



Dear Member,

Welcome to September's BAPN eNews. Please read on for details on courses, opportunities, bursaries and more.

We hope you enjoy this month's read.
Best wishes,

Mary McGraw
BAPN President

Sally Feather
BAPN Secretary

Nephrology Networks document

We are pleased to announce that the document on Paediatric Nephrology Networks has now been published. Click here to see the press release www.rcpch.ac.uk/news/paediatric-nephrology-update

The document is available on the RCPCH www.rcpch.ac.uk/networks, and NHS kidney Care, Renal Association and BAPN websites

Those wishing to obtain a hard copy may contact health.policy@rcpch.ac.uk

We urge all members to read this important document and share it with their lead/link paediatricians in all the local hospitals with which they have contact. This piece of work has been very positively received by commissioners and the time is right for you to use it to lobby for the best possible services in your locality

Announcement of Kids Kidney Research grant application round

Kids Kidney Research has announced the opening of their research grant application round for September 2012.

KKR funds start up research grants for up to GBP 100,000 ideally for a one year period. However they will also accept applications for projects up to 2 years in length by prior agreement. The deadline for applications is 31 December 2011 and funding decisions will be made by 30 June 2012.

Full details of application process, forms terms and conditions are found on website www.kidskidneyresearch.org/projects

Advertising international contacts for BAPN members via RCPCH

If you go to the RCPCH website and click on RCPCH International there is a map of overseas contacts. If you wish to broadcast any overseas contacts you are involved with and have these advertised on the RCPCH website please email international@rcpch.ac.uk

Free trainee membership of Renal Association

The Renal Association are offering trainees a year free membership to the RA provided they sign a direct debit form to continue with membership for further information [click here](#)

RaDaR update

RaDaR continues to move forward with some momentum. Most significantly, many excellent applications were received for the first round of grants to pump prime new working groups and five were successful at this time. Four of these groups will start this year and one in the spring. These groups will target rare renal diseases affecting children and adults.

Currently 2/3rds of BAPN members are signed up for access and we would encourage those who are not yet registered to look at the website and register. With the support of the BAPN and the RA this registry will continue to build cohorts disease enabling research by UK experts previously not possible on this scale.

It is worth noting that each patient recruited to RaDaR is counted in accrual figures and this provides an income fed back to the recruiting trust. If the patient is subsequently recruited to a study (such as the SRNS or MPGN studies) this is counted as a separate accrual unit.

The two pilot studies are progressing well with over 200 patients now recruited. Thanks must go to all the supporting units whose staff have put in a lot of effort. The SRNS study has over 160 patients recruited and as well as analysing clinical data is beginning to analyse first results of the gene study. As well as samples for DNA, they are still very keen for peri-transplant samples of blood and urine and discard plasma from plasma exchange for post transplant recurrence of disease. The MPGN group have full ethical approval and Dr Sally Johnson has distributed the SSI forms and supporting documents to the clinical link in each unit to enable local R&D approval.

Atypical HUS Action campaign

aHUS Action is UK campaign group comprising researchers and clinicians. The purpose of the group is to ensure that the needs of the patients with aHUS are represented in Parliament and Government. This coincides with the application for a nationally commissioned service for aHUS. An e-petition has now been launched and can be signed online at epetitions.direct.gov.uk/petitions/16053. The e-petition states:

We call on the Government to commission a national specialised service for the treatment of atypical haemolytic uremic syndrome (aHUS), fund treatment with complement inhibitors such as eculizumab, and ensure that these services and therapies are available to all patients who need them.

Surgical challenges in paediatric renal transplantation

The final date for Challenges in Paediatric Transplantation this year is going to be 18th November, at the Evelina Children's Hospital, St Thomas' Hospital, London.

Details are being finalised. Please contact Judy Taylor for further information.

e-mail: judy.taylor@gstt.nhs.uk

13th UK Renal Registry Report

The 13th UK Renal Registry Report which contains two paediatric chapters is now available on the UK Renal Registry website.

The report is accessible by following the link www.renalreg.com/Reports/2010.html

Comments on the report & suggestions for future editions are very welcome.

Consultant General Paediatrician with special interest in nephrology required for project board at the Royal College of Paediatrics and Child Health to assist with renal patient information leaflets is required

Funding has been awarded from the British Kidney Patient Association to produce 50 information leaflets over a two year period. The leaflets will be aimed at parents and carers of children and young people with renal conditions, and older children and young people about 12 years and over. We will liaise with the network of paediatric nephrology centres, as well as parents and carers, children and young people, to research, scope and produce high quality and accessible leaflets. We plan to seek accreditation by The Information Standard, a Department of Health supported certification, so that the leaflets are quality assured as a reliable source of information for the public.

The project board will meet quarterly at the College, with options for teleconferencing.

The first meeting will take place in late October Please contact Kirsten on 020 7092 6175 or kirsten.olson@rcpch.ac.uk with any queries.

Interested members may email Kirsten a short written statement (100-200 words) describing their relevant experience and interest for the role by 30th September.

If you have any ideas or would like to include an article or event in eNews, please contact the Renal Association/BAPN Secretariat on 0870 458 4155 or BAPN@mci-group.com