

**NHS BLOOD AND TRANSPLANT  
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE  
THE TWELFTH MEETING OF THE NHSBT CTAG PATIENT GROUP (CTPG)  
ON WEDNESDAY 13<sup>TH</sup> MAY 2020 FROM 1330 – 1530  
MEETING VIA MICROSOFT TEAMS OR DIAL IN**

**PRESENT**

Rob Graham (RG)	CTAG Patient Group Co-Chair, Governor, Royal Papworth Hospital
Jayan Parameshwar (JyP)	CTAG Patient Group Co-Chair, CTAG Chair, Royal Papworth Hospital
Janet Atkins (JA)	Patient Representative, Royal Papworth Hospital
Eliza Bell (EB)	Transplant Recipient, Royal Papworth Hospital
Debbie Burdon (DB)	Patient Representative, Treasurer of FHLTA, Freeman Hospital
Lynda Ellis (LE)	New Start Transplant Charity, Wythenshawe Hospital
Leila Finikarides (LF)	Research Assistant, The Winton Centre
Margaret Harrison (MH)	CTAG Lay Member Representative
Beverley Jones (BJ)	Transplant Social Worker, Wythenshawe Hospital
Alan Lees (AL)	Patient Representative, Harefield Transplant Club, Harefield Hospital
Lisa Mumford (LM)	Head of OTDT Studies, NHSBT
Jane Nutall (JN)	Recipient Transplant Coordinator, Wythenshawe Hospital
Rosie Pope (RP)	Parent of Transplant Recipient, Harefield Hospital
Lucy Ryan (LR)	Transplant Recipient, Royal Papworth Hospital
Marian Ryan (MR)	Specialist Nurse – Organ Donation, NHSBT
Tom Speight (TS)	Policy Analyst, Cystic Fibrosis Trust
Michael Thomson (MT)	Patient Representative, Golden Jubilee National Hospital
Mark Whitbread-Jordan (MWJ)	Patient Representative, Queen Elizabeth Hospital
Bruce Willan (BW)	Communications Officer, NHSBT (deputy for Charlotte Silver)

**IN ATTENDANCE**

Lucy Newman Secretary, NHSBT

**APOLOGIES**

Martin Carby, Ged Higgins, Lorraine Jerrett, Emma Johnson, Dominic Kavannagh, Katie Morley, Charlotte Silver (Bruce Willan deputised), The Somerville Foundation

**MINUTES**

<b>1</b>	<b>Welcome and Introduction</b> RG welcomed members to the first MS Teams Virtual Meeting of the CTAG Patient Group. Two members dialled in, there were no reported problems accessing the meeting today.	
<b>2</b>	<b>CTPG(20)01 – Declarations of Interest</b> There were no declarations of interest in relation to the meeting today.	
<b>3</b>	<b>CTPG(M)(19)02 – Minutes of the last meeting held 13<sup>th</sup> November 2019</b>	
<b>3.1</b>	<b>Accuracy</b> The minutes of the last meeting are approved by the group as an accurate record of the meeting.	
<b>3.2</b>	<b>Action Points</b> Action points arising from the last meeting were: Chairs tenure, terms of reference and lung transplant/ICU bed numbers	
<b>3.2.1</b>	<b>CTPG(20)02 – Chair Tenure (Letter circulated via email 12/02/2020)</b> The letter relating to the extension of tenure for RG as Co-Chair was sent in February, RG received emails from members congratulating him and is pleased to be able to continue in the role for a further two years.	

<p>3.2.3</p> <p>3.2.3</p> <p>3.3</p>	<p><b>Terms of Reference</b>  RG and JyP revised the Terms of Reference last year for the Cardiothoracic Patient Group which are now updated on the website:  <a href="https://www.odt.nhs.uk/transplantation/cardiothoracic/cardiothoracic-patient-group/">https://www.odt.nhs.uk/transplantation/cardiothoracic/cardiothoracic-patient-group/</a>  RG promoted the ODT website: <a href="https://www.odt.nhs.uk/">https://www.odt.nhs.uk/</a> as a useful source of additional information and current updates to transplantation.</p> <p><b>CTPG(20)03 – Lung Transplant / ICU Beds (Letter circulated via email 22/02/2020)</b>  Following the Lung Summit RG wrote to Baroness Blackwood, Fiona Marley and Millie Banerjee about the pressures on ICU beds for lung transplant patients. the letter has been acknowledged; this will be revisited later in the year at a more appropriate time.</p> <p><b>Any Other Business</b>  Max and Keira’s Law  The government is committed to ensuring the process to introduce Max and Keira’s Law on deemed consent is completed but secondary legislation regarding novel transplantation such as face and limb which would not be included in the act, was due to be debated at the end of April. The Department of Health and Social Care is aiming to get the bill to parliament this week or next with exceptional rules negating the requirement for secondary legislation debate. It is unlikely that organ donation will proceed under deemed consent during the COVID-19 pandemic.  <i>**Post Meeting Note: Max and Kiera’s Law came into effect in England on 20<sup>th</sup> May 2020.**</i></p>	
<p>4</p> <p>4.1</p> <p>4.2</p>	<p><b>CTAG Update</b>  <b>CTPG(20)04 CTAGH Hearts Minutes (23/03/20)</b>  The CTAGH Hearts minutes of the March meeting are included for information. RG reviewed the minutes, one item of concern for the Patient Group was the issue faced by some patients around delays receiving Shielding Letters which was raised at both heart and lung meetings. RG stated that he had written to the NHSE, NHSBT and NHS Digital expressing concerns.</p> <p><b>CTPG(20)05 CTAGL Lungs Minutes (01/04/20)</b>  The CTAGL Lungs minutes of the April meeting are included for information. COVID-19 discussion took over much of the lungs meeting, there is little point in trying to implement any of the changes discussed at the Lung Summit in the current climate.</p> <p>If there are any questions relating to the minutes, please email RG or JyP.</p>	
<p>5</p> <p>5.1</p>	<p><b>Cardiothoracic Patient Updates; Impact of COVID-19</b>  <b>Freeman Hospital – Freeman Heart and Lung Transplant Association (FHLTA): DB</b> <a href="https://www.fhlta.org.uk/">https://www.fhlta.org.uk/</a>  Recent committee changes for FHLTA are:</p> <ul style="list-style-type: none"> <li>• Adele Lambert - Chair of FHLTA</li> <li>• Derek Airey - Honorary President of FHLTA</li> <li>• Debbie Burdon – Treasurer</li> <li>• Paul Woodward - Assistant Sports Manager.</li> <li>• Following the cancellation of UK and European Transplant Games, training has halted with the new sports kit sourced by Louise Maclellan yet to be worn</li> <li>• FHLTA awarded funding towards a Doctor in Transplant at the University</li> <li>• FHLTA has also awarded a grant of £12k to Professor John Dark for a transonic flow probe as part of his work in Lung Transplant</li> <li>• A few members of FHLTA contracted and recovered from COVID-19, some at home, some in hospital, all are now doing well</li> </ul>	

- Patients are keeping in contact via social media with quizzes, competitions and virtual exercise classes etc...
- The November AGM and Christmas Party will be confirmed later in the year

## 5.2 Golden Jubilee National Hospital: MT

- Two patients received transplants, and both are doing well
- Two patients attended the Winter Games, both did well and got medals
- Two transplant co-ordinators are redeployed to support increased cardiology throughput in the hospital, which has also taken some COVID Patients from other hospitals to help ease the pressure on the larger hospitals. GJNH have also taken some head/neck cancer patients and general surgery patients to help ease the pressure on general ICU's
- Post-transplant patient clinics have continued to run as telephone and face to face appointments and continue to see patients transplanted within the year
- Other patients have been contacted by the transplant nurse with local arrangements for blood samples to be taken locally
- The future of the clinics is currently being reviewed with NHS Near Me (virtual) clinics being considered

## 5.3 Harefield Hospital: AL & RP

<https://www.rbht.nhs.uk/patients-visitors/patients/patient-support-services/independent-support-groups>

- The annual Harefield Charity Festival in August has been cancelled this year and the Charity has seen a reduction in fundraising since the start of the pandemic
- The Harefield Facebook page has seen increased traffic with members benefitting from the use of social media during these times
- Harefield Hospital has posted updates to the Facebook page which members have found particularly useful
- And members of the group bought and donated items for staff and patients at the hospital
- The Harefield Hospital Garden plans are well under way and will continue to progress, supported by the importance of the healing powers of nature

## 5.4 Royal Papworth Hospital

<https://royalpapworth.nhs.uk/patients-and-visitors/pals/patient-support-groups>

- Transplants have been happening and Royal Papworth has taken some patients with COVID-19
- Some of the transplant team members are redeployed to ICU
- Most face to face clinics have been suspended and arrangements made for drive in blood testing
- The Facebook page has seen an increase in traffic; and new membership of 30% with the page proving a great communication tool
- The Royal Papworth Patient group are supporting a gift bag initiative, where patients in hospital for transplants are given a gift bag with a few key essentials in; an initiative set up by the group, with transplant patients sponsoring the bags

RG gave special thanks to Anne Thompson one of the transplant co-ordinators who has worked in transplant at Royal Papworth and Freeman Hospitals, dedicating c. 40 years' service to transplant patients before her retirement. Anne will be missed but will continue to attend the transplant games.

## 5.5 Queen Elizabeth Hospital: MWJ

<https://www.hospitalcharity.org/patientsupportgroups>

- Two heart transplants were carried out since the start of the pandemic
- Clinic arrangements have been altered to provide remote support to patients during this time

5.6	<p><b>Wythenshawe Hospital: LE/BJ</b>  <a href="https://mft.nhs.uk/wythenshawe/services/cardiology-and-cardiothoracic-surgery/heart-and-lung-transplant/">https://mft.nhs.uk/wythenshawe/services/cardiology-and-cardiothoracic-surgery/heart-and-lung-transplant/</a></p> <ul style="list-style-type: none"> <li>• Fundraising has been affected with some funds still trickling in</li> <li>• The £1million refurbishment is underway and its hoped this will be completed by the end of the summer</li> <li>• LE is the manager for the European Heart and Lung Transplant Games which have been cancelled this year, she will be attending a meeting in the next few weeks where it is hoped the venue for the 2022 Games will be announced</li> <li>• Wythenshawe has carried out 2 transplants so far during the pandemic</li> <li>• The New Start Charity have funded the trial of Sherpa Pak organ transport system, which has been used for four patients with good results. The charity has agreed to fund a further five Sherpa Paks</li> </ul>	
6 6.1	<p><b>Current activity levels of Cardiothoracic Transplant Impact of COVID-19</b></p> <p>Transplant numbers for all solid organs combined have reduced by around 1000 when compared year on year with last year, although some organs have been more affected than others. In May 2019 there were 25 cardiothoracic transplants compared to 14 in May 2020. Centres made the decision to only transplant urgent lungs at the start of the lockdown period, so this was a planned reduction in activity; two lung transplants took place during this time.</p> <p>Most centres are now restarting lung transplant activity. Harefield confirmed that cardiothoracic transplantation has restarted, Royal Papworth will work with urgent patients including those identified at other centres, and other centres will restart activity as the burden of COVID reduces.</p> <p>Great Ormond Street have been more active than any of the other centres because paediatric patients don't seem to be as affected by COVID, but transplants have all been hearts due to those waiting urgently. GOS have transplanted more DCD hearts than anywhere else worldwide. GOS was also asked to increase its bed numbers for emergency patients from other units should treatment be required.</p> <p>JyP is in discussions with infection control at Royal Papworth and hopes non-urgent activity will re-start in June. Logistically, in terms of clinics and out-patient appointments there are still challenges to overcome like social distancing and infection control so the risks of infection will need to be balanced with the need to see patients.</p> <p>Bi-weekly NHSBT update meetings are held to keep centres updated on transplant activity levels.</p> <p><b>For information:</b>  In March 2020 there were 18 heart transplants and 7 lung transplants carried out  In April 2020 there were 12 heart transplants and 1 lung transplant carried out  <a href="https://www.organdonation.nhs.uk/get-involved/news/coronavirus-the-latest-updates/">https://www.organdonation.nhs.uk/get-involved/news/coronavirus-the-latest-updates/</a>  <a href="https://www.odt.nhs.uk/information-for-patients/coronavirus-faqs/">https://www.odt.nhs.uk/information-for-patients/coronavirus-faqs/</a></p>	
7	<p><b>Outlook and Prospects for the 'shielded' community</b></p> <p>Understandably there was discussion in the group about how members are coping with COVID and what might happen next.</p> <p><b>Cardiothoracic patients who have had COVID:</b>  JyP reported information that he had seen on 12/05/20 relating to COVID numbers in transplant patients.</p>	

Overall about 20 heart transplant patients and 15/16 lung transplant patients have been admitted to hospital with proven COVID 19 infection. Sadly, five heart and five lung transplant patients have passed away, but some were being treated for other underlying health conditions or had grafts which were failing. Data from Spain suggests that lung transplant patient outcomes are not as good as for heart transplant patients.

Further understanding of the impact of COVID alongside immunosuppressant and other medications and treatments given to pre and post-transplant patients for all organ transplants is required to model risk based on age, gender etc. Information relating to antibody tests, contagion rates and re-infection rates is also needed to give more informed information; once this is available, medical staff and patients will be able to make better decisions.

**Vaccine:**

The development of vaccines against COVID was discussed. JyP advised that developments of this kind take some time to be implemented due to the rigorous testing required. Currently, advice is that those in the most clinically vulnerable cohort must continue to shield and exercise caution.

**Shielding patients:**

General guidelines will continue to be provided by government / NHSE. Individuals will make their own decisions on how best to manage their own risk and how much risk they feel in acceptable.

**R Number infection ratio:**

Members asked JyP whether anything could be done about the R number and whether there will be a point when people can get back to a more normal life? Downing Street have advised that this cannot be done geographically as small numbers of patients would impact the result, however, it may be that in time the R number or risk to certain patient groups could be assessed.

**Further discussion points and comments from CTPG Members:**

The common discussion points of the impact of the pandemic were wide ranging and included: employment and employer attitudes, financial situations, family well-being and mental health, schooling, government guidance and anticipated length of time shielding, degrees of risk.

One member commented that whilst working from home is possible currently, as a key worker a return to work will be ultimately be necessary. With a partner working in two roles, one where social distancing is not possible, the financial impact of shielding as a family unit is not possible.

Another member is shielding while their partner teaches and may have to return to the classroom.

Another member commented that the pandemic may encourage better hygiene in general. EB feels strongly that, being a year from having taken the biggest ever risk in their life to receive a precious gift and second chance at life through transplant, not being able to go out and live that life to its fullest is difficult to deal with. Daily socially isolated walks at quiet times have become essential.

The feeling within the group during the meeting was that there is overall confusion and conflicting advice and guidelines about recommended activity with social distancing, and advice regarding individuals who are shielding.

Mental health services are and always have been underfunded. This affects transplant recipients as well. DB works within mental health services and reported

	<p>an increase in the number of clients feeling alone and need of help with mental health support.</p> <p>Nationwide many are suffering with depression and anxiety, suicidal thoughts and attempts have increased. Individuals are left to make their own decisions and choices.</p>	
<b>8</b>	<p><b>Any other business</b></p> <p>The group requested further data on survival rates for patients who have been COVID positive and requested that the transplant community are kept updated on developments regarding outcomes of these patients.</p> <p>The group agreed it would be good to meet again before the scheduled November meeting for an update on each centre, August is suggested, and members indicated that they would be happy to participate.</p> <p>RG will investigate a CTPG Facebook Group how best to contact people – liaise with RG over contact options. Would like to have catch up meeting with all centres again before November.</p> <p>Reporting on COVID positive transplant patients from Public Health England and NHS Digital is now live: <a href="https://www.odt.nhs.uk/deceased-donation/covid-19-advice-for-clinicians/">https://www.odt.nhs.uk/deceased-donation/covid-19-advice-for-clinicians/</a></p>	<p><b>L Mumford</b></p> <p><b>R Graham</b> <b>J Parameshwar</b></p> <p><b>R Graham</b></p>
<b>9</b>	<p><b>Date of Next Meetings</b></p> <p><b>CTAGL Lungs</b> Thursday 17<sup>th</sup> September 2020 – MS Teams Meeting</p> <p><b>CTAGH Hearts</b> Monday 28<sup>th</sup> September 2020 – MS Teams Meeting</p> <p><b>CTPG</b> – Wednesday 18<sup>th</sup> November 2020 – MS Teams Meeting</p>	