

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

**MINUTES OF THE TENTH MEETING OF THE NHSBT CTAG PATIENT GROUP  
ON MONDAY 13<sup>TH</sup> MAY 2019 12:30-16:00  
AT PARK CONFERENCE CENTRE, 1 PARK CRESCENT, LONDON, W1B 1SH  
IN THE GULBENKIAN ROOM**

**PRESENT**

Rob Graham (RG)	CTAG Patient Group Co-Chair, Governor at Royal Papworth Hospital
Jayan Parameshwar (JyP)	CTAG Chair, Royal Papworth Hospital
Nawwar Al-Attar (NAA)	Heart Surgeon, Golden Jubilee National Hospital
Rebecca Allen (RA)	Representative for Heart Transplant Families UK
Debbie Burdon (DB)	Trustee, Freeman Heart and Lung Transplant Association (FHLTA)
Martin Carby (MCa)	CTAGL Deputy Chair, respiratory Physician, Harefield Hospital
Lynda Ellis (LE)	Charity Administrator, New Start Charity
Anna Evans (AE)	Representative for Cystic Fibrosis Trust
Leila Firkinarides (LF)	Research Team Representative, The Winton Centre
Laura Grocott (LG)	Heart and Lung Transplant Recipient Coordinator, Queen Elizabeth Hospital
Margaret Harrison (MH)	CTAG Lay Member Representative
Ged Higgins (GH)	Patient Representative, Wythenshawe Hospital
Beverley Jones (BJ)	Transplant Social Worker, Wythenshawe Hospital
Emma Johnson (EJ)	Max and Kiera's Law Advocate, Heart Transplant UK Families Support Group
Alan Lees (ALe)	Patient Representative, Harefield Hospital
Katie Morley (KM)	Lead Nurse Recipient Co-ordinator, Royal Papworth Hospital
Jane Nutall (JNu)	Recipient Transplant Coordinator, Wythenshawe Hospital
Dylan Parrin (DP)	Patient Representative, Queen Elizabeth Hospital
Rosie Pope (RP)	Patient of Heart Transplant Recipient, Harefield Hospital
Sally Rushton (SR)	Senior Statistician, NHSBT
Lucy Ryan (LR)	Transplant Recipient, Heart Transplant Families UK Support Group
Michael Thomson (MT)	Patient Representative, Golden Jubilee National Hospital
Mark Whitbread-Jordan (MWJ)	Patient Representative, Queen Elizabeth Hospital
Paul Woodward (PWo)	Trustee, Freeman Heart and Lung Transplant Association

**IN ATTENDANCE**

Maria Climents (MCI)	Research Team Assistant, The Winton Centre
Ilan Goodman (IG)	Research Team Assistant, The Winton Centre
Lucy Newman (LN)	Secretary, NHSBT
Maria Pufulete (MP)	Senior Cardiothoracic Research Fellow, Bristol University
Phil Walton (PWA)	Project Lead, Deemed Consent – Opt Out Legislation, NHSBT

	<b>Apologies and welcome</b>	<b>Actions</b>
	RG welcomed members and thanked them for attending the meeting today. Special mention was given to EJ in recognition of her work with opt out legislation, and particularly her presentation at the recent BTS conference. RG thanked JyP, SR and LN for their contributions to the meeting and special thanks was also given to speakers invited today; PWa, MP, LF, IG and MC.	
<b>1</b>	<b>CTPG(19)01 - Declarations of interest</b> There were no declarations of interest recorded at the meeting today.	
<i>Please note that it is the policy of NHSBT to publish all papers on the website unless the papers include patient identifiable information, preliminary or unconfirmed data, confidential and commercial information or will preclude publication in a peer-reviewed professional journal. Authors of such papers should indicate whether their paper falls into these categories</i>		

<p>2</p> <p>2.1</p> <p>2.2</p> <p>2.3</p>	<p><b>CTPG(18)02 - Minutes of the CTPG Meeting held on Thursday 25/10/2018 – RG</b></p> <p><b>Accuracy</b> The minutes were approved as an accurate record of the last CTPG meeting.</p> <p><b>Action points</b> Action points raised at the last meeting will be discussed in this CTPG agenda.</p> <p><b>Any other business</b> RG invited JyP to update the group on funding for use of the OCS Heart (Organ Care System) during DCD heart retrievals. NHS England in collaboration with NHSBT have recently agreed a Joint Innovation Fund with funds initially to be used to support DCD Heart retrieval and transplantation including the OCS machine (the latter previously funded by charitable funds). The funding term is initially agreed for a period of three years. Trusts are awaiting further communication about how and when funds will be released.</p> <p>All patient representatives present were very pleased with this outcome and RG thanked all those involved and acknowledged the work of CTPG in raising the profile of OCS funding by previously writing to MPs.</p>	
<p>3</p>	<p><b>CTPG(19)03 - Opt Out Implementation Timetable – PWa</b> PWa was invited to the meeting to speak about Opt Out legislation and what it means for the population, the presentation will be circulated with the minutes of this meeting.</p> <p><b>Action: LN to circulate slideshow to group.</b></p> <p>The group asked questions after the presentation to clarify understanding on some areas of Opt Out, responses are listed below:</p> <ul style="list-style-type: none"> <li>• If no decision about whether to donate organs or which organs should be donated has been recorded on the organ donor register, when a person dies, they are considered an organ donor (previously described as deemed or presumed consent to organ donation), and families/next of kin will continue to be involved in this decision</li> <li>• Opt Out legislation applies to organs and tissues (heart, lungs, liver, kidneys, pancreas, small bowel, heart valves, corneas, skin, bone, tendons and ligaments). Organs for Rare and Novel transplants such as hands, face or uterus are not included in the Opt Out legislation</li> <li>• Marketing of Opt Out started in April 2019 using social media, the main media campaigns will start around December this year</li> <li>• Training for all 300 Specialist Nurses in Organ Donation (SNODs) and their support teams is underway, the draft Code of Practice from the Human Tissue Authority (HTA) is due for release in November and NHSE is fully committed to funding. Nursing and medical conferences will focus on conversations with families about organ donation and support will be given to SNODs and Recipient Coordinators about liaising with the Press and Media</li> <li>• Language used to talk about Organ Donation will be neutral or positive and marketing will focus on individuals making and discussing their choice about organ donation with their families and next of kin</li> <li>• The group feel that emphasis should focus equally on the recipient side of the campaign and ask those who are prepared to receive organs (should they need to) to register their choice to donate their organs too</li> <li>• It is hoped that the consent rate to organ donation (for those not having recorded their express wish) following conversations with a SNOD will be 80% as it is now in Wales following the introduction of Opt Out Legislation</li> <li>• Jersey (now going live 1<sup>st</sup> July), Guernsey and the Isle of Man plan to introduce Opt Out later in 2019/2020 and Scotland plans to introduce it late 2020</li> <li>• Consent for Organ Donation within BAME communities varies greatly between England and Wales, the presence of a higher BAME population in England is one factor</li> <li>• Families will be made aware of the decision made by their loved one in relation to organ donation, and it will still be possible for a family to decide whether their loved one should be an organ donor</li> </ul>	<p>LN</p>
<p>4</p>	<p><b>CTPG(19)04 &amp; CTPG(19)05 - LVAD for Advanced Heart Failure as Destination Therapy – MP/JyP</b> MP was invited to speak; she is a Senior research fellow at Bristol University. MP is leading a team that is bidding for an NIHR grant studying the potential use of LVAD as Destination Therapy (DT) for Advanced Heart Failure; the project is now at the second stage of the application process for approval. Feedback from the HTA following stage 1 of the application</p>	

	<p>process requested increased Patient Public Involvement (PPI) in the project to develop meaningful outcomes more fully, but PPI is not available as LVADs are not used for DT, so there is no Patient Group representing this sector of the population. The patients fitting the DT criteria most closely are those who have LVADs fitted as a Bridge to Transplantation (BTT) including those who have become ineligible for a heart transplant following the implant of the LVAD.</p> <p>Data for this project will be collected from external registries such as the National Heart Failure Audit Reviews and Analysis and will make a value-added comparison of value added between patients who have an LVAD as BTT compared those who receive usual medical care.</p> <p>Qualitative outcomes will be important to measure, for example, one member of the group commented that with an LVAD they had been able to return to work after several years which not only benefitted their confidence; but also made them feel valued in society again and they are proud to be able to contribute to the economy by working. Another commented that they had got married and also booked a cycling holiday – things they would never have been able to do before. The study involves only adults and MP is keen to hear from as many LVAD patients as possible some of whom have an LVAD fitted as BTT.</p> <p><b>Action: JyP will pass details of contacts for physicians at centres involved in the care of LVAD patients.</b></p> <p>JyP commented that while LVAD is used as DT in many countries; outcomes for patients using LVAD as DT are less favourable than in the BTT population. This is largely due to older age in the former group.</p>	JyP
5	<p><b>Patient Centre Updates</b></p> <p><b>AL – Harefield Hospital</b></p> <ul style="list-style-type: none"> <li>• The Harefield Transplant Group make and fill goodie bags every year at Christmas and Easter for patients</li> <li>• RP arranged a Comedy Gala at the London Palladium and raised a staggering £250k to help fund the use of OCS machines at Harefield</li> <li>• RP is also helping to spearhead a project called Harefield Healing Garden to create an area of 'wellbeing' in the grounds of the hospital to aid patient recuperation and recovery</li> <li>• A number of Harefield recipients will be participating in both the British Transplant Games in Newport in July and the World Transplant Games in Newcastle in August</li> <li>• A Transplant Team will also be participating in an endurance karting event to raise money in June</li> </ul> <p><b>MT – Golden Jubilee National Hospital</b></p> <ul style="list-style-type: none"> <li>• The Christmas Lunch held for patients and recipients was sadly cancelled due to building works at the venue, 120 people had been expecting to attend.</li> <li>• Contracts between patients and the hospital have been rolled out and are appreciated by patients as they give clear expectations of the service that is provided in the centre</li> <li>• Newly introduced Nurse led clinics are proving popular with patients</li> <li>• One young patient is playing football at the British Transplant Games and one patient is cycling</li> <li>• GJNH has been granted approval by the National Retrieval Group (NRG) to carry out DCD heart retrieval and transplantation. NAA will ask NHSS to clarify that funding for DCD heart transplantation will be made available in line with NHSE recent announcement to fund DCD heart transplantation</li> <li>• The transplantation service at GJNH is undergoing its 5-yearly review, patients and staff are involved</li> </ul> <p><b>LG – Queen Elizabeth Hospital</b></p> <ul style="list-style-type: none"> <li>• The team at QEH are pleased that OCS Heart will now be funded, they only have two OCS Heart consoles at present</li> <li>• Nurse led clinics will be starting in June</li> <li>• The LVAD Café has been open for about a year and is has received good feedback to date. Currently there is no psychologist available for cardiothoracic transplantation patients at QEH, but one will be appointed in due course</li> <li>• Patients from QEH will be attending the British Transplant Games and the World Transplant Games in the summer</li> </ul> <p><b>GH – Wythenshawe Hospital</b></p>	

5.1	<ul style="list-style-type: none"> <li>• The LVAD Café at Wythenshawe is a well-attended lively group but tends to be self-selecting in terms of wellbeing. Members will be focussing on making the group more accessible to those patients who need the support but feel unable to access it</li> <li>• The E-Bikes project is being scaled more appropriately to ensure it is achievable. LVAD and Heart Transplant patients are keen to support the project, some have tried the E-Bikes, and some have gone on to buy E-Bikes. GH will continue to work on the project with modest events planned for the coming year.</li> <li>• The transplant unit at Wythenshawe Hospital has had a £0.75 million refurbishment which has been greatly appreciated by patients and staff</li> <li>• 22 patients will be attending the British Transplant Games and seven will be attending the World Transplant Games</li> </ul> <p><b>DB/PW – Freeman Heart and Lung Transplant Association (FHLTA)</b></p> <ul style="list-style-type: none"> <li>• £20k has been awarded to Prof. Dark for research with organ perfusion boxes (Sherpa Pak), this project is due to run for 2 years and will involve 20 hearts</li> <li>• An award of £10k was made to the Cardiothoracic Transplant Social Worker who oversees a small budget to help patients and recipients in financial crisis with travel, accommodation and some incidental expenses to ensure that they attend appointments</li> <li>• Adele has been appointed as Vice-chair of the FHLTA and is the GB Delegate for the Transplant Games</li> <li>• Louise has been appointed as sports manager and busy working with the teams to prepare for the British and World Transplant Games later this year</li> <li>• Preparations are underway for Organ Donation Week (2<sup>nd</sup>-8<sup>th</sup> September) to attract the attention of younger generations with support from other local organisations</li> <li>• The FHLTA have developed treatment cards for members to carry with them containing contact information for the transplant team at Freeman to avoid patients from being given incorrect or unsuitable medications whilst receiving treatment within other units for unconnected medical issues</li> <li>• The FHLTA website is undergoing a huge revamp ready for its relaunch in July</li> </ul> <p><b>RG – Royal Papworth Hospital</b></p> <ul style="list-style-type: none"> <li>• After 101 years in Papworth Everard, Papworth Hospital has moved to the new Royal Papworth site on the Cambridge Biomedical Campus closer to Addenbrookes</li> <li>• The Royal Papworth Hospital Patient Group hold their social gatherings in the Papworth Everard Village Hall – the group will discuss whether the meetings should move closer to the site of the new Royal Papworth Hospital later in the year</li> <li>• Patient Group meetings are well attended with about 60-70 attendees, the Christmas meetings are attended by about 80-90 each year</li> <li>• The Royal Papworth Patient Facebook page goes from strength to strength and is popular with patients and their families. It has been very useful in identifying some of the issues that patients face allowing the committee to raise these within the unit and the Executive</li> <li>• A significant number of recipients will be participating in both the British Transplant Games in Newport in July and the World Transplant Games in Newcastle in August</li> </ul> <p><b>British Transplant Society (BTS) Conference feedback</b> EJ, Max and family, and Kiera's parents Joe and Loanna Ball (JB&amp;LB) presented Kiera and Max's story at BTS. It was an overwhelming, emotional and uplifting experience; the audience were visibly moved emotionally and gave a standing ovation.</p>	
6  6.1	<p><b>CTPG(19)06 - Heart Allocation Data – SR</b> The Heart Allocation Data report has been circulated to members, any questions should be emailed to SR – email address available from LN by request. The report uses data recorded between 26<sup>th</sup> October 2016 and 25<sup>th</sup> October 2018 and shows that sicker patients move from NUHAS to UHAS or SUHAS where are more likely to receive a heart transplant with a shorter waiting time than if they had remained registered to NUHAS.</p> <p><b>Action: SR to report on patients who have LVAD as BTT fitted at CTPG in November</b></p> <p>Within CTAGH a Heart Utilisation Sub Group has just been convened, this group will investigate the reasons for ideal donor hearts being declined and report back relevant findings to CTAG in November.</p> <p><b>Six Tier Allocation System</b> The Six Tier Allocation System aims to reduce the waiting time for the sickest patients waiting for heart transplants by splitting the UHAS to categorise patients further. This cannot be</p>	SR

6.2	<p>implemented for at least 2 years because of delays in the IT development at NHSBT. The current SUHAS is working well.</p> <p><b>CTPG(19)07 - Lung Allocation Data – SR</b> The Lung Allocation Data report has been circulated to members, any questions should be emailed to SR – email address available from LN by request. The report uses data recorded for adult lung transplantations between 18<sup>th</sup> May 2017 and 17<sup>th</sup> January 2019. Paediatric lung transplantation is not included in the data below.</p>	
6.4	<p><b>CTPG(19)08 - Review of Urgent Lung Criteria – SR</b> Data extracted covered 18/05/15 – 30/06/18 and was divided into two cohorts – one cohort 18/05/15 – 17/05/17 and 18/05/18 – 30/06/18 (pre and post introduction of the urgent and super urgent lung allocation schemes). Figs 1 and 2 show registration outcomes and median waiting times split by disease group and compared between the two periods; fig 3 shows registration outcomes and median waiting times by urgency group. The report concludes that patients with PF or CF and bronchiectasis have greater access to ULAS and SULAS both schemes have a higher chance of transplantation with a shorter median waiting time, while many PF patients unfortunately die on the waiting list.</p>	
7	<p><b>CTPG(19)09 - Transplant Centre Profiles (Infographics) – SR</b> Infographic versions of transplant centre profiles have been in development for the past year and are designed to be a patient friendly format providing basic data relating to transplants and patient outcomes at each centre. Members felt that the latest version was a significant improvement and thank SR for her efforts. Members are asked to review the infographics and any suggestions for modification to wording or content should be emailed to SR.</p> <p>It is anticipated that the Transplant Centre Profiles will go live this summer in PDF format following the production of the annual transplant report; they will be added to the ODT clinical website in due course. Members of the group also asked whether the profiles will be shared with the NHS Choices website/NHS App as it's a valuable resource.</p>	
<i>Comfort Break</i>		
8	<p><b>Project PROPhET (Perfusion and Recovery of Hearts for Transplantation)</b> Project PROPhET aims to increase the number of DBD donor hearts available for transplantation. Some DBD hearts are currently declined due to peri-transplant injury following Brain Stem Death. Royal Papworth is seeking funding from NIHR to explore the potential for using these organs if they can show sufficient recovery from perfusion techniques.</p>	
9	<p><b>Updates on Previous Agenda Items</b></p> <p>9.1 <b>Lung transplant Risk/Benefit Tool (TRAC) - LF</b> The TRAC Risk and Benefit Tool is a patient facing tool in development to assist patients when they make decisions about whether to register on a transplant waiting list. The tool will be developed for lungs and then kidneys, and will contain information relating to likely waiting time, survival, test outputs etc... This information will be shown in graphs and charts. LF and team will be visiting all transplant centres to speak to patients and clinicians about further information which would be available on the tool. The tool once developed will be available online and offline to help conversations when the patient has left the clinic.</p> <p>9.2 <b>DCD Heart Programme</b> See the update on funding for OCS given under item 2.3</p> <p>9.3 <b>Heart Transplant/LVAD Tariff Review</b> The Heart Transplant Tariff is under review by NHSE. CTAG will update CTPG when this work has been completed.</p> <p>9.4 <b>Scouting Funding</b> Unfortunately, there is no funding available at present to support Cardiothoracic Scouting, so this item will be removed from the agenda until further notice.</p> <p>9.5 <b>Donor Utilisation Initiatives</b> The Lung Utilisation Group (led by JD) met and considered data relating to ideal donor lungs that were declined during a two-year period. Despite best efforts from all centres, lung utilisation rates have not significantly increased. The Lung Utilisation group meetings will not be convened until further notice.</p>	

9.6	<p>A Heart Utilisation Group (led by AR) has recently been convened to identify ideal donor hearts and investigate decline rates and reasons once the Ideal Donor Heart criteria has been identified, it is due to meet on Thursday May 16<sup>th</sup>.</p> <p><b>Older Lung Donors</b> CTAGL recently agreed to start offering donor lungs from older donors to make more lungs available for transplant. Older donor lungs ≥75 yrs (non-smoker/ceased smoking ≥10yrs ago) will continue to be offered. So far there have been three instances where older donor lungs have been used in transplantation.</p>	
10	<p><b>Any Other Business</b></p> <p>Work is underway on the Patient Information Booklets, which are given to patients as they consider registration to transplant waiting lists. National consent leaflets are also in development, and these will be used in addition to locally based leaflets. AL shared the Harefield Patient Information Booklet with RG for Royal Papworth and will share with other members if required.</p> <p>DP asked if there was an App which could manage and update personal information held for patients as he was developing one himself; this could involve Bluetooth connection to medical equipment such as the Spirometer to record accurate and up to date health information which specialists would be able to monitor.</p> <p><b>Action: RG advised he was aware Royal Papworth had looked at something similar a few years ago and would try and find more details for DP</b></p> <p>MWJ raised concern that physiotherapy at the point of rehab from a transplant is limited and access to physiotherapy outside transplant centres is difficult to access for many patients as post-transplant care within the wider community is not well provisioned. AE recommended looking at <a href="https://www.pactster.com/">https://www.pactster.com/</a> a paid website for CF patients offering online classes to follow for fitness and rehab inspiration and education on how to stay healthier. However, there is no transplant section on this website currently. DP commented that this is something he hopes will be included within his app in due course.</p>	RG
<p><b>Date of next meetings</b></p> <p><b>CTAGH Hearts</b> – Wednesday 11<sup>th</sup> September 2019 – 1100-1600 @ Venue TBC</p> <p><b>CTAGL Lungs</b> – Thursday 26<sup>th</sup> September 2019 – 1100-1600 @ Venue TBC</p> <p><b>CTAG Patient Group</b> – Monday 11<sup>th</sup> November 2019 – 1230-1600 @ Venue TBC (Sandwich Lunch 1200-1230)</p>		