

**NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE
MINUTES OF THE NHSBT CARDIOTHORACIC PATIENT GROUP MEETING
MONDAY 16th OCTOBER 2017, 12:30-16:00
AT THE GRANGE ROCHESTER HOTEL, 69 VINCENT SQUARE
LONDON, GREATER LONDON SW1P 2PA**

PRESENT

R Graham	(Co-Chair) Patient Representative, Governor, Papworth Hospital
S Tsui	(Co-Chair) CTAG Chair, Consultant Cardiothoracic Surgeon, Papworth
D Airey	Chairman, Freeman Heart and Lung Transplant Association
J Atkins	Patient Representative, Papworth Hospital
C Kissick	British Heart Foundation
Y Hughes	Policy Officer, Cystic Fibrosis Trust (left before the meeting started)
G Higgins	Patient Representative, Wythenshawe Hospital
B Jones	Transplant Social Worker, Wythenshawe Hospital
A Lees	Secretary, Harefield Hospital Transplant Club
J Nuttall	Cardiothoracic Recipient Co-ordinator, Wythenshawe Hospital
R Quigley	Lead Nurse for Transplant Service, Papworth Hospital
R Pope	Parent of Transplant Patient, Harefield Hospital
S Rushton	Statistician, Statistics and Clinical Studies, NHSBT
J Whitney	Treasurer, Freeman Heart and Lung Transplant Association

IN ATTENDANCE

S Bee	Heart Research UK Ambassador
L Newman	Secretary, Clinical and Support Services, NHSBT
M Thompson	Senior Communications Officer, NHSBT

APOLOGIES

B Harpham	National Director, Heart Research UK
M Harrison	CTAG Lay Member Representative
N Banner	Cardiologist, Harefield Hospital
N Al Attar	Heart Surgeon, Golden Jubilee National Hospital
S Jones	Treasurer, Live Life Give Life
J Williams	Patient Representative, Wythenshawe Hospital
M Thompson	Patient Representative, Golden Jubilee National Hospital
L Ramsay	Lead Nurse Recipient Coordinator

Apologies and welcome

Action

1 Declarations of interest in relation to the agenda

There were no declarations of interest in relation to the agenda.

2 Minutes of the meeting held on Monday 5th June 2017**2.1 Accuracy**

Attendance tracked for Jessica Jones at the last CTPG Meeting was incorrect, Anna Evans deputised for her. Once this amendment is made, the minutes can be ratified as an accurate record of the last meeting

L Newman

2.2 Action Points

During the last Patient Group Meeting, members discussed writing to MPs about NHS tariff rates for transplantation which have remained static for the past 10 years and/or funding for DCD heart retrievals. The group decided to focus on DCD heart retrieval and wrote to MPs accordingly.

Outcomes will be minuted under Section 3, 3.1.

2.3 Any other business agenda items

Sally Bee has been invited to the meeting in her capacity as an Ambassador for Heart Research UK. She has a background in media and personal experience of a heart condition which may require transplant at a later date. She will introduce herself and talk more about her background and plans with Patient Updates under section 4 of the agenda.

Rob Graham has been re-appointed as Cardiothoracic Patient Group Co-Chair for a further two year term until 30th March 2020. S Tsui and Cardiothoracic Patient Group members congratulated Rob on his re-appointment.

3 DCD Heart Transplants

3.1 Patient Group feedback from MPs

Additional costs associated with funding DCD heart retrievals are currently being met by the individual hospital trusts and NHSBT. The business case demonstrates an additional £2.5 million will be required during 2017/18 rising to £3.4million in 2020/21. This would provide an additional 75 DCD hearts donor hearts per year.

R Graham and A Lees, representing Papworth and Harefield respectively, wrote to their MP's to ask them to consider funding for DCD hearts from the four health departments. None of the departments of health have agreed to fund DCD heart retrieval at this time. Underlying reason was not provided, other than financial pressure, but it was speculated that utilisation of DBD hearts to increase the number of suitable hearts transplanted should be evidenced before consideration will be given to funding DCD heart retrievals, in particular the OCS machines, which are not required during DBD transplants.

The letters between R Graham, S McPartland (MP for Stevenage) and the Department of Health are attached with the minutes as CTPG(M)(17)2 Appendix1.

3.2 DCD Heart Activity

Papworth and Harefield commenced with DCD heart retrieval and transplantation in 2015. Manchester have completed the preliminary training and have now performed 3 DCD heart retrieval and transplants.

The high cost of the OCS will continue to prove prohibitive. Manchester will be supported by the New Start Initiative. Harefield and Papworth are both supported by the hospital charity or transplant research grant funding; but the future of funding is uncertain. S Tsui thanked members on behalf of the cardiothoracic transplant centres for writing to their MP's about funding the DCD programme.

TransMedics offer different prices for their OCS machine to different centres, but DCD heart transplants would open the market to TransMedics as all cardiothoracic centres would require the equipment. S Tsui has written to T Baker (Cardiothoracic Transplant Centre Manager Representative) to ask her to consider involvement with national procurement negotiations to secure a better deal with TransMedics for the supply of the OCS Machines to all UK cardiothoracic transplant centres.

Activity reports demonstrate that the UK currently uses 26-30% of DBD hearts, the TOT 2020 strategy aims to increase DBD donor heart utilisation from 30% to 35% of. Higher risks associated with heart transplants (compared to abdominal organ transplants) mean that 40% of suitable DBD hearts are rejected due to the donors having other medical issues making them unsuitable to be a heart donor. Of the remainder, up to 40% are rejected due to poor function.

The length and duration of the organ donation pathway has increased due to a variety of logistical reasons. CTAG have already made inroads in reducing this by making changes to the offering of

cardiothoracic donor organs, and include simultaneous offering where the organ is turned down by super urgent and urgent recipients to try and ensure that there is improved utilisation of suitable donor organs.

A combination of "Scouting" of donors by Cardiothoracic retrieval teams and DCD heart retrieval can potentially increase the number of heart transplants carried out each year by a further 100 hearts per year. Last year approximately 200 heart transplants were carried out in the UK; this figure should potentially rise to 300 over the coming years if both initiatives are supported.

4 Patient Group Updates

Glasgow

There was no update available for Glasgow at this meeting

A Lees – Harefield

Harefield Transplant Club has produced a booklet which aims to give useful practical information for transplant patients and recipients. A Lees offered to share this with the other patient support groups so that they can adopt similar for their centres if they feel it would be helpful. A Lees will forward to L Newman to pass on to the other patient group members. Patients who are looked after by Great Ormond Street are referred to Harefield when they reach the age of 18 and receive this booklet upon transfer of care.

A Lees
L Newman

Aside from actively promoting organ donation, other activity includes the Harefield Annual Cardiothoracic Transplant Reunion takes place in two weeks' time. The club would like to be able to support sporting activity, and have asked whether this something that the hospital charity could assist with but the request has been declined at this stage as this would not be within their remit.

J Nuttall – Manchester

The Manchester Cardiothoracic Patient Group has recently supported the Transplant Games and purchased new sports kit for the Manchester Transplant Sports Team. Christmas Concerts are arranged and promotional activity will continue.

By way of further update, at the beginning of October, the University Hospital of South Manchester merged with the Central Manchester University Hospitals to create a new Manchester University Hospitals Foundation Trust. North Manchester General Hospital will join 12-18 months' time.

J Whitney – Newcastle

The Newcastle Cardiothoracic Patient Group recently held their annual Gala Dinner, and arranged registrations, travel and accommodation for the Dinner. Members also attended the Regatta, and oversaw the sign up of an additional 160 people on the Organ Donor Register. In other news, over 100 transplant recipients from Newcastle attended the Transplant Games, and celebrations are planned for two important events; the 30th birthday of the first baby to receive a transplant at Freeman Hospital, and the anniversary of the first ever transplant which took place at Freeman Hospital 50 years ago on 4th December.

R Graham – Papworth

Regular newsletters are produced for members, who are invited to attend quarterly support meetings. Comments were fed back at a recent Patient Event about a lack of psychological and emotional support for patients and families during the whole transplant journey. The Papworth Patient Group would like to try and offer some support to families and help alleviate the burden on the hospital transplant teams and SNODs. R Graham and R Quigley will meet to discuss further and look at what the Patient Group could do to help offer some emotional and practical support wherever they can. Finally, the Patient Group has also been involved in an application for funding for a project led by the lead Papworth lung consultant.

S Bee – Heart Research UK Ambassador

S Bee is filming for a documentary which will propose that a conscious decision regarding organ donation is made by people reaching the age of 18. This decision would be recorded as proof that a conversation has taken place with next of kin about their wishes. The 'opt in opt out' system used by Wales, seems to have reduced the number of conversations about organ donation, which in turn has resulted in a slight increase in the number of families who now over-ride the decision to donate.

Discussion within the group took place regarding the proposal, and some members felt that forcing a mandatory decision could devalue the gift of life that is given by a donor, and donor families often find solace from the fact that the donor wanted to voluntarily donate their organs. Some members felt that in order to encourage organ donation, school children should be educated about it, which would help them, and potentially their families to make an informed decision which would be less likely to be overridden by next of kin. Discussion concluded that there is much more to be done to encourage more families to converse about their feelings surrounding organ donation as well as what happens before, during and after organ donation. When people are fully informed and have all the information they require, an 'opt in' decision is far more likely. Perhaps organ donation conversations could be improved if they started by asking the question – 'would you accept an organ if you needed one?'

5 Statistics and Clinical Studies

5.1 Overview of Annual Activity

DCD Activity is outlined and reported in CTPG(17)5a. To date, Papworth have completed 29 DCD heart transplants, Harefield have completed six and Manchester had not completed any. These figures were until June 2017. The evaluation phase for DCD heart transplant ended in May 2016. Outcomes after one year for these patients are as follows: 35 of 37 patients have survived, at one month. One patient was re-transplanted at day 26 – but we do not have follow up data for this patient yet. Figures so far show that 84% of DCD heart transplant patients survive to 1 year, a similar outcome to DBD. 12 of the 37 patient required short term mechanical support post-transplant to aid their recovery.

5.2 Super Urgent/Urgent Heart and Lung Updates

Members noted that since the introduction of the Super Urgent and Urgent Lung waiting lists were developed, these lists have remained small and consistent with prediction. S Tsui commented that the new lists are performing exactly as anticipated – with only about 5% of patient being listed and transplanted as Super Urgent or Urgent patients. Rules for listing patients on the Super Urgent and Urgent Heart lists will require some alteration since there are too many patients listed at any one time which reduced their effectiveness. By comparison, the Super Urgent and Urgent Liver lists have far less patients registered as only a small percentage of patients qualify for listing this way.

It was noted that for the Super Urgent/Urgent lung report, 30% of the data was missing. This is due to the recent introduction of the Super Urgent and Urgent Lung lists – 30% of patients transplanted from the list were transplanted less than 30 days ago meaning 30 day outcome data is simply not available yet. Group members requested that the data be split by blood group. S Rushton will follow this up. S Tsui commented that the waiting times for these patients are more influenced by presence of HLA antibodies and less so by blood group.

S Rushton

5.3 Allocation zonal boundary changes

Zonal boundary changes are made to ensure that the percentage share of donors matches as closely as possible to the percentage share of patients registered at each centre. The boundaries are separate for heart and lung. Where the percentage share variant is 5% or above, the allocation zonal boundary has been altered to ensure that the number of first offers the centre receives is proportionate to the number of registered patients on the waiting list.

5.4 Paediatric Allocation Zones

Traditionally, the two paediatric centres, Great Ormond Street and Freeman, have received offers on a rotational basis; however this method does not reflect the differing demand for organs that the two centres have. The cardiothoracic paediatric organ allocation working group proposed and agreed allocation zones would be more appropriate. The proposed zones will see hearts allocated in a 36% (Newcastle) and 64% GOSH split. Lungs will be split with Newcastle receiving 35% and GOSH receiving 65%. These paediatric allocation zones will be reviewed annually by CTAG and adjusted if significant statistical differences are found.

CTPG
Members

Any further statistical queries can be emailed to S Rushton in advance of the next CT patient Group Meeting in June 2018.

5.5 Scouting Update

In order to increase the number of heart transplants S Tsui has been asked to chair a Cardiothoracic Scouting Subgroup which will propose that scouting is commissioned activity. Non scouted donors contribute 24% of DBD hearts; whereas scouted donors contribute 46-51% of donor hearts. Final decisions about scouting will be made by April 2018, all cardiothoracic units are in support, and scouting will bring about a 30-40% increase in available donor hearts. Once authority is given to recruit cardiothoracic scouts, improvements in donor care will be seen, which will also help to significantly reduce the number of rejected hearts.

7 Any Other Business

S Tsui will complete his five year tenure as Chair of CTAG and will attend his last meeting to hand over to the new Chair of CTAG in April 2018; he will remain as Chair of the Scouting Subgroup. R Graham thanked S Tsui for his dedication, support and hard work as Co-Chair of the Cardiothoracic Patient Group.

L Newman will liaise with Cardiothoracic Patient Group Members to ensure that there is no risk of cross infection between CF Members. L Newman

Date of next Meetings:

****NB** ALTERATION TO THE SPRING CTPG MEETING**

Tuesday 5th June 2018, 13:00-16:30 (sandwich lunch provided)

The West End Donor Centre, 26 St Margaret Street, Marylebone, London, W1W 8NB

Monday 12th November 2018, 12:30-16:00 (sandwich lunch provided)

The West End Donor Centre, 26 St Margaret Street, Marylebone, London, W1W 8NB

APPENDIX 1

30 June 2017

Stephen McPartland**MP for Stevenage**

House of Commons

Westminster

Dear Stephen

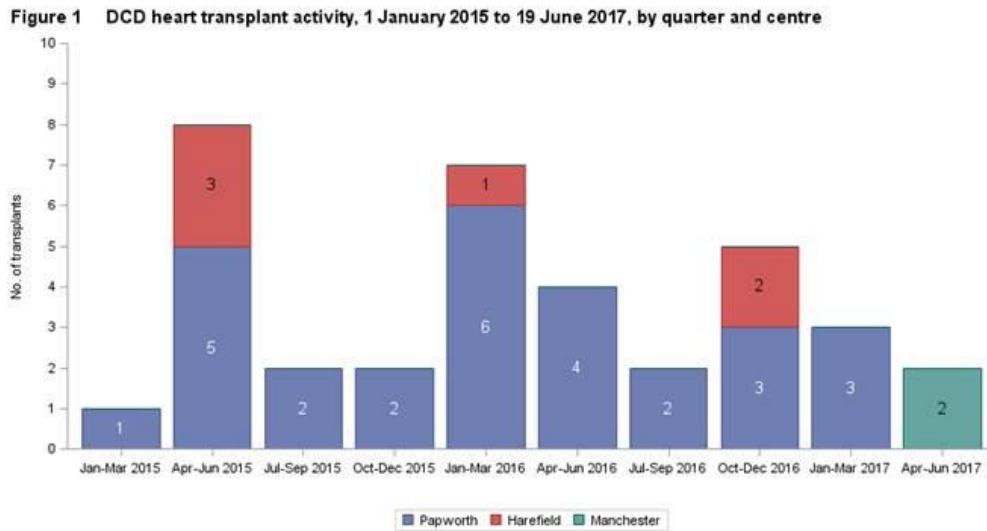
Re: DCD Heart Transplantation

Firstly, let me congratulate you on your re-election as Member of Parliament for Stevenage. Secondly, you may remember we chatted in B&Q (of all places) during the recent election campaign when I also reminded you that you'd previously my wife, Kathryn, who received a combined heart and double lung transplant at Papworth Hospital, at the House of Commons a couple of years ago when she was promoting Organ Donation. We are both members of the Papworth Transplant Patient Representative Group and I am also Co-Chair of the national Cardiothoracic Transplant Patient Group run by NHS Blood and Transplant ("NHSBT").

I am writing to express our concern at the recent decision by the UK's four Departments of Health to decline to finance a core element of a current important heart transplantation initiative.

You may be aware of the pioneering research and work that has been undertaken at Papworth Hospital over recent years into organ donation after circulatory death ("DCD") as opposed to traditional donation after brain death ("DBD") in an effort to increase the heart donor pool and give more patients on the transplant waiting list a real chance at receiving a lifesaving heart transplant.

Following this research, Papworth Hospital performed the first DCD heart transplant early in 2015 and, to date, a total of 36 DCD transplants have been undertaken across three UK transplant units, with very much the lion's share at Papworth, as you can see from Figure 1.



The success of the DCD heart transplant programme has been made possible by using an Organ Care System (“OCS”), which enables the arrested donor’s heart to continue to recover outside of the donor’s body. Each transplant requires the use of a single-use OCS module at a cost of c.£30k - currently there is only one company, TransMedics, who can supply the system. These OCS costs are currently met **entirely by charitable funding**. However, with the success of the DCD heart transplant programme now proven, a business case was put via the NHSBT to the four UK Health Departments to provide this funding going forward. This has recently been declined due to “financial restraints” – see enclosed memo from the NHSBT to all Cardiothoracic Units dated 9th June 2017.

As I have already said to the NHSBT (see letter dated 28th June 2017), it seems completely incongruous that, despite an acknowledged shortage of organ donors, the Health Departments, by refusing to meet the OCS costs, are not prepared to fully support the DCD heart programme which has led, to date, to a significant number of

people receiving a life changing heart transplant, equating to roughly a 10% uplift in heart transplantation over the two financial years 2015/2017.

Now that the programme has proved its success, we believe it is entirely inappropriate to continue to rely on the goodwill of charitable donations for any aspect of DCD heart transplantation funding and would ask for your help in challenging this decision made by the Health Departments.

I would be very happy to meet with you, along with my wife, together with a DCD recipient if possible, to make the case in person if you would so wish.

I have written a very similar letter to Heidi Allen, MP for South Cambridgeshire, the constituency in which Papworth Hospital is based. As I am not one of her own constituents I wanted to write to you in a similar vein to increase awareness of this issue and request your support.

With very many thanks in anticipation of your help and involvement.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Rob Graham', with a stylized, wavy line extending from the end.

Rob Graham

Enclosures

Cardiothoracic Transplant Patient Group letter dated 28th June 2017 to NHSBT
NHSBT letter dated 9th June 2017 to all Cardiothoracic Units