

Trustee meeting

6th of March 2019, 6-8:30pm



In attendance: Amanda Bott, Sue Alderton, Alison Banayoti, Shelley Rahman Haley, Pat Khan, Keith Jackson, Gregg Hutchings, Chris Arden, Mr. Amarin Jarir, Elske Simpson, Wil Woan and Victoria Toiviainen.

Apologies: Chris Young.

Welcome

Announcement that Victoria Toiviainen secured new employment and will be leaving Heart Valve Voice on the 5th of April 2019. The trustees congratulated and thanked Victoria for two wonderful years with the charity and wished her the best in her new appointment. A conversation of a new appointment needs to be had at the next trustee meeting.

Matters arising from previous meeting

- Meeting minutes distributed and updated for the website was achieved.
- Chris Young has approached Chris Allen about the Bodhi watch trail.
- Annual accounts and budget have been completed.
- HVV has approached other EU countries about joining the cycle ride, although due to logistical difficulties it is unlikely they will join in 2019.

Project updates

Gold Standard of Care

Wil reported that Professor Huon Gray (National Clinical Director of Heart Disease, NHS England) has given his support to the *Towards a heart healthy future* report and he will be presenting the report to the NHS 10 year plan clinical team. The report has gained backing from several UK societies: SCTS, BSE, BISMICS and BSE. HVV will approach a number of MPs and House of Lords members to gain further support including Steve McCabe, Lord Tidsey and Baroness Jolie.

HVV have secured funding to develop a TaskForce to look at ways to implement the report. This will include parliamentary questions, Freedom Of Information Requests and meetings with policy makers. Wil is consulting with Huon Gray on his recommendations on the key focus areas.

Patient recovery

The trial will be led by St Thomas Hospital and Kings College Hospital, it will explore the recovery of patients after minimally invasive treatment and more traditional surgery and will be completely randomised. Patient recovery project will be renamed as MOVE-IT and will target 200 patients in the trial. The leads on the trail is Chris Young, Olaf Wendler, Chris Allen and Karen Wilson. During the testing HVV provided patient perspectives which have been adopted, mainly information presented to the patient.

Flu Jab Project

The project has received mixed opinions from primary care, cardiologist and policy makers. Issues were raised about primary care capacity and availability of technology. In bigger practices there is support for the idea due to larger infrastructures and administration. There were suggestions that HVV team should approach a screening committee to gain further support. Wil to follow-up). Chris Arden explains that a robust patient pathway needs to be in place before Heart Valve Voice approaches the committee. Shelley asks to provide the data that shows an annual stethoscope check is necessary and suggests an alternative of 3-5 years check up instead. Interest in supporting the project has been given by Professor Ben Bridgewater (Chief Executive of Health Innovation Manchester). Also likely funding from Liva Nova, Medtronic, GE and Philips.

Conferences update

The HVV team has been attending a number of conference so far this year. Providing only stands and no key note speeches. More frequent attendance by patients to the conferences to incorporate patient stories to the HVV message. Wil gives an open invitation to have trustee members attend the conferences.

Mini Mitral Trail

Pat and Victoria has been speaking to patients who have finished the trial to gather information in order to develop patient stories. The trial helped to introduce younger patients into Heart Valve Voice's patient network. Issues concerning trial design has been raised but HVV will continue to support the trial and are looking forward to seeing the results.

EuroCycle Ride

The event is multi-funded and will be attended by 22 people with a mixture of clinicians and patients. The EuroPCR has given a complimentary stand for the conference and an opportunity to present at conference. Crowdfunding sites will be set up to help the riders fundraise for the event.

Webinars

Ten webinars are scheduled throughout the year, lead clinicians include Dr Yassir Javaid and Dr Matt Fay and Dr Chris Arden. Other webinars will include information on Primary care education, pharmacy and information about innovative treatments available.

Testing events

Stethoscope event has been organised to take place at the Old Trafford for the England Ashes Series. Premier League Football club have offered opportunities for patient focussed events to be held in their grounds and to have heart valve disease patient as mascot during the game. Alison Banayoti will approach Brighton Football club to discuss doing similar events at their grounds.

Photography competition

After the success of last year's photography competition, the HVV team has launched the 2019 photography competition *A new valve and New me:* in partnership with the Royal Photography Society. New patients are involved in the 2019 competition and they are being encouraged to write to their MP, during the competition, to promote awareness of heart valve disease and invite them to the exhibition in the Houses of Parliament. MP Steve McCabe will be hosting Heart Valve Voice into the Houses of Parliament once again.

Patient Events

After the success of the St Pauls Cathedral walk in 2018, several patient was will be delivered in 2019. The locations will include iconic sites in England, Northern Ireland, Scotland and Wales More patients who live in the region are needed at the walks. Several patient engagement days are being planned after the success of the Manchester based event in February.

Magazine

HVV Magazine has been published and was edited by Pat Khan and Kate Betteridge. The magazine is available on our website and has been sent to twenty valve clinics across the UK. The second edition of the magazine has already had interested from BSE and SCTS to include articles and will be distributed in September.

European Heart Valve Disease Awareness Day Alliance

The report produced by Neil Betteridge has been multi-funded and supported across the Alliance. The report shows issues over the structuring and funding with clear suggestions on future governance. Suggestions of joining lhHub or creating a similar structure to ESC were presented. Wil explained that whilst he was devoting time to the Alliance he was assured this was supporting HVV UK through collaboration and opportunities to share resources.

2019 Communications plan

- Publications of Heart Valve Voice material has been published in the Guardian, Mail on Sunday, National Geographic Traveller, Golf Chic and Evening Standard reaching a large audience
 - Guardian - 4,049,000 (2,878,000 over 35s)

- Mail on Sunday - 2,544,000 (2,277,000 over 35s)
- National Geographic - 10,435, 000 (Median Age 44.8; Average Age 45.0)
- Evening Standard - 2,412,000 (1,593,000 over 35s)
- Page views on the website has increased especially patient stories and patient aftercare.
 - 6,990 page views over the last 2 months
 - Home Page - 1,238 views
 - Patient stories - 258 views, average time 00:18:11
 - Photo Competition - 727 views
 - Patients/after-care - 226 views
- Facebook and Twitter followers are increasing:
 - **Twitter (Since March 2019)**
 - 54,100 Impressions
 - 1,023 Profile Visits
 - 37 mentions
 - 37 new followers
 - **Facebook (Since March 2019):**
 - 4,419 Page likes
 - 34,010 people reached
 - 1,286 post clicks
 - 2,338 reactions

We are also in talks with a videographer to produce a series of patient stories that feature a patient discussing their treatment (or eventual treatment) how their diagnosis has affected their lives, how their treatment has changed their lives. They will be patient and family focussed stories from patients of a variety of ages and at differing levels of activity. We have aimed to produce eight patient story videos over the next 6 months. The videos will be shot over 5-6 days to show a variety to the actives and lifestyle patients have.

We launched the HVV Magazine in February. The magazine, distributed to clinics and hospitals all over the UK, will give out at conferences. Bi-annually publications. The first was about introducing HVV and heart valve disease. The second we will reach out to clinicians and patients for contributions. Want to focus on the different areas, Scotland, Wales, Ireland as well as different treatment areas and have more information on recovery etc. We will also reach out to organisations and companies for advertising and additional funding.

Over the year our comms will be focused around the major events we are holding such as the launch of the Gold Standard report - which we have already been pushing through the major publications, the different patient events - St Pauls, Arthurs Seat, the Patient Recovery project, Euro Day, Photo Comp, Flu Jab Campaign

Patient Action Group

The name of the group is being changed to Patient Advocate Group after the direct feedback from the patients at the Manchester patient engagement day. It has now become an open membership due to the increase of patients willing to engage with the charity. Feedback from patient engagement day suggests that patient volunteers wanted more media and engagement training. The need for counselling services was put forward by patients, the HVV team will get advice and guidance on this to ensure we offer correct and consistent offer. A proposal will be brought to the Trustees at the next meeting.

Constitution and Trustee membership

The 2017/2018 accounts has been submitted before the deadline and the 2018/2019 accounts will be sorted by End of May. The trustees approved the changes of the constitution and the action was passed. The new constitution will go forward to the charity commission for final approvals.

HVV Global Impact and National Societies

There is now a better relationships with BHVS after the meeting with President Norman Briffa, there appears to be a better understanding and relationship between the two organisations. All other relationships continue to grow and collaborations are ongoing.

Other Business

Possible dates for the next trustee meeting will be sent out and it is agreed the trustee meetings will be held every three months with it being in June, September and December. Suggestions on meeting face-to-face or through a conference call need to be considered. A list of all major events and conferences will be made available for the trustee members. Also suggestion of creating an account on the HVV website for trustee members only. The minutes of the December 2018 trustee meeting was present on the website and these minutes again should be present on the website as well.