

NATIONAL HAEMOPHILIA COUNCIL
ANNUAL REPORT 2005

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

1. Principal Functions of the Council

The establishment of a National Haemophilia Council was one of the measures 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.

2. 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 2004/2005 are listed in Appendix A.

3. Annual Report

This is the second annual Report of the National Haemophilia Council to the Tánaiste and Minister for Health and Children submitted under the provisions of Statutory

Instrument (SI) No. 451 of 2004, and covers the period 1 January, 2005 to 31 December, 2005, to comply with Regulation 5(1) of the SI.

4. Meetings of Council

The Council met on four occasions – 7 February, 4 April, 5 September, and 7 November, 2005.

5. Secretariat

The Department of Health and Children provided the secretariat to the Council in 2005. The Department had approval from the Department of Finance to appoint an administrator and secretary to the Council. It was agreed that these staff should be located in the Eastern Regional Health Authority area and discussions were initiated with ERHA. However, the Health Reform Programme further delayed the establishment of these posts.

6. 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 2005. This has assisted in optimising the clinical management of haemophilia. This 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.

7. 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 consistent audit and evaluation tools).

The project continued on a pilot basis, and was evaluated, with a view to its mainstreaming in 2006. This evaluation and an assessment of needs from 2006 onwards were submitted to the Health Service Executive in October, 2005 for its consideration and approval. 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.

8. 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 and the audit was very satisfactory. In order that the

UKHCDO would carry out audits of Irish Haemophilia Centres there was a requirement that these centres would submit patient details to UKHCDO. This was unacceptable as it would breach 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. Audits of comprehensive care centres will be undertaken during 2006.

9. 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 met with the approval of the Irish Haemophilia Society.

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

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| 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 Services Executive in 2005 by various haemophilia treatment centres, and which the Council endorsed were:

- Agreement to mainstream the funding for the following posts, which are part of the national IT programme in St James's Hospital
 - Consultant haematologist, national haemophilia project manager, quality assurance officer(these posts have been filled on a contract basis during the pilot phase of the programme)

- Appointment of a psychologist and physiotherapist at Our Lady's Hospital for Sick Children in Crumlin
- Consultant post, with expertise in paediatric haemophilia care, in Cork University Hospital
- Consultant haematologists, with nursing and clerical support in 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 play a national role in haemophilia nurse education from NCHCD.

The Health Service Executive must ensure that these posts are mainstreamed/filled so that services comply with the recommendations of the Lindsay Tribunal.

10. 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 2005 and patient numbers on the national database increased in conjunction with the development of the electronic database system. A press conference was organised under the auspices of the Council to alert the general public about this programme on 21 June and telephone helplines were run by the NCHCD, the Irish Haemophilia Society and the Irish Blood Transfusion Service. This publicity resulted in the identification of one previously unknown case of Hepatitis C.

11. vCJD and Persons with Haemophilia

Because of the confirmed links between blood transfusion and 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.

12. 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 was sent to the Department of Health and Children's Chief Nursing Officer, who advised on certain

aspects of it and the programme was introduced in St James's Hospital in November, 2005.

13. 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 2005.

14. 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.

15. Finance

To date the Council has no independent secretariat and the costs of meetings and other administrative costs were provided by the Department of Health and Children. The Secretariat will be appointed to the Council in 2006.

Appendix A

NATIONAL HAEMOPHILIA COUNCIL – LIST OF MEMBERS

Professor John Bonnar (Chairperson)

Mr Brian O'Mahony (Irish Haemophilia Society)

Mr Michael Davenport (Irish Haemophilia Society)

Dr Barry White (Director, National Haemophilia Centre)

Professor Owen Smith (Consultant Haematologist, Our Lady's Hospital for Sick Children, Crumlin) who resigned in November, and was replaced by Dr Beatrice Nolan also a Consultant Haematologist in Our Lady's Hospital for Sick Children, Crumlin.

Dr Oonagh Gilligan (Consultant Haematologist, Cork University Hospital)

Ms Eilish Hardiman (Director of Nursing, St James's Hospital)

Ms Jude Smith (Clinical Nurse Manager, St James's Hospital)

Ms Angela Fitzgerald, (Hospital Network Manager, HSE)

Ms Mary Jackson, (Blood Policy Division, DoHC)