



**National Haemophilia Council Tele Conference Call Meeting  
Thursday 21<sup>st</sup> June, 2018 at 11.00am  
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. Beatrice Nolan, National Paediatric Haemophilia Director, OLCHC **(By Phone)**  
Ms Ann O'Sullivan, NCC St. James's Hospital **(By Phone)**

**Apologies**

Mr Michael Conroy, Principal Officer, Cancer, Blood & Organ Policy Unit, DOH  
Dr Alison Dougall, Dental Consultant, Dublin Dental University Hospital  
Dr Ruth Gilmore, Consultant Haematologist, University Hospital Galway  
Dr Susan O'Shea, Consultant Haematologist, Cork University Hospital  
Dr Niamh O'Connell, Medical Director, NCC, St. James's Hospital.  
Dr David Vaughan, Director of Quality & Safety, National Children's Hospital Group

**In Attendance;**

Ms. Grainne Leach, Chief Officer, NHC

**The Meeting;**

Dr Harrington called the meeting to order at 11.10am

The special meeting was called in relation to the following:

1. Approve the NHC accounts presented to the Council to C&AG for Certification in March 2018.
2. Modify the strategic plan for the period 2018-2021.
3. Approve the draft Annual Report for 2017
4. Discuss the urgent matter where a number of persons with Haemophilia on Presenting to ED in some Hospitals were charged and some were not.

## **1. THE Draft NHC Accounts for year ending 31<sup>st</sup> December 2017**

- 1.1 The draft accounts were approved as presented.
- 1.2 They had been forwarded to the C&AG for approval on the 28<sup>th</sup> March 2018 but had not been approved as yet
- 1.3 The C&AG office were on to say, that they were not in a position to audit our accounts, until the second half of this year. This was received with dismay. On re-reading of our SI regulations, it was realised and accepted that our accounts were accepted by the Council and given to the Minister by the end of June of each year. One interpretation was that the accounts as presented to Council could be approved by the C&AG at a different later date.
- 1.4 The accounts to have an addendum to state that the Accounts were submitted to the C& AG on March 28<sup>th</sup> 2018 but we were awaiting final approval which according to C& AG's office would be forthcoming in the second half of 2018?
- 1.5 This was accepted by those present given the current situation.

## **2. Draft NHC 2017 Annual Report**

- 2.1 The draft layout and design of the NHC 2017 Annual Report was approved.
- 2.2 The contents were approved with some minor typographical alterations and a few additions.
- 2.3 Ms Gráinne Leach, Chief Officer NHC to modify the draft report as agreed. **GL**
- 2.4 The Draft to be sent to the printer for layout etc. and costing **GL**
- 2.5 The Finalised version to be approved at the NHC July Meeting.

## **3. Draft Strategic Plan 2018-2021**

- 3.1 The draft 2018 – 2021 Strategic Plan was presented and amended
- 3.2 It will be reviewed and will be updated by Ms Leach, and presented to Council at the NHC Meeting on the 5<sup>th</sup> July, 2018.

- 4. Outpatient & Inpatient Charges for Patients with Haemophilia and other related bleeding disorders**
- 4.1** The Irish Haemophilia Society had received a number of complaints from different patients, complaining that they went to their centre, and were subsequently referred to the ED of that hospital, for treatment and were then charged.
- 4.2** The charges for treatment in the different Hospitals is inconsistent
- 4.3** The Council are of the view that if a patient with Haemophilia or other related bleeding disorders had a haematological / thrombosis problem and go to their relevant Centre for treatment but are subsequently referred to the ED for continuing / follow-up care there should be **NO Charge**
- 4.4** The objective of patients with Haemophilia is to access care as soon as possible to minimise the use of all hospital resources including care requirements and so reduce hospital in-patient care and outpatient follow-up.
- 4.5** The Council to meet with the CEO of CUH in relation to this matter. The Council will also arrange a meeting with the General Manager of GUH when Dr Ruth Gilmore returns from leave in October 2018.
- 4.6** The Council to also meet with the Department of Health concerning the same matter and help to reduce the use of precious resources from the hospitals budget.

The Meeting ended at 12 noon.

**The Next meeting of the National Haemophilia Council is on Thursday 5<sup>th</sup> July 2018 at 10.30 in the boardroom of the Office of the I H S**

