NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION DIRECTORATE
THE FOURTEENTH MEETING OF THE NHSBT CARDIOTHORACIC PATIENT GROUP (CTPG)
ON WEDNESDAY 18TH NOVEMBER 2020 FROM 14:00 – 16:00
MEETING VIA MICROSOFT TEAMS OR DIAL IN

PRESENT

Rob Graham (RG)	CTAG Patient Group Co-Chair, Governor, Royal Papworth Hospital
Jayan Parameshwar (JP)	CTAG Patient Group Co-Chair, CTAG Chair, Royal Papworth Hospital
Janet Atkins (JA)	Transplant Support Group, Royal Papworth Hospital
John Dark (JD)	Previously Heart and Lung Transplant Surgeon, Newcastle; CI SIGNET Study
Lynda Ellis (LE)	New Start Transplant Charity, Wythenshawe Hospital
Laura Gorton (LG)	Communications Team, NHSBT
Margaret Harrison (MH)	CTAG Lay Member Representative
Lorraine Jerrett (LJ)	Recipient CT Transplant Co-ordinator, Golden Jubilee National Hospital
Emma Johnson (EJ)	Mother of Heart Transplant Patient Max – Max's Law, Freeman Hospital/GOSH
Beverley Jones (BJ)	Transplant Social Worker, Wythenshawe Hospital
Jessica Jones (JJ)	Cystic Fibrosis Trust
Alan Lees (AL)	Patient Representative, Harefield Transplant Club, Harefield Hospital
James Maud (JM)	LVAD Patient – Queen Elizabeth Hospital, Birmingham
Louise McLellan (LMc)	Patient Representative, Freeman, Hospital, Newcastle
Kirsty McNally (KM)	SNOD Team Manager, London (Deputy for R Westlake)
Lisa Mumford (LMu)	Head of OTDT Studies, CTAG Statistician, NHSBT
Jane Nuttall (JN)	Recipient Transplant Co-ordinator, Wythenshawe Hospital
Rochelle Pointon (RP)	CT Recipient Transplant Co-ordinator, Birmingham
Richard Quigley (RQ)	Lead Transplant Co-ordinator, Royal Papworth Hospital
Karen Quinn (KQ)	Assistant Director – UK Commissioning, OTDT, NHSBT
Laura Roberts (LRo)	Social Worker on Heart Transplant Team at Wythenshaw Hospital
Lucy Ryan (LRy)	Heart Transplant Patient at GOSH, now at Papworth helping with Heart Transplant Families UK
Fred Smith (FS)	CTAG Support Statistician, NHSBT
Sadie Von Joel (SVJ)	Lead CT Recipient Transplant Co-ordinator – Deputy for Laura Stamp
Mark Whitbread-Jordan (MWJ)	Transplant Patient – Queen Elizabeth Hospital, Birmingham

IN ATTENDANCE

Trudy Monday (TM)	Secretary, NHSBT

MINUTES

	Welcome and Introduction Apologies were received from: Rebecca Allen, Eliza Bell, Debbie Burdon, Martin Carby, John Fegan, Leila Finikarides, John Forsythe, Jane Graham, Kathryn Graham, Dominic Kavanagh, Rosie Pope, Nicky Ramsay, Marian Ryan, Mark Whitbread-Jordan, Jonathan Williams, Paul Woodward. R Graham read a message from L Newman and expressed thanks to her for all of her help and hard work over the years; all the best is wished for her new role.	
1	**CTPG(20)06 – Declarations of Interest** There were no declarations of interest recorded in relation to the meeting today.	

2	**CTPG(M)(20)01 – Minutes of the last Meeting held 10th August 2020**	
2.1	**Accuracy**	
	The minutes were approved as an accurate record of the last meeting, subject to the following amendments: **Item 7: Spirometry:** The Highly Specialised team within NHS England has provided funding for new 'smart' spirometers to be used for lung transplant patients to help record and submit their lung function readings in recognition that fewer face to face meetings/consultations are taking place during the pandemic. This should help to ensure that more accurate readings are provided and will provide earlier indications of any deterioration in lung function. It is hoped that these will be rolled out in the coming weeks/months. **Item 2.2.4: Facebook page:** It is possible to search for, and join, the CTPG Facebook group without specifically being contacts of R Graham.	**TM**
2.2	**Action points**	
2.2.1	**Sentinel skin flap**	
	Sentinel Skin Flap Trials would involve a section of donor skin being attached to the forearm / thigh of the recipient; the skin would indicate any signs of rejection in the transplanted organ (via a rash appearing) enabling effective treatment to begin more quickly whilst avoiding the need for invasive investigations such as a lung biopsy for example. 50 responses were received from those patients canvassed at Papworth – these have been fed back to H Giele and feedback is awaited.	
2.2.2	**Spirometer for lung transplantees**	
	Refer to minute 2.1 above.	
2.3	**Minutes of CTAG Lungs Advisory Group 17th September 2020 - CTPG(20)09**	
	Members received the minutes for information. The CTAG Lungs and Hearts meetings used to be part of a joint meeting on one day, but they are now held as two separate meetings.	
2.4	**Minutes of CTAG Hearts Advisory Group 28th September 2020 - CTPG(20)10**	
	Members received the minutes for information.	
2.5	**Any other business**	
	There was no other business raised in light of the items already discussed.	
3	**Donor Statin Study (SIGNET) – CTPG(20)11**	
	J Dark presented slides re. the Donor Statin Study (SIGNET: **S**tatins for **I**mproving or**G**a**N** outcom**E** in **T**ransplantation) to members. This is to be one of the world's largest prospective donor intervention studies. Brain-stem death, and the process of retrieval leads to dysfunction of many potential organs including the heart and lung. Only 20-25% of organs offered for transplant can be used. A study carried out in Helsinki last year involving 84 heart donors indicated that by administering statins to the donor there was: a significant reduction in heart injury and heart failure markers; a small reduction of early acute rejection; but no effect on heart survival at one year. For other organs there was: no benefit or detriment for the kidney; small, non-significant benefit for the lung; a reduction of ALT, a liver enzyme, at 1 week in liver recipients. The SIGNET study aims to involve a much bigger population and look at the effects in all organs, however there are organisational and logistical challenges, as well as	

	ethical and governance challenges. The statin (which is a really common and inexpensive drug) is to be given as soon as donor family consent (sought by the SNOD) for organ donation is given in the brain-dead donor long before the start of the offering process and the recipient identified. The recipient will be informed through transplant centres by letter, however, consent is not required from them. There may be benefit, with no anticipated risk. This study was approved in October 2020 with funding of £1.3 million, and will be managed by the NHSBT Clinical Trials Unit. It will involve 2600 adult brain dead donors, over 4 years, to be randomised after consent for donation and research, half to receive Simvastatin 80mg as a single dose. The main focus of the study will be complications and survival in heart transplant recipients, and outcomes in all organs from these donors followed from data collected in the UK Transplant Registry. **Questions:** - *Does the recipient receive the statin drug as well?* Most heart transplant patients around the world are taking statins anyway, and those patients will not be taking the same statin being used in the SIGNET study. This study is an interesting, simple intervention in the donor with no perceived harm. The Helsinki study has indicated the safety of this specific statin, which is why it will be used in the UK. No significant amount of drug comes with the organ, so it will be safe to use even if the recipient has had complications from statins in the past. - *If the results are as hoped, could the statin be rolled out to paediatric patients?* There is no reason why it should not be, but the study is currently concentrating on the busiest donor centres – more than 6 brain-dead donors per year, and due to ethical consent, paediatric donors cannot be included yet. If there is a case of an adult donor going to a paediatric recipient then yes, it will be followed in the same way. This was a pragmatic decision. - *Is this study seeking to look to improve the condition of the organ from the donor, or improve the survival?* Both; every hour the organ is outside of the body the survival rate is worse. It is hoped that there would be less heart injury with the administration of the statin before retrieval. This, it is hoped, will improve the chances of surviving 30 days and consequently long-term survival. The function of the donor heart is a very big problem in the UK, so any intervention is worthwhile. - *Will adding the statin improve the donor inside the body prior to retrieval?* It is hoped that the "quality" of the organ will be improved. If the function of the organ is better to begin with, it should be beneficial. R Graham thanked J Dark for his presentation. It is hoped for an update in 2- or 3-years' time. In the meantime, there is a link to the SIGNET study on the NHSBT website: https://www.nhsbt.nhs.uk/clinical-trials-unit/current-trials-and-studies/signet/ There is also information on the Newcastle University website: https://www.ncl.ac.uk/press/articles/latest/2020/11/signet/	
4.1	**COVID reflections/current status**	
	In J Parameshwar's summary, he empathised with the patient view and acknowledged that this year has been really hard and will continue to be for the next 6 months as a minimum. It is not a good time to be immunosuppressed or waiting for a heart or lung transplant. Between 1st April and 8th November, 104 heart transplants have been performed – this is a similar number to this time last year (97). Heart transplant activity has been reasonable. This is not the case for lungs as only 52 lung transplants have been performed for the same period, compared to 110 last year, so about half the number. This is mainly because during the first wave, lung transplant activity virtually ceased everywhere whilst heart transplant activity managed to go on. There was a genuine fear that a lung transplant with COVID in the environment was not safe.	

After the first lockdown during July/August, transplant activity increased. Activity in July was higher than in any other July, but the numbers did not make up for what had been previously performed. Some patients on the lung transplant waiting list chose to be inactive.

The second wave is bound to have an impact on activity, however currently, it does not look as bad as the first one. Hospitals are trying to maintain other services as much as possible; heart and lung transplantation as well as other non-transplant activity. NHS England and NHS Blood and Transplant have produced several documents recommending that transplant activity be maintained, however, it depends on how bad any one hospital is affected by the virus. If the ICU is full of COVID patients then transplants will not take place.

Communication between centres takes place every week. So far (apart from Birmingham), all centres including Manchester, have managed to continue transplant activity to a reasonable level and have not had to turn down organ offers which is encouraging. It is hoped that lung transplant activity will not be affected as it was during the first wave. The number of donor offers over the month has dropped as the donor ICUs are busy dealing with COVID patients.

Vaccines

The good news is that there are at least two promising vaccines: early trials show that they seem to work better than expected, but there is no indication as to how long they will last – could be 6 months, or one year, maybe a yearly vaccine will be needed. It has not been communicated yet as to the kind of people involved in the trial (immunosuppressed patients etc); up to 40% were said to be 'diverse'. It is suspected that there were not many immunosuppressed people involved.
J Parameshwar will continue to seek advice from Ines Ushiro-Lumb (Clinical Microbiology Lead for NHSBT) – previously I Ushiro-Lumb has said that it is felt that these two vaccines would be safe for the transplant patients to try. Full data is awaited. The vaccines work in different ways; one has a virus (not the COVID-19 virus) which cannot replicate (multiply) because it is modified, the other induces a response by the patient's immune system by a new technique. It is unknown yet as to what order people will be given the vaccine, including immunosuppressed patients. In the short term it is safe (not too many side effects), but patients will need to be followed up for 2 years or more to look for long-term side effects, to validate its safety, but we cannot afford to wait a long time before commencing a vaccination programme.

Questions:

- *Birmingham have had to turn down some organs, but could they have been used elsewhere?* Birmingham have only turned down one organ, but it was used elsewhere. If a centre could not transplant for a period of several weeks a patient can be moved to another centre, but this is not ideal as the centre would need to partially re-assess the patient being moved. It is not feasible to move a patient at the time a donor organ becomes available. Some kidney transplant patients have been moved to different centres on the day of their transplant, but this is not thought to be safe for heart and lung transplant patients.
- *Is there any global data re. the study of the outcomes in those patients who have had COVID?* NHSBT have been collating data on the UK population; there are now approximately 1400 post-transplant patients on the database (encompasses all organs). The outcomes have shown that approximately 1 in 4 people who have had COVID post-transplant have died. Outcome depends a lot on if the patient is otherwise unwell, and how well the patient has recovered post-transplant; age is another factor.
- *If the vaccine becomes available, is there the view that shielding people can return to some kind of normal life, do they need to be more careful?* It depends on what

	the prevalence of the virus is: if there are more infected people, it is less safe. Returning to a more normal life will only occur once most of the population has either had the vaccine, or most have had the virus. - *Uncertainty at start of the second lockdown re. clinical extremely vulnerable children and whether they should attend school or not – guidance has been available for adults in terms of returning to work, but not for children. Advice was that the clinician was to help with that decision in relation to government advice – was there a reason for that:* The child is at a lower risk than an immunosuppressed adult, and it is a case of balancing the risks and benefits. A child could miss a whole school year until a vaccine is rolled out widely, and there is no indication yet if the vaccination will be for young children. As far as things stand currently, children seem to cope fairly well with COVID infection. There is no right or wrong answer. - *From a patient point of view, any information would be useful, for e.g. general advice, vaccine safety:* As soon as updates are available these will be fed back to centres (usually once per week). There will always be uncertainties, and what is a risk for one person is not necessarily the same risk for another.	
4.2	**NHSBT 10-year Strategy – CTPG(20)12**	
	K Quinn, Assistant Director UK Commissioning, presented a summary on the NHSBT 10-year strategy. Ben Hume, Assistant Director Transplantation Support Services, started the strategy via a consultation conducted approximately 15 months ago. Today, the final version is being written for the NHSBT Board. It is a 10-year UK-wide strategy for Organ Donation and Transplantation, which is going to be focussing mainly over the next 5-10 years on the transplantation side, looking at innovative ways in overcoming the barriers to utilisation, UK-wide assessment and reconditioning of organs prior to transplantation, and supporting developments in new technologies. The 6 key areas of the strategy are: donation, transplantation, outcomes, diversity, sustainability, and research, looking at capacity right across the system (NHSBT, transplant commissioners and health departments) to ensure sustainable funding across the whole pathway. There has been a delay with the final draft as the Board asked for the strategy to be re-written to include the impact of COVID and the heightened awareness of the issues around BAME and Black Lives Matter. The final draft will be submitted to the Board on 26th November where it will be reviewed by the 4 health departments. It has not been possible to put hard targets or measures in place yet, but over the coming months it is hoped that this can be done. **Questions:** - *Is there any focus on particular organs which have been underlooked previously (ref. lungs)?* Yes, this has been recognised: NHSBT and the BTS had a Lung Summit last year and the action plans from that are being built into the strategy. J Parameshwar added that it is not through lack of effort from the NHSBT side, it is down to the cardiothoracic centres to improve organ utilisation. There has previously been more focus on heart utilisation because of the reduced activity compared to lungs 10 years ago. - *Will resourcing form part of the strategy?* K Quinn reported that staffing is an issue which is part of the whole pathway problem. It is hoped for a working group to be established to look at this area. The centres are funded by the transplant commissioners across the country. Adequate resourcing of aftercare is also important.	

5.1	**Annual Report on Cardiothoracic Organ Transplantation – CTPG(20)13**	
	F Smith presented figures from the Cardiothoracic Organ Specific Report for 2019/20 (these are also available on the OTDT website). The slides included data on the waiting list, transplants, waiting list outcomes, transplant outcomes, and rates per million population for heart and lung transplantation. The following were raised: - R Graham highlighted that Birmingham was an outlier re. lung transplantation survival, which has been discussed and addressed at previous meetings. There are ongoing plans to review that but it will take time for those statistics to catch up. F Smith stated that in terms of time periods used, the 5-year time period will be using more historic data. J Parameshwar confirmed that from a cardiothoracic transplant cardiologist view point the 5- and 10-year survival is as important as short-term survival. - R Graham raised a concern around the waiting list for hearts at the Freeman Hospital (large number of patients waiting). J Parameshwar confirmed that the waiting list can be very misleading; it is important to separate those with and without long-term LVADS. The case with Harefield and the Freeman is that they have performed more long-term VADs than say Manchester or Papworth; this will have an impact on the number of patients waiting. - It was asked whether there is any information on the effect of lifestyle on 5- and 10-year survival figures. J Parameshwar stated that weight is not a strong predictor but that the data collected did not make lifestyle factors easy to study. Smoking does impact survival. - L Ryan asked with countries like the US, there are more transplants per million population, so is the reason behind this because there is a higher need for transplantation, or are there more donors because of the increased number of deaths? J Parameshwar reminded members to compare the UK with other like countries in Europe as the US is a big outlier: the donors there are generally 15-20 years younger than in Europe – reasons include the opioid epidemic and gunshot injuries. L Mumford and F Smith were thanked for the data presented.	
5.2	**Current levels of transplant activity – CTPG(20)14**	
	Refer to minute 5.1 above.	
6	**Cardiothoracic Patient Updates (- where provided)**	
	Freeman Hospital – Freeman Heart and Lung Transplant Association (FHLTA) – LM Louisefhlta@mail.com • Bags with Love – Debbie mentioned this project at the last meeting – bags have now been completed and distributed to Adult and Children's wards and gratefully received already by patients. • There is usually a raffle as part of the Christmas social meal but this year an online raffle is being organised to be drawn 12th December; it has been a big success so far with 2000 tickets sold. • A date has now been set for a virtual FHLTA AGM in January 2021. • Freeman have about 3 teams in the WTGF Billion Step Challenge. Due to finish 5th December. **Harefield Hospital – Harefield Transplant Club (HTC) - AL** http://harefieldhamsters.org • The Harefield consultants have been holding more virtual Q&A sessions for transplant patients; the most recent included information on the vaccines. • COVID continues to have a significant impact on the club's activities, whether social or sporting. A virtual quiz night has been organised for 21st November, and the AGM, held virtually, is arranged for 28th November, rather than during the club's Annual reunion (which was understandably cancelled).	

	• The club's FB Group continues to be the de facto communication platform, whether for club matters or members asking for advice on COVID issues as the rules change. **Royal Papworth Hospital – RG** https://royalpapworth.nhs.uk/patients-and-visitors/pals/patient-support-groups • We met with new Co-Director of Transplantation and Lead Transplant Nurse recently to discuss how our clinics may operate in the wake of 'wave two' and as a consequence they have agreed to provide a further video question and answer session for us in the coming days. • Second batch of gift bags for newly transplanted patients have been given over to the Transplant team – these have been particularly well received given visitor restrictions – one patient has said "*Hello, I am just recently out of hospital after getting double lung transplant 8 weeks ago. Receiving my little bag of gifts meant so much, it came at a time when everything was very hard and new problems every day, it was so refreshing for someone to walk in and give me something nice! I'm on the Facebook group but wanted to formally email you too to say thank you".* • Special mention to Eliza Bell (heart transplant patient) who has done a number of podcasts relevant to transplantation. The Transplant Team have been so pleased with these that they have commissioned her to undertake a second series of 14 podcasts which will be of great benefit to future transplant patients. Some of these podcasts will feature interviews with prior transplant patients, as well as key members of the whole Papworth Team (eg surgeons, nutritionists, physiotherapists). Eliza is to be congratulated on this initiative which has been warmly welcomed by a number of patients. The link to her podcasts is www.transplantchats.com **Queen Elizabeth Hospital – MWJ** https://www.hospitalcharity.org/patientsupportgroups • Contact has been made with the Birmingham team re. the spirometry readings; the data is feeding through, and the kits are available. **Wythenshawe Hospital** https://mft.nhs.uk/wythenshawe/services/cardiology-and-cardiothoracic-surgery/heart-and-lung-transplant/ Patient groups are asked to forward any further updates to T Monday.	
7	**Outlook and Prospects for the 'Shielded' Community**	
	It is recognised that patience is key, and the emotional and mental well-being aspect is no easier and affects everyone, especially for those who have been shielding since March. Charitable organisations are receiving lots of feedback from the patient perspective, and many calls, however there are various questions which remain unanswered. There have been delays with Government guidance when it is needed, causing disruption with decisions around schooling and jobs. It is envisaged that these meetings will not be face to face for quite some time, although the autumn 2021 could be possible (it is envisaged that CTAG will not meet until autumn 2021). The next meeting of the Patient Group will be in February 2021 via MS Teams, by which time it is hoped that there will be more news re. COVID and the vaccine – getting as many people vaccinated as early as possible is really important. L Ryan commented that for the clinically extremely vulnerable population it is hoped that employers are being sensible and using the furlough system, although it is	

	recognised that employees are probably more protected in a bigger organisation. J Jones stated that there is some information re. employment on the cystic fibrosis website https://www.cysticfibrosis.org.uk/ if anyone would find it useful. ***Post-meeting note:*** M Harrison is also a Trustee for a Learning Disabilities charity and has since reported on a discussion from a meeting re. Clinically Extremely Vulnerable (CEV) people and furloughing. It is understood that the latest furlough scheme allows organisations to furlough people who are CEV. The Government website confirms this: https://www.gov.uk/guidance/check-which-employees-you-can-put-on-furlough-to-use-the-coronavirus-job-retention-scheme#if-your-employees-health-has-been-affected-by-coronavirus-covid-19-or-any-other-conditions This will of course only benefit individuals in organisations which can benefit from furloughing, but it is helpful.	
8	**Any Other Business** R Graham and J Parameshwar will liaise with T Monday to organise a date for the next meeting. ***Post-meeting note:*** The next CT Patient Group meeting will be held on 4th February 2021, 14:00-16:00 via MS Teams – an invitation will be sent in due course.	**RG / JP / TM**

Dates of Next Meetings:

CT Patient Group – 04/02/2021, 14:00-16:00, via MS Teams
CTAGH Hearts - 22/03/2021, 11:00-16:00, MS Teams
CTAGL Lungs – 31/03/2021, 11:00-16:00, MS Teams