

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

**MINUTES OF THE SEVENTH MEETING OF
THE LIVER PATIENT GROUPS AND ODT
HELD ON WEDNESDAY, 13TH JULY 2016 AT
FRIENDS HOUSE, 173-177 EUSTON ROAD, LONDON, NW1 2BJ**

Present

| Attendees | Organisation |
|-------------------|--|
| Andrew Langford | Co-Chair - British Liver Trust |
| Alison Taylor | Co-Chair - Children's Liver Disease Foundation |
| John Crookenden | Deputy Chair of Liver Patients' Transplant Consortium & Addenbrooke's Liver Transplant Association |
| John O'Grady | Chair of Liver Advisory Group |
| John Forsythe | Associate Medical Director, ODT, NHSBT |
| Ann Brownlee | AIH Support Group |
| Jenni Wyatt | AIH Support Group |
| Kamann Huang | Clinical Support Services, ODT |
| Rachel Halford | Hepatitis C Trust |
| Martin Vaux | LISTEN – King's College Support Group |
| Angela Cattermole | LISTEN – King's College Support Group |
| Kelvin Marshall | Liver4Life, Hepatitis C Positive & Double Liver Transplant Patient |
| Joan Bedlington | LIVERnORTH |
| Linda Turnbull | LIVERnORTH |
| Elisa Allen | NHSBT, Senior Statistician, |
| Valerie Wheeler | Wilson's Disease Support Group – UK |

Apologies

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|--------------------------|---------------------------|
| Sheila Connolly | Friends of Liver Lifeline |
| Lugman Onikosi | Hepatitis B Foundation |
| David Head | Haemochromatosis Society |
| Christopher Bryon-Edmond | iLIVEiGIVE |
| Martin Boughen | Living Liver Donor |
| Robert Mitchell-Thain | PBC Foundation |
| Nicki James | PKD Charity |
| Martine Walmsley | PSC Support |
| Richard Pitman | The Transplant Games |
| Andy Eddy | Transplant Sport |

No Responses

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| | British Organ Donor Society |
| | Leeds Children Transplant Team |
| | Queen Elizabeth Liver Patient Support Group |
| | Royal Free Hospital Liver Transplant |
| | RVH Liver Support Group |
| | Scottish Liver Transplant Unit |
| | St James's Liver Transplant Support Group |
| | Transplant Association |

1 ORGAN DONATION TRENDS AND TRANSLATION TO TRANSPLANT NUMBERS

1.1 J Forsythe gave a presentation and reported the following points:

- donation for liver transplantation has risen steadily over the last ten years as a result of a lot of work put in from Specialist Nurses in Organ Donation (SN-ODs) and Clinical Leads in Organ Donation (CL-ODs) and the transplant teams This has resulted in a small fall in the transplant waiting list last year.
- liver transplants by donor type; DBD (donation after brain death) last year remained the dominant type of liver transplantation. DCD (donation after cardiac death) has steadily increased whilst the trend for living liver donation has dipped and increased over the last 10 years.
- post registration outcome for new elective liver only registrations for 2013/14. 33% of patients are on the transplant list at 6 months with 9% removed/died compared to 5% of patients on the transplant list at 2 years with 17% removed/died.
- data for 'patients on the active transplant list by centre at 31 March 2016' shows the number of transplants undertaken and reflects the size of the transplant centre.
- organs declined by one centre, offered to another centre and then transplanted are recorded under the category of 'Risk adjusted one year patient survival rate from time of listing for adult elective first liver registrations, 1 January 2004 – 31 December 2015'. J O'Grady stated that there will always be a decline rate but getting this at the right level is the challenge.

The data presented does not include private patients and is for NHS patients only.

A Taylor stated that it was good news to see an increase in donation numbers leading to a drop in the waiting list compared to the previous year.

It is too early at this stage to establish whether the change in the Welsh legislation has affected donation rates.

2 UPDATE ON CAPACITY AND RESOURCE/NEW TRANSPLANT CENTRES

2.1 J O'Grady informed members that historically transplant centre service configurations have not changed in the last 25 years. The conclusion of the Lancet Commission is that there is a need for a fundamental review. There will be a Peer Review of all the centres in England and Scotland around October/November of this year and this is likely to address the question of whether the current transplant infrastructure can cope with a 10% increase in donation per year. NHS England will appoint patients/patient representatives to be involved in the visits to the transplant centres; the dates of the visits are yet to be confirmed. Training for the Peer Reviewers are planned

for August. The final discussion on metrics evaluated will be signed off in the next few weeks.

A Langford questioned the approach of the training of the Peer Reviewers taking place next week when the patient representatives had not been appointed yet. J O'Grady stated that there will be training for the patient representatives as well. A Langford stated that it was poor not to have a patient representative from Day 1. J O'Grady to provide A Taylor the name of the contact at NHS England for the selection of patient representatives.

J O'Grady

J Crookenden highlighted that the strategy to increase organ donation by 50% by 2020 will put an increase on all transplant centres and this is likely to happen before the new transplant centres are established and poses a critical capacity issue now. J O'Grady reported that this issue is being monitored closely.

It was reported that all the transplant centres are of the view they can cope with the increase over the next few years. At the Liver Advisory Group meetings an initiative has been set up to look at the reasons for organs that are not used.

3 IMPLEMENTATION OF THE NATIONAL LIVER ALLOCATION POLICY

- 3.1 The current liver allocation scheme for liver transplantation is centre-based using a donor zone arrangement based on the number of registrants. Following detailed analysis of various models of liver allocation, the decision was made to move to a national offering scheme which identifies the patient gaining the maximum benefit from the donor organ. The previous year has been spent working on the logistics and the process at each stage. The offering system is only for adults as the paediatric system is working well with waiting and transplant times being relatively short with one exception. There has been a proposal to change the offering of organs to large children who are currently not getting access to adult organs. This involves the option of children having the option of being dually listed on paediatric and adult waiting lists if they are above a weight threshold to be agreed (e.g. 40 or 45 kg).

Initially, it was felt that the scheme should be introduced for both DBD and DCD organs. Following lengthy discussions it has been agreed to begin with DBD organ allocation to reduce potential problems with the scheme and then to include DCD allocation. The aim is to implement the change to the Liver Allocation Scheme in June of next year. J Forsythe confirmed that funding had been approved for the IT implementation required for the changes to the Liver Allocation Scheme.

Members were informed that donation has been made easier by supplying specialist nurses with I-Pads who can access the donation forms electronically off-line and then download them once they are back at their centres. The electronic process can trigger a referral to a recipient co-ordinator or centre, avoids transcription errors and

leads to a much faster and more efficient process compared to filling in forms by hand.

J Forsythe reported that a new project has been launched to look at shortening the donation time for DCD organs compared to DBD organs. It was commented that the length of the donation process has resulted in families declining organ donation.

4 IT UPDATE AND SERVICE INNOVATION AND RESEARCH DEVELOPMENT

- 4.1 In the absence of A Snape, members noted the presentation outlining the IT innovation and research development undertaken to-date.

5 LIVING LIVER STRATEGY

- 5.1 Professional opinion was sought 18 months ago on the adult to adult living liver donation scheme and submitted to NHS England. Their feedback was there was no change required for commissioning.

The country is divided into three zones: the North, the Midlands and the South looking at how to address the needs of the service such as transplant centres wanting to undertake living to living transplantation but are not fully trained. It is hoped that recommendations will be made and presented at the next LAG meeting in November. Patient groups were requested to form a firm view of how this should move forward i.e. should the decision be profession led or patient group led?

**A Langford/
A Taylor**

It was commented that In the US, living donor transplant numbers have decreased to around 4%. J Forsythe stated that undertaking a live donor transplant is very different to deceased transplantation with the stakes higher for donor and recipient leading to a reluctance to promote living donation. J O'Grady requested a universal viewpoint from the patient groups. A Langford will discuss this at the end of the Patient Group meeting and feed back to J O'Grady.

A Langford

6 FTWUs UPDATE

- 6.1 The Fixed Term Working Units (FTWUs) meet over a 4 - 5 month period and typically involve 4 - 5 individuals examining in detail specific issues of concern to LAG.

Reports from the FTWUs in the last year are listed below.

Paediatric diseases in adolescents and young adults - Chaired by Dr Pat McKiernan

The three criteria addressed by the Working Group were:

1. Are these patients disadvantaged in the organ allocation system?
2. Could these patients be disadvantaged in the proposed new offering/allocation system?
3. To recommend guidelines to maintain quality of care through the transition process.

The recommendation was for adolescents and young adults being considered for liver transplantation should be managed in centres

where there is: a structured transition programme, a named transition coordinator, comprehensive access to specialised support workers incorporating use of mobile technologies, a Clinical Lead for transition in both the paediatric and adult centre and a joint clinic with clinicians from both the adult and paediatric programmes.

Update on alcohol guidelines - Chaired by Dr Andy Holt. A report has been drawn up reviewing all the issues relating to alcohol and access to transplantation. J O'Grady stated that he believed the whole document should become policy rather than guidelines, widely agreed at LAG, but will discuss this with transplant centres and patient representatives. This will be reviewed again at the next LAG meeting in November for finalisation. A Taylor will lead on looking at what is to become policy.

A Taylor

Severe Acute Alcoholic Hepatitis – Chaired by Prof Alex Gimson. This will be taken to BLTG in September to relax the registration criteria to recruit patients. No one has been transplanted under this service evaluation to-date.

Split Liver - Chaired by Prof Peter Friend. This is still work in progress owing to the breadth of professional opinion. The FTWU is in the second phase looking at specific issues. J O'Grady reported that it was the responsibility of the Chairman of the FTWU to include patient representative involvement in the discussions.

Combined liver and kidney transplantation - Chaired by Dr Mark Hudson. These patients wait a lot longer on the waiting list especially if metabolic disease is present.

Early graft dysfunction - Chaired by Prof Alex Gimson. This looks at defining livers struggling to work in the first few days following transplantation. The US classifies early graft dysfunction in 28% of liver transplant recipients. J O'Grady believes the UK should have a more sophisticated definition than this.

Organ Utilisation – Chaired by Prof Nigel Heaton. The first approach in looking at organ utilisation has failed to identify the causes? A different approach has now been adopted to understand why organs are not used and to maximise usage.

It was recommended that FTWU membership should include a Lay Member and a Patient Representative. J O'Grady will notify patient representatives when a new FTWU is set up.

J O'Grady

7 BRITISH LIVER TRANSPLANT GROUP (BLTG)

- 7.1 The BLTG enables all the different specialisms to be represented at one forum to raise the views of clinicians and allied professions in reviewing internal practice and disciplines between centres. Both A Langford and A Taylor are involved with the Group.

A patient survey will be undertaken to gather any concerns on current transplant arrangements for both surgeons and patients. All patient groups were encouraged to complete the survey when it comes through.

8 TRANSPLANT GAMES

- 8.1 The Transplant Games this year will take place in Liverpool on 28th - 31st July. Patient groups were encouraged to follow the event and voice their support with the messages. A Taylor reported that they have secured a place at the 2019 World Transplant Games in Newcastle and will invite J O'Grady to attend.

The biggest issue last year regarding donation is still the consent rate. As all the charities have separate campaigns about consent, focus has been on looking at how to consolidate this. This has come to fruition and the initiative will be launched on Friday 29th July at the Transplant Games with the commitment of all the big charities. The initiative will start with a 'Thunder Clap'. Anyone with a twitter account will automatically be signed up, a hash tag can be used to promote the initiative, so that on the day it will all go out at once. NHSBT communications are also involved in the initiative. A Taylor will provide details to the attendees at the meeting.

A Taylor

It is hoped that the general media will print stories and highlight on TV the initiative from social media.

9 ANTIVIRAL THERAPY FOR HEPATITIS C

- 9.1 J O'Grady reported that the process for access to the drugs has improved rapidly; transplant recipients are now involved in the access process. The issue of whether a patient should be removed from the transplant list if they are quite sick remains unresolved owing to the lack of data/evidence to make this decision. J O'Grady estimated that it would be around 3 years before any impact will be seen from the benefit of the antiviral therapy for hepatitis C.

K Marshall reported that he was doing research on FDC (Familial Dilated Cardiomyopathy) on gene types.

10 AOB

- 10.1 J Crookenden raised the question of whether the Ministry of Justice has responded to its consultation about the role of Coroners following Reforms. J Forsythe reported that a paper from the British Medical Journal on a project involving coroners' work with colleagues will be published on-line in the next few weeks.

Post meeting note:

The article has been circulated to members of the Liver Patient Group.

- 10.2 A Langford expressed his thanks to K Huang for her minute taking at the Patient Group meetings.

11 Date of next meeting:

The date of the next meeting is to be advised.