NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION
THE SIXTEENTH MEETING OF THE NHSBT
CARDIOTHORACIC PATIENT GROUP (CTPG)
ON WEDNESDAY 22 JUNE FROM 10:30 TO 13:30
MINUTES

PRESENT

Robert Burns	CTAG Patient Group Chair
Liz Armstrong	Head of Transplant Development, NHSBT
Andrea Barrett	Patient Representative (Zoom Hearts)
Emma Billingham	Head of Commissioning, NHSBT
Hugh Brazier	Cardiomyopathy UK, DCM Patient Freeman Hosp, LVAD
Sharon Brennan	Harefield Lung Patient and Alzheimer's Society
Andy Bright	Double Lung Transplant Patient / Action for Pulmonary Fibrosis
Debbie Burdon	Patient Representative, Treasurer of FHLTA, Freeman Hospital
Charlotte Carney	Transplant Patient / Cardiomyopathy UK
Lorna Carruthers	Little Hearts Matter
Trevor Collins	Heart Transplant Recipient, Royal Papworth Hospital
Collette Day	Recipient Co-ordinator, Royal Brompton and Harefield Hospital
Lynda Ellis	New Start Transplant Charity, Wythenshawe Hospital
Maggie Gambrill	Heart Transplant Patient, Royal Papworth Hospital
Shamik Ghosh	CTAG Lay Member Representative
Hannah Griffin	Harefield Transplant Co-ordinator
Chris Hannah	Heart Transplant Patient, Royal Brompton and Harefield
Margaret Harrison	CTAG Lay Member Representative
Joanne Heath	Children's Heart Foundation
Ged Higgins	Patient Representative, Wythenshawe Hospital
Jessica Jones	CT Patient Representative / Organ Utilisation Programme, NHSBT
Fiona Kennedy	Somerville Heart Foundation
Ellie Johnson	Transplant Co-ordinator, Birmingham
Rachel Leonard	Recipient Co-ordinator, Royal Brompton and Harefield Hospital
Jane Lockhart	Heart Transplant Co-ordinator, Golden Jubilee Hospital, Glasgow
Alan Lees (AL)	Patient Representative, Harefield Transplant Club, Harefield Hospital
Zoey Malpus	Psychologist, PACT
Derek Manas	Medical Director, OTDT, NHSBT
Jas Parmar (JP)	Chair CTAG Lungs, NHSBT (Royal Papworth)
Janka Penther (JPe)	Harefield Transplant Club
Laura Roberts	Transplant Social Worker, Manchester
Sally Rushton (SR)	Senior Statistician, Statistics and Clinical Research, NHSBT
Lucy Ryan (LRy)	Heart Transplant Patient / Heart Transplant Families UK
Adrian Sims (AS)	Heart and Lung Patient (awaiting transplant)
Tara Smith	Lung Transplant Patient, Harefield
Laura Stamp	Lead CT Recipient Transplant Co-ordinator, NHSBT
Ruth Sutcliffe	Recipient Co-ordinator, Wythenshawe Hospital
Michael Thomson (MT)	Patient Representative, Golden Jubilee National Hospital
Annette Tremlin	Heart Transplant Families UK
Rajamiyer Venkateswaran (RV)	Chair CTAG Hearts, NHSBT (Manchester)
Claire Walter	Patient Involvement Co-ordinator, Cystic Fibrosis Trust
Michelle Woods	General Manager, Somerville Heart Foundation

IN ATTENDANCE

Caroline Robinson	Advisory Group Support, OTDT, NHSBT (Minutes)

	Welcome and Introductions R Burns introduced himself as the new Co-Chair of the CTAG Patient Group taking over from Rob Graham. Apologies were received from Ayesha Ali, Lynsey Beswick, Martin Carby, Darroch Euon, Cath Exley, Ian Maxwell, Helen Newton, Rosemary Pope, Linda Sharp, Sarah Watson,

	• R Burns stated the CT Patient Group meetings aim to look at the wellbeing and health of transplant patients and those on ventricular assistance device (VAD) by seeking information, raising concerns, providing feedback, and receiving information in a spirit of honesty, transparency, and openness. • J Parmar introduced himself as the Chair of CTAG Lungs Advisory Group and as a respiratory transplant physician at Papworth. • R Venkateswaran introduced himself as Chair of CTAG Hearts and consultant cardiac surgeon at Wythenshawe Hospital in Manchester.
1.	**Declarations of Interest - CTPG(20)08**
	There were no declarations of interest
2.	**Introduction to new Patient Chair – CTPG(22)01**
	An introduction to R Burns was circulated prior to the meeting. Robbie is 2 years post heart transplant secondary to congenital heart disease. Previously he worked as a senior manager and inexecutive directorships in the NHS, and he is delighted to now take on this role as Co-Chair of the CTAG Patient Group.
3.	**Minutes and Action Points from Previous Meetings**
3.1	Minutes of previous Patient Group meeting Accuracy and Action Points **- CTPG(22)02 and CTPG(22)19** The Minutes of the previous Patient Group meeting on 12 May 2021 were circulated and were accepted as a true record. All Action Points from last year's meeting were noted as closed.
3.2	Minutes of CTAG Lungs Meeting – 6 April 2022 **– [CTAGL(M)(22)01] CTPG(22)03** - The Minutes were circulated prior to the meeting. J Parmar stated that since the division of the CT advisory groups into 2 new advisory groups for heart and lungs, work had been undertaken on new terms of reference, the structure and membership of CTAG Lungs and development of a workplan for the next 3-5 years. Work will focus on: • Strategic planning - to align with NHSBT strategy and other developments coming through • Lung Allocation – Currently there is a 3-tier system - super-urgent, urgent and routine. While the super-urgent and urgent tiers are allocated nationally, routine allocation is centre based. A subgroup has held a couple of meetings to date looking at ways to improve equity of access and transparency of organ allocation and it has been identified that granularity of data currently available limits what can be done regarding allocation. It is hoped this can be improved to help move to a more equitable system by utilising AI and other developments over the next 2-3 years. • Revised Allocation Zones according to centre activity. Unfortunately, it has taken longer for lung transplantation to recover post COVID than hoped, but it is hoped that by adjusting the allocation zones to account for the numbers of patients listed on the waiting list and where these patients are located will help to improve the situation. • Development of a National Proforma for Referrers – work started on this to make the process for referrers less arduous, but work stalled during COVID and now a new platform is being investigated with a different provider. • NIHR BTRU funding (National Institute of Health and Care Research Blood and Transplant Research Unit – this collaboration between Cambridge and Newcastle Universities, the transplant units and NHSBT has been awarded new funding to look at 6 streams of work in total to include post-transplant experiences and outcomes to enable better analysis of patient related issues to help with allocation of organs in future. Currently, this is based on survival over a period of years, but the new research will look at quality of life as well. Patient Report Outcome Measurements (PROMs) and Patient Report Experience Measurements (PREMs) have already started in other organ groups, so this is a welcome development for CT transplantation.
3.3	Minutes of CTAG Hearts Meeting – 18 May 2022 **– [CTAGH(M)(21)01] CTPG(22)04** - The Minutes were circulated prior to the meeting. R Venkateswaran stated that heart transplantation had continued during COVID and was recovering post pandemic. As of last week, 45 heart transplants had been completed since the start of the new financial year whereas pre pandemic the figure was only 25 transplants by this stage. Key issues include: • DCD Hearts Programme – 200 hearts have been retrieved resulting in 176 heart transplantations and good 30-day and 1 year survival rates. Currently the spending review which includes continuation of this programme is not confirmed, but centre directors from all the transplant centres and the Chair of the Patient Group have signed a joint letter to NHSE asking for support in securing funding to continue the programme.

	• Heart CUSUM triggers – This cumulative sum monitoring looks at activities in heart transplant centres and outcomes. The marker for a trigger to look at results within a particular centre was 30 days, but this has now been increased from 1 April this year to 90 days, aligning with lung CUSUMs. • Heart Allocation – Currently there are 3 tiers for allocation for donor hearts – super urgent (for those on mechanical support for which the waiting time is about 10 days), urgent (for those in hospital where waiting times are increasing) and those who are waiting at home. Elective transplants are rare, Previously, changes to the heart allocation system considered a move to creating 6 tiers, but it is now thought this will be too complex to operate efficiently. The subgroup looking at this issue, led by Sern Lim in Birmingham, is now considering how inotrope dependency is managed across transplant units and what can be done to improve the current variations that exists. • Heart and Liver transplants –The Heart Allocation subgroup is also monitoring requests for patients who need both heart and liver transplants. While numbers remain low, over the last year there has been an increase in requests. • LVAD Complication Project – CTAG Hearts has investigated why LVAD patients have had less favourable outcomes following transplant than other patients and particularly whether this is a device or centre issue. One device has now been taken off the market and monitoring of this group of patients continues. • Sherpapak – This is one of 3 trials taking place. Results from use of this potential replacement for the traditional ice box used to transport hearts have been excellent and were presented at an international heart transplant meeting in Boston in May. Nearly all US centres are now using the box which maintains a steady temperature, aligns the heart in anatomical position and ensures hearts return to normal rhythm quickly leading to less stay in ICU. **ACTION: E Billingham to link with Venkat re ice box commissioning.** • Two other trials – These include use of the Ex-vivo heart machine which keeps organs warm by continuously pumping blood through them and a new custodial solution to preserve the heart being trialled at Papworth).
4.	**NHSBT – Medical Director's Report and NHSBT Updates**
4.1	Derek Manas introduced himself as the new Medical Director for the Organ and Tissue Directorate (OTDT) at NHSBT. While previously the focus for NHSBT was donation, over the last 2 years a new strategy has been developed to concentrate on both donation and transplantation. OTDT's work covers the Organ Donation Register (ODR), Hub Operations (organ offering and matching), the National Organ Retrieval Service (NORS), living donation in other organs, governance and education. From the patient perspective, equity of access to waiting lists and organs is paramount, along with removing unwarranted variation in a unit's acceptance of patients and access to the waiting list. Health inequalities, particularly for ethnic minorities, are also a priority. Patient engagement is critical to help achieve the changes that are needed. For cardiothoracic patients, the new strategy will focus not just on donation and transplantation, but also outcome and quality of life post donation: • Digital Infrastructure for Utilisation (DIU) - will enable development of IT changes to support organ utilisation as well as sustainability of the workforce and R&D. • DCD Hearts – OTDT is funded centrally via the Department of Health and the outcome of the spending review that will allow continued funding of this very successful programme is still awaited. • NRP (Normothermic Regional Perfusion) – the hope is that funding will be given to maintain this across all units.to enable better utilisation of organs for transplantation. • OUP (Organ Utilisation Programme) – this NHSBT programme looks at new techniques and use of Clinical Leads for Utilisation (CLUs) and education and digital infrastructure. • OUG (Organ Utilisation Group) – this was set up by the Department of Health to look at streamlining of commissioning for specialist services and to look at organ utilisation across all units. ARCs (Organ Assessment Recovery Centres) are also being considered for funding as the benefits for increased utilisation of CT organs is enormous. The group's recommendations are expected in September. The latest Medical Director's bulletin can be found on https://www.odt.nhs.uk/odt-structures-and-standards/clinical-leadership/medical-director-bulletin/
5.	**NHSE Update**

5.1	NHS England were unable to attend this meeting. J Parmar highlighted one area of lung transplantation involving a CUSUM signal that had triggered at one centre following a series of events over a period of 18 months. A detailed examination of patient records followed, and improvements have been put in place.
6.	**Patient Chair Update**
6.1	• Patient Chair Report - **CTPG(22)05 -** A report from R Burns was circulated prior to the meeting that highlights key areas: • Patient Population consisting of patients waiting for or those who have previously had a heart or lung transplant as well as patients on the suspended waiting list and those with a ventricular assistance device (VAD) • External Engagement to include key external stakeholders for cardiothoracic transplant patients eg, heart or lung disease-based charities, centre specific charities and patient led support groups to ensure that this patient group is focused on issues that matter most to patients. • Regular Feedback Mechanisms – *see Item 6.2* • Specific Workstreams & Advocacy including NHS Engagement and Psychology Support – *see Item 9*
6.2	Appendix One - **CTPG(22)06 –** This feedback form has been developed by R Burns to ensure that the CTPG is focusing on the key issues that have the greatest impact on the patient group. It will be sent out twice a year to support group leads. The key findings are shown in the report circulated. Concerns about primary care services and access to GPs were highlighted. Frequently, patients struggle to get blood tests they need post-transplant done at their GP practices. It is important that bloods are taken at the right time and primary care services need specific instructions from the transplant centres. It was noted that although shared care protocols have been tried across all transplant centres and organs there had been a failure of engagement from GPs. The main problems are lack of expertise and blood bottles to test immunosuppression and lack of indemnity. NHSE moved immunosuppression to being centre based, but that has not worked either. While new technologies may help with this process, engaging with GPs is not likely to work because of risk and lack of expertise. **ACTION: R Burns to establish a group to review and consider possible improvements to routine post transplant blood monitoring.**
6.3	Appendix Two - **CTPG(22)07 –** The National Organ Utilisation Conference took place on 27 May. The paper circulated is the talk given by R Burns at the conference.
7.	**Activity and Outcome Data - CTPG(22)15**
7.1	S Rushton, Senior Statistician at NHSBT introduced herself and stated she had been heading up CT data for 5 years. Some of the graphs shown in her report circulated prior to the meeting, will be published in the annual report which will be on the ODT Clinical website shortly. In summary: • While the Heart waiting list is increasing, the number of transplants is not growing. Results indicate there are more transplants than donors and this is probably due to overseas donors. The main reason for an increase in those needing transplants is down to improvements in VAD technology that is keeping patients alive for longer. • The Lung waiting list has fallen but is still much higher than transplant activity which is at its lowest in 20 years. A lot of secondary care is still not working well, and referral numbers have dropped as a result. • Heart activity was maintained through the pandemic, but lung (as a respiratory programme) was more adversely affected and has still not fully recovered • 50% of those on the heart waiting list are on mechanical support (in hospital or out) • Another 163 patients on mechanical support are not listed for transplant. • Five years post-transplant there is a survival rate of 71% for hearts and 55% for lungs (adult only). It was agreed that it would be useful to have survival rates for longer than 5 years. **ACTION: S Rushton to look at longer survival rate periods** • Work is ongoing to scrutinise why organs from 'higher quality' donors are often not utilised when they have been offered. At present, more organs are offered than accepted. These are turned down for a variety of reasons, eg poor function, but it is hoped that by focusing on the group where transplants should be more likely, utilisation will improve.
8.	**Items Raised by Representatives**
8.1	Update from Electric Cranks - **CTPG(22)09 (and CTPG(22)18 below)** – Ged Higgins, patient rep for Wythenshawe who has an LVAD and has been on the waiting list for 8 years, gave an account of the activities of Electric Cranks, a cycling club for pre and post operative heart and lung transplant patients

	(including LVAD patients) who use electric bikes to aid recovery and wellbeing. A summary of the club's recent and current activities was circulated prior to the meeting. The club has a Twitter site *@Electric Cranks* and a Facebook site, *The Electric Cranks Cycling Club* and their activities have also featured in various magazines and websites. Connections have been established with Abbot Laboratories who promote the activities of the group and who have provided jerseys and rain jackets, Avaris, who have donated an e-bike, Pumping Marvellous who will film the forthcoming Hadrian's Wall ride and a VAD patient group in Hanover. The group will also connect with the patient group at Freeman's Hospital on its Hadrian's Wall ride. R Venkateswaran praised the work of the group and stated that it demonstrates how well patients can survive on LVADs.
8.2	Update from Freeman Patient Group – **CTPG(22)17** - This update is circulated with these Minutes for information.
9.	**Psychology Support for Transplant Patients**
9.1	Psychology Support in Adult CT transplant and VAD patients – **CTPG(22)10** - R Burns introduced Zoey Malpus, Consultant Clinical Psychologist for Psychological Association of Cardiothoracic Transplant (PACT). Zoey represents a group of psychologists and psychiatrists who work across adult transplant centres in the UK. Zoey was the first consultant clinical psychologist to be appointed within a transplant unit (at Wythenshawe) in 2009.
9.2	National Survey **CTPG(22)11** and **CTPG(22)19**– A copy of the outcome of this recent survey was circulated prior to the meeting. Z Malpus stated that this was completed by 168 patients across the UK and indicated the long-standing concerns patients have that their psychological needs are not being met. The survey illustrated that while those who could access support really valued it, there is considerable variation in transplant centres, with Glasgow scoring the highest in its provision of psychological support and Birmingham the lowest. 41% stated that they had not been able to access a transplant psychologist. About 1 in 10 people accessed local psychology services because they couldn't get it at their local transplant centre, and this was mostly unsatisfactory due to lack of understanding of patients' clinical needs. Some of the comments made by patients are shown in the presentation that was circulated. Better access for both pre-and post-transplant as well as peer support were themes coming out of the survey. An audit undertaken shows that current minimum standards are not being consistently achieved against commissioned services ie: • MDT must include a clinical psychologist - *5/6 centres compliant* • MDT assessment meetings must include a clinical psychologist - *5/6 centres compliant* • Two-week access to psychologist – *1/6 centres compliant* • Psychology included in assessment process - *4/6 centres compliant* • Psychiatry included in assessment if indicated - *6/6 centres compliant* • Patient feedback undertaken and presented / discussed at MDT - *2/6 centres compliant*
9.3	Psychology support in Adult CT transplant care – **CTPG(22)12 -** Based on the data, psychologist numbers need to approximately.double from 7 to 14 WTE. It was agreed that NHS England and transplant centres need to review the findings of the needs analysis, survey, and audit of minimum standards to ensure there is at least 1 WTE psychologist per 350 patients.
9.4	Patient Psychology Needs – **CTPG(22)13 -** A national model of psychological care for transplant is illustrated in the paper circulated involving routine psychological screening in clinics to match the type of psychological intervention to the level of need: • Non case (39%) – raise awareness of psychological care via posters and leaflets, nurses routinely monitor mood in outpatient clinics • Mild (34%) – Offer self-help leaflets/videos, online peer support groups (transplant café) all MDT offers enhanced psychological support • Moderate (22%) – offer individual or group psychological support, online or in person. • Severe (5%) – Clinical psychology or psychiatry referral The lack of long-term care currently for patients (especially those with long term conditions) was acknowledged by the meeting. Resources (eg videos, leaflets, online support or therapy groups) for patients and families could be shared nationally. Virtual therapy groups are now the norm and so national as well as local therapy options could be developed. The aim in the future should be to help those areas that are struggling in providing this care. If trusts fail to meet their commitment to provide a commissioned service, that needs to be reported back to NHS England. The group unanimously supported the recommendations outlined in Section 3 of **CTPG(22)12** **ACTION: R Burns will work alongside J Parmar and R Venkateswaran and NHS England to deliver the recommendations..**
10.	**COVID in the Immunosuppressed - CTPG(22)16**

	J Parmar gave a presentation, circulated with these Minutes, regarding management of COVID particularly for those who are immunosuppressed. Morale currently in the NHS is low following a very difficult 2 years and despite huge successes developing vaccinations and expanding treatment options for COVID. Currently there is a downturn in the number of patients in hospital with COVID. There are 4 phases in licensing and deeming treatment is safe or effective: • Phase I – Young health people/small group size – about 50 people – tests look for possible harm, side effects and dosage • Phase II – People affected by the disease – larger group size of up to 500 people – tests whether treatment is effective in patients, side effects and against a placebo treatment • Phase III – People affected by the disease – group size consists of thousands of people – tests whether treatment is effective in patients, over longer periods over many different countries and often against other possible existing treatments. • Treatment is deemed safe/effective and moves to licensing and the benefits are weighed up by NICE against costs and limitations to help guide use within the NHS. This can take a significant amount of time (10-15 years). • Phase IV – Tests over a longer period in different groups of people and/or in combination with other treatments. The whole process can take a significant amount of time (10-15 years) so during COVID there was a remarkable amount of agility to develop vaccines and other treatments. However, there is now a return to longer delays before treatment can be accessed by the public. Treatments available for non-hospitalised patients who are symptomatic and showing no evidence of clinical recovery can be offered the following treatments: • First line – Nirmatrelvir plus ritonavir (Paxlovid, antiviral) which is not suitable for transplant patients - and sotrovimab (nMAB) (which has shown a relative risk reduction in hospitalisation or death at day 29 of 79%) • Second line – Remdesivir (antiviral) (which has a relative risk reduction of hospitalisation or death at day 29 of 87% • Third line – molnupiravir (antiviral) • Evusheld – (tixagevimab plus cilgavimab) is a long-acting monoclonal antibody for those who are non-responsive to the vaccine. This is in Phase III at present. Patients in the trial have been identified less than 3 days after enrolment. This treatment trial (called Tackle) ran from Jan 2021 to July 2022. The relative risk reduction was 50.5%. Outcomes were considerably better the earlier the treatment was given. This is considered a viable treatment but there is some concern as there were low numbers in the trial (ie 5% were immunocompromised). It offers some potential for non-vaccine responders, but the data is not altogether clear currently. This is being used as a pre-exposure prophylactic response in many countries (although not in the UK currently), but the Chief Medical Officer (CMO) now needs to decide on its use in the UK. It is likely that this will be used for those who have been exposed to the disease rather than as a preventative treatment. There is still a need for ongoing vaccination and early identification of the disease is key. The Melody study was also highlighted as this looks for antibody responses in immunosuppressed people and offers a consistent approach through use of lateral flow tests (LFTs) to pick up the disease early. Patients are identified by the National Disease Registration Service and given rapid access to testing. Immunosuppressed patients with a good response to the vaccine are still advised to exercise some caution, to use masks and to be responsible regarding social distancing.
11.	**Change Programme Board Projects – CTPG(22)14**
	Liz Armstrong, Head of Transplant Development presented information on the National Patient Information Website for Organ Transplantation www.nhsbt.nhs.uk/organ-transplantation which was launched in 2021. This website has information for those considering kidney, lung, liver, heart or pancreas transplantation. Over the last 12 months, surgical drawings and short videos have been added. Since its creation, website visits have increased with 17.5K visitors in May. 80% are new users and 20% are return users. The hope is this will reduce the duplication of effort in transplantation and there is potential to increase subject matter to include other issues such as psychology. J Parmar also shared information on the risk communication tools which can be found at www.odt.nhs.uk/transplantation/tools-policies-and-guidance The following were highlighted: • SaBTO Aide Memoire – this aids decision making for donors with potentially transmissible diseases which could affect utilisation of donor organs.

	• Risk Communication Tools – this helps patients and consultants to look at issues around organ transplantation based on patient characteristics. All tools are based on pre-pandemic data and there is no information around sensitisation and antibodies although this may change in future.
12.	**Any Other Business**
12.1	Future topics for forthcoming meetings include: • Patient Education • PROMS/PREMS – Dec meeting • OUG Update – Dec meeting
12.2	Future communications with Patient Group – patients are asked to state whether they are unhappy to receive details of future events via a joint email.
13.	**Next meeting**
13.1	Weds 7 December 2022 – via Microsoft Teams. The meeting will continue as a virtual meeting for the moment as this allows more participants to attend and contribute. A hybrid option has been explored for other meetings at NHSBT but has proved problematic when using an external venue. The invitation for the meeting in December has been sent but will be sent again over the summer to take account of new members.
13.2	Other Forthcoming CTAG meetings: • CTAG Lungs – Weds 28 September, 10:30-14:30 via Microsoft Teams • CTAG Hearts – Weds 9 November, 10:30-15:00 – Wesley Hotel, London • CTAG Patient Group – Weds 7 December, 10:30-13:30 – via Microsoft Teams

BELOW: New 'Electric Cranks' Cycling Jerseys - CTPG(22)18

ACTIONS FROM THIS MEETING:

1. **Item 3.3 - E Billingham to link with Venkat re ice box commissioning.**

2. **Item 6.2 - R Burns to link with primary care team at NHSE with additional support from other members of CTPG.**

3. **Item 7.1 - S Rushton to look at longer survival rate periods**

4. **Item 9.4 - R Burns will work alongside J Parmar and R Venkateswaran and NHS England to ensure the support is made available throughout the UK.**