NHS BLOOD AND TRANSPLANT
ORGAN DONATION & TRANSPLANTATION DIRECTORATE

THE TWENTIEH MEETING OF THE MULTI-VISCERAL AND COMPOSITE TISSUE ADVISORY GROUP MEETING AT 11:30 AM ON WEDNESDAY 16 OCTOBER 2019, THE GRANGE WHITE HALL HOTEL, 2-5 MONTAGUE STREET, LONDON, WC1B 5BU

PRESENT:

Prof Peter Friend	**Chairman** (and Rep for National Retrieval and Liver)
Dr Girish Gupte	Deputy Chair & Birmingham Intestinal Transplant Centre Rep
Dr Philip Allan	Oxford Intestinal Transplant Centre
Dr Elisa Allen	Statistics and Clinical Studies
Ms Carly Bambridge	Recipient Co-ordinator Rep
Mr Andrew Butler	Cambridge Intestinal Transplant Centre
Prof Derek Manas	National Clinical Governance Lead, ODT
Dr Simon Gabe	Adult and Small bowel and BAPEN Rep
Mr Henk Giele	Composite Tissue Rep (Abdominal)
Dr Susan Hill	Paediatric gastroenterologist and BSPGHAN Rep
Dr Jonathan Hind	King's Intestinal Transplant Centre
Ms Heather Howe	Recipient Co-Ordinator
Prof Simon Kay	Composite Tissue Rep (Hand & Upper Limb)
Ms Sarah Peacock	BSHI Rep
Dr Tracey Rees	Scientific Advisory, ODT
Dr Lisa Sharkey	Cambridge Intestinal Transplant Centre
Mr Hector Vilca-Melendez	King's Intestinal Transplant Centre
Ms Sarah Watson	NHS England

IN ATTENDANCE:

Mrs Kamann Huang	Secretary, ODT

To be ratified

ACTION

Welcome

- Julie Whitney (Head of Service Delivery – ODT Hub) has replaced Jacki Newby (Head of Referral and Offering) on her retirement.

Apologies were received from:
Ms Samantha Duncan, Prof John Forsythe, Ms Monika Hackett, Mr Craig Jones, Prof Elizabeth Murphy, Ms Angie Scales, Mr Khalid Sharif and Ms Julie Whitney.

1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA - MCTAG(19)16

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

ACTION

2 MINUTES OF THE MCTAG MEETING ON 13 MARCH 2019 - MCTAG(M)(19)1

2.1 Accuracy

2.1.1 The minutes of the meeting held on 13 March 2019 were agreed as an accurate record.

2.2 Action Points – MCTAG(AP)(19)2

2.2.1 Liaise with HTA regarding the classification of abdominal fascia in the context of intestinal transplantation and inform J Forsythe to confirm if further action is required (AP2 24.10.18)
There has been no change from the HTA regarding the classification of fascia as tissue and not an organ, resulting in this being subject to different standards. However, the HTA is willing for fascia to be used with a primary graft, regarding this as part of the organ, but not if the fascia is used independently of the primary graft.

The HTA have placed a limit on the storage of fascia of 48 hours, although ideally it would be allowed for up to 14 days in the same way as vessels. A Butler to join the FTWU chaired by D Manas on vessel storage. Kings, Royal Free and Cambridge currently retrieve under the NHSBT licence. A Butler will provide an update at the next meeting. **A Butler** **A Butler**

Detailed analysis of incidents for review

AP2 – A Butler reported that J Casey (Chair of PAG) is willing to allow the loss of a pancreas in order to facilitate transplanting a bowel.

2.3 Matters arising, not separately identified

2.3.1 There were no matters arising.

3 ASSOCIATE MEDICAL DIRECTOR'S REPORT

3.1 Governance

3.1.1 Non-compliance with allocation

3.1.1.1 There were no non-compliances reported with respect to allocation.

The issue of organ allocation was raised, with reference to the situation when an organ is offered for a less sick patient and declined for clinical reasons, but then returned to the offering sequence rather than moving directly to the sicker patient. It was agreed that it is not possible to offer to the unit rather than the patient, but that it is reasonable to communicate with the other unit(s) to request priority if it appears that there is a good clinical case for the organ to be offered outside the offering sequence.

In the paediatric setting, there was discussion of the relative priority of hepatoblastoma and intestinal recipients. The needs of the intestinal transplant patients need to be discussed with all three paediatric centres, before this issue is to go to LAG. It was agreed that this issue would be discussed at the LAG Steering Group meeting in January first and then proceeding to LAG in May 2020. In the meantime, G Gupte will come up with a proposal to be discussed at **G Gupte**

To be ratified

the MCTAG meeting in March 2020. The three liver paediatric representatives should be present at the LAG meeting.

3.1.2 **Detailed analysis of incidents for review – MCTAG(19)17**

3.1.2.1 A letter has been circulated to all transplant centres regarding the implementation of transplanting Hepatitis C positive donor livers. Funding for viral treatment will follow an established process with immediate effect. It is anticipated there will be no more than 50 such transplants per year; 14 livers have been transplanted to-date. Patients undergoing this new type of transplant will be monitored nationally multi-disciplinary teams.

There is still confusion regarding which organs, from a multi-visceral donor, are transplanted. The agreed protocol is for transplant coordinators to inform NHBST which organs have been transplanted and for the SNODs to log what has been retrieved.

D Manas reminded centre representatives that if there is damage to an organ, this needs to be reported. The centre should not repair the damage so that it goes unreported.

There are reports of multiple teams attending retrievals, e.g. heart. It was pointed out that the purpose of the NORS is to provide a streamlined process.

Unused components of limbs that have been transplanted are disposed of locally – it is important that this is recorded. Untransplanted limbs are currently returned to the donor. It is proposed to make this mandatory as the transplantation of hand and limbs increases.

3.1.3 **Process for findings at transplant centres requiring histopathology – MCTAG(19)18a & b**

3.1.3.1 The issue of providing an out-of-hours histopathology service for donor material remains unresolved. The infrastructure established to support the PITHIA trial provides a potential opportunity, although it was pointed out that this does not provide a service to report anything other than renal tissue. A service for the wider range of donor tissue needed to investigate abnormalities discovered at retrieval will require an additional process. The Senior Management Team will put forward a business case with costs for this.

4 Update on limb transplantation

4.1 Key points from a presentation given by S Kay on hand and upper limb VCA:

- The first transplant was undertaken in Lyon in September 1998. The Louisville transplant undertaken in January 1999 still survives.
- The undertaking of unilateral transplantation has been debated over the last 10 years.
- Patients waiting for hand allotransplantation are required to wait a year on the programme to look at compliance, the stability of decision making as well as to determine if there will be psychological rejection by the patient. To-date six such transplants

To be ratified

have been undertaken in the UK and seven patients are under assessment.

Acute rejection from hand transplants presents as a rash. There have been six such episodes over the last six months.

- From 2012- 2019 Leeds have undertaken 10 limb transplants in six patients.
- Participation is very hard to measure in patients e.g.
  - Protocols do not predict real life
  - Acute rejection is common in the first year
  - Unilateral transplants can be very effective
  - Recovery of function is very fast
  - Prolonged hypotension is common at operation.
- The functional results of upper limb prosthetics are often disappointing and the results are poorly audited.
- The future direction is to look at:
  - Hands without function
  - Children
  - Unified multi-axial limb – transplant policy and pathway.
  - Re-cost and report
- We do not know what the potential demand is for hand and limb transplantation as there is no national registry. It is recognised that numbers are increasing with an estimate of around ten such transplants per year. Currently only Leeds undertake this type of transplant with referrals from England and Ireland.
- There is a requirement for more transplant centres to undertake this type of transplant and for the involvement of more micro-vascular surgeons.

5 STATISTICS AND CLINICAL STUDIES REPORT

5.1 Summary from Statistics and Clinical Studies – MCTAG(19)19

Key points were:

- The 2018/19 Annual Transplant Activity Report (published in July 2019) showed a 2% increase in deceased donors but a 2% fall in deceased donor transplants compared with the previous year.
- E Allen will be the new lead for statistical support when S Rushton goes on maternity leave in November.
- There are currently three clinical fellows working with the Statistics team.

6 NATIONAL BOWEL ALLOCATION

6.1 Performance report of the National Bowel Allocation Scheme (NBAS) – MCTAG(19)20

A report was presented detailing patients active on the transplant list between 1 January 2019 to 30 June 2019, a comparison of one year post-registration outcomes, median time to transplant and prolonged registrations.

To be ratified

ACTION

The report now shows waiting times to intestinal transplant separately for paediatric and adult patients. Removals due to deteriorating condition, in Figure 1, are now treated as deaths.

6.2 **Management of patients on the waiting list and waiting points to be restarted after one month suspension**

Points raised were:

There have been 4/5 patients who have been suspended for more than 3 months.

No other organ offering schemes have a maximum suspension time other than cardiothoracic. All offering schemes include suspension times within patients' waiting time calculations.

In the National Bowel Allocation Scheme (NBAS), a patient's total point score is calculated from a number of factors including donor and recipient age, match points and waiting time points. The calculation of the waiting time points includes periods of suspension so a patient may accrue waiting time points while suspended. P Friend asked the group whether the inclusion of long periods of suspension had caused any problems: it was agreed that no problems have been seen and it was agreed that, for consistency with other offering schemes, the NBAS will continue to count periods of suspension towards waiting time calculations, with no cap on maximum suspension time.

7 GROUP 2 BOWEL TRANSPLANTS

7.1 From February to the end of August 2019, there have been no Group 2 transplants.

There have been two Group 1 non-UK patient transplants.

Patients with an S2 form are eligible for transplants in the UK but this may not be the case after BREXIT.

The current Service Specification does not include funding for living donor transplants. This is becoming an issue in paediatric intestinal transplantation, and it was agreed that it would be advisable that this should be changed. Centre representatives to inform their Centre Director to write to NHS England. **Centre Reps**

8 POTENTIAL BOWEL DONORS AND LOCATION – MCTAG(19)21

8.1 A report was presented showing the pathway from consent to intestinal donation and organs lost. Additional information presented includes:

- A change in the offering rates (paragraph 10) relative to previous reports. Recipients will not appear on the matching run if a donor's weight exceeds the maximum weight specified on the recipient's registration form. This has led to a reduction in paediatric offers for 2018/19 as these patients are no longer being offered inappropriately sized organs.
- Table 5 has been added – liver and bowel offering rates for those meeting bowel criteria with consent for both bowel and liver by SNOD team. E Allen reported (not shown in MCTAG(19)21 but available upon request) that the most common reason for not

To be ratified

ACTION

offering is that there is no suitable recipient with the next most common reason being the donor's past history.

- Appendix 1 has been added – Flow diagram of the pathway from DBD donors aged <18 years during 2018/19 to bowel donors.

Questions raised were:

Why is there a difference in the percentage of bowels offered around the country? E Allen will include a test for geographical differences in the next report.

Why are data collected on approaches for donation in adult but not paediatric donors? P Friend to email Dale Gardiner to find out what information is available regarding donor referral rates for paediatrics. **P Friend**

Appendix II – The pathway from DBD donors, aged under 18 years, between 1 April 2016 and 31 March 2019 to bowel donors by financial year.

9 INITIATIVES TO INCREASE PAEDIATRIC DONATION – MCTAG(19)22

Apologies were sent by A Scales before the start of the meeting. This item will be deferred to the next meeting in March 2020. **K Huang**

10 DECLINED OFFERS DUE TO LOGISTICIAL REASONS – MCTAG(19)23

10.1 The NHSBT Board has agreed that if an organ is offered to a named patient but declined for logistical reasons (e.g. no available theatre, beds, i.e. lack of resource) the patient should be informed of the decision.

One option of overcoming a shortage of resource has been to transfer transplants to another centre. This is relatively less feasible in intestinal (and VCA) transplants because of the very limited number of providers.

It was noted that the NHSBT process appears to enable a delay in organ retrieval when needed to facilitate heart transplantation. It was agreed that the case for allowing this for intestinal/multi-visceral retrieval would be appropriate and beneficial on occasions This is currently being addressed.

11 REFERRAL CRITERIA FOR INTESTINAL TRANSPLANT – MCTAG(19)23

11.1 The incidence of Type 2 IF has increased over the last decade, with a rate of increase in HPN of 20% per annum.

It is still the case that patients are referred too late for optimal timing of intestinal transplantation and some revision to the referral guidelines may be needed to help address this. It was agreed that much earlier referral to a transplant unit is needed (i.e. a lower threshold), in order that this treatment is seen as part of the continuum of management of intestinal failure and that the timing of transplantation can be optimised and modified on an individual patient basis.

To be ratified

ACTION

There is a need to educate clinicians and change attitudes by raising awareness in the medical community, and for education to look outwards and not inwards. This requires expertise outside the intestinal transplant community, including patient support groups and social campaigns. S Gabe agreed to chair a short-term working group to develop a strategy to deliver this. **S Gabe**

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

12.1 E Allen has been cross checking information and looking at items required on the ITR. Once this has been completed the data will be transferred, though there are still some governmental issues to finalise. P Friend recommended that the simplest format would be to look at what NHSBT have and offer this to ITR. L Sharkey/J Hind to pick up on the initial work carried out by Georgios Vrakas. **L Sharkey/ J Hind**

13 REVIEW OF INTESTINAL FAILURE DIAGNOSES COLLECTED BY NHSBT - MCTAG(19)24

13.1 A list of diagnoses was presented to members with the additions highlighted in blue.

The recommendation is to change the category headed 'Secondary Diagnosis' to 'Secondary Indications'. **L Sharkey**

G Gupte to provide an updated list of indications for paediatric patients. **G Gupte**

14 SMALL BOWEL TRANSPLANT FOLLOW-UP COMMISSIONING

14.1 NHS England reported that there is funding for long term follow up in transplant centres which will be part of joint care and separately funded.

15 ABDOMINAL WALL TRANSPLANT PATHWAY AND NHSE COMMISSIONING

15.1 Currently one patient has undergone abdominal wall-alone transplant and there are another two who have been referred. Individual funding requests have been denied. A possible solution is to submit this to NHSE for consideration as a new national service.

16 UPDATE FROM THE WORKING GROUPS

16.1 **Quality of Life Working Group: data collection**

16.1.1 **Adults**

There is no new information to report in the last 6 months. It was agreed that this is a vitally important area for data collection and that this requires human resources. P Allan and C Bambridge to continue as the Leads on this. This topic will be raised at the Advisory Group Chairs Meeting. **P Friend/ K Huang**

16.1.2 **Paediatrics**

Refer to 16.1.1 above

To be ratified

ACTION

16.2 **Update from the Working Group on NHSBT data and post-operative data collection**

16.2.1 A detailed proposal will be provided at the next meeting.

16.3 **Update from the Working Group on a patient information and consent document for intestinal transplantation – MCTAG(19)26**

16.3.1 The national consent process has become complicated, but the objective remains.

A Butler agreed to forward the draft proposal for adults to members for consideration. Work is also underway for a paediatric proposal. **A Butler/ K Huang**

17 APPEALS/PRIORITY

17.1 There were no appeals reported regarding bowel intestinal transplantation.

18 UPDATE ON NASIT

18.1 To-date there has been four face to face meetings with teleconference meetings in-between.

There is a need for administrative support for the minutes and general organisation; it is anticipated this will be for half a day per week.

It was agreed that a central location for the face-to-face meetings would be very desirable to avoid the long journeys and unpredictable arrangements experienced currently. S Watson kindly offered to assist by requesting a room within the DoH, with capacity for 20-30 people. K Huang to put L Sharkey in touch with S Watson and copy P Friend. **K Huang**

19 NATIONAL INTESTINAL FAILURE FORUM FOR PAEDIATRICS

19.1 The forum for this should operate similarly to NASIT (adults and paediatrics). This will similarly require funding for administrative support.

20 UPDATE ON OPT-OUT LEGISLATION IN ORGAN DONATION – MCTAG(19)27

20.1 A presentation was circulated to members regarding the anticipated consequences of the change in law around organ donation. NHS England has been updated by NHSBT on the potential increase in transplantation numbers.

21 BOWEL TRANSPLANTATION – STANDARDISATION OF TESTING AND CROSSMATCH PROTOCOLS IN THE UK – MCTAG(19)28

21.1 The existing protocol was written in 2012. S Peacock agreed to set up a short-term Working Group with relevant H&I representatives and clinicians to bring the protocol up to-date, keeping E Allen informed as this might affect the HLA data collection that NHSBT Statistics currently maintain. It would be useful to review the data forms to see if there are any patterns. S Peacock to come back with a proposal and discussion points. **S Peacock**

To be ratified

ACTION

22 FEEDBACK FROM THE LIVER ADVISORY GROUP MEETING ON 8TH MAY 2019

22.1 There were no issues reported relating to bowel transplantation.

23 UK INTESTINAL TRANSPLANT FORUM MEETING 17 JANUARY 2020, BIRMINGHAM

23.1 The schedule for the Forum is to present outcomes in the morning and the afternoon will include discussions about how we standardise intestinal care.

24 ANY OTHER BUSINESS

24.1 The first uterus transplant is to take place in January 2020 (Richard Smith). These transplants will not be funded by the NHS but will be supported by a charity.

25 DATE OF 2020 MEETING:

- Wednesday 11 March 2020 – London
- Wednesday 21 October 2020 – London

26 FOR INFORMATION ONLY:

Papers attached for information were:

26.1 Transplant activity report for August 2019 **– MCTAG(19)X**
26.2 Minutes of LAG meeting: 21 November 2018 **– MCTAG(19)X**

Organ Donation and Transplantation Directorate **October 2019**

Administrative Lead: Kamann Huang

To be ratified