



National Haemophilia Council Meeting
Date: Thursday 18th January 2018 at 10.30am
Venue: Irish Haemophilia Society, Cathedral Court, New Street, Dublin 8. D08 VH64

Minutes

Present

Dr. Barry Harrington, Chairman, National Haemophilia Council
Mr. Michael Conroy, Principal Officer, Cancer, Blood & Organ Policy Unit, DOH
Dr. Beatrice Nolan, National Paediatric Haemophilia Director, OUCHC University Hospital
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
Ms. Ann O'Sullivan, Clinical Nurse Manager, NCC, St. James's Hospital

In Attendance

Ms. Ann O'Sullivan, Clinical Nurse Manager, NCC, St. James's Hospital

Apologies

Dr. Ruth Gilmore, Consultant Haematologist, University Hospital Galway
Ms. Gráinne Leach, Chief Officer, National Haemophilia Council
Dr. Alison Dougall, Dental Consultant, Dublin Dental
Dr. David Vaughan, Director of Quality & Safety, National Children's Hospital Group
Dr. Barry White, Medical Director, National Coagulation Centre, St. James's Hospital

1. Meeting

- 1.1. The Council was called to order at 10.40 hours.
- 1.2. The minutes of the meeting dated November 30, 2017, having previously been circulated, were approved with minor adjustments.

2. Apologies

- 2.1. All apologies were noted.

3. Correspondence

3.1 The Chairman reported that Dr Beatrice Nolan had been reappointed by the Minister for Health, Mr. Simon Harris, to the Council for the next three years from January 2018.

3.2 The finalized accounts from the C&AG were passed and signed on December 17, 2017 and received by the Chairman on January 8, 2018.

3.3 A letter was received from the Chairman of the Public Accounts Committee of the Dail, Mr. Sean Fleming, asking why the accounts were not received on time for the year 2016. The account information was requested from our Chief Officer at the end of January 2017, but were late in being submitted to the C&AG's office for ratification. The accounts are required to be sent by the end of June of each year. (The Absence of the Chief Officer on sick leave for the final four months did not help matters). Dr. Harrington had written to the public accounts committee Chairman, expressing his apologies and the reason for the delay, together with a copy of the certified accounts from the C&AG's office.

3.4 The Chairman was in touch with Ms. Michele Tait concerning the Chief Officer's return to work. The Chair was informed that she had undergone a second operation on her hand at the beginning of January 2018 and would not be returning for another few weeks at least. There was some discussion over what assistance the Chairman might be given to assist him in fulfilling the additional role of Chief Officer during Grainne's absence. After some discussion on the matter I agreed to phone her again in a week or two, to progress the issue and to organize a meeting to discuss this.

3.5 The Chairman received a letter from Dr Barry White as follows:

- Giving his apologies or his absence at this meeting.
- Stating that he had been in touch with Ms. Eilis Hardman, acknowledging that she had now prioritized the appointment of an additional haematology Consultant to OLCHC. It was expected that this would be forwarded in January 2018 for approval to be advertised in March 2018.
- That he had had agreement from Simon Moore of St James's, to provide 50% of the equity to fund the dental equipment for CUH, provided that CUH would provide the remainder.

4. Discussion with Dr. Jeremy Sargent, Consultant in charge of Postgraduate Medical Training.

4.1 At this point in the meeting Dr. Jeremy Sargent arrived and was warmly welcomed to the Council by the Chairman.

4.2.1 He informed the Council, that there were only four postgraduate students accepted into haematology training per year. Considering the number of sub-

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<p>specialties in haematology, that was not enough. It was hoped to increase that number to six.</p> <p>4.2.2 The Council agreed to write NPCP, to request that the Council were of the opinion, that there is currently a shortage of qualified personnel, trained haemostasis / thrombosis in Ireland and indeed in Europe, to fulfill the current needs and looking into the future, that need is likely to become greater, considering the demographics of the current situation in Ireland.</p> <p>4.3.1 The Council informed Dr. Sargent that the Council had agreed already and were in the process in setting up three Undergraduate Student Electives to start this summer.</p> <p>4.3.2 The elective would be open to any 3rd, 4th or 5th year medical student attending an Irish Medical School and would be valued at €1,000.00 each.</p> <p>4.3.3 Each student would have to work with one of the Consultants attached to one of the Comprehensive Care Centre's in Ireland.</p> <p>4.3.4 In addition, the Council would facilitate, in that the eventual outcome of their elective, once written up would be published an opportunity make to have its findings presented.</p> <p>4.3.5 Dr Sargent agreed that this would be a start, in increasing the profile of haematology at undergraduate level, and in haemostasis / thrombosis in particular. That this would eventually lead to an increase in the application for postgraduate training in this field.</p> <p>4.3.6 With that Dr Sargent left the meeting and was thanked by the Chairman for giving up his time to attend out Council and get a greater understanding of the problems affecting the delivery of care to patients require the assistance of a trained haematology Consultant.</p>	<p>BH SO'S</p> <p>BH</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 A Data manager had been appointed and is due to take up her position asap at CUH in the 'Haemostasis and Thrombosis Unit'.</p> <p>5.1.2 The Management at CUH had agreed to provide a matching sum, to that made available from St. James's, to fund the purchase of the dental equipment at CUH.</p> <p>5.1.2 Dr O'Shea reported that a small group, including Dr Danielle McGowan (the second Dentist from HSE South, Community Service), would be set up to oversee this project.</p>	<p>S'OS</p>

<p>5.2 National Coagulation Centre.</p> <p>5.2.1 Ms. Ann O’Sullivan informed the Council that the Lighthouse Project was expected to go live very soon. They are in the process of being trained up during the months of January and February.</p> <p>5.2.2.1 It was reported that Dr Barry White, will take a leave of absence from the NCC for a period to take up a position with the VHI. It was reported that Dr Niamh O’Connell was to replace him during his absence.</p> <p>5.2.2.2 The change of National Director at the National Coagulation Centre will have implications for the Council. Dr. White will be requested to inform the Council in writing. He may need to resign from the Council and Dr O’Connell could replace him. However, this needs to be appointed by the Minister.</p> <p>5.2.2.3 With this in mind, it was strongly suggested that that a special meeting be called as a matter of urgency with:</p> <ul style="list-style-type: none"> • Dr Barry Harrington • Dr Barry White • Dr Beatrice Nolan • Dr Susan O’Shea, • Ms. Michele Tait • Mr. Brian O’Mahony <p>5.2.2.4 The agenda to cover:</p> <ul style="list-style-type: none"> • The Directorship of the NCC • The possible change of Membership of Council • The potential period over which these changes are likely to involve. • The effect, if any, that the name “National Centre” has if attached to such a centre? • The suggested date for that meeting to be February 15 in the I.H.S. office at 10.30 hours. • The Chairman to convene the meeting. • It was also suggested that a discussion should take place with Michele Tait in relation to the Chief Officer during this meeting. <p>5.3 Our Lady’s Children’s Hospital Crumlin</p> <p>5.3.1 Dr. Beatrice Nolan informed the Council that the situation in OLCHC was very acute in relation to the fact that currently there is only one Consultant Haematologist available, to treating patients with haemostasis / thrombosis problems, presenting at OLCHC and also to cover other routine admissions, and those patient at OLCHC. This was a result of attempting to cover Dr. McMahan’s absence due to sick leave. This puts extreme pressure on Dr Nolan and on her responsibilities. This is a known RISK, to the treatment of patients attending OLCHC.</p>	<p>S’OS</p> <p>A’OS</p> <p>BH BW BN S’OS BOM</p> <p>As above</p> <p>BH BN</p>
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<p>5.3.2 The Management in OLCCH has now agreed to make the Locum appointment for 1 year’s duration.</p> <p>5.3.3 Dr Nolan had been in touch with numerous centres, in Canada, Australia and Europe to see if there was any suitable qualified person who might be available to undertake a locum position. So far, nobody had been identified worldwide.</p> <p>5.3.4 This raised the general discussion of how the situation in the country might be alleviated into the future. The general discussion was around the necessity that the following solutions should be introduced immediately:</p> <ul style="list-style-type: none"> • That there should not be appointments of any single handled consultant in any field as this cannot allow for any cover in the case of holidays / sick leave / study leave. • That there needs to be an increase in Specialist Nurse Led clinics. • This will have by necessitated an increase amount of specialist nurse training programs together with an increase in specialist nurse appointments in the various centre’s. <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. The Chairman was also informed that the specialist Haemophilia Nurse, Maura Sweeney is also now on sick leave as she has broken her arm.</p> <p>6. Internal Audits.</p> <p>6.1 All the selected auditors, were advised in December 2017, that the May 2018 audit had been postponed to May 7th, 8th & 9th of May 2019.</p> <p>6.2 Only one reply from Mr. Piet De Klein had been received by the Chairman so far.</p> <p>6.3 We were advised that Mr. David Page, CEO of the Canadian Haemophilia Society had purchased his travel ticket so as to minimize his travel costs.</p> <p>6.4 The Council had anticipated that this might happen and had agreed in our November 2017 Meeting and that any legitimate expenses or travel costs arising, would be discharged by the Council.</p> <p>6.5 When Mr. Pages accounts is presented to the Council, they will be discharged as previously agreed.</p>	<p>All</p> <p>BH</p>
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7. students Summer Project 2018

7.1 This project to proceed in line with that as outlines in 4.3.1, to 4.3.5.

7.2 Dr Susan O’Shea expects to have the program finalized and forwarded to all the Deans, of all the Irish Medical Schools, with a relative short time to receive applications.

7.3 The applicants are then to be interviewed ASAP as soon as the applications are received and thereafter to ascertain who is successful.

7.4 Following the completion of the project, the Council will help in all ways possible, to allow the completed project to be, published or presented in/at a suitable venue.

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8. Any Other Business

8.1 The Council was advised that all patients on the Current Factor VIII, are changing factor on February 6, 2018.

8.2 A number of special meetings for members of the Irish Haemophilia Society are due to take place on January 24, 25 and on February 6 in various venues throughout the country to advise their members of their impending changes to “**ELOCTA**”, the name of the new product.

9. Next Meeting

The next meeting National Haemophilia Council Meeting will take place on Thursday 15th March 2018 at 10.30am in the Irish Haemophilia Society, Cathedral Court, New Street, Dublin 8. D08 VH64

The Meeting ended at 12 40hrs.

Signed: ----- **Date:** -----

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