

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

**MINUTES OF THE EIGHTH CARDIOTHORACIC PATIENT GROUP MEETING  
HELD ON MONDAY 12<sup>TH</sup> NOVEMBER 12:30-16:00 AT THE OLD LIBRARY, CiARB, 12  
BLOOMSBURY SQUARE, LONDON WC1A 2LP**

**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
Nawwar Al-Attar (NAA)	Heart surgeon, Golden Jubilee National Hospital
Rebecca Allen (RA)	Representative for Heart Transplant Families UK
Janet Atkins (JA)	Patient Representative, Governor, Royal Papworth Hospital
Debbie Burdon (DB)	Patient Representative, FHLTA, Freeman Hospital
Chris Callaghan (CC)	Chair of NHSBT Kidney Advisory Group
Anna Evans (AE)	Representative for Cystic Fibrosis Trust
Leila Finikarides (LF)	Research Assistant, The Winton Centre
Margaret Harrison (MH)	CTAG Lay Member Representative
Ged Higgins (GH)	Patient Representative, Wythenshawe Hospital
Emma Johnson (EJ)	Max's Law Advocate, Heart Transplant UK Facebook Support Group
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
James Maund (JM)	Patient Representative, Queen Elizabeth Hospital
Jane Nuttall (JNu)	Recipient Transplant Coordinator, Wythenshawe Hospital
Rochelle Pointon (RcP)	Cardiothoracic Transplant Coordinator, Queen Elizabeth Hospital
Rosie Pope (RsP)	Parent of Transplant Recipient, Harefield Hospital
Sally Rushton (SR)	Senior Statistician, NHSBT
Lucy Ryan (LR)	Transplant Recipient, Royal Papworth Hospital
Michael Thompson (MT)	Patient Representative, Golden Jubilee National Hospital
Mark Whitbread-Jordan (MWJ)	Patient Representative, Queen Elizabeth Hospital

**IN ATTENDANCE**

Lucy Newman (LN)	Secretary, NHSBT
------------------	------------------

**APOLOGIES**

Robert Hall (Cardiomyopathy Association), Richard Quigley (Recipient Coordinator, Royal Papworth), Allison Thompson (Cardiomyopathy Association), Mike Thompson (NHSBT Comms)

Item		Action
	<p><b>Apologies and welcome</b> RG welcomed the members and thanked them for attending the meeting today. Congratulations to EJ for Max collecting his Pride Of Britain Award and the promotional work he is doing towards raising awareness of Max's Law on Deemed Consent to Organ Donation. RG thanked SR for statistical support and LN for administrative support.</p>	
1	<p><b>Declarations of interest</b> There were no declarations of interest at the meeting.</p>	
2	<p><b>Minutes of the meeting held on Tuesday 5<sup>th</sup> June 2018</b></p>	
2.1	<p><b>Accuracy</b> Section 8.1 of the minutes from the last meeting (5<sup>th</sup> June 2018) should read: To date 57 DCD heart transplants have been carried out - 6 at Wythenshawe, one at Freeman; Freeman are trained and ready to embark on the DCD hearts programme in future.  This amendment has been completed and the minutes can now be approved as an accurate record of the last meeting.</p>	
2.2	<p><b>Action points</b> All action points raised at the last meeting will be discussed in the CTPG Agenda</p>	

2.3	<p><b>Any other business</b>          Tariff for cardiothoracic transplantation          NHS England is currently reviewing the tariff for cardiothoracic transplantation, JyP and RG are both involved with this work. It's unlikely that any additional funding will be released due to the review, but current levels of funding may be redistributed within the transplantation process.</p>	
3	<p><b>Patient involvement and the time of deceased organ offering</b>          NHS Policy for patients is No Decision About Me Without Me. For this reason, Chris Callaghan (CC) NHSBT Organ Utilisation Lead is currently working on a project to understand whether patients would prefer to be contacted when a potentially matching organ is offered, or only when an exact organ match is found. Discussion took place about the consent forms completed by the recipient when they are first registered to the waiting list, these forms enable patients to specify the quality of organ they are willing to accept – e.g. lungs from a donor who has smoked in their past.</p> <p>Organ recipients in the group felt that being contacted every time there is a potential organ offer for them would be extremely emotive, but that they would like to know, perhaps annually, about potential offers that had been received by the unit for them, as this would reassure them that offers are being made, that they are on the list, and that their surgeon has their best interests in mind.</p>	
4	<p><b>For Information:</b>  <b>Annual Report on Cardiothoracic Organ Transplantation 2017/2018</b>          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><b>ACTION: SR will review the geographical analysis and consider including several years combined. SR will also consider other comments on the data for future reports.</b></p>	SR
5	<p><b>Patient Centre Updates</b>          Each of the Cardiothoracic Transplant Centre Patient Groups was set up primarily to offer information and support and a forum for pre and post-transplant patients and their families. Patient groups share ideas and resources and offer additional support to that provided by the hospital. Each group is invited to give an update on activity. Representatives from all transplant units were present today.</p> <p><b>Harefield Hospital</b> <b>Alan Lees</b></p> <ul style="list-style-type: none"> <li>• Harefield Hospital hosted the annual patient reunion 19<sup>th</sup> – 21<sup>st</sup> October which was very well attended</li> <li>• A Cake and Craft evening is planned for 29<sup>th</sup> November</li> <li>• Harefield transplant recipients traditionally receive a pin on the 1 year, 10 years, 20, 25 and 30-year transplant anniversaries, one patient has just celebrated the 35 year anniversary of their transplant, and several patients celebrated being 34 years post-transplant in 2017</li> <li>• The GB Transplant Games was well attended, competitors brought home 3 gold, 15 silver and 9 bronze medals between them</li> </ul>	

- The 100 Hearts Comedy Charity Gala will be held at the London Palladium on Wednesday 13<sup>th</sup> February 2019, tickets are available to purchase from the box office
- AL has stepped down as Harefield Transplant Club Committee Secretary but will continue to attend the Cardiothoracic Patient Group Meetings

**Golden Jubilee National Hospital      Michael Thompson**

- The Christmas Lunch for Heart Transplant and Kidney Transplant patients will be held on December 14<sup>th</sup> 2018
- One of the GJNH patients won a medal for cycling
- A local artist is exhibiting to celebrate the transplant anniversary milestone
- Transplant patient contracts have been developed, which establish the expectations of the patient and the hospital
- A nurse led transplant clinic is now open which is run by patients for patients, and offers an open forum for conversations and to discuss concerns, care plans etc...

**Queen Elizabeth Hospital      James Maund/Mark Whitbread-Jordan**

This was the first time that patients from Birmingham had been present at the CTAG Patient Group. A Birmingham L-VAD Patient Support Group will start in December 2018.

**Wythenshawe Hospital      Ged Higgins/Beverley Jones**

- Attendance at the L-VAD café is good
- GH has a meeting lined up with the Cycling Commission to request a 2.5k grant to purchase electric bikes for patients to have the experience of cycling again.
- An L-VAD passport of useful and important information is being developed for L-VAD patients and an App is also in development

**Freeman Hospital      Adele Lambert/Debbie Burdon**

- Due to the sad passing of Joan Whitney, a new secretary for the FHLTA Committee is currently being sought
- FHLTA sponsors the Joan Whitney Trophy which could be awarded to newcomers or for acts of kindness. A Memorial Bench and Tree is also planned in honour of Joan
- The Freeman Heart and Lung Transplant Association (FHLTA) held their 30 years anniversary dinner in 2017
- Funding has been provided for the hospital to employ a Junior Doctor for the Lung Transplant Clinic
- FHLTA sponsored two nurses and three doctors to attend the 2018 NICE Conference
- £5k has been released to John Dark to work in collaboration with a company in Sweden providing organ transportation boxes.
- £30k grant has been awarded for Research into Organ Rejection
- 19 patients entered the Heart and Lung Transplant Games in Italy last summer and 37 patients entered the British Transplant Games
- Eight patients are planning to attend the World Transplant Games
- Adele Lambert is the GB Advocate for the Heart and Lung Transplant Championships
- Several upcoming events are planned, including the Christmas Dinner in a few weeks' time and social events enabling members to network and share experiences
- Derek Airey was awarded an Unsung Heroes Award for his 25years service

**Royal Papworth Hospital      Rob Graham**

- The patient group at Royal Papworth meet every quarter, meetings are well attended and good for networking and sharing experiences, providing social support to pre and post-transplant patients
- Often patients travel some distance to attend the group, pre-transplant patients particularly enjoy the meetings to meet others
- The Group was recently featured on a BBC news programme
- Its team won best Heart & Lung centre at the GB Transplant Games and several members are going to the WTG in Newcastle next year.
- Royal Papworth Hospital is due to move to its new site in May 2019

<p><b>6</b> <b>6.1</b></p>	<p><b>Communicating Risk and Consent</b> <b>Transplant Centre Profiles – update</b></p> <p>The Infographic provided by SR is in its first draft, feedback has been received from CTPG and from centres. The infographic provides centre specific summaries for each organ at each centre and will provide information about pre-transplant waiting times and outcomes, and about post-transplant outcomes at 30 days, 90 days and five years. In time, the documents will be available on the ODT website and at centres and will provide transparency to patients before they decide where they would like to receive treatment.</p>	
<p><b>6.2</b></p>	<p><b>Transplant Risk/Benefit Tool (TRAC)</b></p> <p>Patients have reported that existing forms and information given can be wordy and confusing. A new tool is in development to improve the way that the risks of transplant are communicated and consented to by patients, the tool - TRAC (Transplant Risk/benefit Assessment and Communication) is being developed by the Winton Centre. Initially the tool will be rolled out for Lungs with Livers and Kidneys to follow as the next organs. LF is currently visiting all transplant units and obtaining transcripts of conversations to establish content requirements for the tool, and it is hoped that the tool will be available for use in about 12-18 months' time.</p> <p>It is intended that the tool will be used by clinicians during patient consultations. It will also be available to patients to use after their consultation, to find out more about their chances of survival from their current condition compared to the likely outcome from receiving a transplant, and to share information with their family, during the decision-making process when they are considering their treatment options.</p> <p>RG reminded the group that there is detailed statistical information about pre and post-transplant outcomes on the ODT website. <a href="https://www.odt.nhs.uk/">https://www.odt.nhs.uk/</a> This information is on an average basis, and so the TRAC tool will offer more patient-tailored statistical information.</p>	
<p><b>7</b></p>	<p><b>DCD Heart Update</b></p> <p>DCD heart activity has increased the number of donor hearts available for transplantation.</p> <p>Royal Papworth reported using DCD hearts in those on the non-urgent list as well as those on the urgent and super urgent lists. 10 years ago, 45% of heart transplants were carried out on urgent patients, but now approximately 80% of heart transplants are for those who are registered as urgent or super urgent patients. Members of the group asked why centres can't do more DCD heart transplants; it was explained that the prohibitive costs associated with using OCS machines remains a significant reason.</p> <p>DCD heart transplantation requires the use of OCS, which has never been funded by NHSBT or NHS England (NHSE) despite OCS costing substantially less than LVAD implantation. The use of OCS is only funded by charitable donations. 1 LVAD implantation is cost equivalent to 5 uses of OCS, LVAD implantation and transplantation are both activities funded by NHSE. NHSE and NHSBT have appealed to the Department of Health for them to fund DCD hearts but this has been declined.</p> <ul style="list-style-type: none"> <li>• Royal Papworth has carried out &gt;50 DCD heart transplants</li> <li>• Manchester has carried out &gt;7 DCD heart transplants and has secured charitable funding from the hospital trust for three more</li> <li>• Harefield has carried out &gt;10 DCD heart transplants and raises separate funding to cover the costs of using OCS in every heart transplant, DCD and DBD alike</li> <li>• Newcastle have been signed off to conduct DCD heart retrievals</li> <li>• Glasgow has secured funding from the hospital trust for three OCS machines</li> </ul> <p>Birmingham and Great Ormond Street have yet to embark upon DCD heart transplantation, largely due to funding.</p>	
<p><b>8</b></p>	<p><b>Scouting Service – Update</b></p> <p>The Scout Pilot was introduced five years ago to maximise the chances of organ donors producing ideal hearts and lungs for transplant. An external review was carried out which found that Scouting is successful, so a working group was set up to see if a lower cost model could be delivered. It is anticipated with the new model that 70% of cardiothoracic organ donors could be Scouted, reducing the overall cost of Scouting by approximately 50%; the business case for this will be presented to NHSBT Senior Management Team in December.</p>	
<p><b>9</b></p>	<p><b>Heart Allocation Proposal – update</b></p>	

	<p>CTAG convened the Heart Allocation Sub-Group (HASG), to review the heart allocation policy and decide how to stratify patients in the Urgent waiting list into different levels of severity.</p> <p>HASG proposed a new 6 tier Heart Allocation Scheme, under the new allocation scheme, tier 1 would be Super Urgent, tiers 2-4 would be urgent and tiers 5 and 6 would be non-urgent. The new scheme will be taken to the Transplant Policy Review Committee (TPRC) for approval and will take a further two years to implement within the NHSBT IT workplan.</p>	
<b>10</b>	<p><b>Increased Donor Utilisation Initiatives - update</b></p> <p>Organ utilisation rates vary by unit and by organ; however, in the UK the percentage of donor organs utilised for transplantation is poor when compared to other countries. Whilst there are issues surrounding the data, we know how many organs are offered, so we can determine utilisation rates from this. In response to this, JD set up the Lung Utilisation Sub-Group which identifies lungs which should have been utilised in transplantation but weren't. Telecons are arranged to discuss each individual donor organ to establish the reasons for non-use of the organ and encourage weekly centre specific reviews of transplantation activity.</p> <p>CC leads on a similar organ utilisation project within kidney transplantation, identifying suitable donor kidneys which are then unused, writing to Centre Directors to establish why the organ had been declined. While it is time consuming to set up, it is hoped it will drive centres to improve their organ utilisation rates, by bringing more cautious surgeons to similar standards as those more experienced and confident surgeons.</p> <p>Aaron Ranasinghe has been appointed to lead on Heart Utilisation; John Dark continues to be the lung utilisation lead till March 2019.</p>	
<b>11</b>	<p><b>Any other business</b></p> <p>NHSE is in favour of measuring Quality of Life (QoL), but every patient would need to be monitored throughout their life, recording psychological and physiological wellbeing. Centres are starting to measure QoL which will be a lengthy process but valuable to those awaiting transplants to see information about outcomes. QoL would be monitored and reported by the centre completing the transplant – so in the case of a patient receiving a transplant in a paediatric centre at age 15, despite their care transferring to an adult centre at the age of 18, the QoL would still be followed up by the paediatric centre. If the patient was re-transplanted as an adult, QoL would be followed up by the re-transplanting centre, patients only ever receive one recipient number so tracking would be straightforward.</p> <p>EJ presented an update on the progress of Max's Law (Organ Donation (Deemed Consent)), the Bill is due for the second reading at the House of Commons on 23/11/18. It is anticipated that the Deemed Consent Bill will be passed in Spring 2019.</p>	
<b>13</b>	<p style="text-align: center;"><b>Date of next meetings</b></p> <p style="text-align: center;">CTAGL Lungs – Wednesday 20<sup>th</sup> March 2019, CTAGH Hearts – Thursday 28<sup>th</sup> March 2019 CTPG Cardiothoracic Patient Group – Monday, 13<sup>th</sup> May 2019 CTAGH Hearts – Wednesday 11<sup>th</sup> September 2019, CTAGL Lungs – Thursday 26<sup>th</sup> September 2019 CTPG Cardiothoracic Patient Group – Monday, 11<sup>th</sup> November 2019</p>	