

Heart Valve Voice
Time: August 6th, 2023 18:30 PM
Regular Trustee meeting

Attendance: Phill Read (PR), Chris Cook (CC), Angie Martin (AM), Kerry Pena (KP), Keith Jackson (KJ), Craig Tilson (CT), Lauren Deegan (LD), Chris Arden (CA)

Heart Valve Voice: Wil Woan, Callum Ferguson, Martina Simpson, Trish Bullen, Sean Druggan

Apologies: Alison Banayoti (AB), Lois Bull (LB)

Absence: Yassir Javaid (YJ), Rick Steeds (RS)

Welcome

Phil - Welcomed the Board. He underlined his own personal strategic aim as Chair which is to improve communication across the Board, increase patient engagement and do increase fundraising (JustGiving, Lottery etc). He suggested setting up a Board Whatsapp and asked for further engagement in simple fundraising opportunities.

The Board welcomed Lauren back who has been absent for a few months.

The team discussed various initiatives and partnerships, including efforts to improve early detection of heart valve disease, promote gender equality in cardiology, and enhance patient engagement. They also reviewed the organisation's financial performance, with a surplus reported for the first quarter, and discussed plans for future fundraising and strategic opportunities. Lastly, they welcomed new team members and addressed concerns about feasibility and logistical issues in proposed projects

Phill shared his focus on building trustee engagement and increasing the patient community, while Wil provided updates on various initiatives, including an early detection meeting with the National Clinical Director (Prof Ray) and the President of the Primary Care Cardiovascular Society (Rak Thakkar), a planned meeting on community pharmacy, and an industry round table on Med Tech's role in early detection. Wil explained based on the meeting with Prof Ray and Raj Thakkar we had the following commitments:

NHS partnership on symptom awareness campaigns, aligning heart valve disease as a multi-morbidity issue, and working to get valve disease as a QOF and on the National Register. Wil also shared that they are collaborating with industry partners to create an early detection manifesto, fund a prevalence paper, and support early detection ambassadors. The NCD has also committed to funding further early detection projects.

Gender Equality and Heart Valve Initiatives

Wil update on the progress of various initiatives focused on gender equality and heart valve disease. We have formed a Women's Advisory Board to advocate for gender equality in valve disease and will meet in the Autumn.

Wil has also been appointed to the NHS Expert Advisory Group for Heart Valve Disease, where he will collaborate with clinical experts and NHS policy makers to raise awareness about the issue.

Will also attended the NICE Late-Stage Assessment for TAVI and Heart Valve Voice provided 7 patients to support the MHRA, where patients provided feedback on a potential Transcatheter Tricuspid trial. Phill added the value of Trustee representing Heart Valve Voice as it was his early interaction that led to this partnership.

Media Update

Callum then provided an update on Heart Valve Voice social media and website growth, their collaboration with the Cardiac Network and professional societies, and recent media coverage. He also discussed improvements to the website's donation feature, their application for Google grants, and the upcoming Awareness Week.

Lastly, Callum revealed plans for creating a Cardiovascular Hub in the UK and confirmed the organisation's plan to create business cards with QR codes.

AI-Focused Echo Project Concerns Discussed

Wil talked through a proposed partnership with GE to sponsor a project aimed at educating primary care clinicians on focused echo using AI. Chris Cook and Chris Arden expressed their support for the initiative but raised concerns about its feasibility, particularly in relation to the implementation of focused echo by inexperienced operators and potential logistical issues. They also highlighted the need for careful consideration of project costs and compliance with branding guidelines.

Wil agreed and proposed creating a sub committee(including Rick Steeds, Chris Cook, Chris Arden and some external experts) to support our interaction and messaging on the project.

Lastly, plans for a national patient day on November 24th were announced, aimed at raising awareness about gender inequalities and innovative treatments, with guest of honour Roger Black.

10th Birthday at PCR London Valve (PCRLV)

Wil announced that the team is working on a project with PCRLV which would celebrate our 10th Birthday and provide a platform for awareness raising and fundraising. A hotel conference room at PCRLV has been booked for the 24th November and further details will be shared shortly.

Wil then welcomed Sean, the bookkeeper, to provide an update on the charity's financial performance. Sean shared that he had prepared slides to present key metrics for the first quarter of the year.

Any other Business

As Chris Young has stepped down it is important to have surgical representation. Wil suggested that we invite Dr Dincer Aktuerk from Barts to the Board after a successful phone call with him and the Chair. Dincer is a well-respected surgeon with an interest in minimal invasive surgery and robotic surgery and it was approved to invite him to the Board.