

Meeting of Cardiothoracic Patients' Group

1.00pm – 4.00pm Monday, 9th May 2016

**Hodgkin Building, Kings College Guys Campus
London SE1 1UL**

PRESENT:

Mr Rob Graham, Patient representative – Papworth Hospital (**Co-Chair**)
 Mr Steven Tsui, Chair of Cardiothoracic Advisory Group (**Co-Chair**)
 Mr Nawwar Al-Attar, Surgeon, Golden Jubilee National Hospital, Glasgow
 Ms Rebecca Allen, Heart Transplant Families UK
 Ms Janet Atkins, Transplant Support Group, Papworth Hospital
 Ms Jane Graham, Freeman Heart & Lung Transplant Association
 Mrs Kathryn Graham, Transplant Support Group, Papworth Hospital
 Ms Penny Hartley, Freeman Heart & Lung Transplant Association
 Mr Ged Higgins, Wythenshawe Hospital Patients' Representative
 Ms Beverley Jones, Transplant Social Worker
 Mr Alan Lees, Secretary of Harefield Hospital Transplant Club
 Dr Jenny Mehew, Statistics & Clinical Studies, NHSBT
 Mrs Jane Nuttall, Cardiothoracic Recipient Transplant Co-ordinator, Wythenshawe Hospital
 Ms Heather O'Shea, External Affairs Manager – Communications, NHSBT
 Ms Rosie Pope, Harefield Hospital Transplant Patient Parent
 Ms Amy Smullen, British Heart Foundation
 Mr Michael Thomson, Patient representative from Golden Jubilee National Hospital
 Mrs Joan Whitney, Treasurer, Freeman Heart & Lung Transplant Association

IN ATTENDANCE:

Mrs Kathy Zalewska, Clinical and Support Services (C & SS) Manager, ODT, NHSBT

ACTION**Apologies**

Apologies were received from: Dr Nick Banner, Ms Yolande Cordial, Prof John Forsythe, Mr Keith Jackson, Mrs Jessica Jones, Mr Dominic Kavanagh, Mr Matthew Knight, Ms Lesley Logan, Dame Joan McVittie, Ms Emma Osbourne, Ms Cheryl Riotto, Mr Jonathan Williams, Ms Jan Withington

- 1. Approval of meeting minutes of 23rd November 2015**
The minutes of the previous meeting were agreed as a correct record.
- 2. Action points outstanding:**
It was noted that the issue of potential pressure on transplant services due to a lack of available ITU beds had been discussed at both Papworth and Harefield transplant centres. The Cystic Fibrosis Trust had previously tabled a Parliamentary Question on this issue and R Graham agreed to pick up with the Trust whether a follow up question should be tabled.
- 3. Any other Business:**
There were no further items of business over and above those on the agenda.
- 4. Personnel Changes**
Members noted the appointment of Professor John Forsythe as the new Associate Medical Director for ODT and congratulated Mr Tsui on the renewal of his role as CTAG Chair for a further two years from April 2016.

R Graham

5. Patient Group Issues:**i. Individual Centre Patient Groups best practices/dissemination of information**

Members gave a brief summary of the work of their patient groups:

J Whitney – Freeman Heart & Lung Transplant Association

- Set up in 1996/7 to support heart transplant patients and in 2004 the association was extended to include lung transplant patients.
- Raises awareness of organ donation, and encourages the public to sign up to the ODR.
- Fund raising to fund medical and nursing staff to attend conferences and to purchase medical equipment.
- Subsidises members who want to compete in the Transplant Games.
- Proactive in giving talks, doing bag packs, interviews on local radio to raise awareness.
- Funds accommodation for patients' families when coming to hospital.
- Public event on 7th June raising awareness of research in organ donation and transplantation at Freeman Hospital.
- In 2015 the Association celebrated 30 years of transplantation at Freeman Hospital.
- Purchased a caravan for use by patients and their families.

K Graham – Transplant Support Group, Papworth Hospital

- Established 18 months ago when there were concerns about the hospital move.
- Expanding more into a support network for patients rather than for fund raising
- Held one face to face meeting so far with three more planned for this year.
- Planning to produce a quarterly newsletter and have taken over a notice board in clinic to keep patients informed of activities.
- Annual patients' meeting set up by nursing staff.

G Higgins – Wythenshawe Hospital Transplant Support Group

- Group meets monthly to support patients, families and friends.
- A professional speaker is invited to each meeting ie Specialist Nurse - Organ Donation (SN-OD).
- Raise issues from this meeting with the wider group.
- Easter, summer and Christmas meetings held at a local pub.
- Provides a transplant buddy network.
- Open day held in 2015 attended by lots of LVAD patients and hoping to repeat this in 2016.
- Extended some of the best practice from Glasgow with LVAD cafes and transplant cafes.
- Increasing awareness of organ donation and transplantation.
- Charity website to raise funding.
- No formal managed meetings but will look to perhaps communicate from the monthly meetings via the website.

A Lees – Harefield Transplant Club

- Established in 1982 to promote organ donation through sport, funding patients to enter the National Transplant Games. This promoted the fact that transplant patients can be fit and healthy. Seven lung and six heart transplant patients went climbing in Ecuador in 2015.
- Developed a website and on Facebook and Twitter.
- Produce a newsletter.
- Organise an annual reunion with gala dinner and AGM and award trophies. Funds are raised both for the Transplant Games and the transplant unit.
- Due to the geographic spread of patients it is difficult to organise events for everyone to turn up.
- Difficult to recruit patients to the group due to a lack of access to patient details due to the Freedom of Information (FOI) Act.

M Thomson – Golden Jubilee National Hospital, Glasgow

- No formal patient organisation but there is an informal arrangement established by the transplant co-ordinators.
- Meetings are held once or twice a year for approximately 100 people.

R Allen, who attended the meeting from Heart Transplant Families UK, believed that Great Ormond Street Hospital (GOSH) hold a Christmas party only.

Members suggested ways in which patient groups could support organ donation.

- Contact one of the SN-ODs for involvement
- Obtain a campaign code from Caroline Rodaway, Senior Marketing & Campaigns Officer, to allow NHSBT Campaigns to track the effectiveness of any work.
- H O'Shea agreed to share a link with members to obtain digital on-line assets and details of a new website for printed materials which could be used for Organ Donation Week from 5th – 11th September 2016.
- J Nuttall stated that to overcome the issue of FOI at Manchester, when a patient is activated on the transplant list they are asked if they would be happy for their name to be passed on to the charity. They sign a form which also lists the different sports in which they can participate. Then if they do receive a transplant the charity has the relevant contact details. J Nuttall agreed to forward the template for circulation with the minutes.
- A Lees added that at Harefield a label giving information about the Transplant Club is included inside the booklet that patients are given relating to their prescription.
- At the Freeman the Chairman of the Association visits patients following their transplant.
- R Graham stressed the importance of contacting those patients who are pre-transplant who may need help and guidance. The difficulty of producing a generic newsletter for all centres was highlighted. It is the responsibility of each individual centre representative to disseminate information, such as minutes, from this meeting.

H O'Shea

J Nuttall

- R Pope added that Ian Hampton, Head of Partnerships & Campaigns at NHSBT is working on various advertising initiatives to produce material suitable for different groups to customise for their own areas.
- In response to a query about advertising organ donation on public transport H O'Shea advised of restrictions on advertising and of strict guidelines on NHS brand livery.

ii. Patient/Clinician feedback on peer review seminar in December 2015

A peer review symposium aimed at sharing best practice amongst transplant centres was attended by J Atkins and G Higgins. G Higgins reported that he underwent peer review training in April and, as part of a combined Manchester and GOSH team, will be conducting a peer review at the Freeman Hospital. S Tsui gave a brief summary of the background of the NHS England peer review process. NHS England approached NHSBT around 18 months ago to see if transplant services would like to consider peer review, following which a peer review of cardiothoracic transplantation was carried out. In retrospect the standards put forward were all related to process rather than outcome measures so this was flagged at the end of that process. The process is to be repeated in June 2016 and will include a set of outcome measures known as a dashboard. It was noted that the initial peer review process was slow and tended to lose momentum. The report is still in draft so centres have not had a chance to implement any recommended changes.

6. CTAG - Workplan 2016/17 - CTAG(16)9

i. Super urgent heart allocation and urgent/super urgent lung allocation schemes:

Many patients are waiting on the urgent heart list for between 2 and 4 months so a super-urgent scheme has been developed for both hearts and lungs. The scheme has been approved and is awaiting implementation. As part of the National Hub programme new software is being introduced to allocate organs. The heart pathway has been selected as the first to be implemented using the new software and should be in place by September. This will be followed by the lung pathway which should be in place by the end of the year. In addition, new criteria were agreed for patients on the heart/lung waiting list.

ii. Scouting Project:

A pilot was conducted where scouts were sent to donor hospitals upon initial notification of a potential donor in order to assess the accepted organ. The aim of the pilot was to avoid sending a full retrieval team out if the organ was not deemed to be viable. Data from the first pilot indicated that scouted donors have a much higher probability of the heart being accepted and transplanted. A second pilot was conducted, the data from which supported the earlier conclusions. The ODT Senior Management Team approved continuation of the scout project which will now be incorporated into the normal retrieval service.

R Pope asked how many organs are turned down due to geographical location. S Tsui reported that centres may turn down an organ for a variety of reasons. The system for recording the

reason for turn down is outdated and is being looked at by CTAG.

Work is taking place on outcomes from storing organs on ice versus using portable perfusion machines, the cost difference being around £30,000. Evidence to support the use of machine perfusion is limited at this time although S Tsui suggested that it may be beneficial for marginal or DCD hearts. A DCD heart retrieval programme has been established at Harefield and Papworth using machine perfusion.

7. National Organ Retrieval Service Review (May 2015)

S Tsui reported on the review of the NORS service which took place as there was excess capacity for organ retrieval. Previously all six adult cardiothoracic centres provided a retrieval team and when NHSBT reviewed the retrieval data there were only 1.5 cardiothoracic donors on any day. In fact, for over 95% of days there were no more than 3 cardiothoracic donors at any one time. It was therefore agreed that teams would pair up to share a duty rota resulting in three teams on call at any one time. The pairings are Harefield/Papworth; Birmingham/Manchester; and Glasgow/Newcastle, the centres in each pairing being on call in alternate weeks. Initially, for the first 3 months of the new arrangement, the second (not on call) team will act as backup. Discussions are still taking place on how to incorporate scouting within the new arrangements. If scouting is restricted to the on-call team then some donors will be too far from the on-call team resulting in only 35 – 40% of donors being scouted. The other option is to have a scout on call from the non on-call team. The new arrangements will be reviewed again in 3 months' time and R Graham asked if this group could help in influencing any decision at that time. S Tsui agreed to forward a copy of the recommendations from the NORS review to R Graham.

S Tsui

8. Transplantation Activity:

a) Latest Statistics – including updated transplant survival models-CTAG(16)H11, CTAG(16)L5

J Mehew presented the latest statistics from the recent CTAG meeting. Copies of the presentation will be circulated to members.

C & SS

b) Heart, Lung and Paediatric Cardiothoracic Transplantation Service Specifications – drafts for public consultation – CTAG(16)S4a,b&c

Members received and noted the draft service specifications from NHS England. Although the consultation is now closed R Graham asked for contact details for NHS England in relation to these specifications.

C & SS

c) Transplant waiting times:

- Removal of patients from urgent /super urgent list at 6cms - CTAG(16)H5

Some patients remain on the urgent waiting list for over a year which means that, because they receive preferential organ offers, the offers for these patients must have been turned down. Analysis of why these have been turned down needs to be carried out. Additionally, if patients are still alive 12 months after being urgently listed then a check needs to be undertaken as to whether it is appropriate for them to remain on the urgent waiting list.

- Prolonged heart and lung registrations – CTAG(16)H10 CTAG(16)L4

This report highlights prolonged patient registrations (between 2 and 5 years) on the system. There is a 2 year rule and the report acts as

a trigger point to remind centres to check if it is still appropriate for these patients to remain on the list.

- Access to heart transplant for blood group O patients – CTAG(16)H8

Although blood group O patients continue to wait longer than others for non-urgent heart transplant there is little else that can be done without affecting the urgent scheme. It was noted that selection and allocation policies, including blood group prioritisation rules, will change under the new impending heart allocation scheme.

- Changes to offering times – CTAG(16)S14

Members received and noted proposals for a new offering system based on four offers in order to reduce offering times.

d) GOSH transplant activity – CTAG(16)H7 & CTAG(16)H9

Following evidence of a difference in the proportion of patients transplanted within six months of registration at the two paediatric centres (Newcastle and GOSH), a meeting was held on 5th May where it was agreed to have a national paediatric waiting list and offer hearts in chronological order to paediatric patients listed at Newcastle and GOSH.

e) DCD Hearts – Service evaluation CTAG(16)H4

Three teams in the world have been working to make it safe to revive and transplant hearts from a DCD donor, including Papworth and Harefield transplant centres in the UK. The first DCD heart transplant was performed in July 2014 in Sydney. Papworth performed its first DCD heart transplant in February 2015 and has now undertaken 19 such transplants whilst Harefield has undertaken 4 and Sydney 9. Thirty day survival of these patients is comparable with that for DBD heart transplantation. NHSBT has set up a Clinical Evaluation of DCD heart retrieval in the UK. A business case to fund the service across the UK is being prepared for submission to the 4 UK Health Administrations and submission will be around July with a view to obtaining approval and funding from April 2017. In the interim Harefield and Papworth are working with their own charities to try to continue to support their programmes locally. Two other UK centres have already expressed an interest in this work.

9. Any other business

S Tsui drew members' attention to a book entitled 'Life is for the Living' written by Kathryn Graham and available on Amazon. The book is an account of Kathryn's experience of pulmonary arterial hypertension and heart lung transplant.

Date of next meeting:

To be advised but will follow the autumn CTAG meeting on 14th October 2016.