

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

**MINUTES OF THE EIGHTH MEETING OF
THE LIVER PATIENT GROUPS AND ODT
HELD ON TUESDAY, 11TH JULY 2017 AT
THE WEST END DONOR CENTRE, 26 MARGARET STREET, LONDON, W1W 8NB**

Present

Attendees	Organisation
John Crookenden	Chair of Liver Patients' Transplant Consortium & Addenbrooke's Liver Transplant Association
Andrew Langford	Co- Deputy Chair - British Liver Trust
Alison Taylor	Co- Deputy Chair - Children's Liver Disease Foundation
John O'Grady	Chair of Liver Advisory Group
John Forsythe	Associate Medical Director, ODT, NHSBT
Paul Senior	Addenbrooke's Liver Transplant Association
Elisa Allen	Senior Statistician, NHSBT
Rhiannon Taylor	Statistician, NHSBT
Mike Thompson	Senior Communications Officer, NHSBT
Joan Bedlington	LIVERNORTH
Linda Turnbull	LIVERNORTH
Christopher Bryon-Edmond	iLIVEiGIVE
David Head	The Haemochromatosis Society
Kamann Huang	Clinical Support Services, ODT
Sarah Matthew	Lay Member
Lugman Onikosi	Hepatitis B Foundation - Brighton
Martin Vaux	LISTEN – King's College Support Group
Angela Cattermole	LISTEN – King's College Support Group
Martine Walmsley	PSC Support
Valerie Wheeler	Wilson's Disease Support Group – UK
Caroline Simms	Wilson's Disease Support Group – UK

Apologies

Ann Brownlee & Jenni Wyatt	AIH Support Group
Keith Ellis	Hepatitis C
Lynne Vernon	Lay Member
Richard Hall	Liver4Life
Martin Boughen	Living liver donor
Robert Mitchell-Thain	PBC Foundation
Tess Harris	Polycystic Kidney Disease Charity
Lynda Hayward	PSC Support
Janet Atherton	St James's Liver Transplant Support Group

ACTION**1 ORGAN DONATION TRENDS AND TRANSLATION TO TRANSPLANT NUMBERS**

- 1.1 J Forsythe highlighted the following points from NHSBT's statistical data:
- DBD and DCD donation are both increasing. Though living donation has experienced a decrease over the last four years.
 - There has been a reduction in the transplant waiting list since 2010. Donor numbers is a record number at 1413 for the last year with transplant numbers also reaching a record. Though there are still over 6000 patients on the waiting list.
 - Future steps being taken include looking at every step of the donation process from the point of referral to transplantation as well as looking at all possible routes to maximise organ utilisation e.g. intensive care units.
 - Percentage of new elective isolated liver registrations for 2014/15. Data showed that 50% of patients had been transplanted by 6 months, 67% by 1 year and 74% by 2 years.
 - It should not be interpreted that a centre lying above the national rate of decline for organs should be taken to mean that a centre is more risk adverse. For example, a smaller waiting list will mean that the centre will have a reduced opportunity to match organs and may be more selective. If patients are very risk adverse waiting for the perfect organ, this will affect outlier data.
 - The North West tends to be an area of disadvantage for organ donation compared to the West of the country. A reason for this has been associated with the area being heavily populated and having a high disease rate. Data on disease breakdown by region is not collected but there is data on the breakdown by disease type from the national transplant waiting list. Patient registration and transplant data are also collected and for the first time will include post code. E Allen to email the link for the latest report, once validated by centres, to attendees.
 - The consent rate is improving overall but at a very slow pace compared to targets set. In some parts of the country the consent rate has reached target for the first time. J Forsythe to email the family refusal rate for potential donors on the ODR to C Bryon-Edmund. E Allen to email the National Potential Donor Audit Report and Annual Activity Report to attendees.
 - It is still too early to announce any impact on transplant numbers following the Welsh 'opt out' legislation for organ donation. Scotland has announced a consultation on issues to do with deceased donation and 80% are in favour of 'opt out'. England's Minister is receptive to the concept but no legislation has been planned. A Taylor attended an event in Cardiff in September in relation to

E Allen**J Forsythe****E Allen/
K Huang**

research undertaken by Bangor University on the effect of the opt out change in Wales. It is hoped more information available then.

- A Langford stated that the Muslim Council has over the last six months been actively supporting organ donation; a very positive move. A Taylor stated that NHSBT Stakeholder events held annually focused heavily on how to reach BAME and under represented groups of potential donors.

2 PEER REVIEW

- 2.1 No outcomes are available yet from the Peer Review process which took place in September/October last year though each transplant centre has received their provisional report. The Review involved each transplant centre being visited by a five member team including a patient representative.

Reviews done on cardiothoracic and other solid organs have also not been published by NHS England. J Crookenden stated that a long delay in publishing data will affect the importance of issues. The Patient Group agreed for J Crookenden and A Taylor to write to Marie Cummins at NHS England this week regarding a date for the publication of the results.

**J Crookenden/
A Taylor**

A National Report is expected at BASL (British Association for the Study of the Liver) in September. J O'Grady anticipates the Report may cover general issues such as overstretched resources delivering a 24 /7 but was not anticipating any major problems.

3 NEW LIVER OFFERING SCHEME

- 3.1 The implementation date for the new Liver Offering Scheme was changed from June to December in response to a reasonable request from the development team. The exact date is yet to be confirmed. A lot of work has been undertaken in the last 6 months transferring concepts to logistics which in turn has generated questions requiring new solutions.

A parallel system will be in operation. Only DBD livers will be offered for the first 6 months. If no problems are encountered DCD livers will be included. The primary objective will be selecting the patient from the national waiting list who will benefit the most from the donated liver. A recommendation will be made to set up an independent monitoring group, to include patient representation, to look at data on a three month basis and assess any unintended consequences that arise.

A Taylor highlighted that the 16-24 year age group be offering dual listing and inclusion in the new offering scheme. Dual listing will apply to recipients over the weight of 40 kg.

J O'Grady informed attendees that there is likely to be a transitional period of around 12 -18 months before transplant activity balances out across the centres as there may be imbalances in case-mix at the time of the launch.

J Forsythe stated that the new offering scheme will move from a centre referral system to a patient allocation system. He asked the Liver Patient Group to discuss the issue of the degree of involvement patients want from a centre in declining an offer for them. The time factor will be a key factor to consider. The Kidney Patient Group has also been asked to consider this issue. The issue will be raised as an agenda item at the Liver Patient Group meeting next year.

K Huang

The new scheme will bring changes at different levels for patients, clinicians, and recipient and transplant co-ordinators. NHSBT are working to ensure this is all in place as well as the collection of new data for patient registration. E Allen is working with NHSBT's Communications Department to communicate all these changes. A frequently asked question sheet will be produced. Attendees to liaise with E Allen over the lunch break if they have any issues to be raised.

4 TRANSPLANT CENTRE DASHBOARDS

4.1 Patient Groups were asked what other key information they would like included on the two page summary document outlining key information for each transplant centre.

Following discussion it was agreed to select a handful of metrics from those presented at the meeting. A Langford recommended that the template from Scotland outlining six metrics be used.

Martin Vaux, Caroline Simms, Luqman Onikosi and John Crookenden have agreed to get together to agree on the metrics to be selected. (Email and contact numbers to be exchanged).

K Huang

It is hoped that a draft document will be presented to the next LAG meeting in November.

5 LIVING LIVER STRATEGY

5.1 J O'Grady informed patient groups that professional agreement had been reached to allow adult-to-adult transplant activity in all centres. All centres should have the capacity to develop an adult to adult programme. This has led to a Peer Support Network whereby surgeons have agreed to provide assistance to each other. The renal model is being looked at as a framework to help with the leadership in developing the Liver Strategy; though the clinical issues will be different to that of the Kidney. A draft has been put together for the relevant Commissioners.

The patient groups agreed to help provide a strong voice in the Living Donation Strategy. On behalf of the patient groups and charities, A Taylor and J Crookenden will write a joint letter detailing what they want the transplant centres to deliver and how much involvement they want from a patient perspective.

A Taylor/
J Crookenden

6 FTWUs UPDATE

6.1 Split Liver. The highest number of split livers (44) was reported for the last financial year 1 April 2016 to 31 March 2017. The main

reason for not splitting in over a third of the cases was abnormal or raised liver function tests.

Alcohol guidelines/policy. It was agreed at LAG that the guidelines will remain as guidelines rather than be made policy. This is now operational. The main impact will be we can start assessing patients after three months of abstinence.

Severe Acute Alcoholic Hepatitis. There have been no acute hepatitis patients registered over the three years. Agreement has been taken to relax the registration criteria.

7 BRITISH LIVER TRANSPLANT GROUP (BLTG)

- 7.1 A Langford informed patient groups about the BLTG and the British Liver Trust working with Picker, an international healthcare research charity, to gain feedback and experiences of patients who have recently used liver transplant services in England.

The project will involve working closely with an advisory group of clinicians, nurses, family members and patients. It will concentrate on issues of greatest importance to patients around liver transplants and will complement the data collection.

Anyone interested in knowing more about the work or wish to be involved are asked to contact Susanne Kasbauer at Picker at Susanne.Kasbauer@pickereurope.ac.uk. It is hoped that the results of the project will be available in December.

Post Meeting Note:

Martine Walmsley of PSC Support has agreed to represent the group in this forum moving forward.

8 THE BRITISH ASSOCIATION OF THE STUDY OF THE LIVER (BASL), PATIENT REPRESENTATION AND GATHERING WIDESPREAD FEEDBACK

- 8.1 A Taylor reported that Prof. Graeme Alexander (Chairman of BASL) has asked if the Liver Patient Group would like to attend BASL in 2018. BASL will arrange for a series of speakers involved in fields such as transplantation, haemochromatosis and the LANCET Commission to update patients. At the same time it will provide an opportunity for patients to mix with leading clinicians.

Prof Graeme Alexander will be stepping down soon and the incoming Chair is expected to be Prof Matthew Cramp.

9 AOB

- 9.1 A Langford announced that he would be stepping down as the Chair of The British Liver Trust to take up a new post with Bipolar UK. Thank you to A Langford for all his work and support given to-date to the Liver Patient Group meetings. A new Chair for the British Liver Trust will be announced shortly.

It was announced that the Liver Patient Group meeting moving forward would be chaired jointly by John Crookendon and Alson

Taylor . The groups agreed we could approach to coopt members of the group over the coming year.A review of the running of the meeting can be raised at the next meeting in 2018.

A Taylor informed attendees that she is a patient representative on the European Reference Group for research in rare diseases and asked if there are any issues attendees wished for her to raise on their behalf.

Attendees were informed of the following events taking place:

- 7th Annual General Meeting of Wilson's Disease Support Group on 23 July 2017 in Cambridge.
- The British Transplant Games this year will be taking place in N.Lanarkshire from 27th – 30th July 2017.

10 Date of next meeting:

The date of the next meeting is to be advised.

Organ Donation & Transplantation Directorate

July 2017