Eighteenth Annual General Meeting of the UK Haemophilia Centre Doctors' Organisation

Second Floor, Queen Elizabeth II Conference Centre, Broad Sanctuary, London, SWIP 3EE

Friday 3rd November 2017

Chair: Dr Ri Liesner

Minutes

1. Welcome

Dr R Liesner (RL) welcomed members to the meeting and the QEII conference centre. Attendance list attached (Appendix 1).

2. Apologies for absence

Prof M Laffan (ML) presented the apologies for absence which are attached to the minutes (Appendix 2)

3. Election of New Members **Prof M Laffan**

ML presented new applications for membership. Ryan Rogers was added to list by consent of the meeting. (Appendix 3)

4. Minutes of the 17th AGM held on Friday 14th October 2016 **Prof M Laffan**

The minutes of the previous AGM had been circulated prior to the meeting. There were no corrections requested and they were accepted as a true record. Proposed by D Hart, seconded C Hay and accepted nem con.

There were no items in the minutes not otherwise represented on the agenda.

5. Review of the constitution **Prof M Laffan**

ML explained that the constitution of the charity required review and re-approval every two years. A copy of the current constitution had been circulated with the meeting papers. There were no suggestions for changes.

6. Election of Secretary **Prof P Collins**

ML had served 2 terms as secretary and so was demitting following this meeting. PC thanked to ML for his work. Applications had been invited prior to the meeting. There was only one applicant. Dr K Talks. She was therefore elected unopposed and agreed to take over the role following this meeting.

7. Chairman's report **Dr R Liesner**

Dr Liesner's report was circulated with the papers for the meeting. Many of the points in the report appeared in the agenda and so were not repeated here. RL identified the Working Party (WP) programme as the principal item requiring attention. RL reminded the meeting that last year it had been decided to roll over WPs so that they continued their work, similar to the scientific subcommittees of the ISTH. This would avoid a stop-start aspect to their work. PC had drawn up a set of guideline rules for their operation (see previous advisory board minutes). The new, continuing WPs in this group were Inhibitors, Paediatrics and

VWD. Currently active WPs not rolled over were Musculoskeletal, and Genetics although these may require rolling over in the future. The Data Management WP has a continuous existence but membership turns over as a result of changes in the other WPs and the UKHCDO officers. CH suggested that the Haemtrack user group should be treated in the same way. Responses to the invitation have been received for the new WPs: comorbidities and laboratory and the gynaecology guideline task force. The chairs will be notified and they will then, in conjunction with the Executive, convene the WP membership.

RL reminded the audience it will be the 50th anniversary of the National Haemophilia Database next year and this should be celebrated. She invited members to suggest what form this will take. PCh asked whether London venue was attractive or whether should rotate. CH noted there had been improved attendance for recent meetings held in London. Other comments were that transport was generally easier for a meeting at London. Suitable dates were discussed and it was suggested that later in November would be suitable, but not December

8. Treasurers report and finances **Dr P Chowdary**

PCh reported that the accounts emphasised that the Charity was fulfilling its declared role. She noted that, although membership was free, a number of members still paid the £20 pa. The expenditure was mostly travel and subsistence support for the various WPs.

The Clinical Studies Group (CSG) had a running positive balance as the costs had been much less than projected by the James Lind Alliance. ML suggested giving some of CSG money to the Haemophilia Society (HS) who had accommodated the CSG meetings free of charge. This was agreed.

Acceptance of the financial report and accounts was proposed by CH, seconded DH and agreed nem con.

9. UKHCDO Ltd **Dr R Liesner**

RL described the structure of the organisation and the relationship with the charity. It had been decided that the executive committee of UKHCDO (Charity) should be directors of the Ltd Company and were also its trustees and shareholders.

CH outlined how the sources of funding were mainly fees from NHS (excluding N Ireland) and from projects funded by the Department of Health (DoH) and industry. The outgoing costs are broken down into direct costs which had slowly drifted up and expenses which had risen more dramatically, including rates and VAT. The directors had been insured. A new cost is the offsite archiving of records. These were currently in paper form and included papers from past chairs of the organisation. It was suggested that these could be digitalised at some stage.

Net profit before tax had improved in the last year, attributed to a more purposeful pursuit of projects following appointment of Bruce Cowen. Now the operating profit margin stands at approx. 20%.

Investment (for both Charity and Ltd Company). An investment committee has been formed but there have been few applicants to join this. Ltd board members and trustees of Charity will make up the committee. There is a total of approximately £1M to invest. It had been decided to invest ethically, and the limits of this had been discussed and agreed. Castlefield had been chosen as the ethical investment firm. They had included a positive approach to investment in ethical areas and had a better record than other candidates. This programme is now under way and will begin soon. Charitable and Ltd investments will be kept separate but cover similar areas: medium risk and geographically diverse.

No objections were raised to this approach.

10. Procurement **Alison Greenwood, CMU / Dr R Liesner**

The recombinant factor VIII tender has been completed and barring challenges would come into force on 1st Feb 2018. It is currently in the standstill period (ends 10th Nov) during which time suppliers can challenge

the awards resulting from the tender. There were 5 compliant offers which are all added to the framework. Stakeholder and supplier meetings will be held in the next two months and the preliminary view is that some switching will be required. The tranches awarded are 150M and 2x100M; the remaining bids have no guaranteed volumes awarded. The human cell line framework has been extended to 31st Jan 2109, which will bring the two frameworks into line. Octapharma (Nuwiq) appears on two frameworks as a result of this. The prices on human cell line framework products (Elocta and Nuwiq) remain the same following this extension.

RL. As with previous tenders the volumes will need to be agreed by region so that the usage matches the terms of the contract and this will require some switching of patients within the next few months. CH – asked what the bidders are told about the prices? AG – they are told the characteristics of the winning bid, so that companies will know roughly where they are in relation to this and 'what they need to do to win'. Expect to have details released by mid-November

Next year non-IX/VIII clotting factors will be tendered including 2-3 fibrinogen concentrates, Factor X, porcine VIII, FEIBA and NovoSeven with a new contract in place for 1st July 2018. These new frameworks will allow companies to submit new prices but it is likely that following the tenders, meetings will be held to agree commissioning stance and award criteria.

Recombinant FIX framework ends 31st Aug 2018 and 2 years extension are possible. Noted that extended half-life products are increasing their market share to a total of 22% this year. CH: if no new products then there is a good argument for extending the framework. PC noted that pegylated FIX (Novo) would enter the market at some stage. There was some discussion as to the merits of different FIX products and difficulty in predicting efficacy from the raw PK data, as a result of the extravascular distribution. CH suggest a need for contracting to take into account different targets – dose interval and trough/bleed rates.

Emicizumab is expected to gain a licence for inhibitor patients only in March 2018. Currently there are discussions ongoing as to the best route to bring this to market. It could go onto a framework and a policy is in development to support this; the clinical policy group is chaired by PC. NICE are supporting the policy submission and reviewing the evidence. It is expected that the policy for Emicizumab use in inhibitor patients will be submitted for NHSE approval by April 2018.

The license for non-inhibitor haemophilia A patients is expected in Q2 2019. Meanwhile RL informed the membership that there is a compassionate use programme for serious bleeds (life or limb threatening) and if any members have a suitable patient they need to contact Roche (email supplied if required – contact RL).

11. NHSE Clinical Reference Group **Will Horsley / Dr G Dolan (GD)**

The CRG Chair GD did not attend the meeting. WH reviewed the membership of the Clinical Reference Group (CRG). The Chair is the only funded post. It is hope that representatives from Wales and Scotland will be able to attend.

The CRG meets four time a year and GD also needs to attend the programme of care board periodically to update them.

NHSE have identified four areas for development: Improving Value, Research, Data and NICE. The CRG is doing very well on all of these fronts. Each theme has an allocated lead: Ri Liesner, John Pasi, Charlie Hay and Will Lester respectively.

NICE has not previously looked at haemophilia and had not felt that they had a role, however for three policies NHSE has hired NICE to help with appraisal: Obizur, Coagadex and Emicizumab.

WH outline future work as follows:

- Work on the 3 x Policies being developed with NICE

- Obizur®, Coagadex®, Emicizumab (inhibs)

- Haemophilia dashboard review

We will add more details to metrics which are not well defined. RL asked whether the data would become available. WH replied that it is currently too patchy and inconsistent for this to be done.

- Service review 2019

This is to follow the UKHCDO review. DH asked whether there was any plan to take note of the result and needs identified of the forthcoming service reviews. WH replied that there are 39 contracted providers in the UK and NHSE deals only with them. Revisions of contracts may save some money. LH complained of local problems with commissioners and WH suggested dealing with local specialists who are more sympathetic. LH requested the development of reference documents which would help.

- Further contributions to the Improving Value agenda

PC pointed out that this was partly about money but also reducing bleed rates. WH said that most improving value applications are to do with saving money, but would be happy to take this kind of application forward. PC added that infrastructure funding has not increased and CH commented that treatment is suboptimal-would be beneficial to increase treatment from the savings from tenders. WH suggested that this case is taken forward as there is some goodwill in NHSE with regard to haemophilia.

- Advice for CCGs on funding Radiosynovectomy (RS) for adults. The aim is to move this to specialist commissioning and develop a policy for paediatric RS.
- Policy for RS in paediatrics
- Policy for rVWF – depends on price
- Policy for Emicizumab (prophylaxis)
- *Encompass TTP* – it is proposed that the CRG would include TTP. – RL noted arrival of recombinant ADAMTS13 may precipitate this move.

WH concluded that overall this was regarded as a very good CRG.

12. Consent and Data protection **Prof C Hay**

CH reviewed the role and history of consent for the National Haemophilia Database. Prior to 2000 there was no consent. The 1998 Data Protection Act made it evident that some form of consent was needed. There were three different elements of the NHD that could be identified:

a. Main Database: this functioned on implied consent with an opt out.

It is generally agreed that this is DPA compliant and has been regularly reviewed. By UKHCDO, Caldicott Guardians and Data Protection Registrar. Patient information is regularly revised.

b. Haemtrack: This used explicit, affirmative, 2-layer electronic consent for all users.
c. Genetic Database: This used explicit, written, informed consent. Although this could be more detailed.

A problem has arisen out of the contract for mortality data with NHS digital. After some delay, this has now been resolved following a meeting with CH. This clarified that 1) NHD would not be asked to cull the existing data and 2) they recognised that written consent could only be obtained prospectively over a period of years and may never be complete. The data required for patient care does not need consent (under common law) but the data is also used for research purposes including DoH. It is the mixed use that necessitates patient consent. CH recommended that this should be done face to face using the patient information leaflet, added to patient notes and marked as complete on the NHD – this would be useful if patients change centres. Re-consent may be required if the use of data changes.

Therefore, it is proposed to put a prospective plan in place. Telephone discussion could be done to facilitate postal consent. The consent will not be retrospective and so the 18-month gap will not be filled. The

position of children who refuse on reaching adulthood after their parents had consented may require review of existing data.

PC felt we will have to invest a lot of time in taking consent to avoid loss of the currently almost complete coverage of the patients. Such a loss would be extremely damaging.

13. Peer Review 2018 **Dr J Hanley**

JH presented an update on the collaboration with the West Midlands Quality Review Service (WMQRS) which had been approved at UKHCDO Advisory Board, May 2017. Membership of the Peer Review WP included all the relevant stakeholders.

The next step is to recruit reviewers. Anne Yardumian described her experience as a clinical lead in the similar process for haemoglobinopathy and renal transplant service reviews. She emphasised the benefits of being a reviewer.

Also need to plan how to review networks and joint centres. Some may be done separately, some smaller centres will be done as part of a network. A preliminary questionnaire had revealed a heterogeneous pattern of arrangements. JH presented a preliminary review of networks to help design the review.

A set of Quality standards has been developed and circulated for comments (closes 27th Nov).

Members were encouraged to feedback on the quality standards and to volunteer as a peer reviewer. A good method for capturing patient and carer feedback needed to be developed. Funding will be handled by the WMQRS who will obtain fees from the participating Trusts and coordinate the whole process.

RR asked whether the incentive for Trusts to pay would be to threaten closure without accreditation. AY replied this was not generally so although there was feedback category of 'immediate risk'. The process could lead to a form of designation of centres.

WH will ensure that outcomes of the review will feedback to local commissioning hubs and teams and into the NHS service review.

14. Haemophilia Society Update **Ms E Carroll**

EC thanked UKHCDO for the funding following her last visit 3 years ago. Members were encouraged to join the Haemophilia Society (HS).

The HS has been working to ensure they are as inclusive as possible, growing services and their advocacy voice. Membership has increased to >6000 (from 3000 3 years ago). They are now working on the strategy for the next 5 years and would like to work together with the UKHCDO. Also, would like UKHCDO members to participate in the HS events. EC noted that family events were very popular and successful and were held 4 times a year funding permitting.

50 children had attended a 6-16 youth camp, to encourage activity and increase understanding about managing disorder. This was planned again for next year.

Ageing community – HS had been filming members. It was interesting to note that more are concerned about what happens when they have to go into a care home (they are concerned about disability and infection). Care homes will need help with education about these problems.

HS is running updates for members on new treatments, an Inhibitor camp and working with EHC for better education and understanding especially for less well funded countries.

Female members are increasing for a number of reasons. Young women are interested in becoming advocates for themselves as well as for male disorders.

It is planned to change the society name from HS to something more inclusive, following vote by members.

15. Public Inquiry **Dr R Liesner / Prof C Hay**

EC and RL reported that it had been announced this morning that the inquiry into the transmission of infectious diseases by blood and blood products will be a statutory inquiry and based in the cabinet office. EC stated that HS policy is to recommend that the inquiry is directed at the decisions made by the DoH rather than individual doctors, nurses etc. This will allow lessons to be learned and implemented for the future. It was noted that a similar inquiry in Ireland resulted in agreement that price would not be the sole/primary basis for treatment choices. It is expected that cabinet office will ask for comments on the Terms of Reference for the inquiry. The role of the UKHCDO is not yet clear, although we have said we are ready to help. The government is expected to fund the legal and admin costs of participants.

CH commented that HIV records are fairly complete because it is a notifiable disease but Hep C not so clear. Some data were provided to the Penrose inquiry but these are incomplete. Our previous attempts to gather data retrospectively were over ambitious and overwhelmed centres. We do have some mortality data but this is also incomplete.

CH presented current knowledge of Hep C status. There are over 5000 individuals whose exposure or status is not known. In any event these data are out of date, partly because of the highly effective treatment programme. It is proposed to request from centres the most recent HCV test result including those who are dead for a total of about 7000 patients. This will be done by centres completing a spreadsheet provided by NHD listing the patients whose status is not known. This does not go as far as M Makris' suggestion to also collect data on liver status.

16. WFH Glasgow 2018 **E Carroll**

GD is the nominated UKHCDO representative on the WFH committee. UKHCDO members have had scanty information to date. EC reported that key dates are abstract registration and early bird registration which close on the 17th November. GD has previously informed the membership that the UKHCDO will need to provide an adult doctor every day for approx. 2 weeks total to include the period of satellite meetings, mainly to support nurses and physiotherapists in the treatment rooms. We would like to showcase the work going on in the UK and need to encourage staff to attend and support the treatment room provision for patients.

17. NIHR Bioresource Update **Dr Sofia Papadia**

Dr Papadia from Cambridge provided a progress summary of the different genetic and bioresource projects.

a. BRIDGE this had recruited14250 participants across 15 study groups. BPD is one of these. However, this had now closed and whole gene sequencing (WGS) is now available through the 1000k project and results are transmitted back via MDTs embedded in the Genomic Medicine Centres (GMCs). GEL-100K will also close in September 2018 and be replaced by a new genetics network.
b. Thrombogenomics (TG) is a next generation sequencing (NGS) platform for 96 tier 1 haemostasis genes. Currently free and available via Cambridge.
c. The NIHR rare diseases Bioresource is now recruiting patients with known bleeding disorders. The aim is to generate a national bioresource repository for future research. Aiming for nurse-led enrolment, plasma and serum are added to DNA collection. Genome wide typing and TG analysis is standard. Samples are stored in a repository at Milton Keynes. The pilot at 6 centres has enrolled 572 samples to date. Now would like to roll out to more centres and this has begun.

A pilot for electronic consenting via tablet is being run.

A new MDT model is being established to speed up reporting.

The bioresource will be a national resource, access for which is open to all via submission of a two-page application form. This will then be reviewed and a decision on permission given. DH complimented Cambridge on the way this had been fitted into the functioning of clinics and made as easy as possible.

See Appendix 4 for a summary.

18. UKHCDO website development **Dr P Chowdary**

PCh invited suggestions for improvement or development of the website. CH wanted to generate more patient access because, although it is open to the public, we could make it more user friendly for these groups. Links to HS website exist, interface more useful with icons rather than headings. WO suggested use of a Twitter feed and rolling banner for news items. A useful comparison was the EAHAD website, also designed by MDSAS which may serve as a model.

19. NHD / HCIS / Haemtrack IT update **Rob Hollingsworth**

RH emphasised the benefit of standardised system use for reporting data in the UK. He outlined the new developments:

1. Centres who work across multiple sites, would need an opportunity to access from a central store. MDSAS have developed 'Filestore' to allow this. It is compatible with all different types of data files.
2. Video consultation. The previous version (CLIVE) did not work on iPhone or iPad. Now being updated. Patients do not need a user account but it is encrypted and secure. It could be suitable for telephone clinics and can be recorded if desired.
3. Haemtrack had 1.2M data entries to date and 3000 patients registered. It is now receiving approximately 20000 entries per month. RL pointed out that it is important that the centres validate the entries. Problems with password management have been resolved and there has been a 70% reduction in unlock requests. Haemtrack is now being used worldwide including a commercial Bayer study.
4. Haemtrack V2.0 now being launched. Key features are:
    a. Will work on all devices that have a web browser.
    b. Images can be added to treatment episodes.
    c. Doctors can review patient data on a phone.
    d. Multiple accounts can be managed for one device.
    e. Inpatient usage is added.
    f. Translatable.

Now in pilot phase prior to roll out.

5. HCIS 2.1 including joint scores and an interface for PKfit has been built. Prophylaxis has new fields in HCIS. Web-HCIS developing a stakeholder group to discuss needs.
6. New registration forms for VWD and inhibitors.

20. Annual Report UKHCDO Bleeding statistics and Haemtrack update **Prof CRM Hay**

Appendix 1: In Attendance

UKHCDO Executive Committee	
Dr Ri Liesner (RL)	UKHCDO Chair, Great Ormond Street, London
Prof Peter Collins (PC)	UKHCDO Vice Chair, Cardiff
Prof Mike Laffan (ML)	UKHCDO Secretary (outgoing), Hammersmith, London
Dr Kate Talks	UKHCDO Secretary (incoming), Newcastle
Dr Pratima Chowdary (PCh)	UKHCDO Treasurer, Royal Free, London
Attending	**Centre**
Dr Jayanthi Alamelu	St Thomas' Hospital, London
Dr Julia Anderson	Edinburgh
Dr Neha Bhatnagar	Oxford
Rachael Blackburn	West Midlands Quality Review Service
Dr Sara Boyce	Southampton
Nancy Brodie	Glasgow Adults
Dr Carole Cairns	Belfast
Elizabeth Carroll (EC)	Haemophilia Society
Dr Elizabeth Chalmers	Glasgow R.H.S.C.
Dr Amanda Clark	Bristol
Bruce Cowen	National Haemophilia Database
Dr Nikki Curry	Oxford
Dr Simon Davies	Taunton
Lynne Dewhurst	National Haemophilia Database
Dr Gillian Evans	Canterbury
Dr Keith Gomez	Royal Free
Alison Greenwood (AG)	CMU, NHS England
Dr Charlotte Grimley	Nottingham
Dr John Hanley (JH)	Newcastle
Cathy Harrison	Sheffield Adults - Invited Guest
Dr Dan Hart (DH)	Royal London Hospital
Prof Charles Hay (CH)	Manchester Adults
Dr Joannes Hermans	Nottingham
Dr Rob Hollingsworth (RH)	MDSAS
Dr Lishel Horn (LH)	Leeds
Will Horsley (WH)	NHS England
Dr Sarah Janes	Chichester
Paul Kane	MDSAS

Attending	Centre
Dr David Keeling	Oxford
Dr Anne Kelly	Cambridge
Dr Christine Macartney	Belfast
Dr Rhona Maclean	Sheffield Adults
Dr Bella Madan	St Thomas' Hospital, London
Dr Sarah Mangles	North Hampshire, Basingstoke
Dr Mary Mathias	Great Ormond Street Hospital, London
Dr Carolyn Millar	Hammersmith Hospital, London
Dr Bethan Myers	Lincoln
Dr Niamh O'Connell	Dublin
Prof Willem Ouwehand (WO)	Cambridge
Dr Sofia Papadia	Cambridge
Dr Jeanette Payne	Sheffield Children's Hospital
Dr Charles Percy	Birmingham Adults
Dr Rachel Rayment (RR)	Cardiff
Sarah Rooney	UKHCDO Event Organiser
Dr Martin Scott	Haematology Registrar, Manchester Adults
Dr Emily Symington	Cambridge
Dr Alice Taylor	Great Ormond Street, Hospital
Dr Murugaiyan Thanigaikumar	Lewisham & Greenwich
Dr Will Thomas	Cambridge
Prof Cheng Hock Toh	Liverpool Adults
Anna Wells	North Hampshire, Basingstoke
Dr Andrew Will	Manchester Children's
Dr Mike Williams	Birmingham Children's
Dr Anne Yardumian (AY)	Middlesex
Dr Thynn Thynn Yee	Royal Free Hospital, London

Appendix 2: Apologies

Name	Hospital
Dr Benjamin Bailiff	Coventry & Warwick
Dr Louise Bowles	Royal London Hospital
Dr Ronwyn Cartwright	Worthing Hospital
Dr Deepak Chandra	Coventry
Dr Brian Colvin	Honorary UKHCDO Member
Dr Jason Coppell	Exeter & Barnstaple
Dr Jo Craig	Inverness
Dr Desmond Creagh	Truro
Dr Gerry Dolan	St Thomas Hospital, London
Dr Richard Gooding	Leicester
Dr John Grainger	Manchester Children's
Dr Georgina Hall	Oxford
Prof Frank Hill	Honorary UKHCDO Member
Dr Kate Khair	Great Ormond Street, Hospital & HNA Chair
Dr Will Lester	Birmingham Adults
Dr Gill Lowe	Birmingham Adults
Prof Christopher Ludlam	Honorary UKHCDO Member
Dr Hamish Lyall	Norfolk & Norwich
Dr Jason Mainwaring	Bournemouth & Poole
Prof Mike Makris	Sheffield Adults
Dr Brigitta Marson	Brighton
Prof Amit Nathwani	Royal Free
Dr Sally Nelson	Public Health Medicine – Special Commissioning
Dr Tim Nokes	Plymouth
Dr Samya Obaji	Cardiff
Dr Sally Pollard	Bradford
Wendy Roach	CMU, NHS England –Invited Guest
Dr Clodagh Ryan	Honorary UKHCDO Member
Dr Susie Shapiro	Oxford
Prof Campbell Tait	Glasgow Adults
Dr Joost VanVeen	Sheffield Adults
Dr Henry Watson	Aberdeen
Dr John-Paul Westwood	University College Hospital, London

Appendix 3: New Member Applications

Name	Job Title	Centre	Proposed by
Dr Ronwyn Cartwright	Consultant Haematologist	Chichester	Dr Sarah Janes
Dr Amanda Clark	Consultant Haematologist	Bristol	New Centre Director at Bristol
Dr Kathleen Clarke	Consultant Haematologist	Truro	Dr Desmond Creagh
Dr Emma Fosbury	Consultant Haematologist	Royal Free Hospital, London	Dr Pratima Chowdary
Dr Gill Gidley	Consultant Haematologist	Leeds	Dr Lishel Horn, seconded by Prof Charles Hay
Dr Patricia Guimaraes	Consultant Haematologist	Cardiff	Prof Peter Collins, seconded by Dr Rachel Rayment
Dr Joannes Hermans	Consultant Haematologist	Nottingham	Dr Charlotte Grimley
Dr Anne Kelly	Consultant Haematologist	Cambridge	Dr David Perry
Dr Mahon Mahalakshmi	Consultant Haematologist	Colchester	New Centre Director at Colchester (contacted NHD)
Dr Samya Obaji	Consult Haematologist	Cardiff	Prof Peter Collins, seconded by Dr Rachel Rayment
Dr Catherine Rea	Consultant Haematologist	Eastbourne	New to Eastbourne (contacted NHD)
Dr Martin Scott	Haematology Registrar	Manchester Adults	Prof Peter Collins
Dr Ryan Rodgers	Consultant Haematologist	Edinburgh	Dr Julia Anderson
Dr Alice Taylor	Consultant Haematologist	Great Ormond Street, London	Dr Ri Liesner
Dr Will Thomas	Consultant Haematologist	Cambridge	Dr Gerry Dolan, seconded by Dr Steve Austin

Honorary Member Applications

Name	Job Title	Centre
Dr David Perry	Consultant Haematologist	Cambridge

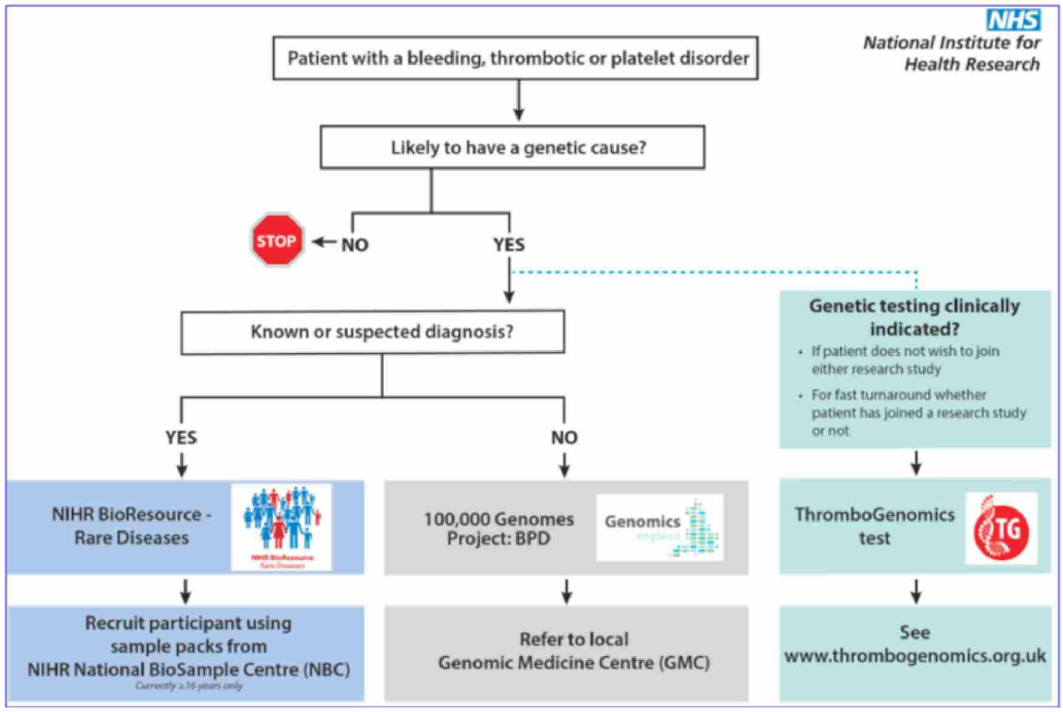
Retired UKHCDO Members

Name	Year	Centre
Dr Rosie Dennis	2017	Edinburgh
Prof Angela Thomas	2017	Edinburgh
Dr Trevor Baglin	2017	Cambridge
Dr Oliver Chapman	2017	Coventry & Warwickshire

Appendix 4: 17. NIHR Bioresource

Eligibility Flow Chart for BPD genetic research: Haemophilia Centres

Currently distributed to the 8 Centres open for Haemophilia Centres Project



Eligibility Flow Chart for BPD genetic research: Haemophilia Centres

Currently distributed to 8 Centres open for Haemophilia Centres Project

Contact details:

NIHR BioResource – Rare Diseases (NIHR BR-RD)

- Download Consent Forms and Participant Information Sheets from here:

https://bioresource.nihr.ac.uk/rare-diseases/recruitment-procedures-documents/

- Sample or transport pack requests, general queries for NIHR BR-RD:

NIHRBR-RD@ukbiocentre.com , **01908 870847**

- For any other procedural queries, including training and ethics:

rarediseases@nihrbioresource.org.uk using "Haemophilia Centres Project" in the subject line

0800 085 3650

100,000 Genomes Project (100KGP)

www.genomicsengland.co.uk

List of GMCs:

https://www.genomicsengland.co.uk/taking-part/genomic-medicine-centres/

ThromboGenomics (TG)

www.thrombogenomics.org.uk

info@thrombogenomics.org.uk