

# NATIONAL HAEMOPHILIA COUNCIL ANNUAL REPORT 2007



National  
Haemophilic  
Council

## **NATIONAL HAEMOPHILIA COUNCIL - ANNUAL REPORT 2007**

*The establishment of a 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 22 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](http://www.nationalhaemophiliacouncil.ie)

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### OVERVIEW OF THE NATIONAL HAEMOPHILIA COUNCIL

*The establishment of a 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 22 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 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.

## CHAIRPERSON'S STATEMENT

*During 2007 the National Haemophilia Council carried out a detailed review of the haemophilia service with particular reference to the preliminary audits of the comprehensive Haemophilia Centres of Our Lady's Children's Hospital, Crumlin, Dublin, Cork University Hospital and St. James's Hospital, Dublin.*

The Council is obliged to Dr. M. Makris, Director of the Haemophilia and Thrombosis Centre in Sheffield, United Kingdom and C. Harrington, Nurse Consultant in Haemophilia, Royal Free Hospital, London, for undertaking this external audit of the Irish Haemophilia Centres in November 2006. Future audits of the haemophilia service will include patient representation. Major service needs were identified in the preliminary audits of the haemophilia care:

### **OUR LADY'S CHILDREN'S HOSPITAL, CRUMLIN:**

The Paediatric Haemophilia Service in Our Lady's Children's Hospital, Crumlin is responsible for the care of over 500 children with haemophilia. This is one of the largest paediatric haemophilia services in Europe and is not a Consultant provided service. A new Consultant Haematologist is urgently required to lead the paediatric coagulation and thrombosis service in Our Lady's Children's Hospital, Crumlin.

### **CORK UNIVERSITY HOSPITAL:**

There are major deficiencies in the haemophilia service in the Cork region. As yet no infrastructure

for a haemophilia centre has been established in Cork University Hospital and laboratory facilities are seriously inadequate.

A Consultant Haematologist to lead the haemophilia service is required and dedicated space for a Haemophilia Centre with support staff to provide appropriate haemophilia care.

### **ST. JAMES'S HOSPITAL, DUBLIN:**

The National Centre for Hereditary Coagulation Disorders in St. James's Hospital Dublin has made excellent progress in improving haemophilia care and communications between patients and professionals in decision making to achieve patient centred care. A centralised inpatient unit with protected beds for haemophilia and hepatology has been on the priority list for a few years. This facility, which is urgently required, has now passed the design stage and building should commence in 2008.

During 2007 the National Treatment Guidelines were finalised and will be distributed during 2008 to all hospitals to ensure that appropriate care will be provided for any patient with haemophilia requiring treatment outside the haemophilia

## 1. INTRODUCTION



Justice Roderick Murphy, President Mary McAleese & Prof John Bonnar at the opening of the Irish Haemophilia Society new headquarters

centres. I wish to acknowledge the co-operation of the Consultant Haematologists in Ireland with the National Centre for Hereditary Coagulation Disorders in St. James's Hospital, Dublin to provide optimum care for all patients with haemophilia and related coagulation disorders.

In June 2007 a signal event was the official opening by President McAleese of the new headquarters of the Irish Haemophilia Society. In her moving address, President McAleese made reference to the ninety one patients with haemophilia in Ireland who had died as a result of treatment with virus contaminated blood products. The Irish Haemophilia Society plan to have a memorial in the new headquarters to commemorate the recent tragic history in the haemophilia community. The new Headquarters provides a focus for the support and services which are required for persons and families living with haemophilia and the new generation of young people who have had the benefits of optimal therapy by regular prophylactic infusion of the required factor concentrates.

In November 2007 representatives from the National Haemophilia Council met with the Health Service Executive to discuss the Service Plan for 2008 and highlight the priorities which are required to improve haemophilia care in 2008. The Health Service Executive has been allocated funding by the Department of Finance to meet the gaps identified by the Lindsay Tribunal of Inquiry and the National Haemophilia Council within hospital services for persons with haemophilia. The National Haemophilia Council expects that this funding will be used in a timely manner for the priority requirements in development of the haemophilia service.

I would like to thank all the members of the National Haemophilia Council for giving their time and expertise to enable the best possible service and facilities to be provided in Ireland for all adults and children with haemophilia and related disorders.

*Professor John Bonnar.*

## ADMINISTRATOR'S STATEMENT

*The year 2007 was my first full year as Administrator to the National Haemophilia Council and significant progress was made in the work of the Council as a Statutory Body.*

The National Haemophilia Council held its meetings in the Department of Health and Children in 2007 and I would like to thank Mary Jackson (Principal Officer, Blood Policy) and her staff for all their help throughout the year.

In early January I accompanied the Irish Haemophilia Society on regional visits around the country and met persons with haemophilia to establish links with the haemophilia community within Ireland. This enabled me to appreciate what was needed on the ground relating to the issues persons with haemophilia had with the health service in Ireland and needed to be addressed by the Council. Regional visits are extremely valuable for the National Haemophilia Council as they provide an adequate forum for consultation and dialogue between the Council and the persons with haemophilia.

Our new logo was approved by the Council in 2007 and this will become our seal on all our publications. A new website was developed and launched in August 2007 and I would encourage

persons with haemophilia to use this website as a resource and a source of contact between patients and the National Haemophilia Council. The 2006 annual report was published in 2007 along with an Information Leaflet that outlines the Council's advisory role of the Council and information on who is represented on the National Haemophilia Council.

On the 24th November 2007 the National Haemophilia Council held the annual Information Day at the Health Service Executive headquarters in Dr Steevens' Hospital. Prof Bonnar gave an update on the Council's work followed by presentations from Dr Barry White on NCHCD Patient Involvement Programme, Dr Beatrice Nolan on 'Haemophilia and the Newborn', Brian O'Mahony on the role of patient involvement in treatment centre audits and Dr Nicholas Goddard from the Royal Free Hospital London gave an excellent presentation on orthopaedic surgery. The day was highly informative and I would like to thank the Health Service Executive for facilitating the event at Dr Steevens' Hospital and the speakers for the sharing of their invaluable knowledge on haemophilia care.

## 1. INTRODUCTION



*Administrator to the National Haemophilia Council Mr Gareth Presch & Chairman Prof John Bonnar at the opening of the Irish Haemophilia Society's new headquarters*

Finally the National Haemophilia Council met with the Health Service Executive on the 17th December 2007 and presented the Service Plan for 2008. The National Haemophilia Council Service Plan will ensure that the service provides improved care for persons with haemophilia in 2008.

The year 2007 has been both exciting and hard work for the Council members to ensure that the Department of Health and Children and the Health Service Executive are advised on the best practice

for treating persons with haemophilia. I would like to thank all the members for their continued hard work and support and look forward to improvements in haemophilia care in 2008. I would also like to take this opportunity to congratulate the Irish Haemophilia Society on their fine new premises which were opened by their patron President Mary McAleese.

***Gareth Presch  
Administrator***

## MEMBERSHIP OF THE COUNCIL

*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 Council members during 2006/2007 are listed below and attendance records Appendix C.*

### **PROFESSOR JOHN BONNAR (CHAIRPERSON)**

John Bonnar was appointed Chairperson of the National Haemophilia Council of Ireland in 2004 by the Minister of Health and Children. He is Emeritus Professor of Trinity College, Dublin and was Professor and 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.

Bleeding disorders and thrombosis in pregnancy have been his major area of research and he has extensive publications in journals and textbooks. 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 and an 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 (IRISH HAEMOPHILIA SOCIETY)**

Brian O'Mahony is the 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, 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.

## 1. INTRODUCTION

### **MR MICHAEL DAVENPORT (IRISH HAEMOPHILIA SOCIETY)**

Michael Davenport is 49 years old and has severe FVIII deficiency. He has been a committee member of the Irish Haemophilia Society since 2001 and Chairman since 2003. Michael is married to Ann since 1979 and they have one son and two daughters. He has a BA in Humanities from St. Patricks College in Drumcondra and has a golf handicap of seventeen which he hopes to play to someday soon!

### **DR BARRY WHITE (DIRECTOR, NATIONAL HAEMOPHILIA CENTRE)**

Dr Barry White is a Consultant Haematologist and Director of the National Centre for Hereditary Coagulation Disorders 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 BEATRICE NOLAN (CONSULTANT HAEMATOLOGIST, OUR LADY'S HOSPITAL FOR SICK CHILDREN)**

### **DR OONAGH GILLIGAN (CONSULTANT HAEMATOLOGIST, CORK UNIVERSITY HOSPITAL)**

Dr. Oonagh Gilligan, FRCPI, MRCP(UK), MRCPPath. Appointed as a consultant haematologist to Cork University Hospital and Mercy University Hospital 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, member of the National Haemophilia Council and Haemophilia Product Selection, Monitoring and Advisory Group.

### **MS EILISH HARDIMAN (DEPUTY C.E.O , ST JAMES'S HOSPITAL)**

Eilish Hardiman is Deputy Chief Executive at St James's Hospital. Previous to this she was 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. She is a qualified Surveyor with Irish Health Services Accreditation Board (IHSAB).

**MS JUDE SMITH  
(CLINICAL NURSE MANAGER, ST JAMES'S HOSPITAL)**

Registered General nurse qualification in Edinburgh in 1990. Started working in the care of adults and children with haemophilia in 1992 in the haemostasis and thrombosis centre in the Royal Free Hospital, Hampstead, London. Took up post as clinical nurse specialist in paediatric haemophilia in the National Children's Hospital, Harcourt Street, Dublin in 1996. Commenced role as Nurse Manager of National Centre for Hereditary coagulation disorders, St James's Hospital, Dublin in 2001. BSc in nursing management from Royal College of Surgeons of Ireland in 2002.

**MS ANGELA FITZGERALD,  
(HOSPITAL NETWORK MANAGER, HSE)**

Angela Fitzgerald is Hospital Network Manager for Dublin North . Angela was 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 Secondary Care. Angela holds an M.Sc Econ in Policy Studies (1995) - Trinity Collage , and a B.A. in Public Administration.

**MS MARY JACKSON,  
(BLOOD POLICY DIVISION, DOHC)**

Joined the Department of Health and Children in 1988. Has worked in various positions, including Health Promotion and Community Health Division. Appointed Principal Officer of Blood Policy Division, Department of Health and Children in 2002. Has professional qualifications in applied biology and also a B.A. in Public Health Management.

### ANNUAL REPORT

This is the fourth annual Report of the National Haemophilia Council to the Minister for Health and Children submitted under the provisions of Statutory Instrument (SI) No. 451 of 2004 (Appendix A), and covers the period 1 January, 2007 to 31 December, 2007, to comply with Regulation 5(1) of the SI.

### MEETINGS OF COUNCIL

The Council met on five occasions in the Department of Health and Children – 22nd January, 23rd April, 18th June, 17th September and 17th November 2007.

### SECRETARIAT

The Administrator and Secretary to the Council were both appointed in early 2007. Both the Administrator and the Secretary to the Council are based in HSE, Mill Lane, Palmerstown, Dublin 20.

### NATIONAL HAEMOPHILIA COUNCILS SERVICE PLAN – PRESENTED TO THE HEALTH SERVICE EXECUTIVE:

The service plan included the following:

#### 1) NATIONAL HAEMOPHILIA COUNCIL RECOMMENDATIONS FOR THE HEALTH SERVICE EXECUTIVE:

These NHC recommendations are based on the hospital audits carried out by an external team comprising of Dr Mike Makris, Haemophilia Director Sheffield Haemophilia and Thrombosis Centre, Sheffield, UK, Christine Harrington, Nurse Consultant in haemophilia and Katharine Dormandy Haemophilia Centre and Haemostasis Unit Royal Free Hospital, London, UK. The audits were carried out in November 2006 in Our Lady's Children's Hospital, Crumlin, Dublin, Cork University Hospital and the National Centre for Hereditary Coagulation Disorders (NCHCD, St James Hospital, Dublin).

#### Our Lady's Hospital for Children (OLCHC), Crumlin, Dublin

- 1.1 A new consultant haematologist is urgently required to lead in OLCHC in paediatric coagulation and thrombosis services. The paediatric haemophilia service at Crumlin is not currently lead by a designated consultant post. The service has over 500 children attending OLCHC and is one of the largest paediatric haemophilia services in Europe.

- 1.2 Data management – The large haemophilia service at OLCHC, Crumlin, urgently requires the services of a data manager. The Clintech system should be established and the system integrated with the National Centre.
- 1.3 Clinical Nurse Specialists are essential in the provision of the service at OLHC to provide further development of home service and school visits. The Haemophilia Nurse Specialists are required to provide specific needs – The role of the Haemophilia Nurse Specialists needs to be expanded to include community care and performance paediatric phlebotomy/ venous access. One paediatric Nurse Specialist is required.

#### **Cork University Hospital (CUH)**

- 1.4 A consultant haematologist with special interest in Haemophilia and Thrombosis is required to have overall responsibility in CUH.
- 1.5 A Haemophilia Centre should be established in CUH which will include accommodation for persons with Haemophilia, Medical Staff and Haemophilia Nurses.
- 1.6 Administrative support is required for the service with a full time haemophilia secretary.
- 1.7 A coagulation laboratory service has to be provided with a formalized 24 hour coagulation laboratory on call rota for the

performance of specialized tests such as factor VIII assays and other specific tests. This requires a specific allocation of space for the coagulation laboratory with staff trained in coagulation disorders.

- 1.8 Sessions with a dental surgeon should be available in the paediatric clinics when children with haemophilia attend for their 6 month review.
- 1.9 A data manager should be employed on a part time basis to provide support for the service and to integrate with the new national haemophilia Clintech system.
- 1.10 A part-time Physiotherapist and a part-time Social Worker are required and sessions should be available at adult and paediatric clinics.

#### **National Centre for Hereditary Coagulation Disorders (NCHCD), St James Hospital, Dublin**

- 1.11 A central unit for inpatients with Haemophilia with protected beds is required for the haemophilia service. Specialist Nurses trained in haemophilia care will be required for the unit. This facility has passed the design stage and work will begin in 2008.
- 1.12 Special arrangements should be made to optimise the inpatient and out patient treatment of persons with Haemophilia who have HIV and/ or Hepatitis C

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### 2) OTHER RECOMMENDATIONS FROM THE NHC FOR HAEMOPHILIA CARE

#### Our Lady's Children's Hospital, Crumlin

- Non-hospital based paediatric dental services: recommendations from Dr Fleming, Dr Dougal and Prof O Smith are to be finalised and a dental and haemostatic algorithm prepared.
- Specialist nurses have to be fully trained in paediatric phlebotomy.
- Information leaflet on portacaths to be produced.

#### Cork University Hospital

- The medical records of patients with inherited bleeding disorders should be kept on site and be readily available on a 24 hour basis.
- Standard operating procedures for patients with haemophilia attending the A&E department should be reviewed and revised.
- The new registration system already in use in Dublin should also be introduced in Cork.
- An audit of walk-in haemophilia patients should be carried out as soon as possible to document the time interval between the time of arrival in the hospital and the time of actual treatment with clotting factor concentrate or DDAVP.

- The haemophilia nurses should undergo performance review.
- The Q-Pulse system already in use at St James's Hospital should be accessed from CUH.

#### National Centre for Hereditary Coagulation Disorders (NCHCD), St James Hospital, Dublin

- There should be a formalized 24 hour coagulation laboratory on call rota for the performance of specialized tests such as factor VIII assays.
- An audit on Hepatitis C RNA positive patients should be conducted to determine the reasons for the poor uptake of recommended treatments with PEG Interferon and Ribavirin.

### 3) NATIONAL HAEMOPHILIA COUNCIL AUDITS WITH PATIENT REPRESENTATION 2008:

Agreement was reached on Audits with Patient Representation which will take place in 2008 in Cork University Hospital, the National Centre for Hereditary Coagulation Disorders (NCHCD), St James Hospital, Dublin and Our Lady's Children's Hospital for Children, Crumlin, Dublin. The audit team will include a doctor and a nurse and a patient representative from the Canadian Haemophilia Society recommended by the Irish Haemophilia Society (IHS).

#### **4) IRISH HAEMOPHILIA SOCIETY REGIONAL VISITS:**

In 2007 National Haemophilia Council representatives accompanied the Irish Haemophilia Society on a number of regional visits and met persons with haemophilia and related bleeding disorders throughout the country. The haemophilia treatment centres in Cork and Galway were also visited during these regional visits.

#### **5) NATIONAL HAEMOPHILIA COUNCIL PREMISES:**

The National Haemophilia Council are planning to move to a more suitable location with the assistance of the Health Service Executive. The Health Service Executive Estates department has been asked to find the Council suitable premises.

#### **6) NATIONAL HAEMOPHILIA COUNCIL ANNUAL REPORT 2007:**

The Annual Report for 2007 is published in June of 2008 as required by the statutory order and reviews the work of the NHC has made in 2007.

#### **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 2007.

#### **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.

#### **FINANCE**

The Administrator and Secretary to the Council were appointed in early 2007. The costs of meetings and other administrative costs were provided through the Health Service Executive. 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.

#### **WEBSITE**

The National Haemophilia Council new website went live in 2007. The web address is [www.nationalhaemophiliacouncil.ie](http://www.nationalhaemophiliacouncil.ie) and will be updated by the Administrator of the Council.

### **INFORMATION DAY 24TH OF NOVEMBER 2007**

#### **Report of Michael Davenport, Chairman of the Irish Haemophilia Society**

The National Haemophilia Council is a statutory body constituted in July 2004 following a recommendation of the Lindsay Tribunal and gives the Irish Haemophilia Society direct input into how haemophilia services operate locally and nationwide. The Council members include the Director of the National Centre, a Consultant Paediatric Haematologist, a Consultant Haematologist from outside Dublin, a Clinical Nurse Specialist, a representative from the Department of Health and Children, a representative from the HSE and 2 representatives from the I.H.S. The Council is chaired by the eminent Professor John Bonnar and reports to the Minister for Health and Children annually.

The 24th of November was the NHC's third Information Day. It was held in the boardroom of Dr. Steeven's Hospital and the theme for the day was 'Haemophilia Update'. Professor Bonnar opened the meeting with a review of the work of the Council and discussed priorities for 2008. These include: the appointment of a Lead Consultant and a Paediatric Nurse Specialist for Our Lady's Hospital for Sick Children, a Lead Consultant in haemophilia, Clinical Nurse Specialist, Social Worker, Secretarial Services, Physiotherapist and a Centre in Cork University Hospital, a specific in-patient unit for haemophilia, and special arrangements for HIV and Hepatitis C in-patients in St. James's Hospital.

We had an excellent review of orthopaedic surgery from Dr. Nick Goddard of the Royal Free Hospital in London. He pointed out that corrective and replacement surgery commenced in the Royal Free in 1964 when factor replacement therapy became available.

Knee synovectomies began in 1971, Hip replacements in 1974 and knee replacements in 1978. The goals of orthopaedic surgery are: pain relief, function restoration and reduction of bleeding. Dr. Goddard discussed other aspects of surgery such as removal of bone spurs, fusions (still optimal for ankles) and bilateral joint replacements (very cost effective and only one general anesthetic is required). He pointed out that joints are lasting longer due to prophylaxis so there should be less surgery as time passes. Replacement knees are lasting longer than replacement hips. Infection rates are very low in the Royal Free Hospital and he believes this is due to the level and duration of factor therapy.

Mobility after surgery greatly depends on mobility beforehand as tissue around a joint hardens with time therefore surgery should be performed at an early stage. Dr. Goddard believes that patients in their thirties should consider joint replacement as they will have better recovery and greater benefit from the new joint.

Dr. Goddard finished by referring to surgery in patients with inhibitors and HIV patients with CD4 levels of 200 or less. Coincidentally, a member of the audience informed me that he had the last hip replacement performed in Dr. Steeven's Hospital in 1987!



◀ *Prof John Bonnar (Chairperson of the NHC) and Surgeon Nicholas Goddard (Royal Free London) at the NHC Information day – Dr Steevens' Hospital*

After an excellent lunch in the dining room, Brian O'Mahony discussed the role of patient involvement in treatment centre audits. It is envisaged that audits will be carried out next year in 3 comprehensive centres in St. James's, Crumlin and Cork. A representative nominated by the I.H.S. with a good knowledge and experience of haemophilia treatment centres will be involved. The patient representative will not have access to individual patient or staff records but will be involved in issues arising from a review of these records, such as patient clinic attendance or staff training requirements.

Dr. Barry White spoke about an NCHCD Patient Involvement Programme as proposed by Margaret Cahill (Quality Assurance Officer) who couldn't attend. The Programme is designed to give all stakeholders in a given service the opportunity to

highlight deficiencies in the service and to suggest improvements, implement them where possible and monitor their effectiveness.

A panel of patients will be recruited to meet on a regular basis, take part in surveys and participate in the programme. The possible issues will include outpatient services, in hospital services for elective or emergency treatment, review clinics, home treatments etc. etc. This programme is expected to commence in 2008 in St. James's and later extend to Crumlin and Cork.

The last speaker was Dr. Beatrice Nolan who gave a very interesting talk on 'Haemophilia and the Newborn'. Dr. Nolan discussed the development of the clotting system in the foetus, diagnosis of haemophilia, delivery risks and patterns of bleeding and intracranial bleeding. She pointed out that one

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third of diagnosed persons with haemophilia have no family history and these babies are at greatest risk as diagnosis only occurs when bleeding does not stop normally.

Also, worryingly, one third of potential carriers do not know their carrier status at time of delivery. This is an unnecessary risk to the baby as up to 33% of newborns, with inherited bleeding disorders, bleed within the first 28 days! It is still a misconception among some potential carriers that if their factor levels are normal then they are not carriers. This was a very informative and important talk and will be repeated at some point next year.

The National Haemophilia Council is a vital tool in the development of haemophilia services for us all as it gives us direct communication with the service providers. The attendance at this years Information Day was limited but those who did attend expressed their delight at the quality of the speakers and information received. I would urge all members and their families to include this annual event as a priority in their diaries due to it's importance to haemophilia services.

*Michael Davenport*  
*Chairman Irish Haemophilia Society*

Please note that the SI has been amended under the Health (Miscellaneous Provisions) Act 2007. This Act can be viewed on the following link: <http://www.oireachtas.ie/documents/bills28/acts/2007/a4207.pdf>

The relevant points are in appendix B below.



#### STATUTORY INSTRUMENTS.

##### **S.I. No. 451 of 2004.**

NATIONAL HAEMOPHILIA COUNCIL (ESTABLISHMENT) ORDER 2004.

S.I. No. 451 of 2004.

NATIONAL HAEMOPHILIA COUNCIL (ESTABLISHMENT) ORDER 2004.

I, MICHEÁL MARTIN, Minister for Health and Children, (herein referred to as “the Minister”) in exercise of the powers conferred on me by Section 3 of the Health (Corporate Bodies) Act, 1961 (No. 27 of 1961) as amended by Section 22 of the Health (Amendment) (No. 3) Act, 1996 (No. 32 of 1996) and adapted by the Health (Alteration of Name of Department and Title of Minister) Order 1997 (S.I. No. 308 of 1997) hereby order as follows:

1. This Order may be cited as the National Haemophilia Council (Establishment) Order 2004.

2. In this Order:

“Chairperson” means the Chairperson for the time being of the Council;

“Council” means the National Haemophilia Council established by this Order.

“Eastern Regional Health Authority” means the

authority established under section 7 of the Health (Eastern Regional Health Authority), Act, 1999;

“haemophilia” means the following disorders: inhibitors to factors VIII and IX, inherited deficiencies of factors, I, II, V, VII, VIII, IX, X, XI, XIII and Von Willebrands Disease;

“health board” means—

(a) A board established under section 4 of the Health Act, 1970, or

(b) An Area Health Board established by section 14 of the Health (Eastern Regional Health Authority) Act, 1999;

“Minister” means the Minister for Health and Children;

“officer” means an employee of the Council, unless the context otherwise requires.

**THE COUNCIL**

3. (1) A body to be known as the National Haemophilia Council is hereby established to perform the functions conferred upon it by this Order.

(2) The Council shall be a body corporate with perpetual succession and a seal and with power to sue and be sued in its corporate name and to hold land.

4. (1) The principal function of the Council shall be to advise the Minister, the Eastern Regional Health Authority, health boards, hospitals and other persons on any matter relating to haemophilia, on its own initiative or at the request of the Minister, the Eastern Regional Health Authority, health boards or hospitals.

(2) Without prejudice to (1) the Council may provide advice relating to:

- (i) the care and treatment of persons with haemophilia;
- (ii) protocols for 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.

(3) The Council may promote its functions through the publication of documents, organisation of conferences and recommending measures to promote the health of persons with haemophilia.

(4) The Council may request advice from any person in relation to the performance of its functions.

5. (1) The Council shall, not later than 30th June of each year, present an annual report to the Minister in relation to the performance of its functions during the preceding year and for the purposes of this provision the period commencing on the date of this Order and ending on 31st December, 2004, shall be deemed to be a calendar year.

(2) The Council shall submit to the Minister such information regarding the performance of its functions as the Minister may from time to time request.

**MEMBERSHIP OF THE COUNCIL**

6. The Council shall consist of not more than 11 members appointed by the Minister, of whom—

- (a) 2 shall be appointed on the nomination of the Irish Haemophilia Society;
- (b) one shall be the National Haemophilia Director;
- (c) one shall be a consultant haematologist with an interest in paediatric haemophilia;
- (d) one shall be a consultant haematologist working outside the functional area of the Eastern Regional Health Authority, who treats persons with haemophilia;
- (e) one shall be a registered nurse with an interest in haemophilia;
- (f) one shall be a member of a registered profession with an interest in haemophilia;
- (g) one shall be nominated by the Chief Executive Officers of health boards;

7. The Minister shall appoint one of the members of the Council to be the Chairperson of the Council.

#### **TERM OF OFFICE**

8. The term of office of the Chairperson and of each ordinary member of the Council shall be 3 years from the date of appointment. Members may be appointed for more than one term of office. The Chairperson shall hold office until he or she ceases to be a member of the Council or until the Minister appoints another person to be Chairperson.

9. A member of the Council may at any time resign his or her membership by letter addressed to the Minister and the resignation shall take effect from the date specified therein or upon receipt of the letter by the Minister, whichever is the later.

10. A member shall cease to be a member of the Council on being requested by the Minister to resign.

11. In the event of a casual vacancy arising on the Council, the vacancy shall be filled by appointment by the Minister and where the vacancy arises from a member who was appointed on the nomination of a body referred to in Article 6 the appointment shall be made on the nomination of that body. The person appointed to fill a casual vacancy shall hold office as a member of the Council for the unexpired period of the term of office of the said member.

#### **MEETINGS OF THE COUNCIL**

12 (1) The Council shall hold such and so many meetings as may be necessary for the performance of its functions, and shall meet not less than 3 times per annum.

(2) The quorum for a meeting of the Council shall be 5, which shall include at least one member of the Irish Haemophilia Society.

(3) The Council may regulate by Standing Orders or otherwise, its procedures and business.

(4) The proceedings of the Council shall not be invalidated by any vacancy or vacancies among its members, or by any defect in the appointment of the Council or any member thereof.

13 (1) The Chairperson may, at any time, upon giving not less than five working days notice call a meeting of the Council.

(2) If the Chairperson refuses to call a meeting of the Council after a requisition for that purpose, signed by not less than five members of the Council, has been presented to the Chairperson, any five members of the Council may call a meeting of the Council.

(3) If the Chairperson, without so refusing, does not, within seven days of the presentation of a requisition for that purpose signed by not less than five members of the Council, call a meeting of the Council, any five members of the Council may call a meeting of the Council.

(4) For each meeting of the Council:

(a) the Chairperson shall, if present, chair the meeting;

(b) in the absence of the Chairperson, the members of the Council who are present shall choose one of their number by simple majority, to be Chairperson of the meeting;

(c) minutes of each meeting of the Council shall be kept by a person designated by the Chairperson and shall be agreed at the following meeting;

(d) the names of the members present at a meeting of the Council shall be recorded in the minutes of the meeting.

14. (1) All acts of the Council and all questions coming or arising before the Council may be done and decided by a simple majority of such members of the Council as are present and vote at a meeting of the Council.

(2) In the case of equality of votes on any question arising at a meeting of the Council, the person chairing the meeting shall have a second, or casting vote.

(3) A memorandum signed by all the members of the Council shall be effective for all purposes as if it was a resolution of the Council passed at a meeting duly convened, held and constituted.

#### REMUNERATION

15. (1) A person shall not receive any remuneration for acting as a member of the Council, but members of the Council may be paid travelling and subsistence allowances in accordance with such scales as may from time to time be approved by the Minister, with the consent of the Minister for Finance.

(2) The Chairman may receive such remuneration as the Minister, with the consent of the Minister for Finance, may determine.

#### COMMITTEES

16. (1) In order to facilitate the discharge of its functions, the Council may establish committees whose functions shall be to assist and advise the Council in relation to the performance of its functions.

(2) Membership of a committee established by the Council may include persons who are not members of the Council.

(3) Any committee so appointed shall act subject to such directions as may be given by the Council, and any expenditure of moneys by such committee shall be subject to the approval of the Council.

(4) A member of a committee established under this Article may be removed from membership by the Council, and the Council may appoint new members to a committee.

(5) The Council may dissolve a committee appointed under this Article.

(6) The acts of a committee established under this Article shall be subject to confirmation by the Council.

#### **FINANCE**

17 (1) The Council shall, not later than the 30th day of September in each year, submit to the Minister a statement of its estimated budgetary requirements in respect of the following financial year.

(2) The Minister may pay to the Council, in each year out of moneys provided by the Oireachtas, a grant or grants, of such amount or amounts as the Minister may decide.

(3) The Council shall keep all proper and usual accounts of all moneys received or expended by the Council, including an income and expenditure account and balance sheet and, in particular, shall

keep all such special accounts as the Minister may from time to time direct.

(4) The financial year of the Council shall be the period of twelve months ending on 31st day of December in any year and for the purposes of this provision the period commencing on the date of this Order and ending on 31st day of December 2004, shall be deemed to be a financial year.

(5) A statement of accounts of the Council for each financial year shall be prepared and after such preparation be subject to audit by the Comptroller and Auditor General under Section (5) (First Schedule) of the Comptroller and Auditor General (Amendment) Act 1993.

#### **CHIEF OFFICER**

18. (1) There shall be a chief officer of the Council who shall be known as, and is in this Order referred to as “the Chief Officer”.

(2) The Chief Officer shall be appointed by the Council and shall hold office for such period and upon such terms and conditions (other than terms and conditions relating to remuneration and allowances for expenses) as the Council may, with the approval of the Minister, determine from time to time.

(3) The terms and conditions relating to the remuneration, superannuation and allowances for expenses of the Chief Officer shall be such as may be determined from time to time by the Minister, with the consent of the Minister for Finance.

(4) The Chief Officer shall carry on, manage and control generally, the administration and business of the Council and perform such other functions as may be determined by the Council.

(5) The Chief Officer shall not be a member of the Council but shall be entitled to attend all council meetings unless the Council otherwise decides.

#### MEMBERS OF STAFF

19. (1) The Council may, with the approval of the Minister, with the consent of the Minister for Finance, appoint such and so many officers as the Council may, from time to time think proper and in appointing any such officers, the Council shall comply with any directions given by the Minister relating to the procedure to be followed.

(2) The Council shall, subject to the approval of the Minister, with the consent of the Minister for Finance, determine the remuneration and conditions of service (including superannuation) of its officers.

(3) The Chief Officer shall, from time to time, assign such duties as he or she considers appropriate to each officer and each such officer shall perform the duties so assigned.

20. The Council may from time to time engage such consultants or advisers as it may consider necessary for the performance of its functions, and any fees due to a consultant or adviser engaged under this Article shall be paid by the Council out of moneys at its disposal.

#### SEAL

21. (1) The Council shall, as soon as may be after the establishment day, provide itself with a seal.

(2) The seal of the Council shall be authenticated by the signature of—

(a) the Chairperson of the Council, or some other member of the Council authorised by the Council to act in that behalf, or

(b) an officer of the Council authorised by the Council to act in that behalf.

(3) All courts shall take notice of the seal of the Council, and every document purporting to be an instrument made by the Council and to be sealed with the seal (purporting to be authenticated in accordance with paragraph (2) of this Article) of the Council, shall be received in evidence and be deemed to be such instrument without proof, unless the contrary is shown.

#### DISCLOSURE OF INTEREST

22. (1) Where the Chairperson, any other member of the Council, the Chief Officer or other officer, a consultant, advisor or other person engaged by the Council, has a beneficial interest in, or material to, any matter which falls to be considered by the Council, he or she shall comply with the following requirements:—

(a) he or she shall disclose to the Council through the Chief Officer, or in the case of the Chief Officer or a member of the Council through the Chairperson,

or, in the case of the Chairperson directly to the Council, the nature of his or her interest in advance of any consideration of the matter;

(b) he or she shall neither influence nor seek to influence a decision in relation to the matter;

(c) he or she shall take no part in any consideration of the matter by the Council, save to such extent as the Chairperson, or where the Chairperson has such an interest, a majority of the Council, may permit.

(2) Where a question arises as to whether or not a course of conduct, if pursued by a person, would be a failure by him or her to comply with paragraph (1) of this Article, the question shall be determined by the Council and particulars of the determination shall be recorded in the minutes of the meeting concerned.

(3) Where a disclosure is made to the Council, particulars of the disclosure shall be recorded in the minutes of the meeting concerned.

23. A person shall not, without the consent of the Council, disclose any information obtained while performing duties as a member or officer of, or a consultant or advisor to, the Council or a committee established pursuant to Article 16 of this Order.

#### **LOANS, PURCHASE AND SALE OF LAND ETC**

24. For the purpose of the performance of its functions:

(a) The Council shall not borrow money without the prior consent of the Minister.

(b) The borrowing of money by the Council shall be subject to such terms and conditions as may be specified by the Minister.

(c) The Council may acquire land or buildings subject to the approval of the Minister.

(d) The Council may, subject to the approval of the Minister sell, exchange, let or otherwise dispose of any land or buildings vested in it.

(e) The Council may charge fees for services it provides, for publications it produces and for attendance at events it organises.

25. This Order will come into operation on the 22nd day of July 2004.



GIVEN under the Official Seal of the Minister for Health and Children, this 22nd day of July, 2004.

MICHEÁL MARTIN,  
Minister for Health and Children.

#### **EXPLANATORY NOTE**

(This note is not part of the Instrument and does not purport to be a legal interpretation.)

The effect of this Order is to establish a Council to advise the Minister for Health and Children, health agencies, and other bodies, on all aspects of haemophilia, on its own initiative or at the request of the Minister.



*Number 42 of 2007*

**HEALTH (MISCELLANEOUS PROVISIONS) ACT 2007**

AN ACT TO GIVE STATUTORY EFFECT TO, AND AMEND, CERTAIN ORDERS MADE UNDER THE HEALTH (CORPORATE BODIES) ACT 1961; TO AMEND THE MEDICAL PRACTITIONERS ACT 2007; TO AMEND SECTION 38 OF THE HEALTH ACT 2004; AND TO PROVIDE FOR MATTERS CONNECTED THEREWITH.

*[21st December, 2007]*

BE IT ENACTED BY THE OIREACHTAS AS FOLLOW

(1) In Article 5(2), “Health Service Executive” shall be substituted for “Minister” in each place that it occurs.

(2) Article 17 shall be amended by—

(a) the substitution, in paragraph (1), of “Health Service Executive” for “Minister”, and

(b) the substitution, in paragraph (2), of “Health Service Executive” for “Minister” in each place that it occurs.

(3) Article 18 shall be amended by—

(a) the substitution, in paragraph (2), of “with the approval of the Health Service Executive given with the consent of the Minister and the Minister for Finance” for “with the approval of the Minister”, and

(b) the substitution, in paragraph (3), of “the Council, with the approval of the Health Service Executive

given with the consent of the Minister and the Minister for Finance” for “the Minister, with the consent of the Minister for Finance”.

(4) Article 19 shall be amended by—

(a) the substitution, in paragraph (1), of “with the approval of the Health Service Executive given with the consent of the Minister and the Minister for Finance” for “with the approval of the Minister, with the consent of the Minister for Finance”, and

(b) the substitution, in paragraph (2), of “with the approval of the Health Service Executive given with the consent of the Minister and the Minister for Finance” for “subject to the approval of the Minister, with the consent of the Minister for Finance” in each place that it occurs.

(5) In Article 24 “Health Service Executive” shall be substituted for “Minister” in each place that it occurs.

## NATIONAL HAEMOPHILIA COUNCIL – LIST OF MEMBERS

## The Council met 5 times in 2007

## Meetings Attended in 2007

Professor John Bonnar (Chairperson)	5
Mr Brian O'Mahony (Irish Haemophilia Society)	3
Mr Michael Davenport (Irish Haemophilia Society)	4
Dr Barry White (Director, National Centre for Hereditary Coagulation Disorders)	5
*Dr Beatrice Nolan (Consultant Haematologist, Our Lady's Children's Hospital, Crumlin)	2
Dr Oonagh Gilligan (Consultant Haematologist, Cork University Hospital)	4
Ms Eilish Hardiman (Deputy Chief Executive Officer, St James's Hospital)	3
Ms Jude Smith (Clinical Nurse Manager, St James's Hospital)	3
Ms Angela Fitzgerald, (Health Service Executive)	1
Ms Jennifer Feighan, (Health Service Executive)	2
Ms Mary Jackson, (Blood Policy Division, DoHC)	5
Administrator to the National Haemophilia Council: Mr Gareth Presch (H S E)	
Secretary to the National Haemophilia Council: Ms Fiona O'Connell (H S E)	

\*Please note that Dr Beatrice Nolan was on leave until the 17th of July 2007 and attended all subsequent meetings.



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