

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

**CARDIOTHORACIC PATIENT GROUP MEETING
ON TUESDAY 5TH JUNE 2018, 13:30 – 16:30
THE BOARDROOM, WEST END DONOR CENTRE
26 MARGARET STREET. MARYLEBONE, LONDON WC1N 1AZ**

PRESENT

Rob Graham (RG)	(Co-Chair) Patient Representative, Governor, Royal Papworth Hospital
Jayan Parameshwar (JyP)	(Co-Chair) Incoming CTAG Chair, Consultant Cardiologist, Royal Papworth Hospital
Steven Tsui (ST)	Outgoing CTAG Chair, Heart Surgeon, Royal Papworth Hospital
Nawwar Al Attar (NAA)	Heart Surgeon, Golden Jubilee National Hospital
Janet Atkins (JA)	Patient Representative, Governor, Royal Papworth Hospital
John Forsythe (JF)	Medical Director, Organ Donation and Transplantation, NHSBT
Kathryn Graham (KG)	Patient Representative, Patient Support Group, Royal Papworth Hospital
Ged Higgins (GH)	Patient Representative, Wythenshawe Hospital
Emma Johnson (EJ)	Max's Law Advocate, Heart Transplant UK Facebook Support Group
Beverly Jones (BJ)	Transplant Social Worker, Wythenshawe Hospital
Catrin Kissick (CK)	British Heart Foundation Representative
Alan Lees (AL)	Secretary, Harefield Hospital Transplant Club
Jane Nuttall (JNu)	Recipient Transplant Coordinator, Wythenshawe Hospital
Rosie Pope (RP)	Parent of Transplant Patient, Harefield Hospital
Richard Quigley (RQ)	Lead Nurse for Transplant Service, Royal Papworth Hospital
Laura Ramsey (LRa)	Lead Nurse Recipient Coordinator, NHSBT
Lucy Ryan (LRy)	Heart Transplant Recipient, Heart Transplant UK Facebook Support Group
Emma Stapley (ES)	Senior Communications Officer, Marketing Communications, NHSBT

PRESENT

Lucy Newman (LN)	Secretary, NHSBT
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APOLOGIES

Nicky Crouchen (NC)	Recipient Coordinator, Harefield Hospital
Margaret Harrision (MH)	CTAG Lay Member
Mike McKevitt (MM)	British Lung Foundation
Mike Thompson (MT)	Patient Representative, Golden Jubilee National Hospital
Sally Rushton (SR)	Senior Statistician, NHSBT

	Apologies and welcome	
1	Declarations of interest in relation to the agenda There were no declarations of interest in relation to the agenda	
2	Minutes of the meeting held on Monday 16th October 2017	
2.1	Accuracy The minutes from 16/10/17 were agreed as an accurate record of the last meeting	
2.2	Action Points AP1 Correction to attendee list: completed AP2 Circulate Harefield Transplant Club booklet: completed. RG working on a revised edition in a similar style Royal Papworth Patients once the hospital has moved sites later this year. AL to forward the newly updated version of the handbook to LN for circulation to the rest of the group	A Lees L Newman

	<p>AP3 Super Urgent/Urgent Heart and Lung Updates split by blood group: The Cardiothoracic Heart Allocation Sub Group (HASG) has been convened to revise listing and allocation criteria for patients awaiting heart transplantation. See minutes item 9</p> <p>AP4 Statistical queries to be emailed to SR in advance of meetings: completed</p> <p>AP5 CF Members to identify themselves to LN to manage cross infection and attendance: completed</p> <p>Any Other Business Agenda Items The group were saddened to learn that Joan Whitney, Treasurer to the Freeman Heart and Lung Transplant Association at Newcastle passed away at the beginning of the year. Joan was a stalwart of the transplant community, and a big supporter of the CTPG and the Transplant Games. Condolences to her family and friends, she will be greatly missed.</p> <p>Congratulations to Steven Tsui and Stephen Large for receiving an NHS Heroes Award on behalf of the team at Papworth for their pioneering work in the field of DCD Heart Transplantation</p> <p>JyP will write to Jorge Mascaro (JM) at Birmingham to ask him to find a patient representative or member of the cardiothoracic team to attend the CTPG</p> <p>Post Meeting Note – Rochelle Pointon has contacted LN and has been invited to the next CTPG in November</p>	<p>J Parameshwar</p> <p>L Newman</p>
3	<p>Transplant Activity – For Information SR presented slides at ISHLT which covered the last two financial years. Heart transplant activity rates have remained broadly static with the inclusion of DCD heart transplant activity.</p> <ul style="list-style-type: none"> • Last financial year 395 donor hearts were unused • 18% of non-urgent patients, 64% of urgent patients and 71% of super urgent patients received a transplant • In the same period, 623 donor lungs were unused • 27% of non-urgent patients, 77% of urgent patients and 60% of super urgent patients received a transplant <p>There was a decrease in the numbers of lungs transplanted last year, but numbers are now back to the previous levels. This may be due to how lung donation and transplantation is recorded, for example, some patients receive a single lung whereas others receive both lungs. One donor could therefore donate one lung to one recipient and one lung to another recipient.</p>	
4	<p>Transplant Centre Profiles Draft Transplant Centre Profiles/‘Infographics’ have been designed by NHSBT Statisticians in response to previous patient group feedback concerning NHSBT and ODT websites, the consensus being that it can be particularly difficult for patients and their families and members of the public to navigate to the information they want to find.</p> <p>The Draft Transplant Centre Profiles do not provide the comprehensive detailed information available from the ODT website but use infographics to provide a snapshot of the number of transplants performed, the average waiting time to transplant and the outcomes for patients following transplant for each centre. They are designed to give basic information about the centres and help patients to make informed decisions about where they would like to receive treatment.</p> <p>The group commented that outcome data should show a longer period after transplant, and not stop at 30 or 90 days but give survival data over a 1, 5 and 10-year period. They also commented that so many variables can influence the data – suitability of available organs, availability of organs, the health of the patients on the waiting list, logistics in the centre (available beds etc).</p>	

	Further comments to be addressed surrounding the paper CTPG(18)03 from AL, GH and RG are attached as APPENDIX 1 to these minutes and are an action point for SR/JF and JyP	S Rushton J Forsythe J Parameshwar
5 5.1	<p>Patient Group Updates</p> <p>Harefield Hospital A Lees</p> <ul style="list-style-type: none"> • In June the GB team comprising 40 transplant patients 25 supporters from all the cardiothoracic transplant centres will be attending the European Heart and Lung Transplant Games in Lignano, Sabbiador, Italy • Harefield transplant patients and supporters will be attending the British Transplant Games in Birmingham in August • The Trust covers two hospitals, the Royal Brompton Hospital (RBH) and Harefield Hospital (HH), and has just provided funding for 3D printing consumables for the RBH • The Trust has also provided funding for a mobile phone app being developed at the RBH. The app enables Cystic Fibrosis patients to have virtual consultations to have their lung function and health matters monitored remotely, reducing the risk of cross infection from clinic attendance, and enabling medical teams to proactively book them in for appointments more quickly if required and to delay appointments where a patient is managing their health well. • The clubs fundraising activities have ranged from a beard 'shave off' to a 34 hour/106km non-stop walk around the Isle of White • The Annual Cardiothoracic Transplant Patient Reunion will take place in October 2018 • The Harefield Transplant Patient Handbook Booklet has had several revisions to content and been professionally printed and bound. The booklet will be shared with other units so it can be used as a starting point for similar information to be produced for their units <p>Wythenshawe Hospital B Jones</p> <ul style="list-style-type: none"> • 27 Wythenshawe transplant patients and supporters will be attending the British Transplant Games in Birmingham in August • A New Start grant has been awarded to start funding OCS • Other fundraising events continue <p>Freeman Hospital E Johnson</p> <ul style="list-style-type: none"> • Unfortunately, Derek Airey was unable to attend the meeting so there was no Freeman Patient Group update • Recent events at Freeman include 'Heart Transplant – A Chance to Live' television documentary (aired in May 2018) which featured seven patients registered at The Freeman Hospital. The programme was also reviewed on Gogglebox, and covered the outcomes of all seven patients, good and bad • EJ is also involved in other TV work promoting Max's Law which will mean all UK residents will be considered organ donors unless they opt out <p>Golden Jubilee National Hospital (GJNH) N Al Attar</p> <ul style="list-style-type: none"> • This year celebrates the 26th year since the first heart transplant was carried out at the GJNH • A memorial garden is planned for patients and their families to be used for reflection and soul healing • The team from GJNH were awarded the 'You're Marvellous Team of The Year Award' from the Pumping Marvellous Foundation • Transplant community and church members continue to raise funds for Heart Transplant Patients • Heart transplant recipients attended the last Winter Transplant Games in Switzerland in January 2018. The team achieved a Gold Medal for Curling, and a Silver Medal for Skiing. 	

	<ul style="list-style-type: none"> • One Heart transplant recipient from GJNH is a competitive cyclist and will be participating in the 2018 European Heart and Lung Transplant Games in Lignano, Sbbiador, Italy <p>Royal Papworth Hospital K Graham</p> <ul style="list-style-type: none"> • The Papworth Hospital Heart and Lung Transplant Patient Group is designed to support patients along their journey rather than raise funds. The support group has almost doubled its meeting numbers to 80-90 and has had to move to larger premises for its quarterly meetings. The next meeting in a few weeks expects attendance from approximately 60-70 members • Membership of the group is available to pre- and post-transplant patients and their families for support • Regular speakers attend the meetings, recently a recipient co-ordinator was invited to talk to the group about writing to their donor family • The group are in process with writing a new book of stories about heart and lung transplants • Current focus is on the move to the new building and renaming of Papworth to Royal Papworth • The BBC filmed a series of programmes to celebrate 70 years of the NHS, one of programmes (to be aired in June) focusses on Papworth Hospital <p>5.1 Writing to your donor family</p> <p>Katie Morley (KM) (Papworth) and Laura Ramsey (NHSBT) have been involved with this project for some time, to try and increase the number of people who write to thank their donor family for the gift of life they have received. Recipient Coordinators can help with this process and lots of work has been going on behind the scenes to revamp resources and provide guide letter templates. It's acknowledged that there is no right time to write, and members felt that often the first year after receiving a lifesaving transplant can be quite traumatic and challenging with many physical and psychological factors to overcome. Therefore, writing to say thank you is not always at the forefront of the mind during this initial period of recovery immediately after receiving a lifesaving transplant. A letter of thanks is often powerful for the donor family to receive and cathartic for the recipient to write, and some recipients and donor families stay in touch. Recipient coordinators will always check with the donor family that they would like to receive letters, and there is a strict KPI turnaround time in which to get the letters sent on. LR will provide more information and assist with guidance on how to write letters if required. LR welcomes feedback from the group and recipient coordinators to work to find a way to improve communication between recipients and their donor families. LN will circulate LR email address with the minutes of the meeting.</p> <p>5.2 Psychological Support</p> <p>Psychological Support networks vary between centres and is not consistent, however, there are no guidelines regarding the level of psychological support should be available. Psychological support is underfunded and there is no service specification for the level of support that should be provided although Psychologists are included in the Multi-Disciplinary Team (MDT) meetings. Recipients require more support and liaison at home, particularly when they live further away from a centre or are particularly vulnerable. One of the issues is that from a General Practitioner's perspective, a patient who has received an organ transplant is in better health and in a better place mentally than they were pre-transplant, so it takes longer for these patients to be able to access the psychological support they need to aid with recovery. As the need for psychological support varies so widely between patients it is difficult to provision for in centres. EJ reported that her son can see a psychologist when he goes for check-ups if he wants to, however, this is due to the additional support in place for paediatric patients, not necessarily adults.</p>	<p>L Ramsey</p> <p>L Newman</p>
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5.3	<p>RP commented that funding has been made available at Harefield to create green space around the hospital. NAA confirmed that a memorial garden has been planned and is in development, and Papworth insisted that there be greenspace and a duckpond for patients. There is hard evidence that views of nature aid recovery and this is something to be considered by all units for future development.</p> <p>Ageing Workforce</p> <p>Many Cardiothoracic Transplant Surgeons are in their 50s and there is a need to recruit more surgeons to meet future needs. This is not a new problem; but cardiothoracic transplant is no longer seen as a speciality, the hours are particularly unsociable and requires personal sacrifices. ST commented that it's more like a hobby when your day job is as a cardiothoracic specialist and was of the view that the NHS hierarchy doesn't always recognise or reward surgeons for going the extra mile. The retention rates are good, but transplantation requires a lot of dedication and stamina, and some surgeons will cease before retirement. The Tariff for transplantation has not been reviewed for at least 20 years and transplantation costs centres money. Each year, there are three training posts made available which are funded for 18months; these have been successful so far.</p>	
6	<p>Patient involvement in organ utilisation decisions</p> <p>Patient involvement in organ utilisation decisions will be discussed at the next CTPG in November 2018 when Mr Chris Callahan (Consultant Transplant and Vascular Access Surgeon at Guys Hospital) who is the lead on the project will attend to present and discuss his paper in more detail. There were mixed feelings among the group, but the general feeling is that patients must be asked whether they want to be involved in all organ utilisation decisions relating to their treatment.</p>	
7 7.1 7.2 7.3 7.4	<p>Increasing donors and donor utilisation</p> <p>Opt out</p> <p>The Opt Out Consultation is now closed and received over 17k responses. The second reading has been passed in the House of Commons in February 2018. The third reading will be in the House of Lords, and this is expected to be imminently as the announcement will have to be made before Politicians break for summer recess. The consensus is that most of the population support Opt Out and the legislation being discussed and passed acts as a springboard for getting the conversation going with family and friends.</p> <p>National Scout Service</p> <p>The National Scout Service initiative would deploy Scouts to hospitals with potential cardiothoracic organ donors to help assess and maintain the donor prior to donation. The Scout would assist the donor team, completing the ECHO and recording pressures etc. Using the National Scout Service, about 44% of suitable donor organs are used, without the Scout service, only about 27% of suitable donor organs are used. The Scout Service initiative was proposed about 4-5 years ago, and while it is recognised, and some aspects are in place, NHSBT has no funding for the whole Service at present. ST and JyP are attending a meeting in July to find out more.</p> <p>Reasons for declining cardiothoracic organ offers</p> <p>Transplant surgeons will always try to maximise suitable organs that can be used when donated, but the number of organs available can vary from donor to donor, and reasons for declining donor organs varies by patient and centre, and may be due to a range of reasons, such as no suitable recipient, no beds available in ITU, poor function or poor pressures etc. The Cardiothoracic Transplant Community are working together to identify why organs are declined in some or all centres; a report is expected in around 6 months' time.</p> <p>Ideal Heart / Ideal Lung Initiatives</p> <p>The Ideal Heart and Ideal Lung Initiatives are another way of looking at the utilisation of donor organs, broken down by either hearts or lungs. JD has taken the lead on reviewing</p>	

	<p>ideal lungs and held two telecons to discuss lungs which were identified as ideal donor lungs but were unused. Centres all also hold regular reviews to establish why 'ideal' donor organs were unused at transplant. Shared learnings resulting from the initial declined ideal lung donor telecons has proven useful and opens opportunities for further discussion within centres and support for those who may be more risk averse to utilise cardiothoracic organs more fully.</p> <p>ST also outlined proposals for establishing Ideal Heart Donor criteria in an effort to critically review and improve donor heart utilisation levels and best practices across the UK Cardiothoracic Transplant Centres.</p>	
<p>8 8.1</p> <p>DCD Heart Transplants Activity</p> <p>8.2 Funding</p>	<p>Using OCS (Transmedics' Organ Care System) within DCD Heart Transplantation has increased the number of heart transplants. However, OCS is costly and presently not funded by NHS England. As DCD Heart Transplantation is part-funded by charitable donations, RG suggested that future statistics might be adjusted to acknowledge this situation.</p> <p>To date 57 DCD heart transplants have been carried out - 6 at Wythenshawe, one at Golden Jubilee; Birmingham are trained and ready to embark on the DCD hearts programme in future. The majority of DCD heart transplantations were carried out at Papworth. To date, there have been 8 deaths following DCD heart transplantation, so rates are comparable to DBD heart transplantation and all but two of the DCD donors went on to donate other organs.</p> <p>Papworth was granted £1m to work on DCD heart transplants, and having completed 45, the funding has now run out* and neither NHS England nor NHSBT will commit to further funding, although both organisations fully support DCD heart transplantation. ST also reported that numbers of patients being fitted with a VAD had reduced due to DCD heart transplants which represented a huge cost saving given the high expense of VAD procedure and ongoing care. The earliest opportunity to review funding possibilities will be in the financial year 2019/2020.</p> <p>RG has been appointed to the NHS England Rare Diseases Advisory Group (RDAG) who also oversee and commission Highly Specialised Services (including Heart and Lung transplantation) and will attend the meeting on 06/06/18. He will seek to obtain an update from Highly Specialised Services and report back to CTPG in November.</p> <p>NHS Tariffs for cardiothoracic transplantation have not altered in 20 years and do not accurately reflect the cost of the transplants. Transmedics are currently the only company with the patent for the OCS machine, which received a \$250m investment to develop the machine. With only 5,000 heart transplants worldwide each year, and 90% of those not including the use of OCS, the cost of purchase and subsequent use of the OCS machine is prohibitive</p> <p>*Subsequent to the CTPG meeting, Royal Papworth received funding from charitable donations to permit a further 6 DCD Heart Transplants.</p>	<p>R Graham</p>
<p>9</p>	<p>Proposed revision to Heart Allocation Policy (including multi-organ approach)</p> <p>The Heart Allocation Sub Group (HASG) was re-convened in April to revisit the existing Urgent/Super-Urgent Heart allocation policy to make allocation more equitable in order to ensure the most vulnerable patients receive the appropriate priority, ranking them according to medical urgency.</p> <p>It was noted that during the year 2016-2017;</p>	

	<ul style="list-style-type: none"> • 38% adults and 69% paediatric patients were listed on the Urgent heart allocation scheme • 15% adults and 2% of paediatric patients were listed on the Super-Urgent heart allocation scheme <p>The newly devised Heart Allocation Policy would have seven tiers, each tier being determined by severity of specific medical criteria to maintain smaller groups of patients with similar medical needs for transplant.</p> <p>Changes to the sizing criteria and tiers will be implemented by IT once the policy amendments have been agreed. This could take time as the IT demands may be complex.</p> <p>HASG agreed that age would be removed from allocation criteria to avoid discriminating against any patient group. Using height and weight of the donor and recipient instead to determine a small donor heart and a standard donor heart; small donor hearts will always be offered to paediatric patients in advance of adults. Patients awaiting combined organ transplants will be allocated within the proposed revised tier structure.</p>	
10	<p>Any other business There was no other business raised and the meeting closed at 16.30</p>	
11	<p>Date of next meeting</p> <p style="text-align: center;">CTAG Patient Group Meeting: Monday 12th November 2018, 12:00 – 16:00 (Sandwich Lunch 12:00-12:30) Central London – Venue To be Confirmed</p>	