

**NHS BLOOD AND TRANSPLANT  
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE  
MEETING OF THE  
NHSBT CARDIOTHORACIC PATIENT GROUP  
ON THURSDAY 17<sup>TH</sup> NOVEMBER 2016, 12:30 – 16:00  
AT THE INTAVENT SUITE, ASSOCIATION OF ANAESTHETISIS, 21  
PORTLAND PLACE, LONDON, W1B 1PY**

**PRESENT:** Mr R Graham (**Co-Chair**), Patient Representative, Governor, Papworth Hospital  
Mr S Tsui, Co-Chair, CTAG Chair, Clinical Lead for Transplantation, Papworth  
Prof N Al-Attar, Heart Surgeon, Golden Jubilee National Hospital  
Ms J Atkins, Patient Representative, Papworth Hospital  
Mr N Banner, Heart Surgeon, Harefield Hospital  
Ms A Evans, Cystic Fibrosis Trust  
Mr G Higgins, Patient Representative, Wythenshawe/UHSM  
Ms J Jones, Policy Advisor, Cystic Fibrosis Trust  
Mrs C Kissick British Heart Foundation  
Mr A Lees, Secretary, Harefield Hospital Transplant Club  
Ms J Nutall, 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 Thompson, NHSBT Communications  
Mr M Thomson, Patient Representative, Golden Jubilee Hospital  
Ms J Whitney, Treasurer, Freeman Heart and Lung Transplant Association  
Mr J Williams, Patient Representative, Wythenshawe/UHSM  
Ms J Withington, Heart Transplant Social Worker, Wythenshawe Hospital

**IN ATTENDANCE:** Miss Lucy Newman, Secretary, Clinical and Support Services, ODT

**APOLOGIES:** Mrs R Allen, Heart Transplant Families UK  
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  
Mr M Knight, CTAG Lay Member Representative  
Mr K Mashford, Patient, Freeman Hospital  
Dame J McVittie, CTAG Lay Member Representative  
Ms H O'Shea, External Affairs Manager, Communications, NHSBT  
Mr S Williams, Heart UK – the Cholesterol Charity

1	Apologies and welcome	ACTION
	The Chair welcomed new members to the group.	
2	Declarations of interest in relation to the agenda – <b>CPG(16)1</b> <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>	
	The Declaration of Interest form will be added to the agenda as a standard item	
3	Minutes of the meeting held on Monday 9 <sup>th</sup> May 2016 – <b>CPSG(M)(16)1</b>	
	3.1 Accuracy and Approval	
	The minutes of the last Cardiothoracic Patient Group Meeting held on 9 <sup>th</sup> May were approved as an accurate record of the meeting.	

4	Action points - <b>CPG(AP)(16)1</b>	
(1)	Parliamentary Question: R Graham noted that a follow up to the question to Parliament on ITU beds sponsored by the CF Trust had yet to be tabled and sought feedback from the group as to the next steps. S Tsui advised that, over the next two months, Professor J Forsythe would be liaising with all UK transplantation units, investigating whether they have capacity and resources to deal with increased transplantations in the event there is a material increase in organ donors which will give greater insight into potential barriers to transplantation. Once this work has been completed, R Graham and S Tsui will discuss the appropriateness of any follow up question to Parliament. J Jones confirmed the CF Trust would be happy to become involved and find a suitable MP to sponsor any possible question.	<b>R Graham S Tsui</b>
(2)	Patient Group Issues: H O'Shea shared the link with members to give access to new printed materials for Organ Donation Week (5 <sup>th</sup> /11 <sup>th</sup> Sept 2016). The template form was circulated with the minutes of the last Patient Group Meeting	
(3)	NORS Review: to be discussed during the meeting at Item 8 - <b>CPG(16)3 (CTAG(16)S22)</b>	
(4)	Transplantation Activity: latest statistics – copies of the latest statistics data has been circulated to members. Contact details for NHS England were sent to R Graham in relation to the Heart, Lung and Paediatric Transplantation Service Specifications	
5	Other matters arising, not separately identified An evaluation of Organ Donor Week and views on the rebranding was requested	
6	<p>Patient Group Updates from centre representatives</p> <p>Members gave a brief summary of recent patient group activities and events</p> <p style="text-align: center;"><b><u>J Whitney – Freeman Heart and Lung Transplant Group, Newcastle</u></b></p> <p>A May Ball was held in Gosforth to raise awareness of Organ Donation, and was attended by over 200 people. Families and Friends of transplant patients were all invited, they paid £18 per head and transplant patients didn't have to pay. One of the band members who played was an organ recipient himself.</p> <p>We supported the British Transplant Games in Liverpool in July.</p> <p>In August the group raised awareness of Organ Donation and the Organ Donor Register with members running stalls at different events:</p> <ul style="list-style-type: none"> <li>• Summer Gala – members ran a stall to raise awareness and members of the public were encouraged to sign up to the Organ Donor register.</li> <li>• Tall Ships Race – members ran a stall to raise awareness of the Organ Donor Register and encouraged the public to sign up. This event alone gained 600 extra signatures on the Organ Donor Register.</li> </ul> <p>Organ Donation Week in September coincided with Fresher's week, and members ran a stall at Newcastle University for three days to encourage students to sign up. Members also ran stalls at Freeman Hospital and in the local Marks and Spencer's.</p> <p>Next Saturday members will meet for the annual Christmas Lunch</p> <p>Members have also written a book to raise funds called 'A Second Chance' which has been written collectively by pre and post-transplant patients.</p> <p>In total, members of the Freeman Heart and Lung Transplant Group encouraged over 1100 additional sign ups to the Organ Donor register</p> <p style="text-align: center;"><b><u>M Thompson – Golden Jubilee National Hospital, Glasgow</u></b></p> <p>This year is the 25<sup>th</sup> Anniversary of Heart transplantation in Scotland. A good turnout is expected for the 25<sup>th</sup> Anniversary of Organ Transplantation Celebration on 9<sup>th</sup> December; over</p>	

120 people attended the last anniversary celebration.

N Al Attar requested that members kindly follow the link as the Golden Jubilee National Hospital attempts to break the Guinness World Record for the largest online photo album of people making a heart-shaped hand gesture. Please click here for more info:

<http://www.nhsgoldenjubilee.co.uk/donations/heart25>

### **A Lees – Harefield Transplant Club, Harefield Hospital**

In July Harefield supported the British Transplant Games in Liverpool and also the European Transplant Championships

During Organ Donation Week in September, members ran fundraising events and hosted a stall to raise awareness at Harefield Hospital

Members hosted a Transplant Reunion Weekend, raising awareness of Organ Donation

Harefield Transplant Club has been actively promoting itself to members of the Royal Brompton Hospital as there are increasing numbers of patients waiting for or undergoing transplants, in particular younger CF patients.

J Jones commented that it can be difficult for people with CF to access support groups in person due to cross infection and communication should take other forms than face to face e.g. social media.

### **G Higgins – Wythenshawe Hospital Transplant Support Group, Manchester**

2016 marks the 30<sup>th</sup> anniversary of the first heart transplant in Manchester and this is to be celebrated with a ceremony at Manchester Cathedral.

Wythenshawe has adopted several measures of Best Practice from Golden Jubilee National Hospital in Glasgow, and is now keen to start its own newsletter – R Graham and A Lees will share the newsletters issued by their respective patient support groups with G Higgins.

The patient representative group held an open day for patients who have received LVADs and will repeat this again next year as an opportunity to network with patients and carers undergoing similar issues. The group will be reviewing support for LVAD Carers.

### **R Graham – Transplant Support Group, Papworth Hospital**

R Graham reported that there had been three Transplant Support Group Meetings this year with another planned in November. A closed Facebook group page has been set up to help cater for those unable to attend and a quarterly newsletter is also produced.

The group has had businesses cards printed which are handed to pre/post transplant patients which has had a positive impact on membership. Patient support group badges have been produced which are proving a good source of fund raising.

In September, a team of 6 of heart transplant recipients, of which two were DCD patients, entered the annual Cambridge Chariots of Fire race, and successfully beat some of the Papworth Hospital Staff Teams. This event is set to raise over £100k for DCD transplantation.

The Transplant Team recently hosted its annual patient event, which was well supported with over 100 participants attending.

In other news from Papworth Hospital, a traditional Topping Out Ceremony was held in late October to celebrate the completion of the structure of the new hospital which is due to open in just over 500 days.

**All  
Members**

**R Graham  
A Lees**

7	Transplant Activity/statistics – <b>CPG(16)2</b>	All Members
<p>The statistics given in the report show transplant activity during the past 10 financial years, with a 15% decrease in waiting lists, 48% increase in transplants and 69% increase in deceased organ donors. During the past year, there were 325 cardiothoracic donors resulting in 383 transplants. There has been a 13% increase in those registered to the waiting list for lung transplants, in the same time period; the number waiting for hearts has tripled.</p> <p>The changes to the heart waiting list are due in part to the following:</p> <ul style="list-style-type: none"> <li>• Diseases and treatments have changed over time</li> <li>• The population is aging</li> <li>• More people have heart disease that would benefit from a heart transplant</li> <li>• Post-transplant survival rates are improving all the time</li> <li>• More patients are now treated with LVAD's – while these patients would benefit from heart transplants, the use of the LVAD can improve the quality of life in the meantime meaning these patients are still on the waiting list, but for extended time periods as the health benefits found in using the LVAD keeps patients alive and well for longer</li> </ul> <p>There was further discussion of these statistics within the group. Concern was expressed by G Higgins that, at a high level, some of the statistics could be misleading e.g. the average wait for a heart transplant was significantly higher for O Blood Group patients. R Graham also commented that any statistics which merged non-urgent and urgent heart transplant activity would not give patients a proper picture. S Rushton invited members to visit the ODT website and provide feedback directly to the Statistics Department via email or the survey set up on the website raising any concerns. This will enable the Stats team to provide variations on published statistics if required.</p>		
8	NORS Review Implementation – <b>CPG(16)3 (CTAG(16)S22</b>	
<p>The NORS review focussed on Donor Organ Retrieval. The review looked at both DCD and DBD retrievals. Scouting activity was outside the scope of NORS review. The review resulted in the following conclusions:</p> <p><b>Number of On Call Retrieval Teams:</b> previously; there had been six cardiothoracic NORS teams on call for organ retrieval. NHSBT looked at previous retrieval activities, which demonstrated that there had been very few days when more than three cardiothoracic retrievals were required. It was decided that from April 2016, that there would only be three on call teams for cardiothoracic organ retrieval. Monday evenings 20:00 hours was found to be the quietest time for retrievals activity and was adopted as the handover time between teams. Each team consists of four members –a surgeon, an assistant surgeon, a theatre practitioner and a scrub nurse.</p> <p><b>Back to back retrievals:</b> Teams would be allowed a minimum of 2 hrs rest/preparation between 2 consecutive retrievals. During Q1 of new NORS rota, no CT team had to do any back-to-back retrievals.</p> <p><b>Work Volumes:</b> Previously, the maximum percentage of on call days worked by any team was averaged at 60%. It was decided that when any team has to work for &gt;70% of its total on call days, a review into NORS capacity would be triggered. If required, additional more on-call teams may be commissioned.</p> <p>During Q1, the new NORS rota has not impacted on organ acceptance rates, which were comparable to previous years.</p> <p>Cardiothoracic NORS Teams are new to joint on-call rotas but the Abdominal Retrieval Teams have worked in this way for years. While reducing the number of CT NORS teams on-call from 6 to 3 meant that they would be busier than before, they are probably not as busy as the Abdominal NORS Teams.</p>		
9	ODT Hub: Urgent and super urgent heart and lung offering pathways update – <b>CPG(16)3</b>	

	<b>(CTAG(16)S20)</b>	
	<p>The new super urgent and urgent heart allocation scheme went live on October 26<sup>th</sup> 2016. This new development is still in its infancy but, so far, there have not been any complaints or incidents.</p> <p>Previously, all patients waiting on the urgent allocation list would have been offered organs chronologically based on the date/time they were added to the waiting list, irrespective of how unstable they might have been. In the new allocation scheme, patients receiving short-term mechanical support will be eligible for the super urgent list. They would receive priority over those on the urgent list who may not be so poorly.</p> <p>J Jones enquired as to whether the super urgent allocation scheme would result in more patients being added to certain centres lists, the danger being that those centres would then have much larger waiting lists. S Tsui explained that the size of the allocation zone for each transplant unit is adjusted annually to ensure that the allocation of donor organs is proportionate to the waiting list size at each centre.</p> <p>The super urgent and urgent lung allocation scheme is next in line and should be introduced in Spring 2017</p>	
10	<b>Scouting update</b>	
	<p>Donor organs often suffer injury from the process of brain death and over 70% of donor hearts are declined after assessment. Scouting has been piloted since 2013/14 to try and increase the proportion of donor hearts accepted and transplanted. In 2013/14, this resulted in a 40% increase in donor heart utilisation, which meant that more heart transplants took place in 2013/14 than any other of the previous 10 years.</p> <p>After the Scout 1 project had finished, a dramatic decrease in the number of heart transplants was noted. A rigorous Scout 2 project was later introduced; which resulted in a similar increase in the numbers of heart transplants as Scout 1.</p> <p>There have been certain criticisms of how Scout 1 and Scout 2 results are interpreted although the cardiothoracic teams believe that it made a real difference. As a result, Prof J Forsythe convened an external review and asked 2 experts from Austria and Italy respectively to look at the results. During this 2-day review, cardiothoracic and abdominal teams gave verbal feedback and on the whole this was positive. The final written report is still awaited. If the recommendations are supportive, then Scouting may become a commissioned activity.</p>	
11	<b>DCD progress/funding update</b>	
	<p>Previously, all donor hearts come from DBD donors in which organ assessment and retrieval can be carried out in a controlled manner, with no disruption to the donor organ blood flow until they are ready to be preserved and removed. With DCD hearts, the circulation will have stopped and a variable amount of damage will be caused. On 3<sup>rd</sup> December 1967, the world's first recorded heart transplant took place, using a DCD donor before the concept of DBD donors had been introduced. As DCD donors often died in uncontrolled situations, this concept was abandoned as it could not be made safer. In July 2014, a hospital in Sydney attempted its first DCD heart transplant in the modern era. Papworth was granted approval for DCD heart transplants in January 2015 and carried out its first DCD heart transplant on February 28<sup>th</sup> 2015. To date, there have been 40 DCD heart transplants worldwide with 38 of the 40 recipients surviving beyond 30 days (95%)</p> <p>At Papworth, there were 36 DBD heart transplant and 15 DCD heart transplants during 2015-16. Therefore, use of DCD hearts resulted in a 42% increase in their heart transplant activity. Adopting DCD heart transplants throughout the UK could see a similar increase in heart transplants being carried out. Manchester has been preparing to start DCD heart transplants and is hoping to proceed in December 2016.</p> <p>To date, at Papworth, most DCD hearts have only gone to those on the non-urgent heart</p>	

<p>waiting list. Non-urgent patients have ample time to consider whether to take part in this research study and would have no pressure to consent. Patients on the urgent list are potential more vulnerable and were therefore not approached to take part in this research project.</p> <p>Papworth Hospital approached NHSBT to request funding for DCD heart retrieval as after their first 5 recipients did well after DCD heart transplants. There is an additional cost of £35K per DCD heart retrieval. NHSBT supported an evaluation of the project for four months and funded seven DCD retrievals during this time; others have been funded by charitable donations. NHSBT is impressed by these early positive outcomes. A business case has been submitted to the four Department of Health in the UK for funding from April 2017. It is hoped that DCD heart retrieval and transplantation can be expanded to all UK centres.</p> <p>Putting DCD hearts on the TransMedics Organ Care System (OCS) may allow a longer timeframe in which to complete the surgery. Using the OCS to maintain a donor heart potentially may be a better option for LVAD patients, although this is speculatively and the timeframe is still tight.</p> <p>N Banner went on to elaborate further for members, explaining that the OCS is the only machine approved for commercial use for keeping hearts in optimal conditions. Without investment from NHSBT, DCD heart transplants will not be sustainable in the UK. The value of a donor heart has been estimated to be worth £1m – if so, comparatively speaking, £35k additional cost would represent a relatively small amount.</p>	
<p>12 Any Other Business:</p> <p>R Graham felt it would be beneficial for the NHSBT to present an evaluation of the Organ Donor week in September particular given the re-branding earlier in the year. M Thompson (NHSBT Marketing Team) will arrange for a speaker and more detailed evaluation of Organ Donation Week and its overall effectiveness at increasing registrations to the Organ Donor Register.</p> <p>National Transplant Week was rebranded in pink, as Organ Donation Week. Members felt that the decision should have been more inclusive as some centres were unaware of the change.</p> <p>Members offered the following feedback:  Pink – members felt that the pink colour is easily confused with LGBT or Breast Cancer colour branding  I Do-nate – gives a confusing message, it may imply monies being donated and not organs.  J Nutall commented that she had not seen any of the new branding, and that Organ Donation Week was not widely promoted in the areas that she works in.  Overall, members of the group felt that there had been no more of a push on this Organ Donation Week than in any other year.</p> <p>Members went on to discuss methods of raising awareness for the Organ Donor Register and encouraging further sign ups.</p> <p>R Graham said that he had given feedback recently in an interview with NHSBT that he believes it important to promote the concept of Organ Donors in schools, potentially using voluntary ambassadors during PSHE lessons. Presentations by transplant recipients have the maximum impact.</p> <p>It was suggested that case studies involving peers their own age would help to drive the message home. R Pope asked whether this could be linked to some kind of sponsorship or whether schools could be incentivised for discussing Organ Donation with students or recognition for encouraging sign ups.</p> <p>An increased use of social media was suggested e.g. YouTube video, given the impact of the current Christmas John Lewis advert; however the cost of using social media for targeted</p>	<p><b>M Thompson (NHSBT)</b></p>

<p>advertising is expensive. Overall it was agreed that there should be a multi-faceted approach to increasing Organ Donor numbers with local initiatives working alongside national promotions.</p> <p>J Jones highlighted the fact that there is a shortage of paediatric organs, and to draw attention to this, the Cystic Fibrosis Trust is featuring a young girl with Cystic Fibrosis on their Christmas card this year.</p> <p>N Al Attar mentioned incentives used elsewhere in the world such as the reciprocal approach used in Israel where those registered on the Organ Donor Register would then have a privileged place on the register should they require it. Other suggested incentives could include reduced funeral costs, and this has been suggested to the DoH numerous times. At present it is illegal to offer any form of remuneration (presumed or explicit) for donated organs and there are no plans to change this. The impact of the new soft opt out Welsh Legislation has yet to be measured.</p> <p>R Graham thanked S Tsui, N Banner, N Al Attar and S Rushton for attending the meeting.</p>	
<p><b>DATE OF NEXT MEETING</b></p> <p>The date of the CTAG Patient Group Meeting (Spring) has been rearranged to Monday 5<sup>th</sup> June at 12.30pm. The venue is to be confirmed.</p> <p>The CTAG Patient Group Meeting (Autumn) has been arranged for Monday 16<sup>th</sup> October 2017 at 12.30pm at The West End Donor Centre, The Board Room, 26 St Margaret Street, Marylebone, London, W1W 8NB</p>	