NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

THE FIFTEENTH MEETING OF THE NHSBT CTAG(L) LUNGS ADVISORY GROUP ON WEDNESDAY 1ST APRIL 2020, 11:00-16:00 VIA MICROSOFT TEAMS/TELECON

PRESENT:

Jayan Parameshwar (JyP)	**CTAG Chair**, Royal Papworth Hospital
Martin Carby (MC)	**CTAGL Deputy Chair**, Respiratory Physician, Harefield Hospital
Mo Al-Aloul (MAA)	Respiratory Physician, Wythenshawe Hospital
Ayesha Ali (AA)	Highly Specialised Services, NHS England
Marius Berman (MB)	Joint Associate Clinical Lead Organ Retrieval, NHSBT
Pedro Catarino (PC)	Centre Director, Royal Papworth Hospital
Melissa D'Mello (MDM)	CTAG Lay Member, NHSBT
John Forsythe (JF)	Medical Director, OTDT, NHSBT
Rob Graham (RG)	Chair, CTAG Patient Group
Gill Hardman (GH)	CTAG Clinical Audit Group Cardiothoracic Fellow, Freeman Hospital
Margaret Harrison (MH)	CTAG Lay Member, NHSBT
Rachel Hogg (RH)	Statistician, Statistics and Clinical Studies, NHSBT
Jim Lordan (JL)	Respiratory Physician, Freeman Hospital
Debbie Macklam (DMa)	Senior Commissioning Manager, NHSBT
Derek Manas (DM)	Joint Clinical Governance Lead, NHSBT
Jorge Mascaro (JM)	Centre Director, Queen Elizabeth Hospital
Katie Morley (KM)	Lead Nurse Recipient Co-Ordinator
Lisa Mumford (LM)	Head of ODT Studies, NHSBT
Jane Nuttall (JNu)	Recipient Co-Ordinator, Wythenshawe Hospital
Jas Parmar (JP)	Respiratory Physician, Royal Papworth Hospital
Nicky Ramsey (NR)	Recipient Co-Ordinator, Harefield Hospital
Rachel Rowson (RR)	Deputising for Marian Ryan (Regional Managers Rep), SNOD
Philip Seeley (PS)	Recipient Transplant Co-ordinator, Freeman Hospital
Andre Simon (AS)	Centre Director, Harefield Hospital
Helen Spencer (HS)	Centre Director, Respiratory Physician, Great Ormond Street Hospital
Richard Thompson	Respiratory Physician, Queen Elizabeth Hospital
Hester Ward (HW)	Consultant in Public Health Medicine, NHS Scotland
Sarah Watson (SW)	Highly Specialised Services, NHS England
Craig Wheelans (CW)	National Services Division, NHS Scotland
Julie Whitney (JW)	Head of Service Delivery (ODT Hub), NHSBT

IN ATTENDANCE:

Caroline Robinson (CR)	Clinical & Support Services, ODT, NHSBT
Lauren Caddick (LC)	Assistant Manager of Service Delivery
Lucy Newman (LN)	Clinical and Support Services, OTDT, NHSBT

Item		Action
	Apologies and welcome Apologies were received from Anthony Clarkson, Catherine Coyle, Ben Davies, Ben Hume, Karen Redmond, John Richardson, Mick Stokes The Chair welcomed all to the meeting and wished everyone good health in the current climate. He also raised the issue of supply of Adoport and asked all to ensure that use of this is monitored in individual centres.	
1	**Declarations of interest** There were no declarations of interest at the meeting.	
2	**Minutes and Action Points of the CTAGL Meeting on 26/09/19**	
2.1	The Minutes of the previous CTAG Lungs meeting held on 26 September 2019 were accepted as a true record	
2.2	Action Points from the previous CTAG Lungs meeting were raised by the Chair. Outcomes and actions from these are detailed in the attached Action Points for this meeting.	
3	**Medical Director's Report** J Forsythe updated the meeting with the latest information, particularly regarding COVID-19. Feedback shows that regular bulletins going out to around 1400 people in the transplant community regarding the current situation are greatly valued. Daily calls between NHSBT senior staff and	

	commissioners of transplantation services and government health care departments are ongoing and aim to keep services open where it is safe to do so. Changes around living donation, donor restrictions and retrievals have been instigated, acknowledging that these teams are working under very difficult situations. If the situation changes centres may be allowed more say in local allocation. Through emergency planning measures, NHSE is trying to protect life-saving cardiothoracic and liver transplantation, particularly urgent and super-urgent transplantation, by completing a scan of local resources at respective transplant centres. To this end, in the last few days, there have been 3 donors and 5 transplants carried out at the highest end of quality organs and these went to the sickest and highest priority patients. On the research side INOAR, QUOD and Pithia are all suspended currently. R Graham stated that he is getting feedback that many organ recipients who are designated as most vulnerable and who are self-isolating have not received the letter sent out from government that would enable them to get help and support (such as supermarket deliveries) and this is now an issue that needs attention. The government website advises those omitted to contact their GP and then the transplant team, but many GPs are unaware and unprepared to deal with what has happened and cannot help. Clinicians are therefore advised that they may receive requests from recipients to add them to the list of vulnerable patients. J Forsythe stated that the advice came down from government departments and not from NHS England or NHSBT. While the data on who should receive the letter was provided, NHSBT had no control on the next steps. It is advised that recipients who are in the priority group and who have not received the letter should self-register. It was also noted that patients of highly specialist services should have been on the list to receive the letter. A comment was made that the letter regarding the changes to donor criteria sent to the CF Trust had not been very clear and many patients are now asking whether transplant activity will continue. The need for communication in simple language was discussed. Whether a letter sent through the post was appropriate in a rapidly changing climate was also discussed. It was noted that non-urgent lung transplant is unlikely to go ahead at present, principally for reasons of safety and lack of appropriate ICU capacity. The Department of Health is aware of issues that have arisen and is now looking at ways in which the situation can be resolved. M D'Mello asked whether, despite the measures being put in place, when COVID-19 poses such an increased risk to patients, clinicians and the public, it is right to continue with retrieval and transplantation and that these decisions are made at a local rather than national NHS level. She also asked about the opportunity cost of all the resources being used for transplant (ie, pre transplant, during and post-transplant), including allied services. J Forsythe stated that there is a very careful review conducted daily across the country to check ICU and other resources. At present, this is being managed well with some specific exceptions, particularly in the London area. Local centres are conducting risk analyses and where a life-saving transplant is required and ICU resource is not needed for surgery elsewhere, transplantation will go ahead. It was also noted that many patients waiting for a heart transplant are using an ICU bed and a transplant is sometimes the best way to move them out of critical care. In addition, the risk for kidney patients on the waiting list may be reduced by going ahead with a transplant rather than remaining on haemodialysis in the present climate.	
4	**Governance Issues**	
4.1	**Non-compliance with Lung Allocation** D Manas reported that there were no recorded incidents of non-compliance with lung allocation since the last meeting.	
4.2	**Clinical Governance Report** There are few injuries to report currently. Lung damage has been noted while placed on EVLP with 3 lungs inadequately prepared (from the same centre). **ACTION: D Manas will chair a small group of surgeons to agree a protocol on how to prepare for EVLP.**	**D Manas**
4.3	**CUSUM Monitoring of 90-day outcomes following lung transplantation** There have been no CUSUM signals in lung transplantation in the last six months.	
4.4	**Group 2 Transplants** There have been no group 2 transplants since the last meeting.	
5.	**Lung Utilisation**	
5.1	**Lung Summit: Actions** Unfortunately, given current COVID-19 issues it was not possible to cover this in as much detail as originally planned at the CTAGL meeting. However, it was reported that this was a very useful day and remains a very high level of priority. A set of recommendations will be taken forward with commissioners and departments of health. These will be picked up again as soon as the current COVID-19 crisis has passed.	

5.2	**Centre Specific Activity Report** A Summary of recent transplant activity was circulated prior to the meeting. According to data on the UK Transplant Registry, as reported in the Weekly Statistics in the current financial year up to 23 February 2020, there have been 1% fewer DBD donors and 6% more DCD donors than the same period in the previous financial year. At the same time, there have been 8% fewer heart transplants and 1% fewer **l**ung transplants.	
5.3	**NHSBT Lung Utilisation Project: Lung Risk Score**	
	The report was circulated prior to meeting. Working under the supervision of Professor Andrew Fisher, Professor John Dark and Miss Karen Booth, the proposed project title is ***Developing strategies to increase donor lung utilisation in UK Cardiothoracic Transplantation***. It is intended that this work will be submitted for the award of PhD at Newcastle University in 2022. Three projects make up the total workload and although these are currently on hold, preparation continues in the background. • Development of the UK Lung Risk Index • Evaluation and quality improvement of UK Donor Care Management • Cardiothoracic organ offers and utilisation behaviour Further information is detailed in the paper circulated. The meeting agreed that the work planned was excellent and very much aligned to the actions arising from the Lung Summit. It was suggested that M Berman should be involved, especially in the development of the donor care bundle. J Forsythe commented that he was very grateful for the work done to date and that support will be given where possible. It was also suggested that buy in from the abdominal teams was important as well as consideration of a buddy system and external as well as internal review. It was also noted that the work C Callaghan has achieved in organ utilisation is resulting in a change of behavior in renal transplant units.	
6	**ODT Hub Update**	
6.1	**Organ offering changes and Fast Track triggers** Work on Fast track triggers has not progressed as quickly as hoped and IT changes are still awaited.	
6.2	**Length of Donation Pathway** Unfortunately, it did not prove possible to present the paper on the Length of Donation pathway to the meeting as planned due to the current COVID-19 crisis. However, of special note for this meeting is that the length of donation increases significantly when cardiothoracic organs are involved. J Whitney reported that workshops and other work had taken place with specialist nurses to look at the issues involved, and a list of recommendations has resulted: • Review how offers are made and increase time for considering a donor from 45 to 60 minutes but ask centres to accept organs in all categories. • Review how fast track offers and how these are made • One point of contact with each centre only – this will now be implemented rather than piloted • A read back system to be put in place to ensure there are clear definitions of the time of the pathway • An acceptance of what data requirements are needed, (eg if an image needed to make decision) and a mandatory data set to be provided at offering. • A concept of a maximum time delay so that multiple delays do not occur. • A 'red button' to speed up the process particularly if a donor family is likely to withdraw consent because of delays in order to get the donation process completed. Developing this further remains a priority when normality returns. Some of areas that were to be suggested in the paper will need to be enacted quickly. The paper will be circulated shortly, and all are encouraged to read this promptly as recommendations will be going forward in future. **ACTION: J Whitney to circulate paper on Length of Donation Pathway** Work is ongoing to ensure speeding up of offering during the COVID-19 crisis. Members raised the issue of Group Offering which was a major problem for centres. The Chair agreed with this and said that it was regrettable that NHSBT had been slow in implementing the changes to offering agreed 6 months ago which would have resolved this situation. Further changes have now been suggested.	**J Whitney**
6.3	**Potential Changes in the Donor Pathway - Super Urgent Liver** Recipients listed for super urgent liver transplant are at risk of rapid and fatal deterioration during the time between offering and transplantation. The deterioration may occur over hours, such that the patient may become un-transplantable. Experience suggests that potentially avoidable retrieval delay contributes to poor outcome in these patients. A paper was circulated prior to this meeting and was passed for implementation at CTAG Hearts. All are encouraged to read the paper.	
6.4	**Recipient Update on Heart/Lung Offering Scheme Changes** This is in user acceptance phase at present and will go live once the COVID-19 issue has passed.	

7.	**Lung Allocation**	
7.1	**Summary of Adjudication Panel Appeals** The Chair thanked all members of the panel for their participation in this process. L Mumford reported: • For urgent adult lung adjudication panel appeals and all urgent adult lung registrations by centre, 18 May 2017 – 29 February 2020, there had been 24 appeals in total of which 17 were approved. • For urgent paediatric lung adjudication panel appeals and all urgent paediatric lung registrations by centre, 18 May 2017 – 29 February 2020 there had been 7 in total, all which were approved. The meeting queried the value of going to appeal for paediatric cases when all are usually approved. It was agreed that on balance, as adjudication panels review new criteria it was preferable to keep the current process in place at present. • For urgent heart-lung adjudication panel appeals and all urgent heart-lung registrations by centre, 26 October 2016 – 29 February 2020 there were 23 in total of which 15 were approved. The appeals Included 5 super-urgent heart-lung appeals - 2 from Harefield, 1 from Manchester and 2 from Papworth (same patient) - all of which were rejected. Two patients were registered for super-urgent heart lung transplant without panel approval and transplanted; (one was approved for urgent listing). Two patients were registered for urgent heart lung transplant without panel approval and have since been removed.	
7.2	**Update of Guidelines on Testing for and Interpreting anti-HLA** There was no update at this meeting	
7.3	**Fast-tracking of European paediatric offers see Paper** A paper was circulated illustrating Paediatric donor heart offers from European centres for paediatric recipients split by offer result, centre and offer year. A feeling was expressed that there was perhaps unhelpful competition between Newcastle and GOSH to take any European offer as quickly as possible and it was suggested Hub Operations could help ensure a more collaborative approach by alternating offers between centres. It was noted that European fast track offers go to all countries at the same time and Hub Operations has no influence on the time allowed and would not know if there is a suitable candidate for an organ without doing a matching run by which time the organ offer is likely to have gone elsewhere. There is also sometimes a lack of data (eg blood group or height) and the offer may get lost in the time needed to gather more information. However, it was agreed it would be useful to see if the current situation could be alleviated in any way. **ACTION: J Whitney will investigate and report back to Newcastle and GOSH.**	**J Whitney**
7.4	**Cardiothoracic and Liver registrations** A paper was presented at the Spring 2018 CTAG meeting showing activity on combined cardiothoracic and liver registrations between 1 January 2000 and 31 December 2017. Following this, it was agreed that heart-liver patients should continue to go through the adjudication panel if they do not qualify for urgent heart registration. It was initially agreed that lung-liver patients were entitled to automatic urgent listing, but this has since been changed and needs approval from the adjudication panel if urgent criteria are not met. There has subsequently been a slight increase in the number of patients registered for a cardiothoracic and liver transplant. The paper circulated shows combined cardiothoracic and liver registrations and outcomes from 1 January 2018 to 29 February 2020 as well as details of any patients submitted to the heart or lung adjudication panels for combined cardiothoracic and liver transplant listing. Since 1 January 2018, there have been 8 patients registered for a cardiothoracic and liver transplant (4 heart and liver, 4 lung and liver). As at 3 March 2020, 5 of these patients are currently active on the list, 2 have received transplants and 1 died on the list. The 4 lung-liver patients generated offers from 80 donors up to 29 February 2020, with one acceptance. The most common reasons for decline were donor type, poor function, and donor history. None of the lung-liver patients required panel approval. The issue was raised that patients listed as multi-visceral on the liver system are listed as combined patients and therefore are a priority. However, this is not the case on the lung list. Concern is expressed as these patients may get local priority but don't get broader priority across the nation. The Chair remarked that the until there is agreement across centres that these patients need national prioritisation, the current position will remain. This had been debated at CTAG Lung 6 months ago. The decisions taken to the Adjudication Panel would continue to be monitored.	
8	**Statistics and Clinical Studies reports**	
8.1	**Summary from Statistics and Clinical Studies** L Mumford reported: • The 2019-20 interim report on cardiothoracic transplantation and the 2018/19 annual report on Mechanical Circulatory Support Related to Heart Transplantation are now on the ODT website.	

	• Work has continued, in collaboration with the Winton Centre for Risk Communication, to develop a tool to support conversations between patients and clinicians at the time of listing with regards to the risks and benefits of transplantation. A lung model is being developed first followed by kidney and then the other organs. • The ODT Hub Programme ends on 31st March 2020. Statistics and Clinical Studies will continue to provide support to the ODT Directorate.	
8.2	**Registry Form Returns** Following poor returns previously, it was agreed that centres would be notified of their current form return rates so that outstanding follow-up can be submitted before June 2020, ahead of the run for the NHSBT annual report. All rates for adult lung forms are above 80%. For paediatrics, GOSH has low return rates across most forms for both hearts and lungs, although it was noted that someone is now employed there to oversee this. **ACTION: Statistics and Clinical Studies to chase form returns prior to release of data for the annual report**	**L Mumford**
9	**NHSE Update**	
9.1	**VV ECMO Update** This has gone out for stakeholder consultation with internal interest with CRG and will then go out for wider consultation. Due to the current situation, all consultation is on pause, but will resume when normality resumes.	
9.2	**Extra Corporeal Photopheresis update** A preliminary policy proposal was submitted in Feb and is now with PPP and NHSE. This is also on hold for the moment. An application is also with HTME and A Fisher is leading a group applying for the use of ECP in a randomised control trial running parallel with the application to NHSE.	
10	**Reports and Discussion Points from the Chair**	
10.1	**CT Centre Directors Telecon** The Minutes were circulated for information	
10.2	**RAG (NRG) Update** The Minutes from the previous meeting were circulated. M Berman reported: • 6 retrieval teams are being monitored daily. Only one cardiothoracic team was inactive on 31 March and at present, there are 5 active teams who are trying to maintain retrieval activity as much as possible. • A project to exchange remote organ imaging between the retrieval surgeon and implanting surgeon has been agreed. Private funding of £2700 from individual hospital charitable funds has been agreed to trial this at Papworth and Edinburgh. Other hospitals are encouraged to seek funding as well. It was agreed that this sort of development is important for clinical governance. **ACTION: M Berman to circulate further data to interested parties outside the meeting.** • ANRP is increasing. A dedicated workshop on this topic is planned and it is hoped as many centres as possible will attend. • I Currie has completed a NORS survey asking teams to look at workforce and sustainability. Delays has been the main feedback from retrieval teams and when cardiothoracic teams are involved, the whole pathway increases significantly. **ACTION: M Berman to circulate survey.**	**M Berman** **M Berman**
10.3	**Recording Quality of Life (QoL) following transplant** The ALTP meeting did not take place due to COVID-19 issues and travel restrictions. An email poll has identified that there are a few different tools in use at the point of assessment. Only Birmingham repeats the score (using SF12) at 6 months; everyone else does this at the point of assessment. There has been no expression of preference for the tool used except from Manchester who wants SF12. All are in favour of a national database. There is clearly a wish to collect quality of life data. It is important to arrive at a consensus on tools and points where quality of life should be measured. The next step will be to go with a proposal and then discuss with Statistics at NHSBT to collect that data collection nationally while being mindful of the fact that centres have not always been good at completing forms for NHSBT. It is therefore important to be realistic in aspirations. **ACTION: M Carby to report on next steps**	**M Carby**
10.4	**HCV Positive Donor Organ update** It was agreed this was difficult to do at present given the follow up needed in the liver unit and with CT. It was advised that all paperwork should be put together for when normality resumes. Papworth and Birmingham have signed up and other centres are encouraged to do so as well.	
10.5	**QUOD Update** M Berman confirmed that QUOD is postponed currently. However, there are significant numbers of samples stored in the biobank for research purposes.	
10.6	**Real Time Retrieval Imaging** See Item 10.2 above	
10.7	**CTAG Workplan** It was agreed that Quality of Life will be added to the workplan.	

	ACTION: L Mumford to add	**L Mumford**
11	**Reports from sub-groups**	
11.1	**CTAG Clinical Audit Group (CAG) Chairs Report** The report was circulated prior to this meeting. Two points were raised. • A 13 months review of the new allocation scheme has now been completed and there is a descriptive analysis in the report of changes in activity and increases and decreases as well as a critical analysis of why this is the case. This is now nearly ready for submission. • It was noted that following collaboration with the CF community approval for data release and linkage with NHSBT and disease related databases is needed by NHS Digital to release anonymised data. In time it is hoped there will be more evidence-based criteria to refine the allocation scheme.	
11.2	**CTAG Patient Group** • Nothing further was added to the comments in Item 3. A Ali was thanked for any help that can be offered to lobby appropriate parties so that extremely vulnerable patients are all recognised in the current climate. • In a follow up to the lung summit the patient group also wrote to Baroness Blackwood, Fiona Marley and Millie Banerjee on 28 January concerning the pressure on ITU beds. This will now be picked up in the future. • It was also agreed that while the next Patient Group meeting in May 2020 will no longer be face-to-face, it should go ahead by other means given the number of concerns facing patients at present. More details about the meeting will follow.	
12	**For Information**	
12.1	**Transplant Activity Report** The paper showing the Donation and Transplantation Monthly activity report as at 14 February 2020 over two financial years was presented.	
12.2	**NHSBT ICT Update for Advisory Groups** This paper was circulated for information**.**	
13	**Any other business**	
13.1	**Travel/accommodation booked for Advisory Group meetings** The Chair encouraged all members to book and any travel or accommodation needed to attend CTAG meetings when face to face meetings resume through the Clinical and Support Team at NHSBT and to consider any bookings well in advance to take advantage of lower fares that may be available	
13.2	**Centre availability** It was agreed that an email should be sent to the Chair on any day a centre is not open.	
13.3	**Lung Referral Proforma** A request has been received by NHSBT to update the Lung Referral Proforma with Papworth's new address. This is not an NHSBT form. **ACTION: It was agreed that R Thompson and J Parmar will update the original form and will circulate to centres** It was also felt that for the future, an electronic referral pathway should be considered to improve quality, information and speed of referrals. If all centres could agree content this could be transferred to a web platform. Martin Carby said that he had helped developed such a form at Harefield and will discuss this with colleagues. **ACTION: Martin Carby to start group email to discuss feasibility of taking this forward.**	**R Thompson / J Parmar** **M Carby**
13.4	**Centre Directors discussion for Liver, Heart and Lungs** **ACTION: D Manas will lead this in order to update centre directors once a week.**	**D Manas**
13.5	**Online form for anyone (recipients/patients) identifying confirmed COVID-19 patients** L Mumford confirmed that this form is available on the NHSBT ODT website and should be completed by anyone identifying these patients. **ACTION: LM to send link to the form for centres to fill in.**	**L Mumford**

Date of next meetings

CTAG Patient Group – Wednesday 13th May 2020 12:00 to 16:30 - TBA
CTAG Lungs Meeting – Thursday 17 September 2020, Mary Ward House, Tavistock Place, WC1H 9SN – 11:00 to 16:00
CTAG Hearts Meeting – Monday 28 September 2020, Mary Ward House, Tavistock Place, WC1H 9SN – 11:00 to 16:00
CTAG Patient Group – Wednesday 18 November 2020, 12:00 to 16:30 - Fine Room 1&2, Asia House, 63 New Cavendish Street, London, W1G 7LP

HOLD THE DATE – Proposed Meetings 2021

CTAG Hearts Meeting – Monday 22 March 2021 – 11:00-16:00 – TBA
CTAG Lungs Meeting – Weds 31 March 2021 – 11:00-16:00 - TBA