



Heart Valve Voice: Trustee Meeting

Date: 11th of December 2018

Location: St. Thomas' Hospital, London SE1 7EH

Welcome

In attendance was Sue Alderton (Trustee member), Keith Jackson (Treasurer), Amanda Bott (Trustee member), and Chris Young (Chairman). Including the directors team Wil Woan (CEO), Victoria Toiviainen (Communications) and Elske Simpson (Administrator).

Apologies were sent from Pat Khan (Patient Ambassador) and Dr. Jarir Amarin (Trustee Member) expressing that they will not be able to attend.

Absent was Dr. Shelley Rahman (Trustee member).

2018 Project updates

Gold Standard of Care

- The Gold Standard of Care report has been completed with Huon Gray agreeing to support the document.
- It has been designed and will be signed off in early January. This will be in preparation for NICE who are holding a meeting on the development of a new valvular disease guideline on the 23rd of January 2019.
- HVV plans to launch a Gold Standard of Care report in conjunction with the meeting on the 23rd January.

Photography competition

- Chris Young expressed his excitement for the 2018 photography competition and encourages the Trustees to agree to repeat the event in 2019.

Patient Recovery Project

- Plans are in place to develop a timeline with Body Watch and set up a group of Key Opinion Leaders to help with the promotion of the project, This will be scheduled for Q1 of 2019.
- The study is expected to go live in March/April, will mostly likely take one year to complete.

Conferences

- While this year we have presented fewer key note speeches, we have attended all major conferences in the UK and Europe. Many attended with Patient Ambassadors.

Trials

- In 2018 several HVV Patient Ambassadors took part in patient engagement events. Examples include the Intelligent Stethoscope project with Cambridge University, Queen Elizabeth Hospital MRI project, Mini Mitral Trial, Sutureless Valves Trial and Evolved.

EuroCycle Ride

- While last year we had difficulty with one of our cyclists who experienced an injury, steps will be in place in 2019 to remedy any issues.
- There will be a slower and faster pace group to accommodate the abilities of the members cycling in 2019.
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- There has been interest from France and Italy in joining but starting their journeys from their respective countries. The team will reach out to them.
- BSEcho are partnering with HVV for the 2019 EuroCycle ride and will be hosting their own team.

Variation Report: Sub-optimal Care Report

- HVV provided endorsement including the Forward from Wil Woan and several contributions from our patients who reported their experiences with heart valve disease. We worked alongside Dougie Muir and several other leading clinicians

King's Fund Roundtable: Optimal Treatment Pathways

- To launch the report Wil Woan represented HVV at a roundtable hosted by the Healthcare Services Journal which was recorded

St. Paul's Cathedral

- All agreed that the event was a success and should be repeated in 2019. Expanding the event and setting up similar activities across the UK.

2019 Projects

The Flu Jabs Project

- HVV will be developing a number of heart valve disease detection programmes that will coincide with GP's flu jab appointment sessions.
- Recommending that 3 to 4 big GP practices should be picked across the UK to implement the use of stethoscope screening possibly using Cambridge's Intelligent Stethoscopes.
- There has already been a number of GPs that have shown interest in the project. Wil Woan, with the help of Chris Arden, will provide a list of GP's names in support before the next trustee meeting.

European Awareness Day

- It was agreed that 2018 European Awareness Day was very successful and there has been interest from Austria, Germany and Belgium to join in 2019.
- An independent consultant has been acquired to prepare a full report of the 2018 Awareness day in order to help with planning for 2019.
- Extending the European Awareness Day into a week.
- The Children's Book that was introduced at the 2018 Awareness Day will soon be reprinted and available for distribution and selling within UK clinics, will also be translated
- The Augmented Reality Cath Lab app has been met with great interest by a number of hospitals.

Testing Events

- We plan to carry out testing events at football and cricket. Southampton F.C has agreed to allow patients to go on the pitch as mascots, and there was discussions of a possibility of being mentioned on 'Match of the Day'.

Internal Business

Trustee members

- Increasing the numbers of trustees on the board, 10 in total which is in line with the constitution. Also ensuring we have appropriate skills e.g. more patient ambassador and more primary care..
- It was agreed to approach Chris Arden to fill one of the positions on the trustee board.

- It was agreed to we approach Alison Banayoti to fill one of the patient ambassador positions on the trustee board.

Financial report 2018

- The financial report of 2018, so far, shows media campaigns as the biggest spending.
- There was a salary increase in 2018 due to taking on new employees and increased use of consultants.
- There has been a slight increase in spending on accommodation but this is due to bigger media campaigns, such as the bike ride, photography competition etc.
- Research has also increased.

External Funding

- Edwards Life Sciences remain our largest funder.
- A series of connections with Medtronic, Abbot and Liva Nova and they are now funding HVV.
- We continue to engage with the imagining companies and meetings are in place in 2019 to secure investments.

Constitution

- The section referred to as 'Members' has been removed from the constitution.
- Constitution and meeting minutes will be circulated.
- Setting possible dates for trustee meetings will be provided early 2019 and meetings will be quarterly.

Website & Social Media Report

- During the period between August and December; impressions and mentions on Twitter have increased; visits to the Twitter profile visits has increased; Facebook likes, clicks and reactions have all increased.
- The importance of Facebook in allowing direct communication with patients and potential volunteers.
- The team has been working on increasing the number of posts they create in order to increase engagement and have had a lot of success this year engaging partners such as BSEcho and MedTech.
- We have also included more videos this year in our social media work including website and have found that these have invited more visitors to our channels and encouraged more interaction amongst our followers.

244,527 Twitter Impressions since June up from 157,500

7,103 Twitter Profile Visits up from 4,545

408 Twitter mentions up from 199

190 new Twitter followers

4,394 Facebook Page likes since June

29,210 people reached on Facebook, up from 9,847

7,358 post clicks on Facebook since June

3,686 reactions on Facebook since June

- HVV has delivered a range of successful articles in 2018; Silversurfers, Dr Hillary 100 Campaign, 10 months of Pulse articles, a Guardian Cardiovascular News, and Times advertorial. We have also delivered content in partnership with SCTS, MTG, BSEcho, a series of GP Webinars, and BSC.

Website Assessment

- Recently, there has been a meeting between the SEO and Web designers to determine a plan to increase the presence of HVV on search engines.

- Trustees propose the idea that patients should be able to sign up for more information on the website.

Patient Action Group

- A suggestion of having a patient ambassador's meeting before the trustee meeting was given.
- Chris Young wants to see minutes and agendas from the trustee meeting being placed on the HVV's website, which will allow patients to comment on it before the next meeting.
- A database of volunteers with information on availability, distance willing to travel etc. This information should be collected through an email or informal phone call.
- Several other trustee members want the structure of PAG to change to include more one-off volunteers.

HVV Global Impact & National Societies

National Societies

- HVV has connections with all of the major valve disease and surgical societies across the UK including BSEcho, BISMICS, BCS, and BCIS.
- Plan a meeting with Keith Pearce, president of BSEcho.
- Also contact with BCIS president, Peter Ledman
- Meeting with Norman Briffa, president BHVS, has been organised for the start of 2019.

Global Impact

- A global impact report is being put together by our consultant Neil Betteridge. This will provide recommendations on models, management structures and operational activities.
- Concerns about the use of HVV's logo on a global stage. Which in turn can have an adverse effect on HVV UK if the HVV's logo is used globally.
- Discussions between a model or a federation needs to be had.
- The report needs to be presented in the next trustee meeting before there is a vote.

Other Business

- Dates for 2019 trustee meetings should be circulated, along with the annual report and the trustee meeting minutes.
- There was suggestions to invite Professional Society members to present at the beginning of meeting to create better relationships with other national societies.