



**National Haemophilia Council Meeting**  
**Thursday 17<sup>th</sup> May, 2018 at 10.00am**  
**Irish Haemophilia Society, Cathedral Court, New Street, Dublin 8 D08 VH64**

**Minutes**

**Present**

Dr. Barry Harrington, Chairperson, National Haemophilia Council  
Ms. Debbie Greene, Administrator, Irish Haemophilia Society  
Mr. Brian O'Mahony, Chief Executive, Irish Haemophilia Society  
Dr. Susan O'Shea, Consultant Haematologist, Cork University Hospital  
Dr. David Vaughan, Director of Quality & Safety, National Children's Hospital Group

**Apologies**

Mr. Michael Conroy, Principal Officer, Cancer, Blood & Organ Policy Unit, DOH  
Dr. Alison Dougall, Dental Consultant, Dublin Dental University Hospital  
Dr. Ruth Gilmore, Consultant Haematologist, University Hospital Galway  
Dr. Beatrice Nolan, National Paediatric Haemophilia Director, OLCHC

**In Attendance**

Dr. Niamh O'Connell, Medical Director, NCC, St. James's Hospital **(Invitation by Chair)**  
Ms. Ann O'Sullivan, Nurse Manager, NCC, St. James's Hospital **(Invitation by Chair)**  
Ms. Catherine Buckley, Quality Assurance Officer, NCC **(Invitation by Chair)**  
Ms. Gráinne Leach, Chief Officer, National Haemophilia Council

**1. Meeting**

- 1.1.** The Council was called to order at 10.05am
- 1.2.** The minutes of the meeting dated the 15<sup>th</sup> March, 2018 having previously been circulated, were approved with minor corrections.

**2. Apologies**

- 2.1.** All apologies were noted.

### **3. National Haemophilia Council Strategic Plan for the period 2018 - 2021**

**3.1** The NHC strategic plan for the 2014-2017 was reviewed at the Council meeting

**3.2** The Strategic Plan for the period 2018–2021 was discussed at the NHC meeting. The Chairperson had reviewed the 2014-2017 Strategic plan prior to the council meeting and had pointed out that most of the goals were still valid. However, some parts would need to be updated for the 2018-2021 NHC Strategic Plan.

**3.3** The Chairperson agreed to draft up the NHC 2018-2021 Strategic Plan, incorporating the recommendations and changes as agreed at the meeting. He will meet with the Chief Officer Ms. Gráinne Leach, Ms. Debbie Greene and Mr. Brian O’Mahony in early June to discuss the NHC 2018-2021 Strategic Plan.

**3.4** The draft NHC 2018-2021 Strategic Plan will be circulated to the Council for discussion, adjustment and adoption by the Council.

**3.5** The NHC 2018-2021 Strategic Plan will be discussed at the NHC meeting on the 5<sup>th</sup> July, 2018.

### **4. Correspondence**

**4.1.1** The Chairperson advised that Dr. Barry White’s resignation from the National Haemophilia Council had not as yet been received by the Minister. Ms. Gráinne Leach had contacted Dr. White in that regard on numerous occasions.

**4.1.2** It is hoped that this issue can be resolved quickly and that Dr. Niamh O’Connell and Ms. Ann O’Sullivan can be appointed by the Minister for Health to replace Dr. Barry White and Ms. Ruth Hunter-Nolan.

**4.1.3** The Chair advised Council that under the S.O. 451 No. 2004, under “Terms of Office” Section 10. “The member shall cease to be a member of Council on being requested by the Minister to resign. The Chairperson agreed to remind Mr. Michael Conroy in the DOH of this matter.

**4.2.1** The Council received clarification on the Long term Illness card from the Chief Officer Ms. Gráinne Leach. This hereditary condition of the “Family” of similar conditions, including Haemophilia A & B including Von Willebrand disease (VWD) and other related bleeding disorders which is not mentioned specifically in the order.

**4.2.2** The Council is of the understanding that the current regulations regarding the LTIC may be under review at present and that the Council should request to be involved in that review. The Council is not fully aware where that review is taking place. The Chairperson recommended that it should be included in the necessary legislation, because Haemophilia is a hereditary chronic condition that lasts a life time and requires specialized acute hospital monitoring and is not suitable for community monitoring or treatment.

**4.2.3** The Council will discuss the issue with Mr. Michael Conroy to see how the Council might influence that review together with other related interested groups and bodies as required.

**4.3** The draft Financial Statement for the National Haemophilia Council for Year ending 31.12.17 is with the C&AG. The audit will commence on the 25<sup>th</sup> May 2018.

**4.4.1** The Draft Annual Report for the year ending 31<sup>st</sup> December 2017 is currently been prepared. It will be circulated and will be approved at our Tele-conference meeting on the 21<sup>st</sup> June, 2018.

**4.4.2** The NHC 2017 Annual Report will be ready for presenting to the Council at the NHC meeting on the 5<sup>th</sup> July, 2018.

**4.4.3** All medical directors of the various CCC's are reminded to have their various publications posted up to Ms. Leach by the end of May 2018 in order that they can be included.

**4.4.4** It was agreed by Council to formally approve the contents and layout of the 2017 NHC Annual Report At the Tele-Conference meeting on the 21<sup>st</sup> June, 2018.

**4.5.1** The Council received a letter of complaint from a sister of a patient who attends St. James's Hospital concerning the patient's treatment in the H&H ward. Dr Niamh O'Connell reported that she had contacted the patient for clearance to discuss the problem and had his permission to disclose the problem encountered.

**4.5.2** Not all treatments especially emergency treatments are suitable to be treated in the H&H ward, e.g. if a patient with Haemophilia has an injured leg he should be brought directly to the Emergency Department where all the necessary auxiliary backup equipment, (e.g. X-rays etc.) is available. If it is possible the patient should inform the NCC of the injury prior to their arrival at the ED in order that the necessary factor etc is available at the same time as the patient reaches the ED.

**4.5.3** An investigation is currently in progress to review and report on this complaint and Dr O'Connell will report the findings to the Council when the review is completed and the patient can be informed of same.

**4.5.4** The Council requested that a note be inserted into the IHS monthly newsletter regarding patients with Haemophilia who have an accident or a serious injury and who need to attend the ED department should inform the NCC prior to their arrival if possible to the ED.

## **5.1 Student Summer Elective Research Project**

**5.1.1** Dr. Susan O'Shea reported that she had unfortunately not been able to contact the various medical schools re the proposed Student Summer Elective Research Project. She did however report that she had engaged with an enthusiastic 4<sup>th</sup> year

Medical Student from UCC to undertake a project with her in CUH this summer (2018).

**5.1.2** Dr. Niamh O'Connell also reported that she had also engaged with a 4<sup>th</sup> year Medical Student from Trinity College Dublin to undertake a project in St. James's Hospital this Summer.

**5.1.3** The Council is very pleased that these projects are in the pipeline for this summer but hoped that it could be formalized, with the various medical schools for 2019.

## **6. Updates from the Comprehensive Care Centre's & University Hospital Galway**

### **6.1 Cork University Hospital**

**6.1.1** The progress in relation to the Dental Unit at CUH has come to an impasse until CUH receives a reassurance that St James's Hospital will fund the monies promised.

**6.1.2** It is reported that this issue should be sorted in the immediate future when St. James's Hospital receives an invoice from CUH stating what the monies will be used for in the Dental Unit in CUH.

**6.1.3** There is still very serious problems with clerical / administrative / data staffing in the unit particularly as the dental appointments system is an additional burden on the existing staff.

Dr O'Shea reported on the shortage of staffing levels in the unit and the danger that this imposes on Staff and Patients. A Data Manager had been appointed but she could not be released because of a double backfill situation in CUH. The Council found this ruling to be intolerable. It was endangering the patient safety situation in particular and was unjustified.

**6.1.4** The Council will arrange an urgent meeting with the Management team in CUH.

**6.1.5.1** Dr O'Shea pointed out that she was job-sharing with Dr Cliona Duggan which constituted a single WTE post and that the work load in the Haemophilia / Thrombosis service had multiplied no end since the Clinic started in 2008.

**6.1.5.2** The CCC has gone from initially starting with 1 clinic on a Friday afternoon to 1 clinic every day and also the workload of ward rounds, plus all associated laboratory work / supervision / liaising with the Cardiac Unit and other departments at CUH, leading to a vast increase in total adult patient Numbers.

**6.1.5.3** This problem as outlined by Dr O'Shea will be prioritized this year and will be brought to the attention of the Management team in CUH as a matter of urgency as outlined in 6.3.

## **6.2 National Coagulation Centre, St. James's Hospital**

**6.2.1** Dr Niamh O'Connell the new Director at the NCC informed Council that the Lighthouse Project was delayed due to discussions regarding the budget for the maintenance costs of the Haemophilia IT system. However, progress was being made and it was hoped that the issue would be resolved in the immediate future.

**6.2.2** It was reported that the current Clintech System has not been maintained by the original Company as their contract was not renewed in January 2018.

**6.2.3** There will have to be a period of staff training which hopefully will begin in the very near future.

**6.2.4** There were a considerable number of Clinical Trials ongoing in the NCC

**6.2.5** Dr Niamh O'Connell, Medical Director NCC was pleased to report to the Council that Dr Barry Kevane has been appointed Locum Consultant to the NCC in Dr Barry White's absence. It is expected that he will commence his duties as Locum Consultant in the NCC on the 16<sup>th</sup> July 2018.

## **6.3 Our Lady's Children's Hospital Crumlin**

**6.3.1** In the unavoidable absence of Dr. Beatrice Nolan this item was postponed to the NHC meeting on the 5<sup>th</sup> July, 2018.

## **6.4 University Hospital Galway.**

**6.4.1** The discussion regarding Haemophilia services in GUH was postponed until Dr Ruth Gilmore returns from leave.

## **7. Report on the National Haemophilia Risk Registrar 2017.**

**7.1** Ms. Catherine Buckley, Quality Assurance Officer, NCC, St. James's Hospital (Ms. Ruth Hunter-Nolan's replacement) presented the report on the National Haemophilia Risk Registrar for 2017.

**7.2** Ms. Buckley informed the Council that items will only be reported and included in the Risk Register if they have previously been reported to the individual hospitals own Risk Register who are involved in the treatment of patients with Haemophilia and other related bleeding disorders.

**7.3** The findings will also be reported initially to the joint meeting of all the CCC's and the Treatment Unit in GUH prior to them being reported to Council.

**7.4** One of the risks across the board was the short staffing problem, especially in CUH, OLCHC and the Treatment Centre in GUH, and the absence of Data Managers available in those 3 centers. **Designated the risk as Moderate.**

**7.5** Another problem reported by Ms Buckley was that in OLCHC, CUH and GUH the Haemophilia / thrombosis Consultants are working in a single handed capacity, which is anything but ideal.

**7.6** There is a serious problem with the Clintech Computer system. The maintenance contract has not been renewed and there are a lot of problems with it. If the system breaks down then none of the 3 CCC's or the TC in GUH has access to the patient data necessary to control the risk to the patient correct individual treatment. **Risk Designated Moderate.**

**7.7** There seems to be a major problem relating to access to the H&H ward in St. James's Hospital. **Designated High.**

**7.8** It is hoped that as the staff experience with the National Risk Register improves and everybody becomes more familiar with its operation in order that the reporting results will be improved.

**7.8** The Council looks forward to the next report which will be presented at the NHC meeting on the 29<sup>th</sup> November, 2018.

## **8. General Data Protection Regulation**

**8.1** By The invitation of the Chair, Ms. Debbie Keyes, Regional Manager Consumer Affairs, HSE, made a comprehensive presentation to the member of the Council present in relation to the new EU regulations which will be introduced on the 25<sup>th</sup> May, 2018.

**8.2** These EU regulations were developed to Limit, Protect and Respect the personal data we all work with. Data should be kept to a minimum and should be accurate.

**8.3** Following discussions with the Council members present it appeared that the HSE and the various hospitals had not as yet issued any advice to staff regarding the new EU GDPR.

**8.4** Dr Harrington thanked Ms. Keyes for her presentation and for coming to the Council with this vital information.

## **9. Internal Audits.**

**9.1** All of the external auditors have agreed to undertake the audit of the 3 CCC's next Year.

**9.2** The Council will consider a Haemophilia Paediatric Consultant. Dr. Beatrice Nolan will make recommendations to the Council.

**9.3.** When Dr Nolan identifies the Consultant in Paediatrics the Council through Ms. Leach our Chief Officer will issue an invitation under the usual conditions.

**9.5** Mr. David Page, National Director of Health Policy, Canadian Haemophilia Society will issue a report on his recent visit to the NCC and OLCCH in the coming weeks. It is hoped that this report will be presented to the Council prior to the NHC meeting on the 5<sup>th</sup> July, 2018.

#### **10. Next NHC Meeting**

**10.1** The Council will hold a **Teleconference meeting on the 21<sup>st</sup> June, 2018** at 11am in the offices of the I H S. The dial-in details for the meeting are as follow:

- **Phone: 0818 301 111**
- **Passcode: 445 110**

The NHC Meeting for July will take place on **Thursday, 05<sup>th</sup> July, 2018** in the IHS at **10.30am**.

The Meeting ended at 12.55hrs.

