

1. Chairman's Report

This is my first Report as Chairman of UKHCDO and this has been an interesting and challenging twelve months. A particular challenge has been the rapid implementation of fundamental changes to the National Health Service, and the complete overhaul of how Clinical Services such as haemophilia should be commissioned. From my experience of this process thus far, it is clear that, we as an organisation have much to thank Charles Hay, previous Chairpersons and Advisory Committee Members for the strong position that we have achieved through close engagement with the Department of Health and the NHS Commissioners. We are acknowledged as a cohesive, responsive and proactive organisation and are generally well regarded. In the current climate of the NHS this is very important. Many of you will be aware that an initiative has been set up to specifically direct commissioning for specialist services within the NHS. Haemophilia and related disorders has been designated as a national specialist service and as such we are an integral part of this process. The body advising on haemophilia services is the Clinical Reference Group (CRG) for Haemophilia and Related Disorders. I am Chair of that group and work very closely with a commissioning lead, Michele Davis from London Commissioners and a Public Health Lead, Sally Nelson from the South Central Region. UKHCDO is a key stakeholder in this initiative and we are well represented with haemophilia physicians from the four regions of England. Also included are haemophilia nurse representatives, patient and carer representatives and a representative for physiotherapy. As with many NHS initiatives, these have been implemented at break-neck speed and there have been very challenging deadlines to generate specific 'products'. Thus far we have met our targets for developing a data book for haemophilia services, clinical dashboard for haemophilia services, an up to date service specification and CQUINs. I am very grateful to Michele Davis and Sally Nelson for their expert contribution and indeed leadership in some aspects of this work and for the dedication of colleagues with UKHCDO and the wider haemophilia community.

Much of what we have achieved in building relationships with the Department of Health and the former and current commissioners has been underpinned by the National Haemophilia Database. There are very few, if any, clinical services in the UK that have a resource such as this and the demands of the new specialised services commissioning process should ensure that NHD will continue to be central to data collection and analysis. Nevertheless the current insecurity surrounding commissioning restructuring means that UKHCDO will have to work to ensure that the value of NHD is recognised and that its funding is secured. The quality and outcome measures required in the coming years by the CRG and SCG will mean that detailed data collection will become even more important and will involve all haemophilia centres and all patients. NHD is already working on ways to simplify data collection through HCSIS and Haemtrack to minimise the administrative burden imposed by these commissioning requirements.

The speed of implementation of the changes to commissioning and the short time frame with which we have had to generate commissioning 'products' to date has meant that communication and consultation has not been as good as it should. Although the UKHCDO advisory committee has been closely involved in the evolution of this process, I acknowledge that many of the other haemophilia centre staff, other haemophilia health care professionals and patients have not been informed as they should and through the UKHCDO we plan to address this through regional meetings, newsletters and educational events.

Another looming issue is the procurement of therapeutic products for haemophilia. Our current contract is extended until 2014 but we need to be able to allow for more discussion and consultation for the next contract beginning April 2014. I have set up a small task force to lead on this for UKHCDO and we will, as before, work closely with CMU.

I have been fortunate to have such an enthusiastic and experienced executive to help maintain and build the efficacy of the organisation and I wish to wholeheartedly thank David Keeling (Vice Chair), Ri Liesner (Treasurer) and Mike Laffan (Secretary) for their commitment to UKHCDO.

One of the areas of our activity that has greatly improved over the last year or so has been the reassertion of rules of engagement for the Working Parties and for a clear agreement for a life span of these groups and the requirement to communicate progress via submission of their minutes to the UKHCDO office in Manchester. David Keeling has been largely responsible for this overhaul and in the last twelve months, he and I have agreed the standing down of several Working Parties the launch or re-launch of others including the von Willebrand Working Party, Paediatrics Working Party and Rare Disorders Working Parties. Our website now holds up to date Guidelines and Publications from UKHCDO.

Dr David Perry has taken over from Dr Jonathan Wilde and their successive efforts have led to an increasingly valuable and effective triennial audit process. The next round of audit is imminent and will include patient representatives, many of whom have undergone specific training for this.

I would like to return to the National Haemophilia Database. As I highlighted earlier, this database has evolved to a level that is the best in the world. It is not yet perfect and there is still much that needs to be done to modify it to meet exacting future demands. I would like to thank Charles Hay for his continued management of the database on behalf of UKHCDO and would also like to thank Lynne Dewhurst, Ben Palmer, Helen Brown, Tom Sharpe, Jess Smith, Sarah Rooney and Rachel Whyld from NHD as well as Rob Hollingsworth and colleagues from MDSAS for their hard work and dedication.

I would also like to acknowledge the support of all the haemophilia centre staff and particularly data managers for their key role in collection of these important data.

The next few years will be difficult for the NHS and for medical specialities such as haemophilia. UKHCDO has been central to shaping haemophilia services in the UK and must continue to lead, through the CRG, to ensure we maintain and develop the high quality care that we have in this country.

I hope that you find this Annual General meeting useful and that you have the opportunity to catch up colleagues and friends.

Dr Gerry Dolan
Nottingham, September 2012
Chairman UKHCDO