

NHS BLOOD AND TRANSPLANT

**MINUTES OF THE MEETING OF THE CARDIOTHORACIC PATIENT SUPPORT
GROUPS HELD AT 1 PM ON THURSDAY, 7TH MAY 2015 AT THE
CORAM CAMPUS, 41 BRUNSWICK SQUARE, LONDON WC1N 1AZ**

PRESENT:

Mr Rob Graham, Patient representative – Papworth Hospital (**Co-Chair**)
Mr Steven Tsui, Chair of Cardiothoracic Advisory Group (**Co-Chair**)
Mr Derek Airey, Chairman,
Ms Rebecca Allen, Heart Transplant Families UK
Dr Nick Banner, CTAG Heart Deputy Chair
Ms Jane Graham, Freeman Heart & Lung Transplant Association
Mrs Kathryn Graham, Chair of Transplant Patient Support Group, Papworth Hospital
Mr Keith Jackson, The British Cardiac Patients Association
Mr Matthew Knight, CTAG Lay Member
Dr Jenny Lannon, Statistics & Clinical Studies, NHSBT
Dame Joan McVittie, CTAG Lay Member
Mr Nick Medhurst, Policy Manager, Cystic Fibrosis Trust
Mrs Emma Osborne, Transplant Association
Ms Amy Smullen, Policy Lead for Organ Donation, British Heart Foundation
Mrs Joan Whitney, Treasurer, Freeman Heart & Lung Transplant Association
Mr Jon Williams, Patient representative, Wythenshawe Hospital

IN ATTENDANCE:

Mrs Kathy Zalewska, Clinical & Support Services, ODT (Secretary)

ACTION

Apologies

Apologies were received from:

Mr Nawwar Al-Attar
Dr Martin Carby
Ms Kathy Collins
Miss Barbara Harpham
Mrs Jessica Jones
Mr Dominic Kavanagh
Ms Lesley Logan
Mrs Debbie Lovett
Mr Graeme Marshall
Mr Kevin Mashford
Prof. James Neuberger
Mrs Jane Nuttall
Ms Cheryl Riotto
Mr Michael Thomson
Ms Jan Withington

1 WELCOME

- 1.1 Attendees were welcomed to the meeting.
R Graham asked N Banner to contact the Harefield Hamsters patients group to encourage them to send a representative to future meetings.

ACTION

2 MINUTES OF THE MEETING HELD ON 12TH NOVEMBER 2014 – CPSG(M)(14)2

2.1 The minutes of the previous meeting were agreed as a correct record.

3 ACTION POINTS**3.1 Action points:**

The majority of actions were in hand or completed.

Following a vote, Mr Rob Graham had been appointed as the Group's co-chair.

The minutes of the 'risk event' meeting held in October would be circulated to members.

K Zalewska

4 Patient involvement in CTAG Patient Support Group

4.1 E Osborne reported that, together with Kevin Mashford, she had recently established the Transplant Association as a registered charity. The three main aims of the Association are:

- for all organ recipients to have access to psychology services whilst on the transplant list as there is currently a disparity in the provision of psychological support between centres. A pilot scheme is taking place at the Freeman Hospital to up-skill nurses to be able to refer patients to psychology services.

- provide a multi-organ, user friendly website for patients to obtain information.

-to organise a cycle ride from Bristol to Newcastle to increase awareness of organ donation and transplantation.

Other work includes the provision of more freely accessible statistical information on transplants; and more differentiation in the sub-groups of disease.

S Tsui agreed that psychological support is variable from centre to centre and this is something that all teams are aware of. Harefield, Manchester and Glasgow have a psychologist integrated into the multi-disciplinary team whereas other don't and rely on inviting a psychologist in when necessary. There are also plans to train nurses to carry out the psychological assessment.

5 Latest statistics relating to organ donation & transplantation

5.1 R Graham highlighted statistics on transplant activity in the UK including:

- 8% drop in transplant activity (England)
- Decrease in deceased donor transplants of 4%

S Tsui commented that there has been no in-depth analysis into why numbers have increased in previous years and then decreased in 2014/15. Speculation is that because 2013/14 was such a good year, activity may have reduced the number of easy matches on the waiting list, thus making it harder to match organs to patients. Also, for the past 2 decades the quality of donors has gradually declined with increasing average age and number of co-morbidities. During 2013/14 a scout project was established which involved a member of the cardiothoracic retrieval team travelling to donor hospitals early on to help manage donors prior to arrival of the retrieval team. After diagnosis of brain stem death, organs start to deteriorate and the scout was deployed to intervene early in the donor management in order to optimise the organs. During this time the number of heart transplants increased by nearly

ACTION

40%. However, this was a one year pilot which finished in March 2014 with insufficient evidence to provide a conclusive link between scouting and the increase in donor hearts. In Nov 2014 agreement was reached to start scout phase 2.

It was highlighted that although NHSBT commissions organ retrieval, NHS England is the body which commissions transplantation services. The question of whether a lack of ICU beds contributes to transplants not going ahead was raised. It was acknowledged that this can happen although it is difficult to quantify as the organ is likely to be offered to another centre which is able to accept it.

NHS England commissioned a peer review for cardiothoracic transplant centres which took place in March 2015. Different centres operate differently and there is no hard and fast rule as to how to ration resources. R Graham highlighted the need for this Group to consider how to support clinicians with this problem. It was noted that the structure of the commissioning services changed around a year ago when NHS England was established and took over from the National Specialist Commissioning Group. Previously NSCG and its predecessors had an identifiable medical advisor for each organ specialty whereas now there is one person covering numerous specialist services for commissioning.

S Tsui outlined the DEVELOP study on ex vivo lung perfusion (EVLP). After the initial phase there were concerns about the outcomes of transplants using EVLP lungs. The protocol was changed and the study restarted in March 2014 on a revised protocol. Unfortunately, recruitment was slow and it was uncertain that this would be a positive study. As a result the study stopped.

R Graham and N Medhurst agreed to liaise with other representatives to consider how to approach these issues for discussion at the next meeting.

**R Graham/
N Medhurst**

6 CTAG meeting 30 April 2015

6.1 CTAG meetings are held twice a year and there are working groups looking at heart allocation and lung allocation. In answer to a query re research funding, S Tsui stated that the remit of CTAG is to focus on policies relating to selection of patients and allocation of organs for transplantation. It is a good forum for looking at lessons learned and sharing of good practice by clinicians. NHS England is responsible for commissioning transplant services whilst NHSBT monitors outcomes and governance.

7 Latest developments in transplantation

7.1

- Updates to correct anomalies re patient size and age in the heart allocation policy and the lung allocation policy, published in June 2014, were recently endorsed by the Transplant Policy Review Committee.
- Working groups were set up to look at criteria for the allocation of urgent hearts and lungs. A user requirement specification is being written to include criteria for patients with ACHD to the existing urgent heart allocation scheme. Work has also been carried out on a new scheme for urgent lung allocation although the implementation of this scheme is likely to be delayed due to a lack of IT resource.

ACTION

- Scout project – Following on from discussion earlier in the meeting it was noted that phase 2 of the scout project has been approved and has been underway since April 2015. Its aims are to collect clinical information to provide evidence as to whether scouts have an impact on the number of donor organs transplanted. The scout project is not a commissioned service and is provided voluntarily by five of the six cardiothoracic retrieval teams although the cost of travel and consumables is covered. The remaining centre does not have the resource to provide the scout service as it is undertaking other equally important initiatives. NHS England is funding a post for data collection and analysis of the project.
- Adjustments to allocation zonal boundaries were implemented in January 2015.
- Papworth Hospital, in collaboration with Stanford University, is working on a project looking at heart donation after circulatory death (DCD). Ethics approval as well as approval from the Human Tissue Authority was gained to proceed with a clinical programme from 1st March 2015. Two DCD heart transplants have been carried out to date at Papworth. Harefield is conducting a similar programme which started on 1st April 2015. Moving forward, a business case is required for commissioning of the retrieval service as both programmes are currently charitably funded.
- E Osborne queried whether xenotransplantation was likely to become a reality. S Tsui stated that Dr Norman Shumway once said "Xenotransplantation is in the future and always will be..... meaning that it was unlikely ever to become a reality.

8 National organ donor retrieval scheme review

8.1 This item to be carried forward for consideration at the next meeting.

K Zalewska**9 National Donation & Transplantation Congress 24th/25th March 2015**

9.1 This item to be carried forward for consideration at the next meeting.

K Zalewska**10 Transplant 2020 update**

10.1 Transplant 2020 is a coalition of patients, professionals and industry dedicated to raising the organ donation consent rate to 80% by 2020. K Graham was invited to speak at an all party parliamentary committee towards the end of 2012; to talk to MPs about life on the transplant list in 2013; and then invited back to lobby MPs prior to today's election. Members were encouraged to sign up as the next phase of the campaign would take place following the election.

11 NHS Consultation Guide overview

11.1 R Graham to circulate the overview response with the minutes.

R Graham**12 Any other business**

12.1 Members were asked to advise R Graham of any items for discussion at the next meeting

All**13 Date of next meeting:**

13,1 The next meeting will take place following the September meeting of CTAG, probably in either October or November actual date to be confirmed.

K Zalewska**May 2015**