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MINUTES FROM THE BAPN EXECUTIVE MEETING

HELD ON FRIDAY 9TH JUNE 2006

VENUE: NEPHROLOGY SEMINAR ROOM,
BIRMINGHAM CHILDREN'S HOSPITAL

1. **Members Present:**
- Mark Taylor – President
 - Heather Maxwell – Secretary
 - Nick Webb
 - Rodney Gilbert
 - Rokshana Shroff (for Simon Waller)
 - Sally Hulton

Apologies were received from:

- Chris Reid
- Sally Feather
- Simon Waller
- Moin Saleem
- Nadeem Moghal

2. **Minutes of the Previous Meeting**

Minutes of the previous meeting were accepted as a true record.

3. **Matters arising from the Previous Minutes**

- a) The 2007 Spring Meeting of the RCPCH will take place on the 26-29 March 2007 which unfortunately falls just after the International Paediatric Transplant Association meeting in Mexico (17-21 March 2007) and at the same time as the British Transplantation Society meeting in Manchester (28-30 March 2007). British paediatric nephrology attendance has been encouraged at both the IPTA and BTS meetings though it is unfortunate that they fall so close to the RCPCH meeting. We will try and obtain the date for the RCPCH Spring meeting in 2008 and 2009.

Action: CMT

There was discussion about renal meetings which are of interest to paediatric nephrologists and the difficulty in attending all of these. The next Renal Association meeting will be held in Brighton between 21-23 May 2007 and Mark Taylor asked for

suggestions for speakers for a paediatric session at this meeting. Suggested names were William Van't Hoff to speak on cystinosis, Phillip Lee on mitochondrial diseases and foetal programming with a speaker from Southampton. The committee members were asked to suggest names to Mark Taylor within the next week.

Action: ALL

Trainees have been encouraged to go to the Renal Association and the paediatric session at the Renal Association will be named one of the mandatory training days for trainees. In principle it is proposed to have training days close to other meetings to encourage attendance at these meetings.

b) Committee representation – Joint Speciality Committee

Professor Savage has previously represented the BAPN on the Joint Speciality Committee for Renal Medicine. This committee takes an overarching look at all activities affecting renal medicine. Mark Taylor will discuss with Maurice Savage as to who would best represent the BAPN on this committee.

Action: CMT

c) NSF for Renal Services. Individual paediatric nephrologists have been involved in the NSF. The BAPN as a group has not. Discussion took place as to the need to provide an analysis of the NSF or whether to work with the programme of Criteria for Success and develop these criteria for paediatric nephrology. A paediatric nephrology document has been developed by the NSF team and is due to be launched on Thursday 15th June 2006. It was felt important to make sure that all relevant aspects of the renal and children's NSF were brought together to be used with Criteria for Success.

d) A Review of Specialist Services. We are unaware of any progress with this review and Mark Taylor will check on this.

Action: CMT

e) Adolescent Services. This is an important area for both paediatric and adult nephrology services and it is hoped to have one of the Renal Association autumn one day meetings on this topic. It was felt that the 2007/2008 meeting might be appropriate.

Action: CMT

f) Changing face of renal medicine in the UK. A report from this committee is due out later this year.

g) Renal Association Council. At the last Executive meeting Rodney Gilbert was asked to collect information sheets from the UK paediatric nephrology units. New information sheets have been obtained.

h) Renal Association Clinical Practice guidelines. The haemodialysis module is available. Discussion took place as to the format of the associated paediatric document. It was felt that this should be a separate document and did not require continuous referral to the adult document. Sally Feather will be asked to provide an outline of the paediatric document for circulation and this will be discussed at the next telephone conference.

Action: SF

4. **New Executive Posts**

- a) Communications Officer. A new post of Communications Officer is being proposed. The duties of this post would be to maintain an up-to-date and active website. It was felt that it was not necessary for the officer to have IT experience but that they should be dynamic and enthusiastic. It may be appropriate to pay a professional website designer to get the website up and running.
- b) Chair of Clinical Standards Committee. This was seen as an important post on the Executive which would require a dynamic person to keep abreast of all of the work that was being done in other areas within the renal community.

Nominations for these posts will be sought from the membership and a deadline set for the not too distant future.

Action: ALL

5. **Reports**

- a) Treasurers Report. The BAPN is in a relatively healthy financial position at the present time. However, not all members are paying the up-to-date subscription fee and the membership list has been updated and persons not paying will be chased up. A list of Honorary members (who are mostly retired paediatric nephrologists) will also be compiled.

Discussion took place as to the pros and cons of becoming a company limited by guarantee. This would give the BAPN some security and identity but would reduce any liability. It would become easier to enter into contracts were the BAPN a company limited by guarantee. Discussion took place as to the benefits of this as opposed to becoming a subsidiary of the Renal Association. Both of these alternatives were seen as more appropriate than becoming a registered charity. The Renal Association have offered assistance in helping with the paperwork should the BAPN wish to become a company limited by guarantee.

- b) Registry Committee. Chris Reid supplied a written report. Considerable discussion took place as to the way forward for the BAPN registry. There would seem to be several issues at the present time but it would be prudent to have a telephone conference within the next 2 weeks to discuss software issues and blocks to units downloading electronically, to the existing data sets and to the analysis of existing data.
- c) Research Report. Nick Webb discussed the NIHR monies that are available for research. Further areas have been highlighted including mental health, diabetes, stroke, dementia and medicines for children. £15 million is available for each of these areas and applications are being sought at the present time. Bids for up to £2 million over 5 years can be placed. However, each has to go through a lead Trust and there must be a hospital manager on the application. Outline bids have to be in by Friday 16th June 2006. The BAPN are submitting a bid as part of a portfolio which covers past performance, an outline of the service and work to be done over the next years. The chances of the bid being successful are small but it was felt important to apply.

Trusts will no longer receive a R&D label which is to be replaced with this system. Research must be such that it will "reach" within the next 3-5 years.

The BAPN bid will include the nephrotic syndrome trial, study looking at graft failure in adolescent transplant recipients and a reflux study that is under development in Bristol.

- d) Nephrotic Syndrome (Primary Therapy Trial). This trial has been set up and is due to start recruiting patients shortly.
- e) C2 Studies. Data from these studies has been analysed and a paper has been circulated. Comments are awaited from the BAPN members involved in this study.
- f) Lipid Audit. A report has been circulated regarding the Lipid Audit and comments are awaited.
- g) Myfortic Study. Novartis have offered to support an Investigator initiated (but not company sponsored) study looking at the use of Myfortic in maintenance of renal transplant patients with CNI toxicity. David Milford is hoping to organise a meeting July of interested parties.
- h) Astellas Study 02-035. Follow-up data from this study are being collected with a view to publication.
- i) EBV Vaccine. There are stability issues with the higher dose vaccine and there has been no further progress with this trial.
- j) The Lupus Group. Michael Beresford, Paediatric Rheumatologist in Liverpool, has asked some BAPN members for support to be involved in this study. We are uncertain as to whether this is the whole of the BAPN, but Nick Webb will write to Michael Beresford and offer the support of the BAPN as a whole.

Action: NW

6. **External Committee Updates**

- a) Renal Association – discussed above.
- b) Renal Association Standards Committee – discussed above.
- c) BRS. There have been no meetings of the BRS since the last BAPN Business meeting. The BRS are involved in Criteria for Success and have developed a patient haemodialysis survey which can be adapted for paediatric patients should we wish. The BRS, through the Multidisciplinary make-up, are seen as an important group for the BAPN to work with.
- d) Kidney Alliance. There have been no new developments since the last BAPN meeting.
- e) NICE. The HTA for immunosuppressive therapy in children and adolescents with renal transplants has been published. No appeals were made against this. The anaemia in renal failure guideline is way under way and members have been consulted about this by Jonathan Evans who is on the guideline group. The UTI in Childhood guideline is still work in progress.
- f) KPAG. Chris Rudge has written to Heather Maxwell regarding the issuing of non-compliance reports for placing non-favourably matched kidneys in easy to match paediatric recipients. In most instances there is a good reason why this “non-compliance” has occurred. In future Chris Rudge has asked that there is no automatic letter sent out when this happens, but if there are instances that cause concern, then he will discuss these with the BAPN Rep on KPAG.

Heather Maxwell discussed with Chris Rudge that the BAPN were keen to prevent sensitisation in paediatric renal recipients, and to this end, it would be appropriate to

look at intelligent mismatching for paediatric recipients. Heather Maxwell will write to Sue Fuggle at UKT in this regard.

Action: HM

The issue on non-heart beating donation for paediatric recipients was also raised at KPAG. At present paediatric recipients are not routinely listed for non-heart beating donors.

Heather Maxwell has presented UKT data on adolescent graft outcome at several meetings. She is keen to obtain further information on graft loss in this age group and will work with UKT initially to obtain this data, but it is likely that units will need to be approached for more detailed data.

g) **ESPN Reports**

No further update

h) ERA. The ERA have agreed to appoint a database manager to be based at the Registry, but funding is still an issue. Jane Tizzard, who represents the BAPN on this committee, has asked that the BAPN can confirm that they will pay €1000 per year to support this initiative.

i) IPTA Dick Trompeter sits on the IPTA Council and also chairs the education committee and will be responsible for the postgraduate training programme to be held at the next IPTA meeting in Cancun in Mexico in 2007. In addition he has been proposed as Secretary/Treasurer to take over from Richard Fine after the next meeting. This position will be confirmed at the Cancun meeting. Dr Trompeter is hoping to encourage European membership of the IPTA.

7. **Information Strategy**

This was not discussed in Kate Verrier-Jones absence.

8. **National Guidelines and Protocols**

When considering clinical standards the term "Guidelines" does not have any medical/legal risk whereas a "Protocol" should be reserved for research and normal research governance applies. It is hoped that the new Clinical Standards sub-committee of the BAPN will assist in the development of diagnostic and therapeutic guidelines which will appear on the BAPN website.

9. **PbR**

A written report was provided by Nadeem Moghal and this was discussed in brief by the Executive Committee.

10. **Forthcoming Meetings**

A calendar of BAPN meetings is attached. The ESPN 2009 meeting, to be held in Birmingham, will take place between 2nd – 5th September. This will be a joint meeting between the BAPN and the Renal Association.

3a	Obtain dates of RCPCH Spring meetings for 2008/2009	CMT
3a	Names of speakers for Renal Association meeting	ALL
3b	BAPN representation on Joint Speciality Committee, RCP	CMT
3d	Progress of specialist services	CMT
3e	Prepare renal adolescent day	CMT
3h	Circulate paediatric renal haemodialysis clinical practice guideline module for discussion	SF
4b	Nominations for new executive posts	ALL
5j	Nick Webb to write to Michael Deresford re: support for lupus group study	NW
6f	Write to Sue Fuggle re intelligent mismatching in paediatric renal transplant recipients.	HM
6h	Rodney Gilbert to write to Jane Tizard re ERA Data Manager	RG