Mission Statement

“To advise and recommend on the optimum provision of treatment and care for persons with haemophilia and related bleeding disorders.”

Vision

“To set the international benchmark for the provision of effective advice and inclusive involvement in optimising the management of haemophilia.”

The establishment of a National Haemophilia Council (NHC) was approved by Government following the recommendations of the Lindsay Tribunal in 2001. The Regulations placing the Council on a statutory footing were signed by the Minister for Health and Children on the 22nd July, 2004 and amended to include the Health Service Executive in the Health (Miscellaneous Provisions) Act 2007.

Minutes of meetings and details of National Haemophilia Council activities are available at: www.nationalhaemophiliacouncil.ie
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PREAMBLE

GENERAL INFORMATION

National Haemophilia Council,  
HSE Offices,  
Mill Lane,  
Palmerstown,  
Dublin 20.

Auditor,  
Comptroller and Auditor General,  
Treasury Block,  
Lower Yard,  
Dublin Castle,  
Dublin 2.

BACKGROUND

The establishment of the National Haemophilia Council was approved by Government following the recommendations of the Lindsay Tribunal in 2001. The Regulations placing the Council on a statutory footing were signed by the Minister for Health and Children on the 22nd July, 2004 and amended to include the Health Service Executive in the Health (Miscellaneous Provisions) Act 2007.

The principal function of the Council is to advise the Minister, health service agencies and other persons on any matter relating to haemophilia, on its own initiative or at the request of the Minister or a health agency.

It may provide advice in relation to:

(i) the care and treatment of persons with haemophilia;
(ii) Protocols for the treatment of haemophilia;
(iii) Health services (including counselling services) for persons with haemophilia;
(iv) Education and training of staff who provide services for persons with haemophilia;
(v) Education and health promotion for persons with haemophilia and their families;
(vi) The changing needs of persons with Haemophilia in order to help ensure that health services respond effectively to such changing needs;
(vii) Developments arising from research into haemophilia;
(viii) Appropriate support services for the families of persons with haemophilia.
HAEMOPHILIA SERVICES IN IRELAND

1.0 Structure
There are four levels of haemophilia service provided in Ireland:

- Comprehensive Care Centre (Level 1)
- Haemophilia treatment centre – hospitals which treat patients with haemophilia (Level 2)
- Hospitals with a Haematologist that provides services to a large geographical area (Level 3)
- All other hospitals with Emergency Departments

Level 1
The National Centre for Hereditary Coagulation Disorders (NCHCD) based at St. James’s Hospital, Dublin, the Paediatric Haemophilia Service based at Our Lady’s Children’s Hospital, Crumlin (OLCHC) and Cork University Hospital (CUH) all function as comprehensive care centres. Adults are treated at St. James’s Hospital and Cork University Hospital, while Children are treated at Our Lady’s Children’s Hospital and at the Haemophilia Centre at Cork University Hospital. All the Comprehensive Care Centres (CCC) provide access to a 24 hour on-call service (by phone and on site) for haemophilia and other related bleeding disorders.
Level 1 centres are audited on a triennial basis by an international team of auditors.

Level 2
University Hospital Galway is a haemophilia treatment centre for adults and children. The spectrum of services provided in the centre is dependent on the expertise and resources in place. Haemophilia nurses should be available in the centre. Patients should be treated on a shared care basis with the appropriate Comprehensive Care Centre where the patient is registered.
Level 2 centres are audited on a triennial basis by a national audit team from the various Comprehensive Care Centres.

Level 3
These hospitals need to have available a single treatment dose, for the management of inherited bleeding disorders. They need to be aware of the requirement for urgency of immediate contact with haematology services in Comprehensive Care Centres or Haemophilia Treatment Centre (Level 1 or 2) St. James’s Hospital Dublin, Cork University Hospital and Our Lady’s Children’s Hospital Crumlin with expertise in the management of patients with haemophilia and related bleeding disorders.

The local haematology service will manage the patient in conjunction with the associated Level 1 hospital as required.
CHAIRPERSONS STATEMENT

To say that this could be described as a “trying year” would be a gross understatement. It developed at two levels, one was personal and the other concerned the organisational difficulties in relation to the day to day operations of the Council. Unfortunately due to a number of health issues which resulted in me undergoing surgery on a number of occasions, I was unable to carry out some of my duties as Chairperson for some of 2013.

From an organisational point of view Mr. Gareth Presch the Chief Officer originally appointed by the HSE, when the Council was set up in 2006 went on a three year career break in early June 2013. Mr. Presch’s departure was also at the same time that the HSE itself was going through an internal reorganisation. This meant that with Mr. Presch’s departure the NHC lost its office base in Dr. Steeven’s Hospital.

At the June 2013 Council meeting I agreed to take on the duties of Chief Officer and Secretary of the Council, in addition to being its Chairperson on an interim basis. This interim arrangement was put in place until some other arrangements could be made to service the needs of the Council. The Chairperson of the Irish Haemophilia Society (IHS), through its Chief Executive Officer Mr. Brian O’Mahony offered to allow the Council to use their offices at Cathedral Court, New Street Dublin 8 as an immediate temporary base.

The Irish Haemophilia Society’s Executive Committee approved this temporary arrangement. I as Chairperson was trying to ensure that the Council would maintain its independence as a separate body designated by a statutory Instrument. After much discussion it was agreed at our October 2013 meeting to accept the offer of the IHS to base the offices at the same address as the IHS premises in Cathedral Court as an interim measure. The Council made many efforts to obtain suitable administrative support.
During 2013 Council was also concerned that it had been three years since an international audit of the 3 Comprehensive Care Centre’s in Ireland had taken place. The Council requested that this be organised again for 2014. It was agreed that Dr. David Perry and Mr. David Page would be invited and that a new nurse representative, Ms. Chris Harrington, from the Royal Free London Hospital all be invited to undertake the audit. It was also agreed that Dr. Marian Hill (Clinical Genetic Scientist) from Nottingham University Hospital would also be invited to be part of the audit team for 2014.

The absence of adequate dental services in Cork University Hospital was identified as a deficiency in the services available to patients attending the Hospital in the original audits of 2008 and 2011. I undertook as Chairperson of the NHC to try and resolve this issue and towards the end of 2013 progress was made locally in relation to provision of more adequate dental services for people with haemophilia in 2014 and future years.

The other significant development in 2013 was that the membership of the Council changed. Ms. Mary Jackson moved departments within the Department of Health. She was replaced by Mr. Michael Conroy, Principal Officer, Blood, Cancer & Organs Policy. Ms Eilis Hardiman also resigned in 2013. Ms. Ann Grogan’s term of office was due to be completed by the end of December 2013. The persons reappointed by the Minister for Health were Dr. William Murphy, Dr. Beatrice Nolan, Dr. Barry White, Dr. Ruth Gilmore and Dr. Susan O’Shea, together with the representatives from the Irish Haemophilia Society, Mr. Brian O’Mahony, and Ms. Debbie Green.

I was delighted to be appointed as Chairperson until July 2014.

Dr. Barry Harrington,
Chairperson of the National Haemophilia Council.
CHIEF OFFICER’S STATEMENT

As noted in the Chairperson’s statement, The Chief Officer of the NHC went on a three year career break in June 2013. This resulted in the Chairperson taking on the additional role of interim Chief Officer. One of the first tasks was the production of a set of financial accounts for the 2012 financial year by the Council which were subsequently approved and audited by the Controller and Auditor General (C&AG).

The vacancy left by the departure of the Chief Officer also meant a delay in the production of the Annual Report for the Council for 2012. It was agreed that the 2012 Annual Report would be produced in 2014 along with the 2013 Annual Report.

Dr. Barry Harrington,
Interim Chief Officer of the National Haemophilia Council
COUNCIL MEMBERSHIP

the Minister for Health of up to eleven members, two of whom are appointed on the nomination of the Irish Haemophilia Society. The Irish Haemophilia Society’s two nominees are Mr. Brian O’Mahony, (Chief Executive Officer of the Irish Haemophilia Society) and Ms. Debbie Greene (Administrator of the Irish Haemophilia Society). The Council members during 2013 are listed below and their attendances at Council meetings are listed in the Appendices.

Dr. Barry Harrington (Chairman)

Dr. Barry Harrington was born in Dublin, qualified as a Dentist in 1964 at the Royal College of Surgeons in Ireland. Dr. Harrington worked in private dental practice in Northern Ireland and Dublin (1964-1985). In September 1985 he was appointed a Consultant. In 1986 he was appointed as Consultant Dental Surgeon to the National Centre Hereditary Coagulative Disorders attached to St. James’s Hospital. Dr. Harrington became a member of the Executive Committee of the Irish Haemophilia Society in 1988 to 2002. Dr. Harrington was a member of the Irish Dental Association (1964- to-date) and was President from 1998 - 1999. After his official retirement in 2004, he continued as a part-time teacher at the DDUH until 2010. Dr. Harrington was appointed as Chairman of the National Haemophilia Council by Dr. James Reilly, Minister for Health in July 2011.

Dr. Barry White

Dr. Barry White is a Consultant Haematologist and Director of the National Centre for Hereditary Coagulation Disorders (NCHCD) at St James’s Hospital. He was appointed to these positions in 2001. He undertook his training as a coagulation specialist at St James’s Hospital and the Royal Free Hospital London and has undertaken extensive research in the area of coagulation disorders. Dr. White is also National Director, Quality and Clinical Care, Health Service Executive (HSE).

Mr. Brian O’Mahony

Mr. Brian O’Mahony is Chief Executive of the Irish Haemophilia Society. He represents the Society as Vice Chair of the Haemophilia Product Selection and Monitoring Advisory Board established by the Minister in 2002. He previously served as Chair of the Irish Haemophilia Society for 17 years and as President of the World Federation of Hemophilia (WFH) for 10 years. He continues to work as a volunteer with WFH. Among his activities are writing, advocating, facilitating training on strategic planning, national procurement systems, and lobbying. He is a Fellow of the Institute of Biomedical Sciences and of the Academy of Medical Laboratory Sciences. He also has professional qualifications in occupational health and safety and in management. Brian O’Mahony has severe Haemophilia B.
Dr. Beatrice Nolan

Dr. Beatrice Nolan was appointed as a Consultant Haematologist to St James’s Hospital in 2001 with a commitment to Our Ladies’ Children’s Hospital Crumlin (OLCHC) in 2008. Dr. Nolan was appointed full-time Lead Consultant Haematologist in relation to paediatric haemophilia and allied bleeding disorders at the Children’s Hospital in Crumlin with a national remit.

Dr. Susan O’Shea

Dr. Susan O’Shea was appointed lead Haemophilia Consultant in Cork University Hospital in 2009. Dr. O’Shea is Director of the Coagulation Centre in Cork University Hospital. Dr. O’Shea has underwent speciality training in disorders of Haemostasis and Thrombosis in Duke University Medical Centre in the United States, before she returned to Ireland. Dr. O’Shea has been involved in clinical research in many areas of coagulation.

Dr. William Murphy

Dr. William Murphy was appointed Medical and Scientific Director of the Irish Blood Transfusion Service in 1996. He received his training in Edinburgh and at McMaster University in Ontario in Canada. He was Senior Lecturer in Medicine at the University of Edinburgh and Consultant Haematologist to the Scottish National Blood Transfusion Service 1991 – 1996. He has made numerous publications to the medical literature and has an active research project related to clinical grade red cells.

Ms. Debbie Greene

Ms. Debbie Greene joined the Irish Haemophilia Society in 2003. Ms. Greene is the Administrator of the Society having taken up the role in May 2009. Ms. Greene oversees the day to day running of the office including the organization of Information Days, Regional Meetings and Conferences, Staffing, Event Management, the Website and is the Editor of all Irish Haemophilia Society Publications. Ms. Greene is a member of the Irish Haemostasis Research Foundation and is also involved with the World Federation of Hemophilia Twinning Program. Ms. Greene represents the Society at various Comprehensive Care Centre Team Meetings.

Dr. Ruth Gilmore

Dr. Ruth Gilmore qualified in 1998 from National University of Ireland, Galway. Subsequently, she did her postgraduate Haematology training in Ireland and did a Masters in Medical Informatics as well as an MD on Thrombin Generation in Trinity College Dublin whilst working at the National Centre Hereditary Coagulation Disorders in St James’s Hospital. Dr. Gilmore was appointed a Consultant in Haematology to Galway University Hospital in 2011. Her research interests include rare bleeding disorders, thrombin generation and the use of computers in Health Care. Her areas of special responsibility are Hemostasis and Thrombosis, Obstetric Haematology and Paediatric Haematology. Dr. Gilmore was appointed to the Council in July 2013.
Ms. Anne Grogan

Ms. Anne Grogan qualified as an RGN in St James’s Hospital in 1996 and completed a degree in nursing in Trinity College in 2000. Her career spans over 15 years during which she has worked in many fields to include haematology and oncology, both in Wales and Saudi Arabia. Ms. Grogan also has extensive experience of working with clients with liver disease, in particular those who have State Acquired Hepatitis C. Ms. Grogan has worked as a Hepatitis Treatment / Liver Transplant Liaison Co-ordinator at St James’s Hospital. In 2007 she completed an MSc thesis in the area of Hepatitis C. Since October 2007 she has worked as the Nurse Manager in the NCHCD.

Ms. Mary Jackson

Ms. Mary Jackson is Principal Officer in the Department of Health and Children, formerly in the Blood, Organs and Cancer Unit.

Mr. Michael Conroy

Mr. Michael Conroy is a Principal Officer in the Department of Health and Children, Blood, Organs and Cancer Unit and replaces Ms. Mary Jackson.
REVIEW OF 2013

ANNUAL REPORT

This is the tenth Annual Report of the National Haemophilia Council (NHC) to be submitted to the Minister for Health under the provisions of Statutory Instrument (S.I.) No. 451 of 2004. It covers the period from 1st January 2013 to 31st December 2013.

MEETINGS OF THE NATIONAL HAEMOPHILIA COUNCIL – 2013

In 2013 the National Haemophilia Council met on five occasions:

• 28th January
• 22nd April
• 10th June
• 10th October
• 28th November

The attendance at the meetings is listed in Appendix A.

SECRETARIAT

The administrative and secretarial support to the NHC was provided by the Chief Officer and the Secretary and was located at the offices of the Health Service Executive, Room 101, Dr Steevens’ Hospital, Dublin 8 up to June 2013. In July 2013 the Chairperson of the Council Dr. Barry Harrington agreed as an interim arrangement to take on the duties of Chief Officer and Secretary on an interim basis until a more permanent arrangement could be organised.

STRATEGIC PLAN 2011-2013

The Council noted that the previous Strategic plan for 2011 - 2013 would come to a conclusion by year end. The Chairperson agreed to re-draft a new Strategic Plan for the years 2014 – 2017 as a consultative document. The Council agreed to prioritise the development of the new Strategic Plan in the year 2014.
NHC MEETINGS WITH HAEMOPHILIA COMPREHENSIVE CARE CENTRES

ST JAMES’S HOSPITAL
NATIONAL CENTRE FOR HEREDITARY COAGULATION DISORDERS

The Council held an annual meeting with the haemophilia team in St James’s Hospital in 2013. The key areas of discussion were as follows:

1. Patient record management - “Clintech”
2. Progress on the development of the new in-patient unit
3. Discussion on the report of the audits carried out in 2012
4. Haemophilia Product Selection and Monitoring Advisory Body

OUR LADY’S CHILDREN’S HOSPITAL CRUMLIN

The Council held an annual meeting with the haemophilia team and Mr. Lorcan Birthisle, Chief Executive Officer of Our Lady’s Children Hospital, Crumlin. The key areas of discussion with the CEO were as follows:

1. Update on the Haemophilia Services at Our Lady’s Children’s Hospital Crumlin
2. The non-availability of a Community Haemophilia Nurse
3. Parent questionnaires
4. The haematology laboratory facilities related to Von Willebrand’s assay availability as an in-house necessary facility.

CORK UNIVERSITY HOSPITAL (CUH)

The Council held several meetings with the Haemophilia team in CUH. The key areas of discussion with CUH were as follows:

1. New Haemophilia Centre and its operation.
2. The availability of in-house laboratory services
3. Patient record management system - “Clintech”
4. The dental service available, especially to adult patients.

All the items that were discussed were highlighted in the international audits undertaken in 2012. It is hoped to have any issues identified, resolved before the next international audit scheduled for March 2014.
RESEARCH IN HAEMOPHILIA

Below is a list of research papers on haemophilia and related bleeding disorders published in peer review journals from the National Centre for Hereditary Coagulation Disorders. Included also is a list of publications from the Irish Haemophilia Society (IHS).

Publications from Haemophilia Comprehensive Care Centres

St. James’s Hospital, Dublin

- Impact of a new vaccine clinic on hepatitis B vaccine completion and immunological response rates in a HIV infected cohort C. Rock, E deBarra, S. Kelly, C. Dowling, C. McNally, Colm Bergin


- Tilley DO, Albert MA, Smolenski A, Cox D, O’Donnell JS, Douglas CW, Watson SP, Kerrigan SW. Glycoprotein Ib and FcRIIα play key roles in platelet activation by the colonizing bacterium, Streptococcus oralis.


Publications from Cork University Hospital


• Dr. Muhammad Khan poster presentations
  Single centre Audit of the use of Fibrinogen concentrates over two years at Mercy University Hospital Cork, poster presented at HAI 2013.

Clinical trials at Our Lady’s Children’s Hospital, Crumlin, 2013

• Study of Recombinant Coagulation Factor VIII Fc Fusion Protein, BIIB031, in Pediatric PTP Subjects with Haemophilia A
  Sponsor: Biogen Idec
  ClinicalTrials.gov identifier: NCT01458106
  EudraCT number: 2011-003073-28

• Long- Term Safety and Efficacy of Recombinant Human Coagulation Factor VIII Fusion Protein (r FVIII Fc) in the Prevention and Treatment of Bleeding Episodes in Previously Treated Subjects with Hemophilia A
  Sponsor: Biogen Idec
  ClinicalTrials.gov identifier: NCT 01454739
  EudraCT number: 2011-003072-37

• Study of Recombinant Coagulation Factor IX Fc Fusion Protein, BIIB031, in Pediatric PTP Subjects with Haemophilia B
  Sponsor: Biogen Idec
  ClinicalTrials.gov identifier: NCT 01440946
  EudraCT number: 2011-003076-36

• Long- Term Safety and Efficacy of Recombinant Human Coagulation Factor IX Fusion Protein (r FIX Fc) in the Prevention and Treatment of Bleeding Episodes in Previously Treated Subjects with Hemophilia B (B-YOND)
  Sponsor: Biogen Idec
  ClinicalTrials.gov identifier: NCT 01425723
  EudraCT number: 2011-003075-11
• A multi-centre phase III uncontrolled open-label trial to evaluate safety and efficacy of BAY81-8973 in children with severe haemophilia A under prophylaxis therapy. Sponsor: Bayer
Clinical Trials.gov identifier: NCT01311648 EudraCT number: 2010-021781-29

• PROPACT: Retrospective Prophylaxis Patient Case Collection
Sponsor: Novo Nordisk
Clinical Trials.gov identifier: NCT00882778
Observational Study on Safety of Room Temperature Stable NovoSeven in Patients with Haemophilia A or B
Sponsor: Novo Nordisk
Clinical Trials.gov identifier: NCT01220141
EudraCT number: N/A

• Intensity of factor VIII treatment and inhibitor development in children with severe hemophilia A: the RODIN study.
Blood 2013 May 16; (20): 4046-55

**Publications from the Irish Haemophilia Society – 2013**

• Spring Magazine
• Summer Magazine
• Autumn Magazine
• Winter Magazine
• Annual Report 2012
• Positive News (two editions)
• World Federation of Hemophilia Supplement
• Haemophilia Heroes
• Sibling Superstars
• Mild Haemophilia
• Portacaths
• Wallet sized contact cards
• 8 Posters for WFH Congress
• Ageing and haemophilia


• Treatment for life for severe haemophilia A – A cost utility model for prophylaxis vs. on-demand treatment: A. FARRUGIA, B O MAHONY, D NOONE et al Haemophilia 2013 1-11.

Monograph on Haemophilia care in Europe, 2012: BRIAN O MAHONY Published by the European Haemophilia Consortium, April 2013
HAEMOPHILIA PRODUCT SELECTION AND MONITORING ADVISORY BOARD (HPSMAB)

During 2013 the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) met six times to advise on the selection of factor concentrates. The board carried out a negotiated procurement process for recombinant FIX and extended the current tender contract for recombinant FVIII. The Board also monitored international developments in relation to the safety, supply and availability factor concentrates including new developments in factor concentrates. To this end, several of the board members attended or lectured at an international conference on longer lasting factor technologies, organised by the Irish Haemophilia Society, which took place in Dublin in November 2013.

The members of the HPSMAB are:

- Dr. Barry White (Chairperson)
- Mr. Brian O’Mahony (Vice-Chairperson)
- Dr. William Murphy (Irish Blood Transfusion Service)
- Dr. Beatrice Nolan (Our Lady’s Children’s Hospital, Crumlin)
- Ms. Mary Jackson / followed by Mr Michael Conroy in July 2013 (Department of Health and Children)
- Dr. Susan O’Shea (Consultant Haematologist, Cork University Hospital)
- Mr. Declan Noone (Irish Haemophilia Society)
- Mr. Jeff Connell (National Virus Reference Laboratory, University College Dublin)
- Mr. Patrick Costello (Irish Medicines Board)
- Ms. Evelyn Singleton (NCHCD)

Administrative support was provided by Mr. Gareth Presch, Chief Officer, National Haemophilia Council up until his departure in June 2013. Subsequent to that the services were provided to the Council by the Chairperson Dr. Barry Harrington.

REQUESTS BY THE MINISTER FOR HEALTH AND CHILDREN FOR ADVICE

No specific requests were made by the Minister for advice (as per Regulation 5(2)) from the Council during 2013.
FINANCE

The costs of meetings and other administrative expenditure was funded by the Health Service Executive in 2013. The funding of the National Haemophilia Council by the Health Service Executive was placed on a statutory basis in the Health (Miscellaneous Provisions) Act 2007. The Council’s expenditure is audited by the Office of the Comptroller and Auditor General.

Below is a breakdown of the expenditure in 2013.

<table>
<thead>
<tr>
<th>Expenditure</th>
<th>2013</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salaries &amp; Expenses</td>
<td>€39,855</td>
<td>€60,086</td>
</tr>
<tr>
<td>Annual Report / Publications</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>Stationery &amp; Phone</td>
<td>-------</td>
<td>€4,500</td>
</tr>
<tr>
<td>Financial Audit</td>
<td>€1,000</td>
<td>€940</td>
</tr>
<tr>
<td>Professional Services</td>
<td>€600</td>
<td></td>
</tr>
<tr>
<td><strong>Total Expenditure</strong></td>
<td><strong>€41,455</strong></td>
<td><strong>€58,442</strong></td>
</tr>
</tbody>
</table>

Signed: ..............................................................................................
Dr. Barry Harrington
Chairperson

Date: .................................................................................................

ETHICS IN PUBLIC OFFICE ACT, 1995 AND 2001

Details on the implications of the Act were circulated to Council members and a statement of interests form was signed by all members in 2012/2013.
WEBSITE

The website is a key tool for the Council to promote its work and inform persons with Haemophilia about the services currently being provided in Ireland. The website has not been maintained or updated in 2013 due to the absence of full time administrative support, however it is hoped that this will be rectified in 2014. The current NHC website address will remain unchanged at: www.nationalhaemophiliacouncil.ie

The National Haemophilia Council also launched a facebook page in 2011. www.facebook.com/nationalhaemophiliacouncil

NOTE:

1. The S.I. has been amended under the Health (Miscellaneous) Provisions act, 2007. This Act can be viewed on the NHC website.

2. Statement of Adoption and Compliance with the Code of Practice for the Governance of State Bodies – The National Haemophilia Council is compliant.
APPENDIX A

NATIONAL HAEMOPHILIA COUNCIL
ATTENDANCE AT MEETINGS

In 2013 the Council met five times:
• 28th January, 2013
• 22nd April, 2013
• 10th June, 2013
• 10th October, 2013
• 28th November, 2013.

<table>
<thead>
<tr>
<th>Names</th>
<th>Meetings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Barry Harrington (Chair) – Appointed July 2011</td>
<td>5</td>
</tr>
<tr>
<td>Mr. Brian O’Mahony, Irish Haemophilia Society - Reappointed July 2013</td>
<td>5</td>
</tr>
<tr>
<td>Ms. Debbie Greene, Irish Haemophilia Society - Reappointed July 2013</td>
<td>5</td>
</tr>
<tr>
<td>Dr. Barry White, Director, NCHCD &amp; National Director, Clinical and</td>
<td></td>
</tr>
<tr>
<td>Quality Care, HSE - Accepted the HSE nominee in early 2011.</td>
<td>4</td>
</tr>
<tr>
<td>Reappointed June 2013</td>
<td></td>
</tr>
<tr>
<td>Dr. Beatrice Nolan, Consultant Haematologist, Our Lady’s Children’s</td>
<td>5</td>
</tr>
<tr>
<td>Hospital, Crumlin - Reappointed July 2013</td>
<td></td>
</tr>
<tr>
<td>Dr. Susan O’Shea, Consultant Haematologist, Cork University Hospital</td>
<td>3</td>
</tr>
<tr>
<td>Reappointed July 2013</td>
<td></td>
</tr>
<tr>
<td>Dr. William Murphy, National Medical Director, Irish Blood Transfusion</td>
<td>3</td>
</tr>
<tr>
<td>Service – Appointed June 2013</td>
<td></td>
</tr>
<tr>
<td>Ms. Anne Grogan, Clinical Nurse Manager, St James’s Hospital</td>
<td>5</td>
</tr>
<tr>
<td>Ms. Mary Jackson, Blood Policy Division, Department of Health and</td>
<td>3</td>
</tr>
<tr>
<td>Children – Resigned in July 2013</td>
<td></td>
</tr>
<tr>
<td>Mr. Michael Conroy, Principle Officer, Department of Health, Blood</td>
<td>2</td>
</tr>
<tr>
<td>Organ &amp; Cancer Policy Unit - Appointed August 2013</td>
<td></td>
</tr>
<tr>
<td>Mr Gareth Presch, (HSE) Chief Officer to the National Haemophilia</td>
<td></td>
</tr>
<tr>
<td>Council: Attended 3 meetings until his departure on career break in</td>
<td></td>
</tr>
<tr>
<td>June 2013.</td>
<td></td>
</tr>
</tbody>
</table>
Glossary
(In alphabetical order)

Clintech: Electronic Patient Record System

DOHC: Department of Health and Children

HPSMAB: Haemophilia Product Selection and Monitoring Advisory Board
The Haemophilia Product Selection and Monitoring Advisory Board is a body set up to advice and make recommendations to the Minister for Health and Children on the selection of products for the treatment of Haemophilia and von Willebrand’s Disease and related bleeding disorders. The HPSMAB formally advises the Minister for Health & Children and recommends the products used by conducting National Procurement Tender processes.

HSE: Health Service Executive

IHS: Irish Haemophilia Society

NHC: National Haemophilia Council

NCHCD: National Centre for Hereditary Coagulation Disorders
The NCHCD offers a service to patients with a wide range of bleeding and clotting disorders on an in-patient and outpatient basis, from investigation and diagnosis, to long-term management of severe coagulation disorders. The centre provides comprehensive care with a multidisciplinary approach to include; nursing, physiotherapy, social work, counselling and dentistry.

CUH: Cork University Hospital

NCHDs: Non Consultant Hospital Doctors

OLCHC: Our Lady’s Children’s Hospital, Crumlin