

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

**MINUTES OF THE THIRTY FIRST MEETING OF THE
LIVER ADVISORY GROUP
HELD ON WEDNESDAY 10TH MAY 2017
LONDON**

PRESENT:

Prof John O'Grady	Chairman
Prof Derek Manas	Deputy Chair, BTS Rep and Surgeon, The Freeman Hospital Newcastle upon Tyne
Dr Kosh Agarwal	Deputy for Dr Varuna Aluvihare, King's College Hospital
Ms Helen Aldersley	Recipient Co-ordinator Representative
Dr Elisa Allen	Statistics and Clinical Studies
Mr John Asher	Medical Health Informatics Lead, ODT
Dr Susan Beath	Paediatric Hepatologist, Birmingham
Ms Hazel Bentall	Lay Member
Ms Emma Billingham	Senior Commissioning Manager, NHSBT
Mr Andrew Broderick	Transplantation Support Services, ODT
Mr John Crookenden	Liver Transplant Consortium
Dr James Ferguson	Physician, Queen Elizabeth Hospital, Birmingham
Prof John Forsythe	Associate Medical Director, NHSBT
Prof Peter Friend	Chair of Bowel Advisory Group
Dr Tassos Grammaticopoulos	Physician, King's College Hospital, London
Prof Nigel Heaton	Surgeon, King's College Hospital, London
Mr Ernest Hidalgo	Surgeon, St James's University Hospital, Leeds
Ms Cathy Hopkinson	Statistics and Clinical Studies
Dr Diarmaid Houlihan	Physician, St Vincent's University Hospital, Dublin
Dr Mark Hudson	Physician, Freeman Hospital, Newcastle
Mr Ben Hume	Assistant Director, Transplantation Support Services, NHSBT
Mr John Issac	Deputy for Prof Paolo Muiesan, Queen Elizabeth Hospital, Birmingham
Ms Sally Johnson	Director, Organ Donation and Transplantation, NHSBT
Dr Rebecca Jones	Physician, St James's University Hospital, Leeds
Mr Andrew Langford	Liver Patient Group Co Chair – British Liver Trust
Dr Joanna Leithead	Physician, Addenbrooke's Hospital, Cambridge
Ms Wendy Littlejohn	Recipient Co-ordinator Representative
Ms Sarah Matthew	Lay Member
Ms Tanya Partridge	Duty Office Representative
Mr James Powell	Surgeon, Royal Infirmary, Edinburgh
Dr Sanjay Rajwal	Paediatric Hepatologist
Ms Susan Richards	Organ Donation Representative, Eastern and Midlands
Dr Ken Simpson	Hepatologist, Royal Infirmary of Edinburgh
Dr Douglas Thorburn	Physician, Royal Free Hospital and BLTG Rep
Ms Lynne Vernon	Lay Member
Mrs Sarah Watson	Highly Specialised Services, NHS England
Prof Stephen Wigmore	BTS Representative

IN ATTENDANCE:

Mrs Kamann Huang	Clinical & Support Services, ODT
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ACTION**APOLOGIES & WELCOME**

Dr Varuna Aluvihare, Prof John Dark, Prof Sue Fuggle, Mr Paul Gibbs, Dr Alex Gimson, Mr Emir Hoti, Mr Charles Imber, Dr Edmund Jessop, Prof Paolo Muiesan, Ms Jacqueline Newby, Prof Rutger Ploeg and Mr Anthony Snape, Mr Mick Stokes and Ms Alison Taylor.

1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA – LAG(17)1

1.1 There were no declarations of interest.

2 MINUTES OF THE MEETING HELD ON 23 NOVEMBER 2016 - LAG(M)(16)2**2.1 Accuracy**

2.1.1 The minutes of the previous meeting were agreed as an accurate record with the inclusion of the following amendment:

Page 6, Section 4 “Update on NHS England”, paragraph 3, first line. Remove the wording “and accessibility and there will be an Intestinal and CT review”.

2.2 Action points – LAG(AP)(17)1

2.2.1 All action points have been completed or referred to as an Agenda Item. Those with a Verbal Report are listed with an update below:

AP5. J Forsythe had a useful meeting with the new chief coroner who showed support for increasing solid organ donation amongst coroners. J Forsythe will follow up on the details of a high profile case referred to a coroner but not to NHSBT.

J Forsythe

AP14. The policy with respect to release of data to investigators outside the UK was discussed at the Advisory Groups Chairs’ meeting and a recommendation was a permissive approach matched with appropriate scrutiny.

2.3 Matters arising, not separately identified

2.3.1 There were no matters arising.

3 GOVERNANCE ISSUES**3.1 Liver splitting activity – LAG(17)2**

3.1.1 E Allen presented a paper on donors meeting criteria for liver splitting, livers transplanted and livers declined. Data from 1 April 2007 to 31 March 2017 showed a slight rise in the percentage split, a fall in 2014/15, but then rising to the highest number of reported split livers of 44 for the last financial year.

The main reason for not splitting in over a third of the cases was abnormal liver function tests. Two other main reasons were no suitable recipients being available or a lack of suitable paediatric patients for the left lateral segment.

P Friend stated that the paediatric case is the index case. The new allocation system will not affect the identification of organs suitable and available for splitting. Failure to make an appropriate liver available for splitting will be reported as a non-compliance with allocation policy.

ACTION**3.2 Non-compliance with allocation**

3.2.1 There were no cases of non-compliance with the allocation of livers reported.

3.3 Detailed analysis of incidents for review – LAG(17)3

3.3.1 J Forsythe gave a report in the absence of J Dark.

ODT is looking at helping surgeons monitor retrieval issues (as there is not the same level of monitoring for organ retrieval compared to the outcomes reported for transplanted organs).

The reporting of infections from perfusion fluid around organs, have been good but included organisms that were not considered notifiable when this procedure began. J Dark to review what organisms to report, probably with focus on fungal cultures.

J Dark

There are issues with the timely diagnosis of pathological lesions found at retrieval and there remains a need for a robust service in the future. J Dark is leading an ODT review on this.

3.3.1 QUOD (Quality in Organ Donation) biopsy – LAG(17)4a & 4b

3.3.1.1 In the absence of R Ploeg, J O'Grady presented his paper on 'Information Leaflet for Recipients of Livers from donors participating in QUOD'.

Members stated that the following amendments to the report would be useful:

- Specific data should be cited for perceived risk.
- Change the contact to say 'Recipient Transplant Co-Ordinator'.
- Include information pertinent to the patient at the time of listing and on the day of transplantation
- A paediatric version should also be created.
- H Aldersley requested a clinical contact to deal with specific questions about the biopsy.
- Ongoing monitoring and training for carrying out the biopsy.
- Is hands on/video training required to effectively disseminate this information to the patient?

A Langford stated that it would be beneficial to include Lay and Patient involvement in the report from a governance point of view.

4 ACTIVITY, ORGAN UTILISATION AND OUTCOME MONITORING**4.1 Summary of CUSUM monitoring of outcomes following liver transplantation – LAG(17)5**

4.1.1 J Forsythe informed members that the response to CUSUM triggers in a number of cases in other Advisory Groups had been to arrange a local MDT review of the cases concerned with external input from experts; for this process a term 'internal/external' had been coined. Examples included cases in Lung, Kidney and Pancreas review.

A paper will be presented on CUSUM monitoring at the next LAG meeting.

E Allen

He reported back to LAG on two incidents around a live liver, adult to adult donation that had occurred in one centre. The investigation of these incidents, following comments from peers in other centres, are being taken further by colleagues in NHS E. The latest he had heard was that the review process had stalled. He will update members further when further information is available.

ACTION

J Forsythe reported that he had been approached by a centre that had reported three 'on table' deaths in a relatively short period. An 'internal/ external review was arranged with the knowledge of colleagues from NHS E. This was led by D Manas. The report has been agreed with all parties and concluded. J Crookenden stressed the importance of transparency and dissemination of 'lessons learned' to all units. J Forsythe was in agreement and will ask D Manas and the centre involved to develop shared learning points as quickly as possible.

J Forsythe**4.2 Dashboard on activity and organ utilisation – LAG(17)6a & 6b**

4.2.1 Members were requested to inform E Allen of any change in the contact name for each centre to receive the dashboard reports.

Transplant Centre Dashboards - to introduce a report with simple information for patients and stakeholders with a summary for each centre for all solid organs and showing how this compares with the national rate. This will be available on the ODT website. J O'Grady reported that the Lay Members for each of the solid organ Advisory Groups have been requested to liaise with the clinicians to discuss which metrics, presented in Item 3 of the paper, are to be used. Some generic information will be required.

Feedback from members regarding metrics to be used included:

- S Beath – as the paediatric number is quite small a comparison with previous periods would be helpful.
- A Langford – a metric for patient experience/quality.
- J Isaac – a metric for the transplant waiting list on an annual basis.
- J Ferguson – a metric to indicate ethnic background. A Langford reported there is an on-line patient support group with a membership of 20,000 with mixed ethnic adults. Funding has just started for monitoring patient experience of transplantation.

S Johnson requested S Watson to release something now from NHS England on funding for increased activity and organ utilisation rather than have more discussions.

S Watson**4.3 Declined liver offers – LAG(17)7**

4.3.1 The most common reasons for declining liver offers from DBD or DCD donors, but subsequently transplanted, were donor related followed by logistical issues and lack of any suitable recipients.

It was highlighted that the data in Table 1 'Centre offer decline rates, by donor type' showing just the total numbers without any supporting information was not useful. Members agreed to remove Table 1 from the paper.

Table 2 – J O'Grady commented that the data presented showing crude trends was not an accurate overall picture. Further analysis is required to drill down into the categories. Super Urgent donation data were also omitted. J Forsythe reported that the BTS has published NHSBT's organ utilisation strategy to 2020 looking into why organs are declined, the ideal donor and decline rate for ideal donor organs and the length of the donation process. J Forsythe thanked members for their centre's feedback.

E Allen

ACTION**5 National Offering Scheme****5.1 Timescale to Implementation**

5.1.1 B Hume updated members on the following:

- a demonstration on the Super Urgent Liver List, which will be available via a web-based login account in the period from June (test) and late July (live). This will enable transplant centres to view the SU list from that time.
- implementation timeframes are, at this present time:
 - Cardiac and Routine Lung Allocation Schemes have already been delivered on time;
 - SU Lung Allocation Scheme will be delivered on 17th May;
 - SU Liver list is scheduled for live use by late July (with a testing phase from June).
- a fuller Transplant List, allowing view, registration and update of patient details is scheduled for release in October.
- the matching and offering changes associated with Adult DBD Liver Allocation Scheme and all the existing components of the wider Liver Allocation Schemes are scheduled for November
- the Organ Allocation Scheme will go live in December. B Hume reported that it was not possible to give a definite date other than it would be in December.

J O'Grady advocated for a national meeting to take place first to so that everyone hears the same information first and then work on the details. For example, a Transplant Co-Ordinator will require different information from clinicians.

S Johnson reported that once the scheme goes live, it will be down to the transplant centre to provide all the required data for registering patients with the aid of prompts from the system. It was highlighted that both a transplant and recipient co-ordinator should be involved with the process before it goes live.

J Asher stated that the aim of the whole Hub is to keep the transplant pathway safe and sustainable, both for the Duty Office and the Customer. A stakeholder representative for the Kidney has been nominated; a similar representative for the Liver has yet to be identified. A first meeting will be held shortly to obtain stakeholder feedback.

5.2 Transition performance monitoring – LAG(17)8

5.2.1 E Allen presented a paper with an outline proposal to monitor the new liver offering scheme after its introduction. Data will be gathered for adult DBD first. The first report will be published in 3 months after the system goes live, then at 6 months and if appropriate on a yearly basis.

Members were asked for their feedback to the metrics suggested in paragraph 9 of the paper. It was requested that any feedback should be relayed to the Liver Core Group as this has implications for future schemes. J Ferguson asked whether a specific group should be set up to monitor the new liver offering scheme with a reference/start point and include external

ACTION

involvement. It was reported that the Dashboard Report will capture extreme patterns i.e. if a centre gets fewer offers and will also monitor the national decline rate.

5.3 ODT Hub

5.3.1 Refer to Minute point 5.1 Timescale to Implementation.

6 LIVER TRANSPLANT COMMISSIONING**6.1 NHS England**

6.1.1 S Watson informed members that she had now liaised with each of the transplant centres regarding funding. She will have a clearer overview by the end of March 2018. The contract for the next two years is likely to come out of the Peer Review. There is no agreement by NHS England at a national level for immunosuppression from transplant centres. S Watson was not able to answer the question of whether funding reflected the 9% increase in transplant activity.

N Heaton raised the issue that operating with 'en bloc' contracts provided no insight into funding allocated (e.g. the amount allocated and spent on liver transplants) or the core contribution by transplant centres and how this compares with other centres.

There is a Service Specification providing an outline to service providers. P Friend stated that if the service level drops NHS England can decrease funding which seems to be the only form of measurement of the need for funding.

6.2 Peer Review

6.2.1 The Peer Review was completed mid December 2016. The Cardiothoracic Report is due at the end of May 2017 but no Liver Report was available against the given timeframes.

S Watson to check if comments from centres have been included in the report, its status, and update J O'Grady.

S Watson**7 CLINICAL SERVICE EVALUATIONS****7.1 HCC downstaging – LAG(17)9**

7.1.1 The service development evaluation to transplant HCC down-staging patients introduced on 2 March 2015 has registered 12 patients. There is no report available yet as patients have not reached the agreed assessment time points after transplantation.

7.2 Acute alcoholic hepatitis – LAG(17)10

7.2.1 In the absence of A Gimson no paper or verbal update was provided.

8 FTWU REPORTS**8.1 Split livers**

8.1.1 P Friend updated members on the draft Liver Splitting Operational Policy covering 10 points discussed previously.

ACTION

Geography - the right lobe is to go to the nearest transplant centre.

Index case - The recommendation was that maybe the surgeon responsible for the index case should be responsible for decisions regarding composite tissue.

N Heaton raised the point that we do not know who is splitting the liver and where it goes as the anatomical detail for splitting is not recorded. Another concern was quality control regarding liver splitting tending to be undertaken during the night. A case was cited of a liver available for splitting with the CT team coming to retrieve one hour later and assessed and then another hour assessed for pancreas retrieval.

The process for split liver offering is to offer to paediatrics first and then adults under 40 kg. D Thorburn commented training in this area varies and requires improvement. P Friend reported that the Draft will state that experienced clinicians at adult transplant centres can make the decision in undertaking paediatric transplant. J O'Grady stated that a 60-70 kg donor will not be barred from splitting. The right lobe will go to a small adult normally.

8.2 Alcohol guidelines/policy – LAG(17)11

8.2.1 In the absence of A Gimson it was reported that the FTWU is now closed. Details of the Policy will be available in the public domain in the near future.

8.3 Early graft dysfunction – LAG(17)12

8.3.1 No paper or verbal update was available in the absence of A Gimson.

9 NRP BUSINESS CASE – LAG(17)13

9.1 E Billingham reported on the development of a business case in support of normothermic regional perfusion. The Draft will be completed by the end of May 2017 and a request for funding for a national NRP service made by September of this year. Evaluation criteria will be looked at and there will be a consultation following submission of the business case. E Billingham to report back on whether a patient representative is required for the Group.

E Billingham**10 HEPATITIS DAAS AND IMPACT ON DONATION**

10.1 K Agarwal, Kings College, presented a draft of a pilot study looking at the safety of utilising HCV+ve donors in selected consented HCV-liver recipients. This could have a significant impact on waiting times for selected patients with end stage liver patients with a clinical need for accelerated access to transplantation. The US has reported seeing a 15% increase in livers being transplanted. Guaranteed access to DAAS early after transplantation was an absolute requirement underpinning the CSE. Other points to consider were: does the UK need better data before proceeding? How many C hepatitis patients are there and is there support for understanding the welfare of these patients under strict monitoring?

This was a topic at BTS (British Transplantation Society) and the perception was this can be done. All centres and NHS England were supportive of this mandate.

ACTION

11 STATISTICS AND CLINICAL STUDIES REPORT**11.1 Summary from Statistics and Clinical Studies – LAG(17)14**

11.1.1 A paper was presented giving an update with a summary of recent presentations and projects.

Two other key points for noting were:

- the new SU (super urgent) process was introduced on 13 April 2017. A revised Super-urgent Liver Recipient Registration form (FRM4324) has been circulated to all transplant centres.
- Prof D Collett, Associate Director of Statistics and Clinical Studies will be retiring at the end of June.

12 DCD LIVER SCREENING – LAG(17)15

12.1 A Broderick presented a paper to formalize the process for assessing and screening DCD donor suitability.

- SNODs to take details from the referrer and complete an assessment looking at DCD exclusion. (In 12 months 2,000 have been excluded and 1,550 with DCD exclusion criteria. Further information will be collected).
- the screening process would be to call two centres: the first call to a zonal centre for the hospital and the second call to 1 of 4 pre-designated centres (four for the North and four for the South).
- if kidneys are **not** acceptable liver screening will be undertaken. Birmingham and Kings are to be the two main screening centres. W Littlejohn commented that they receive 30-40 enquiries for DCD daily for Kings.

J Forsythe reported that he is addressing a separate problem regarding DCD being offered at 4 am and 10 pm. It was recommended that a FTWU be set up to put together a process for screening organs in a more efficient way. Membership to include A Langford. J Isaac to put forward a name from the Birmingham centre.

J IsaacPost Meeting Note:

A Langford is stepping down as Chief Executive of the British Liver Trust in August. Vanessa Hebditch is the contact until A Langford's replacement is announced.

13 ADULT TO ADULT LIVER DONOR TRANSPLANT

13.1 D Manas reported that the adult to adult liver donor transplant process is to create a strategy, to mirror the kidney living donor process, with a Peer Support process. A draft document has been put together which was circulated to a small group before being submitted to NHS England. Governance will be required if the process is to be adopted nationally. S Watson acknowledged receipt of the draft report.

ACTION**14 NATIONAL APPEALS PANEL****14.1 Outcome of Appeals – LAG(17)16**

J O'Grady reported that the SU Appeal process has now been launched. The first case has gone through and worked well with no problems reported by the Duty Office.

15 BOWEL ADVISORY GROUP**15.1 Report from the Bowel Advisory Group meeting: 15 March 2017****15.1.1 P Friend gave a summary of the key points:**

- Prioritising adult intestinal patients to be offered paediatric donors. BAG has agreed to treat adult patients who weigh more than 35kg but with a restricted abdominal cavity as paediatric patients. E Allen reported that analysis has shown no evidence of disadvantages to paediatric intestinal patients but she will conduct a simulation to see if paediatric liver patients could be disadvantaged.
- a paper has been written regarding the function, agreements and Terms of Reference for NASIT (National Adult Small Intestinal Transplantation Forum).
- there will be two Service Specifications; one for paediatrics and one for adults.
- Bowel Advisory Group to be renamed MCTAG – Multivisceral and Composite Tissue Advisory Group to include transplanting composite tissue. Two new representatives to MCTAG will be Prof Simon Kay and Mr Henk Giele.

E Allen**16 ANY OTHER BUSINESS****16.1 King's College Hospital Pilot Proposal – LAG(17)22**

16.2 N Heaton put forward a proposal to offer auxiliary grafts to selected severe haemophiliac patients in a pilot study. Achieving a level of 1% patients (which is achievable) would be sufficient. Grafts would be open to DCD and living donors. This would result in significant cost savings. The proposal was approved.

17 DATE OF NEXT MEETING:

Wednesday 22 November 2017, London

18 FOR INFORMATION ONLY

The following papers were attached for information to members:

18.1 Transplant activity report: March 2017 - LAG(17)17**18.2 Group 2 Transplants – LAG(17)18**

**18.3 Minutes of the Bowel Advisory Group meeting: 12 October 2016
- LAG(17)19**

ACTION

18.4 **Minutes from the National Retrieval Group: 29 March 2017 - LAG(17)20**

18.5 **Super urgent survival for paracetamol and non-paracetamol- LAG(17)21**

New Appointments in NHSBT

- Mr Greg Methven, Director of Manufacturing and Logistics - 6 February 2017.
- Mr Steve Park, Assistant Director Communications - 6 March 2017, at Speke.
- Mr Alex Hudson, Head of Organ Donation Register – 27 March 2017.
- Ms Jacqueline Newby, 12-month secondment as Head of Referral & Offering - 3 April 2017.
- Mr Mark Rogers, Interim Assistant Director for Business Transformation Services - April 2017.
- Ms Millie Banerjee, appointed as Chair of NHS Blood and Transplant for four years from 1 June 2017.
- Ms Katherine Robson, appointed as NHSBT's new Director of Workforce, starting 1st July 2017, following the retirement of David Evans.

Organ Donation & Transplantation Directorate

May 2017

Administrative Lead: Kamann Huang