

**ANNUAL REPORT
2006**

**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.

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

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Introduction:

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.

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

The National Haemophilia Council was established by the Minister of Health and Children by Statute No. 45 (July 2004) following the Report of the Lindsay Tribunal of Enquiry into the Infection with HIV and Hepatitis C of Persons with Haemophilia and Related Matters (September 2002). The principal function is to advise the Minister, Health Service Agencies and other persons on any matter relating to haemophilia.

The National Haemophilia Council provides a unique approach to a specific area of specialised health care. Essentially the Council is a partnership of persons with haemophilia and health professionals working together to ensure that all aspects of inherited bleeding disorders are managed to optimum standards in a safe patient centred service. Over the last three years major progress has been made in Ireland in the clinical management of haemophilia to achieve high quality control of haemophilia products through the cold chain delivery programme based at the National Centre for Hereditary Coagulation Disorders at St. James's Hospital, Dublin. A national patient database, electronic patient record and protocols have been evaluated and are aimed to improve patient care throughout the country.

In 2006 external audits of the quality of the present service in the Irish Haemophilia Centres in Dublin and Cork were carried out. While the service has generally improved, additional health care professionals and major improvements in hospital infrastructure for patient care are urgently required in both Dublin and Cork. These requirements are essential to provide appropriate standards of care for persons with haemophilia and we expect these facilities to be provided within the next 1 – 2 years.

I wish to thank all the members of the Council for the giving of their time and expertise to achieve a safe and high quality service for all adults and children with haemophilia throughout Ireland.

Professor John Bonnar.

Administrator's Statement

The year 2006 was a very successful year for the National Haemophilia Council and although I was only appointed as administrator to the Council in November 2006, I could see a vast amount of progress had been made in the previous ten months of 2006. The Council's work in 2006 attributed to progress being made in the following areas: The cold chain delivery programme, information and communication technology (ICT) project, quality and audit, haemophilia services and clinical protocols, appointments and the National Haemophilia Council's website.

Meetings of the Council were held in the Department of Health and Children (DOHC) in 2006 and the DOHC also provided administrative support to the Council. I would like to thank the DOHC for their support.

The Council held an information day in St James's Hospital on the 18th of November where the Chairman of the National Haemophilia Council, Professor John Bonnar introduced me to both patients and health professionals and also stressed the need to improve the facilities and resources in some of the Haemophilia treatment centres outside Dublin. Professor Owen Smith from Crumlin Children's Hospital then gave a speech on the development of paediatric services. In the afternoon, Dr. Paul Giangrande (Medical Director of the World Federation of Haemophilia), Dr Barry White (National Haemophilia Director, St James's Hospital) and Brian O'Mahony (Chief Executive of the Irish Haemophilia Society) spoke about the future of haemophilia care. The day was a great success with approximately 40 attendees. The Council plans to have its next information day on 24th November 2007 in Dr Steevens' Hospital.

I would like to take this opportunity to thank all the members of the Council for their continued hard work throughout the year, and I look forward to working with them and the patients so we can aim to provide a world class health service for people with haemophilia in 2007.

Gareth Presch
Administrator

Membership of the Council

Statutory Instrument No. 451 of 2004 (Appendix A) 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 2005/2006 are listed below and in Appendix B.

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 in this area. 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 Advisory Group 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.

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), MRCPath. 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)

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.

2. Review of 2006

Annual Report

This is the third 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, 2006 to 31 December, 2006, to comply with Regulation 5(1) of the SI.

Meetings of Council

The Council met on six occasions – 9 January, 20 March, 2 May, 3 July, 4 September and 6 November 2006. Attendance is also noted in Appendix B.

Secretariat

The Department of Health and Children provided the secretariat to the Council in 2006. The Department had approval from the Department of Finance to appoint an administrator and secretary to the Council. The administrator and secretary have been appointed and began their work with the Council in early 2007. Both the administrator and the secretary to the Council are based at Health Service Executive, Mill Lane, Palmerstown, Dublin 20.

Cold Chain Delivery Programme

The cold chain storage and delivery system for products, using EAN (European Automatic Numbering) barcodes and based at the National Centre for Hereditary Coagulation Disorders (NCHCD) continued successfully during 2006. This has assisted in optimising the clinical management of haemophilia. The system ensures high quality control standards are in place for the storage, delivery and administration of haemophilia products. It also ensures that a rapid, accurate and validated recall of products can take place if necessary.

Information and Communication Technology (ICT) Project

The ICT project, based at the NCHCD continued to be developed during the year.

The components of the ICT project are:

- A national patient database
- An electronic patient record
- Integrated clinical protocols (with scope for continuing audit and evaluation tools).

Having been positively evaluated in 2005 it was mainstreamed in St James's in 2006, with its roll out to other comprehensive centres planned for 2007. The project involves the NCHCD linking with all main haemophilia treatment providers with input of data on patients onto the national database. The system has the support of the Irish Haemophilia Society, as its overall aim is to improve patient care throughout the country.

Quality and Audit

The Council has formed close links with the UK Haemophilia Centre Doctors Organisation (UKHCDO). The NCHCD was last audited by Professor Christine Lee on behalf of UKHCDO in late 2003. In order that the UKHCDO would carry out audits of Irish Haemophilia Centres in 2006 there was a requirement that the centres would submit patient details to UKHCDO. This was unacceptable because of patient confidentiality. Following further discussions with UKHCDO it was agreed that Irish clinicians would remain as affiliated members of UKHCDO, but an independent Irish audit instrument would be devised and independent experts commissioned to carry out the audit of Irish centres. It was agreed that the audit team would consist of an expert clinician, a nurse with expertise in haemophilia care and a representative of the Irish Haemophilia Society. The intention was to have a patient representative nominated by the Irish Haemophilia Society, on the audit panel. Agreement was not reached with the UK auditors on the process for patient involvement and therefore a patient representative was not included in the 2006 audit. It is the view of the National Haemophilia Council that future audits must include an independent patient representative nominated by the Irish Haemophilia Society. The recommendations and findings of the preliminary audit team will be examined by the Council which will advise on a further formal audit, which will be carried out by an audit team including a member of the Irish Haemophilia Society during 2007.

The audit report for each hospital indicated that services provided were generally satisfactory. However the reports made recommendations on how services could be enhanced to provide optimum care. The recommendations for each hospital are below:

Our Lady's Children's Hospital Crumlin, Dublin

- A new consultant haematologist to lead on paediatric haemophilia and thrombosis services is urgently required.
- Specialised coagulation laboratory tests including FVIII should be available on a 24hour basis on a formalized rota.
- Data management support is required especially with the introduction of the Clintech system. One option may be for the Data Manager from the National Haemophilia Centre at St James's Hospital to spend time at the Crumlin site.
- The haemophilia nurse specialists should incorporate peripheral venepuncture into their repertoire in order to provide continuity of care and fulfill their role in home treatment training.
- The nurses should also be supported in assessing the need and appropriateness of school and home visits, taking account of the wide catchment area of the Centre. Community visits and liaison should be incorporated into their role.

- Results of investigations should be filed more promptly and the process should be formally audited.
- The physiotherapist should be encouraged and enabled to attend conferences and visit another paediatric centre as part of his/her continuous professional development.
- Improved facilities and space for the coagulation section of the haematology laboratory are required.

Cork University Hospital

- Dedicated Haemophilia space should be identified within the hospital to form a physical space for the “haemophilia centre” This should include office space for the haemophilia nurses.
- A haemophilia secretary should be employed.
- A consultant in Haemostasis and Thrombosis to take overall responsibility for the haemophilia centre should be employed.
- The medical records of patients with inherited bleeding disorders should be kept on site and be readily available on a 24hour basis.
- More space and more dedicated staff need to be identified for the coagulation laboratory.
- A dental surgeon should be available in the clinics when children attend for their 6 monthly reviews.
- The haemophilia on-call service should be provided, at middle grade, by a haematology doctor on all days rather than at weekends as now.
- A data manager should be employed on at least a part time basis to provide support for the service, especially when the new Clintech national haemophilia system is introduced.
- The Social Worker and Physiotherapist should be attending adult review clinics as well as paediatric ones.
- Subcutaneous high concentration DDAVP should be introduced to replace the intravenous formulation currently used.

- An ansaphone should be provided for the haemophilia nurses.
- Standard operating procedures for patients attending the A&E department should be reviewed and revised.
- The new card registration system due to be introduced in Dublin should also be introduced in Cork at the same time.
- An audit of patients attending outside routine clinics should be carried out to document the time between arrival in the hospital and actual treatment with clotting factor concentrate or DDAVP.
- The haemophilia nurses should undergo performance review.
- The Q-Pulse system currently developed at St James's Hospital should be introduced as most of the shared protocols are already used..

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

- Improved and preferably centralized and protected beds for inpatients with haemophilia should be identified. The nurses covering these beds will need to be trained in haemophilia care.
- There should be a formulized 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 reported poor uptake of recommended PEG interferon and ribavirin treatment.

Auditors:

- Dr Mike Makris, Haemophilia Director
Sheffield Haemophilia and Thrombosis Centre, Sheffield, UK
- Christine Harrington, Nurse Consultant in haemophilia, Royal Free Hospital, London, UK
- Katharine Dormandy Haemophilia Centre and Haemostasis Unit, Royal Free Hospital, London, UK

Haemophilia Services and Clinical Protocols

The Irish Haematology Society liaises with the National Haemophilia Council through the consultants who are members of the Council. The Director of Haemophilia Services is based at the NCHCD in St James's Hospital. Paediatric services are provided at Our Lady's Hospital for Sick Children, Crumlin. Other specialist services are provided at Cork University Hospital, University College Hospital, Galway, Limerick Regional Hospital and Waterford Regional. Dr White, in consultation with colleagues in the Irish Haematology Society continued the development of clinical protocols for haemophilia treatment, setting out best practice in relation to management of persons with haemophilia. The protocols were agreed by the Irish Haematology Society and have also been approved by the Irish Haemophilia Society.

The agreed structure of care involves the provision of four levels of service:

- Level 1 Comprehensive care centres (at NCHCD, Our Lady's Hospital Crumlin and Cork University Hospital)
- Level 2 Haemophilia treatment centres, i.e. hospitals that would treat patients with haemophilia (University College Hospital, Galway, Limerick Regional, Waterford Regional, Sligo General)
- Level 3 Hospitals with a haematologist, providing cover to a large geographical area
- Level 4 All other hospitals with Accident and Emergency Departments.

The priorities identified for the attention of the Health Service Executive in 2006 by various haemophilia treatment centres, and which the Council endorsed were:

- Posts linked to the National IT programme, which were mainstreamed in St James's
- Appointment of a psychologist, physiotherapist and social worker at Our Lady's Hospital for Sick Children in Crumlin – these posts have just been filled
- One Consultant haematologist, with nursing and clerical support in Cork University College Hospital
- Upgrading of Clinical Nurse Manager 3 post in NCHCD to an Assistant Director of nursing post to allow for that person to have a national role in haemophilia nurse education from NCHCD

Appointments:

Dr Clodagh Ryan was appointed as Paediatric Haematologist to Cork University Hospital.

Dr Beatrice Nolan was appointed to replace Professor Owen Smith on the National Haemophilia Council.

Mr Gareth Presch was appointed as Administrator to the National Haemophilia Council.

Virology /Hepatitis C, HIV, Hepatitis B, and Persons with Haemophilia

Since 2002 the NCHCD had been aiming to compile a comprehensive database of all persons with haemophilia and related clotting factor disorders in order to ensure that anyone who had received clotting factor concentrates prior to 1992 had been contacted and offered virology testing for Hepatitis C. This work continued during 2006 and provided a more comprehensive register on the national database in conjunction with the development of the electronic database system.

vCJD and Persons with Haemophilia

Because of the known links between blood transfusion and variant Creutzfeldt-Jacob Disease (vCJD), the NCHCD continued to monitor the situation in relation to the management of the small number of haemophilia patients considered “at risk” for vCJD because they were administered batches of UK manufactured products where there was a potential that the donors of some of these products may at some stage develop vCJD.

Clinical Supervision, Support and Competency Assessment for Nurses providing Haemophilia Care

Inherited bleeding disorders are rare and complicated conditions and effective management of these conditions is particularly complex and involves the administration of comprehensive care and support by a team of diverse specialists and health care professionals. Nurses involved in haemophilia care play a pivotal role in the delivery and coordination of this care and support.

Two members of the Council developed a programme of clinical supervision, support and competency assessment for nurses involved in haemophilia care. This initiative was rolled out in 2006 to nurses providing haemophilia care at St James Hospital.

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 2006.

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 Council had no independent secretariat to the end of 2006 and the costs of meetings and other administrative costs were provided by the Department of Health and Children. The Secretariat has been appointed to the Council. In 2007 the Council will receive funding from the Health Service Executive.

Website

The National Haemophilia Council website went live in 2006. The web address is www.nationalhaemophiliacouncil.ie and will be updated by the Administrator of the Council.

Information Day

The second information day organised by the National Haemophilia Council was held in St. James's Hospital on 18th November. Forty people with haemophilia including some parents attended the meeting together with nurses and members of the Council. The first speaker was Professor Bonnar, Chairman of the National Haemophilia Council who gave an update on the work of the Council during 2006. Professor Bonnar stressed the need to improve the facilities and resources in some of the haemophilia treatment centres outside Dublin. The next speaker was Professor Owen Smith who gave an update on the development of paediatric services. There were a number of questions from the audience which demonstrated clear concern in relation to the future location of the new National Children's Hospital in the context of ensuring seamless consistent care for children with haemophilia.

The main session in the afternoon was a Symposium on the future of haemophilia. There were three speakers in this session, Dr. Paul Giangrande, Medical Director of the World Federation of Haemophilia, Dr. Barry White, National Haemophilia Director, St. James's Hospital, and Brian O'Mahony, Chief Executive of the Irish Haemophilia Society. All three speakers set out their views on possible future developments. Dr. Giangrande spoke about the evolution of recombinant products and the exciting work being currently undertaken in relation to the availability of recombinant factor concentrates with a longer half life which will require prophylaxis therapy possibly on a once a week basis, as opposed to the current three times per week.

Dr. Giangrande also discussed the potential use of products from transgenic animals, the production of less immunogenic concentrates which would cause a lower rate of inhibitor formation, and the future development of gene therapy. The development of gene therapy has been a major hope for people with haemophilia around the world for the past number of years. For the development of successful gene therapy a number of major obstacles have to be overcome and we are uncertain when gene therapy may become available. Dr. Giangrande concluded with the current state of the National Health Service in England and his concerns on the economics of haemophilia care.

Dr. Barry White spoke about optimising services for people with haemophilia in Ireland over the next 5 years, and speculated that the next 5 - 10 years will see the introduction of long acting treatment, enhanced treatment of HIV, enhanced cure rates for Hepatitis C, and possible breakthroughs in inhibitor management. He stated that in his view, over the next 10 - 20 years all of the major advances may come from outside the field of haemophilia, but will result in better treatment for HIV, Hepatitis C, joint disease and inhibitors. Major advances in gene therapy could result in a cure or certainly in the availability of longer acting treatment. He hoped we may see haemophilia cured in-utero in the majority of cases, there may be a dramatic reduction in the number of patients with haemophilia and a reduced need for factor concentrates. There was then discussion in relation to the future requirement for haemophilia services, if some of these predictions came to pass.

Brian O'Mahony also speculated on some future developments. He stated that in his view, longer acting factor VIII will be available within 5 years, a recombinant von Willebrands concentrate may be available in 6 years and gene therapy in 10 to 20 years. He stressed the need for more global data to be collected on the incidence of inhibitors, with better comparison of the prevalence due to plasma derived and recombinant concentrates. He then addressed the issue of the economics of care and spoke about the "willingness to pay" survey in Sweden which showed that tax payers in Sweden were willing to pay for high quality haemophilia care, when the benefits of such care and the benefits in terms of quality of life were explained. He continued on the future of comprehensive care centres and the challenges facing haemophilia societies in the future. These challenges included dealing with complacency, non involvement and adapting to change. He emphasised the continued need for haemophilia societies, when the children who now have haemophilia are adults and face new challenges as a result of longer life expectancy. The Symposium was an enjoyable event for all.

Appendix A



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.

(L.S.) 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.

Appendix B

NATIONAL HAEMOPHILIA COUNCIL – LIST OF MEMBERS

Meetings Attended in 2006

Professor John Bonnar (Chairperson)	6
Mr Brian O'Mahony (Irish Haemophilia Society)	6
Mr Michael Davenport (Irish Haemophilia Society)	6
Dr Barry White (Director, National Centre for Hereditary Coagulation Disorders)	6
Dr Beatrice Nolan (Consultant Haematologist, Our Lady's Hospital for Sick Children) Prof Owen Smith attended in Dr B Nolan's absence from November (Consultant Haematologist, Our Lady's Hospital for Sick Children)	4
Dr Oonagh Gilligan (Consultant Haematologist, Cork University Hospital)	2
Ms Eilish Hardiman (Deputy Chief Executive Officer, St James's Hospital)	2
Ms Jude Smith (Clinical Nurse Manager, St James's Hospital)	4
Ms Angela Fitzgerald / Ms Jennifer Feighan, (Health Service Executive)	5
Ms Mary Jackson, (Blood Policy Division, DoHC)	6

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)



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