

**NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE**

**MINUTES OF THE TENTH CARDIOTHORACIC PATIENT GROUP MEETING
HELD ON MONDAY 13TH NOVEMBER 2019 FROM 12:30-16:00 AT
CORAM CAMPUS, 41 BRUNSWICK SQUARE, LONDON WC1N 1AZ**

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
Janet Atkins (JA)	Patient Representative, Governor, Royal Papworth Hospital
Eunice Booker (EB)	Organ Donation Advocate, Donor Family Network
Debbie Burdon (DB)	Patient Representative, FHLTA, Freeman Hospital
Lynda Ellis	Sure Start Transplant Charity, Wythenshawe Hospital
Leila Finikarides (LF)	Research Assistant, The Winton Centre
John Forsythe	Associate Medical Director, ODT
Laura Grocott (LG)	Heart & Lung Transplant Recipient Co-ordinator, Queen Elizabeth Hospital
Margaret Harrison (MH)	CTAG Lay Member Representative
Ged Higgins (GH)	Patient Representative, Wythenshawe Hospital
Lorraine Jerrett	Recipient Nurse, Golden Jubilee National Hospital
Beverley Jones (BJ)	Transplant Social Worker, Wythenshawe Hospital
Adele Lambert (ALa)	Patient Representative, FHLTA Sports Manager, Freeman Hospital
Alan Lees (ALe)	Patient Representative, Harefield Transplant Club, Harefield Hospital
Lisa Mumford (LM)	Head of ODT Studies, NHSBT
Rosie Pope (RP)	Parent of Transplant Recipient, Harefield Hospital
Rachel Rowson (RR)	Specialist Nurse Organ Donation, NHSBT
Lucy Ryan (LR)	Transplant Recipient, Royal Papworth Hospital
Marian Ryan (MR)	Specialist Nurse Organ Donation, NHSBT
Charlotte Silver (CS)	Senior Communications Officer, NHSBT
Frederick Smith (FS)	Statistician, 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
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APOLOGIES

Dominic Kavanagh, Jane Nuttall, Richard Quigley, Nicky Ramsay

Item		Action
1	<p>Apologies and Welcome</p> <p>RG welcomed the group and thanked them for attending. Nawaar- Al-Attar received special thanks, he has supported the CTPG since inception, but has now handed membership over to Lorraine Jerrett (LJ) as the Centre Representative for GJNH. Special mention to Eunice, speaking on behalf of the donor family network, Lisa Mumford who has taken over CTAG while Sally is on maternity leave, thanks also to John Forsythe who rearranged another meeting to be able to attend CTPG today.</p>	
2	<p>Declarations of interest</p> <p>There were no declarations of interest in relation to the meeting today.</p>	
3 3.1	<p>Minutes</p> <p>Accuracy</p> <p>There are two minor corrections to be made to previous minutes:</p> <p>Item 5 – GH Wythenshawe Hospital transplant unit is just about to start the £0.75m refurbishment of the unit.</p> <p>Item 6.4 – the date 18/05/18 required alteration to 18/05/17.</p> <p>These items have been amended and the minutes of the last meeting can be approved as an accurate record of the last meeting.</p>	

3.2	<p>Action Points Any action points raised at the last meeting will be covered during this meeting</p>	
3.3	<p>Chair Tenure Expiry RGs tenure as Co-Chair of CTPG comes to an end in May. Members interested in applying for the role of CTPG Chair are welcome to contact RG to find out more about what the role entails. LN will request Expressions of Interest in the role of CTPG Co-Chair when the minutes of the meeting today are circulated.</p> <p><i>Post Meeting Note: Letter from John Forsythe attached</i></p>	
3.4	<p>Any Other Business At the last meeting Dylan Parrin (DP) a Birmingham Patient, asked about development of a smartphone app which would track patient feedback from tests such as lung function tests directly to clinicians without having to attend clinic. DP has developed his own app but linking to the hospitals is proving tricky. There are a number of similar smartphone apps available but none of them link particularly well with the hospitals.</p> <p>DP's app enables him to monitor and download his lung function results, which could then be emailed to the cardiothoracic department looking after him, it also enables him to receive reminders and alerts to take medications. Birmingham uses an app which signposts patients in the right direction if they report symptoms, but again there is no guarantee that this would work with different hospitals.</p> <p>JF was asked whether he foresees this as being an area of improvement that could be written into the 2025 strategy, however, NHSBT does not commission transplant and cannot impose on or standardise individual trusts to provide a unified app or unified systems.</p> <p>ACTION: LN to circulate information about the 2025 strategy plans will be released as soon as it is available.</p>	LN
4	<p>Patient Centre Updates</p>	
4.1	<p>DB/ALa – Freeman Hospital</p> <ul style="list-style-type: none"> • Currently rebranding the old Freeman Heart and Lung Transplant Association (FHLTA), new pin badges have been issued with the new logo on, and the website went live on 1st July • 20 members of the FHLTA attended the Transplant Games in Wales • FHLTA are in the process of reviewing policies and procedures and will be involved in a number of promotional events in advance of Opt Out Law coming into force in Spring 2020 • The FHLTA AGM and Christmas Party is has been booked for 23rd November in York. DB and ALa both attended the European Organ Donation Day in London in October and found it interesting 	
4.2	<p>MT/LJ – Golden Jubilee National Hospital</p> <ul style="list-style-type: none"> • Unfortunately, there have been no patient group meetings as the hotel that is normally used (next door to GJNH) has been undergoing building works for the past 15 months and has another three years until completion • One member (Steven), a cyclist, entered the transplant games and did very well • 2 members of the group will be participating in the winter transplant games Members of the patient group ran a promotional stand during Organ Donation Week to encourage sign ups and conversations • Patient contracts and care plans are being reviewed • Patients who are registered to urgent or super urgent lists who are waiting as inpatients are invited to attend a weekly supper club where they can meet and socialise over supper of their choice • This includes patients on femoral balloon pumps who are now actively mobilised when they had previously been in bed • The first DCD heart recipient is home and doing well following their transplant 	
4.3	<p>ALe – Harefield Hospital</p> <ul style="list-style-type: none"> • The Harefield Hospital Transplant Charity have commissioned various art work at Harefield including a Ceramic Wall Mural and Planting green spaces for patient recuperation 	

	<ul style="list-style-type: none"> • The Meadowlands Festival in Oxford this year raised funds for Harefield Transplant Charity • The group held their annual reunion at the end of October in Bournemouth which was well attended • One member of the Charity makes goody bags for inpatients waiting for transplants • Pins to commemorate 10 years since receiving a heart transplant are issued by the charity and they have just commissioned pins to commemorate 5 years since receiving a lung transplant – with the first batch of the new commemorative pins being issued a few weeks back. • Video conferencing clinics for lung patients are being considered, but at present, patients would still have to attend hospital to complete various diagnostic tests prior to consultation 	
4.4	<p>RG – Royal Papworth Hospital</p> <ul style="list-style-type: none"> • The patient group at Royal Papworth holds 4 meetings per year with guest speakers invited • The Christmas party takes place the week after next with 60/70 attendees expected • The Royal Papworth charity agreed to help arrange a skydive, one recent heart patient completed the skydive and raised over £2k in doing so • The patient group also invite the transplant teams to their meetings • The Christmas Carol service is taking place at Ely Cathedral in December • The patient group have developed business cards which are handed to patients, these contain contact details for support and sport teams and the dates of the planned patient group meetings, the group has also developed its own Twitter account and Facebook page • One Royal Papworth patient spoke at the Lung Summit and one spoke at the European Organ Donation Day • Some patients rode with Jas Parmar and Richard Quigley in the London to Paris Cycle Ride • The Royal Papworth Team won the best overall transplant team award at the transplant games, and the World Transplant Games was also well attended by patients from Royal Papworth 	
4.5	<p>LG – Queen Elizabeth Hospital</p> <ul style="list-style-type: none"> • Three QEH Patients took part in the World Transplant Games and won medals in Bowling and Badminton • The Patient Group is raising money to fund a 2 bedroomed home away from home for transplant patients and their families to use • One heart recipient who was transplanted over 25 years ago recently took part in a three peaks challenge and Jan Locket took part in a golf tournament • Dom Kavannah has produced a book of photography (A Second Shot at Life), ridden in the Velo, dyed his hair blonde and various other fund raising has raised over £10k for the transplant unit. • Long Term inpatients are better supported socially by the introduction of movie nights, book club nights and games nights • Sarah (5yrs post transplant) makes gift baskets • The hospital is in the early phase of renovating a room which will serve as a quiet space for thought and reflection space for patients • LVAD cafes continue and QEH have now introduced MOT ATLAS clinics for patients the for the first anniversary of their transplant. The clinics have been successful with Lung patients and will now be incorporated into the post transplant care for Heart patients 	
4.6	<p>GH/LE/BJ – Wythenshawe Hospital</p> <ul style="list-style-type: none"> • Wythenshawe Hospital will be hosting the Transplant Patients Christmas Party next week with approx. 130 attending • The Wythenshawe transplant unit is just about to undergo refurbishment work • Ged Higgins has been using an EBike for the past 5 years and has now gathered a group of fellow patient EBike enthusiasts (six with VADs, one post transplant) called the Cranks • The Cranks recently cycled 30 miles through the Peak District and are planning to cycle Hadrian's Wall in May next year • The Cranks are currently awaiting printing of their Cranks cycling jerseys • GH has successfully negotiated reductions on EBike training sessions for fellow Wythenshawe heart and lung patients who can get introductory sessions at reduced rates • During Organ Donation Week 4/5 patients rode from Salford Royal to some of the other Transplant units to raise awareness of Organ Donation 	

5	<p>For Information:</p> <p>Annual Report on Cardiothoracic Organ Transplantation 2017/2018</p> <p>The waiting list for lung transplantation (combined adults and paediatrics) currently has 6% fewer patients than last year, and the waiting list for heart transplantation currently has 14% more patients than last year. Despite this, there has been an increasingly upward trend in the number of patients on the cardiothoracic transplant waiting list. The same number of heart transplants and 20% more lung transplants were carried out during the last year.</p> <p>It was observed that the number of patients on the waiting list can fluctuate widely at centres suggesting a difference in approaches to listing.</p> <p>The transplant outcomes data looks at patients who have received a cardiothoracic transplant and the short, medium and longer-term outcomes for those patients. Patients commented that there appears to be some discrepancy between the registration rate in certain areas of the country compared with the transplant rate; for example, Yorkshire has a 4.6 registration rate and 1.1 transplant rate. This could just be a quirk of the last year, so Stats should consider including several years in the geographical analysis.</p> <p>There is interest in Quality of Life indicators and disease-specific waiting list outcomes. A question was also raised about why transplant activity was so high in 2013/14 and about 10-year survival outcomes.</p> <p><i>ACTION: LM will review the geographical analysis and consider including several years combined. LM will also consider other comments on the data for future reports.</i></p>	LM
5	<p>Donor Family Network Presentation</p> <p>Eunice Booker attended the meeting to speak on behalf of the Donor Family Network. Eunice gave a very powerful and emotional speech about her daughter, Kirsty, who became an Organ Donor in 2006 when she was just 26 years old. RG thanked Eunice for sharing her humbling story with the group.</p> <p>Discussion took place within the group to discuss “writing to your donor family”. Eunice explained how very difficult and yet relieving it was to receive correspondence from the families who received donations from Kirsty.</p> <p>Within the recipient nurse teams, work is being done to promote the benefits of writing to donor families and all letters are now coordinated and managed through one central NHSBT office. It was also raised that Social Media is becoming more widely used and perhaps this could be considered alongside letter writing. Ben Cole and Katie Morley from NHSBT are working to produce guidance for centres and teams about correspondence being discussed immediately and then at follow up trigger points when visiting clinics for post-transplant check-ups.</p>	
6 6.1	<p>Update from Statistics and Clinical Studies by LM</p> <p>Annual Reports on Cardiothoracic Organ Transplantation</p> <p>On 31/03/19 there were a total of 295 patients waiting for a heart transplant (an increase from 284 on 31/03/18) and a total of 351 patients waiting for a lung transplant (a decrease from 357 on 31/03/18). During this time period there were a total of 1600 deceased organ donors. A total of 608 patients are registered on the on the heart waiting list, 310 of those were active registrations at 31/03/19.</p> <p>A total of 612 patients are registered on the lung waiting list, 270 of those were active registrations at 31/03/19. A total of 26 patients are registered on the heart/lung waiting list, 7 of those were active registrations at 31/03/19.</p> <p>Of the total of 962 DBD Donors: 153 donated their heart resulting in 149 transplants 139 donated at least one lung resulting in 126 transplants</p> <p>Of the total 638 DCD Donors: 33 donated their heart resulting in 31 transplants 58 donated at least one lung resulting in 39 transplants</p> <p>The median average cardiothoracic transplant waiting times are: Non-urgent hearts 611 – 1559 days</p>	

<p>6.2</p> <p>6.2.1</p>	<p>Urgent hearts 26 – 34 days Paediatric non-urgent hearts 55 – 103 days Paediatric urgent hearts 0 – 1044 days Non-urgent Lungs 252-326 days There were no patients waiting for urgent lungs when the data was collated.</p> <p>Update on Transplant Centre Infographics The Transplant Centre Infographics and a short survey for feedback are available from the ODT website: https://www.odt.nhs.uk/statistics-and-reports/organ-specific-reports/. The survey will remain open for approximately 6 months to achieve as many survey responses as possible. Members can offer feedback via the survey, feedback can also be emailed to CardiothoracicStatistics@nhsbt.nhs.uk.</p> <p>Q & A on Infographics Patient Group Members are asked to review the infographic and share it within their centre patient support groups before they complete the survey with their feedback. Initial feedback taken at the meeting included:</p> <ul style="list-style-type: none"> • Information to be made available about Super Urgent patient wait times and outcomes • Average number of transplants per centre • Infographic displayed locally by centre not just nationally • Should the data be listed in ascending or descending order rather than alphabetically? • The colours on the bar graphs and pie charts should be more clearly defined/patterned • *Could patients waiting who are fitted with LVAD be included? • Should the information be split by gender? <p>ACTION: JyP will liaise directly with the Patient Group Member requesting LVAD waiting time information</p>	
<p>7</p>	<p>European Organ Donation Day (EODD) European Organ Donation Day was held in London this year on 12th October. The main focuses of EODD this year were DCD Heart Transplantation, Technology in Transplantation and increasing the number of Black and Minority Ethnic Organ Donation Registrants. It was well attended by European and British delegates. The presentations can be viewed here: https://www.edqm.eu/en/transplantation-events-training-resources 2020 EODD will be on Saturday 10th October 2020 in Warsaw.</p>	
<p>8</p>	<p>Lung Summit Feedback JF had concerns that number of potential lung donors has increased while the number of lung transplants carried out has been in gradual decline -20% lower last year, so the Lung Summit was arranged to establish the reasons behind this decline. The Lung Summit enabled multi-disciplinary teams, clinicians and patients to meet and discuss the reasons behind the decline in lung transplants. Often logistical reasons can be to blame, for example ICU Units can only manage certain number lung transplant patients at any one time. Super Urgent listing for lung transplant requires the patient to be on ECMO, which is not currently funded by NHSE and relies on trust and charitable donations for funding.</p> <p>ACTION: RG to consider writing on behalf of CTPG to relevant body(ies) about lack of ICU beds potentially compromising the drive to increase organ donation from Opt-out legislation.</p> <p>Within the cardiothoracic community there is a willingness to try and resolve the problem, but costs and space are factors which have a big impact on a unit having the resources available to support patients before and after lung transplantation. The situation will be monitored on an ongoing basis with feedback at CTAG in 2020.</p>	<p>RG</p>
<p>9</p>	<p>CTPG Terms of Reference The CTAG Heart and Lung Wider Group Terms of Reference have been reviewed, in line with this the CTAG Patient Group Terms of Reference are due for review.</p> <p>ACTION: RG will work on the necessary alterations and liaise with NHSBT regarding any changes.</p>	<p>RG</p>

<p>10</p> <p>10.1</p> <p>10.2</p> <p>10.3</p> <p>10.4</p> <p>10.5</p> <p>10.6</p> <p>10.7</p> <p>10.8</p>	<p>Cardiothoracic Transplant Advisory Group Updates</p> <p>DCD Heart Transplantation and Funding Funding for DCD Heart Transplantation has been agreed in the last couple of weeks by NHSBT/NHSE and will remain in place for a maximum of three years. Centres who have access to OCS Machines will retrieve for those who don't – it is likely that Royal Papworth will retrieve around 50% of the DCD hearts offered in England. There will be no change to the allocation zones for DCD hearts at this stage.</p> <p>First Heart/Lung DCD Transplantation Royal Papworth Hospital received permission to use carry out the first DCD Heart Lung bloc transplant. The procedure involved the use of an OCS Console to manage the heart and lungs, and overall it went very well.</p> <p>The patient is home and remains stable and well. Thanks go to Andre Simon at Harefield Hospital who was extremely helpful in the facilitation of this transplant.</p> <p>Super Urgent Heart/Lung Review CTAG Heart and CTAG Lung were asked to consider whether a Super Urgent Heart/Lung Category should be introduced. An application was submitted to the adjudication panels to requested permission to add a patient to this category while they waited to receive a heart and lung transplant.</p> <p>Both CTAG Heart and CTAG Lung Panels considered this, but the criteria a patient would need to fulfil prior to being added to a Super Urgent Heart/Lung waiting list would make transplantation too much of a risk due to poor outcomes. CTAG Members have agreed to review this in five years' time when there is more outcome data for Urgent Heart/Lung transplant recipients.</p> <p>Paediatric Heart Transplantation Concerns were raised earlier in the year over a seemingly high number of paediatric patients with pumps waiting for heart transplants and blocking ICU beds while they wait. Paediatric patients can wait longer than adults when they have had a pump fitted, although there is a higher risk of stroke in patients waiting on a pump and more likelihood that paediatric patients will have to receive treatment outside the UK. There are also less paediatric organs offered for transplant which is another factor in longer waiting times for paediatric patients. Paediatric surgeons must maintain a more aggressive stance on accepting hearts for paediatric transplant.</p> <p>Declining Donor Heart Offers for Named Patients for Logistical Reasons Under the Duty of Candour, patients will be asked at listing whether they would like to be told if an organ offered for them is declined due to logistical reasons (lack of theatre space/ICU beds etc). NHSBT will identify when an organ has been declined for logistical reasons and then ask centres to inform/write to patients to confirm this. This process will be rolled out in renal transplant, other organs will follow. This Group has previously suggested that its members may be unlikely to take up such a request as the psychological impact may prove to be counter-productive.</p> <p>Hepatitis C Positive Donor Hearts Using organs from Hepatitis C Positive (HCV) donors may increase the donor pool making more organs available, its anticipated by about 30-40 per year, often from younger donors. HCV can be treated relatively easily and quickly within approx. 6-12 weeks. JyP has emailed centres to establish those who would be willing to accept HCV positive organs for their patients, decisions for each recipient would be recorded on the donor decision forms.</p> <p>HCV testing began in 1991, and prior to that 5 patients had previously received HCV positive organs. None of the patients who had received the HCV positive organs died from HCV. Comparatively speaking, treatment for HCV infection costs 15-20% of the cost of fitting a VAD.</p> <p>Individual Centre Lung Review Birmingham had CUSUM trigger in 2017 which has been reviewed; with a full report issued to CTAG in April 2018. Recommendations and learning points have been shared with other units.</p> <p>Recording Quality of Life following Transplant</p>	

	<p>QoL data is important as it enables a comparator to be given between life before and life after transplantation. At present QoL is mainly measured in lung transplantation as lung patients are more frequently admitted to hospital to await their transplant, whereas heart patients are often able to wait at home. MC and JsP are working on developing a scale for monitoring QoL data at pre-set intervals to measure for improvements.</p> <p>Birmingham have been collecting pre and post-transplant QoL data for some time with their own questionnaire, and Manchester collects QoL data for pre-transplant patients, but there is no uniformity or guaranteed collection of QoL data at the other heart and lung transplant centres.</p>	
11	<p>Any Other Business</p> <p>Cardiothoracic Scouting was evaluated and deemed worthwhile, because it could increase the number of cardiothoracic organs available for transplantation by approximately 17%. Despite two business case proposals being submitted to the Board, Scouting was not commissioned due to one centre not supporting the business case and a lack of available funding.</p> <p>RG thanked members and guests for their attendance and participation at todays meeting. Nawwar Al-Attar sends his best wishes to the group and well wishes for the future.</p>	
12	<p style="text-align: center;">Date of next meetings</p> <p><i>CTAGH Hearts – Monday 23rd March 2020 @ Mary Ward House, 5-7 Tavistock Place, WC1H 9SN</i> <i>CTAGL Lungs – Wednesday April 1st 2020 @ Mary Ward House, 5-7 Tavistock Place, WC1H 9SN</i> CTPG – Wednesday 13th May 2020 @ Asia House, 63 New Cavendish Street, London, W1G 7LP</p> <p><i>CTAGL Lungs – Thursday 17th September 2020 @ Mary Ward House, 5-7 Tavistock Place, WC1H 9SN</i> <i>CTAGH Hearts – Monday 28th September 2020 @ Mary Ward House, 5-7 Tavistock Place, WC1H 9SN</i> CTPG – Wednesday 18th November 2020 @ Asia House, 63 New Cavendish Street, London, W1G 7LP</p>	