



**National Haemophilia Council Meeting
Thursday 15th March, 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)**
Dr. Beatrice Nolan, National Paediatric Haemophilia Director, OLCHC
Mr. Brian O'Mahony, Chief Executive, Irish Haemophilia Society

Apologies

Dr. Ruth Gilmore, Consultant Haematologist, University Hospital Galway
Ms. Debbie Greene, Administrator, Irish Haemophilia Society
Dr. Susan O'Shea, Consultant Haematologist, Cork University Hospital
Dr. David Vaughan, Director of Quality & Safety, National Children's Hospital Group
Dr Niamh O'Connell, Medical Director, NCC **(By Invitation of Dr. Barry Harrington)**

In Attendance

Ms. Ann O'Sullivan, Clinical 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 10.50 hours.
- 1.2. The minutes of the meeting dated the 18th January 2018, having previously been circulated, were approved with minor corrections.

2. Apologies

- 2.1. All apologies were noted.

<p>3. Correspondence</p>	
<p>3.1 The Chairperson advised that Dr. Barry White has not resigned from the National Haemophilia Council. Ms. Gráinne Leach will contact Dr. White in that regard. It is hoped that a replacement appointment for Ms. Ruth Hunter-Nolan will be made to the Council shortly.</p>	<p>GL</p>
<p>3.2 The draft Financial Statement for the National Haemophilia Council for Year ending 31.12.17 presented to the Council from the Chief Officer were Certified and approved by the Council.</p>	<p>GL</p>
<p>3.3 The Draft Annual Report for the year ending 31st December 2017 is currently been prepared and will be ready for presenting to the Council at the next Council meeting on the 17th May, 2018.</p>	<p>GL</p>
<p>3.4 The Council is awaiting a report regarding the progress in developing the Medical Student Summer Program from Dr Susan O’Shea.</p>	<p>GL / SOS</p>
<p>4. Results of Discussion with Dr. Jeremy Sargent, Consultant in charge of Postgraduate Medical Training.</p>	
<p>4.1 The Council postponed any further discussion on the results following our discussions with Dr. Jeremy Sargent at the January meeting concerning advancing the timing of the Haematology / Thrombosis program within the overall postgraduate medical training program.</p>	<p>SO’S/BN NO’C</p>
<p>5. Updates from the Comprehensive Care Centre’s & University Hospital Galway</p>	
<p>5.1 Cork University Hospital</p>	
<p>5.1.1 Discussions in relation to the Comprehensive Care Centre in CUH were postponed to the next meeting as Dr. Susan O’Shea was absent from the meeting.</p>	
<p>5.1.2 The Management team in CUH is requesting written confirmation from St. James’s Hospital confirming the €50K promised to CUH to assist in financing the development of the Dental Treatment Unit in CUH for the treatment of patients with Haemophilia and other related bleeding disorders who attend the CCC in CUH.</p>	<p>GL / SOS</p>
<p>5.2. National Coagulation Centre, St. James’s Hospital</p>	
<p>5.2.1 Ms. Ann O’Sullivan informed the Council that the Lighthouse Project was delayed as there were some issues regarding the finance arrangements and the ongoing maintenance of the system.</p>	<p>NO’C AO’S</p>
<p>5.2.2. Ms. O’Sullivan informed the Council that Ms. Emma Sherlock, Physiotherapist attached to the NCC has taken leave of absence and will be replaced in mid-April with a WTE Physiotherapist.</p>	<p>NO’C AO’S</p>

<p>5.2.3. Ms. Gloria Rooney, Social Worker in the NCC has been transferred to another department in St. James’s Hospital. It is hoped that her position will be filled in the coming weeks.</p>	<p>NO’C AO’S</p>
<p>5.2.4 Mr. Brian O’Mahony asked the question “are Haemophilia patients with Long Term Illness Cards exempt from Hospital A & E / OPD / Inpatient charges and what if anything is covered by the “Long Term Illness Card”. (LTIC) The question arose because a patient attending the National Coagulation Center was transferred to Tallaght Hospital at the request of the Consultant at St James’s Hospital and was then charged an attendance fee for admission to the Day Ward in Tallaght Hospital. The Council requires the information regarding the LTIC and whether the LTIC entitled the cohort of patents with Haemophilia to be exempt from such charges and if not that the Council should address the issue that they should be exempt from Hospital charges.</p>	<p>GL BOM BH</p>
<p>5.2.5 Ms. O’Sullivan informed the Council that there has been a change to achieving the Advanced Nurse Practitioner status in any specialty field of medicine. It is proposed that if a nurse in any field of nursing declares her interest and then undertakes a 500 hour program in that field, then they can be declared competent, in that particular field and be registered as an Advanced Nurse Practitioner.</p>	<p>AO’S NO’C ALL</p>
<p>5.2.4 It was agreed that even with the anticipated changes that it is still a good idea to proceed with the Haemophilia Audiovisual Education Program for Nursing staff.</p>	<p>AO’S NO’C All</p>
<p>5.3. Our Lady’s Children’s Hospital Crumlin</p>	
<p>5.3.1 Dr. Beatrice Nolan informed the Council that Dr. Corrina McMahon had returned from sick leave to OLCHC in early February 2018.</p>	
<p>5.3.2 Dr. Nolan informed the Council that a Consultant Haematologist post with 29 hours IBTS/ 10 hours OLCHC has been approved and advertised. OLCHC hours to cover increased transfusion workload related to North / South Cardiac Initiative</p>	<p>GL</p>
<p>5.3.3 Dr. Nolan also reported that an agreement had been made that a second Haematologist / Thrombosis Consultant should be appointed to OLCHC. This was expected to be finally approved at a meeting on the 15th March, 2018 and the position would be advertised in the coming months. Once the position has been approved and the position advertised than a locum position, can be advertised immediately.</p>	<p>BN BH NO’C</p>
<p>5.3.4 Dr. Nolan had identified a candidate who may be interested in either or both positions.</p>	<p>BN</p>
<p>5.3.5 Dr Nolan also reported that her secretary was currently on maternity leave and since the last NHC meeting in mid-January 2018 she has had 5 temporary Officers covering her secretarial support which make it very difficult for her on a daily basis.</p>	<p>BN</p>

<p>5.3.6 Dr Nolan reported that one of her very young patients had developed an allergic reaction to one of the new products. However, the patient has been put on small daily infusion dose with no reaction and achieving over 16% rise which seems to be very satisfactory.</p>	<p>BN</p>
<p>5.3.7 A patient who is awaiting Orthopedic Treatment in OLCHC has been transferred to St. James’s Hospital and is being assessed by Mr. Johnny McKenna, Orthopedic Consultant, St James’s Hospital for orthopedic treatment.</p>	<p>BN NO’C BH</p>
<p>5.3.7 Dr Nolan reported that Dr Paddy Fleming, Consultant Dental Surgeon (CDS) OLCHC was currently out on sick-leave. There was great pressure being put on the other CDS Dr Kirsten Fitzgerald as she was solely providing dental services to the entire Hospital dental service needs in OLCHC.</p>	<p>BH BN</p>
<p>5.4 University Hospital Galway.</p>	
<p>5.4.1 The discussion about services in GUH was postponed until Dr Ruth Gilmore returns from maternity leave.</p>	
<p>6. International Audits.</p>	
<p>6.1. The three Chief Executives of the 3CCC’s have been informed by letter from Ms. Gráinne Leach, Chief Officer of the NHC of the change of dates for the International Audits of the 3 CCC’s.</p>	<p>GL</p>
<p>6.2 Mr. David Page, National Director of Health Policy, Canadian Haemophilia Society had purchased his travel ticket for May 2018 to conduct the International Audits of the 3CCC’s. He had booked the flights in 2017 so as to minimize his travel costs, prior to the Council cancelling the International Audits from 2018 to 2019. It was agreed by the Council that he would be reimbursed for his travel costs.</p>	<p>GL ALL</p>
<p>6.2 The Council agreed that since Mr. Page had booked his flights in 2017 and that he was coming to Ireland the Council would cover the costs of a 3 day site visit. Mr. Page will undertake an assessment of the patient facilities at the NCC, the H & H ward in the NCC, St James’s Hospital OLCHC and meet with Haemophilia patients regarding their interactions with the new Haemophilia Lighthouse Project.</p>	<p>BN NOC BOM GL BH</p>
<p>6.3 Ms Gráinne Leach will write to the CEO’s of OLCHC and the NCC informing them that Mr. Page will be on the premises of both hospitals as requested by Dr. Beatrice Nolan.</p>	<p>GL</p>
<p>6.4 Mr. Page will be in Dublin from the 1st – 5th May, 2018.</p>	<p>GL</p>
<p>7. Any Other Business.</p>	
<p>7.1.1 Dr Barry Harrington, Chairperson informed the Council members present that the Council would have to develop a new Strategic Plan for the period 2018 - 2021.</p>	<p>BH</p>

<p>7.1.2 It was agreed that a few meetings or part of the NHC meetings would have to be devoted solely to this project. Dr. Harrington suggested that the next NHC meeting on the 17th May 2018 would start at 10.00 hours and that the first hour would be dedicated to this project. Dr Harrington requested that Ms. Leach would send out a copy of the Strategic Plan 2014 - 2017 with the minutes of the meeting dated 15th March, 2018.</p>	<p>ALL GL</p>
<p>7.2 Mr. Brian O'Mahony notified the Council that the postponed AGM of the Irish Haemophilia Society, which would be celebrating its 50th Anniversary of its foundation would now take place at the same venue (Royal Marine Hotel Dun Laoghaire) from Friday 13th April to Sunday 15th April 2018 and that all Council members are invited to attend.</p>	<p>BOM ALL</p>
<p>7.3.1 Dr. Barry Harrington requested that a Briefing Session be given to the members of the NHC regarding the new General Data Protection Regulation from the relevant person in the HSE.</p>	<p>BH GL</p>
<p>7.3.2 Ms. Gráinne Leach will identify the relevant person in the HSE and request a briefing session regarding the new EU GDPR.</p>	<p>GL</p>
<p>8. Next NHC Meeting</p>	
<p>The Next NHC Meeting will take place on Thursday 17th May, 2018 in the IHS at <u>10am</u>.</p>	
<p>The Meeting ended at 11 55hrs.</p>	

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