

NHS BLOOD AND TRANSPLANT**MINUTES OF THE MEETING OF THE CARDIOTHORACIC PATIENT SUPPORT GROUP
HELD AT 1 PM ON MONDAY, 23rd NOVEMBER 2015 AT THE CYSTIC FIBROSIS TRUST,
ONE ALDGATE, LONDON EC3N 1RE****PRESENT:**

Mr Rob Graham, Patient representative, Papworth Hospital (**Co-Chair**)
 Mr Steven Tsui, Chair of Cardiothoracic Advisory Group (**Co-Chair**)
 Mr Derek Airey, Chairman, Freeman Heart & Lung Transplant Association
 Ms Katherine Collins, NSD Scotland
 Dr Martin Carby, Consultant Physician, Harefield Hospital
 Mr Ged Higgins, Patient representative, Wythenshawe Hospital
 Mr Keith Jackson, British Cardiac Patients Association
 Ms Beverley James, Deputy for Ms Jan Withington
 Ms Jessica Jones, Cystic Fibrosis Trust
 Mr Matthew Knight, CTAG Lay Member
 Dr Jenny Lannon, **Principal Statistician**, Statistics & Clinical Studies, NHSBT
 Mr Alan Lees, Harefield Transplant Club
 Ms Debbie Lovett, Department of Health
 Ms Jane Nuttall, Cardiothoracic Recipient Transplant, Wythenshawe Hospital
 Prof Nawwar Al-Attar, Head of Transplant Unit
 Ms Rosie Pope, Parent of Patient, Harefield Hospital
 Mr Michael Thomson, Golden Jubilee Patient Representative
 Mrs Joan Whitney, Treasurer, Freeman Heart & Lung Transplant Association
 Mr Jon Williams, Patient representative, Wythenshawe Hospital

IN ATTENDANCE:

Mrs Claire Williment, Head of Transplant Development, NHSBT
 Mrs Reema Palekar, ODT Clinical & Support Services, NHSBT

ACTION**APOLOGIES**

Apologies were received from: Ms Rebecca Allen, Dr Nick Banner, Mrs Kathryn Graham, Ms Barbara Harpham, Mr Dominic Kavanagh, Ms Lesley Logan, Dame Joan McVittie, Prof James Neuberger, Ms Emma Osborne, Ms Amy Smullen, Ms Jan Withington, Mr Nick Medhurst, Ms Janet Atkins, Ms Cheryl Riotto, Ms Jane Graham.

1 WELCOME

- 1.1 Attendees were welcomed to the meeting including new members Mr Alan Lees, Mrs Rosie Pope, Ms Jessica Jones and The Cystic Fibrosis Trust were thanked for providing the venue for the meeting.
 Minutes of the Meeting held on 7th May 2015 CPSG(M)(15)1 were approved as a correct record.

2 ACTION POINTS FROM THE LAST MEETING**Any Other Business**

- 2.1 The group was reminded that the Agenda had been drafted based on previous actions arising, from CTAG and the ODT website review. Members were encouraged to look at the ODT website (www.odt.nhs.uk) which provides a plethora of information, including NHSBT Solid Organ Advisory Group papers and

minutes.

2.2 Engagement with Harefield patients

Harefield is now represented on the Group.

2.3 Potential membership of this group into transplant 2020

Transplant 2020 is a coalition of patient groups, clinical organisations and industry dedicated to raising the rate of consent to organ donation. Given the potential conflict of interests for at least one of the bodies represented at the CTAG Patient Group, it was decided that this Group would not seek to join Transplant 2020, instead leaving individual patient groups to decide whether to join or not.

2.4 TRANSPLANT STATISTICS/ LOCAL ISSUES

In a review of statistics, the Group had identified a potential pressure on transplant services due to a lack of available ITU beds. This had been discussed with the Cystic Fibrosis Trust and, at Papworth, with the Chief Executive (by letter) to explore the risk of transplants not proceeding. The response from Papworth Chief Executive stated that the issues were being reviewed. Parliamentary Question had also been raised regarding this issue.

The clinicians present gave insight into the complexities of the issue including a range of logistical issues such as the acceptance of offered organs and availability of theatre staff. It was noted that data is now disseminated on a weekly basis to centres regarding organs offered, accepted and declined. This report is used to look at organ outcomes and for informing teams regarding whether offered organs that they have declined were successfully transplanted at other centres.

It was noted that the reasons for offered organs being refused is multi-factorial. It includes not just lack of beds/ staff, but also the recipient condition, whether the transplant team is already undertaking a transplant or other urgent operation. No single dataset will give the whole picture.

From a commissioning viewpoint, provided that all useable hearts are transplanted in the UK, then there is, perhaps, less concern what is happening at Centre level. However, at local level, any logistical barriers to accepting any organ can be frustrating and could potentially contribute to the death of a patient on that particular Centre's waiting list.

Other options for patients, such as bridging interventions i.e. ECMO, can be extremely resource intensive and Trusts may not always be able to support these routes due to the opportunity cost on other clinical activities.

A further follow-up Parliamentary Question should be considered regarding the impact on organ transplantation.

The CF Trust is hoping to meet with J Neuberger in the near future to discuss how logistical difficulties impact on organ utilisation.

3 TRANSPLANTATION ACTIVITY

3.1 Latest statistics

J Lannon presented key trends in cardiothoracic transplant activity and patient outcomes:

§ The slides were taken from the NHSBT Cardiothoracic Organ Specific Report (<http://www.odt.nhs.uk/uk-transplant-registry/organ-specific-reports/>), which includes a significant amount of additional data and commentary. This report will be circulated to the group, and is also available on the ODT website.

§ It was noted that those centres with the highest acceptance rates may have

more patients on their waiting list to choose from.

Another reason may be that they are willing to take greater risks, but the statistics suggest there is no difference in outcomes for patients. For example, those who appear to be willing to accept and transplant a marginal heart or lung do not have a higher early post-transplant mortality.

- § Mr G Higgins sought further clarification on certain aspects of the slides and he agreed to detail his points after the meeting so this could be followed up on and addressed.

3.2 **NHS Budget overspends**

It was queried whether the NHS budget allocations have a negative impact on transplant rates. It was noted that this does cause some barriers, as discussed earlier regarding ITU capacity. However, the largest imposition posed by the restricted budgets is in innovation. New approaches and innovative devices, such as DCD hearts and ventricular assist devices, are very expensive and lack of available funding impacts on the ability to trial new innovations.

3.3 **IT update for transplant lists**

It was confirmed that NHSBT's new IT platform is approaching development and will incorporate the updated urgent heart allocation scheme in the first wave of development. Urgent lung allocation would be incorporated at a later date.

4 **HEART/ LUNG ALLOCATION WORKING GROUPS**

4.1 **DCD activity**

S Tsui provided an update on the donation after circulatory death (DCD) heart service evaluation. The key points included:

- § New form of heart donation in the modern era, although it builds on the very first transplants performed, which used organs from DCD donors.
- § To date, 10 DCD hearts had been transplanted at Papworth and 3 at Harefield.
- § UK is leading in this development having performed 13 out of the 19 adult DCD heart transplants worldwide. These have all been funded by research grants and donations to the Trusts.
- § Australia has also commenced a programme and performed 6 DCD heart transplants to date.
- § The technique utilises the TransMedics Organ Care System (OCS) to help maintain the donated heart for a longer period of time.
- § The DCD heart project has potential to increase heart transplants by 40-50%, subject to further service evaluation results.
- § Work has been undertaken with NHS Blood and Transplant and UK Health Departments to develop a Service Evaluation to fund a further 10 cases of DCD hearts. This is due to commence imminently.

At this stage, there is no guarantee of any additional funding beyond the service evaluation to enable an ongoing DCD heart transplant programme despite the impact being potentially transformational. Mr M Carby said the innovative work by Mr Large and the Papworth Team should be congratulated.

4.2 **National standards for organ retrieval (NORS) review**

It was clarified that NHSBT does not commission transplants – only the retrieval service. NHSBT undertook a review, which identified that abdominal retrieval teams are busier than cardiothoracic retrieval teams. It is therefore suggested that, as NHSBT funds a 24/7 service from six cardiothoracic retrieval teams, there is spare capacity within the current arrangements. The NORS review therefore suggested that the number of cardiothoracic teams should be reduced to no more than four teams. Work is ongoing to identify how this recommendation could be implemented.

5 ANY OTHER BUSINESS**5.1 Cardiothoracic peer review**

It was noted that a Symposium was being held on the 17th December 2015 to share lessons learned through the CT Peer Review programme, focussing on disseminating innovative and best practice, as well as providing an update on next steps and actions taken as a result of the programme. Members of the Group were welcome to attend. Claire Williment will circulate further details.

5.2 Scouting project

Following the completion of the Scout Pilot in 2013-14, the Scout project had entered its second phase to explore how the Scout intervention impacted on cardiothoracic organ donation. This project is on-going.

5.3 Potential change of name of group

Members agreed to change the name of the group to CTAG Patient Group.

R Palekar**5.4 Urgent listing**

The notes of the recent CTAG meeting mentioned the criteria for listing patients for urgent heart transplants. This needs to be consistent across teams to ensure equity of access. Centres will be required to provide evidence of approval from the Adjudication Panel to the Duty Office for those cases where 'other' is selected as the reason for listing. The patient will only be listed as urgent following approval from the Adjudication Panel.

5.5 Paediatric heart transplants

Work is planned to explore the demand for paediatric heart transplants and how this can be met.

6 DATE OF NEXT MEETING

6.1 The next meeting will take place in spring 2016, actual date to be confirmed.

November 2015