



National Haemophilia Council Meeting
Thursday 13th September 2018 at 10.30am
Irish Haemophilia Society, Cathedral Court, New Street, Dublin 8 D08 VH64

Minutes

Present

Dr. Barry Harrington, Chairperson, National Haemophilia Council
Dr. Alison Dougall, Dental Consultant, Dublin Dental University Hospital **(By Phone)**
Dr. Beatrice Nolan, National Paediatric Haemophilia Director, OLCHC
Dr. Niamh O’Connell, Medical Director, NCC, St. James’s Hospital
Mr. Brian O’Mahony, Chief Executive, Irish Haemophilia Society
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. Ruth Gilmore, Consultant Haematologist, University Hospital Galway
Ms. Debbie Greene, Administrator, Irish Haemophilia Society
Ms. Ann O’Sullivan, Nurse Manager, NCC, St. James’s Hospital

In Attendance

Dr. Cleona Duggan, Consultant Haematologist, Cork University Hospital
Dr. Susan O’Shea, Consultant Haematologist, Cork University Hospital
Ms. Gráinne Leach, Chief Officer, National Haemophilia Council

1. Meeting

1.1. The Council was called to order at 10.30am

1.2. The minutes of the meeting dated the 5th July 2018 having previously been circulated were approved.

2. Apologies

2.1. All apologies were noted.

3. Composition of Council

3.1 Dr Barry Harrington, Chairperson welcomed Dr Cleona Duggan, Consultant Haematologist, CUH to the NHC meeting. The Council had been informed that Dr Duggan's appointment by Minister Simon Harris is in progress.

3.2 Dr Harrington thanked Dr Susan O'Shea for all her contributions to the Council and wished her well in her future career.

4. Correspondence

4.1 All correspondence was noted.

4.2 Dr Harrington was not satisfied with the correspondence received by email from the C& AG's office. He will revert back to the C&AG's office regarding audits of the NHC Financial Statements.

BH

5. Comprehensive Care Centre 's and Galway University Hospital

5.1 Cork University Hospital

5.1.1 Dr Susan O'Shea has resigned from her position in CUH. She was in attendance at the meeting by invitation of the Chairperson.

5.1.2 Dr O'Shea's 0.5WTE position as Consultant Haematologist in CUH must be replaced by a Consultant Haematologist as a matter of urgency. The 0.5WTE replacement is due to take up his position in October, 2018.

5.1.3 Dr O'Shea made a recommendation to Council at the NHC meeting on the 17th May, 2018 that an additional Consultant Haematologist be included in the HSE Estimates for 2019.

5.1.4 The Council has felt for some time that there is a strong need for a second Full time WTE Consultant Haematologist with Special Interest in Haemostasis and Thrombosis in Cork University Hospital due to the significant demands and growth of the Haemophilia services in CUH.

5.1.5 A Letter was issued to Mr Liam Woods, National Director, Acute Operations, HSE requesting an additional WTE Consultant Haematologist with Special Interest in Haemostasis and Thrombosis for CUH.

5.1.6 A letter of acknowledgment was received by Council from Mr Woods regarding Council's request for the appointment of a new Consultant Haematologist to CUH. This matter has been brought to the attention of Mr. Gerry O'Dwyer, CEO, SSWHG for inclusion in the 2019 Estimates.

<p>5.1.7 Dr Duggan informed Council that St James’s Hospital Finance Department had confirmed the following with CUH regarding the Dental Services in CUH:</p> <ul style="list-style-type: none"> • Joint funding confirmed SSWHG (€50k) and SJH (€50k) • SJH funding to be released in due course • To be formally acknowledged when received • Initial orders placed estimate value €50k <p>5.1.8 It is hoped that the Dental Unit in CUH will be fit for purpose in early Spring 2019 and will be fully operational before the International Audit in May 2019.</p> <p>4.1.9 Dr Duggan informed Council members present that Dr. Daniel McGeown, Dental Specialist, CUH who was to develop the Dental Service in CUH is currently on Leave. However, she was in regular contact with the Project Team in CUH regarding Dental Services for Patients with Haemophilia who attend the CCC in CUH as required.</p> <p>5.1.10 There is currently no Locum cover available for the Dental Specialist in CUH. Dr. McGeown has intermitted that a locum replacement is not required.</p> <p>5.1.11 Dr Alison Dougall informed Council about her concerns regarding Dental Guidelines for Patients with Haemophilia. New staff and locums covering Consultants were not practicing the same protocols for Dental Treatments for patients with Haemophilia. It was suggested to meet with the new Consultants in Cork and Galway. This was agreed by Council.</p> <p>5.1.12 Dr. Niamh O’Connell suggested that this important item be on the Agenda at the next Four Centre’s Meeting. This was agreed by Council.</p> <p>5.1.13 The CCC in CUH has no dedicated secretary to support the delivery of the administrative services in the CCC in CUH.</p> <p>5.1.14 Dr Cleona Duggan, will take over the responsibility from Dr O’Shea’s position as Council representative on Dr. Jeremy Sargent, National Haematology Specialist Director, Education Committee.</p> <p>5.1.15 Dr O’Shea informed the Council that the Medical Student assigned to the CCC in CUH had completed the research project in the summer of 2018. Mr Brian O’Mahony will allow the research project to be presented at a future IHS meeting for patients with Haemophilia.</p>	<p>CD</p> <p>CD / GL / BH</p> <p>CD / AD / GL/ NOC</p> <p>CD</p> <p>CD/BOM/DG/GL</p>
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<p>5.1.16 The Council met with the Management Team in CUH on the 30th August, 2018 in CUH. The Council were greatly reassured that progress is been made in the issues addressed at the meeting. Dr Harrington informed the Management team in CUH that the International Audit of the Comprehensive Care Centre in Cork University Hospital will take place on Thursday 9th May, 2019.</p>	<p>CD / GL / BH</p>
<p>5.2 National Coagulation Centre, St James Hospital</p>	
<p>5.2.1 Dr Niamh O’Connell informed the Council that the Medical Students assigned to the NCC in St. James’s Hospital had completed their research projects in the summer of 2018. The student’s names are Kate Johnston and Yeshey Seldon.</p>	
<p>5.2.2 Dr O’Connell and Mr Brian O’Mahony will liaise with each other regarding the research projects to be presented at future IHS meeting sfor patients with Haemophilia. The projects have been presented to the HAI.</p>	
<p>5.2.3 Mr Brian O’Mahony I H S will liaise with Dr O’Connell regarding the presentation of this project to the members of the IHS and the publication of the papers.</p>	<p>BOM / NOC/ GL/ DG</p>
<p>5.2.3 Dr O’Connell informed the Council that unfortunately the development of the Modular Continuing Education Program for Nurses, interested in Haemophilia treatment care, has had to be postponed for this year as the CNM3 nurse is on leave. The replacement nurse will commence in the NCC in St James’s Hospital on the 17th September, 2018.</p>	<p>NOC / AOS</p>
<p>5.2.4 The new Consultant Locum in the NCC Dr Barry Kavane started in the NCC in July 2018 covering Dr Barry Whites Clinics.</p>	
<p>5.2.5 Dr O’Connell informed the Council members present that the Lighthouse Project had a number of wrinkles which were currently been addressed. It is expected that the management team in St James’s Hospital will sign the contract for the recurring costs of the system in the coming weeks.</p>	<p>NOC</p>
<p>5.2.6 Dr O Connell informed the meeting that there were major problems with the current IT Haemophilia Clintech System. The system was giving problems at weekends and the I T Departments in SJH were assisting the NCC with these issues.</p>	<p>NOC</p>
<p>5.2.7 It was agreed that the serious problems with the Clintech system should be reported on the SJH Risk Register.</p>	<p>NOC /AOS</p>

5.3 Our Lady's Children's Hospital Crumlin

5.3.1 Dr Beatrice Nolan reported that the NHC had a meeting with the management team of Our Lady's Children's Hospital Crumlin in OLCHC on the 5th September, 2018.

BN / GL

5.3.2 Dr Nolan had requested the meeting as there was a continuous litany of problems in the CCC in OLCHC.

5.3.3 Dr Nolan reported that the items discussed at the meeting were below standard of a Comprehensive Care Centre. There issues are as follows:

- Toilet facilities access for patients who are wheelchairs users is totally inadequate at St. Michael's Ward.
- Access to Orthopedic Services for children with Haemophilia and other related bleeding disorders is below what would be expected in a modern Comprehensive Care Centre.
- Access to Physiotherapy Assessment and Treatment is less than would be expected to be available to the National Comprehensive Care Centre for Children.
- Access to MRI services is again below what is needed and expected to be available, to treat Paediatric patients attending the CCC in OLCHC.
- There is inadequate private space for paediatric patients with an acute bleed to be treated in the Day Ward.
- Proper and more extensive appropriate signage would be a great asset for patients attending for Haemophilia Services in the CCC in OLCHC.
- The CCC did not have properly trained secretary who is competent in using the Clintech IT System and other services in the CCC during Maternity Leave of Dr Nolan's Secretary.
- The situation in the CCC in OLCHC also exposed the Hospital to a major increase in the potential risk of providing Haemophilia and other related disease's services in a professional caring manner.

BN / GL

5.3.4 At the meeting the Management Team assured Council that they were providing a satisfactory solution to the ongoing issues that Dr Nolan had highlighted.

<p>5.3.5 Dr Nolan reported to the Council that she was satisfied of the outcome of the meeting with the Management Team in OLCHC. She has arranged to meet with the Operations Manager in OLCHC in order that the issues highlighted are addressed immediately.</p> <p>5.3.6 Dr Nolan asked Council members present what is the budget for Factor per year and what are the savings for the Exchequer from the Factor budget.</p> <p>5.3.7 The Council was informed that there was a new Director of Finance in St. James's Hospital where the budget for Factor is held.</p>	<p>BN / GL</p>
<p>5.3.8 Dr Nolan reported that she urgently needed a Quality Manager and a Data Manager for the CCC in OLCHC.</p> <p>5.3.8 It was agreed that the discussion regarding equal services for patients with Haemophilia in the 3CCC's and GUH would be discussed at the next 4 Centre's meeting.</p> <p>5.3.9 Dr Nolan informed the NHC meeting that there was a Coffee morning for Parents and Guardians of paediatric patients under 5 years of age on Friday 12th October, 2018 in OLCHC. This event will take place on the 3rd Floor of the Medical Tower in OLCHC.</p>	<p>BN/GL</p>
<p>5.3.10 Dr Nolan invited Council members to the Coffee morning on Friday 12th October, 2018 in OLCHC.</p> <p>5.3.11 Dr Nolan informed Council that she was using Clinical Trial money to fund a Research Nurse.</p> <p>5.3.12 It was agreed by Council to Invite Dr Eilish Hardiman, CEO of the Children's Hospital Group to an NHC meeting in the first quarter of 2019 for an update on the developments of the New National Children's Hospital. The Council will also discuss the requirements needed for Paediatric Patients with Haemophilia who will attend the new Hospital.</p>	<p>GL</p> <p>GL</p>
<p>5.4 GUH</p> <p>5.4.1 The discussion about services in GUH was postponed until Dr Ruth Gilmore returns from leave.</p> <p>5.4.2 The meeting was informed that Dr Ruth Gilmore may be returning from leave in October 2018.</p>	<p>GL</p>

<p>6. Brexit</p> <p>6.1 The Chairperson of the Council is concerned about the implication for patients with Haemophilia who would travel to the UK and may need Factor Supplies.</p> <p>6.2 Mr Brian O’Mahony informed the Council that the HPSMAB were addressing the implications of Brexit on patients with Haemophilia . the HPSMAB is currently working on issues that may arise when the UK exit the EC.</p> <p>7. Development of Haematology Summer Undergraduate Projects</p> <p>7.1 The Chairperson is very much in favour of the formalization of the establishment of the Haematology Undergraduate Program. This program will work through the Medical Schools in Ireland.</p> <p>7.2 It was hoped by Council that Medical Students would have increased exposure to Coagulation at an earlier stage in their medical studies and it was noted by the Chairperson that Medical Students study for 3 months in Coagulation in 3rd Year Medicine.</p> <p>7.3 Dr Nolan would like students to have more exposure for Paediatric Coagulation.</p> <p>7.5 Dr Niamh O’Connell reported that there were a number of people in training for the ICAN Fellowship ???</p> <p>7.6 Dr Harrington is concerned about the recruitment of Consultant Haematologist in the future and retaining current staff in the field of H&T.</p> <p>8. The NHC 2017 Financial Statement</p> <p>8.1 The NHC 2017 Financial Statement has not as yet been certified by the C&AG’s office. The Chairperson will write to the C&AG’s office for an update on the audit status of the NHC 2017 Financial Statement.</p> <p>8.2 It was noted by Dr. Niamh O’Connell that in the SI No. 451 of 2004 the NHC Establishment Order Under the Finance Section 17 (5) can be subject to audit by the C&AG.</p> <p>9. The NHC 2017 Annual Report</p> <p>9.1 The NHC Annual Report was circulated to Council Members present. The report included the 2017 NHC Financial Statement which is still awaiting Certification by the C&AG. It was agreed not to send the 2017 NHC Annual Report to the Minister until the NHC Accounts were certified.</p>	<p>BH / GL</p> <p>BH</p> <p>BH</p>
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10. The Draft Strategic Plan 2018-2021

10.1 The 2018 - 2021 draft Strategic Plan was not discussed at the meeting and will be reviewed and updated by the Chairperson and the Chief Officer and presented to Council at its November meeting having previously been circulated.

GL/BH

11. Hospital Charges For Patients with Haemophilia

11.1 Mr. Brian O'Mahony, CEO of the I H S had received a number of complaints over the last quarter from patients with Haemophilia complaining that they had been requested to pay for Hospital Charges when they attended the ED and the Outpatients Departments in their respective Comprehensive Care Centre and the Treatment Centre.

11.2 The Hospital charges vary from one Hospital to another throughout the country. Dr. Nolan reported that as far as she was aware patients attending OLCCH were not charged for treatment.

11.3 It was noted by the Chief Officer that HAA Card holders were exempt from Hospital Charges.

11.4 Haemophilia is a Long Term Illness.

11.5 It was agreed that the National Haemophilia Council will investigate all Hospital charges for patients with Haemophilia and other related bleeding disorders.

12. International Audits of the 3CCC's May 2019

12.1 Dr Beatrice Nolan informed Council that she had met with Dr Kathelijjn Fischer, Consultant Paediatric Haematologist, University Medical Centre Utrecht, Netherlands recently. She had received the letter of invitation from Council and has accepted the invitation to be part of the audit Team for the International Audits of the 3CCC's in May 2019.

13. National Ambulance Service

13.1 Mr. Brian O'Mahony had requested the Directive from the National Ambulance Service (NAS) regarding the Directive re Haemophilia patients needing the Ambulance Service. Ms Gráinne Leach gave the Directive to Mr O'Mahony.

14 Draft dates for NHC Meeting 2019

14.1 It was agreed by Council to change the day of the Council meetings from Thursday to Wednesdays in 2019. The draft dates for the NHC meetings in 2019 are as follows:

- Wednesday 16th January, 2019
- Wednesday 6th March, 2019
- Wednesday 1st May, 2019
- Wednesday 3rd July, 2019
- Wednesday 18th September, 2019
- Wednesday 20th November, 2019

15. Next meeting

The Next meeting of the National Haemophilia Council is on Thursday 29th November, 2018 at 10.30 in the boardroom of the Irish Haemophilia society

The Meeting ended at 12.20pm