NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE (ODT)

MINUTES OF THE TENTH MEETING OF THE LIVER PATIENT GROUPS AND ODT HELD ON WEDNESDAY, 17TH JULY 2019 AT THE MONTAGUE ON THE GARDENS, 15 MONTAGUE STREET, LONDON, WC1B 5BJ

Present

Attendees	Organisation
Alison Taylor	Co-Chair - Children's Liver Disease Foundation
John Crookenden	Co-Chair - Liver Patients' Transplant Consortium & Addenbrooke's Liver Transplant Association
Doug Thorburn	Chair LAG
John Forsythe	Medical Director, ODT, for NHSBT
Kamann Huang	Clinical Support Services, ODT
Neil McClements	Haemochromatosis UK
Rachel Halford	Hepatitis C Trust
Christopher Bryon-Edmond	iLIVEiGIVE
Lynne Vernon	Lay Member
Joan Bedlington	LIVErNORTH
Fiona Hale	LIVErNORTH
Robert Mitchell-Thain	PBC Foundation
Tess Harris	Polycystic Kidney Disease Charity
Martine Walmsley	PSC Support
Karen Rockell	PSC Support
Rhiannon Taylor	Statistician, NHSBT
Valerie Wheater	Wilson's Disease Support Group – UK

ACTION

1 Apologies

Janet Atherton — St James's Liver Transplant Support Group
Martin Boughen — Living Liver Donor
Ann Brownlee — AIH Support
Pamela Healy — British Liver Trust
Luqman Onikosi — Hepatitis B Foundation - Brighton
Phil Spalding — Hep C Positive
Sarah Matthew — Lay Member
Ian McCannah — Royal Free Hospital Liver Transplant

2 Minutes from the last meeting – 11 July 2018 – LPG(19)1

The minutes of the last meeting held on 11th July 2018 were agreed as an accurate record.

3 ORGAN DONATION TRENDS AND TRANSLATION TO TRANSPLANT NUMBERS – LPG(19)2

3.1 A summary of the liver donation and transplantation activity slides for the last 10 years presented were:

- overall the transplant level has increased with a slight decrease in the last year. Donor numbers are their highest at 1600 and the waiting list has decreased each year except for a slight increase for the past year.
- DBD and DCD donation has increased overall though living donation fell for the previous year.
- The median waiting time by blood group is 99 days for adults.
- 60% of patients were transplanted within 6 months for new elective liver only registrations.
- The transplant rate for the 6-month post registration outcome for new elective liver only registrations by centre ranged from 47% to 73%.
- Liver transplants by donor type showed a slight decrease for both DBD and DCD compared to the previous year.
- The number of liver transplants, by donor type and centre, showed an increase except for three centres.
- Adult first deceased donor liver only transplant increased for all centres except for two for elective and SU transplants.
- Paediatric first deceased donor liver only transplant increased for two of the centres out of the three.
- The majority of deceased liver donors were above 50 years of age.
- Named adult elective liver offer decline rates by centre showed two centres above the 95% decline rate and one below. There was also a high accept of DCD.
- All centres are accepting a lower rate of offers. This was 60% but is now at 20% following implementation of the NLOS. Data is currently not held for the waiting list by centre but is shown by blood group.
- Cambridge and Edinburgh are currently leading on machine perfusion. 8% of livers overall were transplanted by machine perfusion last year with Cambridge performing 42%.
- We are getting more DBD offers. A centre undertaking more DBD may decline more DCD.
- The risk adjusted 1-year survival rate for adult elective deceased donor first liver transplants form 1 April 2014 - 31 March 2018 were within the 99% rate except for one centre. This is an excellent achievement.
- It was requested that the categories for primary disease for risk adjusted 1-year patient survival needs to be further broken down to define the actual diseases in the categories.
- Risk adjusted 1-year survival for adult elective first liver registrations for 1 January 2007 to 31 December 2018. It was commented that the waiting pool was statistically adjusted to the significant difference in donors. Data from the NLOS will prove beneficial in examining this.

- Risk adjusted 1-year patient survival for adult SU deceased donor first liver transplants showed a good result.

The paper will be made available to the wider public on 19th July.

Machine perfusion update
P Friend is currently leading on work for machine perfusion. This is a technique where the organ is removed, suspended and kept at normal blood temperature and then resuscitated. It was hoped that a trial study could be undertaken to ascertain the real benefits but unfortunately it has been turned down, so other ways to take the trial forward are being looked at to understand and improve the science.

There are various types of machine perfusion.
One is where the intervention happens after a period of cold storage, another is normothermic machine perfusion (NRP) in the circulation of the organs to be removed at the donor operation. Edinburgh and Cambridge are moving more towards NRP. It is now mandatory in France to use NRP for DCD transplantation, where the liver is to be retrieved. NHSBT has put forward a case for using NRP to the DHs of the UK and has had agreement from Wales, Scotland and Northern Ireland; it has yet to have a decision from DHSC.

4 NATIONAL LIVER OFFERING SCHEME (NLOS) UPDATE

4.1 The NLOS was introduced on 20th March 2018 with the objective of creating equality for matching patients with an organ on a national, rather than a regional basis. The previous Transplant Benefit Score Scheme looked at scoring patients with the highest benefit/longest survival from an organ transplant; calculated 5 years after transplantation.

One year's data post NLOS shows an increase in patient registration for Super Urgent and elective patients compared to a slight reduction in transplant activity.

12 months data post NLOS showed:

- patients on the waiting list, when the scheme was implemented, and still remaining on the list seemed to be waiting longer than the new patients added. This will be looked at by the Monitoring Group at their next meeting in July.
- Fast Track (FT) which offers organs, falling out of the patient named scheme, to all seven transplant centres has risen from 8% to 28%. There has been a 30% overall increase in offers nationally against a slight decline in the number of transplants overall. A FTWU (Fixed Term Working Unit) has been set up to review all the pathways of how the livers get into the FT system.
- There has been a reduction in the percentage of patients whose indication is HCC undergoing DBD transplantation with the overall transplantation figure falling slightly. Data showed an increase in HCC patients being removed from the waiting list. On analysis by the Core Group, it was noted that those patients who were removed had short waiting times with an indication of poor biology or possibly an underestimation of the growth of the cancer when they were put on the waiting list.

- A reduction in the number of patients' survival at 90 days. This was at 98% for the year prior to implementation compared to 89% post implementation. This is being looked at to understand why. R Taylor is looking at updating the parameters (27 individual data points; 6 being linked to donors) with the hope of improving and to accurately select the need and benefit for the patient. Zonal liver transplantation was at 73% pre-scheme and is at 20% post scheme. This indicates that livers are going to the recipients who has the most benefit.
- There has been an increase in 30 minutes overall for CIT; from 8.5 hours to 9 hours.
- Other points noted were overall, the mortality rate and waiting list has fallen. There is a trend for older patients being transplanted; over 60 - 69 years of age. DBD transplants, post implementation, shows no evidence of outcome deteriorating.

We currently hold data for the number of named patient offers where the centre has declined the offer and the patient has subsequently been removed from the list. J Forsythe will look at the number of offers declined due to a lack of resource in a policy change that will shortly be introduced. **J Forsythe**

The NLOS Monitoring Group will be reviewing 15 months post implementation data at the July meeting.

R Taylor and M Hudson were thanked for all their hard work undertaken on the National Liver Offering Scheme.

5 FIXED TERM WORKING UNITS UPDATE

5.1 The FTWUs are set up for a duration of around 4-6 months, with patient/public representation (PPI), to address specific issues around liver transplantation arising out of the Liver Advisory Group meetings.

We currently have the following FTWUs in place:

- Fast Track - chaired by Derek Manas, PPI – Martine Walmsley (PSC Support)
- Liver Splitting – chaired by Magdy Attia, PPI – Alison Taylor (Children's Liver Disease Foundation)
- Cholangiocarcinoma - chaired by Nigel Heaton/John Isaac, PPI – Helen Morement (Cholangiocarcinoma Charity)
- Deteriorating Cirrhotic/ACLF Pilot - chaired by Will Bernal, PPI – Robert Mitchell-Thain (PBC Foundation)
- Neuroendocrine Tumours – chaired by Paul Gibbs, PPI – John Crookenden (Addenbrooke's Liver Transplant Association)
- HCC Explant Review – chaired by Abid Suddle. This FTWU looked at imaging and explant of patients to better estimate liver tumours and will be giving its final report to LAG in November.

- Furthermore, there is an HCV positive donor into HCV negative recipient programme monitoring group – chaired by Ahmed Elsharkawy, PPI – Chris Sandford.

6 HCV positive donors to HCV negative recipients

In the past HCV positive donors have only been transplanted in HCV positive patients. There is now a new generation of drugs which are very effective and has few side effects for treating HCV patients. This has created the possibility for recipients who have never had HCV to be transplanted from HCV positive donors. Patients will develop the HCV but they can be treated successfully to eradicate the virus effectively. J Forsythe has asked for these drugs to be available for this indication as there is obvious significant benefit for potential recipients who have been properly informed and consented.

The Welsh and Scottish Government is prepared to fund the direct acting agents with N Ireland following soon. NHS England have yet to agree funding for England; they are reviewing the process. On an operational level, until England get approval, this will mean a piecemeal approach across the UK.

Ahmed Elsharkawy has been chairing a monitoring group to look at transplanting HCV positive donors to HCV negative recipients. A set of criteria has been drawn up for a transplant centre to undertake this type of transplantation.

The Welsh Centre has prepared a document which can be shared. D Thorburn to ask Mike Stevens to agree to share. **D Thorburn**

7 Liver splitting and paediatric transplantation

7.1 As per the Guidelines, the left lobe of the liver is normally allocated to paediatrics and the right lobe to adults. Prior to NLOS there was an increase in the mortality in paediatrics with insufficient donors under 17 years of age. Historically livers split for a paediatric and not offered were given to local centres who had their own priorities.

With the NLOS being handled centrally, all livers available for splitting are offered to all paediatric centres resulting in 94% livers being split in the first year. However, there is currently a question regarding the accuracy of the liver splitting criteria. The main reason for not splitting was donor reasons, this will be looked at again. Currently 100 to 110 good livers taken out of the scheme for splitting is given to the adult who will benefit the most as giving the right lobe to an adult is not as beneficial as receiving the whole liver. The main benefit of splitting the liver is to the child.

The Transplant Benefit Score (TBS) calculates the score, based on the whole liver and part of the liver, to determine who are the best adults for the right lobe by the centre. These are shown to be slightly younger, fitter and smaller patients.

8 Organ Utilisation

J Forsythe reported that there is currently a Board Level policy looking at declines where an offer has been made to a named patient but where the decline is owing to a lack of resource. Wording for how this information will be communicated has been looked at by the transplant commissioners and the DoH. The process of informing patients will start with the kidney transplant centres. NHSBT will be writing to the Kidney Advisory Group end of July/beginning of August for centres to start informing patients in October. This issue will also be discussed at the Kidney Patient Group meeting on 18th July. A trial of the communication process with kidney transplant centres will be undertaken first before being rolled out. **J Forsythe**

It was highlighted that it will be down to patient groups in how they react/deal with the information.

The suggestion was made by patient representatives that the patient groups might design template letters to have available to write to the various people/organisations e.g. the Director of the Trust.

9 Demand and Capacity for Liver Transplant

9.1 Possible options discussed to meet increased demand and capacity for liver transplantation included to adopt a centre sharing scheme, which is has currently been undertaken for kidneys. There is currently a Transplantation PLC (Pan London Co-Operative) whereby centres are considering sharing their facility and resources.

It was highlighted that it would be inefficient practice to demand more resources if existing resources are not being fully utilised. The PLC principle could be adopted elsewhere in the country and discussions for this initiative are at an early stage.

It was acknowledged that there is an aging population amongst clinicians. BLTG are undertaking a survey of all liver transplantations along with looking at the number of consultants and staff running a centre with the objective of establishing what will be required in 5 years' time.

10 Improving quality in Liver Services (IQILS) Update

10.1 IQILS is a set of standards for liver care with 45 units working to this in England and Wales but this does not exist in Scotland. It was mentioned at the last Steering Group meeting that there may be a funding issue. Discussion took place on how to get Scotland on board. D Thorburn suggested getting in touch/write to James Ferguson, the clinical lead on IQILS, (QEII Birmingham), Adrian Stanley (Royal Infirmary of Scotland) or Ewan Forrest (Glasgow Royal Infirmary) or the subject could also be raised at BASL in Glasgow in September. M Walmsley will relay this back to IQILS. **M Walmsley**

11 Transplant Centre Profile Infographics – LPG(19)3

11.1 The one-page Summary Snapshot, has been updated to incorporate feedback from patient groups, and has been presented to LAG. More detailed information on the sections will still be available in the

Transplant Activity Report. The intention is for the Summary Snapshot to be produced for all the organs for patients nationally.

Following further discussion, R Taylor will make the additional amendments: **R Taylor**

- Change 'How long will I wait?' to 'How long do people wait?' for centres.
- Include what is the median waiting time for each blood group.
- Change 'Which groups have the best survival at 5 years?' to 'What is 5 year survival?'
- Additional comments and descriptive text to be confirmed.

12 Opt-Out Update and the Fatwa released by Mufti Mohammed Zubair Butt

12.1 The Opt-Out scheme is now in place for Jersey and still in progress for the Isle of Man. The new Bill is expected in Scotland very soon.

Post meeting note:
Royal Assent has now been granted for Scotland and implementation will take place in the Autumn 2020.

The Opt-Out scheme has been in operation in Wales since 2015. The Scheme has now been approved in England with implementation planned for Spring 2020. We are currently working through all the governance issues to take account of the different jurisdictions within the country.

The Fatwa has achieved a fair level of publicity but there is still some misleading information on social media. It was highlighted that postings from patient groups to correct this would be listened to rather than from NHSBT.

13 British Liver Transplant Group (BLTG) Update

13.1 M Walmsley reported that she is a patient representative on BLTG with involvement in funded projects e.g. undertaking Quality of Life questionnaires with the project now undergoing final validation and another project looking at the new liver transplantation guidelines.

Her two-year term is now coming to an end. Following discussion, the Group agreed that M Walmsley should continue her role, with assistance from R Mitchell-Thain and J Crookenden. A Taylor will update D Manas in writing. **A Taylor**

14 Live Liver Donation Update

14.1 The percentage of live liver transplants for adults is around 4% annually. The Liver Patient Group felt that live liver transplantation for adults should continue but expressed concerns for donors, as the risks are very much higher than for live kidney transplants. There are three transplant centres undertaking live liver transplantation. It was commented that the operational process for both donors and recipients could be improved by reviewing the resources to run more efficiently.

The NHSBT 2020 Strategy could include expanding the groups of patients and indications for adult to adult live donation with the inclusion of patient and Lay Member representation.

It was reported at LAG that live liver donation should not be looked at in isolation, but as another option to undertake more transplants, and should be part of the liver donation strategy to include wider issues such as reducing the mortality rate, using new technology and the increasing rate of DCD, which is higher than our European countries.

J Crookenden will liaise with D Manas further on donor risk and establish if there will be any funding from the Commissioners. **J Crookenden**

15 Pre-habilitation and post-transplant rehabilitation Update

15.1 Karen Rockell and Martine Walmsley raised the topic of pre-habilitation and post-transplant rehabilitation with hepatologists at BASL. BASL will be sending out a questionnaire on pre and post transplantation and will discuss the results. The objective is to collect data and analyse what the term 'good' (patient needs to be as fit as possible) looks like and it is hoped that providing this evidence will be a stepping stone to obtaining funding.

16 AOB

1. K Rockell (PSC Support) reported that through her daily interaction with patients post-transplant, a key message relayed was the inconsistency of information in the post-transplant education packs from the different transplant centres e.g. What you should be doing in terms of annual smears, checking for skin cancer, what you can and cannot eat. It would be beneficial to produce agreed core basic information in the Liver Patient Guidelines. K Rockell stated that she would be happy to be involved with developing the Guidelines. It was stated that the BTS are looking at something similar.
2. J Forsythe stated that the NHSBT Strategy for 2020 is in the early stages of planning and will ask for patient group involvement. .

17 Date of next meeting:

The date of the next meeting is to be advised.

Organ Donation & Transplantation Directorate **July 2019**