



**NATIONAL HAEMOPHILIA COUNCIL
ANNUAL REPORT 2009**



National
Haemophilia
Council



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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.



Introduction

Overview of the National Haemophilia Council (NHC)

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 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

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

Four levels of service will be provided

- Comprehensive care centre (level 1)
- Haemophilia treatment centre – hospitals which treat patients with haemophilia (level 2)
- Hospitals with a haematologist who provides cover to a large geographical area (level 3)
- All other hospitals with Emergency Departments (level 4)

Level 1

The National Centre for Hereditary Coagulation Disorders (NCHCD) based at St James's Hospital and the Paediatric Haematology Service based at Our Lady's Children's Hospital, Crumlin will function as comprehensive care centres for adults and children respectively. Both the NCHCD and Our Lady's Children's Hospital, Crumlin will each provide a 24 hour on call service (by phone and on site) for haemophilia and related disorders. The NCHCD will also provide a 24 hour laboratory service for emergency assays. The adult and paediatric services at Cork University Hospital aspire to achieve comprehensive care status and this should be the long term objective.

Level 1 centres will be audited on a biennial basis.

Level 2

University College Hospital Galway and Limerick Regional Hospital may function as haemophilia treatment centres for adults and children. The spectrum of services provided in these centres will be dependent on the expertise and resources in place. Haemophilia nurses should be available in these centres. Patients should be treated on a shared care basis with St James's Hospital or Our Lady's Children's Hospital, Crumlin. These patients will have direct access to services at the NCHCD or Our Lady's Children's Hospital, Crumlin.

Level 2 centres will be audited on a triennial basis.

Level 3

Hospitals at Tullamore, Letterkenny, Sligo, the Waterford Regional Hospital and Our Lady of Lourdes Hospital, Drogheda will provide haemophilia care to patients attending in an emergency situation. These patients will be shared with St James's Hospital and Our Lady's Children's Hospital, Crumlin.

Level 3 centres will be audited periodically.

Level 4

All other hospitals with emergency departments will represent sites where patients may attend in an emergency situation. These hospitals need to have a single treatment dose for the management of inherited bleeding disorders. They need to be aware of the requirement for immediate contact with haematology services with expertise in the management of haemophilia.



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2.0 Accessing services

All patients with haemophilia and related disorders will be registered on the Clintech (National Haemophilia Electronic Patient Record) for the purpose of data management and home treatment.

2.1 Non-acute care

All patients with severe haemophilia will have access to a review clinic at a level 1 centre on a six monthly basis and those with mild or moderate haemophilia on a yearly basis.

All patients will have access to the following services at the National Centre for Hereditary Coagulation Disorders at St James's Hospital and Our Lady's Children's Hospital, Crumlin. Patients can self attend or can be referred by haematology doctors or haemophilia nurse specialists.

1. Consultant Haematologist with expertise in haemophilia care
2. Haemophilia Nurse
3. Social Worker with special interest in haemophilia
4. Psychologist with special interest in haemophilia
5. Genetic counselling and testing service for haemophilia
6. Orthopaedic Surgeon with special interest in haemophilia
7. Physiotherapist with special interest in haemophilia
8. Dentist with special interest in haemophilia
9. HIV Specialist with special interest in haemophilia
10. Hepatologist with special interest in management of hepatitis C and hepatitis B in patients with haemophilia
11. Data management (NCHCD)

2.2 Acute care

2.2.1 A Consultant with expertise in haemophilia will be on call twenty-four hours a day at the NCHCD. In addition, a Consultant Paediatric Haematologist will be on call 24 hours a day at Our Lady's Children's Hospital, Crumlin.

2.2.2 Haemophilia nurses are present on site at Cork University Hospital, University College Hospital Galway, Our Lady's Children's Hospital, Crumlin and the NCHCD. The Haemophilia Nurse Specialist may manage the patient under the direction of a Consultant Haematologist.

2.2.3 Complicated clinical presentation should be discussed with the Haematologist with expertise in the management of haemophilia.

2.2.4 Out of hours management of patients with haemophilia (other than simple bleeds that could normally be managed in the home setting) should be discussed with the Consultant with expertise in the management of haemophilia.

2.2.5 A 24 hour service is provided at the NCHCD and at Our Lady's Children's Hospital, Crumlin for the management of emergency factor assays. Correction tests should be available in regional haematology centres to rule out acquired haemophilia.



Chairman's Statement

The National Haemophilia Council (NHC) has been in existence since 2004 and during the five years major progress has occurred in the haemophilia service for children and adults in Ireland. The Council operates as an active partnership between the haemophilia community and the health professionals responsible for the haemophilia service. Our agenda is to provide the best possible care and treatment for persons with haemophilia and related bleeding disorders. Prevention is the best medicine and our aim is to ensure that all children and adults with haemophilia will have safe and appropriate care with optimal use of Factor Replacement Therapy in accord with clinical need. With the advances in haemophilia care, appropriate support services for families and persons with haemophilia and good education programmes we have a new generation of young people who lead healthy active lives without the morbidity of bleeding complications and who will have normal life expectancy. During the last five years the National Haemophilia Council has had the full co-operation of the Irish Haemophilia Society, the Department of Health and Children and the Health Service Executive to identify and remedy the gaps in the haemophilia service. In this work the Council has been guided by two yearly independent external audits which now include patient representation.

The National Centre for Hereditary Coagulation Disorders (NCHCD) in St. James's Hospital under the direction of Dr Barry White provides all the services expected from a Haemophilia Centre and the quality of the outpatient haemophilia



Dr Barry White and Prof. John Bonnar addressing an IHS conference.

service as stated by the international auditors is as good as can be found anywhere in the world. Despite the economic recession, St James's Hospital has committed funds to provide a new inpatient facility for patients with haemophilia as the deficiencies in this area compromise the otherwise excellent haemophilia care. The NCHCD at St James's Hospital has a close working relationship with the paediatric haemophilia service at Our Lady's Children's Hospital and the haemophilia service being developed in Cork University Hospital.

The large paediatric haemophilia service in Our Lady's Children's Hospital, Crumlin, provides a high quality paediatric service now under the care of Dr Beatrice Nolan, Consultant Haematologist with national responsibility for paediatric haemophilia care. The haemophilia service has been greatly improved with the new Haematology Day Unit in Our Lady's Children's Hospital. Following meetings between the NHC and the HSE, funding



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has been provided for a haemophilia community nurse specialist but filling this post has been delayed due to the moratorium on appointments in the public sector. Development of the paediatric haemophilia service within the community is a priority and delay is likely to increase costs.

A serious concern in the NHC has been the slow progress at Cork University Hospital in providing an adequate infrastructure for a Haemophilia Centre for the care of children and adults with haemophilia despite funds having been allocated by the HSE in 2008. The lack of an out-patient treatment centre and office accommodation for the haemophilia service is in stark contrast to the facilities available in Dublin. In September 2009 Dr Susan O'Shea took up her appointment as Lead Consultant for Haemophilia in Cork University Hospital with the part-time administrative support of a Data Manager and Clerical Officer. A suitable location for the haemophilia centre has been agreed, the plans have been approved and the funds are available. We expect to see the Haemophilia Centre in Cork University Hospital commissioned in 2010. Dr Susan O'Shea has replaced Dr Oonagh Gilligan on the National Haemophilia Council. I would like to pay tribute to the unceasing efforts of Dr Oonagh Gilligan to improve the haemophilia service in Cork University Hospital during her five years on the NHC.

At this time of severe restraints on health expenditure we will continue to optimise the national programme for haemophilia care by strengthening close working relationships and enhancing co-operation between the haemophilia centres at St James's Hospital, Our Lady's Children's Hospital, Crumlin and Cork University Hospital to ensure that high quality patient centred care is delivered throughout the country.

I wish to thank all the members of the Council for giving their time and expertise to the work of the Council. I would like especially to thank Fiona O'Connell, Secretary to the Council until 2009 and Angela Fitzgerald representing the Health Service Executive and now Deputy CEO at St James's Hospital. I welcome Fionnuala Duffy as the new representative of the HSE on the Council and Monica McGill as the Secretary to the Council. Lastly, I thank Gareth Presch for all his enterprising work and support as Chief Officer to the National Haemophilia Council.

Professor John Bonnar
Chairman of the National Haemophilia Council



Chief Officer's Statement

In 2009 the National Haemophilia Council made recommendations and worked with the Health Service Executive and the Department of Health and Children to improve haemophilia care in Ireland.

Following the audits of the haemophilia centres in 2008 and the subsequent recommendations that came from the audits, the Council continued to meet with the Health Service Executive and the three CEOs from St James's Hospital Dublin, Our Lady's Children's Hospital, Crumlin and Cork University Hospital to ensure progress had been made following the audits' recommendations. These three hospitals are where the comprehensive haemophilia care centres are based.

The Council met with the Minister for Health and Children in 2009 and briefed Minister Harney on the progress made in providing haemophilia care in Ireland. Updates on the three comprehensive care centres were given. Chairman Prof Bonnar presented Minister Harney with the Council's 5th Annual Report.

During 2009 the Council made several visits to Cork University Hospital to meet with management and the haemophilia team at Cork to ensure the recommendations of the 2008 audit were being implemented.

Significant progress was made in 2009 at CUH. Following the audit of 2008 the Council made recommendations to the Health Service Executive who acted on these recommendations. As a result, Dr Susan O'Shea was appointed as Lead Haemophilia Consultant at CUH. Dr O'Shea also became a member of the

NHC following her appointment to CUH in 2009, and replaced Dr Oonagh Gilligan on the Council.

I would like to take this opportunity to thank Dr Gilligan for her dedicated work on the National Haemophilia Council and I would like to wish her all the very best in the future.

Other significant improvements at CUH saw the appointment of a 0.5 data manager and a 0.5 clerical officer to support Dr O'Shea.

The key recommendation following the 2008 audit was to establish a comprehensive haemophilia centre in Cork University Hospital. The Council, working with the Health Service Executive, secured funding for this project in 2008 and it is expected that 2010 will see the official opening of a new haemophilia centre at Cork University Hospital.

Our Lady's Children's Hospital is the largest paediatric haemophilia service in Europe. During 2009 Dr Beatrice Nolan was appointed to lead the national paediatric haemophilia service. Dr Nolan is also a member of the NHC. The Council met with Mr Lorcan Birthistle, CEO of OLCHC in 2009 and discussed the haemophilia service at OLCHC. This meeting is now an annual event and the Council will continue to meet with the CEO of OLCHC to ensure that the paediatric haemophilia service in Ireland provides the best possible care for children with haemophilia. Following meetings with OLCHC and the HSE, the NHC secured funding for a haemophilia community nurse specialist. This post has



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currently been delayed by the public sector moratorium, but the Council will continue to work with the HSE to ensure this post is filled as soon as possible.

In late 2009 members of the Council met with Mr Ian Carter, the CEO of St James's Hospital. The key discussion point was the haemophilia in-patient unit at St James's Hospital. Mr Carter gave assurances to the Council that the new in-patient unit would be built by 2012, with work commencing in late 2010. Following the meeting with Mr Carter, Prof Bonnar and I met with the haemophilia team at the NCHCD in St James's Hospital.

The Council also had a replacement Secretary appointed in 2009, so I would like to take this opportunity to welcome Monica McGill and wish her all the best in the future, and also to thank Fiona O'Connell for her work with the Council.

I would like to especially thank Fionnuala Duffy, Brian O'Mahony, Dr Barry White and Professor John Bonnar for the support they have given me in 2009.

I feel it must also be noted that all members of the National Haemophilia Council receive no remuneration for their work on the Council and all members must be commended for the time and effort given in this respect.

When I look back on the year and reflect on the work of the NHC throughout 2009, I can see a vast amount was achieved in a considerably short period of time. 2009 can be viewed as another step forward in the right direction. We all work in difficult and challenging times but progress can continue to be made when there are clinicians, managers, health professionals and patients working together to improve the service. With the National Haemophilia Council we are fortunate to have that drive and determination in abundance and this is shown by the considerable commitment we see from Prof John Bonnar.

Gareth Presch
Chief Officer
National Haemophilia Council



Council Membership

Statutory Instrument No. 451 of 2004 provides for the appointment to the Council by the Minister for Health and Children 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, (CEO of the Irish Haemophilia Society) and Mr Michael Davenport (Chairman of the Irish Haemophilia Society). The Council members during 2008/2009 are listed below and their attendance at Council meetings are listed in the Appendix.

Professor John Bonnar (Chairman)

John Bonnar was appointed Chairman of the National Haemophilia Council of Ireland in 2004 by the Minister for Health and Children. He is Emeritus Professor of Trinity College Dublin and was Head of Obstetrics and Gynaecology from 1975 – 1999 and Consultant Obstetrician and Gynaecologist at the Rotunda Hospital and subsequently in St James's Hospital and the Coombe Hospital. From 1983 – 1987 he was Dean of the Faculty of Health Sciences in Trinity College Dublin.

Bleeding disorders and thrombosis in pregnancy have been his major area of research and he has many publications. His MD (Hons) was awarded for his research in coagulation disorders in

pregnancy. He is a Fellow of the Royal College of Physicians of Ireland and Royal College of Obstetricians, Honorary Fellow of the American Gynecological and Obstetrical Society. Since 1995 he has been the Vice President for Ireland in the Medical Protection Society. From 1999 to 2002 he was Chairman of the Institute of Obstetricians and Gynaecologists of the Royal College of Physicians of Ireland.

Mr Brian O'Mahony

Brian O'Mahony is the Chief Executive Officer 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, and 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.



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Mr Michael Davenport

Michael Davenport has severe FVIII deficiency. He has been a committee member of the Irish Haemophilia Society since 2001 and its Chairman since 2003. He has a BA in Humanities from St Patrick's College in Drumcondra.

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.

Dr Beatrice Nolan

Dr Beatrice Nolan was appointed as a Consultant Haematologist to St James's Hospital in 2001 with a commitment to Our Lady's Children's Hospital, Crumlin. In 2008 Beatrice was appointed full-time Lead Consultant Haematologist on paediatric haemophilia and allied bleeding disorders with a national remit.

Dr Oonagh Gilligan

Dr Oonagh Gilligan, FRCPI, MRCP (UK), MRCPPath. was appointed Consultant Haematologist to Cork University Hospital and Mercy University Hospital in 2002. In addition to running a large clinical and laboratory practice, other current responsibilities include Chair of Division Oncology CUH, Haemophilia Director CUH, Stem Cell Programme Director CUH, Chair of Transfusion Committee, Deputy National Speciality Director for Haematology training, and member of the Haemophilia Product Selection Monitoring and Advisory Board.



Prof. John Bonnar, Dr Barry White and Mr Brian O'Mahony conducting a press conference on vCJD at the Irish Haemophilia Society's office in February 2009.



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Ms Eilish Hardiman

Eilish Hardiman is CEO of the National Paediatric Hospital Development Board. Previous to this she was Deputy CEO of St James's Hospital prior to being appointed as Director of Nursing and held other nurse management posts in practice development and gerontological nursing in St James's Hospital. Eilish has several professional nursing qualifications and an Executive MBA.

Ms Anne Grogan

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. Anne also has extensive experience of working with clients with liver disease, in particular those who have State Acquired Hepatitis C. She 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 Angela Fitzgerald

Prior to her appointment to the position of Deputy CEO at St James's Hospital, Angela Fitzgerald was Hospital Network Manager for Dublin North-east, Director of Planning, Commissioning and Change with the HSE Eastern Region and Director of Monitoring and Evaluation with the ERHA. She also worked in the Department of Health and Children in the area of Secondary Care. Angela holds an MSc. Econ. in Policy Studies (1995) – Trinity College Dublin, and a BA in Public Administration.

Following her appointment at St. James's Hospital, Ms Angela Fitzgerald was replaced by Ms Fionnuala Duffy as the Health Service Executive's nominee in 2009.

Ms Fionnuala Duffy

Fionnuala Duffy is Assistant National Director, Acute Service Planning and Development, Integrated Service Directorate – Reconfiguration, HSE. Fionnuala was a Senior Commissioner with the Eastern Regional Health Authority. She also worked in the Department of Health and Children in the area of Secondary Care. Fionnuala holds an MSc. in Health Service Management – Trinity College Dublin, and a BA in Public Administration.

Mr Matthew Collins

Matthew Collins is the Principal Officer of the Blood & Tissue Policy Division in the Department of Health and Children.



2. Review of 2009

Annual Report

This is the sixth Annual Report of the National Haemophilia Council submitted to the Minister for Health and Children under the provisions of Statutory Instrument (S.I.) No. 451 of 2004. It covers the period from 1st January 2009 to 31st December 2009, to comply with Regulation 5(1) of the S.I.

Meetings of Council

The Council met on five occasions in 2009: 19th January, 9th March, 8th June, 14th September and the 16th November. Attendance at meetings is listed in the Appendix.

Secretariat

Administrative and secretarial support to the NHC is provided by the Chief Officer and the Secretary who are located at the offices of the Health Service Executive, Room 101, Dr Steevens' Hospital, Dublin 8.



Some of the attendees at the meeting of the National Haemophilia Council at the Irish Haemophilia Society offices in September 2009.



NHC Strategic Plan 2008-2010

The key areas of the NHC Strategic Plan are as follows:

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.

Context of NHC

- Statutory Instrument (S.I.)
- Patient/Clinicians/Health Service Policy/Health Service Management working on a unique basis under S.I.
- Agreement on centralisation of care
- International patient involvement in formal evaluation
- Ability to respond publicly and co-operatively to a crisis in a timely manner

Values

- Equity
- Patient centred care
- Advocacy
- Inclusiveness
- Accountability
- Respect

Goals

1. Optimise the development and function of the NHC
2. Advocate provision of optimum haemophilia care nationally
3. Provision of appropriate information and education/research
4. Ensure viability and effectiveness by measuring performance and outcomes



Goals

1) **Optimise development and function of the National Haemophilia Council**

Objectives:

1. Set annual targets/measure outcomes
2. Advise the Minister and Health Service Executive on any matter relating to haemophilia
3. Hold an annual meeting with the Health Service Executive and the Minister
4. Benchmark our work against best international practice/trends in managing haemophilia
5. Hold an annual meeting with the CEOs of the comprehensive care centres. (St James's, OLCCH, CUH)
6. Hold an annual meeting with the haemophilia teams at the comprehensive care centres
7. Over the next three years arrange to meet with regional hospitals
8. Council members to have basic grounding in all aspects of haemophilia
9. Produce a document that shows how the NHC model works
10. Receive a formal update from the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB)

2) **Advocate provision of optimum haemophilia care nationally**

Objectives:

1. Set clear priorities for the development of haemophilia care in the three comprehensive care centres, informed by the biennial audit reports
2. Advise on the allocation of funding to meet priorities identified in the 2008 Audit within 12 months (NHC Service Plan 09)
3. Publication, dissemination, and utilisation of the National Haemophilia Treatment Guidelines
4. Ensure optimum communication from hospitals to the comprehensive care centres when dealing with patients
5. Have clear mechanisms to deal with failure to implement policy recommendations
6. Include international development as an agenda item at NHC meetings
7. The NHC Chief Officer will meet with members/patients/hospitals and report back to the Council on a regular basis



Goals

3) Provision of appropriate information and education/research

Objectives:

1. Biennial review and update of treatment guidelines
2. Document, publish and disseminate the agreed process of implementing guideline changes
3. Optimise the value of the information day meeting for healthcare workers and patients
4. Add a link from the NHC website to individual hospital websites and other appropriate websites
5. NHC to hold an annual press briefing
6. Organise regular specifically focused international meetings in Ireland
7. Devise, implement and evaluate the continuous professional development of nursing staff-training pack
8. Make recommendations on training requirements for non-consultant hospital doctors (NCHDs)
9. Co-operate with the Irish Haemophilia Society on NHC publications/education

4) Ensure viability and effectiveness by measuring performance and outcomes of the NHC

Objectives:

1. Develop formal and informal feedback mechanisms
2. Develop measurement tools for all objectives
3. Review the strategic plan annually
4. NHC Chief Officer will present a one page update on the progress of the strategic plan at every NHC meeting (this brief document will be a permanent agenda item for all NHC meetings)



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NHC meeting with the Minister for Health and Children

The Council met with the Minister for Health and Children on 22nd June 2009 in the Department of Health and Children, Hawkin's House where Prof. John Bonnar (Chairman) presented the Minister with the fifth NHC Annual Report. Prof. Bonnar updated the Minister regarding the haemophilia service in Ireland. The audit recommendations of 2008 were also discussed with the Minister. Prof. Bonnar also informed the Minister of the need for a haemophilia centre at Cork University Hospital and a new haemophilia in-patient facility at St James's Hospital. The Minister thanked the Chairman for the continued hard work of the National Haemophilia Council.

Members of the NHC who attended the meeting were:

Prof. John Bonnar, Chairman

Mr Brian O'Mahony, CEO, Irish Haemophilia Society

Dr Barry White, Director, NCHCD, and National Director, Clinical and Quality Care, HSE

Mr Matthew Collins, Principal Officer, Department of Health and Children

Ms Eilish Hardiman, CEO, National Paediatric Hospital Development Board

Dr Oonagh Gilligan, Consultant Haematologist, Cork University Hospital

Dr Beatrice Nolan, Consultant Haematologist, Our Lady's Children's Hospital, Crumlin

Mr Gareth Presch (then Administrator of the NHC) also attended.

NHC meetings with the Health Service Executive

The Council met on a number of occasions with the Health Service Executive in 2009 and will continue to work with the Health Service Executive in 2010. The Council would like to thank especially the former National Director of the National Hospitals Office – Ms Ann Doherty – for all her help and assistance in 2009.

The Council was represented at these meetings by:

Prof. John Bonnar, Chairman

Dr Barry White, Director, NCHCD and National Director, Clinical and Quality Care, HSE

Mr Brian O'Mahony, CEO, Irish Haemophilia Society

Mr Gareth Presch (then Administrator of the NHC) also attended.

NHC meeting with Our Lady's Children's Hospital, Crumlin

The Council met with the CEO Mr Lorcan Birthistle in June 2009 to discuss the haemophilia service in Our Lady's Children's Hospital. This paediatric haemophilia service is one of the largest in Europe. Members of the Council discussed the audit recommendation of 2008 with the CEO. The key recommendations of the 2008 audit at Our Lady's Children's Hospital, Crumlin were to appoint a Lead Consultant and a Clinical Nurse Specialist (CNS) in Haemophilia. Dr Beatrice Nolan



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was appointed in 2008; the appointment of the CNS remains outstanding. The Council will continue to work with Our Lady's Children's Hospital to ensure optimum haemophilia care is provided for children with haemophilia.

Attendees at the meeting between the NHC and the CEO of Our Lady's Children's Hospital were:

Prof. John Bonnar, Chairman, NHC

Mr Lorcan Birthistle, CEO, Our Lady's Children's Hospital, Crumlin

Mr Brian O'Mahony, CEO, Irish Haemophilia Society

Dr Barry White, Director, NCHCD and National Director, Clinical and Quality Care, HSE

Ms Eilish Hardiman, CEO, National Paediatric Hospital Development Board

Dr Beatrice Nolan, Consultant Haematologist, Our Lady's Children's Hospital, Crumlin

Mrs Sharon Hayden, Assistant Director of Nursing, Our Lady's Children's Hospital, Crumlin

Mr Gareth Presch (then Administrator of the NHC) also attended the meeting.

NHC meetings with Cork University Hospital

The NHC met with the management of Cork University Hospital in 2009 to discuss the audit recommendations of 2008. The need for a dedicated haemophilia centre was again highlighted as a priority. The Council has worked with the Health Service Executive to secure funding for a new haemophilia centre at Cork University Hospital. Following meetings, a location was identified for the new haemophilia centre. Plans and costings were agreed, and the centre is scheduled to open in 2010.

The Council also worked with the HSE in 2009 to secure the appointment of Dr Susan O'Shea to lead the haemophilia service at Cork University Hospital. A half time Secretary and Data Manager were also appointed in 2009.

The following attended the meetings with CUH on behalf of the NHC:

Prof. John Bonnar, Chairman, NHC

Mr Brian O'Mahony, CEO, Irish Haemophilia Society

Dr Oonagh Gilligan, Consultant Haematologist, Cork University Hospital

Dr Susan O'Shea, Consultant Haematologist, Cork University Hospital

Dr Beatrice Nolan, Consultant Haematologist, Our Lady's Children's Hospital, Crumlin

Mr Gareth Presch (then Administrator of the NHC) also attended the meetings.



Meeting with the CEO of St James's Hospital

In November 2009, members of the Council discussed the Audit report of 2008 with Mr Ian Carter, the CEO of St James's Hospital. The service at the National Centre for Hereditary Coagulation Disorders is a high quality one. The need for an in-patient facility at St James's Hospital was discussed and the CEO gave his assurances to the Council that the facility is of the highest priority for his office. The CEO expects building to commence in the final quarter of 2010 and the new haemophilia in-patient unit to be opened by 2012.

The Haemophilia Dental Service at St James's Hospital was discussed and a shortfall of funding was identified. The Council worked with the HSE in 2009 to secure the required funding for this service.

The following people attended on behalf of the NHC:

Prof. John Bonnar, Chairman
Mr Brian O'Mahony, CEO, Irish Haemophilia Society
Ms Fionnuala Duffy, AND, Integrated Services Directorate, HSE
Dr Barry White, Director, NCHCD, and National Director, Clinical and Quality Care, HSE
Ms Anne Grogan, Nurse Manager, NCHCD, St James's Hospital

Mr Gareth Presch (then Administrator of the NHC) also attended.

Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB)

During the year the HPSMAB met six times to advise on the selection of factor concentrates and to monitor developments in relation to factor replacement therapy internationally. The Board completed a new tender for the provision of recombinant Factor VIII for 28,000,000 IUs per year for a two-year contract. The Board also discussed the use of cryoprecipitate versus fibrinogen as a treatment for afibrinogenemia and the implications of discovery at autopsy of prions in the spleen of a person with haemophilia in the UK.

The HPSMAB members are:

Dr Barry White (Chairman)
Mr Brian O'Mahony (Vice-Chairman)
Dr William Murphy (Irish Blood Transfusion Service)
Dr Beatrice Nolan (Our Lady's Children's Hospital, Crumlin)
Ms Lara Hynes (Department of Health and Children)
Dr Oonagh Gilligan (Consultant Haematologist, Cork University Hospital)
Mr Jeff Connell (National Viral Reference Laboratory, University College Dublin),
Mr Patrick Costello (Irish Medicines Board)
Ms Evelyn Singleton (NCHCD)
Mr Declan Noone (Irish Haemophilia Society)

Administrative support was provided by Mr Gareth Presch (then Administrator), and Ms Monica McGill, Secretary to the National Haemophilia Council.



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 2009. The Council briefed the Minister on haemophilia matters nationally during the meeting with her in June 2009.

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 2009.

Finance

The costs of meetings and other administrative costs were provided by the Health Service Executive in 2009. 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 was audited by the Office of the Comptroller and Auditor General in 2009 for the years 2007 and 2008. The Council also submitted to the HSE an administration budget in 2009 for its projected costs in 2010.

Website

The NHC's website received approximately 500 hits per month in 2009. 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 is continually updated and revised by the Chief Officer of the NHC who administers the website, the address of which is:

www.nationalhaemophiliacouncil.ie

Please note that the S.I. has been amended under the Health (Miscellaneous Provisions) Act 2007. This Act can be viewed on the NHC's website.



Appendix

National Haemophilia Council – attendance at meetings The Council met five times in 2009

	Meetings Attended in 2009
Prof. John Bonnar (Chairman)	5
Mr Brian O'Mahony (Irish Haemophilia Society)	5
Mr Michael Davenport (Irish Haemophilia Society)	4
Dr Barry White (Director, NCHCD, and National Director, Clinical and Quality Care, HSE)	4
Dr Beatrice Nolan (Consultant Haematologist, Our Lady's Children's Hospital, Crumlin)	5
Dr Oonagh Gilligan (Consultant Haematologist, Cork University Hospital)	2
Ms Eilish Hardiman (CEO, National Paediatric Hospital Development Board)	2
Ms Anne Grogan (Clinical Nurse Manager, St James's Hospital)	2
Ms Angela Fitzgerald, (Health Service Executive)	2
*Ms Fionnuala Duffy, (Health Service Executive)	2
Mr Matthew Collins, (Blood Policy Division, Department of Health and Children)	4
Chief Officer to the National Haemophilia Council: Mr Gareth Presch (HSE)	
Secretary to the National Haemophilia Council: Ms Monica McGill (HSE)	

* Ms Duffy replaced Ms Fitzgerald on the NHC during 2009.



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 advise and make recommendations to the Minister for Health and Children on the selection of products for the treatment of 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
The Irish Haemophilia Society was founded in 1968 by members of the medical profession, people with haemophilia, their families and friends who felt the need to provide support and advice for members and to improve the quality of life for people with haemophilia.

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.

NCHDs – Non Consultant Hospital Doctors

OLCHC – Our Lady's Children's Hospital, Crumlin



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