NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE

THE TWENTY-FIRST TELECONFERENCE OF THE NHSBT KAG PAEDIATRIC SUB-GROUP ON WEDNESDAY 17th OCTOBER 2018 12-15:00

PRESENT:

Dr Jan Dudley (Chair), Consultant Paediatric Nephrologist, Bristol
Miss Chloe Brown, Statistics and Clinical Studies, NHSBT
Dr Martin Christian, Consultant Paediatric Nephrologist, Nottingham
Dr Mairead Convery, Consultant Paediatric Nephrologist, Belfast
Miss Anusha Edwards, Consultant Transplant Surgeon, Bristol
Dr Helen Jones, Consultant Paediatric Nephrologist, Evelina London
Mr Nicos Kessaris, Consultant Transplant Surgeon, GOSH/Guy's/Evelina London Children's Hospitals
Dr Jon Jim Kim, Consultant Paediatric Nephrologist, Nottingham
Mrs Julia Mackisack, Lay Member
Dr Stephen Marks, Consultant Paediatric Nephrologist, GOSH
Mr Omar Masood, Consultant Transplant Surgeon, Leeds
Dr David Milford, Consultant Paediatric Nephrologist, Birmingham
Dr Henry Morgan, Consultant Paediatric Nephrologist, Liverpool
Ms Lisa Mumford, Statistics and Clinical Studies, NHSBT
Dr Pallavi Yadav, Consultant Paediatric Nephrologist, Leeds
Mr Khalid Sharif, Consultant Transplant Surgeon, Birmingham
Dr Graham Smith, Consultant Paediatric Nephrologist, Cardiff
Dr Yincent Tse, Consultant Paediatric Nephrologist, Newcastle

IN ATTENDANCE:

Miss Sam Tomkings, Clinical and Support Services

APOLOGIES:

Prof Susan Fuggle, NHSBT Scientific Advisor
Dr Rodney Gilbert, Consultant Paediatric Nephrologist, Southampton
Dr Tracey Rees, BSHI Representative
Dr Ben Reynolds, Consultant Paediatric Nephrologist, Glasgow
Mr Vlad Shumeyko, Consultant Transplant Surgeon, Glasgow
Mr Mick Stokes, Head of Hub Operations, ODT
Prof. David Talbot, Consultant Transplant Surgeon, Newcastle
Dr Afshin Tavakoli, Consultant Paediatric Nephrologist, Manchester

Action

1 Declarations of interest in relation to the agenda- KAGPSG(18)9

There were no new declarations of interest.

2 Minutes of the meeting held on the 25 April 2018 – KAGPSG(M)(18)1

2.1 **Accuracy**

The minutes of the previous meeting were agreed as a correct record.

To be ratified

Action

2.2 **Action points - KAGPSG(AP)(18)1**

Action points with a verbal update are listed below.

AP1 ABOi and HLAi transplant data – S Marks confirmed all centres have received the ABOi and HLAi proforma and a request was made to for units to feedback their data by November. **All Units**

AP 1 DCD kidneys in 2nd transplant recipients – It was highlighted at the last meeting that not enough data was available in paediatric DCD kidney outcomes in 2nd transplant recipients, therefore C Brown made the suggestion to consider looking at all paediatric DCD kidney transplants and complete an unadjusted analysis to find out if the outcome differs from the DBD paediatric transplants. J Dudley also suggested that the views of KAG should be sought with regard to the specific issue of DCD outcomes in adults receiving 2nd kidney transplants. She noted that the findings of such analyses in adults may be relevant to children and young people. Members supported the requirement for both analyses. **C Brown** **J Dudley**

O Masood requested using the data from younger DCD kidneys which are considered for paediatric transplantation and could be comparable. **C Brown**

AP 3 Centre specific organ decline rate – The suggestion was made at the last meeting to revise the form and consider whether this could be an ongoing prospective audit which NHSBT could continue supporting as this paper provides information which helps understand the reason for declines and capture the recommendations for accepting organs. L Mumford highlighted that, since part of the ongoing IT development within the Hub Operations, is to more appropriately capture the reasons for decline, there may be a duplication of work should this audit continue. S Marks felt this paper is very worthwhile to help identify and address centres who have experienced logistical issues. Members supported this, therefore it was agreed to continue with the audit for 2019 and review the requirement for this once the IT support is in place. J Dudley requested a proforma for data collection should be agreed and will be circulated. **C Brown** **C Brown / J Dudley**

AP 4 2017 kidney offer decline rate audit – Identified in the last paper was an offer that was accepted at a centre where there was subsequently no surgeon available to complete the transplant. This was raised at KAG. L Mumford advised Chris Callaghan will review and write to centres where an offer was declined which met the standard criteria to identify why the kidney was declined.

S Marks liaised with John Forsythe to gain approval for the contraindications paper to be uploaded to the ODT website, however it was felt that there is a large amount of data available regarding contraindications, therefore a separate document is not required. Members discussed how to facilitate access to obtain this information as it was agreed the SaBTO website is not easy to navigate. A Edwards is part of the consent strategy group which are considering ways to gather lots of information across all organs and age groups and agree where this should be held. In addition, NHSBT are working with the Winton Centre who developed an electronic algorithm for cancer patients and the aim is to achieve a similar tool for transplantation.

A Edwards will forward the modified form used within the Bristol centre for adult patients to assist with categorising the medical reasons to C Brown and J Dudley. **A Edwards**

AP 5 RaDar database link to NHSBT – S Marks raised this at KAG. Chris Watson advised this is something which could be developed in the future.

To be ratified

Action

2.3 **Matters arising, not separately identified**

2.3.1 NHSBT Kidney Allocation Design

Chris Watson requested L Mumford produce additional simulations for consideration as concerns were raised by patient groups at both the NHSBT Kidney Patient Support Group meeting in July 2018 and at UK Kidney Week in June 2018 about the length of time older patients were having to wait for a kidney transplant in return for the poorest quality donor kidneys. Simulation 36 is the proposal that is acceptable across all the groups.

Paediatrics will continue to wait the shortest time to transplant, however there will be an increase of around 47 days which is slightly longer than that of the current 2006 scheme.

It was acknowledged Birmingham has a longer waiting time and therefore concerns were raised that the new scheme would increase this. L Mumford confirmed the longer waiting time is partially due to higher registrations of ethnic minority patients at Birmingham and highlighted as part of the new matching scheme, the waiting times for this centre may improve.

L Mumford advised this proposal will be presented at KAG in November.

L Mumford asked members if they feel this is an acceptable proposal. There were no objections received from members regarding the proposed scheme. J Dudley requested representatives from KAG PSG present this to their colleagues and feedback comments by 7th November, at which point, in the absence of any objections, a formal positive response will be sent to L Mumford and C Watson. **All Representatives**

3 2017 Kidney offer decline rate audit

Refer to action point – AP4.

4 ABOi and HLAi transplant data – KAGPSG(18)10

An update of the paper presented at the last teleconference was received.

Of the 25 ABOi transplants, follow up information on patient and graft survival has been reported on 23, of which none are reported to have failed and the majority of incompatible transplants did have immediate graft function following transplantation.

The main immunosuppression patients received at 3 months post transplant was steroid, mycophenolate and tacrolimus.

Members agreed these data are valuable and may highlight the importance of ABOi and HLAi incompatible transplants.

5 Access to transplant and transplant outcome measure in children (ATTOMic)

From the data received from the 12 centres, a well-received presentation was given at the European Society of Nephrology. Funds have been granted from the European Society for Paediatric Nephrology to look at the data across the UK and whether this is similar to other European centres and the factors which differ from one centre to another, although this information is difficult to obtain.

To be ratified

Action

A grant has been submitted to extend the work with Kidney Care UK.

6 Harmonisation of transplant immunosuppression

M Christian updated the group on the current work and discussions held to highlight the variety of different immunosuppression used across centres in the UK.

NICE technology appraisal recommended Basiliximab, tacrolimus and MMF as routine therapy. No recommendations were made for steroids or azathioprine

The proposal is to agree on 2standardised immunosuppression regimes to help produce more meaningful outcome data, therefore the suggestion was made for a task and finish group to take this forward and meet on 29/11/18, before the Challenges in Paediatric Transplantation meeting on 30/11/18. The meeting will include a representative from each paediatric renal centre, a paediatric surgeon, paediatric transplant nurse, a paediatric pharmacist and trainee and a patient/parent representative. M Christian has circulated an expression of interest to all centres and a number of responses have been received. The aim of this group is to decide on an appropriate timetable and roadmap and an agreed proposal will be made. M Christian encouraged all centres to take part. S Marks and J Dudley will also discuss this at the BAPN KQuIP meeting on 9/11/18.

J Dudley requested that all centre representatives to send their transplant protocols to J Dudley and S Tomkings as soon as possible. **All Centre Representatives**

7 RaDaR database link to NHSBT
Refer to action point – AP 5.

8 Proposal for a National Consent Form – KAGPSG(18)11a & KAGPSG(18)11b
A Edwards attended a Communication of Risk and Consent workshop aimed at the adult community. The object of the workshop is to improve the way consent is received. Members of the workshop agreed information available in an electronic format within 3 layers, providing basic, slightly more detail and over and above information is an appropriate way to deliver the information to patients. In addition, it was agreed that unit specific data should be provided. The intent is for this to be utilised nationally.

A Edwards confirmed that the changes suggested at the April KAG PSG meeting to the paediatric national consent form have been completed and the document was recirculated for final comments. KAG PSG members have now formally signed this off.

J Dudley has liaised with David Hughes the president of the BAPN regarding the use of their logo. David indicated that the BAPN could approve the final documents but wished to liaise with the Renal Association with regard to the use of the BAPN logo. J Dudley will forward the final version of the form to John Forsythe and Chris Watson and ask for further consideration for use of the NHSBT logo. **J Dudley**

Members agreed to begin using the form January 2019.

To be ratified

Action

A suggestion was made for this form to be piloted again, however members felt an email from NHSBT/Chair of KAG PSG confirming this is a nationally approved form would be sufficient. **J Dudley**

9 Outcomes for small infants compared to older children

A paper was received at the last meeting from a study looking at the data regarding outcomes in small infants compared to older children.

The suggestion is to use a combination of the recipient's weight at the time of transplant, however if that data is missing, the recipient weight at the time of registration could be used and on comparing the two, the median difference in weight was 1.6kg. This analysis can take place and be brought to the April KAG PSG meeting. No objections were received. **C Brown**

10 Living Donor Kidney Transplantation 2020 Strategy

S Marks updated members on the ongoing work of the group to consider ways of improving outcomes in both donors and recipients. S Marks ran through the different workstreams which are commissioning, donor safety and tariff and the final group is looking at recipients at higher immune risk considering access and availability.

The next meeting will be taking place on 14th November 2018.

The question was raised if discussion took place concerning donor safety and enrolling donors on the UK Renal Registry. S Marks advised a discussion was held regarding the best way to collect ongoing donor data, however it was felt a large amount of resource would be involved using the Renal Registry. It was noted, some centres have over 90% follow up data. L Mumford added that the Renal Registry may not have consent to collect information on living donors that are CKD stage 3 and above.

11 Academic pursuits (update on abstracts and publications)

S Marks updated the group on the current abstracts and publications.

The long term outcome paper which was a 25 year review has been finalised and submitted for publication with transplant international.

The first draft of the initial manuscript of ATTOMIC is available. Clarification is required to confirm whose name should be added to the form for each centre. Any member from this meeting who would like their name added to the form to contact S Marks. **All Members**

The PTLD project will be handed over to another medical student as the previous student has become a junior Doctor. The information already available has been published. S Marks confirmed this will include one representative from each unit.

JJ Kim advised that some data has been published for DSA outcomes. The next step will be to complete this nationally. JJ Kim noted that new methods of HLA matching could provide more detail about risks and, if completed though NHSBT KAG PSG, maybe useful for HLAi and ABOi incompatible transplants. L Mumford advised that in the past requests have been made to analyse HLA in different ways. She has forwarded JJ Kim's request to John Forsythe for guidance. L Mumford will contact JJ Kim once a response has been received.

To be ratified

Action

JJ Kim will put together a proforma for tabling at the March KAG PSG meeting. **JJ Kim**

12 For Information Only:

12.1 Centre-specific transplant list and transplant activity – KAGPSG(18)12

Noted for information. S Marks requested all centres review this and let them know if any information is available. **All Members**

13 Any Other Business

The Surgical Challenges Meeting is taking place on 30th November.
Anyone is interesting in attending the Harmonisation Meeting should contact Y Tse.

A finalised protocol for an antibody rejection and how this should be treated study will be available by the end of the week. Ethical approval will be sought for children as well as adults. S Marks will circulate the information to all centres. **S Marks**

H Jones asked if there will be plans to translate the national consent form, however the majority of units use a translator. D Milford suggested that there may be benefit in circulating a brief questionnaire to ethnic minority families asking if it would be beneficial to translate the national consent form in writing. A Edwards will draft a questionnaire. **A Edwards**

14 Date of next meeting:

Face to face: Wednesday 20th March 2019, 11am MSE Meeting Rooms, London

Organ Donation & Transplantation Directorate **October 2018**

To be ratified