



ALL-PARTY PARLIAMENTARY GROUP ON HEART VALVE DISEASE

Inaugural Meeting Minutes

The meeting took place on Wednesday 25th November 2020, 11am – 11.45am on Zoom.

Parliamentarians

- Steve McCabe MP, Labour
- Baroness Masham of Ilton, Crossbench
- Lyn Brown MP, Labour
- Virendra Sharma MP, Labour
- Lord Rennard, Liberal Democrat
- Henry Smith MP, Conservative
- Dr Lisa Cameron, SNP
- Tanmanjeet Singh Dhesi MP, Labour
- Fabian Hamilton MP, Labour

- Chris Green MP, Conservative
- Baroness Finlay of Llandaff, Crossbench

Non-parliamentarians

- Wil Woan, CEO, Heart Valve Voice
- Callum Ferguson, Head of Content, Heart Valve Voice
- Professor Huon Gray, Chair of the Heart Valve Voice Clinical Advisory Panel
- Robbie Toomey, Four Communications

The Inaugural meeting opened with the election of the Chair and Vice-Chairs of the group. First, the secretariat moved that Steve McCabe MP would put himself forward for the role of Chair. He did so, and attendees unanimously voted for him to Chair the group. Next, attendees voted on the prospective Vice-Chairs, and again, these votes were passed with unanimous consent. Once the formal parts of the inaugural meeting were complete, the secretariat passed back to the newly elected Chair of the Group, Steve McCabe MP, who officially opened the meeting.

Steve welcomed and thanked attendees for taking part in the meeting, and introduced the group by giving an overview of his own experiences with mitral valve surgery. He then gave a summary of some of the challenges in the heart valve disease (HVD) space, including variation and inequality in access to optimal care, as well as the impact that external pressures, such as COVID-19 were having on the capacity of the NHS. He went on to outline that the ambition for the group was to increase the awareness of HVD in the UK and help to ensure that patients receive timely diagnosis and the optimal management and treatment of their condition.

Steve then handed over to Wil Woan, Chief Executive of Heart Valve Voice (HVV), who gave an overview of the organisation, outlining that they are the UK's dedicated HVD charity, and that they work with patients and clinicians to help increase the awareness of HVD in the UK and improve diagnosis and treatment. Wil went on to talk about the fact that the condition affects over 1.5 million people over the age of 65 in the UK. Going onto state that while it is a treatable condition, with many traditional and innovative ways of managing the condition, the unfortunate fact is that far too many people are not being diagnosed and treated early enough, particularly in the wake of COVID-19. Wil also mentioned some of the current work HVV are doing in this space, outlining the extensive stakeholder and media engagement the charity did during Heart Valve Disease Awareness Week in September, as well as the new #JustTreatUs campaign, which not only urges patients not to let their fear of COVID-19 stop them from seeking medical help, but also calls for primary care to have the confidence to refer more patients, and for secondary care to maximise treatment capacity.

Wil then passed over to Professor Huon Gray, who introduced himself as the former National Clinical Director for heart disease at NHS England from 2013 to 2019. He outlined that if HVD goes untreated, then the prognosis is sometimes worse than some cancers. He spoke positively about how NHS England had made a commitment to ensure that valve disease received the attention it deserved, including a mention within the NHS Long Term plan. He then spoke about how he came out of partial retirement to support Heart Valve Voice's good work and lead their

new clinical advisory panel, going on to say that this perhaps mirrored the unfinished nature of his work in the HVD space. Following on from this, Wil stepped in to give some more detail into HVV's work setting up key advisory groups, such as the Clinical Advisory Panel, which will include the President of the UK's Major Cardiovascular Societies, as well as well-known stakeholders from the primary care and pharmacy space, to ensure a holistic view of the HVD care pathway.

Steve McCabe MP then opened up the discussion so that attendees could ask questions and take part. Virendra Sharma MP spoke first, talking about his personal interest in the group, as his mother had died due to heart disease. He then talked about his ambition to see the group focus on in levelling up the understanding of the condition and its symptoms, particularly within BAME and left-behind communities.

Following Virendra's contribution, Wil Woan spoke about the Valve for Life initiative, outlining that it is a European Association of Percutaneous Cardiovascular Interventions (EAPCI) initiative to increase delivery of trans-catheter valve therapies (including TAVI) in member countries with low levels of valve intervention. He discussed that the initiative has operated successfully across Europe for a number of years, and it was launching in the UK. He referenced that while this campaign had a narrower focus, the APPG would be a holistic body, looking at the overall HVD pathway.

Baroness Masham asked a question on whether HVD cases had been muddled up with COVID-19 cases, due to similar presenting symptoms, e.g. breathlessness. She also outlined her personal interest in the focus of the group, as her father passed away due to a heart attack when he was 52. Responding, Professor Gray outlined that due to the similar presenting symptoms, it could lead to delayed recognition of HVD. He also outlined that moderate HVD and a diagnosis of COVID could lead to patients experiencing a severe case of COVID, and that a key difference between COVID and HVD, was that HVD symptoms are progressive, while COVID is rapidly onset.

Baroness Finlay then asked a question regarding how often valve disease was diagnosed alongside other heart conduction defects. Professor Gray outlined that with the aortic valve disease, the number of patients with conduction issues was relatively small, but that with mitral valve disease, atrial fibrillation commonly complicates valvular heart disease.

Fabian Hamilton MP also discussed his interest in the topic, talking about his fundraising work, where he cycled from Harewood House to Westminster for Heart Research UK; the charity of which he is also a Trustee. He went on to ask if HVV were accessing available funding from Heart Research UK. In response, Wil outlined that HVV was not using funding from the charity, and that it does not fund research directly, but he went on to outline his position on numerous research groups, such as the National Cardiac Surgery Research Trials Initiative, including the clinical study groups on Heart Valve Interventions and Minimally Invasive, Hybrid and Percutaneous Techniques. He also shared that HVV supported the UK Mini Mitral trial, the UK TAVI trial and that he was part of the Medical Technology Group as well.

Steve then moved to bring the session to a close, recapping the important discussions that had taken place, in particular, referencing the need to focus on the BAME community, which Virendra had brought up earlier. In discussing next steps, it was suggested that it would be valuable for Professor Gray and Wil to go away and put some thought into developing an optimal HVD pathway, similar to the cancer care pathway.

Finally, Baroness Masham asked whether the APPG would also take into account other areas of the UK, including Scotland and Wales. Wil responded, assuring the Baroness that the group would certainly focus on all parts of the UK, before going on to outline the work HVV have been doing in Wales, Scotland and were planning to do in Northern Ireland. Separately, Wil gave details on the APPG's website and social media channels. He also spoke about the APPG's plans in 2021, including the possibility of establishing an APPG Inquiry focused on interrogating the current provision of heart valve disease care in the UK; responding to the NICE consultation on heart valve disease presenting in adults; and supporting the #JustTreatUs campaign, through Parliamentary Questions and relevant debates.

Steve closed the meeting, thanking the participants again for attending, and outlining that he would be in touch in the near future regarding the APPG's plans for 2021.