Minutes of the Board of Trustees' meeting, held at The Haemophilia Society, Ground floor, Willcox House, 140 – 148 Borough High Street, London SE1 1LB on Wednesday 4 February 2015

Present:
Alan Burgess (AB)
Helen Campbell (HC) - by phone
Kate Khair (KK)
Bernard Manson (BM)
Andy Martin (AM)
Simon Mower (SM)
GRO-A – arrived at 2.30pm
Jeremy Young (JY) left at 2.30pm

Apologies:
Richard Brook (RB)
Bill Payne
Barbara Scott (BS)
Stephen Wilkie (SW)

In attendance:
Liz Carroll (LC)
Christina Burgess (CB)
Dola Akinnibosun (DA) – Minutes

BM welcomed everyone to the meeting. The minutes follow the order of the agenda and not necessarily the order of discussion.

Minutes and Matters Arising

The minutes for the meeting held on 26 November 2014 were reviewed and adopted. The action points were reviewed and were completed or are discussed in the appropriate place below, except for the action to inform members as part of a mailing that there would be no Christmas HQ and to explain why. This was not done, and should be done in the next mailing. **(Action LC)**

The updated minutes from the September Board meeting were also approved and adopted.

Staff updates

CEO Report
See appendix A for full CEO report
Highlights of the verbal update:

Governance

- We have started a Gift Aid audit to ensure we have up to date declarations for everyone
- We were able to use the Raiser's Edge database successfully for the first time to contact members with our change of address Christmas card. We have also started asking everyone to provide an email addresses if they have them as this will greatly reduce our costs and time.

Influencing updates

- NHS England has proposed a new co-commissioning model where local hospital Trusts share responsibility for specialist services. The Board discussed this point and agreed that this is a worrying development as it could be detrimental to care. We will continue monitoring this

while supporting the work of the Specialist Commissioning coalition and working closely with the UKHCDO to ensure that our views and concerns are expressed publicly.
- The website has lots of coding errors which we identified with the help of our volunteer. Although most have of these have been resolved, there is still much work to be done on it. E.g. we recently discovered a malicious software installed on our 'Join us' button which generated loads of spam emails. This means that we had to install CAPTCHA on the website.

APPG, Penrose, the Burden of Illness survey, and MacFarlane Trust were discussed separately as agenda items. Under AOB there was a further discussion on influencing the NHS.

Actions:
To review mailing preferences on Raiser's Edge for the Board members to ensure we are sending membership correspondence by emails rather than posting (DA);

Specialist Commissioning – To write a letter from The Haemophilia Society Board of trustees to NHS England and the Secretary of State for Health with our concerns about the proposed plans for co-commissioning and the impact this could have on the bleeding disorder community as well as display on the website. Also copy Shadow Health Ministers (LC in conjunction with KK and BM)
Fundraising Report (given by LC on behalf of SW)
See appendix B for the full report
Highlights of the verbal update

- The overall news is that things are looking very positive. Community events and challenges have increased with most of the places for next year's challenges already full.
- We are also inviting the pharmaceutical companies to reconsider how they provide funding i.e. fund activities around an area of activity as a whole e.g. ageing, rather than based on individual projects.
- The 'Swim around Britain' challenge with our Celebrity Ambassador, Jack Bridge and sponsored by Bayer, has been very successful as we have 126 challengers who are beating Jack in the race. We plan to make the final day of the challenge coincide with our 65th birthday on 29 July.
- We had received some pushback on trust applications because of our current high level of reserves. We would monitor this and consider other ways of presenting our bids.

The Board expressed their satisfaction with fundraising activity.

Membership and Planning Report
See appendix C for the full report
Highlights of the verbal update

- The Newly-Diagnosed weekend held recently was a great success thanks especially to the help from the health volunteers who went along. GRO-A trainee physiotherapist and Youth Ambassador was very reassuring for parents as he shared his experiences and even demonstrated administering his own treatment. The next weekend will be on 6-8 February.
- There are still available places on the Youth weekend coming up in March.
- Membership continues to grow and we have enrolled 40 new members since the last Board meeting.

Report from Resources

Management accounts - Year-to-date figures to December 2014 are better than expected, however some of this is due to timing and January's management accounts will be more reflective of the true position. We have however had a significant increase in income from pharmaceutical companies and community fundraising activities. We anticipate a year end deficit of around £100k which is equal to the lost government grant, but significantly better than the predicted deficit when the budget was prepared. The board expressed thanks to Liz and the team for a job being well done.

Recruitment of new Chair: update – Resources committee has reviewed the proposals received from 3 different recruitment agencies and decided to invite 2 of them (Peridot and Inzito) to meet with the appointments committee, with the aim of selecting one of them by the end of February.
Action: DA to circulate Role specification draft to the board this week.

Governance

2015-15 plan and budget draft 1
Overall admin and governance core costs have reduced dramatically. There are additional costs in 2015/6 (i) for recruiting a chair and (ii) to purchase advance event and air tickets to Orlando for the WFH 2016 as we need to have a good presence at that event. It is hoped to reduce the current deficit of £100k to break even within the next 2 to3 years.

There is an increase in services this year with a broader range of services to meet diverse needs. For example we will go from 2 to 5 youth weekends We will include events around inhibitors and ageing, a carriers' conference, and trial some information days on HIV, Hepatitis C and working with our members in Northern Ireland to see how we can meet their needs. We will launch our Youth Ambassador programme, increase our publications and also expand the core group of volunteers.

We will increase membership, develop membership packs tailored to meet the requirements of specific members and ensure that our services are accessible to members across the UK. Local groups will be revitalised, with visits from CB and SW to shape the role of local groups. The local group forum will also take place this year. Governance of local groups (particularly finance) will be a key focus.

We have planned an upsurge in community fundraising and challenge events while members' interest in fundraising activities also continues to rise. Overall, we expect by the end of next financial year a deficit of £85k to £100k but this allows for the significant increase in services and membership engagement. This reflects a progression towards breaking even within the next 2 – 3 years.

The job description for the additional admin staff agreed at the last meeting has been drawn up and is ready to be advertised.

Decision: The board gave approval to start spending towards services in the first 6 months as venues etc. need to be booked. Further spending will be reviewed as income is secured. A full reforecast will take place at 6 months.
Action: SM to circulate abridged version of the budget and plan to the board for review and feedback

4-year plan update
It was agreed to discuss this at the next board meeting.
Action: DA to re-circulate the 4-year plan to the Board in preparation for discussion and publish on the website once signed off

Governance training for trustees
LC fed back that Community Action Southwark seems to be the best provider at reasonable cost (recommended by BS). It was agreed to go ahead with a bespoke training for all trustees and a poll was conducted to check trustees' preference for when to hold this.
Decision: It was agreed to have full day training, if possible the day before or after a board meeting. Suitable date to be confirmed. **Action: LC**

Trustee audit and gap analysis

This has not been progressed due to other priorities. It was agreed that this will be discussed at the next meeting following further investigation.

Action: BM and LC to investigate tools and resources.

Salary structure review

Not all the information required to make a decision was available. LC has information on the NJC scale used by most charities but is seeking guidance on how this is applied in other charities and how job roles are positioned and reviewed if the scale is adopted. It was agreed to continue discussions on this at the next meeting.

Appointments Committee (re Chair recruitment)

It was agreed that the Committee would undertake the recruitment process and make a recommendation to the board which would make the final decision. It was agreed that HC should join the Appointments committee so that it included one of the newer trustees. This made the membership BS, HC, BM, SM, and JY, with LC attending as appropriate.

Decision: HC to join the Appointments Committee.

Action: BM to try to locate document with the Committee's terms of reference to circulate.

Meeting with the MacFarlane Trust

LC met with Jan Barlow CEO and Roger Evans (Chair) of The MacFarlane Trust (MFT). There were 2 main areas Jan and Roger wanted to discuss:

1. **Recruitment of The Haemophilia Society nominated MacFarlane Trustee**

As there is now a vacancy for the Haemophilia Society nominated trustee to the MacFarlane Board, Jan and Roger wanted to discuss what should happen now. They feel in response to the APPG inquiry they could suggest merging the 3 charities that currently exist, which could lead to a trustee being recruited then dismissed in the near future, so it may be better to wait and see what happens. Roger expressed interest in being involved in the process should The Haemophilia Society choose to proceed with recruiting their nominated trustee now. Although he has not been involved in recent recruitment, he has been in the past and this was successful. He also requested that the nominated trustee be someone who had not been a trustee previously. LC asked for a copy of any role description and if there had been a Board skills/gap analysis or any information that would help in recruitment.

2. **The Haemophilia Society response to the recent APPG inquiry report and upcoming Penrose report.**

LC was asked about the Haemophilia Society's response to the APPG Report, and some discussion took place about the challenges of such research in a community that is often private. Also, not all affected persons are registered so that personal survey links could not be sent. However, it was the best that could be achieved in the circumstances and it was agreed that it did reach a broader range of people affected than any other survey has done. Jan and Roger felt it had given voice to people who are not usually heard. However, they were concerned that the Haemophilia Society might 'stitch them up'. LC explained that the Board had not discussed their response yet and that this was an agenda item for the upcoming meeting. Jan and Roger talked through their thoughts on future systems of support including that merging the 3 charities would cost more, but would reduce admin and the number of Boards for Jan to have to manage. Nonetheless, any change could cause considerable distress to many beneficiaries who do not want the status to change.

The possible implications of the Penrose report were then discussed and LC stated that this will have an impact UK wide and might bring things to a head early in to the new parliament. The Haemophilia Society would keep the pressure on whoever is in government to make an announcement as quickly as possible. Jan then expressed her opinion that the DH should wait for as long as possible before making any decision as more people will have died and there will be less people to pay and fight for payment. LC did not comment on this point.

The meeting ended with LC agreeing to report the conversation to the Board and revert to Jan and Roger about the Trustee nomination.

The Board discussed the nominated trustee and queried whether Matt Gregory's term was also up as a nominated Trustee. LC reported that Jan had said he had been reappointed.

Considerable discussion took place about the Board's view on the nominated trustee recruitment and, the experiences of current and previous nominated trustees, as well as the response to the APPG survey and Jan Barlow's observations.

Decisions: The Board identified that we have the right to nominate a trustee and therefore we should do so, as it is important to have a presence to represent the affected community even when some nominated trustees are often dissatisfied or resign prematurely. It was recognised that this is a difficult role and anyone nominated should be made aware of this.

The Board does not believe that the current system of 5 organisations is fit for purpose. We recognise that some people are very happy with the system as it is, and that current funding is not sufficient to meet beneficiaries' needs. However the overwhelming majority of our members' experiences, as well as our own interactions with these organisations, lead us to the conclusion that any future support should be managed by a different structure and by a different staff team. The Board does not have confidence that beneficiaries' needs are at the forefront of the decisions made by the leadership team at The Skipton Fund, Caxton Foundation and MacFarlane Trust. We also recognise that beneficiaries have lost trust in the current administration and this must be addressed.

The Board would like to call for a public apology from the Prime Minister in response to Penrose following publication, before parliament dissolves.

Actions:
LC to draft a letter on behalf of the Board to Jane Ellison MP copied to the APPG, Shadow Health Ministers, Secretary of State for Health, Alistair Burt MP and Baroness Meacher. This should state our view that the current administration and system is not fit for purpose, giving some examples of why.
LC to investigate whether Matt Gregory (MG) was reappointed by The Haemophilia Society or the MacFarlane Trust and if it was not by The Society, inform Jane Barlow that 2 trustees will need to be appointed by the Board.
LC to draft a letter to Jan Barlow informing her that we wish to appoint one (or two depending on the decision on MG) trustee to MacFarlane and our response to the APPG survey and subsequent letter to Jane Ellison MP.
Both letters will be circulated and approved by the Board before being sent.

Areas of activity

Burden of Illness study
GRO-A reported that 97% of the quota of physicians required for accurate statistical representation across the 5 EU countries have been engaged and 24% of the surveys are already completed. There is, on the other hand, a challenge in getting the UK physicians on board. Whereas some of the EU countries are oversubscribed, only 18 of the 49 positions that we anticipated from the UK have been filled. LC had a recent conversation with a few Consultants who were concerned about requiring local Trust approval, and they seem to be misinformed. GRO-A and LC have discussed the way forward. However, on the whole, the survey is generally progressing well.

Other aspects of administration of the Advisory Group were discussed to keep the Board updated. LC informed the board that the initial payment of £30,000 will not be received until July. We had misunderstood the fine detail of the contract thinking this would be paid this financial year, however this is not a problem as we are concerned with total income, not immediate cash flow.
Action: LC to contact Gerry Dolan, Chair of UKHCDO to encourage participation and clarify the points of confusion GRO-A with KK's help on wording to support LC)

Penrose and APPG update

The **APPG** Inquiry report launch where AB spoke was well-attended and we were pleased that Baroness Meacher (Society President) attended. Although some campaigners were upset with the Department of Health statistics quoted, this does not seem to have caused problems in the longer term. The Inquiry and subsequent Back Bench Debate, which was very well attended by MPs and the affected community was very emotional and has generated a lot of presswork which is positive in the run up to the publication of the Penrose report. The Board was pleased with the outcomes of the APPG survey and the media activity generated from this, and that we were able to find case studies for several radio and TV interviews as well as Liz undertaking some herself. It was agreed that the momentum is building and activity must continue until the report is published.
Action: LC to write a letter to the APPG and Minister (Jane Ellison MP) Secretary of State for Health (Jeremy Hunt) lending support to the report (Board members to read and feedback)

The Penrose inquiry report will be made public on 25/3/15. We have been informed by Thompsons Solicitors that the private embargoed hearing will take place a week prior, on 18/3/15. The Board meeting has therefore been moved from this date to allow for AB and LC to attend. LC will also attend the public launch. LC is still trying to find details of how the process will work. **(Action: LC to follow up with Thompsons)**

Extensive discussion took place on our possible response. The board was of the opinion that had the society been named in a negative light, we would already have received a warning letter inviting us to respond. In light of the short time available between seeing the report and publication, the decision was to focus on key points in the report in order to plan an early response without getting drawn into passing comments on specifics such as individual persons named. It was agreed to draft areas to look for and collate some case studies to show the impacts on individuals and families as part of our response. The Board meeting on 23 March will give an opportunity to finalise our early response.
Action: AB/LC to draft points to look for in liaison with BM. LC to seek case studies and media attention.

It was recognised that we were spending a large amount of time on this, but the confluence of Penrose and Alistair Burt's initiative represented a real opportunity for progress and it was worth making this effort now.

Clinical Advisory Group

AM has drafted new terms of reference for the group with LC and Mike Makris. The system has been tested with some recent publication reviews. It was agreed that this provides a robust system for ensuring accurate information provision and ensuring that The Society would be up to date with all key issues.
Decision: Revised terms of reference agreed by the board.
Action: AM to circulate to the CAG

AOB

World Federation of Haemophilia (WFH) – Orlando Congress 2016

KK has been asked by our nominated multi-disciplinary team committee representative, Andrew Brewer, which topics we wish to put forward to the committee for inclusion in the conference in

Orlando. This is because his consultation led to a range of topics too wide for all of them to be nominated.
Action: KK to circulate list for board members to consider and feedback.

<u>Irish Haemophilia Society and Haemophilia Nurses Association conference dates clash</u>
Both conferences will hold from 5 to 7/3/15 and we do not have enough staff available to attend both. **Action: GRO-A volunteered to attend the Irish Society AGM and conference on behalf of the society. LC to inform the Irish Haemophilia Society.**
KK to chase up invitation to the HNA conference as it hasn't arrived.

<u>Next AGM venue options</u>
The board discussed potential locations for the next AGM and it was agreed that it should be a northern venue as we have been further south for a few years. It was agreed to consider Leeds as first option with Liverpool as alternative. We will see if this has an impact on numbers, as although London is easily accessible, it is a long way for many and can be costly.
Action: DA in conjunction with HC for tips on suitable venues in Leeds.

<u>Haemophilia Wales</u>
For information: This is a new charity set up in Wales led by Lynne Kelly, an ex-trustee of the Society. It was agreed to try to establish the same cooperative relationship with this as we have with Haemophilia Scotland, while reaffirming that the remit of the Society continues to cover the whole UK.

<u>WFH Congress 2018 Glasgow</u>
The next Board would hear a presentation from the working party. Our key activity for this time next year was appointing various "heads of" as part of the organising structure. **Action: LC to get what further information was available from WFH and to set up a conference call meeting of the working group before the next board meeting.**

<u>Advocating within the NHS</u>
There was a general discussion around this. Advocacy was a key objective of the Society, but to do the job properly would require a dedicated senior staff member, which would cover England and possibly Northern Ireland but would still leave us disadvantaged in Scotland and Wales. While we could aspire to employing such a person, it was clearly an aspiration for beyond this year and next. We had to consider how we could free up some of LC's time to let her do at least some basic advocacy within NHS England. We should keep this in mind in our discussions on strategy and planning.

Next meeting
Monday 23 March

Chief Executive Report February 2015

Overview

We have now moved office and settled in well. The move period was very disruptive with several hitches, however we are almost fully sorted and functioning. We have a full staff team for the first time since I started a year ago, which is a very positive step.

Governance

Audit

Our accounts have been lodged with Company House, the Charity Commission and The Office of the Scottish Charity Regulator, all within the required timescales, the accounts are also available on the website.

Gift Aid

We have begun a Gift Aid audit of our files to identify everyone who has a Gift Aid Declaration and anyone we think should have one, but hasn't. We will be contacting everyone necessary to ensure all records are accurate and comply with legislation as we discovered not all declarations were recorded properly.

The Raisers Edge Database

We have finally been able to use the database properly and were able to mail all our members with a change of address Christmas card. We have 1800 members email addresses, which is a great increase from previously. This will enable us to communicate with more people by email at a greatly reduced cost for many of our communications. We are looking at e bulletins etc. particularly for fundraising and highlighting services to specific groups of members.

Staff

Cynthia is now on a permanent contract with us 3 days a week and GRO-A has returned from maternity leave. We are about to advertise the new admin post agreed at the November Board meeting.

Trustee training

I have investigated potential trustee governance training and the best offer is from Community Action Southwark which would be a full day's bespoke training for all our trustees in our office at around £840.

Staff salary scales

I have been working on identifying appropriate staff salary scales and job evaluation tools. The most used scale it the charity sector is the NJC scale, which I have details of, however I am looking at other options as we all CEO pay comparisons as these are usually different.

Influencing updates

APPG

As secretariat we arranged the AGM for the APPG which took place on 10 December, the APPG was then reregistered on the official Parliamentary list, so can continue running. Diana Johnson MP and Jason McCartney MP were re-elected as co-chairs.

The APPG inquiry report was launched on 14 January in parliament with around 10 MPs attending and a number of the community affected by contaminated blood. The co-chairs of the group Diana Johnson MP and Jason McCartney MP spoke about the report and asked Alistair Burt to give an overview of his work with the Prime Minister. Alan Burgess then spoke about his personal and family experience of living with contaminated blood and as a beneficiary. Alan then spoke candidly about being a trustee for the McFarlane Trust, which was not a positive experience. The meeting was generally well received although some of the community were upset the report mentioned the estimated 33,000 people with Hep C the DH quote.

The Back Bench Debate on contaminated blood took place the day after the APPG inquiry report launch and was very well attended by MPs and the affected community. The Society were thanked for their support for the APPG work. There was cross party agreement that this issue must be addressed, an apology given and compensation agreed. The debate close with Andy Burnham MP speaking as Shadow Health Minister broadly supporting the view that this must be resolved whatever the new government looks like Followed by Jane Ellison MP, Public Health Minister. Many were disappointed by Jane Ellison's lack of commitment to anything concrete. She confirmed that the government were looking at this issue and were waiting for Penrose to report before making any decision or announcement. She did announce an extended access scheme for some people with cirrhosis from Hepatitis C which would be available from April, we are in the process of finding out what exactly this means to the community.

The 2 days of activity generated a great deal of press attention. I was interviewed for Scottish ITV and by BBC radio as well as several papers picking up the official press release and quoting me. Many members were also interviewed having contacted their local papers. Both ITV and BBC have asked to keep in touch with us so they can report on Penrose, which is very positive.

We have hard copies of the report and it is available on our website, so please do let us know if anyone would like a copy.

Penrose

Penrose will be published on 25 March with a press and public meeting in Edinburgh, which I will attend. There is an embargoed viewing of the report on 18 March in Edinburgh that Alan Burgess will attend. I will accompany Alan so we can plan our response. We have proposed moving our March Board meeting to Monday 30th March to enable the Board to discuss our response before it is publically available. We will discuss the issues we will need to look for in the report during the board meeting.

The Skipton Fund, Caxton Foundation, McFarlane Trust

I met with Jan Barlow, CEO and 4 of their trustees along with Jason McCartney MP the day before the APPG report launch for them to comment on the report. They were pleased with the report and felt it showed them in a positive light. Which was surprising given the content of the report.
I am meeting with Jan Barlow and Roger Evans on 29 January at their request, however I do not yet know what they wish to talk about. I will be bringing up the issue of our nominated trustees as there will be 2 vacancies as Alan resigned in January and Matt comes to the end of his term at the end of January.

Specialist Commissioning

NHS England have proposed that specialist commission should move to a co commissioned model, where local hospital Trusts are co responsible for specialist services. There is a lot of confusion over what this means, but the biggest concern for our community is that each hospital will have a set budget, rather than just a national on in England. This has the potential to lead to an inequality in care, patients not being able to transfer freely between haemophilia centres (for example for specialist surgery), and hospital Trusts being unwilling to take on complex patients. There is a great deal of concern over this and I have been working with eh Specialist Healthcare Alliance who have been leading on this work as it impact all specialist services. I have also been liaising with the UKHCDO and NHS England and looking at what we can do to influence decision makers.

Communications

Website

A volunteer has been looking at the technical aspects of the website and has identified around 100 coding errors and mistakes in the design of the site. The majority of these have now been resolved, but a few still remain. It has been a tortuous and time consuming process as there is no documentation available on how to manage, change or load content to the site, the company do not produce a user manual, so we have requested this. However we are uploading pages each week and the photos are now on the site we had taken at the AGM. There is a lot more work to do but it is improving.

The Facebook pages continue to be very active and require a lot of management, but are a valuable resource for the community.

Burden of illness study

The study is now open and is recruiting, the UK is lagging behind other countries in recruitment numbers so a reminder is going out this week, however overall things are very positive. If things don't improve I will write to the UKHCDO and ask them to support us in this. We are in the process of planning a second steering group meeting for February.

I have clarified the timing of the first payment of £30,000 as we were anticipating this to be paid at the start of the study, however the sponsors don't pay the university in full until July 2015, so we won't get the first payment until August 2015.

I have also been in discussion with David from Healthcare decisions about the potential of another study looking at ageing and bleeding disorders, and the impact on people's lives, as this is the first generation to experience the comorbidities of older age. This would work on a similar agreement, but with the possibility for the Society holding the research grant. This will be discussed at the Board meeting.

External meetings and events not included already

- Spoke at the EHC meeting on haemophilia Councils about the changes and challenges of the haemophilia Alliance following the NHS changes. Helen Campbell attended this meeting as well, Helens place was funded by an EHC grant.
- Attended an NHS England meeting on user representation on CRG's.
- Met Interaction with Stephen and Christina to plan Talking Red for 2015.
- Attended the UKHCDO data management working party.
- Met several companies to plan the radio campaign for WHD
- Attended a patient advocacy forum looking at how charities work with pharma companies.
- Attended the Hepatitis C Coalition meeting.
- Attended the UKHCDO advisory Board, looking concerns over specialist commissioning.

Liz Carroll

Fundraising Report February 2015

As predicted at our last Board Meeting, Q3 of our financial year was very successful and saw increases in Christmas activity as well as continued positive messaging and financial support from our Pharmaceutical partners. Bayer, CLS Behring, Pfizer and Octapharma all increased their giving bringing our YTD total to a very satisfying £87,668 up on target, with one more fundraising quarter still to be undertaken of the financial year.

As stated in my last report, we started our Christmas card and Annual Draw campaign in late September and were inundated with Christmas card orders and Annual Draw paperwork. Although we had to introduce a new process for fulfilment of all card and raffle orders we managed to see an increase in activity for both income streams. Our best success in Christmas cards to date meant we ended the season with only 38 packs of cards left. We will be much more strategic in our plans for the 2015 Christmas campaign. I plan to introduce a more efficient method of ordering Christmas cards which should reduce the element of risk of unsold stock and also increase efficient fulfilment methods for dispatch and thanks. We will introduce an integrated Christmas campaign joining cards, annual draw and annual appeal with a strong message, strong visuals and strong marketing collateral. We also intend to use our social media platforms to give feedback about potential choices of cards and if an electronic version would be of interest to our members and supporters. As a result of a more strategic approach to Christmas 2015 I project that we will increase total income to approximately £33,000.

Our new Celebrity Ambassador Jack Bridge has seen a very strong response to his 'Swim around Britain' challenge which is sponsored by Bayer. Members and supporters have been very responsive and we currently have 126 challengers who have so far achieved 8145 miles against Jack's current 4290 miles. This has surpassed our expectations and as a result we have decided to reduce the length of the challenge to approximately 6 months with the intention of having the final day of the challenge to coincide with our 65th birthday on 29 July. Income from the challenge is currently on 10% of the £5000 target but we will be encouraging new challengers to get involved as part of our WHD and 65th anniversary activities.

As in previous years we will be encouraging members and supporters to undertake fundraising events to mark this year's WHD on 17 April. We will again feature 'wear it red' activities and as a result of increased numbers using our social media platforms and participants in recent challenges and fundraising runs we hope that income will be more than the £500 gained from last year's event.

As a result of the recent office move, I have started to work through the existing Trust and Grant paperwork and files which had been amassed over the years. To date, most of the paperwork I have researched reflects donations of community and corporate support as opposed to specific trust and grant income. I plan to have updated and restored all the relevant files and paperwork which might be of use for future applications by the end of February. I have been working with Chris Keeling-Row who is advising/guiding me on the process and who has begun to compile a long list of potential trusts to approach in tandem with any existing bodies we might previously have had success with. We are on target to start making trust and grant applications for the start of the new financial year once conversations around the subject of our reserves has been undertaken by the Board as this has already negatively influenced a couple of recent conversations I had with potential trust funders.

Although the return of GRO-A from maternity leave comes after the close of our third successful financial quarter, it is important to note the positive impact her arrival has already made for the fundraising 'team'. GRO-A will be leading on all of our planned community events for the coming year and is very excited about the challenge of a specific fundraising target and the responsibility of providing excellent 'customer care' to our event participants. GRO-A is currently looking to register remaining participants for the Brighton Marathon, British 10K and Iceland trek having already filled all our guaranteed places for the London Marathon and RideLondon events. GRO-A will also be responsible for introducing new community activities and events, especially those which can be introduced to our local groups throughout the country. The final quarter of our financial year will be very busy for GRO-A with preparations for the Brighton, London and Edinburgh marathons and a combined projected income of approximately £15K.

Finally, our proposals are already in place for the coming financial year and I am excited at the prospect of a very busy and potentially lucrative year for the charity. I plan a strong and sustainable increase in our fundraising across the different streams in 2015-16 with further growth for Individual Giving and Donor Journey Plans to be added in the following year. My first six months were exciting and challenging and I expect the coming year to be even better!

Income to 31 December 2014
Income - £514,344.53 (153%)
Income target - £335,600.00

Community Events & Challenges
Justgiving – £61,661.75
Virgin Money Giving - £31,900.16
YTD - £93,561.91

Annual Appeal & Christmas
The total target for the Annual Appeal, Christmas cards and Annual Draw was £24,000. The total income showed a strong 8% increase on the target at £26,044.48. We will structure Christmas differently in 2015 with an integrated campaign which will feature a Christmas Appeal as well as the usual Cards and raffle activity. We will also re-introduce the July Appeal which will request members and donors to support our summer weekend and retreat activities.

Pharmaceuticals
Baxter - £20,600
Bayer - £74,500
CLS Behring – £65,000
Pfizer - £25,567.6
Sobi - £5,500
Octapharma - £5000
TYD - £196,167.60 (181%)
Target - £108,500.00
This bodes well for a projected income of £220,000 for the next financial year.

Future events and campaigns
Talking Red – Year 2 in development
World Haemophilia Day 2015 in development
'Swim around Britain' working with Bayer deliver the project with Jack Bridge
'Head Over Heels for Haemophilia' Skydive Campaign
Bespoke GRO-D cycle event – Chelmsford to Paris Cycle Event
Brighton Marathon
Virgin Money London Marathon
Edinburgh Marathon
British 10K
Bournemouth Marathon
RideLondon
London to Paris

Great North Run
Royal Parks
Iceland Trek 2015
Christmas Campaign

Stephen Wilkie

Membership and Planning Report February, 2015

Most of the work since the last meeting has been in preparing for the two Newly Diagnosed Family weekends, one that was held last weekend and one to be delivered 6 -8 February. There has also been a focus on planning for 2015-16.

Membership

- 40 new members have joined since the last Trustee Board meeting. Current membership: 3778.

Support for current Membership

- Preparation has begun for two workshops, one south, 19 March, and one north, 31 March, we are co-organising with the Hepatitis C Trust, exclusively for our members. Each event will have a follow-up day two weeks later and further evaluation after six weeks. Content for the workshops will focus on enabling people to live well, including sessions on nutrition and keeping as physically fit as possible. This is possible as The Hep C trust received money a few years ago from The DH that had been earmarked for Skipton and McFarlane, but was underspent. The Hep C trust need to spend this by April so asked if we could work together on this.
- May, 2015. An event is being organised in Northern Ireland for this sector of our membership. We are keen to further improve and support our members there. We began this process following our attendance at the EHC Conference in Belfast, and the subsequent attendance of three northern Ireland families at our AGM in November.

Upcoming services

Women's Services Project

- The build up to the Talking Red campaign, which culminates in events in June, has commenced. Encouragingly, Haemophilia Centres are beginning to put weight behind the campaign, with engagement of clinical personnel and requests for information and fliers for them to disseminate to the women visiting their clinics.
- A carriers' conference is being planned
- A group for single mothers caring for a child with a bleeding disorder is also being considered, as this is a section of our community that would certainly benefit from support. This may possibly be as part of the carrier group.

Newly diagnosed family events

23 – 25 January, 2015.

The first week-end was held at Sherwood Forest, Center Parcs. It was attended by 17 families (34 adults and 38 children in total) and facilitated by Christina Burgess along with two haemophilia nurse volunteers: Vicky Vidler (Nurse Consultant - Non Malignant Haematology, Sheffield Children's Hospital) and Jemma Efford (Haemophilia Clinical Nurse Specialist, Great Ormond Street), paediatric physiotherapist, Nicola Hubert, Great Ormond Street, and trainee physiotherapist/HS volunteer, GRO-A GRO-A who has severe haemophilia A. The volunteers' input was invaluable and greatly appreciated by all the families.

As well as having completed a pre-assessment of understanding and need, each family will also complete a post-event evaluation form. We will be following up these families in three months' time to establish the long-term, hopefully positive impact this type of event has. This information will also serve as evidence to help support and reinforce future funding applications for similar initiatives.

The following is a quote from one of the families who attended the event:

'The weekend at Sherwood Forest really exceeded our expectations and more. I just feel like a massive weight has been lifted, which I never knew was actually there. I think as a parent with a child of any condition you get fixated on them as they are your world and you then forget about yourself and how it's actually affecting you. It was a very emotional weekend, but in a positive way.

To be in a room with other people who actually 'get it' just made the world of difference and we will be forever grateful for the experience the Haemophilia Society enabled us to take part in. I cannot recommend this enough to other parents.

A huge thank-you to the volunteers. It was extremely valuable to have such experienced practitioners present. Again, GRO-A *experience and personality were invaluable and it was so reassuring to see and speak to him as I do worry about the boys growing up and about the challenges they face. We felt so welcomed from the moment we arrived.'*

From feedback at the event, the weekend appeared to have succeeded in providing what the parents of a newly diagnosed child appear to need most, the opportunity to meet with other families, thus reducing the isolation many feel, and the provision of information, advice and tips on enabling their child to live well, presented by knowledgeable clinicians and practitioners. The added benefit of having someone such as GRO-A to share his experiences, including a demonstration where he administered his own treatment, was extremely reassuring for parents providing them with a positive vision of their own child's future.

N.B. The second week-end will take place at Longleat Forest, Center Parcs on 6 – 8 February.

Youth Weekends
Applications are coming in thick and fast now for the 'Big Week-end' planned for 27 – 29 March, 2015. As well as young people (girls and boys) aged 14-16 with a bleeding disorder, the week-end is also open for siblings, many of whom have been affected in their own way.
King's Fund Co-Design Services Tool

We will be using the King's Fund service co-design tool for two upcoming 2015 projects: Inhibitors, April 2015, and Ageing, September 2015.

Publications

Several new publications are nearing completion along with a revised publications list.

Website
The new website is up and running and being populated with relevant and informative content. Content is being shaped by the members themselves with some members being part of the Readers' Panel and the inclusion on the website of a selection of members' own stories. More content is being added as fast as we are able to produce it!

Christina Burgess