NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION

MINUTES OF THE TWELVETH MEETING OF THE LIVER PATIENT GROUPS AND OTDT HELD ON WEDNESDAY, 7TH JULY 2021 AT 11.00 AM VIA MS TEAMS VIDEO CONFERENCING

Present

Alison Taylor	Chair - Liver Patients' Transplant Consortium
Doug Thorburn	Chair of the Liver Advisory Group
John Isaac	Deputy Chair of the Liver Advisory Group
John Forsythe	Medical Director, OTDT, for NHSBT
Joan & John Bedlington	LIVErNORTH
Martin Boughen	Living Liver Donor
Ann Brownlee	AIH Support Group
Christopher Bryon-Edmond	iLIVEiGIVE
John Crookenden	Addenbrookes liver transplant Association
Laura Gorton	NHSBT Communications
Fiona Hale	LIVErNORTH
Rachel Halford	CEO Hepatitis C Trust
Sam Hargreaves	NHSBT Communications
Tess Harris	Chair – Polycystic Kidney Disease Charity
Pam Healy	CE British Liver Trust
Neil McClements	Haemochromatosis UK
Maxine Tapp	PSC Support
Rhiannon Taylor	Statistics and Clinical Research – OTDT, NHSBT
Sarah Matthew	Lay Member
Robert Mitchell-Thain	PBC Foundation
Linda Turnbull	LIVErNORTH
Lynne Vernon	Lay Member
Sadie Von Joel	Lead Recipient Co-Ordinator – ODTD, NHSBT
Martine Walmsley	PSC Support
Valerie Wheater	Wilson's Disease Support Group UK

In Attendance: Kamann Huang — OTDT
Lewis Downward — (Observer - Statistics, OTDT, NHSBT)
Jenni Banks — (Observer - Statistics, OTDT, NHSBT)

ACTION

1 **Apologies**

Janet Atherton - St James's Liver Transplant Support Group
Helen Morement - Cholangiocarcinoma Charity

2 Minutes from the last meeting – 8 July 2020 – LPG(21)1

The minutes of the last meeting held on 8th July 2020 were agreed as an accurate record.

3 COVID-19 impact on organ donation, recovery programme and future surges – LPG(21)2

Data shows that following each surge, donation and transplantation numbers have recovered. The weekly trend has been up and down though no reasons could be identified for the periods when the numbers went down.

Congratulations were expressed to the donation, retrieval and transplantation teams during the last 16 months of the pandemic and for maintaining 75% of donation and transplantation. A huge thank you was given to D Thorburn and J Isaac for their dedication in working closely with commissioning to ensure transplantation took place during very difficult circumstances which included transferring patients between centres. A positive message out of the pandemic is how the challenges have brought the donation, retrieval and transplantation teams to work together as one whole team.

The surge we are currently in was predicted so there have been no major changes to that already undertaken. A further surge is predicted for September and it is anticipated that this will not impact hospitals on a large scale.

Overall, there has been a 20% reduction in adult liver transplantation over the last year, whilst paediatric transplantation levels have been maintained. There has been a 13% reduction in registrations with a significant rise in the overall waiting list (630 patients on the waiting list; the largest number seen in the last 10 years) due to a reduction in transplant activity. During the first wave only high urgency patients were transplanted as a priority. It was observed that patients transplanted were in poorer health but the outcomes were still very good with similar lengths of stay in hospital. This is a testament to the hard work and commitment of the centres.

Transplant centres are recovering but will be challenged by the backlog and waiting lists. Birmingham was the worst centre impacted with 1200 admissions. Following the last wave 195 patients are now are on their waiting list as well as trying to catch up with elective surgery. It was highlighted that there is a real need to fight for transplantation to continue as a priority.

Both Haemochromatosis UK and the Children's Liver Disease Foundation praised the dedication shown by the clinical teams and centres.

More information is now being gained from vaccines. There have been two publications, one is an academic paper on organs donated following vaccination resulting in rare cases of blood clots (VITT - vaccine induced thrombosis and thrombocytopenia) with a concern for organs not being able to be used. Statistical and Clinical Research are currently developing a registry for vaccinated patients on the waiting list and outcomes following transplantation. Data from two cohorts, those vaccinated and those unvaccinated showed that one vaccination reduces the incidence of infection for the patient whilst those unvaccinated had a higher incidence of infection. Double vaccinations indicated good protection from COVID even for immune suppressed patients. It is recognised that differences in the behaviour of people could be a result of the data provided but data has shown that there has been a 85% success in outcomes from vaccinated patients post-transplant.

4 NHSBT Strategy and new Organ Utilisation Group

The NHSBT Strategy (a ten-year vision for the UK) 'The Organ Donation and Transplantation 2030: Meeting the Need' has now been launched

following a delay from the pre-elections. One of the four pillars is focusing on organ utilisation.

The Secretary of State for Health and Social Care has asked NHSBT to create an Organ Utilisation Group working alongside them, chaired by Professor Steve Powis. The objectives are essentially to maximise potential organ transplantation and establish what the barriers are in preventing this. to provide a healthcare system that delivers equity, excellence and innovation. Viewpoints from national and international stakeholders will be sought but it is hoped that this will revolutionise transplantation.

5 Transplant Activity

Summary points of the slides presented were:

- Number of deceased donors, transplants and patients on the active transplant list. For the year 2019/20 compared with 2011/12, there was a 25% decrease in the active waiting list, a 31% increase in donors and a 22% increase in transplants. For the year 2020/21 compared with 2019/20 there was a 25% decrease in donors and 22% decrease in transplants. However, both were higher than in 2011/12.
- For the same time period 2011/12 to 2020/21 there was a 11% increase in liver donors and a 1% increase in liver transplants. The number active on 31 March 2021 was low (123) but this is because the majority of adult patients were suspended on 31 March 2021 with only clinically urgent patients active.
- The total number of patients on the transplant list has increased with 578 active and 88 suspended on 30 June 2021.
- The median active waiting time to liver transplant for elective patients registered 1 April 2018 to 31 March 2020 was 72 days for adults and 74 days for paediatrics.
- For the last 10 years there has been a 9% decrease in DCD and a 3% increase in DBD for liver transplants.
- The national one-year survival rate for adult elective patients is 94.2% and ranges between 89% and 96% by centre. The national one-year survival rate for adult super-urgent patients is 90.2% and most centres were within the rate apart from one centre which was due to the low number of transplants in general.

The report will be published later this month.

6 National Liver Offering Scheme (NLOS)

Since the introduction of the NLOS in March 2018, the NLOS Monitoring Committee has been meeting on a regular basis. One of the consequences of the scheme has been the overall increase in transplants for patients newly registered. We are currently examining this, although this was evidenced before the implementation of NLOS. Other resultant changes have been harder to explain. One was the reduction in offering to HCC patients and it is believed that the prediction of survival without transplantation was over estimated. To rectify this the TBS (Transplant Benefit Score) was reduced due to the over estimation to enable offers to be made.

Work has been ongoing for the last 18 months, with some interruption due to COVID, to update the parameter estimates. The proposed TBS change was approved at the LAG May meeting and the next stage is to work with IT to implement the changes.

Once LAG approves the final changes, the calculator will be updated and disseminated to centres for use to see the impact of updating the TBS for patients.

7 Fixed Term Working Units Update

New indications for transplantation

ACLF (Acute chronic liver failure) - Chaired by Will Bernal looking at identifying a way to get donor offers for patients with cirrhotic chronic liver disease who are not eligible for the Super-Urgent (SU) transplantation tier. To-date, two patients have been registered and transplanted.

Cholangiocarcinoma – This has looked at two categories of patients. Those with hilarcarcinoma with PSC, tumours less than 3 cm and those with intropatrophic carcinoma, tumours less than 2 cm led by N Heaton. A new implementation group is now required for the pilot scheme, chaired by R Prasad and he will work with T Shah leading on NET (Neuroendocrine tumours) and to develop a pathway with new adjuvant therapy before liver transplantation. The aim is to put forward the recommendations at LAG in November to sign off the final steps and for the programme to commence next year. PSC Support were very grateful for the work undertaken to reach this stage for their patients with a zero option.

Neuroendocrine tumours (NET) – An implementation group has been established chaired by T Shah. All registrations will be undertaken at local centres and a national MDT (multi-disciplinary team) has been set up to provide medical guidance when patients will be placed on the waiting list. The expectation is for the programme to start towards the end of the year.

Hilar Carcinoma (HCC) – **Minimal Listing**
This is a FTWU chaired by A Suddle and A Marshall to draw up the minimal listing criteria for HCC, which has never previously been undertaken. A report will be submitted to LAG in November.

HPS (**Hepatopulmonary syndrome)** – work led by J Leithead looked at patients who developed hypoxia from low oxygen levels, who were not easily identified and to ensure this subset of patients with severe HSP were appropriately prioritised and transplanted within their window of transplantation, as for CC, HCC and NET patients. Further work is being undertaken by the LAG Core Group to examine why the very severe HSP patients are not served well by the variant syndrome (VS) method of prioritisation indicating a waiting time of two years. One recommendation is to allocate a TBS or number of days waiting for the disadvantaged patient.

HCV positive donor organs into HCV negative recipients. This is led by A Elsharkawy and will look at donation across all organs. Advice and resources are being provided to help improve the sign up of centres.

Colorectal carcinoma (CRC) metastasis – K Menon is chairing the work to look at whether liver transplantation is a good pathway for CRC metastasis and will develop a pilot study. Data from Norway has indicated good patient survival though there is a requirement for subsequent liver transplants. The recommendations will be raised at the November's LAG meeting for approval.

Data collection for changes to UK Transplant Forms
The Chair to lead this work is yet to be confirmed and will entail reviewing all the liver forms completed and returned to NHSBT and suggesting fields that are clinically relevant that are not currently collected e.g. frailty.

All the Working Groups are supported by patient group involvement.

8 Transplant Centre Profile Infographics

The information for the profiles for the centres looking at registrations and chances of survival after one and five years can be accessed via the link below. Please note that the data will be updated in September after the publication of the organ reports.

(https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/23098/adult-liver-infographic-19-20.pdf)

R Taylor will check if the QR code can be added. **R Taylor**

9 UK Liver Alliance and UK Patients' Alliance

UK Liver Alliance

There are four work streams being led by the Steering Group: (1) early detection with diagnosis and primary care, including pathways to secondary care, (2) reducing variation in hospital care across regions, (3) to ensure Liver has the right workforce and (4) to ensure the patient is at the heart of all activity. The third meeting has been held and a communications plan has been agreed. This will initially start internally within the liver community followed by the media and it is hoped that this will drive through change.

UK Patients' Liver Alliance

This was established to provide a central patient voice. As work under this group now overlaps with LPTC (Liver Patient Transplant Consortium), it has been agreed that LPTC will morph into the UK patient Liver Alliance to avoid duplication. The Terms of Reference has been agreed. It is hoped that there the first update will be provided towards the end of this year.

The Chair stated that this will provide a greater influential unified voice for patients.

10 AOB

- The outcome of the Aspirate Market Entrants proposal for additional liver transplant centres in the SW and NW of the country by RDAG (Rare Diseases Advisory Group) has not been approved. The recommendation is for NHS England to undertake a national review of liver transplantation in response to feedback from all stakeholders.
- A new tool to help communicate risk to patients is being developed jointly between NHSBT and the Winton Centre, University of Cambridge, to aid clinicians when discussing the risks and risk-adjusted estimates of post-registration outcomes with patients registered for liver transplantation.

11 Date of next meeting: To be Advised

July 2021