to give an indicative budget. Product issued to patients could be traced via blood bank but actual usage could not be traced.

We understand a case for a data manager was turned down. These administrative areas require very close attention and work.

There appears to be a dislocation between the clinical service and the Trust management and commissioners – there is no clearly identified manager or link through to the commissioning process. Activity in this area is reactive and deals with problems rather than service investment and development in its broadest sense.

In short, financial control and management structures are poor and require urgent attention.

### ***Recommendations***

- A data manager is appointed – this is vital.
- A database is developed – HCIS would be ideal.
- Appropriate system for data collection, recording and management is put in place.
- A senior Trust manager is identified with clear responsibility for the haemophilia service and regular meetings are set up to address service issues, financial planning and development.
- A dialogue is similarly started with the commissioners to proactively consider haemophilia issues.
- Protocols, nursing, medical and others need to be reviewed and updated.

### ***Laboratory issues***

There laboratory is understaffed, somewhat separate from the clinical provision and has no R+D element.

### ***Recommendations***

- There should be more medical haemostasis involvement in laboratory issues and management.
- Staffing within the laboratory should be reviewed as it is significantly under-resourced for the work it is required to carry out as a CCC haemostasis laboratory.
- A programme of service development is required to be drawn up to develop the service provision above its most basic current level.

### ***General recommendations***

A development plan is put in place to

- Engage in teaching
- Address R+D needs
- Potential participation in clinical trials
- Undertake regular appraisal and personal development plans along with clinical governance issues
- Development of a business plan for physiotherapy support
- Potential home delivery programme

Most of these comments were not news to the staff at BCH. We would recommend that the BCH element of the service is re-audited within 12 months as this may be helpful for the new Director in managing and maintaining change within the Centre.



## **11. SUMMARY OF AUDIT FINDINGS AND RECOMMENDATIONS**

Haemophilia care in Northern Ireland is delivered through two centres. The Royal Belfast Hospital for Sick Children provides a very high quality, well managed and ordered service for children with bleeding disorders. Although there continues to be physical fragmentation of the service the service provided to children is excellent. A formal programme for “transitional care” between the Adults and Children’s Centres needs to be developed.

The adult service at the Belfast City Hospital has been effectively leaderless for a number of years. The centre has as a consequence lost direction and purpose. The clinical service survives in tact, but strained, whilst the associated functions of a haemophilia centre (teaching, training, research and development) have been all effectively lost. Data and management systems are poor, laboratory direction is lacking, nursing structures and functions require attention and as an overall consequence morale is very low.

These areas require urgent attention and will provide a huge challenge for the new Centre Director.

A list of recommendations detailing the above concerns has been provided.

We would recommend reaudit of BCH in 12 months. We hope this audit will support the new Director in their work within the Centre.

## APPENDIX 1

**Schedule for UKHCDO Audit 2006**

CCC	Director	CNS
Belfast		
Birmingham (UHB Adults)		
Birmingham (BCH Children)		
Cambridge		
Cardiff		
Edinburgh		
Glasgow		
GOS		
Kent		
Leeds		
Leicester		
Liverpool		
Manchester (MRI Adults)		
Manchester (MCH Children)		
Newcastle		
North / South Hants		
Nottingham		
Oxford		
Royal Free		
Royal London		
St Thomas'		
Sheffield		