

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

**MINUTES OF THE TWENTY- FIFTH MEETING OF THE  
LIVER ADVISORY GROUP  
HELD ON WEDNESDAY 21<sup>st</sup> MAY 2014  
AT ODT, BRISTOL**

**PRESENT:**

Prof John O'Grady  
Ms Helen Aldersley  
Dr Varuna Aluvihare  
Dr Elisa Allen  
Ms Charlotte Brown  
Mr John Crookenden  
Prof John Dark  
Dr James Ferguson  
Mr Paul Gibbs  
Dr Alex Gimson  
Dr Tassos Grammatikopoulos  
Prof Nigel Heaton  
Mr Ernest Hidalgo  
Mr Edward Holland  
Dr Diarmaid Houlihan  
Dr Mark Hudson  
Mr Charles Imber  
Dr Rebecca Jones  
Ms Wendy Littlejohn  
Dr Alistair MacGilchrist  
Prof Derek Manas  
Ms Kate Martin  
Mr Paolo Muiesan  
Prof James Neuberger  
Prof Rutger Ploeg  
Mr James Powell  
Mrs Kathleen Preston  
Dr Sanjay Rajwal  
Ms Susan Richards  
Dr Douglas Thorburn  
Ms Martine Walmsley

**Chairman**

Recipient Co-ordinator Representative  
Physician, King's College Hospital  
Statistics & Clinical Studies, NHSBT  
Observer, Duty Office  
Liver Transplant Consortium  
National Clinical Lead – Governance, NHSBT  
Physician, Queen Elizabeth Hospital, Birmingham  
Surgeon, Addenbrooke's Hospital, Cambridge  
Physician, Addenbrooke's Hospital, Cambridge  
Deputy for Dr Alistair Baker, King's College Hospital  
Surgeon, King's College Hospital, London  
Surgeon, St James's University Hospital, Leeds  
Deputy for Ann Yates, Duty Office  
Physician, St Vincent's Hospital, Dublin  
Physician, Freeman Hospital, Newcastle  
Surgeon, Royal Free Hospital  
Physician, St James's University Hospital, Leeds  
Recipient Co-ordinator Representative  
Physician, Royal Infirmary of Edinburgh  
Surgeon, Freeman Hospital, Newcastle  
Statistics & Clinical Studies, NHSBT  
Surgeon, Birmingham, Queen Elizabeth Hospital  
Associate Medical Director, NHSBT  
National Clinical Lead for Organ Donation  
Royal Infirmary, Edinburgh  
Lay Member  
Paediatric Hepatologist  
Regional Manager, Organ Donation, NHSBT  
Physician, Royal Free Hospital  
Liver Transplant Consortium

**IN ATTENDANCE:**

Mrs Kamann Huang

Clinical &amp; Support Services, ODT

**ACTION****APOLOGIES & WELCOME**

Mr Murat Akyol, Dr Alistair Baker, Prof Dave Collett, Dr Susan Fuggle, Dr Bill Griffiths, Mr Emir Hoti, Dr Edmund Jessop, Mrs Rachel Johnson, Dr Patrick McKiernan, Mr Jonathan McShane, Prof Darius Mirza and Mrs Ann Yates.

**WELCOME TO LAY MEMBERS**

J O'Grady welcomed Mrs Kathleen Preston to the Liver Advisory Group meeting as a Lay Member. Unfortunately Mr Jonathan McShane, the second Lay Member, was unable to attend.

# 1 **DECLARATIONS OF INTEREST IN RELATION TO AGENDA – BAG(14)1**

1.1 There were no declarations of interest.

## 2 **MINUTES OF THE MEETING HELD ON 13 November 2013 – LAG(M)(13)2**

### 2.1 **Accuracy**

The minutes of the previous meeting were agreed as a correct record.

### 2.2 **Action points – LAG (AP)(14)1**

All action points have been completed or are listed on the agenda with the exception of those listed below:

**AP4 – Centre specific reports on organ offers:** Centre reps agreed that it would be beneficial to list organs declined by one centre and accepted by another centre. J O'Grady will liaise with R Johnson.

**J O'Grady/  
R Johnson**

**AP6 – Review of changing AFP level in the UK guidelines for liver transplantation for patients with HCC:** Work on this will be undertaken by the FTWU Liver Core Group. The upper AFP level of 1,000 has been endorsed and communicated to the liver transplant community. The Duty Office was not aware of the change but this has now been rectified.

**AP9 – Proposal for Birmingham participation to a European trial on liver transplantation from colorectal liver metastases:** This will be put to the Ethics Committee. The possibility of setting up a national study was discussed.

**AP15 – Collaboration with Hannover:** A Gimson will be the LAG Lead and will liaise with Dr Schrem.

**AP16 – AOB:** J O'Grady will make arrangements to visit the three centres still outstanding.

#### 2.2.1 **Matters arising, not separately identified**

2.2.1.1 K Preston has taken on the role of independent Chair of the NORS Review which is starting to get underway.

N Heaton would like sight of the terms of reference for the NORS review. He expressed concerns about the historical costing of the contract. N Heaton will express his concerns in writing to K Preston.

**N Heaton**

## 3 **ASSOCIATE MEDICAL DIRECTOR'S REPORT**

### 3.1 **Developments in NHSBT – J Neuberger**

#### 3.1.1 **New appointments/Communication**

3.1.1.1 J Neuberger raised a concern regarding a recent circulation on SaBTO guidance sent to Heads of Centres and received feedback that two or three centres had not received it. Feedback was invited on how communication could be improved.

**3.2 Governance issues****3.2.1 Liver splitting activity – LAG(14)3**

- 3.2.1.1 Members agreed that hepatoblastoma patients will retain their priority status in the liver allocation sequence but the policy will now include a requirement to consider livers offered to these patients for splitting. This change will be audited in the regular liver splitting report produced for LAG every six months. E Allen will draft the proposed changes and forward to J O'Grady for approval. Following approval, E Allen will agree the implementation date and inform all relevant parties. The Allocation Policy will be amended to reflect this.

E Allen

E Allen

E Allen will continue liaising with N Heaton to improve the Liver splitting activity report.

E Allen/  
N Heaton**3.2.2 Non-compliance with allocation**

- 3.2.2.1 There was one incident reported arising in January 2014 but not identified until May 2014. The incident relates to a DBD liver declined for a Group 1 patient by King's College, Cambridge and the Royal Free, not offered for a Group 1 patient to Edinburgh, Newcastle and Leeds, and subsequently accepted and transplanted for a Group 2 patient by King's. The liver should have been offered to Edinburgh, Newcastle and Leeds. Measures have been taken within the Duty Office to investigate the causes of this error and prevent this recurring.

**3.2.2.1.1 Use of liver outside allocation**

A case was highlighted of a liver declined by Birmingham but subsequently used for another recipient without any consultation. J Dark will follow this through to resolution.

J Dark

It was highlighted that in the event of a delay in the retrieval process by cardiothoracic retrieval teams, all relevant parties must be informed so that adjustments can be made to their operational schedules. R Ploeg stated that the NORS Review will take this on board.

R Ploeg

**3.2.3 Incidents for review**

- 3.2.3.1 There were no incidents brought up for review.

**3.2.4 Summary of CUSUM monitoring of outcomes following liver transplantation**

- 3.2.4.1 There were no triggers reported.

**3.3 Update on NHS England****3.3.1 Liver transplant demand and capacity review – LAG(14)4**

- 3.3.1.1 Members discussed current capacity, funding for en bloc contracts, reimbursement for over performance, investment for new infrastructure and staff to deal with the increase in organ donation. J Ferguson suggested looking at the historical pace of growth of transplant centres as evidence of whether they will have capacity to meet activity targets to 2020. J O'Grady stated that an independent evaluation and stress test needs to be undertaken to reach a national strategy on this complex issue. J O'Grady will write to E Jessop.

J O'Grady

**3.3.2 Appointment of new Clinical Fellow**

- 3.3.2.1 There will be an advertisement in the BMJ shortly. NHSBT will be involved in the recruitment proposal.

**3.4 IT Progress report – LAG(14)5**

- 3.4.1 A programme is being developed by NHSBT to identify how systems and processes can be improved over the next five years. A real concern is how the existing technology will cope with the implementation of the new liver allocation system.

**4 STATISTICS AND CLINICAL STUDIES REPORT****4.1 Summary from Statistics and Clinical Studies – LAG(14)6**

- 4.1.1 Reporting will be streamlined in the coming year. The Annual Activity Report will continue to be produced and, where possible, centre reports will be published annually with a shorter interim report every six months. These will be available on the ODT website.

J O'Grady will draft a proposal on how to streamline the sharing of NHSBT data (currently via the 'Data Application' process) to reduce demand of resources from within the Statistics team. The aim is to introduce a more open data sharing system like in the US.

J O'Grady

**5 LIVER ADVISORY GROUP WORKPLAN REVIEW**

- 5.1 J O'Grady gave an update on the five key areas outlined in the Workplan:
- Four FTWU's are working on defining clinical priorities for the new liver allocation scheme. Updates were presented for all four and it was noted that all were on target to deliver their recommendations on time;
  - Progress is being made on increasing organ utilisation with J Dark;
  - Indications for listing for Acute Liver Failure are being incorporated into the liver allocation scheme, which was previously free standing;
  - No testing has been required to-date for new and evolving indications;
  - Work is continuing on 'Trust and Development';
  - Defining relationships with professional bodies - this is being developed with the British Liver Transplant Group in affiliation with BASL and will be a free standing group. BLTG will work closely with LAG and bring greater clarity to the roles of the respective bodies. A meeting is planned for 18 September which will include discussion on the new liver allocation scheme, living related donation and audit. Members are encouraged to attend.

**6 CORE GROUP AND FTWU REPORTS****6.1 'Backbone' of Allocation System – LAG(14)7**

- 6.1.1 A Gimson reported on the work undertaken by the FTWU looking at the development of a universal liver transplant allocation system, including aspects of UKELD parameter harmonization across transplant units. The work has developed three allocation models; post-listing survival, post-transplant survival and a combination of these two. The allocation work will

A Gimson

## ACTION

incorporate HCC variables. J O'Grady recommended conclusions to be reached in preparation for the meeting on 18 September.

E Hidalgo will join the group as the surgical representative.

## 6.2 Exceptions, disadvantaged patients and re-transplantation – LAG(14)8

- 6.2.1 The paper by A McGilchrist looked at how patients awaiting a liver transplant who are disadvantaged by a National Allocation System based on UKELD be allocated a donor organ. Following discussion it was agreed that A Gimson review the selection criteria for elective re-transplant.

A Gimson

N Heaton raised a concern on the lack of understanding on how patients who require a re-transplant are being allocated organs – are they being transplanted with marginal livers? There is no data analysis for outcome on re-transplants for primary non-function and there are no agreed minimum listing criteria for re-transplant patients. Further work is required in these areas.

## 6.3 Hepatocellular Carcinoma – LAG(14)9(a), (b), (c) & (d)

- 6.3.1 It was agreed that the minimum listing criteria would not include HCC patients with lesions less than 2 cm when alternative therapy can be delivered. With regards to the question of whether HCC patients outside the accepted transplant criteria should be considered for down-staging, J O'Grady stated this would be addressed in the review of allocation. J O'Grady suggested that proposed changes could be tested prospectively in parallel with the current selection system prior to implementation.

## 6.4 Acute liver failure – LAG(14)10

- 6.4.1 Current data are not sufficiently robust to conclude on whether there is a transplant survival benefit for patients transplanted for paracetamol-induced acute liver failure at three years and beyond. Further work is also required before a decision can be made on whether patients with sub-acute liver failure can be listed sooner. Work is to be completed by September.

K Simpson/  
J O'Grady

## 6.5 Living-related transplantation – LAG(14)11

- 6.5.1 Work is underway through the FTWU on Adult to Adult Living Donor Liver Transplant (LDLT). Unfortunately there is no Hepatologist in the group as the selected member's clinical role has changed. A replacement will be identified.

There is currently no strategy for Adult to Adult LDLT. The question is whether to have a strategy akin to the Living Kidney Donor Transplant Scheme set up since 2010. There will be an agenda item on 'Living-related Liver Donation' at the Liver Patient Support Group meeting on 4 July 2014. This topic is also included in the agenda for the BLTG meeting in September. The consultation and review process should be completed by October.

K Huang

## 7 COMMISSIONING ARRANGEMENTS AND SERVICE IMPLICATIONS

- 7.1 Feedback from the Clinical Retrieval Group (CRG) is that the Commissioners have asked for protocols and cost to be standardised across all transplant centres.

J Crookenden raised a concern about patients being discharged from a transplant centre back to their local GP and the cost of immuno-suppressant drugs being more costly when purchased through a pharmacy.

J O'Grady reported that the cost of drugs has been reviewed by NHS England following a tender process.

## **8 SEVERE ACUTE ALCOHOLIC HEPATITIS (SAAH)**

### **8.1 Service evaluation**

- 8.1.1 The forms have been developed with the latest revisions made in February 2014.

### **8.2 Feedback to the Severe Acute Alcoholic Hepatitis (SAAH) announcement – LAG(14)21**

- 8.2.1 J Neuberger thanked members for their contribution to the SAAH programme. The programme has been endorsed by Andrew Langford representing the British Liver Trust. M Warmsley commented that the announcement has been well reported in the Press.

## **9 REVISED LIVER SELECTION AND ALLOCATION POLICIES**

- 9.1 Changes to the liver selection and allocation policies that were endorsed last Autumn have been implemented and are reflected in the current versions of the policies available via the ODT website.

## **10 ACTIVITY AND ORGAN UTILISATION SCORE CARD – LAG(14)12**

- 10.1 A draft version of the centre-specific 'Activity, Utilisation and Outcomes Score Card' was presented to members. It comprises three parts (1) Real data for the last quarter fully anonymised, (2) Real data for the last quarter with centre identifier, and (3) Cumulative data up to 12 months (though it would be beneficial to have more data).

Feedback received from members included:

- the word 'score card' needs to be changed as this assumes performance;
- a definition is required for the re-transplant rate;
- show a changing trend line from the last quarter, and
- 'Index of aggressiveness' to be changed with alternative wording, e.g. 'Utilisation of marginal livers'

Members agreed that the data needs to be valid and accurate. Once members have confidence in the data the information will be made available to the public. The decision as to whether the centres should be named will be made at a future point. It was agreed that if scorecards are requested under the Freedom of Information Act, they should not be released until data have been validated by centres.

**E Allen**

## **11 OUTCOME OF APPEALS – LAG(14)13**

- 11.1 It was commented that Appeals of a technical nature tend not to get a quick

response as opposed to Appeals of a clinical nature. Members agreed that

**ACTION**

the Chair of the National Appeals Panel will take an executive decision if a majority of centres have not responded within seven days. E Allen will make the relevant changes to state this in the Liver Selection Policy.

**E Allen**

## **12 QUOD (QUALITY IN ORGAN DONATION)**

### **12.1 Update on QUOD**

- 12.1.1 R Ploeg gave a presentation outlining a national initiative to create a platform with a focus on research that will improve quality in organ donation. The QUOD programme will look at robust infrastructure, a national database recording donor and recipient demographic and clinical information, donor optimisation, pathways of injury and repair and valid markers for outcome. A pilot study will be undertaken in Scotland led by Lorna Marson and will be carried out in four phases.

### **12.2 LAG nomination to QUOD**

- 12.2.1 Paul Gibbs will be the LAG representative on QUOD.

## **13 ABO INCOMPATIBLE LIVE DONOR TRANSPLANTS**

- 13.1 R Jones asked if it was appropriate for Leeds to increase ABO incompatible live donor transplants. The commonest reason for the rejection of donors is ABO incompatibility and this is an increased risk carried by the recipient in an emergency setting. There is currently limited data available in this area. R Jones to present a protocol for the BLTG meeting on 18 September for discussion.

**R Jones**

## **14 DECLINED LIVER OFFERS – LAG(14)14**

- 14.1 E Allen presented an annual report on the most common reasons given by centres for declining liver offers from DBD and DCD donors whose liver was subsequently transplanted. A comparison of the survival of patients who received a liver that was accepted on first offer against those where the liver was declined at least once and subsequently transplanted showed no significant differences. Members agreed that the annual report should continue to be produced which will be a useful tool for monitoring offering data. Members requested to include longer term survival analyses (3/ 5 years). The suggestion was made to change the word 'Declined' in survival plots.

**E Allen**

## **15 UPDATE ON ANTIVIRAL THERAPY**

- 15.1 NHS England has a substantial sum of money available for early access to the new DAAs for hepatitis C based on urgency of clinical need. Members agreed that all patients on the waiting-list for liver transplantation should be automatically included in the category of eligible patients, J O'Grady will write to Professor Graham Foster (relevant CRG).

**J O'Grady**

## ACTION

**16 MEETING WITH PATIENTS AND PATIENT GROUPS**

- 16.1 The next Liver Patient Support Group meeting will be held on Friday 4 July 2014. J O'Grady will draw up the agenda and send out a letter of invitation to the patients support groups.

**J O'Grady/  
K Huang**

**17 BOWEL ADVISORY GROUP****17.1 Report from the Bowel Advisory Group meeting: 9 April 2014**

- 17.1.1 In the absence of D Mirza, J O'Grady informed members that of the five super-urgent multi-visceral transplants involving a liver that have been undertaken, three patients are still living. All transplants were carried out between November 2012 and November 2013 at Cambridge transplant unit.
- J O'Grady will ask V Aluvihare, as hepatologist, to attend the National Association of Small Intestinal Transplants (NASIT) which takes place every alternate month.

**J O'Grady/  
V Aluvihare**

**18 ANY OTHER BUSINESS****18.1 Liver validation errors**

- 18.1.1 J Neuberger outlined six registrations from ODT on-line since February 2014. Five were UKELD score validation errors (UKELD being below 49) and one was a tumour size error. Clinical summaries for all have been sent through for review.

**18.2 LAG Peer Review Proposal – LAG(14)22**

- 18.2.1 The LAG Peer Review is to enforce quality assurance and adherence to guidelines. (The Peer Review for CTAG was approved by their members).
- The initial stage to improve service will involve pilot sites to be assessed and run by Liver Quest. Accreditation pilot licenses will be awarded on attainment of the required standard. Once approval has been given by BASL the scheme will be implemented next year. The proposal will be brought up at the meeting on 18 September.

**18.3 Living Liver Donor Transplantation**

- 18.3.1 Refer to agenda item 6.5.

**19 DATE OF NEXT MEETING:**

**Wednesday 19 November 2014 – ODT, Bristol**

**20 FOR INFORMATION ONLY****20.1 Group 2 transplants – LAG(14)15**

- 20.1 Members received a paper reporting on liver transplants performed for Group 2 patients and liver transplants performed for Group 1 non-UK resident EU patients between 1 April 2013 and 31 March 2014.



## ACTION

**20.2 Transplant Activity report: March 2014 - LAG(14)16**

20.2 A paper outlining the activity of all organ transplants up to March 2014 was given.

**20.3 Minutes of the Bowel Advisory Group meeting: 30 October 2013  
– LAG(14)17**

20.3.1 Minutes of the Bowel Advisory Group meeting held on 30 October 2013 were presented to members.

**20.4 Minutes from the Clinical Retrieval Group: 28 March 2014  
– LAG(14)18**

20.4.1 Members received a copy of the minutes of the Clinical Retrieval Group meeting held on 28 March 2014.

**20.5 Update on Patient Consent Scheme – LAG(14)19**

20.5.1 Of the 5202 patients registered on the national list for a liver transplant, 99% have given consent for use of their personal data.

**20.6 Frenchay Hospital Closure – LAG(14)20**

20.6.1 Members were informed that Frenchay Hospital, currently in Birmingham's liver distribution zone, is closing on 19<sup>th</sup> May 2014. Staff and patients will be transferred to Southmead Hospital, in the King's College liver distribution zone.

**Organ Donation & Transplantation Directorate**

**May 2014**

**Administrative Lead: Kamann Huang**