



**National Haemophilia Council Meeting
Thursday 5th July, 2018 at 10.30am
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 **(By Phone)**
Dr. David Vaughan, Director of Quality & Safety, National Children's Hospital Group
Mr. Michael Conroy, Principal Officer, Cancer, Blood & Organ Policy Unit, DOH
Dr. Beatrice Nolan, National Paediatric Haemophilia Director, OLCHC

Apologies

Dr. Alison Dougall, Dental Consultant, Dublin Dental University Hospital
Dr. Ruth Gilmore, Consultant Haematologist, University Hospital Galway
Dr. Niamh O'Connell, Medical Director, NCC, St. James's Hospital **(Invitation by Chair)**

In Attendance

Ms. Ann O'Sullivan, Nurse Manager, NCC, St. James's Hospital **(Invitation by Chair)**
Ms. Gráinne Leach, Chief Officer, National Haemophilia Council

1. Meeting

- 1.1. The Council was called to order at 10.40am
- 1.2. The minutes of the meeting dated the 17th May, 2018 and the 21st June, 2018 having previously been circulated were approved with minor changes.

2. Apologies

- 2.1. All apologies were noted.

<p>3. Composition of Council</p> <p>3.1 The Chairperson noted that Dr Susan O’Shea had submitted her resignation from the National Haemophilia Council to the Minister for Health with effect from the 1st September 2018. The members of the Council is very sorry that she was leaving the NHC and thanked her for her contributions to the Council’s deliberations and functions over the last 10 years. The Chairperson and the Council wished Dr O’Shea every success in her new position.</p> <p>3.2 The Council endorsed Dr O’Shea’s recommendation that her position be filled by Dr Cleona Duggan, Consultant Haematologist, Cork University Hospital who had job-shared with Dr O’Shea over the last Number of years. This position falls under SI 451 of 2004. Section 6, Subsection d), of the order SI.</p> <p>3.3 The Council will write to the Minister for Health to recommend Dr Cleona Duggan for his consideration to fill that position.</p> <p>3.4 The other positions which the Council is awaiting ratification on are the appointments of Dr Niamh O’Connell and Ms. Ann O’Sullivan from the National Coagulation Centre in St. James’s Hospital. It is the Councils understanding that these ratifications are progressing and will be ratified by the Minister in the coming weeks.</p> <p>4. Presentation of Lighthouse Project</p> <p>4.1 Mr. Feargal Mc Groarty, National Haemophilia System Project Manager, IMS Department, St James’s Hospital attended the Council meeting and made a presentation to Council members present regarding the development of the I T Lighthouse Project.</p> <p>4.2 The preferred provider has been selected and the project is progressing very well. However, the final approval for the ongoing maintenance has as yet to be “signed off” but it is hoped that this can be achieved in the coming weeks.</p> <p>4.3 It is hoped that the project would be “Live” by the last quarter of this year (2018).</p> <p>4.4 The implementation will be on a phased basis. The staff (main users of the system) in all outlying user stations i.e. NCC, CUH, GUH, and OLCHC) will go live at the same time. Subsequently it will be necessary to train the patients in its use.</p> <p>4.5 It is expected that the whole system will be completely “Live and Active” by the early part of 2019.</p>	<p>GL</p> <p>GL</p> <p>GL</p>
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5. 3 Comprehensive Care Centre 's and Galway University Hospital

5.1 Cork University Hospital

5.1.1. Dr Susan O'Shea is resigning from her position in CUH. She has informed the Minister for Health of this fact and has recommended Dr Cleona Duggan, Consultant Haematologist, in CUH as her replacement on the National Haemophilia Council.

5.1.2. The Council fully endorsed Dr O'Shea's recommendation.

5.1.3. The Council will write to the Minister for Health to that effect.

5.1.4. Dr O'Shea's .5 WTE position as Consultant Haematologist at CUH must be replaced by another equivalent Consultant Haematologist asap, however, due to the increase in the workload in the CCC in CUH over the last 10 years, the new position should be converted to a full time position (WTE). This recommendation has been communicated to Mr Liam Woods National Director, Acute Operations, HSE and has been acknowledged by him

5.1.5. A letter confirming this to be sent to the CEO of CUH to ensure that the appointment is included in their estimate for 2019.

GL

5.1.6. Dr O'Shea reported that the "Letter of Confirmation from St James's Hospital to CUH, concerning the finances of the Dental Unit at CUH, has been received by CUH. However, the Dental Specialist who was to develop the service is currently on leave.

**AD / SOS /
CD/ BH /GL**

5.1.7. It is the Council's understanding, that Dr Cleona Duggan, will assume the responsibility from Dr O'Shea's position in being a representative on Dr Sargent's Education Committee.

5.1.8. The service being provided by the staff at the CCC at CUH is different from that provided at the Comprehensive Care Centre's in OLCHC and the NCC. The Haemophilia Services in the CCC in CUH is for both adults and children.

GL

5.1.9. The CCC in CUH has no dedicated secretary to organise the delivery of the administrative services of the unit, nor a dedicated Physiotherapist to assist with the treatment of the Adult and Children Patients. When appointments to the CCC have been made the filling of "Back Up positions" are not filled quickly enough to provide a seamless service.

SOS / CD / GL

<p>5.1.10. Dr O’Shea reported that there has been a considerable increase in the number of DNA Patients attending the Outpatients Department. It was considered by the Council that this situation should be pointed out to the Haemophilia Cohort of Patients via the I H S newsletter</p> <p>The Medical Student in the CCC in CUH has completed this program the CCC in CUH. He is now writing up his project. The IHS and Brian O’Mahony will assist with the presentation of this project at a future I H S meeting.</p> <p>5.1.11. The Council will invite Dr Cleona Duggan to the NHC Meeting on the 13th September 2018 at the invitation of the Chairperson. It is hoped that Dr Susan O’Shea will also attend.</p> <p>5.1.12. A new Consultant Haematologist (non Coag.) Dr Vitaliy Mylytiv has been appointed and will take up his position in Jan. 2019.</p>	<p>BOM / DG</p> <p>SOS / BOM / DG</p> <p>GL</p>
<p>5.2 Our Lady’s Children’s Hospital Crumlin</p>	
<p>5.2.1 Dr Beatrice Nolan reported a continuous litany of problems in the CCC in OLCHC. The management team in OLCHC is not providing a satisfactory solutions to the ongoing issues. The issues include not having a properly trained secretary who is competent to work with the Clintech IT System and other services in her unit. This has been ongoing for months and it has not been addressed in a proper manner. Dr. Nolan is is very frustrated with this situation.</p>	
<p>5.2.2 The situation in the CCC in OLCHC has also exposed the Hospital to a major increase in the potential risk, in providing the Haemophilia and other related disease’s services in a professional caring manner.</p>	
<p>5.2.3 It was agreed by Council that Dr Nolan & Dr David Vaughan would meet separately to discuss and formulate a joint approach to reduce the risk and provide an alternative Model of Care, and hopefully provide a different solution to Dr Nolan’s problems and the increased risk associated with the staffing levels in OLCHC.</p>	<p>BN / DV</p>
<p>5.2.3 Dr Nolan reported that 2 new Research Nurses had been appointed at OLCHC.</p>	
<p>5.2.4 Dr Nolan reported that she had met with Dr. Kathelijn Fischer Consultant Paediatric Haematologist from Utrecht, who had agreed to join the audit team to undertake the general audit of the CCC’s in May 2019.</p>	

<p>5.2.5 Ms Grainne Leach, Chief Officer will write to Dr. Kathelijn Fischer and officially invite her to be a member of the Audit team in 2019.</p>	<p>GL</p>
<p>5.2.6 Mr David Page’s report on his site visit to OLCHC was discussed at the meeting. The following is a list of the major items he identified as below standard of a Comprehensive Care Centre.</p>	
<ul style="list-style-type: none"> • The situation regarding the toilet facilities regarding access for patients who are wheelchairs users is totally inadequate at St. Michael’s Ward. Where arrangements were made locally to alleviate this situation it is not available if a patient with CF is occupying that bed. This problem is urgent. 	<p>ALL</p>
<ul style="list-style-type: none"> • 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. 	<p>ALL</p>
<ul style="list-style-type: none"> • Access to Physiotherapy assessment and treatment, is less than would be expected to be available to the National Comprehensive Care Centre for Children. 	<p>ALL</p>
<ul style="list-style-type: none"> • Access to MRI services is again below what is needed and expected to be available, to treat paediatric patients attending the modern CCC unit. 	<p>ALL</p>
<ul style="list-style-type: none"> • There is inadequate private space, for paediatric patients with an acute bleed, to be treated in the Day Ward. 	<p>ALL</p>
<ul style="list-style-type: none"> • Because the Children’s Hospital has an extensive footprint, and patients have to travel over extensive distances, proper and more extensive appropriate signage would be a great asset to the CCC in OLCHC for patients attending for Haemophilia Services in the CCC in OLCHC. 	<p>ALL</p>
<p>5.3 National Coagulation Centre</p>	
<p>5.3.1 Ms Ann O’Sullivan reported that, Ms Catherine Buckley (responsible for the National Haemophilia Risk Registrar) National Coagulation Centre, St James’s Hospital , has reaffirmed, that all the CCC’s and the one TC, must first report all related risk incidents to their own hospitals in the first instance, before they report it to her, for inclusion in the National Risk Register.</p>	<p>ALL</p>
<p>5.3.2 Ms O’Sullival also reported that a medical student had completed their elective study period at the NCC in St. James’s Hospital. It is hoped that the IHS will offer the same exposure to this student as to the student in the CCC in CUH to publish and or present their research Haemophilia project.</p>	<p>NOC / AO’S / BOM/ DG / GL</p>

<p>6. Development of Haematology Summer Undergraduate Projects</p> <p>6.1 Due to time constraints and other commitments, the formalization establishment of this project through the Medical Schools in Ireland, was not able to be proceed this year. However, two undergraduate medical students did undertake projects for the Summer of 2018 one in Cork University Hospital and one at St. James’s Hospital.</p> <p>6.2 It is hoped that Dr Duggan would be able to take up this project for the next period in 2019.</p>	<p>SOS / CD / GL</p>
<p>7. The Draft NHC Annual Report for the year ending Dec. 31st 2017</p> <p>7.1 The draft layout and design were approved.</p> <p>7.2 The contents were approved with some minor typographical alterations and a few additions.</p> <p>7.3 Ms. Leach to modify the draft as agreed.</p> <p>7.4 The Draft to be sent to the printer for layout etc.</p> <p>7.5 The NHC Annual Report will include the drafted accounts for the Council’s already approved Financial Statement at its May 2018 meeting, but has not as yet been certified by the C&AG’s office.</p> <p>7.6 A suitably worded addition to the accounts will be added to note that the accounts have been submitted to the C&AG’s office in March 2018 for approval that is not as yet been approved.</p>	<p>GL</p> <p>GL</p> <p>GL</p> <p>GL</p> <p>GL</p> <p>GL</p>
<p>8. The Draft Strategic Plan 2018-2021.</p> <p>8.1 The draft Strategic Plan was presented and amended for the period 2018-2021.</p> <p>8.2 It will be reviewed and will be edited etc by Ms Leach, and presented to Council at its September Meeting, having been previously circulated</p>	<p>ALL</p> <p>GL</p>
<p>9. Outpatient and Inpatient Charges For Patients With Haemophilia and other related Bleeding Disorders.</p> <p>9.1 The I H S has received a number of complaints from different patients, complaining that they went to their Comprehensive Care Centre, and were subsequently referred to the ED of that hospital, for treatment were charged for attending the ED.</p>	

<p>9.2 The amount charged is not consistently the same in every case.</p> <p>9.3 This requires further investigation of all the relevant charges and other facts.</p> <p>9.4 This generated much discussion at the Council meeting. It was established that if any patient was firstly seen by the patients GP and then referred to ED at any hospital, that this did not generate a Hospital Charge.</p> <p>9.5The Standard Operating Procedures, for all patients with Haemophilia and other related bleeding disorders, is that they should initially contact the Centre that they are initially registered, in the first instance. If the Centre is closed or the patient is in a serious condition (following Road traffic Accident) then they may be brought to any ED. There they should present their “Bleeding Alert Card”.</p> <p>9.6 There is a direct implied instruction related, to these standard operating procedure, that such a patient is instructed by the Relevant Centre Medical Personnel to go to the relevant ED and therefore, NO Attendance Charge should be generated.</p> <p>9.7 It was decided to draft a “General Referral Letter to all ED’s”</p> <p>9.8 The decision will be discussed at the NHC meeting in September.</p> <p>Next meeting The Next meeting of the National Haemophilia Council is on Thursday, 13th September 2018 at 10.30 in the boardroom of the Irish Haemophilia society</p> <p>The Meeting ended at 12.35 noon.</p>	<p>ALL</p>
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