Chairman's Report

Welcome to the QEII centre in Central London and the 2016 Annual General Meeting of the UKHCDO. I hope you will find it a useful, informative and enjoyable meeting.

We have made some alterations to the format of the meeting this year; on the Thursday we are concentrating on the progress made by the UKHCDO Working Parties and these sessions will be open to everybody to listen and feedback on findings and ideas for future work. Two of the working parties are due to re-form later this year and there will be opportunity for newer members to apply to participate. On the Thursday we will also hear about some other completed and on-going research studies including a presentation from the Dutch group on the OPTI-CLOT project, a collaborative UK/Dutch study looking at pharmacokinetic dosing in haemophilia B. On the Friday morning we will have two 'hot topic' lectures on monitoring enhanced half-life (EHL) products and a gene therapy update followed by the standard AGM business and presentation of the annual statistics. Please do feedback after this meeting as this will help planning of future meetings.

As we all know we are living in difficult times within the NHS with enormous shortfalls in the funding required to pay for existing and innovative services and treatments. The National procurement exercises that we have undertaken over the last few years have enabled us to make considerable savings and we now have very favourable factor concentrate prices when compared to other prices globally. During the last year the UKHCDO has continued to be very closely involved with the Commercial Medicines Unit (CMU) in the latest factor concentrate procurement exercise. The previous tender was a collaborative project between the UKHCDO and the NHS England appointed Clinical Reference Group (CRG) for Haemophilia. The latter was disbanded in early 2016 and reformed some months later but despite this disruption we were able to provide clinical input and oversight of the procurement process. The frameworks are now in place and we are able to purchase the majority of these factor concentrates for our patients; details have been communicated with all Centres. I would like to extend our gratitude for the continued support we receive from Alison Greenwood and Wendy Roach from the CMU.

The recent tender will enable us to treat some of our patients with the new extended half-life products. The UKHCDO guideline on the use of 'extended half-life' products, written by a Task Force set-up in 2015, was published earlier on this year and is an informative document to refer to when discussing the use of these products. In England there has been recent commissioning guidance on how we can use these concentrates in a cost-neutral or cost-saving way; again this was circulated to members recently.

The NHSE CRG has not met since the last AGM due to its dissolution but it has now been reformed and we will have a CRG update session during the AGM. Despite the hiatus in CRG status we were pleased to hear in mid-2016 that the UKHCDO protocol for immune tolerance was adopted as an NHSE official policy. This means that ITI for children in England should only be done according to this protocol as this is the only ITI that is commissioned. We are planning detailed collection of outcome data using this protocol which will be co-ordinated by the Inhibitor Working Party.

The UKHCDO has a good track record at peer review and audit but moving forward on this has been somewhat on the back burner over the last year or so. I am delighted to welcome John Hanley as the new Audit Lead for the UKHCDO and look forward to working with him and a multi-disciplinary 'audit team' (yet to be formed) to develop a new audit tool to use for 2017. It is likely that future audits will have more credibility with commissioners if they include assessments of outcome measures and evidence of adherence to national protocols and guidelines.

During the AGM we will as usual hear about the work and projects being done by the NHD and updates to HCIS and Haemtrack. Haemtrack usage uptake has continued to increase across the country and it has benefits that improve patient care. NHS England has adopted Haemtrack usage as a CQUIN for 2016/17; the development of this was time-consuming and it is a complicated CQUIN which has been adopted by the majority – but not all – of the English centres. It is being refined for 2017/18 and may well become mandatory for all Centres.

My first year has Chairman ('Chairperson') has gone very quickly and required more hours of input than I envisaged; there are still a number of tasks I have not yet addressed but hope to be able to in the coming months. I am very grateful for the support of the rest of the Executive and particularly want to thank David Keeling who will be stepping down as Vice-Chair at the AGM and I am delighted that he will be replaced by Professor Peter Collins who we welcome onto the Executive Committee. I would like to encourage all members to come to me and the other Executive Committee members with queries, suggestions and feedback on any bleeding disorder issues. In the coming year the UKHCDO will continue to work closely with the newly formed NHSE Clinical Reference Group (and NHS Scotland, Wales and N.I) on moving forward with improving haemophilia care. Lastly I would like to thank all members of the NHD staff and their hard work in supporting the UKHCDO and the challenging times that we are working in.

Dr Ri Liesner
UKHCDO Chair
October 2016