TO BE RATIFIED CTAGH(M)(17)2

NHS BLOOD AND TRANSPLANT ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

MINUTES OF THE TENTH MEETING OF THE NHSBT CTAG HEART ADVISORY GROUP ON WEDNESDAY 13TH SEPTEMBER 2017, 10:00 – 12:00 IN THE INTAVENT SUITE, ASSOCIATION OF ANAESTHETISTS, 21 PORTLAND PLACE, MARYLEBONE, LONDON W1B 1PY

PRESENT:

Mr S Tsui Chair

Mr J Asher Medical Health Informatics, ODT

Prof N Al Attar Surgeon, Golden Jubilee National Hospital, Glasgow

Dr N Banner Cardiologist, Harefield Hospital, Middlesex

Dr V Carter BSHI Representative, Newcastle

Mr P Catarino BTS Representative, Surgeon, Papworth Hospital, Cambridge

Mr C Chalk CTAG Lay Member Representative

Ms N Crouchen Recipient Transplant Co-ordinator, Harefield Hospital, Middlesex

Prof J Dark
Ms J Foley
National Clinical Lead for Governance, ODT
Head of Clinical Governance, NHSBT

Mr P Flynn Welsh Health Specialised Services Committee

Prof S Fuggle Scientific Advisor, ODT

Mrs M Harrison CTAG Lay Member Representative Mr A Hasan Surgeon, Freeman Hospital, Newcastle

Mr J Mascaro Surgeon, Queen Elizabeth Hospital, Birmingham

Ms J Newby

Dr C Lewis

Ms L Logan

Dr J Parmar

Dr J Parmar

Miss S Rushton

Head of Referral and Offering, NHSBT

Cardiologist, Papworth Hospital, Cambridge

Regional Manager, Organ Donation Services, ODT

Chest Physician, Papworth Hospital, Cambridge

Statistician, Statistics and Clinical Studies, NHSBT

Dr J Simmonds Deputy for Dr M Burch, Great Ormond Street Hospital, London

Mr R Venkateswaran Surgeon, Wythenshawe Hospital, Manchester

Ms S Watson Commissioner, NHS England

Miss E Wong Statistician, Statistics and Clinical Studies, NHSBT

IN ATTENDANCE:

Mr A Kourliouros Observer, Clinical Fellow, Papworth Hospital, Cambridge Mr J McGuinness Surgeon, Mater MiserIcordiae University Hospital, Dublin

Prof R Ploeg National Clinical Lead for Organ Retrieval, NHSBT

Ms S Rendel QUOD Bio-bank, Oxford

Dr Z Reinhardt Paediatric Observer, Freeman Hospital, Newcastle Ms D Russell Observer, General Manager, Harefield Hospital

APOLOGIES:

Ms T Baker Transplant and Divisional Manager, Harefield Hospital Dr M Burch Cardiologist, Great Ormond Street Hospital, London

Prof J Forsythe Associate Medical Director, ODT Dr E Jessop Medical Advisor, NHS England

Ms S Johnson Director of Organ Donation and Transplantation, NHSBT

Mrs J Nuttall Recipient Co-ordinator Lead, Wythenshawe Hospital, Manchester

Prof S Schueler Surgeon, Freeman Hospital, Newcastle

Mr O Senbaklavici Deputy for Mr J Lordan

Mr M Stokes Head of Hub Operations, NHSBT Dr M Winter National Services Division, Scotland

Action

1 Declarations of interest in relation to the agenda

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

Minutes of the meeting held on Monday 26th April 2017 2.1 Accuracy

In section 5.4 of the minutes dated 26/04/17, paragraph 3 should read:

The Paediatric centres do not have access to the super-urgent listing scheme.

L Newman

Post meeting note: This amendment has been made and the minutes ratified as a correct copy for publication.

2.2 Action Points

1 - Submission of UK VAD data to IMACS:

S Rushton will contact IMACS, who will send UK VAD data to Euromacs. This issue is tied up with the further discussion about the future of the UK VAD Database which will be considered in more detail during item 7.1.1 on the shared agenda. S Tsui has already written to NHS England and Theo De By at Euromacs with confirmation that NHSBT data submitted to IMACS may also be used by Euromacs.

S Rushton

2 - Clinical Governance Newsletter:

The clinical governance newsletter has been on hold, pending a decision. The group agreed that a trial newsletter would be published approximately one month after CTAG Wider Group Meetings, to signpost readers in the wider cardiothoracic community to useful relevant information, good practice, learnings and policies relating to cardiothoracic transplantation. J Asher reported that the password protected section of the new ODT Clinical Website will be useful for communicating such things and for this purpose a database of all email addresses of transplant surgeons will be compiled. J Dark will lead on the newsletter, working with J Foley and its usefulness/effectiveness will be reviewed after two publications.

J Dark/ J Foley

3 - QUOD papers and Project Proposal

Refer to shared minutes Item 8.

4 - DCD Heart Utilisation @ Newcastle

A Hasan has written to G Oniscu requesting approval to commence with DCD heart retrieval and transplantation at Newcastle.

5 – Update on heart selection and allocation policies

This work has been completed - urgent heart-lung block patients will continue to be listed on the urgent heart allocation scheme.

6 - Super urgent and urgent heart allocation schemes summary

Full completion of registration forms for patients being registered to the urgent heart schemes is improving, however some centres are still not completing all fields and incomplete forms will not be accepted by the Duty Office in the future. Centre Leads to Centre Leads encourage full completion of the registration forms prior to submission. In time, validation rules will be programmed to prevent incomplete registration forms from being processed.

7 – Prolonged heart registrations

This is an annual action for all centres to review and confirm those patients who are listed as long waiters are still correct. Birmingham, Harefield and Papworth have completed this three outstanding centres to confirm their lists to S Rushton at their earliest convenience.

N Al Attar R Venkateswaran A Hasan

Governance issues 3

3.1 Non-compliance with heart allocation

There were no incidences of non-compliance with heart allocation since the last report in April 2017.

3.2 Group 2 Transplants

NHSBT should be notified if a Group 2 patient is transplanted. At present, for cardiothoracic there has only been one recorded case in the last 10 years; the donor was from the Republic of Ireland. Queries regarding patients who fall outside the remit of Group 1 transplantation and care should be referred to National Services Division Scotland or NHS England for guidance regarding the funding of transplants, costs associated with aftercare and post-transplant treatment.

3.3 Heart incidents for review

There were no heart incidents for review.

3.3.1 Clinical Governance report

Incidents around heart transplantation are mainly due to delays mobilising the NORS Team. This process will become smoother as further changes to the Hub and the offering process are implemented.

Number of people in theatre: A cap will be put on the number of people who can be in the retrieval theatre at any one time - on occasion there have been up to 30 people in theatre which is too many.

Filming: The GMC gives permission to take images of organs from donors. Filming for the purpose of education must adhere to the SOP and consent from the family must be obtained. Filming undertaken to expedite decisions is acceptable without family permission and WhatsApp has been found to be one of the more effective ways of communicating images/films for decision making.

Culturing ice outside packaging bags: No SOP exists regarding the management of ice machines which produce ice for organ transport boxes. To date there have been no clinical incidents relating to this, however the ice can generate positive cultures and should therefore be as clean as possible. Newcastle recently replaced their ice machine, and keeps it solely for producing ice for retrieval use. J Dark agreed to send the Newcastle SOP to S Tsui to forward to cardiothoracic NORS teams. It is recommended that each cardiothoracic NORS team should be thoroughly cleaned on a regular basis. Newcastle and Manchester have already purchased new ice machines for retrievals, and Harefield clean

J Dark

their machine regularly. Glasgow, Papworth and Birmingham will investigate the ice machines at their centres and report back to CTAG. This example of Good Practice should be implemented by all centres, but this cannot be mandated due to additional costs.

Late Declines: Organs which are accepted and otherwise viable have sometimes been declined late in the process. The most recent reason for a late decline is discussed in Issue 16 Cautionary Tales, June 2017. Late declines are recorded as incidents at present. CTAG agreed that an ideal heart donor could be defined and will decide on the criteria for this. CTAG agreed that a monthly teleconference would take place to discuss cardiothoracic organs declined during the previous month. All centres should dial in to the teleconference. J Mascaro has kindly agreed to lead on this process

CTAG Wider Group

J Mascaro

3.4 Summary of CUSUM monitoring of 30 day outcomes following heart transplantation

No cardiothoracic CUSUM signals have been identified during the past 5 months. NHSBT Statistics and Clinical Studies proposed updating the baseline data from 2008-2011 to a more recent period. Changes will be brought to the next CTAG meeting for information.

S Rushton

4 Heart Allocation

4.1 Super Urgent Heart Allocation Scheme Audit

Statistics and Clinical Studies carried out an audit of the Super Urgent Heart Allocation Scheme to investigate patient numbers and outcomes since its implementation in October 2016. Nawwar Al-Attar noted that many of the post-transplant IABPs used at Glasgow were already in-situ pre transplant and do not represent PGD. Other centres to report on whether theirs are in-situ or de novo IABs. Data collection form may need amending.

Manchester Papworth Newcastle Birmingham Harefield

Asif Hasan reported that the Newcastle patient outside of standard category 11 has now been transplanted and is doing well.

Patients are mostly listed on the SUHAS under category 11 of the listing criteria and the average wait is 10 days. Due to the high number of patients registered with an IABP, it has been decided by the CTAG Core Group that such patients will only qualify for the UHAS and advancement to the SUHAS will have to be approved by the CTAG Adjudication Panel. If approved, SUHAS listing will be valid for 7 days and patients would revert to the UHAS unless another application is made to the Adjudication Panel and approved for a further 7 days. C Lewis has drafted a pro-forma for this SUHAS application. S Rushton to finalise the pro-forma and L Newman will circulate for comments.

S Rushton L Newman

It was agreed that the forms must be completed and submitted to Adjudication for patients on IABP to be considered for SUHAS. From now on, this SUHAS listing will be valid for 10 days, following which the patient will revert to the UHAS unless a further application is approved by the Adjudication Panel for a further 10 days. The Duty Office will be able to check the SUHAS at 09:00 daily and remove any patients who do not have a current registration form logged with either the Duty Office or the Adjudication Panel. Further discussion on the operational mechanism to be discussed outside of the meeting.

J Newby S Rushton

Other findings so far are that waiting time for these patients has been significantly reduced but more data and further analysis needs to be carried out to assess the whole picture. S Rushton to bring further analysis, including percentage of SU transplants done by each centre and percentage of patients on short-term support before and after SUHAS, to the next CTAG.

S Rushton

4.2 Convening a new CTAG Heart Allocation Sub-Group (CTAG HASG)

TPRC questioned why age has been used as a cut off for cardiothoracic allocation. Unless there is a robust clinical reason behind this, CTAG and NHSBT could be challenged on

grounds of age discrimination and there has recently been such a challenge.

The 2 Paediatric Centres agreed that there is no clinical justification for using age as a cut off in heart allocation; however size and age are still essential selection criteria for lung transplantation due to the growth potential of adolescent donor lungs. Further discussion is required to revise the current heart allocation policy and remove the age threshold. S Tsui will write to centres for them to nominate a representative to attend the new CTAG HASG.

S Tsui

5 Update on DCD Hearts – review of activity and outcomes

Harefield have not recently performed any DCD heart transplants – they have received limited numbers of DCD heart offers.

Manchester has completed five DCD runs which resulted in four retrievals and three transplants. Of the three transplant recipients two have gone home and one is currently an in-patient 65 days after transplantation. Manchester ran out of DCD retrieval kits, however they have been able to secure funding to purchase a further six circuits.

Papworth has completed 31 DCD transplants to date with 100% survival at 30 days and 91% survival at one year. A manuscript summarising early outcomes has been submitted to the JHLT.

Others:

Newcastle has been liaising with Papworth for training and has used the OCS machine in 4-5 transplants.

Glasgow has an OCS machine and everything else is in place to start using this for DBD runs. They need to do at least three DBD OCS runs before embarking on proctored DCD runs. N Al Attar needs to write to G Oniscu to confirm that Glasgow is planning to progress with the agreed process, and will commence the necessary training in order to facilitate them retrieving DCD hearts.

N Al Attar

It was noted that there had been a slight downturn in DCD activity, which may be down to fewer offers or other reasons, such as not having a suitable recipient to accept the DCD heart offer. Furthermore, it was noted that not all DCD heart offering activity is recorded on NTxD. S Rushton will discuss with the Hub whether this information can be logged centrally. It is essential to gather the reasons for declining DCD hearts to develop a clearer understanding of the number of DCD hearts being offered and why some are not accepted. When a DCD heart is available and not used within the retrieval centre, it should then be offered to other centres according to the agreed offering sequence. Centres need to log the number of DCD heart offers they receive and reasons for decline. This should be reported at the next CTAG meeting.

Harefield Papworth Manchester

Another issue facing all centres is funding for DCD retrievals; currently individual centres fund the OCS for DCD heart retrieval but this position is not sustainable long term.

S Rushton discussed the circulated DCD heart report. Retrieving and transplanting DCD hearts will reduce the waiting lists and waiting times for patients on the lists. To date, since February 2015, 37 DCD hearts have been transplanted with an 85% survival rate at one year, which is comparable to the national average of 83% for DBD heart transplants. NHS England are keen to see DCD heart transplantation brought into standard practice and are aware that funding is the responsibility of the hospital.

UK centres could join forces to try to negotiate a better deal with Transmedics who supply the OCS Machine. S Tsui will write to T Baker to ask her as the outgoing TMF representative to assist with co-ordinating this initiative with all of the transplant centre managers.

S Tsui

6 LVAD Update

The Policy Working Group for LVAD Destination Therapy met on 5th May 2017. A draft

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policy will shortly be circulated for comment before going to the wider NHSE. It clarifies the criteria for LVAD/DT.

Destination Therapy using LVADs is currently not commissioned in the UK; if a team is competent and the patient wants to pay for the treatment, then it can go ahead. Papworth has carried out Destination Therapy for payment and negotiated a fee with the patient's health insurance company – but this is a decision left to the discretion of individual units.

A VAD database meeting has been convened by Edmund Jessop on 21/09, which is the same day as the Scout sub-group meeting, and there is some concern that the meeting must be adequately attended. Discussion will focus on Euromacs and the future of the UK VAD database.

7 Any other business

There was no further business raised at the meeting.

The CTAG Patient Group Meeting will take place in central London on Monday 16th October 2017 from 12.00-16.00. Members to contact L Newman to register their attendance.

8 Date of next meeting2018 CTAG Wider Group (Heart) Meetings:

Wednesday 25th April 2018, 15:00 – 17:00 – venue TBC Wednesday 26th September 2018 10:00 – 12:00 – venue TBC

Organ Donation & Transplantation Directorate

September 2017

