



National Haemophilia Council Meeting
Friday 15th February, 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 Cleona Duggan, Consultant Haematologist, Cork University Hospital
Ms Debbie Greene, Administrator, Irish Haemophilia Society
Dr Niamh O'Connell, Medical Director, NCC, St. James's Hospital
Mr Brian O'Mahony, Chief Executive, Irish Haemophilia Society

Apologies

Dr Alison Dougall, Dental Consultant, Dublin Dental University Hospital
Dr Ruth Gilmore, Consultant Haematologist, University Hospital Galway
Dr Beatrice Nolan, National Paediatric Haemophilia Director, OLCCH
Ms Ann O'Sullivan, Nurse Manager, NCC, St. James's Hospital
Dr David Vaughan, Director of Quality & Safety, National Children's Hospital Group

In Attendance

Ms Gráinne Leach, Chief Officer, National Haemophilia Council

1. Meeting

- 1.1. The Council was called to order at 10.10am
- 1.2. The minutes of the meeting dated the 29th November, 2018 having previously been circulated were approved.

2. Apologies

- 2.1. All apologies were noted.

<p>3 Correspondence</p> <p>3.1 All Correspondence received was noted.</p> <p>3.2 A Letter of invitation was issued to Ms Eilish Hardiman, CEO, Children's Hospital Group to attend an NHC meeting in the first quarter of 2019 for an update on the developments of the New National Children's Hospital.</p> <p>3.3 A Letter was received from the Acute Division HSE informing Council that the Councils request for an additional WTE Consultant Haematologist in CUH was not included in the Estimates for 2019.</p> <p>3.4. Dr Barry Harrington, Chairperson informed Council that he had submitted his resignation as Chairperson of the NHC to Minister for Health Simon Harris.</p> <p>4. 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 it was 5 months since Dr Susan O'Shea had resigned from CUH. There had been a locum in place in the CCC CUH but the locum had resigned on the 25th February, 2019. There is currently no cover for the Clinical Director of the CCC in CUH.</p> <p>4.1.3 Dr Duggan informed Council that she had updated the Risk Register in CUH regarding the vacant 0.5 post of the Clinical Director in the CCC in CUH.</p> <p>4.1.4 The Consultant Haematologist (replacement post for Dr Susan O'Shea) was approved by CAAC on Tuesday 5th February, 201. The SSWHG were in the process of advertising the post with the Public Appointment Service.</p> <p>4.1.5 The Council is concerned that the request for an additional WTE Consultant Haematologist in CUH was not included in the Estimates for 2019. It was agreed by Council to write to Mr Gerry O'Dwyer CEO, SSWHG to request that the 0.5 Consultant Haematologist post be upgraded to 1 WTE Consultant Haematologist post for the CCC in CUH as the current situation regarding Clinical cover is not tenable.</p> <p>4.1.6 The Council is concerned that if the post is not filled asap that the Comprehensive Care Centre in CUH could be downgraded to a Treatment Centre following the next International Audit of the CCC in CUH on the 8th May 2019.</p>	<p>GL</p> <p>BH / GL</p> <p>GL</p> <p>GL</p>
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4.1.7 Ms Gráinne Leach, Chief Officer, NHC 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.

4.1.8 The Chief Officer was informed by Ms Delaney that significant progress has been made by the Project Team at Cork University Hospital in relation to the realization of the Dental Service in the Comprehensive Care Centre in CUH.

4.1.9 The current status in relation to the CUH Dental Service Project in the CCC in CUH is as follows:

- **Project Team Meetings:** Dental Service Project Team Meetings are continuing with the next meeting scheduled for Monday 18th February 2019 (MDT attendees include Clinicians, Biomedical Engineering, Health Estates, Medical Physics, Business representative).
- **Structural works:** Structural works are progressing well under the expert guidance of Health Estates Department.
- **Medical Physics:** Medical Physics working closely with Health Estates Department and will be commissioning the new Unit later this month.
- **Equipping Process:** Equipment purchased is being delivered and commissioned.
- **Standard Operating Procedures / Policies Procedures Guidelines:** Policy Procedures and Guidelines (PPG's) are being developed by the Multidisciplinary Team.
- **Patient Communication:** Patients are aware of this positive development. Further patient engagement is planned closer to confirmation of the official opening date. The CUH Coagulation Unit is currently reviewing and updating their Cork University Hospital website contribution in preparation for service commencement.
- **Clinic patient reception and Check-in:** will be performed by existing Coagulation Unit Reception staff and activity data will be collated prospectively.
- **Service opening:** It is envisaged that the Service will be operational by late March 2019 (Week beginning Monday 25th March, 2019).
- **Patient Experience feedback:** Patient feedback will represent an integral component of service provision once the Unit is opened.
- **The Dental Surgeon has returned from Leave**

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<p>4.1.10 Dr Duggan informed Council that there were staff admin changes in the CCC in CUH. A new secretary has been appointed and will support the Haemophilia services to patient who attend the CCC in CUH.</p> <p>4.1.11 Dr Duggan informed Council that the Clinical Nurse Specialist in the CCC in CUH has not been replaced. There is currently a trained nurse in the CCC who would like to be appointed permanently to the CCC.</p> <p>4.1.12 It was agreed by Council to write to the Director of Nursing in CUH to request the appointment of the Clinical Nurse Specialist to the CCC asap.</p> <p>4.2 National Coagulation Centre, St James Hospital</p> <p>4.2.1 Dr Niamh O’Connell informed Council that the Lighthouse Project was in the early stages of testing the system. The staff from Valentia Technologies is on site at the National Coagulation Centre, St James’s Hospital.</p> <p>4.2.2 Dr O’Connell informed Council members present that the Finance Department in St James’s Hospital had agreed to support the Lighthouse Project.</p> <p>4.2.3 It is intended to get a post filled in the NCC to support the implementation of the Lighthouse Project.</p> <p>4.2.4 Dr O’Connell informed Council that due to the Nurses strike clinics had to be rescheduled and planned surgery of patients deferred.</p> <p>4.2.5 The team in St. James’s Hospital has reintroduced a successful program for managing the Orthopedic list for patients with Haemophilia to access Orthopedic Surgery in St. James’s Hospital.</p> <p>4.2.6 Dr O’Connell informed Council that the Haemophilia Treatment Guidelines had been updated and requested Council to put the Guidelines up on the NHC website.</p> <p>4.2.7 The Clinical Nurse Specialist in the NCC has returned from leave. Dr O’Connell acknowledged the great work of a staff member covering nursing leave in the very busy NCC.</p> <p>4.2.8 There will be a submission for a request for an additional Data Manager for the NCC.</p> <p>4.3 Our Lady’s Children’s Hospital Crumlin</p> <p>The report from OLCHC was postponed until the next NHC meeting as Dr Beatrice Nolan was unable to attend the NHC meeting due to her colleague on leave.</p>	<p>GL</p> <p>NOC</p> <p>NOC</p>
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<p>4.4 Galway University Hospital</p>	
<p>The report from GUH was postponed until the next NHC meeting as Dr Ruth Gilmore was unable to attend the NHC meeting due to staff shortages in the Treatment Centre in GUH.</p>	
<p>5. Development of Haematology Summer Undergraduate Projects</p>	
<p>5.1 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 2019. However, due to work commitments of Dr Beatrice Nolan at OLCCH the planned project has been deferred until 2020. The Chairperson felt it was too late to circulate the projects to the Medical Schools as the medical students would have their plans made for the summer of 2019.</p>	<p>GL</p> <p>GL</p>
<p>6. NHC 2018 Accounts</p>	
<p>6.1 The Chief Officer has completed the NHC 2018 Accounts for submission to the C&AG.</p>	
<p>7. The Draft Strategic Plan 2019-2022</p>	
<p>7.1 The 2019 - 2022 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>GL</p>
<p>7.2 The Plan will be reviewed and updated by the Chairperson and the Chief Officer and will be circulated to Council members.</p>	<p>GL</p>
<p>8. International Audits of the 3CCC's - May 2019</p>	
<p>8.1 Ms Grainne Leach informed Council that the NHC Audit Proforma for the International Audits of the 3 Comprehensive Care Centre's has been updated to match the Irish requirements for the audits which will take place on the following dates in May 2019:</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, OLCCH 	
<p>8.3 The Auditors will arrive on Monday 6th May, 2019 and depart from Dublin airport by 18.00 hours on Thursday 9th May 2019.</p>	<p>GL</p>

9. Dates for NHC Meeting 2019

It was agreed by Council at the NHC meeting on the 15th February, 2019 to reschedule the dates of the Council meetings for 2019.

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

- Wednesday 1st May, 2019
- Wednesday 18th September, 2019
- Wednesday 27th November, 2019

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10. AOB

The post for the Chairperson to the National Haemophilia Council will be advertised on the Public Appointments System.

11. Next meeting

The Next meeting of the National Haemophilia Council is on **Wednesday 1st May, 2019 at 10.00am** in the boardroom of the Irish Haemophilia society

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The Meeting ended at 12.05pm.

