



National Haemophilia Council Meeting
Wednesday 1st May, 2019 at 10.00am
Irish Haemophilia Society, Cathedral Court, New Street, Dublin 8 D08 VH64

Minutes

Present

Dr Barry Harrington, Chairperson, National Haemophilia Council
Mr Michael Conroy, Principal Officer, Cancer, Blood & Organ Policy Unit, DOH
Dr Alison Dougall, Dental Consultant, Dublin Dental University Hospital
Dr Cleona Duggan, Consultant Haematologist, Cork University Hospital
Dr Ruth Gilmore, Consultant Haematologist, University Hospital Galway
Dr Niamh O'Connell, Medical Director, NCC, St. James's Hospital
Mr Brian O'Mahony, Chief Executive, Irish Haemophilia Society
Dr Beatrice Nolan, National Paediatric Haemophilia Director, CHI at Crumlin
Ms Ann O'Sullivan, Nurse Manager, NCC, St. James's Hospital
Dr David Vaughan, Director of Quality & Safety, National Children's Hospital Group

Apologies

Ms Debbie Greene, Administrator, Irish Haemophilia Society

In Attendance

Ms Gráinne Leach, Chief Officer, National Haemophilia Council
Dr William Murphy (At the invitation of Dr Barry Harrington, Chairperson of the NHC)

1. Meeting

- 1.1** The Council was called to order at 10.05am.
- 1.2** Dr Barry Harrington welcomed back Dr Ruth Gilmore back to Council, from leave and also welcomed Dr William Murphy to attend the meeting. Dr Jeanne Moriarity was also invited to attend but was unable to attend.
- 1.1.** The minutes of the meeting dated the 15th February, 2019 having previously been circulated were approved.

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| <p>3 Correspondence</p> <p>3.1 All Correspondence received was noted.</p> <p>3.2 Letter received from Ms. Eilish Hardiman, Chief Executive, Children’s Hospital Group confirming that she will attend the NHC meeting on Wednesday 18th September, 2019.</p> <p>3.3 Letter received from Minister for Health Simon Harris acknowledging receipt of Dr Barry Harrington’s resignation as Chairperson of the NHC from the 31st July, 2019.</p> <p>4. 3 Comprehensive Care Centre’s and Galway University Hospital</p> <p>4.1 Cork University Hospital</p> <p>4.1.1 Dr Cleona Duggan updated Council regarding the CCC in CUH.</p> <p>4.1.2 Dr Duggan informed Council that the 0.5WTE Consultant’s post had been advertised on the 30th April, 2019. There is currently no funding for this post.</p> <p>4.1.3 Dr Duggan informed Council that an additional 0.5 WTE admin staff member has been appointed to the CCC in CUH on the 29th April, 2019 to support the Haemophilia services to patient who attend the CCC in CUH. However commencement date depends on the Warfarin clinic reception vacating the area. The warfarin clinic reception on site was agreed as a short term, temporary arrangement.</p> <p>4.1.4 Dr Duggan informed Council that the Clinical Nurse Specialist in the CCC in CUH has still not been replaced. The previous CNS post was seconded elsewhere and it is not clear whether or not a replacement CNS post has been approved.</p> <p>It was agreed by Council to write again to the Director of Nursing in CUH to request the appointment of the Clinical Nurse Specialist to the CCC asap.</p> <p>4.1.5 The Chief Officer received the following update from CUH regarding the dental service in the CCC in CUH:</p> <ul style="list-style-type: none"> • The Dental Service runs one day per week serving Children and Adults on an alternating basis. It is serviced by Dr Danelle McGeown (Dental Surgeon (Specialist in Special Care Dentistry) and a Dental Nurse. • The level of the dental service available at CUH, mimics that, that is valuable to patents who attend at the NCC in St. James’s. | <p>ALL</p> <p>GL</p> <p>GL</p> <p>GL</p> <p>GL</p> |
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- All dental treatment is provided in liaison with the Medical Team reviewing the patient history and specific treatment need to ensure safe, effective and successful dental treatment.

4.2 National Coagulation Centre, St James Hospital

4.2.1 Dr Niamh O’Connell informed Council that the Lighthouse Project system is currently been tested by the staff from Valentia Technologies and been led by the support of the staff in the NCC on site at the National Coagulation Centre, St James’s Hospital.

4.2.2. The Lighthouse Project Steering Group are meeting with staff in the CCC in Children’s Hospital Ireland at Crumlin on Thursday 2nd May 2019 to review the current stages of the project and address the current system which is unstable.

4.2.3. Dr O’Connell informed Council that the preparation for the International Audits was in hand and that all documentation was ready for the audit of the NCC.

4.2.4. The Locum Consultant in the NCC is leaving St James’s Hospital on the 9th July 2019 to go to a permanent post in another hospital.

4.2.5. The request for an additional Data Manager for the NCC has been approved and interviews will take place in the coming month.

4.2.6. The nursing staff in the NCC has organized a National Haemophilia Study Day on Friday 17th May 2019 in the Centre for Learning & Development, Trinity Centre, St. James’s Hospital on Haemophilia & Related Bleeding Disorders.

4.2.7 The nursing manager for the NCC who has been on leave will be returning in June 2019.

4.3 Childrens Hospital Ireland at Crumlin

4.3.1 Dr Beatrice Nolan informed Council that the Consultant Paediatric Haematologist post approved in 2018 has not been filled.

4.3.2 Dr Nolan informed Council that currently there is 0.3WTE Physiotherapist, equivalent to about 12 hours per week available to haemophilia patients in the CCC in CHI at Crumlin.

Overview of physiotherapy service at CHI Crumlin to be circulated for next meeting.

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4. Galway University Hospital

4.1 Nursing: Dr Ruth Gilmore informed Council that there is still no formal cover for the CNS in Haemophilia. Nursing recruitment is an on-going issue but it is hoped that formal cover will be in place in coming months. Dr Gilmore advised that the Council will need to write to hospital management if this does not happen, as it was raised as a risk in the last audit, and still has not been acted upon two years later.

4.2 Laboratory: Senior staff rotating through special Coagulation with support of Specialist Scientist. This is working well and factor VIII, IX and VW screens are available on the routine analysers now when required.

4.3. ICT: Dr Gilmore will liaise with Dr Niamh O’Connell, NCC regarding specific timelines and requirements for the Interface of the Lighthouse Project with the NCC.

4.4. Medical: The Haemophilia / Thromboses Clinic is clinically very busy. Increasing number of outpatients and inpatient consultations and referrals. No dedicated junior staffs are appointed to the team at GUH.

Increasing referrals from outside hospitals

5. Irish Haemophilia Society

5.1 Mr Brian O’Mahony informed Council that the Outreach staff member had left the I H S and it was hoped to recruit a new staff member in the coming month.

5.2 Mr O’Mahony informed Council that to mark World Haemophilia Day on the 17th April 17th 2019, the Irish Haemophilia Society in collaboration with the RCSI in Dublin had held a symposium in the RCSI with the theme of the day **Haemophilia – The Future is Now - New Approaches to an Ancient Condition.**

5.3 WHD2019 had received a lot of media coverage on World Haemophilia Day with the added bonus of been on the Six One News on RTE Television on the day. A series of buildings and landmarks in Dublin and Cork were also lit up red on the day.

5.4 Mr. O Mahony informed Council that the I H S is organizing many events in 2019.

6. Development of Haematology Summer Undergraduate Projects

6.1.1. The Chairperson had drafted a set of documents to the Deans of the Medical Schools to introduce the development of Haematology Summer Undergraduate Projects for 2020. It is hoped that this project will come to fruition in 2020.

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| <p>7. NHC 2018 Accounts</p> | |
| <p>7.1 The Chief Officer informed Council that she was submitting further documentation to the C&AG as requested by them to complete the audit of the NHC 2018 Accounts.</p> | <p>GL</p> |
| <p>8. International Audits of the 3CCC's - May 2019</p> | |
| <p>8.1 The International Audits of the 3 Comprehensive Care Centre's will take place on the following dates:</p> | |
| <ul style="list-style-type: none"> • Tuesday 7th May, 2019 - NCC, St. James's Hospital • Wednesday 8th May, 2019 - CCC, Cork University Hospital • Thursday 9th May, 2019 - CCC, CHI at Crumlin | <p>ALL</p> |
| <p>8.1.2. The Council to host a dinner for the International Auditors and Council members on the Tuesday evening 7th May, 2019 in Dublin.</p> | <p>ALL</p> |
| <p>8.2 The Chief Officer informed Council that all business regarding the audit was in hand. The Auditors are arriving into Dublin on Monday 6th May, 2019 and will depart from Dublin on the evening of Thursday 9th May 2019 with the exception of Mr. David Page who is travelling to Canada on the 10th May, 2019.</p> | <p>GL</p> |
| <p>9. PAS</p> | |
| <p>9.1 The Chief Officer informed Council that the post for the incoming Chairperson to the National Haemophilia Council will be advertised on the Public Appointments System in the coming days.</p> | <p>GL</p> |
| <p>10. Chairpersons Farewell</p> | |
| <p>Dr Barry Harrington, Chairperson of the National Haemophilia Council in his last official duty as Chair of the NHC thanked all Council members for their help and contribution to delivering an efficient, effective service to all patients with Haemophilia and other related bleeding disorders in Ireland. He also thanked previous members of the Council who gave of their time and expertise in developing and furthering the aims of the National Haemophilia Council.</p> | |
| <p>Dr Harrington also thanked the Chief Officer, Ms Gráinne Leach for all her work in making the Council's activities run smoothly.</p> | |
| <p>In his closing statement to the Council Dr Harrington stated the following:</p> | |
| <p>"One of my main priorities as Chairperson of the NHC was getting the availability of a routine Dental Treatment Service made available to both adult and children patients with Haemophilia and other related bleeding</p> | |

disorders who attend the Comprehensive Care Centre attached to Cork University Hospital (CUH).

It was important to have similar Dental Services for patients attending the CCC in CUH to those that are available at the other two Comprehensive Care Centers at the NCC and OLCHC (now called Children’s Health Ireland at Crumlin). Thankfully, we were advised on the 2nd April, 2019 by Ms. Martine Delaney, Business Manager & Quality & Safety Lead, Directorate of Medicine, Cork University Hospital that the new newly realized Dental Service in the Comprehensive Care Centre necessary to provide such a service has been commissioned and is fully operational. It was expected to treat its first patients on Monday April 8th 2019 and it will be ready for the International Audit of the CCC in CUH on Wednesday 8th May, 2019.

Dr Harrington acknowledged and thanked the continued co-operation of all the Management Team in CUH under the direction of Mr Tony McNamara, Chief Executive CUH who made this project possible in collaboration with Dr Michael Thornton, Principle Dental Officer, Community Dental Service, HSE South, who released the appropriately trained and qualified Community Dental Officer, Dr Danielle McGeown, Senior Special Needs Dental Surgeon who will manage and provide the appropriate dental care to this cohort of patients (adults and children) attending the Comprehensive Care Centre in Cork University Hospital and into the future.

In his capacity as retiring Chairperson of the NHC Dr Harrington considered it prudent to review Council’s activities over the last eight years to consider any issues that were not completed or are targeted by Council to be undertaken into the future.

All the following projects have been identified by Council as worthwhile projects that should be pursued by Council into the future.

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The National Haemophilia Council Website

The National Haemophilia Council website is currently up to-date. I understand that there is an issue in the “computer language” used to develop the current site originally, which makes it difficult now to modify the existing site, add details, or change/ modify the site.

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Modular Educational Program for Specialist Haemophilia Nurses

It has been agreed to develop a series of Modular Training Programs for persons who are or are about to become involved with the treatment of patients with Haemophilia and other related bleeding disorders. These programs should be available “on-line” for initial training, retraining or revision.

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| <p>It was agreed that the National Coagulation Centre in St. James’s Hospital and the Nurses attached to the NCC in collaboration with the Education Department at the Royal College of Physicians Ireland (RCPI) would develop this concept for the role out of this important project to all appropriate personnel.</p> <p>Since the concept was initiated, The Irish Nursing Board’s requirements for Special Training Recognition requirements have changed. This project must take requirements into account as required. Whatever the changes, the project must end up with an assessment system, associated with the project that will lead to a recognized registered qualification for the participants.</p> <p>The modules should be conceived as graduating from background information to general nursing student to information on the current appropriate treatment for patients with Haemophilia and other related bleeding disorders or as a refresher course for such nurses.</p> <p>It is anticipated that once the concept is devised, that further modules would be developed and produced aimed at medical students, Junior Hospital Doctor, Senior Hospital doctors/ Registrars etc.</p> <p>One of the modules should contain advice/ instructions of how to interact with other family members of patients who have or have been recently diagnosed with this condition. It is envisaged that this might / could be sold to other suitable Institutions / International agencies to fulfill their continuing education training needs.</p> <p>Medical Students Elective Summer project</p> <p>It has been agreed at Council that it was in the interests to encourage medical students, to become engaged in the field of Haemophilia / Thrombosis early in their career. To that end, Council agreed to sponsor three (3) elective student projects, of €1,000.00 from Council together with a €1,000.00 each from the NCC and OLCHC. The project would be open to any medical students in any of the six Medical Schools in Ireland.</p> <p>From a timing point of view, it was considered too late to initiate this project this year (December /January 2019). However, I do think that it is prudent to schedule this important project to be ready to be delivered to the various Medical Schools by the 1st September 2019 for completion by the autumn of 2020.</p> <p>Treatment Guidelines for Children</p> <p>The Treatment Guidelines for Children need to be updated and posted on the Council’s website.</p> | <p>ALL</p> <p>GL</p> <p>BN / GL</p> <p>BN</p> |
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11. Dates for NHC Meeting 2019

The remaining dates for the NHC meetings in 2019 are as follows:

- Wednesday 18th September, 2019 – **Rescheduled 1st October 2019**
- Wednesday 27th November, 2019

ALL

12 Next meeting

The Next National Haemophilia Council meeting will be held on Tuesday 1st October, 2019 at 10.30am in the boardroom of the Irish Haemophilia society

The Meeting ended at 12.00 mid-day.