Chairman's Report

As my period as chairman draws to a close and I prepare to pass the baton on to a (slightly) younger and (hopefully) more energetic successor, I pause to reflect on the changes and achievements of the past six years and consider how UKHCDO may respond to new challenges and uncertainties just over the horizon.

Whilst many UKHCDO activities continue as before, e.g. working parties, guideline production and collection and publication of data and epidemiological research, the organisation has strengthened its organisation, funding and influence during this time.

Our guidelines are now dually accredited by both UKHCDO and BCSH and may be viewed on both websites (thanks largely to David Keeling) and we are even trying to organise a guideline jointly with RCOG. These guidelines and our other publications are invariably amongst the top ten most downloaded documents from Haemophilia or BJ Haematol and have become a benchmark around the globe, helping to establish UKHCDO as an international "Brand".

Over the past nine years we have established a UKHCDO secretariat and National Haemophilia Database in Manchester supported by a software group (MDSAS), which has transformed both the activities of the Database and of the organisation. During that time, the number of registrants has increased by 50% and increases at the rate of at least 1000 registrants per year. We now monitor treatment registrations and adverse events quarterly and also produce reports within three months (rather than two years in arrears as was formerly the case). Our data is now used for national contract management, national healthcare planning, market planning for industry, pharmacovigilance and research. We have developed modules for monitoring home-treatment and home delivery and phone applications and patient-centre video-links are in development. The secretariat also supports the organisation of the UKHCDO Working Parties and the complex organisation of the Triennial Audit, one of UKHCDO's most important activities.

This has gone hand in hand with a need for further financial development of UKHCDO, since this range of activities costs about three quarters of a million pounds each year to support. UKHCDO Ltd was established as the trading arm of UKHCDO (Registered Charity) initially to handle the funding of the AGM and scientific meeting. UKHCDO Ltd took over the financial management of the National Haemophilia Database and UKHCDO secretariat in 2006, becoming effectively a small business with a turnover of about £750,000 pa. UKHCDO Ltd is now established on a secure financial footing through diverse funding streams from DH, SCGs, and unrestricted grants from Industry.

Inevitably, however, much of the increase in data collection has been driven by the planning and accountability needs of SCGs, and DH, rather than research. On the other hand, UKHCDO has gone from a small charity with less than £50,000 in the bank to a small business with sufficient funds to consider supporting travelling scholarships and other initiatives to attract Juniors to our sub-speciality, employing our own independent statistician to support clinical research.

We have continued to nurture the constructive working relationship with the Department of Health (England) and The Health Protection Agency originally established under Frank Hill's Chairmanship. We continue to meet and advise DH regularly, and I believe that this has been helpful for both DH and UKHCDO and has very much benefited our patient group.

The most obvious outcome from this collaborative relationship was the "Recombinant for All" program and the subsequent two rounds of national contracting for clotting factor concentrates, which have halved the price of recombinant factor VIII and save the NHS upwards of £80 Million pounds per year. This was a great deal of work for Haemophilia Centres and only possible because Haemophilia Centre Directors behaved in a close collaborative way.

Whilst many may have mixed feelings about the medium term strategic disadvantage that national contracting may confer (it halved the budget!), without this collaboration, factor VIII budgets were likely to have come under considerable pressure and it might not have been possible to maintain all patients on recombinant factor VIII. As it is, a significant proportion of the saving from reducing unit price has been swallowed up by annual increases in the number of units used, although this last year has seen the smallest increase in usage (3.93%) for many years. With the average patient with severe haemophilia costing upwards of £100,000 pa to treat, treatment practices are coming under increasing scrutiny.

Our relationship with DH has also given us a valuable opportunity to advise on the organisation of Haemophilia care, the response to the Archer Enquiry, implementation and organisation of the revised Skipton Fund and variant CJD. These initiatives have inevitably caused centres a great deal of administrative work over the past three years, including documenting treatment in relation to vCJD, providing data for the construction and subsequent management of the National Contract for Clotting Factors, chasing data and relatives to facilitate payments from the Skipton Fund, inhibitor pharmacovigilance in relation to product switching and finally the DH Hepatitis C look-back exercise. Much of this has come at a time when SCGs are making increasing data demands on haemophilia centres and CQUINS are destined to increase data demands further. Many haemophilia centres are currently unable to cope with these many data demands and so we will have to carefully consider ways in which we can streamline data collection, minimise it, if possible, collect it more smartly and finally address the resource implications of data collection at a haemophilia centre level.

The problem is that since healthcare budgets are under greater pressure than for several decades, Haemophilia care is bound to come under greater scrutiny. Severe haemophilia costs more to treat per patient than anything else except very rare enzymopathies and yet we have minimal prospectively collected outcome data with which to justify current clinical practice, let alone increasingly intensive replacement therapy. Furthermore, there is a three-fold range in the median intensity of treatment from centre to centre, which remains unexplained. Since the change of government there have been increasingly urgent demands for treatment to be justified using measures of outcome. For that reason, last autumn we established a Clinical Outcomes Subgroup of the Data Management Working Party, chaired by John Pasi and including input from SCGs, to urgently consider the type of outcome measures we could use. His report is to be found later in this volume. Many centres will find these recommendations aspirational, since they may require more physiotherapy time (to measure joints) than is currently available to them (though would regard joint monitoring no more than normal good clinical practice). Representations may have to be made to commissioners for resources to collect this data.

One easy and quick way to collect outcome data, however, is through the use of HAEMTRACK or its paper equivalent for collecting home treatment and home delivery data. Appendix 3 of the Bleeding Disorder Statistics gives a summary of the HAEMTRACK data collected so far from almost 800 patients who have started to use this system in the last 18 months. The advantage of this system is that the patient collects the data and reports it to the haemophilia centre in real-time and the system actually saves the centre work. Compliance (both centres and patients) would have to be improved to optimise the value of this data. However, incomplete though the data may be, it is already very interesting and providing valuable insights.

Under the able direction of Dr Jonathan Wilde, the Triennial Haemophilia Centre Audit has continued to develop. After each round of audit, the audit tool and process has been reviewed and amended. Most recently we had the largely successful experiment of including a patient auditor which will become a standard feature of future audit/accreditation exercises. Partly as a result of this process of evolution, the audit reports have maintained and increased their authority and influence and are the single most important piece of evidence considered by SCGs when considering whether a Haemophilia Centre should be designated as a specialist service. Dr Wilde stepped down from this role in the past year and we should thank him for organising the Audit over the last three cycles. The direction of the Audit accreditation has now been passed to Dr David Perry, who is chairing the current multidisciplinary review of the audit tool and audit process and is steering audit towards a system of formal Haemophilia Centre Accreditation. The review group includes representatives from SCGs, the Haemophilia Nurses Association (HNA) and the Haemophilia Society.

Haemophilia Centres have been audited against the standard set down in HSG 93(30) and the expansion of this, the Haemophilia National Service Specification. Although both very successful documents which have underpinned the development of haemophilia services in the UK, neither document reflects current administrative arrangements. Furthermore, administrative arrangements in England and the devolved administrations have become progressively more divergent. We therefore perceived a need to revise HSG 93(30) and the National Service Specification and UKHCDO submitted a proposal to do this to DH. Both DH and the SCGs agreed that this would be a useful exercise, but the approach to this has changed with the change of government and remains to some extent, in flux. DH no longer issue health service guidelines and so would not issue a rewritten HSG 93(30). This would naturally fall to the new Specialist National Commissioning Board (NCB, see below). Unfortunately the NCB will not come into existence till April 2012 and even then only in shadow form for a further 12 months. In the meantime, responsibility for rewriting what is likely to be an interim national service specification in the currently agreed NHS template has been passed around and currently resides with North West SCG. This is progressing with considerable input from UKHCDO. The clinical sections have been very heavily based (or even simply reproduced) the current service specification, which required little revision. The administrative sections are difficult to write since administrative arrangements have not yet been settled and seem to change from week to week. This process does not address the needs of the devolved administrations at all, of course, and some thought will have to be given to this.

In anticipation of the passage of The Health Service Act through parliament without major amendment, many of the administrative changes anticipated by the act have already been taking place. Perhaps because the Act has not yet been passed and perhaps because of the "pause for consultation" the timetable has slipped a bit and the details change from week to week but some major changes appear to be becoming more certain. It is, for example, planned that the SCGs will be replaced by a National Commissioning Board with four regional offices, North, South, Midlands & East and London. This board will operate in Shadow for a year, starting in April 2012 and coming into full operation in April 2013. It is expected that the Board will assume many of the operational administrative roles currently residing with DH, although DH will continue to have responsibility for less operational areas such as HCV, vCJD etc. It is expected that the board will adopt a unified contractual model but there has been no formal discussion with UKHCDO about the format that will be adopted. It has been suggested informally that the Board may only wish to contract through Comprehensive Care Centres but this has not been raised with us formally and the implications of such a step, presumably the formation of contractual networks to include smaller centres, are not clear. UKHCDO must continue to maintain its continuous active dialogue with SCGs, the emerging Board and DH in order to influence the development and implementation of the administrative changes as far as is possible.

Negotiations have taken place over the last year to take HNA under the UKHCDO wing in much the same way as the very valuable UK Haemophilia Data Manager's Forum. The RCN has been an increasingly uncomfortable home for Specialist Nurses, and whilst wishing to maintain a reasonable degree of professional independence. HNA needed some logistic support and collaboration to be independent of HNA. This was discussed in the Advisory Committee in July and it was agreed to welcome HNA into the fold. We will help to administer their funds, provide some secretarial and logistic support and committee rooms for their committee meetings and generally try to support HNA. It is in everyone's interest that HNA should thrive.

I relinquish the chair of UKHCDO with mixed feelings. It has often been hard work and very time consuming but also at times fun and certainly interesting. I have enjoyed my interaction with colleagues both medical and non-medical and with the Department of Health, SCGs and The Haemophilia Society. I am often asked by colleagues from other countries how we manage in the UK to achieve so much by working together so collaboratively. Although tempted to attribute this to my own natural charisma, I have to admit that the advantage we have is to a large extent historical. The database and UKHCDO were both formed about the same time and data collection and collaborative behaviour were part and parcel of running a haemophilia centre from the very beginning. It is easy to build on solid foundations. UKHCDO have achieved a great deal through this collaborative approach over very many years, to the benefit of our patient group and many individual UKHCDO members. We need to continue to collaborate in the future as UKHCDO rises to meet new challenges during a period of considerable administrative and financial uncertainty.

I would like to thank the Executive Team, Gerry Dolan, Ri Liesner and David Keeling, for all their support and advice during my period of office and to all my colleagues on the Advisory Committee and beyond for their help and for not being slow to give their opinion. There is usually a vigorous and healthy debate around the table but perhaps fewer sparks than at one time. Although a previous chair described chairing the Advisory Committee as "like herding cats", I can't say that this has been my experience and I am grateful!

Finally I would like to thank Lynne Dewhurst and Ben Palmer and the NHD team and Rob Hollingsworth and the MDSAS team, without whose support and hard work very little that UKHCDO now do would be possible.

I am confident that I am handing over to a strong team already immersed and experienced in the issues that they will have to deal with. I wish Gerry all the best in his Chairmanship.

Dr Charles RM Hay
Manchester, 29th September 2011
Chairman UKHCDO