

**NHS BLOOD AND TRANSPLANT  
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE  
MEETING OF THE  
NHSBT CARDIOTHORACIC PATIENT GROUP  
ON MONDAY 5<sup>TH</sup> JUNE 2017, 13:00 – 16:00  
AT THE ROYAL COLLEGE OF OPHTHALMOLOGISTS,  
18 STEPHENSON WAY, LONDON, NW1 2HD**

**PRESENT:** Mr R Graham (**Co-Chair**), **Patient Representative, Governor, Papworth Hospital**  
Mr S Tsui, Co-Chair, CTAG Chair, Consultant Cardiothoracic Surgeon, Papworth  
Prof N Al-Attar, Heart Surgeon, Golden Jubilee National Hospital  
Ms J Atkins, Patient Representative, Papworth Hospital  
Ms A Evans, Cystic Fibrosis Trust  
Mrs M Harrison, CTAG Lay Member Representative  
Mr G Higgins, Patient Representative, Wythenshawe/UHSM

Mr A Lees, Secretary, Harefield Hospital Transplant Club  
Ms A Mitchell, Deputy for Ms L Logan, Regional Manager, Organ Donation  
Services, NHSBT  
Ms J Nuttall, Cardiothoracic Recipient Co-ordinator, Wythenshawe Hospital  
Mrs R Pope, Relative of transplant patient, Harefield Hospital  
Miss S Rushton, Statistician, Statistics and Clinical Studies, NHSBT  
Mr M Thomson, Patient Representative, Golden Jubilee Hospital

**IN ATTENDANCE:** Mr Zeeshan Asghar, Partnerships Manager, NHSBT Communications  
Mrs Kathy Zalewska, Secretary, Clinical and Support Services, ODT, NHSBT

**APOLOGIES:** Mrs R Allen, Heart Transplant Families UK  
Dr N Banner, Cardiologist, Harefield Hospital  
Dr M Carby, Lung Physician, Harefield  
Mrs K Graham, Transplant Support Group, Papworth  
Ms B Harpham, National Director, Heart Research UK  
Ms P Hartley, Transplant Support Group, Papworth  
Mrs J Jones, Policy Adviser, Cystic Fibrosis Trust  
Mrs C Kissick, British Heart Foundation  
Mr K Mashford, Patient, Freeman Hospital  
Sinead Wright, NHSBT Communications  
Mr J Williams, Patient Representative, Wythenshawe Hospital  
Mr S Williams, Heart UK – the Cholesterol Charity  
Ms J Whitney, Treasurer, Freeman Heart and Lung Transplant Association  
Mr J Williams, Patient Representative, Wythenshawe/UHSM

	<b>Welcome</b>	<b>ACTION</b>
	R Graham welcomed new participants to the Group and asked members to introduce themselves.	
<b>1</b>	<b>Declarations of Interest in relation to the agenda – CTPG(17)01</b>	
	There were no declarations of interest in relation to the agenda.	
<b>2</b>	<b>Minutes of the meeting held on Thursday 17<sup>th</sup> November 2016 – CTPG(M)(16)2</b>	
2.1	<b>Accuracy and Approval</b>	
	The minutes of the last Cardiothoracic Patient Group Meeting held on 17 <sup>th</sup> November 2016 were approved as an accurate record.	
2.2	<b>Action points - CTPG(AP)(16)2</b>	

	<p>AP1 – As part of work looking into potential barriers to transplantation, feedback had been sought from transplant centres on whether they had the capacity and resources to deal with the increased numbers of transplants resulting from an increase in the number of organ donors. Transplant centres receive a marginal cost (tariff) per transplant but this does not reflect the true marginal cost to the transplant centre. Additional costs are incurred by Trusts when the recipient needs to remain in hospital meaning centres tend to take on lower risk cases. Members felt that this negative incentive should be challenged and R Graham agreed to draft a letter for members to send to lobby their local MP. S Tsui explained to members the different ways in which transplants and transplant related treatments are funded. Some specialist services are reimbursed fully for the cost, ie respiratory ECMO service. This is reimbursed on a daily tariff which means that the centre receives funding for the number of days the patient remains on ECMO. The VAD service (bridge to transplant) is funded differently, as NHS England fund the cost of the device and pay a fixed tariff for treating the patient. If paid on a daily tariff there is less incentive for centres to improve outcomes and reduce complications. By sharing risk there is some pressure on trusts to improve their performance.</p> <p>AP2 The newsletters circulated by both Papworth and Harefield had been shared with Wythenshawe as requested.</p> <p>AP3 – ODT Statistics Reports: Refer to minute 5.1.</p> <p>AP4 – Campaigns: Refer to minute 5.</p>	<b>R Graham</b>
2.3	<b>Any other business agenda items</b>	
	There were no further matters arising.	
<b>3</b>	<b>Patient Group Updates</b>	
	<p>Members gave a brief summary of recent patient group activities and events</p> <p><b><u>M Thompson – Golden Jubilee National Hospital, Glasgow</u></b></p> <ul style="list-style-type: none"> <li>• Very successful meeting on group's 25<sup>th</sup> anniversary.</li> <li>• Negotiating with the Trust's communications department on the development of a hospital newsletter.</li> </ul> <p><b><u>A Lees – Harefield Transplant Club, Harefield Hospital</u></b></p> <ul style="list-style-type: none"> <li>• Donated funding to a genetics programme at Harefield as well as for 3D printing at the Royal Brompton Hospital.</li> <li>• Working with Great Ormond Street Hospital on patient transition to Harefield Hospital.</li> <li>• Talks to local schools/businesses re organ donation awareness.</li> <li>• Other activities included Tough Mudder and Rat Race</li> </ul> <p><b><u>J Nuttall – Wythenshawe Hospital, Manchester</u></b></p> <ul style="list-style-type: none"> <li>• Wythenshawe celebrated 30 years of transplants in April with afternoon tea at a local hotel and a service at Manchester Cathedral.</li> <li>• Prof Yonan, previous transplant centre director at Wythenshawe, retired recently; the new director is Mr Venkateswaran. An education meeting was held at a hotel in Manchester followed by a retirement celebration for Prof Yonan.</li> <li>• Fund raising events – open day celebration, countryside day, staff taking part in a 10k run.</li> </ul> <p><b><u>R Graham – Transplant Support Group, Papworth Hospital</u></b></p> <ul style="list-style-type: none"> <li>• Meetings are held quarterly with a growing number of people attending.</li> <li>• The Facebook page is working and active.</li> <li>• The new hospital is at the forefront of everyone's minds as it is now less than 12 months away.</li> <li>• A Papworth patient who received a heart transplant 8 years ago is walking around the coast of Great Britain in aid of the British Heart Foundation.</li> </ul> <p>R Pope explained that as part of her work for the Royal Brompton &amp; Harefield charity an</p>	

	entertainment event is held every 2 years. In order to reach as many people as possible members were asked for ideas on how to access the currently untapped resource of alumni at hospitals as data protection prevented charities from contacting patients. The suggestion of using Facebook had its limitations as many groups are private or posts can only be read by members. The best solution appeared to be to give patients a letter containing details of the charity on admission to hospital.	
4	<b>Organ Donation Week/ Re-Branding Evaluation</b>	
	As requested at the previous meeting, a member of the NHSBT Marketing Team, Z Asghar, presented an evaluation of progress on the 'Yes I Donate' Organ Donation Behaviour Change Campaign' together with an update on the progress of Organ Donation Week. In response to a query on how NHSBT measures the attractiveness of these campaigns it was noted that campaigns such as Organ Donation Week have specific links which can be tracked and measured. An update on activity over the past six months on the Behaviour Change Strategy was also received.	
5	<b>Transplant Activity</b>	
5.1	<b>Transplant Centre Dashboards – CTAGS(17)07</b>	
	The majority of reports produced currently are directed at transplant centres as they are clinically focused. Members received a paper giving two examples of reports which could be used to make information on organ donation and transplantation more accessible for patients and members of the public. It is envisaged that the final report would be more patient focused and would include metrics relevant to patients. Members were asked to email S Rushton with their feedback on the metrics contained within the reports.	
5.2	<b>Recent Developments in Cardiothoracic Transplantation – CTPG(17)02</b>	
	<ul style="list-style-type: none"> <li>• S Rushton gave a presentation on recent developments in cardiothoracic transplantation including:</li> <li>• An overview of the UK heart and lung transplant programmes</li> <li>• UK lung transplant list outcomes</li> <li>• Changes in the organ allocation sequence and zones</li> <li>• Scouting and DCD hearts</li> <li>• National Organ Retrieval Service (NORS)</li> </ul>	
5.3	<b>Recent Decline in Lung Transplant Activity – CTAGL(17)05</b>	
	Members received a paper from S Rushton outlining the recent decline in lung transplant activity. From January to September 2016 lung transplant activity was particularly low but from October to December 2016 activity increased to normal figures. In April 2017 two new tiers were introduced for adults and paediatrics (super-urgent lung and urgent lung) due to concerns about patients dying on the lung waiting list.	
6	<b>Allocation Work</b>	
6.1	<b>Super-Urgent and Urgent Heart Allocation Schemes – summary since October 2016 – CTAGH(17)05, CTAGH(17)09</b>	
	Members received the revised Heart Allocation Policy and a paper summarising the super-urgent and urgent heart allocation schemes since implementation/changes. It was noted that since the changes the new system of donor heart allocation appears to be working well.	
6.2	<b>Super-Urgent and Urgent Lung Allocation Schemes Update – CTAGL(17)07</b>	
	Members received the revised Lung Allocation Policy detailing the revisions to incorporate changes to the existing lung allocation scheme and introduction of the new super-urgent and urgent allocation schemes, including the rules for accepting one lung in a bilateral lung offer.	
6.3	<b>Heart and Lung Allocation Zones – CTAGS(17)12</b>	
	A paper summarising zonal boundary changes separating allocation zones into heart zones and lung zones, which was presented to CTAG, was received for information.	
7	<b>DCD Heart Update</b>	

	<p>S Tsui updated the meeting on progress with DCD heart transplants. Donor families are approached when the local transplant centre is active in DCD heart retrieval, therefore until now only hospital in the Harefield and Papworth retrieval zones were approaching families of potential DCD heart donors. Wythenshawe is now also consenting recipients for and retrieving DCD hearts. An arrangement has been put in place for any DCD hearts that cannot be used by the zonal centre will be offered to the other two active centres in rotation.</p> <p>If requests are received for DCD heart donation from families in other zones and the SNOD is able to support the donation then NHSBT has agreed to facilitate these requests by allowing SNODs to take consent and by providing transport for one of the three active DCD heart teams as per a DBD donor. Currently all three centres are funding DCD heart retrieval through charitable donations. NHSBT applied to the four Health Departments for funding but this was declined due to cost. The current arrangements are not sustainable due to the additional support required within the transplant centre. Patient representatives expressed their disappointment at this outcome and felt this issue was also worthy of lobbying MPs per Item 2.2. Patient reps to reflect on best way of drafting MP letter given the two issues highlighted, although both funding related, are quite distinctive.</p>	R Graham
<b>8</b>	<b>Upper age limit for Lung Donation – CTAGL(17)12, CTAGL(17)12b</b>	
	Members noted that a proposal submitted to CTAG recently to raise the upper age limit for lung donation to age 75 for both DCD and DBD (but only for known non-smokers) was recently agreed. This will be implemented in due course.	
<b>9</b>	<b>NORS implementation update</b>	
	In April 2016 changes were made to the National Organ Retrieval Service in shadow form and became fully commissioned from July 2016. No donors have been lost since the new arrangements were introduced, mainly due to the inclusion of an additional non on-call system with agreed triggers.	
<b>10</b>	<b>Scout update – CTAGS(17)02</b>	
	The External Review of the scout project was carried out and the report was circulated this week. The review was supportive of the project and recommended that this should be built into business as usual. NHSBT is supportive of implementation and work will take place looking at how to implement this as a fully commissioned service.	
<b>11</b>	<b>ODT Website Development</b>	
	The website is currently being migrated across but issues are being experienced which mean that any new material is being held until these have been resolved. However, any urgent additions are being added as and when appropriate.	
<b>12</b>	<b>Any Other Business</b>	
	There were no further items of business.	
	<b>Date of next meeting</b>	
	The next meeting is scheduled to be held on Monday, 16 <sup>th</sup> October 2017 from 12.30 pm at West End Donor Centre 26 Margaret Street, London.	