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

MINUTES OF THE NINTH MEETING OF THE LIVER PATIENT GROUPS AND ODT HELD ON WEDNESDAY, 11TH JULY 2018 AT THE ROYAL COLLEGE OF ANAESTHETISTS, CHURCHILL HOUSE, 35 RED LION SQUARE, LONDON, WC1R 4SG

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
John O'Grady	Chair LAG
John Forsythe	Associate Medical Director, ODT, NHSBT
Judi Rhys	British Liver Trust
Kamann Huang	Clinical Support Services, ODT
Gabriel Oniscu	Chair of RINTAG, Edinburgh Transplant Centre
Derek Manas	BLTG Rep, Freeman Hospital, Newcastle upon Tyne
Christopher Bryon-Edmond	iLIVEiGIVE
Sarah Matthew	Lay Member
Joan Bedlington	LIVErNORTH
Linda Turnbull	LIVErNORTH
Fiona Hale	LIVErNORTH
Martin Boughen	Living Liver Donor
Peter Friend	Oxford Transplant Centre
Robert Mitchell-Thain	PBC Foundation
Tess Harris	Polycystic Kidney Disease Charity
Martine Walmsley	PSC Support
Rhiannon Taylor	Statistician, NHSBT
Valerie Wheater	Wilson's Disease Support Group – UK

Apologies

Ann Brownlee & Jenni Wyatt	AIH Support Group
David Head	Haemochromatosis UK
Luqman Onikosi	Hepatitis B Foundation - Brighton
Rachel Halford	Hepatitis C Trust
Donna Barrington-Smith	LISTEN – King's College Support Group
Lynne Vernon	Lay Member
Lisa Beaumont	Leeds Children Transplant Team
Donald Cairnduff	Royal Victoria Hospital Liver Support Group
Ian McCannah	Royal Free Hospital Liver Transplant
Janet Atherton	St James's Liver Transplant Support Group

ACTION

1 ORGAN DONATION TRENDS AND TRANSLATION TO TRANSPLANT NUMBERS – LPG(18)1

1.1 J Forsythe gave a summary of the key points from the paper presented:

- a record 66% consent rate was achieved against a target of 80%. For the last financial year there were 1574 donors, another record, resulting in 5075 transplants of which just over 1000 were live donations.
- The transplant waiting list has decreased from 8012 patients in 2010 to 6044 in 2018.
- Post registration outcome for new elective liver only registrations show that 2 years on from 2015/16, 78% of patients have been transplanted.
- Risk adjusted 1 year patient survival rates for both adult elective first liver registrations and super urgent first liver transplants for all centres remain within their risk-adjusted centre rate. The stats from time of listing have been introduced into the metrics in the last couple of years.

Legislation in Scotland regarding consent for organ donation is now at the stage of producing a draft Bill to be reviewed on a financial level and then taken to Parliament. The process will take 12-18 months. In England, public consultation on 'opt out' for consent for organ donation is now closed. Government consultation is expected to be released before 27 July 2018. Guernsey, Jersey and the Isle of Man will have their own legislation.

We are taking further steps regarding managing the increase in organ donation and the subsequent increase in transplant activity which has led to significant problems coping with the 'peaks' in certain transplant centres. The BTS (British Transplant Society) has held a Summit on the issue of capacity which included representation from every transplant centre e.g. surgeons and recipient co-ordinators. There is a concern and a big challenge for the current system to deal with increasing numbers of transplants. J Forsythe encouraged the support of individual patient groups for the move for more finance to cope with the increase in transplant activity. It was recommended and agreed for A Taylor to draft a letter to the new Secretary of State and circulated to all patient groups with their signatures. The content of the letter should not be general and should concentrate on a specific issue. J Forsythe to provide A Taylor with an email link to the Impact assessment document and summary from the BTS Summit and the Peer Review.

A Taylor

J Forsythe

2 NEW LIVER OFFERING SCHEME UPDATE

2.1 The new Liver Offering Scheme was launched on 20th March 2018 and went well operationally. The first set of data from the scheme will be going to the Monitoring Group on Monday 16th July 2018.

Overall the transplant activity rate has increased 11% with a significant increase in splitting. No major events have been reported to the Monitoring Group. The parallel allocation scheme for patients without chronic liver disease or with exceptions was expected to handle 4-6% of patients registered but at the point of transition this group accounted for 19% of active registrants. This group included many long-waiters including patients with polycystic disease. The next big next decision is determining when DCD patients will be integrated into the new Liver Offering Scheme. The original plan was to proceed after 6 months unless concerns emerged from the early experience.

J Forsythe reported on three months data that showed the new Liver Offering Scheme resulted in 84% of livers retrieved and transplanted compared to 81% before the new scheme. In general, the figures for review in the new scheme were very satisfactory.

On behalf of PSC Support, M Walmsley expressed her thanks on the launch and operation of the New Liver Offering Scheme and for taking into account criteria for PSC patients. A Taylor commented that paediatric transplantation had also increased.

The results/trends from the new Liver Offering Scheme will be reviewed every 3 months; though it is expected that it will be around 9-12 months before a stable state is reached.

3 PEER REVIEW UPDATE

3.1 J O'Grady informed members that a national Peer Review report is available. This was conducted by NHS England in 2016 with the process involving site visits to transplant centres with patient representation.

The Peer Review identified good practice as well as steps to be implemented in the future. Issues of concern were fed back to the individual transplant centres and the responses from the centre has met with the approval of the commissioners. Three of the main concepts of the Peer Review highlighted by J O'Grady were:

(1) the patchy network arrangements for referral into the national service;

(2) consistence and sustainability of training;

(3) not all transplant centres can guarantee 24/7 cover for all aspects of the service.

4 TRANSPLANT CENTRE PROFILE INFOGRAPHICS – LPG(18)2

4.1 J Forsythe presented a paper and informed members that currently if a patient requires a liver transplant and is to be referred to a particular transplant centre, there is a wealth of information on the Organ Donation website but it relies on the individual knowing where to access the information. Therefore, the recommendation is for concise data to be available for each liver transplant centre. ODT is at the stage of fine tuning the information but would like feedback from clinicians and patients on the concept before it is launched.

ACTION

J Forsythe informed members that one feedback from the Kidney Patient Group meeting was to use absolute numbers rather than the common use of percentages for its data. ODT is currently working with the Winton Centre in Cambridge, a specialist organisation in providing how data is presented, on the areas of consent for organ donation and patients on the waiting list. Once all feedback is received ODT will run the proposed concept by this organisation.

Feedback given at the meeting on the concept was:

- PSC liked the document which was easy to understand. However, their preference was for data which was relevant to Primary sclerosing cholangitis e.g. aetiology, the waiting time for their blood group or the average recovery time for PSC patients. Factors affecting waiting time was very well received.

- likelihood of receiving a DBD or DCD liver (number of calls received before getting a transplant), the outcome for a DBD or DCD liver and the distance from a liver transplant centre from a patient's home. It was commented that the belief is that the closer a patient lives to a transplant centre the higher the number of calls the patient will receive.

- it would be beneficial for patients to see the name of the transplant centres written on the bar chart for the average waiting time.

- possibility to show patients surviving 1 year after first adult elective liver transplant data as a pie chart.

J Forsythe will take on board feedback given at the meeting. **J Forsythe**

5 MACHINE PERFUSION OF THE LIVER – P FRIEND

5.1 The increase in demand for transplantation has in part been a result of the incidence of liver failure and cancer. This has led to patients dying whilst on the waiting list even in the context of access to the waiting list being restricted to patients with better prognosis. Despite this, only 62% of deceased donors result in a liver transplant.

The current process of cooling organs is not ideal as it prevents the delivery of oxygen, leads to an accumulation of metabolites and limited viability assessment with marginal organs being more problematic. Current trials of the use of machine perfusion have shown immediate graft resuscitation, the potential for viability assessment and improved organ utilisation.

The technique of machine liver preservation is perfusing solution through the organ which delivers oxygen and maintains temperature. The two approaches are Hypothermic and Normothermic machine perfusion, differentiated by temperature and the degree of oxygenation.

Hypothermic perfusion of the liver provides the benefit of delivering oxygen given to organs that are cold and keeping the mitochondria working. Hypothermic oxygenated perfusion (HOPE) involves perfusing organs for 1-2 hours before transplantation.

Normothermic machine perfusion (NMP) recreates physiology and allows normal metabolic activity.

Four UK transplant centres have joined three non-UK European transplant centres in a randomised trial of machine liver perfusion which has shown a 49% reduction in damage to organs. The primary outcome measure of this trial was liver enzyme release, which is a marker of cell damage.

In the UK high risk livers are particularly poorly utilised. Fifteen years data for liver transplantation based on the use of 4 risk quartiles shows 83% utilisation in the lower 3 quartiles, contrasting with 34% utilisation in the highest quartile. Increasing utilisation of organs is vital if the number of liver transplants is to increase.

The viability assessment for the use of NMP is based on factors ranging from metabolic, synthetic, hepatocellular injury, inflammatory and perfusion parameters. The VITTAL study at the University of Birmingham has involved functional testing of organs declined by all UK transplant centres (with at least 1 of 7 defined risk factors) with 4 hours perfusion, then assessment and transplantation if meeting criteria.

Will donor organ perfusion make a difference? Trials have confirmed feasibility and safety with logistical benefits and could transform the way transplantation is delivered. There is also an opportunity to deliver organ specific therapies. The NICE public consultation is now open. P Friend encouraged the patient groups and charities to show their individual organisation's support for the use of donor organ perfusion. A Taylor to send K Huang a link to access to be circulated to the patient groups. **A Taylor/ K Huang**

6 LIVER RECONDITIONING AT THE TIME OF ORGAN PROCUREMENT – G ONISCU

6.1 DCD perfusion options were presented. The normal procedure is to get the organ out as quickly as possible and cooling it. However Normothermic Regional Perfusion (NRP) involves connecting the donor abdominal circulation to the perfusion machine to recondition the organs in-situ. This recirculates the oxygenated warm blood to the abdominal organs, essentially converting the DCD donor to a DBD donor scenario. This approach reduces the warm ischemia and allows organs to better tolerate subsequent cold ischemia. NRP allows you to look at the organ function by evaluating factors such as ALT (alanine transaminase), glucose and bilirubin. NRP is already undertaken in Spain, France and Italy. In the UK, Cambridge and Edinburgh have undertaken most of the work to-date.

A clinical study showed that out of 70 DCD donors, 43 livers were used and 27 livers were discarded. The clinical outcome showed that bile duct complications were dramatically reduced and graft survival increased. NRP was found to lead to a significant benefit after adjusting for all other factors affecting the development of ischemic damage to the biliary tree in DCD livers and is believed to be the future standard for liver retrieval from DCD donors.

ACTION

DCD NRP liver transplant outcomes in Spain showed an 87% graft survival rate at 1 year compared to 78% without using NRP.

The conclusion of NRP trials has shown improved graft function, no ischaemic cholangiopathy and increased organ utilisation. NRP is now mandatory in France.

The experimental evidence is that livers can be made transplantable from two types of technology fitting together; perfusion machine and NRP (NRP only for DCD though).

J Friend has tried to put a case together for NRP but the extra cost is the current issue (£4k per use for a liver). The cost of purchasing the machine is not known. The cost benefit of using NRP is the patient not having to stay overnight. D Manas commented that the needles used to burn cancer in the liver is £3k a time with a lower success outcome.

P Friend will look at the NICE document and give feedback to A Taylor. **P Friend**

7 BRITISH LIVER TRANSPLANT GROUP (BLTG) UPDATE

7.1 D Manas is the Chair of the BLTG. The Group was launched in 2014 (replacing the UK and Ireland Liver Transplant Group annual meeting) as an organisation to represent and present professional interests of the liver transplant community in the UK, form strategic and academic developments and to deliver structure and authority.

The BLTG is not an independent organisation but is supported by BASL (British Association for the Study of the Liver) which is the umbrella organisation. The BLTG works closely with BTS (The British Transplant Society) and LAG (The Liver Advisory Group) and has a strong emphasis on education and training, helping to shape the future needs of the UK liver transplant community and to provide an avenue of communication to NHS England.

The BLTG/BASL/BSG (British Society of Gastroenterology) transplant guidelines was last written in 1999 and are due to be updated. More formal NICE endorsed liver transplantation guidelines are to follow. BTS/BLTG HCV and HBV guidelines are now published. The strategy is for liver machine perfusion technology and PPI (Patient and Public Involvement) Group to add support for improvements to liver transplantation.

The LDLT (Live Donor Liver Transplantation) is a national strategy led by L Burnapp in collaboration with NHS England, NHSBT, BTS and BSG. The specifications for the Strategy are now complete and it is hoped to get members and patients' buy-in at the Annual Meeting.

D Manas informed members that he is happy to hold a communication session for patient groups on 18th September 2018 in York. A Taylor and M Walmsley expressed their interest to attend and will publicise this date further to interested parties. J Crookenden would like to raise the topic of consent at the forum. **M Walmsley**

8 FTWUs (FIXED TERM WORKING UNITS) UPDATE

8.1 J O'Grady reported that 14 out of the 16 FTWUs have delivered on their objectives. One of the most recent FTWU set up is to assess cholangiocarcinoma as an indication for transplantation and will be chaired by N Heaton. Another FTWU will primarily advise on the governance of transplantation g=for hepatocellular carcinoma but will also look at the issue of governance in relation to organs given to patients on a privileged basis e.g. access to the super-urgent waiting. J O'Grady asked for names of a patient representative to sit on each of the two FTWUs.

9 AOB

9.1 No issues were raised.

10 Date of next meeting:

The date of the next meeting is to be advised.