To be Ratified at next meeting **LPSG(M)(14)1(Am)**

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

MINUTES OF THE FOURTH MEETING OF LIVER PATIENT SUPPORT GROUPS AND ODT HELD ON TUESDAY, 4TH JULY 2014 AT THE ROYAL COLLEGE OF ANAESTHETISTS, LONDON

PRESENT:

John Crookenden	Chairperson
John O'Grady	Chair of Liver Advisory Group
James Neuberger	Associate Medical Director, ODT (NHSBT)
Ann Brownlee	AIH Support Group
Sandy Forsyth	British Liver Trust
Alison Taylor	Children's Liver Disease Foundation
Mike Davis	Haemochromatosis Society
Phil Spalding	Hepatitis C Positive - Swindon
Christopher Bryon-Edmond	iLIVEiGIVE
Jonathan McShane	Lay Member on Liver Advisory Group
Martin Vaux	LISTEN - King's College Support Group
Andy Strachan	LISTEN - King's College Support Group
Richard Hall	Liver4life
Joan Bedlington	LIVErNORTH - Charity for liver patients in N. East
Tilly Hale	LIVErNORTH - Charity for liver patients in N.East
Robert Mitchell-Thain	PBC Foundation
Martine Walmsley	PSC Support/Liver Patients' Transplant Consortium
Lynda Hayward	PSC Support
John Gibbs	Queen Elizabeth Liver Support Group
Ian McCannah	Royal Free Hospital Patient Rep
Elisa Allen	Statistics and Clinical Audit - NHSBT
Susan McRae	The Hepatitis C Trust - London
Andy Eddy	Transplant Sport
Kamann Huang	Clinical Support Services, ODT - Secretary

APOLOGIES:

Shabana Baig	Hepatitis C – Greater Manchester
Kathleen Preston	Lay Member – Liver Advisory Group
Lisa Beaumont	Leed's Children Transplant Team
Janet Atherton	St James's Liver Transplant Support Group
Valerie Wheater	Wilson's Disease Support Group - UK

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

This financial year, we have seen an increase in DBD (donation after brain death) donors but a significant drop in DCD donors (donation after cardiac death) with a 3% fall in overall transplants. We are not sure of the reasons which may in part relate to a fall in the number of potential donors. This has resulted in an increase on the transplant

waiting list causing concern.

ACTION

A Scottish study found that only seven organs were yielded from 117 potential DCDs, indicating how work intensive this type of donation is. This is one of the areas of focus being looked into by one of the liver subgroups.

A month's audit exercise is planned looking at every donor, the decision points and where along the pathway organs are being lost.

Suggestions/comments for increasing awareness and donation:

- evidence outcome in ICU e.g. visiting with a child who has undergone an organ transplant and recounting the tale. C Bryon-Edmond informed attendees that specialist nurses tend not to see the end result.
- carry out DBD testing regardless of whether donation is to take place.
- utilisation of organs from prison or drug users is very much down to individual surgeons.
- promote organ donation via posters at blood donation centres. This is a key area of increasing public awareness.
- local residents, as opposed to organisations, to give informal talks at their schools.
- ensure next of kin are aware you are on the donor register to avoid the question being asked at a stressful time. Family consent has been the key factor in preventing organ donation if a donor does not carry an organ donor card.
- specialist nurses who have had training have a higher success rate for consent compared to those who have not. Specialist nurses for organ donation (SNODs) undergo a mandatory refresher course each year. NHSBT are currently reviewing training.
- gain support from ICU doctors and nurses to request consent for organ donation within their own clinical teams.
- frequency in asking families for organ donation makes the process easier and builds confidence compared to asking infrequently.

The Potential Donor Audit (PDA) is available on the ODT website and can be found at: http://www.odt.nhs.uk/odt/potential-donor-audit

2 CAPACITY AND RESOURCE WITHIN TRANSPLANT CENTRES

J O'Grady reported that NHSBT are currently looking critically at its spending with the announcement that there is 4.5% less funding for next year. There is a feeling that funding may be diverted from specialist services to community services.

The cost of transplantation across centres varies significantly from £70K to £100K. As a group we need to get a better understanding of

ACTION

costs, justify it more effectively and going forward we need to factor in a 15% year on year increase in activity up to the year 2020.

There has been no view of UK liver transplant services over the last 20 years. Important questions listed below need to be answered:

- should there be more or less transplant centres?
- should they be in different parts of the country?
- what are the barriers?

As a group of professionals, we need to assess our own capability to ascertain what resources are required for each centre.

J O'Grady will give feedback to the Liver Patient Support Group on the issues raised. **J O'Grady**

J Crookenden asked if there was the capacity within the current retrieval teams to handle an increase in donation. J Neuberger stated that retrieval teams are not currently operating to maximum capacity in part due to the operational structure. Kathleen Preston, a Lay Member on the Liver Advisory Group, will be heading up a review of the National Organ Retrieval teams.

There are two stakeholder meetings being held:

- Thursday 17th July 2014 - National Organ Retrieval Service where interested parties to give their views, and
- Thursday 18th September 2014 – The British Liver Trust Group meeting.

J Crookenden thanked J O'Grady for the pro-active measures being taken.

3 NATIONAL ALLOCATION SYSTEM – WORK IN PROGRESS

Work started three and a half years ago looking at how organs are allocated within the UK. We are probably one of the last countries in the world to have a centre based allocation scheme.

Death on the transplant waiting list is still uncomfortably high and there is a need to come up with a system to reduce the rate.

Work is ongoing looking at the different types of patient that need to be included in an allocation system. Patients with chronic liver disease whose disease progression accounts for about 70% are being called the 'backbone' group. Alex Gimson has been leading this. A model based on patient need and a model based on patient benefit for an organ will be trialled using figures from 2013. Further stages of work will look at priority listing, disadvantaged patients, hepatocellular carcinoma and acute liver failure. It is hoped that the work will be completed by the Autumn for some decisions to be made for a robust model to deliver an agreed outcome with all resources signed up.

A liver fixed term working unit (FTWU) is currently looking in depth at

the data and models.

ACTION

The work will be presented to the British Liver Transplant Group which is affiliated to the British Association for the study of the liver (BASL) which will look at auditing in terms of delivering the data and be reflective in looking at drug use before transplant and measuring the quality of life.

J O'Grady informed members of transplant centres undertaking a national internal audit day at BLTG which would be signed off and approved by the Liver Advisory Group and fulfil the audit requirements of all other stakeholders. Following discussion it was agreed that a nominated patient spokesperson could attend as part of the audit team.

4 SERVICE INNOVATION AND RESEARCH DEVELOPMENT

The UK has historically been at the forefront of innovation in liver transplantation. However the capacity to innovate is now falling behind and there is a desire to reinvigorate this aspect of liver transplant services.

The latest challenge is to look at highly selective transplants in young adults with alcoholic hepatocellular carcinoma. Getting patient involvement in looking at new areas before going ahead has been well received. An agreed capacity needs to be built into the allocation system to enable this.

It was commented that patient groups were not given enough notice to respond to a press release on the alcoholic hepatitis protocol. J Neuberger will take this back to the NHSBT press office though he commented that it was quite possible their internal press office did not release the date themselves. **J Neuberger**

5 LIVING RELATED LIVER DONATION STRATEGY

To-date only a few adult-to-adult living liver transplants have taken place in the UK. We need to understand why demand for this has been so low in order to develop the service.

The liver FTWU has been looking at this with a number of consultants along with patient feedback. The question on the lack of demand for adult-to-adult living liver transplantation will be raised at the British Liver Transplant Meeting on 18 September. Lisa Burnapp leads on the work for adult-to-adult living kidney transplants so replicating the work for livers should not pose too much of a problem.

The majority of patients on the waiting list are suitable for living liver transplants and it is a potential way of reducing deaths on the list.

Feedback on the possible reasons for the lack of demand were:

- the risk for adult-to-adult kidney transplants is lower than that for livers.

- the media emphasising more on liver deaths than for kidneys has not helped the situation.

ACTION

The British Liver Trust suggested handing out a booklet/leaflet at the time of patient listing on what is involved and how the process of adult-to-adult living transplantation works would be beneficial.

J O'Grady will draw up some questions for patients to discuss within their own organisations. **J O'Grady**

6 ANTIVIRAL THERAPY FOR HEPATITIS C

NHS England have made available £20m for rapid access to anti-viral therapy for hepatitis C patients who need treatment in a short timeframe, before NICE can make a decision. This funding will treat 500 patients. Patients on the waiting list with liver failure should get access to these drugs but patients with hepatocellular carcinoma in the absence of liver failure may have to wait. Information on patient outcome post transplant is limited.

A couple of issues to take into account are:

- what happens when a patient improves whilst being treated on the waiting list and there is uncertainty if a transplant is now required, or if a patient is listed for transplant, comes off the transplant list following an early improvement from treatment, but still requires a transplant later down the line will then be disadvantaged.
- if the timing of the transplant becomes a priority after anti-viral therapy should patients get priority?

J O'Grady believes that the anti-viral therapy should be used as treatment after transplantation.

7 AOB

J Neuberger informed attendees of a discussion with a licensed private London hospital for a possible new liver transplant programme for group two patients – non UK and EU entitled patients. It was acknowledged that this must be tightly audited and monitored in order to avoid the service being discredited by the Press. There was general acceptance of J O'Grady's belief that all donated organs should be used. Not having a suitable entitled recipient should not mean that a liver should be wasted. In addition, using this type of organ in the past has led to innovation which should be encouraged.

It was emphasised that those involved in the operation should understand very clearly that their prime duty is and always must be to an NHS patient and not to private practice. The ethical and moral complications are very complex.

Should the private treatment for group two liver patients be made legal NHSBT will comply. The Liver Advisory Group will set up a group to provide oversight of the proposal for private treatment. **J O'Grady**

8 DATE OF NEXT MEETING: To be advised.