

**NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION DIRECTORATE
THE THIRTEENTH (INTERIM) MEETING OF THE NHSBT
CARDIOTHORACIC PATIENT GROUP (CTPG)
ON MONDAY 10TH AUGUST 2020 FROM 1400 – 1530
MEETING VIA MICROSOFT TEAMS OR DIAL IN**

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PRESENT

Rob Graham (RG)	CTAG Patient Group Co-Chair, Governor, Royal Papworth Hospital
Jayan Parameshwar (JyP)	CTAG Patient Group Co-Chair, CTAG Chair, Royal Papworth Hospital
Eliza Bell (EB)	Transplant Recipient, Royal Papworth Hospital
Debbie Burdon (DB)	Patient Representative, Treasurer of FHLTA, Freeman Hospital
Martin Carby (MC)	CTAGL Lungs Deputy Chair
Lynda Ellis (LE)	New Start Transplant Charity, Wythenshawe Hospital
Laura Grocott (LG)	Heart & Lung Transplant Recipient Co-ordinator, Queen Elizabeth Hospital
Margaret Harrison (MH)	CTAG Lay Member Representative
Lorraine Jerrett (LJ)	Recipient Nurse, Golden Jubilee National Hospital
Beverley Jones (BJ)	Transplant Social Worker, Wythenshawe Hospital
Alan Lees (AL)	Patient Representative, Harefield Transplant Club, Harefield Hospital
Lisa Mumford (LM)	Head of OTDT Studies, NHSBT
Rosie Pope (RP)	Parent of Transplant Recipient, Harefield Hospital
Rachel Rowson (RR)	Specialist Nurse – Organ Donation, NHSBT (Deputy for Marian Ryan)
Charlotte Silver (CS)	Senior Communications Officer, NHSBT
Tom Speight (TS)	Policy Analyst, Cystic Fibrosis Trust
Michael Thomson (MT)	Patient Representative, Golden Jubilee National Hospital

IN ATTENDANCE

Lucy Newman (LN) Secretary, NHSBT

MINUTES

	Welcome and Introduction Apologies were received from: Emma Johnson, Lucy Ryan, Jane Nuttall, Marian Ryan, John Forsythe, Katie Morley, Laura Stamp	
1	CTPG(20)06 – Declarations of Interest There were no declarations of interest recorded in relation to the meeting today.	
2	CTPG(M)(20)01 – Minutes of the last Meeting held 13th May 2020	
2.1	Accuracy	
2.2	The minutes were approved as an accurate record of the last meeting.	
	Action Points	
2.3	2.2.2 Survival rates – see item 4 Transplant survival rates for patients who contracted COVID-19 will be discussed under item 4 of the agenda.	
	2.2.3 Interim Meeting This meeting is the interim meeting requested by members at the last CTPG Meeting.	
	2.2.4 Facebook Page	

	<p>RG has set up a Facebook page – Cardiothoracic Transplant Patient Group. Members need to be contacts of RG to be added, please search for the page or RG to request membership of the page. The page will be a patient forum and source of communication for the patient group outside the regular CTPG Meetings. Members can email RG or LN for further information.</p> <p>Any Other Business RG mentioned an automated lung function machine, a Spirometer which is being trialled and will be discussed under item 7 of the agenda.</p> <p>RG received an email regarding skin grafts to identify potential organ rejection in post-transplant patients which will be discussed under item 7 of the agenda.</p>	
3	<p>Current Activity Levels of Cardiothoracic Transplant Latest cardiothoracic transplant statistics show the number of heart transplants to date this year is 58, the same as this time last year. The number of lung transplants to date this year is 32, compared to 63 this time last year, approx. 50% down. Heart activity has been particularly good and continued during the pandemic, mainly transplanting Urgent and Super Urgent patients; there was also an increase in the number of DCD heart transplants. Lung transplant activity ceased in late March due to COVID-19 and did not restart till May. Activity did not return to near normal levels until June 2020.</p> <p>In the past month 18 heart transplants and 10/12 lung transplants were carried out across all centres, many of which have returned to near normal activity levels. MC commented that Harefield has carried out several lung transplants and reported two further lung transplants last weekend.</p> <p>Nationally, not all patients have opted to go back onto the lung transplant list yet, but total numbers of patients registered, and the number of lung transplants carried out is better than anticipated at the last meeting.</p> <p>RG commented on the proportion of DCD hearts used, JyP confirmed that use of DCD hearts for transplant fluctuates. Funding for DCD heart transplantation was made available to trusts from July 2019, and this has had an impact on DCD numbers used. The national DCD heart project starts in September 2020 from which date all centres will be offered DCD hearts.</p> <p>TS asked whether there has been a formal evidence review to inform centres about what approach they should take should there be a second surge of COVID-19. This will be addressed under item 4 on the agenda.</p>	
4	<p>CTPG(20)07 – Cardiothoracic Transplant COVID19 Survival Statistics Statistics involving pre- and post-transplant patients who were reported to NHSBT as having contracted COVID-19 up until 24th July were reported to the group.</p> <p>In total, 29 heart recipients, seven of whom died (24%) and 26 lung recipients, nine of whom died (34%) were reported to NHSBT as having contracted COVID-19. Whilst overall mortality is high, it's not as high as feared, early reports from other countries predicted higher levels of patient mortality in lung recipients early in their post-transplant recovery. Conversely 31 patients waiting for lung transplants have died since January; balancing with the nine patients who have died from contracting COVID-19 over the past four to five months, it is viewed as being reasonable to continue with heart and lung transplantation.</p> <p>Patients who contracted COVID-19 and died post-transplant tend to be those who have underlying or transplant related health issues and may be generally less well. In relation to the question raised by TS; evidence shows the percentage of transplant recipients who received transplants since January 2020 and died from COVID-19 is low for all organs, including hearts and lungs, so it would be reasonable to continue</p>	

transplant activity where safe and reasonable, as there appears to be no excessive risk in the early post-transplant period.

A second wave may not hit the whole of the UK and is more likely to result in local lockdowns. If this happens, the default position of NHSBT and NHS England is that centres should remain open for transplant activity. If the second wave results in local lockdowns with some centres closed and others open, it could be managed in the short term. However, if the recommendation is for a centre to close for an extended period, (more than a few weeks) one contingency for this would be to give patients the opportunity to move to an alternative transplant centre for their treatment. This option would be available to higher risk patients on the waiting list where there is space for the alternative centre to take them.

For post-transplant patients, most follow up appointments in the past few months have been by phone or video call. Patients who are unwell or overly concerned are still seen face to face.

Funding has been made available by NHSE for a device that can record spirometry and transfer data to the centre. Centres are developing administration services to handle the data this will provide for clinicians, which should alleviate some of the difficulties currently faced by patients attending virtual appointments, but who also need to have tests carried out locally with data transferred to the centre overseeing care. Once suitable software is in place the Spirometers will be rolled out to patients for feedback ahead of a national roll-out.

Centres report they would like to see more pre- and post-heart transplant patients face to face for better observations as there is no similar monitoring system for heart patients, particularly those who are unwell, having difficulties or need further medical support / intervention.

Regarding COVID related deaths, there is no explanation why more men than women are affected, or why patients from BAME backgrounds have less favourable outcomes from COVID-19. This is seen in all areas, not just in pre- and post-transplant patients.

It was noted that the Association of Local Authority Medical Advisors (ALAMA) have published a tool which calculates a worker's vulnerability by applying a COVID adjusted age compared to actual age based on various factors which gives an indication of the comparative risk for individual employees.

<https://alama.org.uk/covid-19-medical-risk-assessment/>

Royal Papworth reports no new COVID patients for about a month and Harefield is similar. Patients were transferred to Royal Papworth for ECMO treatment and during the peak, intensive care units were at full capacity with COVID patients. Now only three or four patients remain in hospital and these are longer term patients admitted some months ago.

TS asked whether the outbreak has provided any other opportunities for transplant centres or units relating to RGs letter about increasing bed capacity in ICU wards in May2020. JyP / MC report that there has been no permanent increase in ICU bed capacity for lung transplant patients; it's unlikely that hospital infrastructures will change in any significant way to increase capacity in the future.

RG asked whether there is an anticipated increase in patients registering for lung transplants as a result of COVID-19. Clinical feedback was that it's too early to predict at this stage. Two or three patients who have had COVID have been referred for lung transplant assessment, but it is too early in the disease course to consider lung transplants in acutely unwell patients as they may not have the best outcomes.

5.1	<p>Freeman Hospital – Freeman Heart and Lung Transplant Association (FHLTA) – DB https://www.fhlta.org.uk/</p> <ul style="list-style-type: none"> • Members of the transplant community expressed concerns about shielding and have approached FHLTA for advice. Guidance given by the group is to follow the government shielding advice • FHLTA held a virtual coffee morning in June which was well attended • Lots of patients have been taking part in sponsored walks and virtual games and sports in their gardens or outdoor spaces in place of attending the British Transplant Games in Coventry this year • FHLTA has a project called ‘FHLTA With Love...’ following feedback from post-transplant patients and nurses about what patients need or are missing post-transplant, these are little treats patients can have such as mindfulness activities, long charging cables for phones, stress relievers, toiletry items, things patients may not have if admitted as an emergency patient or when they are in hospital for an extended time period. This has been received positively by patients 	
5.2	<p>Golden Jubilee National Hospital – MT & LJ</p> <ul style="list-style-type: none"> • GJNH remained open and has been busy throughout the pandemic with patients being admitted to GJNH from outside the area to enable other lifesaving treatment and surgery to continue wherever possible • Clinics are running as often as they can, trying to see all patients who are in the first-year post-transplant in a face to face setting. The virtual setting is good for some patients who are living further away from the centre 	
5.3	<p>Harefield Hospital – Harefield Transplant Club (HTC) - AL & RP http://harefieldhamsters.org</p> <ul style="list-style-type: none"> • Lung consultants at Harefield held a virtual Q&A session with patients, including having pre-session questions submitted. Patients reported that this was an excellent session and a video was also produced and issued for patients and AL commented that as a post-transplant patient, he found it very useful session. • Social and sporting activities have been put on hold for the time being • HTC intends to hold a virtual AGM in October 2020 • The HTC Facebook page allows members to air any concerns and receive views from their peers on matters appertaining to COVID. • Since COVID, virtual consultations have been introduced for heart patients although it is uncertain at this stage whether appointments will remain virtual or whether they will revert to physical appointments. • Nurses and staff have been recycling disused storage boxes from operating theatres to plant as grow boxes for patients and visitors to Harefield to improve their surroundings and give small green spaces • AL has provided information about virtual CTPG Meetings to group members and will pass details of those who wish to attend virtual meetings to LN 	AL / LN
5.4	<p>Royal Papworth Hospital – RG https://royalpapworth.nhs.uk/patients-and-visitors/pals/patient-support-groups</p> <ul style="list-style-type: none"> • Unfortunately, the social events / meetings which were due to take place in September and November at Royal Papworth have been cancelled • Patients have been participating in the virtual transplant games • Membership of the Royal Papworth Patient Group Facebook page has increased by 12% since the last meeting to approximately 450 members since lockdown started, which is almost double the number of members from before the pandemic • The gift bag initiative (for newly transplanted patients) has been received very positively and donations of £1,800 will ensure the program has enough funding for the next two years. 	

5.5	<p>Queen Elizabeth Hospital – LG https://www.hospitalcharity.org/patientsupportgroups</p> <ul style="list-style-type: none"> • As with other units, patients have been participating in the virtual transplant games • The Facebook group page has seen an increase in activity with patients sharing advice which has led to an increased sense of community between patients • Lung transplantation was paused for a time at the start of the pandemic, but activity has since resumed with increasing numbers on the list and good outcomes for transplanted patients 	
5.6	<p>Wythenshawe Hospital – BJ & LE https://mft.nhs.uk/wythenshawe/services/cardiology-and-cardiothoracic-surgery/heart-and-lung-transplant/</p> <ul style="list-style-type: none"> • BJ reported that the aftercare teams for transplant patients are working more closely and intend to have joint meetings with pre- and post-transplant patients where the physiotherapist, occupational therapist and dietician are able to meet patients at the same time to have more positive appointment outcomes for patients • Physios have started online appointments, but the joint work has yet to commence • The refurbishment of the centre has restarted following a brief pause • The Facebook page has received increasing membership and has been extremely useful in keeping patients in contact via social media. <p>Some pre-transplant lung patients currently on Oxygen, who would be unable to attend CTPG Meetings in London have expressed an interest in joining the virtual meetings, pre-transplant patients would be welcomed as there are few pre-transplant patients currently in the group. BJ will gather details to pass to LN to include in the next calendar invitation for the meeting on 18th November.</p>	BJ / LN
6	<p>Outlook and Prospects for the ‘Shielded’ Community</p> <p>JyP opened discussion with a question to the group about how they feel, and whether they have any questions or concerns as a result of shielding and the associated support mechanisms (such as food parcels etc...) coming to an end, with lockdown restrictions easing nationally, but local regional / district lockdowns being introduced instead.</p> <p>Facebook feedback at some of the hospitals is that patients would have liked clearer guidance in uncertain times. JyP recommended that pre-transplant patients contact their consultant for their advice on shielding for specific health indications. Outside this, the centres are following Government guidelines. Initially some patients felt that NHSBT / NHSE was withholding information they should have been given sooner – JyP clarified that the information on shielding was released to everyone at the same time and hospitals had no way of knowing in advance that shielding would be advised. It was noted that NHSBT was not involved in the formulation of the shielding policy.</p> <p>EB mentioned that during the lockdown she was able to start a Podcast for transplant patients called ‘Transplant Chats with Eliza’, which can be found on Apple Podcasts or Spotify. Check out the link here: https://transplantchats.com/. This is a series of Podcasts in which EB meets various individuals at different stages of their transplant journeys and talks about all solid organs not just cardiothoracic. EB commented that she has increased her walking which she has really enjoyed and has visited a few shops since lockdown restrictions eased. EB feels that as she has been given a</p>	

	<p>second chance at life via a transplant, she wants to be able to enjoy it so has had to find the balance between being cautious while still enjoying life.</p> <p>Anxiety over COVID-19 seems to be decreasing, some people have gone back to work remotely, some are back in offices etc... some are loving it, others remain anxious. Patients commented that when the shielding came to an end, so too did the support for the shielded community.</p> <p>DB works in mental health and commented that she has been working from home, and continued to work throughout but at times she has felt distanced from the team so has been able to arrange a fortnightly meeting with colleagues on site whilst there are larger spaces available to facilitate social distancing during the day.</p> <p>Some patients commented that it had been difficult to arrange face to face appointments when they wanted a physical appointment at some centres, the advice is to keep trying as there are appointments which become available at shorter notice.</p>	
7	<p>Any Other Business</p> <p>RG has been contacted by Henk Giele (Nuffield Department of Surgical Sciences, Oxford University) to find out how CTPG members feel about Sentinel Skin Flap Trials. The intention is that at the time of transplantation, a section of donor skin would be attached to the forearm / thigh of the recipient, the skin would indicate any signs of rejection in the transplanted organ enabling effective treatment to begin more quickly whilst avoiding the need for invasive investigations such as a lung biopsy for example. If patients decide to participate in the trial, they would still require a lung biopsy if the skin flap indicated potential signs of organ rejection. Clinicians have been approached about the study and there has been a mixed response. RG to canvass opinion from Papworth patients to feedback to HG.</p> <p>The trials started with intestinal transplants as the intestine is more difficult to biopsy. Members felt there would be more psychological implications having visible skin from the donor attached externally.</p> <p>There is no face to face meeting planned for November, it will be a Teams Meeting. *Post Meeting Note – Outlook Invitation amended and sent 19/08/20. Times will be altered to 2-4pm when these minutes are distributed. The next face to face meeting is scheduled for May – this will be confirmed nearer the time in line with government guidance.</p> <p>If any members have concerns or questions outside the meeting, please contact RG, JyP, MC who will try to help answer any queries, LN is happy to forward any enquiries on behalf of members.</p>	RG
<p style="text-align: center;">Dates of Next Meetings</p> <p style="text-align: center;">CTAGL Lungs Thursday 17th September 2020 via MS Teams CTAGH Hearts Monday 28th September 2020 via MS Teams CTPG Wednesday 18th November 2020 @ 2pm – 4pm via MS Teams</p>		