Chairman's Report

Welcome again to the QEII Centre in Central London and the 2017 Annual General Meeting of the UKHCDO. I hope you will find it an exciting, informative and enjoyable meeting. We have planned a full educational day on the Thursday, aiming to cover many current topic issues of scientific and clinical interest. These sessions will be open to all members, some trainees, guests and Sponsors. The Friday sessions are closed to Members and invited guests only and we will deal with standard AGM business and discuss other current ongoing issues of importance, finishing with a brief presentation of the annual statistics.

The last year has brought a number of challenges for me, the Executive Committee and other UKHCDO members and there is the promise of even more significant issues for us to address as an organisation going forward. The announcement by the Government of a Judicial Inquiry to investigate treatment-related infection of haemophiliacs in the early 80's is one of those on the horizon for 2018 and beyond. Most of us practising now were not involved in the care of haemophiliacs at that time but many of us since have been intimately involved in the care of patients infected by HIV and/or hepatitis C and we recognise the devastating effect that these infections have had on the patients and their families. As an Organisation we are committed to complying with the Inquiry process, although at the time of writing this report there is as yet no indication as to the format the Inquiry will take or indeed who will lead it. We will have a session on the Inquiry during the AGM and we have asked the CEO from the Haemophilia Society to update us on the Inquiry from the Society's perspective.

Over the last year we have made progress in a number of UKHCDO initiatives. We have changed the Working Party (WP) terms of reference so that the core WPs become 'rolling' WPs and no longer need to be fully disbanded and then reformed which we hope will be more seamless and promote better continuity in terms of research and guideline output. Under these new rules we have 'rolled over' the Paediatric, Inhibitor and von Willebrand Working Parties with partial changes in membership. Following discussions and requests at the AGM and Advisory Committees we have also introduced new Working Parties and Task Forces such as the Co-Morbidities and Laboratory Working Parties and the Prophylaxis guideline and Gynaecology guideline Task Forces. The new 'Data Analysis Group' has been formed as a sub-group of the Data Management Working Party and meets monthly by teleconference. It has a wider remit but a major role of this Group is the assessment and prioritisation of requests for data from a number of sources, many of which generate income which supports the running of the NHD. Once the data reports are generated these are reviewed by the Group and some lead to abstracts and publications. The 'Peer Review' Group has been working with the West Midlands Quality Review Service to develop robust process and quality review standards that will be the used for the Peer Review process planned for 2018. You will hear about this in detail during the meeting. Overall, we have been very gratified by the enthusiasm of members to participate in all these new Groups; this is appreciated as we are well aware that this work is often done in personal time. We are also grateful for the input and support we have received from our nursing and physio colleagues and patient representatives.

The UKHCDO Ltd Company is the commercial arm of the UKHCDO Charity and I, the rest of the Executive Committee, the NHD Director (Professor Hay) and the NHD Manager have been working with the other UKHCDO Ltd Directors over the last few months to define fully the relationships and lines of responsibility between the Charity, the Ltd Company and the NHD. This is still a work in development but we have made progress towards being able to write a

formal operational policy and a job description for the NHD Director, both of which will define these issues more clearly for the future.

Since we last met at the 2016 AGM we have been able to move some of our patients from standard half-life to enhanced half-life products and this has been done within the constraints of the contractual obligations in place from the last tender. NHSE stipulated that in order to use these products there should be no increase in overall cost when switching and patients should comply fully with Haemtrack to enable us to fully assess the change in cost and volumes used. These patients have largely - but not fully - complied with the Haemtrack app/software and we, as treaters, do need to continue to urge our patients to make their treatment practices as transparent as possible by using Haemtrack as this is a valuable part of their day-to-day haemophilia management. Haemtrack use continues to increase significantly month on month – due partially to the on-going CQUIN in place - and we will get a brief update presentation during the AGM on Haemtrack patient reported data.

The 2017 recombinant FVIII tender had been in the planning phase for many months and following some delays it was finally advertised this summer with a closing date in mid-September. We are hopeful that there will be new products competing and once the volume bands have been awarded we will be in contact to inform you if you need to switch patients to achieve these volume commitments and the lowest spend possible. Once again, this tender was a collaborative project between the UKHCDO and the NHS England appointed Clinical Reference Group (CRG) for Haemophilia and, as with previous tenders, we benefitted from considerable expertise and support from Alison Greenwood and Wendy Roach from the Commercial Medicines Unit (now also part of NHSE). Our challenge going forward in coming years will be the introduction of the novel agents and new treatments into the UK market which is one of the most competitive in the world.

The NHSE CRG for 'Specialised Blood Disorders' is now fully operational and has met a number of times since last year's AGM. We will get feedback on its work programme during the meeting. The CRG and co-opted treaters are working on 3 NHSE policies that are progressing through the NICE Clinical Support Programme prior to going into the 2018 prioritisation round. These include policies for 2 currently licensed treatments that are not commissioned, namely Obizur and Coagadex and the 3rd is a policy for the use of Emicizumab in inhibitor patients.

Finally, I would like to express my gratitude for the continuing support of the rest of the Executive Committee and I particularly want to thank Mike Laffan who will be stepping down as Secretary. His replacement is not yet finalised. I would also like to thank Professor Charlie Hay and all the other members of NHD staff for their hard work in supporting the UKHCDO and Sarah Rooney for her organisational skills in arranging the AGM.

Dr Ri Liesner,
UKHCDO Chair
October 2017