## **Report to CTAG Hearts – October 2023**

#### 1. Introduction

1.1 This report outlines the key work undertaken by the CTPG Chair, CTPG members and CTPG meetings since the last CTAG Hearts meeting.

## 2. Patient Feedback

2.1 The routine patient feedback gathering exercise has recently been completed and can be seen in Appendix 1.

## 3. Engagement and Representation

- 3.1 Engagement across the country has continued with the CTPG Chair attending various support group meetings and regularly liaising with related charities and stakeholders.
- 3.2 Many CTPG members and other cardiothoracic transplant patients continue to be actively involved in promoting organ donation, this was especially prevalent during the September 2023 Organ Donation Week.
- 3.3 The CTPG Chair has worked with the Children's Heart Federation and Paediatric Transplant Directors at GOSH and Newcastle to produce a paediatric heart transplant information leaflet.
- 3.4 The CTPG Chair attended the OUG Conference on 19 May 2023, an advanced heart failure education day on 19 June 2023, and the NHSE MCS Meeting on 30 June 2023
- 3.5 The CTPG Chair has worked with the British Society of Heart Failure to successfully advocate for heart failure to be an eligible condition to receive Paxlovid if testing positive for Covid 19.
- 3.6 The CTPG continues to be a formal stakeholder in NICE appraisals relating to Covid prevention, treatment, and processes. Details can be viewed in a dedicated report.
- 3.7 The CTPG Chair has written to the CTAG Hearts Chair with questions relating to the 2022/23 Annual Heart Transplant Report.
- 3.8 The CTPG Chair has written to the OTDT Medical Director and NHSE HSS Medical Advisor with questions relating to long term VAD outcomes and NHSBT / NHSE governance processes.

# 4. CTPG Meeting 25 October 2023

4.1 The next CTPG meeting is on 25 October 2023. The meeting agenda is shown in Appendix 2