

**MINUTES OF THE TWENTY- THIRD MEETING OF THE
LIVER ADVISORY GROUP
HELD ON WEDNESDAY 15TH MAY 2013
AT ODT, BRISTOL**

Chair

Chair, Liver Selection and Allocation Working Party
Physician, King's College Hospital, London
Associate Director of Statistics & Clinical Audit, NHSBT
Statistics & Clinical Audit, NHSBT
Physician, St James's University Hospital
Head of Clinical & Nursing Governance, NHSBT
Physician, Queen Elizabeth Hospital, Birmingham
Deputy for N Jamieson, Addenbrooke's Hospital, Cambridge
King's College Hospital, London
St James's University Hospital, Leeds
Deputy for Prof Oscar Traynor, St Vincent's Hospital, Dublin
Physician, Freeman Hospital, Newcastle
Recipient Co-ordinator Representative
Surgeon, Freeman Hospital, Newcastle
Physician, Birmingham Children's Hospital
Surgeon, Birmingham, Queen Elizabeth Hospital
Associate Medical Director, NHSBT
Royal Infirmary, Edinburgh
Paediatric Hepatologist, Leeds General Infirmary
Regional Manager, Organ Donation, NHSBT
Statistics & Clinical Audit, NHSBT
Royal Free Hospital, London
Business Systems, NHSBT
Physician, Royal Free Hospital
Duty Office Manager, ODT

Clinical & Support Services, ODT

2 MINUTES OF THE MEETING HELD ON 14 NOVEMBER 2012 – LAG(M)(12)2(Am)

2.1 Accuracy

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

2.2 Action points – LAG (AP)(13)1

All action points have been completed or are listed on the agenda with the exception of, or items providing further updates, listed below:

AP6 – Donor allocation – zone realignment: The changes to the allocation zones were circulated to members and implemented in January. The zones will be reviewed again in the Autumn.

AP8 – Interim Allocation Scheme: Reason for Patient Mortality: - Work is continuing.

AP9 – Combined cardiothoracic/liver transplantation update: An amended proposal for initial cases with cystic fibrosis, and those with a very severe disease not be included initially, has been circulated to members. There have been no patients selected yet though two patients are being prepared for the procedure with discussions amongst the centres involved and S Tsui.

2.2.1 Matters arising, not separately identified

There were no other matters arising.

3 ASSOCIATE MEDICAL DIRECTOR'S REPORT

3.1 Developments in NHSBT – J Neuberger

3.1.1 New appointments

3.1.1.1 Following the retirement of David Mayer as National Clinical Lead for Organ retrieval, Professor R Ploeg will be responsible for the Clinical retrieval group and the delivery of NORS and develop training and accreditation programmes Mr R Cacciola will focus on commissioning and governance of retrieval.

D Gardiner from Nottingham University Hospital has been appointed Deputy National Clinical Lead for Organ Donation.

Applications for the new Chair of LAG have been received and interviews will be held in June. Concern was raised that the liver community should be represented. J Neuberger reported that the appointment procedure follows the recommendations made by the Independent Review and with the revised Terms of Reference for the Solid Organ Advisory Groups but LAG has been asked to nominate an independent panel member

Each Advisory Group will have two lay members, appointed for 3 to 4 years. Recruitment will be by tender and patient groups have been asked to assist in the process.

It was highlighted that Core and Sub Groups are free to invite lay members and patient groups to their meetings.

A Gimson will circulate the Terms of Reference to members.

3.1.2 **NHSBT Strategy update**

- 3.1.2.1 Following the Organ Donation Task Force work-plan ending April 2013, input has been received from LAG members to help develop the Strategy to take it to 2020. The emphasis will be on moving away from increasing donation and towards increasing organ transplantation. The launch of the Strategy will be in July 2013.

3.1.3 **Update on SOAG review**

- 3.1.3.1 All centres have been sent a letter on the 5 March 2013 regarding the implementation plan.

3.2 **Governance Issues**

3.2.1 **Non – compliance with liver splitting**

3.2.1.1 **Liver splitting activity report – LAG(13)2**

- 3.2.1.1.1 The report indicated that there had been an improvement in the data for reasons why livers were not considered for splitting. C Counter highlighted to members the importance of returning a completed split liver information form.
- The topic of using the left lobe was raised. Members discussed providing greater clarity in the National Splitting Programme as well as having a national mentor i.e. a transplant centre which has had experience of transplanting the left lobe may be the way forward. N Heaton to write a paper looking at cases that have been undertaken in the last two years, which centres have performed the procedure, what has been the outcome and to provide recommendations. The paper will be discussed at the next meeting.

N Heaton

Raise this as an agenda item at November's meeting.

CSS

3.2.1.2 **Revised liver splitting policy – LAG(13)3**

- 3.2.1.2.1 The revised liver splitting policy was presented to members for information. A case was discussed regarding splitting a liver from Leeds, whereby the decision was made not to transplant in London a few hours before theatre. M Akyol highlighted that no procedures will prevent this sort of occurrence and it is ultimately down to the centre's nominated surgeon to make the right clinical decision.

Outcome data is essentially based on data for implanting organs and the name of the surgeon splitting the liver should be on the Liver Splitting Form. Any issues as to the site where splitting is to occur should be discussed between the two centres. Non-paediatric centres will maintain a list of surgeons capable of splitting livers successfully. M Akyol stated that only one name is recorded on the form, whereas it is likely that more than one surgeon will actually be involved in the splitting. This should also be formally documented in the Liver Splitting Policy. It was highlighted that under point 2.9.1.5 on the Revised Liver Splitting Policy the wording should be revised to add 'and the implanting paediatric transplant centre has the right to over-rule'.

C Counter

3.2.1.3 **Splitting of liver for group 2 paediatrics**

- 3.2.1.3.1 M Akyol asked members whether a liver should be split where there is no group 1 paediatric recipient but there is a group 2 paediatric recipient. There is currently no written guidance about this. Members agreed that there was no obligation to split and the decision should be made by the individual surgeons.

3.2.2 **Non-compliance with allocation**

- 3.2.2.1 There were no instances of non-compliance with allocation.

3.2.3 **Incidents for review**

3.2.3.1 **Blood Group Incompatible Registrations for Adult Super Urgent Patients – LAG(13)4**

- 3.2.3.1.1 Current policy allows for super urgent paediatric patients to be registered for “any” blood group. A Yates sought approval from members to allow the same ruling for super urgent adult registrations. Following discussion it was proposed that the decision should be guided by clinical data and M Akyol will raise this at the next LSAWP meeting on the 5th July.

M Akyol

In the meantime, requests for a super urgent adult patient to be registered for “any” blood group should go to the Appeals Panel. A Gimson will include wording in the selection policy to cover this scenario.

A Gimson

3.2.3.2 **Suspension of super urgent patients**

Guidance was sought from members regarding the rare occurrence of super urgent patients on the registration list being suspended and if they could retain their original priority on relisting. Members agreed that these patients could retain their original priority on reactivation within five days of suspension. If the suspension period exceeded five days the patient would need to have a new registration.

3.2.3.3 **Liver Fast Track Scheme notification system – LAG(13)5**

A Yates highlighted the issue of only two transplant centres ensuring the provision of a manned faxed number being available 24/7 leading to the rest of the centres having to be paged with the notification of an offering.

It was agreed that the notification process for the liver fast track scheme be changed to both fax and SMS notification to either pagers or mobile phones. This will be implemented from 10 June 2013.

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

There were no triggers reported.

3.3 **NHSBT Research**

3.3.1 **Research Governance Policy for Supporting Research Proposals**

NHSBT is currently exploring with the UK Tissue Bank to manage the overall allocation and placement of organs for research on NHSBT's behalf with the aim of having one phone call for the collection of organs. Conflicting interests need to be carefully monitored to ensure that an organ agreed for research is not undertaken at the expense of an organ for transplant.

J Neuberger will circulate a proposal to members for comment before the November LAG meeting.

J Neuberger

3.3.2 **Allocation of organs for research projects**

Refer to 3.3.1 above.

3.4 **IT priorities progress report – LAG(13)6**

J Neuberger informed members that discussion took place at the Advisory Group Chairs' meeting in December regarding the preference for a system which primarily updated the whole of the transplant database with the secondary objective to prioritise amendments to the allocation policies or vice versa. The consensus was for the amendments to the allocation policies to be the priority followed by the next step of updating the national transplant database.

4 **Associate Director of Statistics and Clinical Audit's report**

4.1 **Conference presentations, current and future work – LAG(13)7**

A study undertaken with A Burroughs to compare UKELD, MELD and the transplant list model has been incorporated into the work to develop a universal allocation scheme.

Analysis is also underway to look at whether a patient should accept a liver from a donor after circulatory death with a reduced optimal outcome or remain on the transplant list for a liver from a donor after brain death for a better outcome.

4.2 **Advisory Group workplan – LAG(13)8**

A paper was presented to members for information outlining the schedule of fixed term and annual projects.

4.3 **Survival from time of listing – LAG(13)9**

A paper was presented on the survival time from the point of listing to the time of patient death. Data indicated that there was no difference in survival between centres in risk adjusted and unadjusted analyses.

This information will be available on the ODT website should clinicians wish to provide more information to patients during consultations and will be de-anonymised.

Discussion took place regarding the obligation to list surgeon's results for patient outcomes. It was highlighted that this may be inappropriate since outcome is linked in with NORS, policy, SNODs and on occasions working alongside another surgeon. J Neuberger and D Manas will discuss this further outside of the LAG meeting. J Neuberger will also raise this at the Advisory Group Chairs' meeting and at BTS.

J Neuberger

4.4 **RCS/NHSBT joint audit contract**

The joint contract will now be with NHS England, and is expected to be renewed for a further year. Revised arrangements for the contract are being put in place, whereby NHSBT will take on responsibility for the Clinical Fellows, and will underwrite contracts with them for three years.

Once the contract and funding has been agreed, arrangements for the appointment of the Fellows will be discussed at the LSAWP meeting in July.

M Akyol

5 **Liver Selection and Allocation**

5.1 **Report from Liver Selection & Allocation Working Party**

The "Interim recipient allocation scheme" was implemented on 1st April 2013 which incorporates UKELD. The system was reported to be working well.

5.1.1 **Update on Interim Allocation Scheme – LAG(13)21a & 21b**

The challenge and extra work involved in listing why patients higher up on the registration list were not selected for transplant to the "selected" patient was discussed. Stratification reasons such as weight may be used as a reason. It was re-iterated that the scheme was implemented for legal reasons.

M Davies highlighted that ethnicity i.e. "white/non white" needed further clarification on the registration form.

C Counter

5.1.2 **Sequential data collection**

C Counter emphasized to centres the importance of returning their monthly forms and highlighted two centres that were yet to return any forms; Birmingham and Newcastle.

5.1.3 **Minutes of LSAWP meeting held on 1 February 2013 – LAG(13)10a & 10b**

M Akyol reported that ethnicity was an issue the patient support groups felt uncomfortable with in using UKELD to rank patients. It was commented that ethnicity was no different to other variables such as gender, blood type or sensitisation. A Gimson will write to T Norman regarding ethnicity for further clarification.

A Gimson

5.2 **Outcome of appeals – LAG(13)11**

Appeals account for less than one percent of all transplants carried out since September 2007 with outcomes being reasonably good. The process of appeals is not to over-rule the Allocation Policy but to deal with patients outside

the transplant listing criteria and encourage discussion of best practice between centres.

The question was asked if the timescale for responding for elective or super urgent patient cases was being met. A Gimson stated that the timescale for responding in both cases is the same.

Units wishing to undertake live donor liver transplantation (LDLT) outside of the criteria for deceased liver transplantation should use the appeals panel process for external peer review of decision. Emergency deceased donor re-transplantation would not be possible after "out of criteria" LDLT.

Members agreed they would:

- prefer to have detailed clinical information on the recent appeal cases as presented in Table 1 going forward. However, as this information is patient identifiable it should only be tabled at the LAG. A Gimson also asked members to complete the Appeals Panel proforma when emailing a case for appeal. **C Counter**
All
- like an annual summary of patients accepted by the appeals panel to include transplant outcomes and at a later stage, to receive one, two and three year patient survival data in a table. **C Counter**

A Gimson informed members there will be a review of live donation with E Jessop leading this. J Neuberger stated that NHSBT's statutory obligation is for deceased donors and not for living donation. A Gimson will write to E Jessop to look at the principles of live donation in line with the criteria for deceased donors. A proposal will then be circulated to members for comment. **A Gimson**

5.3 **Update on simultaneous liver and kidney transplantation for patients with atypical HUS – E Jessop**

No feedback to-date has been received from the National Commissioning Board regarding funding for this type of transplant, and it is probable that a response may not be received in the near future.

5.4 **Update on liver transplantation in the SAAH**

A Gimson reported that liver transplantation in the SAAH will go ahead in conjunction with advice given from the National Research Ethics Committee. The Board will want to view full case details along with details of the decision making process. It was noted that two centres remain opposed to this scheme. The number of liver transplantation in the SAAH will probably be around 20 cases and it is not the intention of LAG to publicise this scheme nationally.

5.5 **Declined liver offers – LAG(13)12**

Members were presented with a paper on transplanted livers from donors after brain death (DBD) and circulatory death (DCD) from 1 April 2010 to 31 March 2013 where the liver had previously been offered and declined by at least one centre. A comparison of outcomes of those transplanted livers accepted on first offer with those declined at least once was requested. **C Counter**

A Gimson will collate from the Centres their DCD criteria. N Heaton agreed to circulate some minimum DCD criteria which would indicate that the donor would be expected to have satisfactory outcome not dissimilar from DBDs and **A Gimson/
N Heaton**

all centres would, in future, be expected to use such donors if they had an appropriate recipient.

6 Review of current UK guidelines for liver transplantation for patients with HCC – LAG(13)13

It was reported that a paper had been published looking at how many patients were selected on new extended criteria. The numbers were very small and the survival rates were seen to be worst but it could not be established whether this was due to HCC or some other criteria.

The challenge here is dealing with cases where the patient has had a tumour removed but the tumour returns. J Neuberger stated that consensus needs to be reached on whether to change the existing criteria. It was agreed that the LSAWP should be tasked with developing new criteria for the next LAG meeting addressing maximum level of AFP, downstaging, rescue transplantation and criteria for transplantation in LDLT. M Akyol to discuss this at the LSAWP meeting and provide a report at the LAG meeting in November.

M Akyol

7 Review of adult-to-adult living donor programme in England

The uptake of adult to adult liver transplantation is a growing area and consideration needs to be given as to whether this type of transplant should be commissioned in certain transplant centres. This will be carried forward to the next LAG meeting in November.

CSS

8 Use of normothermic regional perfusion (NRP) for DCD category III organ retrieval and liver transplantation – LAG(13)15

Meetings have been held on this topic. The challenge is that clinical experience to-date is still limited as not enough livers using this technique have been transplanted. A key question to consider is whether this technique provides a new source of organs or is it a means of maintaining organs. As with all new technology funding will be an issue as well as the technical implications.

There will be a meeting in Newcastle in October 2013 looking at this topic and members are invited to attend. A Gimson to circulate details to members nearer the time.

A Gimson

9 Bowel Advisory Group

9.1 Minutes of the Bowel Advisory Group meeting: 24 October 2012 – LAG(13)16

Minutes of the Bowel Advisory Group meeting held on 24 October 2012 was presented to members for information.

9.2 Report from the Bowel Advisory Group meeting: 6th March 2013 – D Mirza

In the absence of D Mirza, A Gimson reported that there had been two recent super urgent multi-visceral transplants involving a liver. BAG will discuss whether a new specific criterion for super-urgent multi-visceral transplantation should be developed or, because such cases are so rare, they are always

dealt with in the Appeals process. A Gimson will report back at the next LAG meeting regarding his decision.

10 ANY OTHER BUSINESS

10.1 Non-directed altruistic organ donation – LAG(13)22

A letter from L Burnapp was presented to LAG raising the question for centres to consider altruistic referrals and to be preferred points of contact for potential donors instead of going through NHSBT. Centre representatives were asked to email L Burnapp (Lisa.Burnapp@nhsbt.nhs.uk) only if they wanted to be excluded from this process.

All

N Heaton raised the question of financial compensation from NHSBT for living donation for single families. S Falvey reported that there was a national policy based on the existing Welsh policy.

10.2 J Neuberger reported on a meeting with a representative of the Jehovah Witnesses. Their members will not accept blood or blood products but they will accept solid organ transplants. J Neuberger asked if any centres were not comfortable with carrying out this type of transplant. Following discussion J Neuberger will put forward N Heaton as the contact at King's College to the Jehovah Witnesses, Mervyn Davies at Leeds and A Gimson at Cambridge. Others who wish to undertake such procedures should contact J Neuberger who will pass on their details to the Jehovah Witnesses.

10.3 The new Chair of the LAG will take over at the November meeting. A Gimson agreed to attend and provide a handover.

11 DATE OF NEXT MEETINGS

Wednesday 13 November 2013 at Conference Hall, Canterbury Halls, University of London.

12 FOR INFORMATION ONLY

12.1 Group 2 transplants – LAG(13)17

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 2012 and 31 March 2013.

12.2 Transplant Activity report: March 2013 - LAG(13)18

A paper outlining the activity of all organ transplants up to March 2013 was given.

12.3 Registrations and transplant activity – LAG(13)19

Information on elective and super-urgent registrations and transplants over the three year period from 1 January 2010 to 31 December 2012 was given to members.

12.4 Minutes from the Clinical Retrieval Group: 15 February 2013 – LAG(13)20

Members received a copy of the minutes of the Clinical Retrieval Group meeting held on 15 February 2013.

Organ Donation & Transplantation Directorate**May 2013**