

# Heart Valve Voice Trustee Meeting 6:00pm, 22nd of January 2020 WeWork, 30 Stamford, London

**Attendance:** Amanda Bott, Alison Banayoti, Sue Alderton, Pat Khan,

Keith Jackson

Heart Valve Voice: Wil Woan, Elske Simpson

**Technical difficulties:** Shelley Ramen Hayley

**Apologies:** Chris Young, Jarir Amarin, Chris Arden

# Matters arising:

WII Woan would like to once again apologised for the room at the last Trustee meeting. We
were let down by PCR London and in the future private rooms at WeWork will be secured.

 Constitution has been amended in accordance with the Trustee input and this will be circulated on the 27th of January 2020.

Confirmation of 2020 Trustee meeting: March, June, September.

#### **Governance Review**

- Staff Appraisal have been completed and signed off by the Chairman.
- Pay appraisals have been completed and signed off by Pay Committee.
- Callum Ferguson has been appointed and will start work on 10th of February 2020.
- Health and Wellbeing budget agreed by Chairman and Treasurer.
- ACTION: A full HR review will take place before end of January 2020 and a report will be send to Chairman and Treasurer.
- ACTION: Callum to produce and send fortnightly Trustee updates. Dates will be confirmed shortly.
- ACTION: Elske to circulate the new Expense form.

#### Constitution

- The Constitution has been amended in accordance with Trustee input and will be circulated on the 27th January 2020.
- The constitution amendments need ratifying by 75% of the committee.
- ACTION: Arrangements will be made for Trustees to vote through conference call on the 10th of February, details to be circulated the week beginning 27th of January.

# 2020 Strategy

- The HVV 2020 Pledge was circulated before the meeting and discussed.
- ACTION: Develop milestones and indicators of success and report back at the June meeting.
- 2020 Pledges were agreed upon as a strategy moving forward.
- Wil Woan confirmed that the Gold Standard of Care will play a key role in all our work in 2020.

#### **Taskforce**

The TaskForce identified specific areas of work and the HVV Team are working through them.

## 1) Innovation

- Wil Woan discussed the Innovation Meeting scheduled for the 30th of January.
- Attendance includes: Ben Bridgewater (chair), BSEcho, GE, Philips, Cambridge University, Edwards Life Sciences, Abbott, Medtronic, BioSensors, Chair of the Greater Manchester Health Bodies, clinical experts.

## 2) Primary Care Networks

- Wil is developing a strategy for engaging Primary Care Networks and will present to Trustees in early February.
- Wil to create an Advisory Board for primary care.

## 3) Existing Health Initiatives redesign for valve disease

 Wil explained the delays to the Flu Jab Project with St. Bart's Hospital. The project will include digital stethoscopes and handheld echo devices.

## Reports

- The Welsh State of the Nation report has been a great success. Wil met the National Clinical Director for Cardiac Services and has agreed to work in partnership.
- New scoping ideas for a Scottish version of the *State of the Nation* report. HVV is working with Industry to secure funding to replicate the Welsh activity in Scotland.
- Amanda Bott suggested we reach out to Linda McKee (Golden Jubilee Hospital Glasgow Advanced Nurse Practitioner)

# **Heart Valve Voice Advisory Board**

- Decision deferred to ensure more clinical experts on Trustee Board are involved in the decision making.
- Further discussion is required although candidates could be shortlisted from the Presidents of professional societies.

#### **Activities**

- January's #MileWalk was a success and we look forward to the February's Walk.
- A number of visual ideas were discussed for the walk for people who participated to show their support of the campaign. (Stickers, coffee cups, badges etc)

#### Conferences

- Elske will be developing comprehensive plans for conference activities.
- Ideas for future HVV awards could include young clinicians or younger professionals to get them involved with the charity.

# **Patient Engagement**

- Pat Khan and Alison Banayoti presented their Patent Engagement documents and it was agreed that the document provided an excellent scope for future work.
- HVV will host a Patient Day on the 10th February to engage patients and discuss a range of subjects.
- Subjects include:
  - Structure of PAG, feedback to trustees, Candidates for trustees shortlisted from the PAG group.
  - Budgets.
  - Dedicated hours and roles of PAG.
  - Training on social media.
  - · Mental Health.
- ACTION: Email agenda, Structure of day, background of patients coming.
- ACTION: March report on the website.
- ACTION: Approach Professional societies have patients sit on courses, patient engagement to sit on introductory courses, patient engagement days and engage trainee clinicians.

#### **European Awareness Week**

- The date has been confirmed as the week beginning the 14th of September until the Sunday the 20th.
- Activities will include Street Doctor, 60th year of first mitral valve operation and the launch of the European Standard of Care.
- ACTION: HVV to bring UK activity plan to Trustee meeting in March.

## **Global Heart Hub**

- The membership continues to grow. New additions include Mexico and Japan.
- The Dutch equivalent of NICE recently announced changes to the access of TAVI which meant patients would be denied treatment. This decision went against ESC guidelines. Wil, as the Chairs of the Heart Valve Council, wrote to challenge the decision. The new changes has been delayed and will be reviewed, this demonstrates the power of direct interaction through Patient Advocacy and the Global Heart Hub.

# Other business

- Suggestions to review into rehab support of the patient pathway.
- Merchandise for heart valve voice.
- Scope a project reviewing the after-care of patients.
- Generate interest from local companies.