

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

**MINUTES OF THE SIXTH MEETING OF
LIVER PATIENT SUPPORT GROUPS AND ODT
HELD ON TUESDAY, 14TH JULY 2015 AT
MSE MEETING ROOMS, LONDON**

Present

Andrew Langford	Co-Chairperson - British Liver Trust
Alison Taylor	Co-Chair Children's Liver Disease Foundation
John Crookenden	Addenbrooke's Liver Transplant Association
David Head	Haemochromatosis Society
Christopher Bryon-Edmond	iLIVEiGIVE
Martin Vaux	LISTEN – King's College Support Group
Martin Boughen	Living Liver Donor
Robert Mitchell-Thain	PBC Foundation
Nicki James	PKD Charity
Martine Walmsley	PSC Support
Valerie Wheeler	Wilson's Disease Support Group - UK
John O'Grady	Chair of Liver Advisory Group
James Neuberger	Associate Medical Director - NHSBT
Kamann Huang	Clinical Support Services - ODT, NHSBT
Kate Martin	Statistics and Clinical Studies - NHSBT

Apologies

Louanna Prince	Communications - NHSBT
John Bedlington	LIVERnORTH
Joan Bedlington	LIVERnORTH
Tilly Hale	LIVERnORTH
Ann Brownlee	AIH Support Group
Lisa Beaumont	Leed's Children Transplant Team
Ian McCannah	Royal Free Hospital Liver Transplant
Janet Atherton	St James's Liver Transplant Support Group
Susan McRae	The Hepatitis C Trust
Emma Osborne	Transplant Association
Andy Eddy	Transplant Support

No Responses

	British Organ Donor Society
	Friends of Liver Lifeline – Plymouth
	Hepatitis C Nomads – online forum
	Liver4 Life
	Polycystic Kidney Disease Charity
	QE Liver Patient Support Group
	RVH Liver Support Group
	Scottish Liver Transplant Unit

1 ORGAN DONATION TRENDS AND TRANSLATION TO TRANSPLANT NUMBERS

1.1 Key points highlighted were:

- Increase in patients on the waiting list;
- NHSBT audit all potential deceased donors under 75 years of age dying outside cardiothoracic units;
- Referral rates for organ transplantation have increased;
- The consent rate for organ donation remains around 60%;
- A large percentage (up to 18%) of patients die whilst on the transplant waiting list which is a concern;
- Characteristics of deceased adult liver donors: 2% are over 70 years of age, the median is around 50-60 years of age, 90% of donors are white with male donors slightly exceeding female donors;
- Some ethnic groups are disadvantaged owing to lack of ethnic donation with blood group B being prevalent amongst the Asian community where donation rates are lower.

CUSUM monitoring on outcomes following liver transplantation is done in real time. Should a signal arise, NHSBT will write to the transplant unit director who will look into the signal to establish if there is a problem and will in turn provide feedback to J Neuberger, J O'Grady and E Jessop who acts on behalf of all the commissioners and Health Departments.

It was reported that of the 924 livers retrieved, 842 were used for transplantation and 82 livers not being used. Reasons for this are stated in the activity report. Sometimes, the decision that an organ is not suitable for transplant is made by the retrieval team rather than the transplantation team. A Langford stated that any information in this area would be useful to the patient groups.

C Bryon-Edmond commented that it was disheartening to hear that a small percentage of donated livers are not being utilised. Attendees will discuss at the end of the meeting the formal wording to be used in the letters that are sent to families following donation. A Langford will email the agreed wording to J Neuberger.

A Langford

J Neuberger welcomed any feedback from attendees for inclusion in a letter which he will forward to the Assistant Director for Donation

Of the 842 transplants undertaken the question on how many livers were transplanted on overseas private patients was raised.

J Neuberger reported that numbers are small and NHSBT ensures that livers used for private patients have been declined for all NHS-entitled patients. More information is published in the activity report.

J Neuberger reported that NHSBT have appointed two surgeons to work with clinicians and the wider transplant community to support increasing organ utilisation.

A strategy is being developed to look at behaviour and how to target the right audience to increase public awareness on organ donation.

A Langford reported on the 'wee chat' campaign in Scotland to encourage people who sign up to organ donation to have a 'wee chat' so that families are aware of their wishes.

2 CAPACITY AND RESOURCE/NEW TRANSPLANT CENTRES

2.1 J O'Grady reported on three key issues to consider on a macro level in expanding the structure for liver transplantation:

- NHSBT's current role i.e. resources to ensure maximum appropriate organ utilisation, ensuring equality of access and maintaining and improving standards;
- preparing for the increase in organs up to the year 2020;
- the Lancet Commission made eleven recommendations. One being the review of liver transplant services. The British Liver Transplant Group (BLTG) meeting on 8th September 2015 aims to scope out the framework for liver transplantation. This will include a review of the current activity and outcomes, the strengths and weaknesses of the current status, and will hear the US perspective on performance metrics and reimbursement. Formal patient input will be included in addition to general discussion. It is hoped that there will be representation from senior commissioners. The outcome of the review may take up to 12-18 months. J O'Grady agreed that two representatives from the Consortium could attend, instead of the one, on this occasion.

One current issue for liver transplantation is the discordance of view regarding large areas of population not supported by the existing structure for transplantation. Areas with liver transplantation services are not necessarily mapped to the pattern of the burden of liver disease but tend to have better developed overall liver services. Having more transplant centres is likely to result in shorter travelling times for patients but there will be significant resource implications.

3 NATIONAL ALLOCATION SYSTEM – OFFERING SEQUENCE UPDATE

3.1 J Neuberger reported that NHSBT are statutorily responsible for managing the national organ offering sequence. A national offering scheme is used for the super urgent scheme and a centre based scheme for non super-urgent recipients.

Currently there is a lot of discussion regarding the proposal for a national allocation scheme. NHSBT will accommodate this as best it can if approved though the major issue will be its capacity to deliver this solution and implementing the IT infrastructure.

NHSBT's problem is that NTxD is a very difficult programme to update. Small changes are not easy to make and cause unintended consequences. An example is the implementation of the 'Intestinal Failure - Associated Liver Disease Scheme' (IFALD) implemented a couple of years ago. The Board has recognised that the current IT system needs overhaul and has agreed to a £6/7m IT upgrade

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programme over 5 years but this will require support from the commissioners. There will be agile working so that new technologies can be incorporated during the development of the IT systems. Where possible, 'off the shelf' packages will be used. Two patient representatives with professional experience in IT stated that a 5 year IT plan would be considered too long by industrial standards. It was acknowledged that owing to the pace of technology the existing IT model may be out of date by the time it is even implemented.

A lot of resource has currently been focused on the development of the new Organ Donor Register (ODR) transferring existing registered patients to the new system to ensure the new register is fully operational in advance of 1 December 2015 when the Welsh organ donation opt-out system comes into effect.

A Taylor highlighted that the charity groups would be happy to support expediting the IT pace of implementation. It was suggested that it may be helpful to table a 'non-threatening' question in Parliament to ensure this issue maintains prominence. J Neuberger commented that NHSBT's Chief Executive, Ian Trenholm could be invited to a Patient Support Group meeting to provide further detailed plans if required.

4 IT UPDATE AND SERVICE INNOVATION AND RESEARCH DEVELOPMENT

- 4.1 A new technology using 'Organ Ox' in machine perfusion is currently undergoing trials and has been carried out on the first twenty patients. Instead of using donated organs which are kept on ice the machine will keep the organ at body temperature. Data from the trials will be monitored though data from the ongoing randomised controlled trial in Europe (including UK) will probably not be available for around three years. J Neuberger will forward an abstract on machine perfusion for K Huang to circulate to members. J Neuberger believes that focus should be on marginal livers. An Advisory Group has been formed to support service development and innovation though NHS England are somewhat fragmented at the moment as a governing body so it has been difficult to get feedback. It will fall to the Chief Medical Officer (CMO) to request NICE to progress proposals and there is currently a two year delay. Renal perfusion for kidneys underwent a similar process but had to wait two years for any feedback.

**J Neuberger/
K Huang**

5 LIVING LIVER STRATEGY

- 5.1 The Living Liver Strategy for adults was discussed at the previous meeting and the Commissioners have asked for a formal view from the Liver Advisory Group. As a result, a Fixed Term Working Unit (FTWU) has been working for the last four months looking into a set of questions to formulate a strategy to recommend to LAG.

Work on the 'Living Liver Strategy' was discussed at a national meeting with representation from all transplant centres looking at:

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- (i) the demand for living liver donation.
- (ii) whether every transplant centre be allowed to undertake living donation and should there be a minimum number carried out for the centre to remain active.

The feedback from the meeting was 'Yes' to both the questions. The recommendation was that living liver donation should be maintained and developed as a service. The achievements seen with the Renal Transplant Programme will be adopted and developed further. All transplant centres should be included in the living donation programme but it is recommended that a centre with high activity should be paired with a low activity centre.

A report has been sent to the Commissioners in January but no feedback has yet been received. J O'Grady reported that the BLTG meeting in September will support the recommendations. If no feedback has been received after the BLTG meeting J O'Grady will follow it up. A Langford has six monthly meetings with Simon Stevens, the Chief Executive of NHS England, and offered assistance in pursuing feedback if required.

6 FTWUs UPDATE

- 6.1 There have been eleven FTWUs created and those currently in progress are:
- Paediatric diseases in adolescents and young adults
 - Liver splitting - led by Prof Peter Friend.
 - Optimising organ utilisation, and
 - Alcohol policy.

A Langford requested patient representation on the FTWUs as early as possible rather than halfway through the process.

7 ANTIVIRAL THERAPY FOR HEPATITIS C

- 7.1 J O'Grady reported that patient access to antiviral therapy for Hepatitis C in the UK before transplantation is very good. However he highlighted that the therapy should not defer the decision to transplant. There is not sufficient data on antiviral therapy to evidence saving patients from undergoing transplantation i.e. they become well enough to remove them from the transplant list. Current data for treatment post transplant is less robust than for pre-transplant data and there is less funding for treatment post transplant. 30% of patients are seen to develop an aggressive disease following therapy treatment and transplantation. The other factor to take into account is the upfront cost and not the after cost of treatment.

8 WALES OPT-OUT ORGAN DONATION IMPLEMENTATION

- 8.1 The new Organ Donor Register (ODR) was implemented on 1 July 2015 to accommodate the new Welsh opt-out organ donation scheme. This means that from 1 December 2015 a resident in Wales will automatically have their organs donated for transplant unless they

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express the decision not to donate. Once a person has registered on the ODR, the Human Tissue Act 2004 deems this as legal consent for donation. However, in practice, a family may override this decision. Therefore awareness programmes are emphasizing the importance and need for donors to inform their families of their decision. In reality surgeons will not fight families for donation even though consent has been given by the deceased to avoid adding further distress to families.

J Neuberger reported that very few complaints have been received following letters sent out to people asking if they have made the right decision following their decision to opt out of the donation scheme.

C Bryon-Edmond outlined his personal experience regarding the poor consent procedure on the sudden death of their son. J Neuberger requested the details of the incident to be emailed to him. C Bryon-Edmond commented that visits to the Senior Nurses for Organ Donation (SNODs) from patients having had organ transplantation will make them realise the real value to life and not to just see their role as a job.

C Bryon-Edmond

Anthony Clarkson is responsible for the training of SNODs and ensuring staff are properly trained will affect consent from families. Factors such as culture, religion and donation from cardiac death (DCD) will play a large part in the refusal for consent to organ donation.

In general, younger people are more supportive of donation though the demographics of those consented are currently unknown. Campaigns for organ donation with the DVLA and media sites such as Facebook and Twitter has helped with increasing organ donation.

Ceri Rose is the NHSBT contact to assist patient groups and charities in their initiatives.

9 AOB**9.1 Organ Donation Campaign**

9.1.1 C Bryon-Edmond informed attendees of his recent campaign 'Green Stars' which generated an overwhelming response from 65 thousand people signing up for organ donation in 15 days and gained news coverage from the BBC. A second campaign 'The Transplant Games' held in Bolton enlisted 2.5 thousand people to sign up. A third campaign for the end of July will target Newcastle. The aim of the campaigns is to get as many people as possible to look at the site www.brightgreenstars.com and spread the word for organ donation. A request was made to add the names of some of the charities to the site.

9.1.2 Date of next meeting:

The date of the next meeting is to be advised.