

## Yorkshire and the Humber Kidney Transplant Forum

Wednesday 11 November 2015

0900-1215

Waterton Park Hotel, Walton Hall, Walton, Wakefield, West Yorkshire, WF2 6PW

### NOTES

AGENDA ITEMS		Action Owner
1.	<p><b>Welcome, Introductions, Overview &amp; Discussion</b>            Dr John Stoves, Y&amp;H Renal SCN Clinical Lead &amp; Consultant Nephrologist, BTHFT</p> <p>Dr Stoves welcomed everyone to the forum and gave an especial welcome to Dr Yadav, Paediatric Nephrologist, who has joined the forum for the first time.</p> <p>Dr Stoves advised that the meeting will focus on three areas: reviewing work undertaken so far, debating pre-emptive listing and discussing access to deceased donor transplantation in Yorkshire and the Humber.</p> <p>Dr Stoves advised of the structure of the Strategic Clinical Networks and the key renal network priorities, and gave an overview of the issues that have been discussed in previous meetings. Please see the slide pack for more information.</p>	
2.	<p><b>Review of Previous Meeting and Actions including:</b></p> <ul style="list-style-type: none"> <li>• <b>Transplant Currencies</b></li> </ul> <p>Dr Stoves advised the forum that work is ongoing to develop a tariff for all elements of transplant care including the work-up pathways for potential living donors and potential transplant recipients. Both transplanting and non-transplanting centres have been asked to contribute to the second phase of a national project. A meeting has been scheduled for January 2016. Dr Stoves advised that Bradford had previously submitted data and enquired if other non-transplanting centres could represent the region. Dr McCullough advised that York would be able to contribute data and would attend the January Meeting.</p> <p><b>ACTION: Dr McCullough to contribute data for York to the currencies audit.</b></p> <p><b>ACTION: Dr McKane to share details of the January Meeting.</b></p> <p>Dr Stoves enquired if both Leeds and Sheffield were contributing to the audit as transplanting centres, and this was confirmed.</p>	<p>Keith McCullough</p> <p>Will McKane</p>

The group then discussed some aspects of the proposed transplant tariffs, with Dr McKane clarifying that low clearance clinics can be combined with transplant work-up activities (some centres have stand-alone transplant assessment clinics, and it is still unclear whether there will be payment by clinic attendance or payment by pathway completion.

- **Progress with BK Screening**

Dr Stoves advised the forum that following Dr Edey's presentation on BK screening Bradford have adopted the same screening schedule. Dr Stoves advised that some cases are being picked up and this has allowed early intervention that will hopefully reduce the incidence of BK transplant nephropathy.

Dr Edey advised that Hull have not lost any grafts in the patients for whom BK was picked up in the last 12 months. Dr Edey stated that if immunosuppression is reduced the viremia will go away and they have not had to use leflunomide.

Dr Baker reported that Leeds are not currently undertaking BK screening due to infrastructure issues but are very keen to do it, as a couple of patients have developed BK that could have been avoided with screening. Dr Baker stated his aim to start before the next meeting. It was also noted that it would be helpful to add this to the BHLY system (work in progress)

Dr Edey stated that the best time to capture BK in patients is at the three month screening. Dr McKane enquired if Dr Edey had a written protocol for screening. Dr Edey replied yes and agreed to share the protocol.

***ACTION: Dr Edey to circulate the BK screening protocol to all.***

**Matthew Edey**

Dr McCullough stated that York have not yet undertaken screening due to staffing issues. However, a transplant nurse is now in post and so will investigate the possibility of putting screening in place.

Dr McKane advised that in Sheffield the virology team feel there is not yet enough evidence to support putting a screening service in place and there are issues with the IT infrastructure in the Trust.

Dr Edey advised the group that there have been no cost challenges to implementing the screening and only one false positive result has been identified. Dr Stoves enquired of the forum if they felt a communication should be issued to laboratories advising that there may be an upswing in referrals if all centres start screening, and would there be an advantage in sending samples to a single regional centre. The forum discussed varying laboratory costs and the laboratory in

Warwick was identified as charging more than the laboratory in Leeds. It was agreed that the Trusts in the region who use the Warwick laboratory should make enquiries to the Leeds laboratory. Dr Baker agreed to share the contact details for the laboratory in Leeds.

***ACTION: Dr Baker to email the forum regarding laboratory contacts in Leeds.***

- **Patient Satisfaction Surveys Regional Review and Patient Satisfaction in Leeds (Richard Baker)**

Dr Stoves gave an overview of the patient surveys used in Bradford and advised that these were circulated at the last forum meeting. Dr Stoves asked the forum for opinions on patient satisfaction. Dr Edey stated that a survey was undertaken in Hull approximately two years ago and had positive results and noted that another survey should be undertaken in the near future. Dr Baker stated that Leeds have undertaken a living donor and recipients survey. Dr Stoves suggested that each Trust shares their patient satisfaction surveys to facilitate the sharing of best practice across the region.

***ACTION: Sarah Boul to contact each Trust to get copies of surveys and will then circulate to share best practice.***

- **BAME Organ Donation Event: Bradford**

Dr Stoves invited Mr Ali and Mr Rafique to provide an update on their work in the BAME communities of Bradford. Mr Ali provided feedback from an event held in June 2015 stating that it had been his intention that the event would engage people from different communities but this proved difficult. However, the event did provide the opportunity for patient networking where people could share their fears/expectations etc. Dr Stoves also provided an overview of the meeting and stated the importance of medics and patients working together to raise the profile BAME organ donation, make the campaign sustainable and increase donation rates. He and Mr Rafique had taken part in a live TV broadcast in October, and further media work is planned. Dr Stoves thanked Mr Ali for his hard work and dedication.

Mr Ali advised that he is still trying to campaign to raise awareness and enquired of the group if they could provide contacts on which he could call for short notice interviews with the press and local radio stations. Mr Ali stated that the press are interested in organ donation and it is essential that the messages get out into the community and places of worship. Dr Baker advised Mr Ali that NHS Blood and Transplant will be holding an event in 2016 and he would be keen for Mr Ali and Mr Rafique to attend to help raise the profile of BAME organ donation.

***ACTION: Dr Baker to provide Mr Ali with further information***

**Richard Baker**

**Sarah Boul**

**Richard**



	<p>emptive transplantation is increased. Please see the presentation slides for more information.</p> <p>Following the presentation the forum discussed the need to harmonise pathways across the region. The forum also discussed suspension rates and reasons why patients are suspended. The forum advocated the early suspension of potential living donor recipients from the cadaveric transplant waiting list. The forum also discussed how best to share information about marginal kidneys with potential transplant recipients. The forum stated that the average quality of deceased versus living donor kidneys is widening.</p>	
<p>4.</p>	<p><b>Access to Deceased Donor Transplantation in Yorkshire and the Humber</b>  Dr Will McKane, Consultant Nephrologist, STHFT</p> <p>Dr McKane presented to the group on access to deceased donor transplantation in Yorkshire and the Humber based on data available from the UK Renal Registry and NHS Blood and Transplant. Dr McKane also provided an overview of the fast track scheme. Please see the presentation slides for more information.</p> <p><b>Questions/Comments:</b>  Question: Does the offer decline rate include surgical opinion and tissue type mismatches?  Answer: I believe so yes.</p> <p>Comment: The single biggest inequity in Yorkshire and the Humber is actually getting a transplant.  Comment: I agree and feel further discussions with surgeons, particularly in Sheffield are required. In Leeds there is a desire to open up the fast track scheme nationally and patients should be able to choose their listing centre.  Comment: We should consider developing a regional fast track system.</p> <p>Question: How do you decide on dual or single transplant?  Answer: In Leeds we will do a dual transplant from an older donor. Nationally they would get separated but centres can take dual. For kidneys over the age of 70 a dual is often necessary.</p> <p>Question: Will changing the fast track scheme bring equity?  Answer: London have rejected the scheme, as it is perceived to be inequitable.</p> <p>Question: Should we as a region reject the scheme as well?  Answer: Patients and Commissioners should be putting pressure on KAG regarding the inequity of the scheme.</p>	

	<p>Comment: Discussions between Leeds and Sheffield should be opened with regards to the fast track scheme. Kidneys kept in Leeds could be offered to Sheffield patients as well as Leeds patients.</p> <p>Question: Can medics make the policy changes or does it need to be other powers?  Answer: Policy change is difficult to influence and there is lots of work to do on this area.</p> <p>Question: Is there national disparity i.e. does Scotland work differently to England and Wales?  Answer: UK regions can work differently and the implementation of policies can be delayed but patients are not disadvantaged.</p> <p>The group discussed the fast track scheme and inequity to access in depth and concluded that as a region it would be beneficial to lobby the KAG and RTSM on this topic by campaigning for a faster pace of change with an end goal of both kidneys being shared with all 5 regions. If this approach is unsuccessful then discussions between Leeds and Sheffield will be pursued with regards to opening the Leeds fast track list to Sheffield patients to ensure DCDs are shared.</p> <p><b><i>ACTION: All to lobby KAG and RTSM for a more rapid pace of change with an end goal of sharing both kidneys with all 5 regions.</i></b></p>	All
6.	<p><b>Next Steps and Closing Remarks</b>  Dr John Stoves, Y&amp;H Renal SCN Clinical Lead &amp; Consultant Nephrologist, BTHFT</p> <p>Dr Stoves summarised the discussion held by the forum and thanked all the attendees.</p>	
7.	<p><b>Any Other Business</b></p> <p><b>BHLY Screens:</b> It was raised that the Live Donor Form needs to go on the BHLY system. Dr Stoves stated that a meeting would be held in February 2016 to review the BHLY system and ensure necessary forms are available.</p> <p><b>Metrics:</b> Dr Stoves advised the group that pre-emptive listing data is being collected. The group agreed to have an open and transparent approach with no anonymization of data. It was agreed that the Transplant Lead in each Trust would review the data thus far.</p> <p><b>ACTION: Sarah Boul to send the data collected so far to the transplant leads for review.</b></p>	Sarah Boul

	<p><b>Next Meeting:</b> The group discussed content for the next meeting and felt that the meeting needed to have a patient focus with case studies presented. It was also agreed that paediatrics would deliver a presentation to the forum.</p>	
8.	<p><b>Date of the Next Meeting</b> The group agreed that it would be useful to hold another meeting in 6 months' time. Wednesday afternoon was stated as a preferred meeting time and it was suggested that the forum meets in Bradford.</p> <p>An exact date and venue will be confirmed in due course.</p>	

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