



National Haemophilia Council Meeting
Thursday 29th November, 2018 at 10.30am
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 **(By Phone)**
Ms. Debbie Greene, Administrator, Irish Haemophilia Society
Dr. Beatrice Nolan, National Paediatric Haemophilia Director, OLCHC
Dr. Niamh O'Connell, Medical Director, NCC, St. James's Hospital
Ms. Ann O'Sullivan, Nurse Manager, NCC, St. James's Hospital

Apologies

Dr. Cleona Duggan, Consultant Haematologist, Cork University Hospital
Dr. Ruth Gilmore, Consultant Haematologist, University Hospital Galway
Mr. Brian O'Mahony, Chief Executive, Irish Haemophilia Society
Dr. David Vaughan, Director of Quality & Safety, National Children's Hospital Group

In Attendance

Ms. Gráinne Leach, Chief Officer, National Haemophilia Council
Ms. Catherine Buckley, NCC, St. James's Hospital

1. Meeting

- 1.1. The Council was called to order at 10.30am
- 1.2. The minutes of the meeting dated the 13th September, 2018 having previously been circulated were approved.

2. Apologies

- 2.1. All apologies were noted.

<p>3 Correspondence</p> <p>3.1 Because of the delay in approving the 2016 NHC Accounts by the C&AG in 12/ 2017, as a result of which, the Chairperson received a letter from the PAC in the Dail asking for an explanation, as to why the accounts were late. At the time he replied but there was no follow up. The 2017 accounts were submitted in March 2018, in the same style and layout similar to the 2016 accounts, but as yet have not been approved by the C&AG.</p> <p>3.2 The Chairperson wrote to Mr Seamus McCarthy, Comptroller and Auditor General, C&AG to ascertain how the Council might comply with the Council’s S.I. requirements of publishing our results by June 30th each year.</p> <p>3.3 The 2017 NHC Accounts were submitted to the C&AG’s Office by the 25th March 2017. A delay has developed with various modifications to the layout and design required in the Financial Statement. The figures in the accounts have not been changed at any time since they were submitted.</p> <p>3.4 The process is nearly completed and the Council will have the appropriate design and layout for ongoing future accounts for 2018 ready for submission in early January 2019 in which case the Council might get audited earlier by the C&AG’s office.</p> <p>4. Appointments</p> <p>4.1 Dr Barry Harrington, Chairperson informed Council that Minister Simon Harris had appointed Dr Cleona Duggan, Consultant Haematologist, Cork University Hospital to the National Haemophilia Council from the 4th September, 2018 for 3 years.</p> <p>5. Comprehensive Care Centre ‘s and Galway University Hospital</p> <p>5.1 Cork University Hospital</p> <p>5.1.1 Ms Gráinne Leach, Chief Officer informed Council that Dr Cleona Duggan was unable to attend the NHC meeting due to staff shortages in the Comprehensive Care Centre in CUH.</p> <p>5.1.2 Ms Leach informed Council members present that Dr Duggan would send an update to Council regarding the CCC in CUH in the coming week.</p> <p>5.1.3 Ms Leach informed Council that she had requested an update from Ms Martine Delaney, Business Manager, Directorate of Medicine, CUH regarding the Dental Service in the Comprehensive Care Centre in CUH</p>	<p>GL</p> <p>GL</p> <p>GL</p> <p>GL</p> <p>GL</p> <p>GL</p> <p>GL</p> <p>GL</p>
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<p>5.1.4 The Chief Officer received the following information from Ms Delaney:</p> <ul style="list-style-type: none"> • Project Team Meetings: Dental Service Project Team Meetings are continuing with the next meeting scheduled for Monday 3rd December 2018 (attendees including Clinicians, Biomedical Engineering, HSE Estates, Medical Physics, Business representative). • Structural works: Structural works are progressing well under the guidance of Health Estates Department • Medical Physics: Medical Physics working closely with Health Estates Department will all aspects of the Project on track • Equipping Process: Equipment purchased is being delivered • PPG's / SOP's: Policy Procedures and Guidelines (PPG's) will be developed closer to commissioning of Unit. • Patient Communication: Patients are aware of developments. Further engagement planned closer to confirmation of opening date. • Service opening: Date to be confirmed – contingent upon the Dental Surgeon's return from Maternity Leave (most likely late Spring 2019) <p>5.1.6 New Consultants Post in CUH - The Chief Officer informed Council that the Councils request for an additional WTE Consultant Haematologist in CUH was discussed at the SSWHG Operations Team meeting on the 5th November, 2018 and the request has been escalated by the SSWHG to the National Office for inclusion in the estimates for 2019.</p> <p>The Chief Officer will clarify the issue with Mr Liam Woods, National Director, Acute Operations, Health Service Executive,</p> <p>5.2 National Coagulation Centre, St James Hospital</p> <p>5.2.1 Dr Niamh O'Connell informed Council that the letter of complaint which had been received by Council had been addressed and resolved with the patient concerned and the relative that had submitted the complaint letter.</p> <p>5.2.2 The Council requested that the I H S in its newsletter should highlight that if a patient was being transported to hospital by ambulance, they were required to transport the patient to the E.D of that hospital, but they should contact the appropriate Comprehensive Care Center that the patient is registered at.</p>	<p>CD / GL / BH</p> <p>GL/ CD</p> <p>GL</p> <p>DG</p>
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<p>5.2.3 There are problems for patients with Haemophilia to access Orthopedic Surgery in both Adult and Child patients. The team in St. James’s Hospital has reintroduced a previously successful program for managing the Orthopedic list which will hopefully alleviate the problems encountered.</p>	<p>NOC / AOS</p>
<p>5.2.4 Ms Ann O’Sullivan informed the Council that the criteria and design of a development of the Modular Continuing Education Program for Nurses interested in Haemophilia Treatment Care, has changed. It is hoped that a suitable program can be developed during the latter part of 2019.</p>	<p>AOS</p>
<p>5.2.5 Dr O’Connell informed the Council members present that the Lighthouse Project had a number of contract issues which were currently been addressed. The management team in St James’s Hospital will sign the Contract for the recurring costs of the system in the coming weeks. It is hoped that the program can be initiated in early 2019.</p>	<p>NOC</p>
<p>5.2.6 The Clintech system has ongoing issues with unscheduled downtime and system support is limited. The replacement of Clintech is urgently required (Lighthouse project) and the issue is listed as high priority on the Risk Register.</p>	<p>NOC/AOS</p>
<p>5.3 Our Lady’s Children’s Hospital Crumlin</p>	
<p>5.3.1 Dr Beatrice Nolan reported that there was little progress following the meeting with the management team of Our Lady’s Children’s Hospital Crumlin in OLCHC on the 5th September, 2018. The issues discussed were still not resolved.</p>	
<p>5.3.2 All the issues in the CCC in OLCHC were recorded in the National Risk Register. They are:</p>	
<ul style="list-style-type: none"> • 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 • There is inadequate private space for pediatric 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 situation in the CCC in OLCHC has 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.
- No proper ventilation or air conditioning in the Haematology / Coagulation Laboratory in OLCHC.
- No proper ventilation or air conditioning in the patient waiting areas attached to the Haemophilia Comprehensive Care Centre.

5.3.3 Dr Nolan reported that there were inadequate number / correctly positioned calibrated weighing scales located in the CCC. Easy access is essential when conducting clinical trials.

5.3.4 The availability of a WTE Physiotherapist (which has been subsumed into the wider Physiotherapy services) is wholly inadequate to treat patients with Haemophilia.

5.3.5 As reported above the Orthopedic Services to patients with Haemophilia are inadequate together with the access to MRI imaging. Some of the young patients accessing this service need to be sedated, and the availability of an Anesthetist is essential to this service

5.3.6 It will be important that these issues are aired during the next planned audit in May 2019.

BN

5.3.7 Dr Nolan reported that the Coffee morning for Parents and Guardians of patients under 5 years of age was held on Friday 12th October, 2018 on the 3rd Floor of the Medical Tower in OLCHC. The event was successful, however the attendance was low.

5.3.8 It was reiterated that Ms. Eilish Hardiman, CEO of the Children's Hospital Group be invited to attend the 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 Pediatric Patients with Haemophilia who will attend the new Hospital.

BN / GL

5.4 Galway University Hospital

5.4.1 Ms Gráinne Leach, Chief Officer informed Council that Dr Ruth Gilmore was unable to attend the NHC meeting as Dr Gilmore is the only Consultant in GUH and she is on-call. Her colleague was away so there is no cover for her.

5.4.2 Dr. Gilmore as requested by the Chief Officer submitted the following report to the Council regarding the update for GUH:

<ul style="list-style-type: none"> • Dr Gilmore is back from leave • Senior staff rotating through special Coag with support of Specialist Scientist • Specialist Scientist currently acting as Chief due to Chief on sick leave • Nursing recruitment is an on-going issue due to maternity leaves but the hope will be that haematology will have 7 CNS's with dedicated cover for the Haemophilia Nurse Specialist Ms Maura Sweeney in the next 6 - 12 months. • 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. <p>6. Development of Haematology Summer Undergraduate Projects</p> <p>6.1 The Chairperson has drafted a set of documents to the Deans of the Medical Schools to introduce the project, and the second one related to the criteria for those medical students who might wish to participate.</p> <p>6.2 The documentation is currently with Dr Nolan for review. It is hoped that it can be sent out to the Medical Schools in early January 2019.</p> <p>7. The NHC 2017 Annual Report It was agreed by Council to send the 2017 NHC Annual Report to the Minister for Health Simon Harris. A covering letter would state that the accounts were with the C&AG, and when they had completed their audit the accounts would be forwarded to the Minister.</p> <p>8. NHC 2018 Accounts</p> <p>The Chief Officer of the Council is trying to arrange to have the accounts for this year (2018) completed and submitted to the C&AG in early January 2019</p> <p>It is hoped by Council that the C&AG will audit the NHC 2018 Financial Statement in the first quarter of 2019.</p> <p>9. The Draft Strategic Plan 2018-2021</p> <p>9.1 The 2018 - 2021 draft Strategic Plan was discussed at the meeting. It was agreed by Council members present that they would review the draft Strategic Plan as it was considered to be too long and it needed to be more achievable.</p>	<p style="text-align: center;">GL / BN/BH</p> <p style="text-align: center;">GL / BH</p> <p style="text-align: center;">GL / BH / All</p>
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<p>9.2 The Plan will be reviewed by the Chairperson and the Chief Officer and will be resubmitted to Council members in January 2019</p> <p>10. National Haemophilia Risk Register 2018</p> <p>10.1 Ms. Catherine Buckley, Quality Assurance Officer, National Coagulation Centre, St James’s Hospital presented the National Haemophilia Risk Register 2018 report to the Council Members present.</p> <p>10.2 Most of the items registered on the report had already been noted on each Hospitals Risk Register and were all previously noted by Council.</p> <p>10.3 The Chairperson thanked Ms. Buckley for compiling and presenting the report to Council.</p> <p>10.4 The Chairperson recommended that the report be attached to the minutes as an appendix.</p> <p>11. International Audits of the 3CCC’s - May 2019</p> <p>11.1 Ms Grainne Leach informed Council that Ms Catherine Buckley, Quality Assurance Officer, National Coagulation Centre, St James’s Hospital and Dr O’Connell had been in contact with Dr John Hanley, Consultant Haematologist, Newcastle Hospital, UK in relation to changes in the UKHCDO Audit Proforma. This is being piloted in late 2018 / early 2019 in the UK Centres and further feedback will be sought in due course.</p> <p>11.2 It was agreed by Council Members that the National Haemophilia Council would use the same UKHCDO Proforma Audit Form for the International Audits in 2019 that was used for the International Audits of the 3CCC’s in 2014.</p> <p>11.3 The Chief Officer informed Council that the Lead Auditor Professor Cedric Hermans had to be back in Brussels on the evening of the 9th May, 2019. It was agreed to rearrange the dates of the audits so that Prof Hermans can be facilitated.</p> <p>11.4 The National Haemophilia Council International Audits of the 3 Comprehensive Care Centre’s will now take place on the following dates in May:</p> <p>Tuesday 7th May, 2019: NCC, St. James’s Hospital</p> <ul style="list-style-type: none"> • Wednesday 8th May, 2019: CCC, Cork University Hospital • Thursday 9th May, 2019: CCC, OLCHC <p>11.5 The Auditors will depart from Dublin airport by 18.00 hours on Thursday 9th May 2019. Therefore the audit of Our Lady’s Children’s</p>	<p>GL</p> <p>AOS</p> <p>GL</p>
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<p>Hospital Crumlin will have to be completed by 15.00 hours to allow time to get to the airport.</p>	<p>GL</p>
<p>11.6 Ms. Leach to advise the auditors of the change of the schedule for the Audits.</p>	
<p>12. Dates for NHC Meeting 2019</p>	
<p>It was agreed by Council at the NHC meeting on the 13th September, 2018 to reschedule the days of the Council meetings from Thursday to Wednesdays in 2019. The dates for the NHC meetings in 2019 are as follows:</p>	
<ul style="list-style-type: none"> • Wednesday 30th January, 2019 • Wednesday 6th March, 2019 • Wednesday 1st May, 2019 • Wednesday 18th September, 2019 • Wednesday 27th November, 2019 	<p>GL</p>
<p>13. AOB</p>	
<p>13.1 I.H.S Won Patient Organisation Project of the Year 2018</p>	
<p>The Irish Haemophilia Society won the Patient Organisation Project of the Year award for their 50th Anniversary Programme at the Irish Healthcare Awards on the 17th October 2018. The Council congratulated the Irish Haemophilia Society on winning the Award. A lot of hard work went into marking and commemorating the society's 50th Anniversary this year for the various event and projects in 2018.</p>	
<p>The documentary movie 'Facing the Rising Sun' on the history of the society (and premiere), 50th Anniversary AGM complete with 50th Anniversary Exhibition Room, Memorial Service and discussions, an expanded World Haemophilia Day, a Gala Fundraising Dinner and of course the fantastic street art project, now permanently on display in the foyer of St. James's Hospital.</p>	
<p>The I H S were very pleased to be nominated for the award and to win the award of Patient Organisation Project of the Year 2018</p>	
<p>13.2 Chairperson's Resignation</p>	
<p>The Chairperson informed the Council that the period of his appointment by the Minister of Health will end on the 31st July 2019. In September 2019 he will be 80 years of age and he thinks that after 9 years as Chairperson of the National Haemophilia Council it is a proper time to offer his resignation to the Minister.</p>	<p>BH / GL</p>

He is mentioning the subject now as he wants to give the Council time to find a suitable person to continue the service.

14. Next meeting

The Next meeting of the National Haemophilia Council is on **Wednesday 30th January, 2019 at 10.00am** in the boardroom of the Irish Haemophilia society

The Meeting ended at 12.35pm.