

**NHS BLOOD AND TRANSPLANT
ORGAN DONATION & TRANSPLANTATION DIRECTORATE**

**THE SEVENTEENTH MEETING OF THE MULTI-VISCERAL AND COMPOSITE TISSUE
ADVISORY GROUP (FORMERLY BAG) MEETING
AT 11:30 AM ON WEDNESDAY 21 MARCH 2018, CONFERENCE ROOM,
MEDICAL SOCIETY OF LONDON, LETTSOM HOUSE, 11 CHANDOS STREET,
MARYLEBONE, LONDON, W1G 9EB**

PRESENT:

Prof Peter Friend	Chairman (and Rep for National Retrieval and Liver)
Dr Philip Allan	Oxford Intestinal Transplant Centre
Dr Elisa Allen	Statistics & Clinical Studies, NHSBT
Ms Carly Bambridge	Recipient Co-ordinator Representative
Mr Andrew Butler	Cambridge Intestinal Transplant Centre & PAG Representative
Prof John Forsythe	Associate Medical Director, NHSBT
Prof Sue Fuggle	Scientific Advisor, ODT
Dr Simon Gabe	Adult and small bowel and BAPEN Rep
Mr Henk Giele	Composite Tissue Abdominal Representative
Dr Girish Gupte	Birmingham Intestinal Transplant Centre
Dr Susan Hill	Paediatric gastroenterologist and BSPGHAN Rep
Dr Jonathan Hind	King's Intestinal Transplant Centre
Dr Edmund Jessop	Public Health Advisor, NHS England
Mr Hector Vilca-Melendez	King's Intestinal Transplant Centre
Prof Elizabeth Murphy	Lay Member
Ms Jacqueline Newby	Referral and Offering, ODT
Ms Susan Richards	Specialist Nurse Organ Donation Representative
Ms Sally Rushton	Statistics & Clinical Studies, NHSBT
Dr Lisa Sharkey	Cambridge Intestinal Transplant Centre
Dr Georgios Vrakas	Deputy for Mr Srikanth Reddy, Oxford Transplant Centre

IN ATTENDANCE:

Mrs Kamann Huang Secretary, ODT

ACTION

Apologies were received from:

Dr Martin Barnardo, Ms Melissa D'Mello, Prof Simon Kay,
Ms Joanne Roach, Mr Srikanth Reddy, Mr Khalid Sharif,
Mr Mick Stokes and Ms Sarah Watson.

Ms M D'Mello (Lay Member) will transfer to CTAG from 1 April
2018.

Dr Simon Travis will be replaced by Dr Philip Allan in future
meetings. MCTAG expressed their thanks to the work undertaken
by Dr S Travis to-date.

**1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA
- MCTAG(18)1**

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

2 MINUTES OF THE MCTAG MEETING ON 11 OCTOBER 2017 - MCTAG(M)(17)2

2.1 Accuracy

2.1.1 The minutes of the meeting held on 11 October 2017 were agreed as an accurate record.

2.2 Action Points – MCTAG(AP)(18)1

2.2.1 Offers outside the acceptance criteria (Re: 15.03.17 Meeting)

This refers to a change in Intestinal Policy to give paediatric status to intestinal patients with contracted abdominal cavity weighing more than 35 kg and to ascertain any potential disadvantages on liver patients.

E Allen reported that the paper and analysis undertaken on intestinal policy and the impact on liver was no longer required following feedback from P Gibbs at Addenbrookes. The proposal was therefore not discussed at LAG on 22 November 2017. A Butler informed members that this was incorrect and they still had a patient on the waiting list (3-4 years now). K Huang to invite A Butler to the next LAG meeting on 2nd May for further discussion.

**K Huang/
A Butler**

Pancreas-containing grafts for non-UK EU citizens. There are occasional referrals of patients from other EU countries. Although the availability of donor intestines is adequate, previous discussions at both MCTAG and PAG have determined that high quality donor pancreases should not be discarded as part of the back-table preparation of intestine-only grafts for non-UK patients. However, if the patient requires a pancreas as part of a multi-visceral graft, the situation is different. Discussion at the recent PAG meeting had concluded that EU citizens with appropriate authorisation for treatment in the UK should have the same access to these organs as any NHS-entitled UK citizen.

AP8 - Potential bowel donors and location. The paper looking at small donors, organ utilisation and non-consented donors less than 30 kg will be presented at the next MCTAG meeting on 17 October.

S Rushton

AP9 – Refer to Agenda Item 11.

AP11 – A Butler informed members that a Form has been generated.

2.3 Matters arising, not separately identified

2.3.1 There were no matters arising.

3 ASSOCIATE MEDICAL DIRECTOR'S REPORT

3.1 Developments in NHSBT

3.1.1 Consent and information at the time of transplant

3.1.1.1 J Forsythe outlined 3 main projects raised at BTS:

- Consent and Information at the time of transplant. The current process of informing patients and taking consent are good but further improvements are still needed. Workshops were held last

year on patient consent and included both legal and Lay Members' input. The next stage is to define the process better which will require a small group for each organ to specify the content and incorporate patient feedback for the different levels of information. The recommendation is to have a core amount of information with further levels of information should patients require this. We are currently looking at tools to help highlight this information and would like to request the support of MCTAG members to achieve this.

- Donor Characterisation review led by S Fuggle. This is now at the implementation stage with H&I and microbiology.

- Organ Retrieval. A new record of 1500 donors in the UK was achieved for the first time. Keith Rigg will be chairing the review for demand and capacity for organ retrieval.

3.2 Governance

3.2.1 Non-compliance with allocation

3.2.1.1 There were no non-compliances reported with allocation.

3.2.2 Detailed analysis of incidents for review – MCTAG(18)2

3.2.2.1 J Dark's report outlined two incidents of relevance. One regarding an Organ Summary form not stating that rectus fascia was taken resulting in the family letter being incorrect and the second was a lack of traceability of abdominal fascia that had been retrieved. Both incidents have been resolved.

A Butler informed members that a meeting with the Human Tissue Authority (HTA) will be held on Tuesday 27th March. The HTA classify rectus fascia as tissue rather than an organ.

H Vilca-Melendez expressed his wish to join the meeting being organised and hosted by J Forsythe. This was agreed.

4 ODT HUB UPDATE

4.1 The Business Case for the Hub Programme 2018/19 has recently been approved by SMT and one of the main focus areas will be producing electronic HTA A and B forms, something raised by this group already. A further update will be given at the next meeting.

The National Liver Allocation Scheme went live on the 20th March 2018. One major benefit of the scheme is that the recipient size is matched to donor weight and the matching runs of offers will not include recipients where there is a size mismatch.

There were a couple of issues brought up at the meeting regarding a fast track offer not received at Addenbrookes because of a pager issue and an issue involving an offer of a liver and bowel without a kidney when the recipient also needed a kidney at Birmingham Children's Hospital. J Newby will investigate and report directly to the individuals involved.

The question was asked regarding sharing of organs from outside of the UK. It was stated that the current arrangement with the Republic of Ireland is not statutory but undertaken more along the lines of

professional and clinical agreement but in light of political changes, a formal MOU, in order to preserve present practice, is being investigated.

With regards to offers of organs from Euro-Transplant, again this is currently undertaken on an informal basis. A Butler will approach France and Euro-Transplant to look at how suitable donors might be referred.

A Butler

5 TRANSFER OF UK INTESTINAL DATA TO THE INTERNATIONAL INTESTINAL TRANSPLANT REGISTRY (ITR)

- 5.1 E Allen has held a teleconference with Dr Everett, the Director of the International Intestinal Transplant Registry to discuss the logistics of the transfer of UK intestinal data. One option could be via the Cloud system. Patient identifiable information will not be transferred. E Allen will meet with A Gane, Information Governance, to seek guidance and to confirm if consent is required for holding anonymous information.

S Rushton
(E Allen)

It was stated that there will be a change in regulation which will in turn require every Registry to be checked.

6 STATISTICS & CLINICAL STUDIES REPORT

6.1 Summary from Statistics and Clinical Studies – MCTAG(18)3

E Allen presented a paper from Statistics and Clinical Studies summarising recent presentations, current and future work in intestinal transplantation.

NHSBT is currently funded for two clinical fellows to support its programme of audits and analyses. One is for an ongoing post in cardiothoracic transplantation based in Papworth. The second post is currently being advertised to work in abdominal organ transplantation.

A Clinical Fellow has been recruited to start in early 2018 to work on organ utilisation with C Callaghan and the Statistics team.

E Allen will be going on maternity leave in early April for one year. Members expressed their best wishes and thanks for her work. S Rushton will be the Lead support during her absence.

7 NATIONAL BOWEL ALLOCATION

7.1 Performance report of the National Bowel Allocation Scheme (NBAS) – MCTAG(18)4

Data presented showed that since the introduction of the NBAS in 2013 there has been an increase in the proportion of patients transplanted and a decrease in the number of deaths within 1 year of listing for both adult and paediatric patients, along with a reduction in the median waiting time for patients requiring a liver and those who do not require a liver.

It was highlighted that a patient at Kings registered for a multi-visceral transplant received a liver only (Table 1, patient number

11). This patient needs to be followed up on the Liver Transplant Form.

8 GROUP 2 TBOWEL RANSPLANTS – MCTAG(18)5

8.1 No Group 2 intestinal transplants were undertaken in the last 6 months from 1 August 2017 to 31 January 2018. One Group 1 adult intestinal transplant was undertaken for a non-UK resident EU patient for the same period. Organs for non-EU elective patients have in the past been dealt with on a case by case basis.

9 PATIENT SURVIVAL OUTCOMES

9.1 Patient survival after intestinal transplantation – MCTAG(18)6

Data for Figures 5 and 6 for adult patients at 90 days and 1 year survival following intestinal transplantation by transplant era and by transplant type respectively showed no evidence of difference; the data includes the outcome of SU intestinal transplants shown in Table 1. Table 2 showed the cause of death for 8 patients following abdominal wall transplants between July 2009 and December 2017.

Centre representatives were reminded of the return of prompt transplant follow up forms to enable more accurate data reporting.

S Gabe requested that it would be beneficial to have 5 years data by transplant type. E Allen/S Rushton to include this in the report.

S Rushton

10 UPDATE FROM THE WORKING GROUPS

10.1 Update from the Quality of Life Working Group: data collection – MCTAG(18)7

10.1.1 S Travis reported that since September 2017 there has not been enough data to undertake another analysis.

L Sharkey acknowledged that data collection can now commence following agreement on the type of data to be collected.

Disease specific and generic metrics are required to understand the impact and to allow for comparison of outcomes across other chronic conditions. The proposal is to start looking at this in the adult centres and then develop the same approach for the paediatric centres.

Members agreed for a small group (P Allan, L Sharkey and a rep from King's) to take this forward and how it is to be funded.

**P Allan/
L Sharkey**

10.1.2 Paediatric Quality of Life Tools and Recipient Form – MCTAG(18)8

C Bambridge presented a paper on PEDs QL to capture data throughout the child's life span from 2 to 18 years. There is also a tool for infants and a separate parental questionnaire. The analysis tools are well validated and psychologists from King's College are in favour. There are a range of modules available including GI disorders and transplantation which could be adapted for intestinal

To be ratified

**MCTAG(M)(18)1
ACTION**

transplantation. C Bambridge to work with paediatricians, J Hind and G Gupte to discuss the data collection further.

**C Bambridge/
J Hind/
G Gupte**

10.2 **Update from the Working Group on NHSBT data and post-operative data collection – MCTAG(18)9**

10.2.1 G Vrakas reported on data enhancement looking at 3 sections: pre-transplant, intra-operative and post-transplant data and HLA typing. The long-term plan is to look at common ways of reporting rejection and classification. The aim is to come up with a proposal to be circulated and modified following feedback and have the forms ready by October 2018.

**G Vrakas/
S Reddy**

The monitoring points for liver patients is at 3 months and 1 year post transplant. A Butler and G Vrakas were asked to include NHSBT Statistics in the process. H Vilca-Melendez agreed to be involved to represent paediatrics.

**A Butler/
G Vrakas/
Statistics/
H Vilca-Melendez**

10.3 **Update from the Working Group on a patient information and consent document for intestinal transplantation – MCTAG(18)10**

10.3.1 A Butler confirmed that recommendations made at the previous meeting have now been included in the report. Once agreed, it will be made available to all transplant centres.

The suggestion was made to include a better way of representing risk with possibly the use of pictograms. J Forsythe recommended that presenting a core information alongside additional depths of information would be beneficial. A Butler to send the draft report to Liz Armstrong and J Forsythe.

A Butler

Once the report is finalised G Gupte and J Hind are to put together a paediatric version.

**G Gupte/
J Hind**

11 **UPDATE ON ADOLESCENT TRANSITION IN SMALL BOWEL TRANSPLANTATION**

11.1 G Gupte reported that patients are currently being transitioned to Oxford and Cambridge with the option being given to families.

It was acknowledged that although it is important for patients to get support from their local IF centre the complete long term support care should not be restricted locally.

12 **APPEALS/PRIORITY**

12.1 There were no appeals reported regarding bowel intestinal transplantation.

13 **UPDATE ON ADULT AND PAEDIATRIC SERVICE SPECIFICATION**

13.1 G Gupte and J Hind to send the final amendments to E Jessop with a copy to K Huang.

**G Gupte/
J Hind**

14 ABDOMINAL WALL TRANSPLANTATION – MCTAG(18)11

14.1 H Giele gave a presentation to attendees. A summary of the points outlined were:

- 26 abdominal wall transplants (with intestinal /MMVT) were undertaken between 2016/18. This is undertaken for intestinal dysfunction and to aid difficult abdominal closure after transplant.
- The consent rate amongst patients for abdominal wall transplant (AWT) is high but low for sentinel skin flaps. Sentinel skins is currently part of a research programme.
- Patients at Oxford have been allowed to trial remote immunological monitoring, based on the occurrence of a skin graft rash at an early stage in graft rejection.
- One patient with an extensive tattoo on the abdominal wall graft was able to overcome the psychological effect of the visible abdominal wall transplant.
- Skin grafts are currently not part of national organ retrieval and can only be retrieved in certain parts of the country.
- The number of transplants, including AWT, has been adversely affected by the lack of ICUs.
- Issues for future consideration:
 - how we encourage consent for sentinel forearm flaps;
 - how to assess the benefit of immunological monitoring of sentinel skin flaps.

15 INCONSISTENT USE OF HTA A FORMS IN BOWEL TRANSPLANTS

15.1 The issue was raised by the HTA and has now been resolved.

16 UPDATE ON NASIT**16.1 Guidelines**

16.1.1 S Gabe confirmed that the NASIT Terms of Reference have been amended, agreed at the last meeting on 1 November 2017, and been circulated.

16.2 Paediatric Group

16.2.1 S Gabe to send J Hind the dates for the NASIT meetings. The decision to create a paediatric NASIT is yet to be confirmed.

S Gabe**17 ANY OTHER BUSINESS**

17.1 G Gupte will email K Huang the details of the 4th meeting of the Network of Intestinal Failure and Intestinal Transplantation in Europe (NITE) on the 28th – 29th June 2018 to circulate to members.

**G Gupte/
K Huang****18 DATE OF NEXT MEETINGS:**

- Wednesday 17 October 2018 – West End Donor Centre, London

19 FOR INFORMATION ONLY:

Papers attached for information were:

19.1 ICT Progress Report – **MCTAG(18)12**

19.2 Transplant activity report for January 2018 – **MCTAG(18)13**

19.3 Minutes of LAG meeting: 22 November 2017 – **MCTAG(18)14**

19.4 Intestinal Patient Data Record Consent – **MCTAG(18)15**

19.5 New Appointments

Organ Donation and Transplantation Directorate

March 2018

Administrative Lead: Kamann Huang

To be ratified