



Dear Member,

Welcome to May's edition of the BAPN eNews. Please read on for details on meetings, updates, vacancies and more.

We hope you enjoy this month's read.

Best wishes,

Mary McGraw
BAPN President

Sally Feather
BAPN Secretary

Reminder BAPN AGM

Tuesday 7th June 2011, Birmingham

The BAPN AGM will be taking place at the Renal Association/British Renal Society meeting in Birmingham ICC on Tuesday 7th June at lunchtime. Final room details will be emailed with agenda.

National Commissioning & Designation for aHUS

Most of you will be aware that two multicentre studies of eculizumab in adolescent /adult aHUS patients have recently been undertaken. The interim results for these are favourable and will be presented at the RA/BRS Conference in Birmingham. Because of this an outline application was submitted to NHS Specialised Services for national commissioning and designation for aHUS. This was considered by the Advisory Group for National Specialised Services on the 1st April and the applicants have been invited to submit a full application. In essence, this if successful will provide national funding for the investigation and treatment (including eculizumab) of patients in England with aHUS. Separate arrangements are in place in Wales, Scotland and Northern Ireland but it is anticipated there will be negotiation with the appropriate authorities to establish similar funding structures.

The national specialised commissioning team have asked that BAPN members provide, in the full application, details of the number of patients (paediatric and adult) that will need this service in the future. Sally Johnson has been in contact with all paediatric nephrology centres in order to collect paediatric data. The National Commissioning is being led by Professor Tim Goodship and Sally Johnson in Newcastle.

Paediatric Renal Unit Self-Assessment Document

The Clinical Standards and Guidelines have developed a new self assessment tool, adapted from the West Midlands Renal Network "Quality Requirements for Services for Patients with End Stage Renal Failure, including Renal Transplantation" document. This aim of this document is to improve services for children and young people with end stage renal failure (ESRF) cared for within UK paediatric renal units. By using this document to assess your unit, you may be able to improve the quality of services for patients with ESRF and their families.

The Quality Requirements in the document are based on the National Service Framework (NSF) for Renal Services, the Children's NSF and a range of other guidance. National Service Frameworks can be interpreted in different ways and may not yet be implemented in full. The QRs therefore clarify the service that is expected within two to five years. They provide the answer to the question: "For each service, how will I know that the NSF and other guidance have been implemented?"

You can download the document from the Clinical Standards page of the [BAPN website](#). This is a draft document and comments are welcomed. Please send feedback to Dr David Milford, David.Milford@bch.nhs.uk, by end of July 2011.

Call for Applications - Rare Disease Working Group

Kidney Research UK, in partnership with the British Kidney Patients Association, and working with the Renal Association announces a call for applications from those who wish to apply to setup and run a Rare Disease Working Group. Grant support to cover meeting and literature activities is available along with central infrastructure support coordinated under the RA Rare Diseases Committee. For further details and an application form please [click here](#).

Enquiries should be directed to Elaine Davies on 01733 367835 or elainedavies@kidneyresearchuk.org.

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