

**NHS BLOOD AND TRANSPLANT  
ORGAN AND TISSUE DONATION AND TRANSPLANTATION  
THE FIFTEENTH MEETING OF THE NHSBT  
CARDIOTHORACIC PATIENT GROUP (CTPG)  
ON WEDNESDAY 12 MAY 2021 FROM 10:00 TO 13:00**

**MINUTES**

**PRESENT**

Rob Graham (RG)	CTAG Patient Group Chair
Janet Atkins (JA)	Transplant Support Group, Governor, Royal Papworth Hospital
Eleanor Blann	Dept of Nursing and Physiotherapy, University Hospitals Birmingham
Debbie Burdon (DB)	Patient Representative, Treasurer of FHLTA, Freeman Hospital
Trevor Collins (TC)	Heart Transplant Recipient, Royal Papworth Hospital
Lynda Ellis (LE)	New Start Transplant Charity, Wythenshawe Hospital
John Forsythe (JF)	Medical Director – OTDT, NHSBT
Simon Gach (SG)	Double Lung Transplant Patient, Royal Papworth Hospital
Maggie Gambrell (MG)	Heart Transplant Patient, Royal Papworth Hospital
Margaret Harrison (MH)	CTAG Lay Member Representative
Kimberly Hayles (KH)	Transplant Recipient Patient, Harefield Hospital
Ged Higgins (GH)	Patient Representative, Wythenshawe Hospital
Lorraine Jerrett (LJ)	Recipient CT Transplant Co-ordinator, Golden Jubilee National Hospital
Beverley Jones (BJ)	Transplant Social Worker, Wythenshawe Hospital
Jessica Jones (JJ)	Cystic Fibrosis Trust
Stephen Kirkham (SK)	Heart Transplant Patient, Golden Jubilee
Alan Lees (AL)	Patient Representative, Harefield Transplant Club, Harefield Hospital
Jane Nuttall (JN)	Recipient Transplant Co-ordinator, Wythenshawe Hospital
Harsa Parmar (HP)	Heart and Lung Transplant Recipient, Royal Papworth Hospital
Jas Parmar (JP)	Chair CTAG Lungs, NHSBT (Royal Papworth)
Rochelle Pointon (RP)	CT Recipient Transplant Co-ordinator, Birmingham
Rosie Pope (RPo)	Parent of Transplant Recipient, Harefield Hospital
Richard Quigley (RQ)	Lead Nurse Transplant, Royal Papworth Hospital
Sally Rushton (SR)	Senior Statistician, NHSBT
Lucy Ryan (LRy)	Heart Transplant Patient at GOSH, (now at Papworth helping with Heart Transplant Families UK)
Sandeep Shah (SS)	Heart Transplant Recipient, Royal Papworth Hospital
Adrian Sims (AS)	Heart and Lung Patient (awaiting transplant)
Michael Thomson (MT)	Patient Representative, Golden Jubilee National Hospital
Rajamiyer Venkateswaran (RV)	Chair CTAG Hearts, NHSBT (Manchester)
Sadie Von Joel (SVJ)	Lead CT Recipient Transplant Co-ordinator
Sophie Walters (SW)	Heart & Lung Transplant Coordinator, University Hospitals Birmingham
Mark Whitbread-Jordan (MWJ)	Transplant Patient – Queen Elizabeth Hospital, Birmingham

**IN ATTENDANCE**

Caroline Robinson (CR)	Clinical and Support Services, OTDT, NHSBT (Minutes)
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	<b>Welcome and Introductions</b>
	R Graham welcomed everyone to the meeting, particularly those who are attending for the first time. Apologies for today's meeting were recorded from Louise Davey and Neil Henson.
	R Graham recorded his thanks to J Parameshwar who has stepped down as CTAG Heart and Lungs Chair for his invaluable help with and advocacy for this Patient Group and for his excellent chairmanship of both the CTAG Advisory Groups over the last few years. In future there will be two co-chairs for these Advisory Group meetings; J Parmar (the new Chair of CTAG Lungs) and R Venkateswaran (the new Chair of CTAG Hearts) were both welcomed to the meeting.
<b>1.</b>	<b>Declarations of Interest - CTPG(20)08</b>
	There were no declarations of interest

<b>2.</b>	<b>Minutes and Action Points from Previous Meetings</b>
2.1	<u>Minutes and Action Points from previous CT Patient Group meeting –18 November 2020</u> <b>CTPG(M)(20)03</b> - The Minutes were circulated before the meeting and R Graham confirmed that he and J Parameshwar approved them. The Minutes were accepted as a true record. It was highlighted that at a previous meeting R Graham had written to Baroness Blackwood regarding resource issues and the fact that transplant patients were being turned down due to a shortage of ICU beds and that there had been no feedback circulated to members of this group yet. R Graham confirmed that there had been no response to his letter (except from NHS England stating they would respond in due course) and that issues around COVID had taken precedence over the last year. J Forsythe confirmed that development of the new 10-year NHSBT strategy and other aspects towards recovery post COVID were continuing. While the issue of ICU beds has not been chased yet, it remains a serious issue to be followed up in due course.
2.2	<u>Minutes of CTAG Lungs Meeting – 31 March 2021 - CTAGL(M)(21)01</u> - The Minutes were circulated prior to the meeting
2.3	<u>Minutes of CTAG Hearts Meeting – 22 March 2021 - CTAGH(M)(21)01</u> - The Minutes were circulated prior to the meeting
2.4	R Graham confirmed that he had raised the issues of vaccine efficacy for those people who are immunosuppressed and the need for better emotional and psychological support for post-transplant patients at both CTAG Hearts and CTAG Lungs meetings.
<b>3.</b>	<b>NHSBT – Medical Director’s Report</b>
3.1	J Forsythe started by acknowledging the work of J Parameshwar for his work as CTAG Hearts and Lungs Chair and the importance of his role in CT transplantation. He stated that it has been reassuring to have Jayan at his side during this most challenging period. J Parmar and R Venkateswaran were welcomed again to their new roles as CTAG Hearts and Lungs Chairs.
3.2	<u>COVID 19 activity</u> – J Forsythe presented a graph showing donation and transplantation of all organs from April 2019 to 4 May 2021. This shows that during the 1 <sup>st</sup> surge in April 2020 there was a massive drop in donation and transplantation mainly due to the logistics of carrying on the service during a time of high pressure on all parts of the NHS. At this time, NHSBT adopted a command and control position to ensure that the donors going ahead would end in transplantation. It was also unclear at this point what dangers staff were facing travelling around the country. The numbers recovered in July and August but dropped again during a further wave of COVID in October. At that time, transplantation numbers were not hit as severely as this surge had been anticipated and plans were in place to manage demand. In January 2021 the impact was more on ICU capacity and this hit CT and liver transplantation particularly which was different from the previous surges. Overall, donation and transplantation numbers were maintained remarkably well and at the end of the financial year were down by only 20%.  All transplant centres are now open, although one centre has limited access to staffed ICU beds for routine transplantation. Patients have been offered the opportunity to be transferred to other centres and thanks were expressed to those units who have helped facilitate this, especially for routine lung transplantation. J Forsythe stated that he was immensely proud and grateful to all those across the NHS who have worked incredibly hard to keep the service running so effectively during this hugely challenging period.
3.3	<u>VITTS (Vaccine Induced Thrombosis and Thrombocytopenia)</u> – NHSBT has been heavily involved in the work around this condition and has been able to identify patients with VITTS due to its unique UK wide view of ICUs. There is ongoing liaison with the MHRA and other organisations along with access to and investigation of donor samples so that all available information can be passed on for further work in this area.
3.4	<u>Vaccination</u> – NHSBT put together a bid for research funding to NIHR (National Institute for Health Research) to look at those who are under immunosuppression and the effects of vaccination post transplantation. Unfortunately, when this bid for government funding was submitted it was unsuccessful, so there is currently reliance on work and publications that have been completed elsewhere. NHSBT is now looking at this issue in a different way and has a registry that looks at people who have been either transplanted or those on the waiting list who have contracted COVID. The agreement to join up this with those who have been vaccinated has taken a long time, but it should now be possible to look at the data retrospectively and to monitor how good the vaccinations are.  Members of this Patient Group may be interested in a recent article which is the best study available currently that has been published in the Journal of the American Medical Association (JAMA) (see link):

	<p><a href="https://jamanetwork.com/journals/jama/fullarticle/2779852?fbclid=IwAR2JroGOzpSe1Oi5yqCjXwFzHIQyt24a015fo9R-zsz_3M5BJcC3PO-plr4">https://jamanetwork.com/journals/jama/fullarticle/2779852?fbclid=IwAR2JroGOzpSe1Oi5yqCjXwFzHIQyt24a015fo9R-zsz_3M5BJcC3PO-plr4</a></p> <p>This looks at the antibody response in immunosuppressed patients following solid organ transplantation and the effectiveness of the mRNA vaccines (not AZ). The report acknowledges that it doesn't measure the memory B or T Cell response for this virus which may be an important factor in providing protection against COVID. Overall, of the 658 participants, 98 (15%) had measurable antibody response after dose 1 and dose 2; 301 (46%) had no antibody response after dose 1 or dose 2; and 259 (39%) had no antibody response after dose 1 but subsequent antibody response after dose 2.</p> <p>There is no research funding available at NHSBT to make a further submission. The meeting discussed whether patient groups can facilitate this process and it was noted that a collaborative approach with the Chairs of other patient groups may be beneficial. Although this group of patients is relatively small, it is a surrogate group for the immunosuppressed generally and this would need to be underlined if a further bid for funding was made. Testing for individual antibody responses in routine bloods was also discussed and it was highlighted that this is not available in every laboratory and a centralised approach that may need funding is something that would be needed to do this for everyone. It is also not known what level of antibody response is needed to either prevent someone catching the disease, becoming seriously ill or dying. It was however, noted that the emotional perspective needs to be taken into account to allow transplant patients to be confident about decisions they make every day.</p> <p><b>ACTION: J Forsythe to discuss this issue with Ines Ushiro-Lumb</b></p> <p>J Parmar stated that an antibody test is being done with Papworth patients and there is a plan to send out a finger prick test once this is validated. However, a lot more granular detail is needed than just an antibody response. Other work for the future includes work on boosters, making the vaccination better and other drug treatment. The major concern for the future is variants that may appear, and it is likely that booster vaccinations to help deal with these are likely to be offered towards the end of this year.</p> <p><b>ACTION: J Parmar to take work ongoing at Papworth to the next NHSBT Clinical Team meeting</b></p> <p>The meeting discussed the possibility of groups of immunosuppressed patients coming together to do joint lobbying and this issue will be explored further. Members may be interested in the NHSBT bulletins that come out regularly. For further information, click on the link: <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>
3.5	<p><u>NHSBT 2030 Strategy</u> – J Forsythe thanked the patient group for their input and help with the strategy. Although this was ready to go a few months ago, it was delayed due to the pre-election period for Scottish and Welsh elections and NHSBT was not allowed to publish it at that time. It will now be launched around June and will be largely as it has been seen before.</p>
<b>4.</b>	<b>Introduction of New Chairs for CTAG Hearts and CTAG Lungs Advisory Groups</b>
4.1	<p><u>Chair of CTAG Lungs</u> – J Parmar stated that as well as being the new Chair of CTAG Lungs Advisory Group, he is a respiratory consultant at Royal Papworth Hospital. Although the advisory group will have a lung focus, he reassured those awaiting both heart and lung organs that work will continue to ensure there is no disconnect in the service. He introduced key workstreams for the coming months:</p> <ul style="list-style-type: none"> <li>• <u>Improving donor lung utilisation</u> - This has been a challenging issue, especially over the last year due to COVID. A number of initiatives are now underway to address this issue and it is hoped that coming out of COVID there will be an improvement including:       <ul style="list-style-type: none"> <li>○ Greater involvement of physicians in donor lung acceptance</li> <li>○ A CLU (Clinical Leads for Utilisation) initiative update</li> </ul> </li> <li>• <u>Workforce and Resilience, Surgical and Medical workforce planning</u> - Emphasis will be placed on ensuring that the workforce of the future is adequately trained to continue the work of lung transplantation once existing surgeons move on or retire through:       <ul style="list-style-type: none"> <li>○ Engagement with Surgical and Medical training bodies</li> <li>○ Encouraging collaborative working across units</li> </ul> </li> <li>• <u>Pre- and Post-Transplant Care</u> – the need for greater psychological support for post-transplant patients and issues around vaccines has already been raised. Work continues for:       <ul style="list-style-type: none"> <li>○ Named patient offering with an aspiration to define transplant benefit to allow the greater equitability and transparency of organ allocation</li> <li>○ Quality of Life assessment for all patient's post-transplant/marginal donors</li> <li>○ Adoption of enhanced recovery program for marginal recipients</li> </ul> </li> <li>• <u>Research initiatives</u> – J Parmar highlighted a research project that is being funded by NIHR (National Institute for Health Research). This focusses on extra-corporeal photopheresis which translates as</li> </ul>

	<p>dialysis and a mechanism to remove bad humours (affected T cells) that damage lungs. This will be funded across the 5 centres in the UK. Unfortunately, this is stuck at Treasury and Dept of Health level at present until regulatory hurdles are overcome. Other work includes:</p> <ul style="list-style-type: none"> <li>○ Vaccine studies</li> <li>○ National ECP trial for CLAD</li> <li>○ Completion of the consent project with Winton centre</li> </ul>
4.2	<p><u>Chair of CTAG Hearts</u> - R Venkateswaran (known as Venkat) introduced himself as the new Chair of CTAG Hearts Advisory Group. He is a cardiac transplant surgeon in Manchester doing both heart and lung transplantation. Venkat trained at Birmingham and completed his transplant fellowship at Papworth and has been at Birmingham for 11 years. He has been Director of Transplantation at Manchester since 2014 and was responsible for completing the first LVAD implants in 2011. He has been Clinical Director of Cardiac Surgery and Transplantation for the last 3 years. Jayan is a hard act to follow but Venkat has known Jas Parmar for a long time, and they will work together for both CTAG Hearts and Lungs. He highlighted his priorities as follows for the next 3 years:</p> <ul style="list-style-type: none"> <li>• <u>Improving Heart Utilisation</u> – Venkat’s primary goal and passion is donor management and he has done a lot of research in this area, particularly research in Birmingham with Prof Stephen Bonser on what is still the largest trial in the world to show that optimising deceased donors properly will maximise retrieval.</li> <li>• <u>Scouting</u> – This is where the cardiac team goes to the donor hospital to assess the organ for transplantation. Most donors come from small hospitals and scouting may ensure that a marginal donor could become a realistic option for transplantation due to optimisation of the organ.</li> <li>• <u>Training and Retention of Surgeons</u> – Many transplant surgeons are leaving the UK due to better offers of work abroad. It is critical that ways are found to retain these people in the NHS. Venkat is a member of the Society for Cardiothoracic Surgery in Great Britain and Ireland (SCTS) and while there has been a sub-group for every speciality, this has not included transplantation until now. Stephen Tsui (former Chair of CTAG Heart and Lungs) is the chair of the new working group that aims to look at ways of training and retaining more surgeons across all centres for heart transplantation in the UK</li> </ul>
5.	<p><b>CT Patient Chair Report (including vaccine efficacy and psychological support for post-transplant patients)</b></p>
5.1	<p><u>Vaccine Efficacy and Funding</u> - R Graham highlighted the vaccine rollout which has been outstanding with two thirds of the population vaccinated with their 1<sup>st</sup> jab and one third with both vaccinations. However, it has been disappointing to hear that the funding around vaccine efficacy for the immunosuppressed was turned down and there is currently a reliance on limited information from the USA. It was also frustrating that it has taken a long time to get vaccinations for household members of those who are immunosuppressed and that there has been a withdrawal of certain financial lifelines (ie Statutory Sick Pay). Overall, it feels like there is a lack of co-ordinated communications for the immunocompromised during COVID and while NHSBT does a good job communicating with clinicians and the pre-transplant community, there is little comms for the post-transplant community from a recognised central / collective body. The Q&amp;A published by NHSBT was welcomed but it was felt this currently underplays the vulnerability for transplant patients. Subsequent to the meeting Lisa Burnapp, NHSBT said <i>"we will make sure that we reflect the latest evidence in an updated version and address any gaps that have appeared since our last update"</i>.</p> <p>Discussions took place concerning what could be done by this Patient Group to express concerns about vaccine efficacy and the guidance for transplant patients and the wider immunocompromised community. The OCTAVE study which started for all immunosuppressed patients at the end of April was highlighted. However, there will be no results from this until April 2022.</p> <p>In the meantime, it was suggested that it may be worthwhile contacting the JCVI to ask what help is going to be available, eg, booster vaccinations, a 3<sup>rd</sup> vaccine, mixed vaccine etc. The need for a focus to any approach like this and to be very clear about what achievement is wanted was emphasised. An overall transplant community group was highlighted as a potential need so that all transplant recipients get communication at the same time and is proactive rather than reactive to issues. M Harrison suggested that it would also be worth finding out when the work being done with registry data information will bring some results. It was suggested that charities attached to hospitals could be approached for funding to try and encourage additional funding elsewhere.</p>

	<p>It was also suggested that approaching MPs and Parliament may be worthwhile. S Kirkham stated that the Chair of the All Party Parliamentary Group for Disability and the member of the Health All Party Parliamentary Group have written a letter that has gone to the Minister for Health and the outcome of this is pending. It was suggested that a generic letter, but with a clear focus, could be created which patients could personalise when approaching MPs or parliamentary groups.</p> <p><b>ACTION: Rob Graham and Jessica Jones to consider the best approach regarding raising the profile of this issue for patients (potentially by the use of a generic letter for patients to use).</b></p> <p>The issue of the children of patients reaching the age of 16 who are still considered a child and vaccinations was raised and it was noted that there are some trials starting now for younger adults.</p> <p><b>ACTION: Debbie Burdon to contact Emma Johnson to find out if she is aware of any projects for children.</b></p>
5.2	<p><u>Psychological Support</u> - R Graham stated that psychological support for post-transplant patients remains insufficient. It relies on work done at individual centre level and these centres having sufficient funding. J Parmar agreed that this is an important issue and stated that unfortunately sometimes this issue is traded off if medical treatment options are considered more critical. It was agreed that availability of this could be added to the website (see Item 9). It is noted that not all centres have the same provision for psychological support and that this is going to be a difficult issue to resolve.</p> <p><b>ACTION Post meeting R Graham advised J Forsythe that he would approach Highly Specialised Services, NHS England directly on this issue.</b></p>
<b>6.</b>	<b>Report from NHSBT Statistics and Clinical Research Team - CTPG(21)02</b>
6.1	<p>A presentation from Sally Rushton (circulated after the meeting) provided recent cardiothoracic transplant activity and COVID 19 data. Please see this paper for specific data highlighted in the meeting. Further information can be found at: <a href="https://www.odt.nhs.uk/covid-19-advice-for-clinicians">https://www.odt.nhs.uk/covid-19-advice-for-clinicians</a> for COVID 19 data and <a href="https://www.odt.nhs.uk/statistics-and-reports/organ-specific-reports">https://www.odt.nhs.uk/statistics-and-reports/organ-specific-reports</a> for annual reports and summary infographics.</p>
<b>7.</b>	<b>Cardiothoracic Patient Updates – Updates provided post meeting are shown below:</b>
7.1	<p><u>Harefield</u> - A Lees provided a cardiothoracic patient update from Harefield:</p> <ul style="list-style-type: none"> <li>• Various garden areas have been completed at Harefield Hospital. The Harefield Transplant Club (HTC) has supported a courtyard garden by the transplant ward (for transplant patients). Former patients have also supported a healing garden (for patients, visitors and staff.) Both gardens were specifically designed to help physical and mental wellbeing.</li> <li>• Harefield consultants are considering having another virtual meeting soon with the lung patients. They have done these before and they were very successful.</li> <li>• The sporting and social events for 2021 have been cancelled; the European and World sporting events are dependent on the Covid situation internationally. Work &amp; home life with Covid has impacted the club.</li> <li>• The Royal Brompton and Harefield NHS Foundation Trust has now merged with Guy's and St Thomas' NHS Foundation Trust.</li> </ul>
7.2	<p><u>Royal Papworth</u> - R Graham provided an update from Royal Papworth Hospital:</p> <ul style="list-style-type: none"> <li>• Transplants for non-urgent patients have recommenced and all the Transplant Team is now back from ITU; routine face to face clinics are also resuming.</li> <li>• No social meetings have been held, but a tentative booking of a venue for September is being considered.</li> <li>• Similarly, the BT Games has been postponed for a second year.</li> <li>• In the absence of the social meetings, the Facebook group has grown to 500+ to communicate information e.g.: <ul style="list-style-type: none"> <li>○ members have been provided with written updates on vaccine efficacy following consultation with the transplant team</li> <li>○ Various bodies have been lobbied to express concerns that more needs to be done to reassure transplant patients</li> <li>○ Members have been provided with a letter to help in negotiations with employers when returning to work</li> </ul> </li> <li>• The Gift Bag initiative/project launched at the beginning of lockdown continues to prove a success with the third delivery of bags being made to patients in the last month. This project means that</li> </ul>

	<p>each newly transplanted patient receives a gift bag containing essential/useful items such as bed socks, notepad and pen, face wipes, lip balm etc together with key information including contact details for our Support Group. Each bag has been sponsored by an existing transplant patient with a personalised message for the next two years.</p> <ul style="list-style-type: none"> <li>• Special mention is made to Eliza Bell (23, heart transplant patient) who has started releasing her second series of 14 podcasts which will be of great benefit to future transplant patients. Some of these podcasts feature interviews with prior transplant patients, as well as key members of the whole Papworth Team (e.g. 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 <a href="http://www.transplantchats.com">www.transplantchats.com</a></li> <li>• Thanks to Spencer Deane and Angela White who have started a series of monthly Zoom quizzes for our group.</li> <li>• In conclusion, despite the fact that face-to-face meetings have not taken place in the usual support group format, the committee has been busy collating and relaying information to all members. The support of the Transplant Team in this regard has been much appreciated, particularly Jayan Parameshwar, Jas Parmar, Steven Pettit and Richard Quigley.</li> </ul>
<b>8.</b>	<b>Donor Letter Writing</b>
	<p>Sadie Von Joel (Lead Recipient Transplant Co-ordinator) introduced members of this group to a video that looks at donor letter writing. The video emphasises that both donor families and transplant recipients can write, email or send pictures and that there are lots of different ways of corresponding. For those who do want to correspond and don't know how to or what to write the video helps to explain the process. Transplant Centres and Family Aftercare can help and send any correspondence into an email box. The campaign to encourage letter writing will be relaunched in July and Recipient Centres and Facebook pages should have more information. It is accepted that the other party may not want to respond when a letter is sent, and it is not always clear whether the letter has ever been received. It was confirmed that NHSBT will send a quarterly report to say when the letter arrived and when it was sent out to help deal with this issue. To see the video click on the this link: <a href="#">Message in a Bottle</a>. Please note this is a big file to play from the link so it may be easier to watch if it is compressed into mp4 format or is downloaded first. If you have any feedback contact <a href="mailto:Sadie.VonJoel@nhsbt.nhs.uk">Sadie.VonJoel@nhsbt.nhs.uk</a></p>
<b>9</b>	<b>OTDT website update</b>
	<p>Chris Callaghan (Kidney and Pancreas Transplant Surgeon at Guy's Hospital) joined the meeting to present information around the OTDT website - see link: <a href="https://www.nhsbt.nhs.uk/organ-transplantation/">https://www.nhsbt.nhs.uk/organ-transplantation/</a>. One of Chris's roles at NHSBT is to look at organ utilisation and ways to provide the right information to patients on the waiting list to support their decision making. There has been a small patient facing section on <a href="http://www.odt.nhs.uk">www.odt.nhs.uk</a> but this has been limited so there has been a major overhaul of patient facing information for all solid organ groups to highlight benefits and risks, receiving an organ, living with an organ transplant. There is a lot of information as this is clearly an increasing need for patients and the website aims to support people from the time of listing, in discussions with their surgeons and at the time of organ offering. Member of this group can feedback on their thoughts about the website by clicking on the link on the website '<a href="#">Give Feedback</a>'.</p> <p>It was agreed by the group that the information for pre-transplant patients is excellent, very useful and will be a very good resource. The website will have a soft promotional launch initially as it is still evolving. In future it is hoped to include videos, animations and drawings and it was agreed that making the website as interactive as possible is a good idea. After this there will be more Comms from NHSBT to make more people aware of it. It was noted that some members of this group have already circulated the details of the website to their local groups and Jas Parmar confirmed that he has also used it in his clinics where he has had positive feedback. Sadie Von Joel confirmed that she has circulated it to all the recipient co-ordinators across all organ groups and it is being used in training which will help to standardise information that is given to patients. The group thanked Chris for this excellent work.</p> <p><b>ACTION: Any suggestions for charities to be included on the website to be sent to <a href="mailto:caroline.robinson@nhsbt.nhs.uk">caroline.robinson@nhsbt.nhs.uk</a></b></p>
<b>10</b>	<b>Any Other Business</b>
10.1	<p><u>Electric Cranks update - CTPG(21)01</u> – An update from G Higgins regarding the latest activities of the Electric Cranks Cycling Club at Wythenshawe was circulated prior to the meeting. The Electric Cranks are pre- &amp; post-op 'Heart &amp; Lung' Transplant Centre patients who are using electric bikes to aid their</p>

	recovery & wellbeing. There is more information on how their activities are helping them on their Twitter account, <a href="#">@ElectricCrank</a> s
10.2	<u>Patient Volunteer needed</u> – The Research team at NHSBT is forming a working group to look at consent issues at the time of listing. Meetings are likely to be held via Microsoft Teams rather than face to face once a week for the first two months to get ideas and thoughts on how to gather patient data and how this is stored. A lay person has been recruited to take part and a patient volunteer is now needed. J Atkins and A Sims volunteered to take part at the Patient Group meeting and any other people who are interested should contact R Graham who will pass their names to S von Joel.
<b>11</b>	<b>Dates of Forthcoming Meetings</b>
	<ul style="list-style-type: none"> <li>• CT Patient Group – 17 November 2021</li> <li>• CTAG Lungs Meeting – Weds 8 September 2021</li> <li>• CTAG Hearts Meeting – Thurs 30 September 2021</li> </ul>

**ACTIONS FROM THIS MEETING:**

1. J Forsythe to discuss the issue of individual antibody testing at the time of routine bloods with Ines Ushiro Lumb (Head of Transfusion Microbiology, NHSBT)
2. J Parmar to bring the work of the Papworth team regarding antibody testing and potential finger prick tests to the next NHSBT Clinical team meeting.
3. R Graham and J Jones to consider the best approach (eg work on a generic letter for patients to use to approach their MPs and parliamentary groups) to raise the profile for immunosuppressed patients regarding vaccine efficacy
4. D Burdon to contact Emma Johnson to find out if she is aware of any projects on vaccination for children/children in immunosuppressed households.
5. R Graham to approach Highly Specialised Services, NHS England on the inadequacy of psychological provisions for post-transplant cardiothoracic patients.
6. Members to give feedback on the 'Message in a Bottle' video to [Sadievonjoel@nhsbt.nhs.uk](mailto:Sadievonjoel@nhsbt.nhs.uk)
7. Members to give feedback on the OTDT website on the 'Give Feedback' button on the website.
8. Members to give feedback on any charities that could be included on the OTDT website to [caroline.robinson@nhsbt.nhs.uk](mailto:caroline.robinson@nhsbt.nhs.uk)
9. Members interested in taking part in a research working group on consent to contact R Graham in the first instance.