

# **The British Association for Paediatric Nephrology**

*Founded 1972*



## **Annual Report 2010**

## Welcome from the President

Welcome to the 2010 Annual Report of the British Association for Paediatric nephrology (BAPN), the first that the BAPN has produced in this format. This year we have become a Division of the Renal Association, which produces its own annual report, so we have chosen in recognition of this to produce our own detailed account of the current status of our organisation.

The BAPN, which was formed in 1972, is the specialist society for paediatric nephrology. Its aims are

- To set and to improve the standard of medical care of children with renal disease.
- To formulate and express opinions on policy concerning the care of children with renal disease.
- To conduct clinical and scientific meetings in order to advance the knowledge and skills of doctors with responsibility for children with renal disease.
- To conduct collaborative research and audit and to disseminate results.
- To consider the training, continuing education and professional development of paediatricians with responsibility for children with renal disease

Our membership has grown considerably over the years and now includes not only consultants in paediatric nephrology working in tertiary centres but also trainees and an increasing number of general paediatricians with special expertise in paediatric nephrology.

Many already busy people have contributed to the success of our organisation and I would like to take the opportunity to thank all those who have contributed to that success. This report summarises our key activities over the past year and I hope will inspire others to become actively involved in the future so that we can continue to thrive and grow.

A handwritten signature in black ink that reads "Mary McGraw". The signature is written in a cursive style and is positioned above a thick, horizontal black line that serves as a separator.

Dr Mary McGraw

President BAPN

## President's report

### Dr Mary McGraw

As president my main roles are:

#### *Chair the BAPN Executive Committee*

Through this role I help set the strategy for the organisation. One of my key objectives for this year has been to ensure that as an organisation we consider the whole patient pathway of children with renal disease. We have therefore been keen to encourage more paediatricians with an interest in paediatric nephrology to become active members of the organisation and I am delighted we have been successful in doing so. We have also embarked on an important piece of work on improving the standard of the care of children with kidney disease through paediatric networks. This work, undertaken jointly by the BAPN, the Royal College of Paediatrics and Child Health and NHS Kidney Care will result in a report to be published in 2011 and which we hope will provide useful guidance for all those commissioning providing and using paediatric nephrology services.



#### *Act as a trustee of the Renal Association*

In this role I help set the strategy for the Renal Association and have been keen to ensure the needs of children with renal disease, and clinicians caring for those children, are considered in all areas of activity of the organisation. In 2010 adult and paediatric nephrologists have worked together closely in both producing a guidance document on transition (Helping adolescents and young people with renal failure) and on providing an integrated strategy for those with rare diseases (Rare diseases: an integrated strategy for patients in the UK) and have planned more joint work for 2011. Through working closely with our adult colleagues we have a greater opportunity to ensure the needs of children are heard and I wish to ensure we take every advantage of those opportunities.

#### *To act as a spokesperson for, and to represent, the BAPN, as required by organisations including the Department of Health and the Royal Colleges.*

This work includes responding to the many consultations received from organisations such as the Department of Health and the National Institute for Health and Clinical Excellence. It also includes lobbying on behalf of children with renal disease and their families. An example of this was lobbying the Medicine and Healthcare products Regulatory Agency (MHRA) and European Medicines Agency (EMA) following the withdrawal of the Neo-Recormen pen which adversely affected many of our patients and the care we can give them. Whilst we were not successful in getting the pen re-issued I do believe we made very clear that far greater consultation and control is needed before products are withdrawn from the market and that the special needs of children must be considered.

The exciting aspect of being the president is that I never know quite what will land in my portfolio next and so I look forward to another stimulating year.

## Secretary's report

Dr Sally Feather

I have just begun my three year term of office as BAPN secretary following the BAPN AGM in June 2010, following in the very able footsteps of Jane Tizard. I am sure we would all like to extend our thanks to Jane for all her hard work.

In 2010, the BAPN has joined forces with the Renal Association so now we have the support of the MCI secretariat and I would like to thank them for supporting some of the administrative roles of the BAPN secretary post.

This year, following a postal vote, the membership has agreed to alter the BAPN constitution as follows: The Association will be a Division of the Renal Association, adult nephrologists will be included as members, the chair of the Medicines for Children Research Network Clinical Study Group will serve on the executive committee for the duration of their tenure, an annual subscription is to be paid to the Renal Association, and a restricted fund of the Renal Association entitled BAPN exists for donations and is managed by the BAPN.

Finally the membership agreed to appoint a lay member to the executive committee for 3 years. I am pleased to announce that following the decision applications were organised and Mr Shahid Muhammed has been appointed as lay member to BAPN executive. We look forward to working with him.

We are now using a monthly eNews format in order to inform BAPN members of news items and hope this is proving useful!

We welcomed the following new members to the BAPN in 2010:

Dr Deepa Athavale, Nephrology Grid Trainee, Manchester  
Dr Mark Bradbury, Consultant Paediatric Nephrologist, Manchester  
Dr Michelle Hamilton-Ayres, Consultant Paediatrician, Cheltenham General Hospital  
Dr Daljit Hothi, Consultant Paediatric Nephrologist, Great Ormond Street Hospital  
Dr Lyda Jadresic, Consultant Paediatrician, Gloucestershire Royal Hospital  
Dr Guy Millman, Consultant Paediatrician, York Hospital  
Dr Ben Obi, Consultant Paediatrician, Royal Surrey County Hospital  
Dr Stephen Wadams, Consultant Paediatrician, Poole Hospital





## **Treasurer's report**

**Dr Judith van der Voort**

As Treasurer my roles in 2010 were:

*Transition of our financial affairs becoming part of the Renal Association*

I had discussions with the treasurer of the RA and the following changes were agreed when joining the RA: the membership fees would be paid directly to the RA of which we would automatically become a member. The RA would provide £4000 yearly to fund our executive expenses and a yearly donation of £750 to the Kidney Alliance would be made. A fee of £30 was agreed for the new SPIN membership. The monies from the BAPN account were ring-fenced within the RA accounts for our own use. A yearly financial statement of the BAPN monies has and will be provided by the treasurer at the Annual General Meeting.

### *Payments from our ring-fenced accounts*

I liaise with the project managers of the RA secretariat, to action payments from our ring-fenced account. After joining the RA the BAPN had £34,249.40, a one off payment of £3000 was made for the MCRN CSG Nephrology. We supported some non-executive travel expenses totalling £119.05. This left the BAPN ring-fenced account with £31,130.35.

### *BAPN membership*

This year we have seen the change from being BAPN members to being members of both BAPN and RA, as well as an increase in our membership numbers with many trainees and paediatricians with expertise and interest in nephrology joining. I am the first port of call for potential new members and have produced an information leaflet to facilitate the process. We are in the process of reviewing the joining procedure.

### *Member of Executive Committee*

On the quarterly executive committee meetings I provide the committee with an up-to-date summary of our finances. All members contribute to the discussions around the agenda items and to further planning and decision making of BAPN affairs.



## **Audit & Registry Committee Report**

### **Chair: Dr Carol Inward**

The BAPN Audit & Registry Committee was formed in 1997 under the chairmanship of Dr Alan Watson who retired this year. We would like to acknowledge the huge contribution he made to the care for children with renal disease in the UK and their families.

The work of our committee is to provide data on the care of paediatric nephrology patients through the ERF registry and the audit programme so that the BAPN can use this information to monitor and improve patient care.

This year there have been two important developments in Department of Health regulations for Trusts which are relevant to this work. Collection of the National Renal Data Set has been made mandatory and Renal Registry data must be included in Trusts Quality accounts for 2011. Details of the national renal dataset are available on the website of the NHS Information Centre.

The membership of the committee in 2010:

- Chair: Dr Carol Inward
- Ordinary members: Dr Farida Hussein, Dr Malcolm Lewis, Dr Manish Sinha
- Paediatric nephrology trainee: Dr Helen Jones
- Research Secretary: Professor Moin Saleem
- Treasurer: Dr Judith van der Voort

Meetings were held quarterly with colleagues from the UK Renal Registry (UKRR):

- Director UKRR: Dr David Ansell
- Chair UKRR: Dr Charlie Tomson & Dr Damian Fogarty
- UKRR Manager: Mrs Hilary Doxford
- Renal Statistician: Mr Dirk
- Informatics Manager: Mrs Fiona Braddon
- Programmer: Mr Matthew Brealey
- Project Manager: Ms Sue Shaw
- Adult Nephrology trainee: Dr Clare Castledine

Minutes of the meetings are published on the BAPN website.

### *BAPN Registry Data*

At the beginning of the year the main focus of our registry activity was to promote data collection following the 31/12/2009 census date. In particular, work with colleagues at Great Ormond Street Hospital for sick Children and Southampton has enabled these teams to submit electronic data to the registry in 2010. Belfast, Evelina, Glasgow, Liverpool and Newcastle submitted their data on paper.

Since registry colleagues have received data in various formats, merging the data for storage has required painstaking work. A considerable amount of time has been taken to validate patient identifiers prior to uploading the data into a temporary Filemaker database in preparation for later merger with the UKRR database.

Due to the complexity of this work and staffing difficulties at the registry, it was not possible to complete the analyses of the 31/12/2009 data this year, and publication of the whole UKRR report has been delayed. It is anticipated that the paediatric analyses will be available to the paediatric teams by April 2011.

The 12<sup>th</sup> UKRR report including two paediatric chapters was published in 2010:

UK Renal Registry 12th Annual Report (December 2009): chapter 14: demography of the UK paediatric renal replacement therapy population in 2008.

Lewis MA, Shaw J, Sinha MD, Adalat S, Hussain F, Castledine C, van Schalkwyk D, Inward C. *Nephron Clin Pract.* 2010;115 Suppl 1:c279-88.

UK Renal Registry 12th Annual Report (December 2009): chapter 15: clinical, haematological and biochemical parameters in patients receiving renal replacement therapy in paediatric centres in the UK in 2008: national and centre-specific analyses.

Hussain F, Castledine C, van Schalkwyk D, Sinha MD, Lewis M, Inward C. *Nephron Clin Pract.* 2010;115 Suppl 1:c289-308.

#### *BAPN Audit*

We are working towards establishing a programme of national audit.

The BAPN audit of renal biopsy has been published:

Renal biopsies in children: current practice and audit of outcomes.

Hussain F, Mallik M, Marks SD, Watson AR; British Association of Paediatric Nephrology *Nephrol Dial Transplant.* 2010 Feb;25(2):485-9.

Standards for renal biopsy in children have been agreed and are now on the BAPN website following work with the Clinical Standards and Guidelines committee.

Reports for publication have been prepared and submitted following the BAPN audit of Blood Pressure Control in paediatric transplant patients. The manuscripts are being revised with a view to re-submission in 2011. A related study looking at obesity in paediatric renal transplant patients was presented at the IPNA meeting in New York in September and a manuscript is in preparation for publication. Guidelines for the management of hypertension in paediatric renal transplant patients have been prepared for consultation and submitted to the Clinical Standards and Guidelines committee.

We are very grateful to the BKPA for their generous financial support of our current BAPN audits. These national audits of anaemia in children receiving RRT and Infant Dialysis are in progress. An abstract of the preliminary findings of the infant dialysis audit will be presented at the RCPCH meeting in 2011. We are also grateful for the involvement of colleagues at UKRR in these projects.



## **BAPN Research Secretary's report**

**Prof Moin Saleem**

### *Meetings*

The RCPCH meeting in Warwick was held in April 2011, and a half day nephrology session was organized in conjunction with the Bone and Metabolism group. 13 original abstracts were presented, and there were two excellent invited speakers, Mr Fergal Monsell and Dr Rukshana Shroff.

### *KKR funding*

A sum of money was allocated to the BAPN from Kids Kidney Research for clinical research projects. Project proposals were invited, and initially adjudicated by the Clinical Studies Group (CSG). Out of a broad field of applicants, the money was awarded to Dr Hugh McCarthy, for further development of the National Renal Rare Disease Registry (RaDaR).

### *Academic Nephrology*

There are currently 4 academic trainees registered for PhDs in the UK – 1 in London, 2 in Bristol, and 1 in Edinburgh. In addition there is 1 MRC intermediate fellow (Bristol) and 1 Clinical Senior Lecturer (London).

### *CSG report*

The Nephrology Clinical Studies group now meets 3 times a year, and facilitates the development, implementation and accrual for clinical trials on a national scale. All UK tertiary centres are represented, as well as consumer, trainee, paediatric urology and MCRN representation.

Portfolio funded trials include the PREDNOS study; RaDaR; and the Teaching Parents Study.

Minutes of meetings are available on the BAPN website.

### *Rare Disease Initiative*

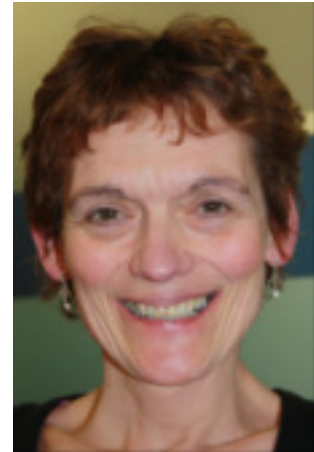
A committee for Renal Rare Diseases has been formed by the Renal Association, and is chaired by Dr Mark Taylor. This committee will oversee the implementation of the National Rare Disease Strategy, including development of RaDaR, and formation of new rare disease working groups (RDWG), aided by substantial new funding from BKPA/KRUK.

## CSAC Report

### Chair: Dr Maggie Fitzpatrick

The paediatric nephrology CSAC is a committee of the RCPCH whose role is to advise on aspects of specialist training relating to paediatric nephrology. The CSAC is currently actively involved in curriculum development and advising on the appropriate assessments for level 3 trainees.

The CSAC has met four times over the past 12 months. It has nine members comprising of the chair, two training advisors, the president and secretary of the BAPN, a general paediatrician with a special interest in nephrology (SPIN consultant paediatrician), a trainee representative, a member of the adult renal SAC and a representative from the RCPCH. There were two new appointments to this committee over past year who both took up posts in September 2010 - Dr Kay Tyerman replacing Dr Sally Hulton as specialty training advisor and Dr Helen Jones replacing Dr Hugh McCarthy as trainee representative.



### *NTN Grid appointments*

NTN Grid process 2010 – there were 11 applicants to the grid, 6 were short-listed and 4 were made offers and accepted training posts in London (2) to rotate between GOS and the Evelina, the West Midlands (Birmingham Children’s Hospital ) and West Scotland ( RHSC Glasgow ). The process for the NTN grid for 2011 is now underway.

### *Current Trainees*

Total number of current trainees is 12:

- 2 in locum consultant paediatric nephrology posts
- 1 in locum PICU clinical fellow post (appointed as a paediatric nephrologist Feb 2011 Canada – due to take up post later this year)
- 4 engaged in research
- 4 in clinical practice
- 1 on maternity leave

There were 2 trainee educational meetings in 2010 – Glasgow/January and London (Evelina )/July. So far there has been 1 trainee educational meeting in 2011 - Manchester/January 2011. All meetings were well attended and positive feedback was received.

### *BAPN Paediatric Nephrology Guidelines*

The trainees are now working with the Clinical Standards and Guidelines group regarding the development of paediatric renal guidelines. The current proposal is that trainees help develop paediatric specific guidelines using existing guidelines for adult nephrology from the Renal Association on AKI, CKD including growth and bone disease, PD, HD and Renal Transplantation. There is ongoing discussion regarding how best to progress these, with a general agreement that this should be an exercise led by a consultant paediatric nephrologist with 2 trainees engaged in each guideline.

### *Consultant Appointments*

There were 5 consultant paediatric nephrology appointments in 2010: Dr A Lunn - Nottingham, Dr Kerecuk – Birmingham (from a consultant post in Newcastle), Dr S Johnson – Newcastle, and Dr Y Tse – Newcastle. In 2011, Dr Karl McKeever and Dr Mairead Convery have been appointed to positions in Belfast, one due to the retirement of Prof Savage, and the second to fill Dr Eva Simkova 's post, who has left the UK,

The CSAC/BAPN has dates for future consultant retirements for workforce planning.

### *Curriculum Development*

The Framework for competencies for level 3 training in Paediatric Nephrology on the RCPCH website is now being updated by the CSAC to be modelled on the adult renal curriculum which was updated in 2010 and is available on the jrcptb website.

The Framework of competencies for level 3 training SSM in Paediatric Nephrology directed at potential SPIN doctors is on the RCPCH website. Modules are now being taken up and the CSAC has had a number of interested enquiries. The CSAC is developing a framework to monitor this process.

3 trainees in paediatric nephrology participated in the ST7A pilot in July 2010. It is believed that this scheme will become mandatory for all specialty trainees in the future. Feedback from trainees and assessors was generally positive.

## Communications Officer's report

### Dr Leah Krischock

As Communications Office my main roles are:

#### *Maintaining and updating the BAPN website*

[www.BAPN.org](http://www.BAPN.org). The website was put together through much hard work by my predecessor, Dr Eric Finlay. A major part of my role as Communications Officer is updating the information provided on the website, including information on the activities of the BAPN, resource materials developed by the subcommittees, and links to other websites and organisations. This is sometimes more challenging than one might think, and I am grateful for Eric's continued help resolving the IT issues that inevitably arise. The website is a resource for the members of the BAPN, providing access to minutes of meetings of the various groups in which BAPN members participate, and hosts a range of resources such as standards, guidelines, patient satisfaction questionnaires, Kidney Care Plans, and a library of patient information sheets on which units can base their own locally adapted information sheets. The calendar of events is a useful tool which can be used to plan continuing professional development activities.



The website is also the public face of the BAPN, and has information on each of the thirteen paediatric renal units in the UK. Many of the enquiries I receive from the public are requests for patient information on renal disease. For the time being, I cannot provide such information, however this is an area that the Clinical Standards and Guidelines Group are working on.

The Communications Officer serves a term of three years, and I am now halfway through my term. I am always interested to hear comments from members regarding their website, particularly as to whether they think improvements can be made, and I thank those of you who completed the online survey recently sent out. Over the next year and a half I will explore options for outsourcing the maintenance of the BAPN website, so that improvements can be made, and also so candidates for the next Communications Officer need not be limited to those with website experience.

#### *Membership of BAPN Committees*

As Communications officer I am a member of the Clinical Standards and Guidelines group as well as the Executive committee. This has given me the opportunity to add my opinion in critiquing the many documents and guidelines sent to the BAPN as well as to represent the BAPN at the NICE scoping exercise into the review of immunosuppression in renal transplant recipients guideline. Our responses to such guidelines and standards documents can be found on the Clinical Standards and Guidelines page of the website. As a junior consultant, sitting on the BAPN Executive committee has provided me with an excellent opportunity to learn more about the politics of health care and the promotion of kidney care and paediatrics within the UK.

## Clinical Guidelines and Standards Subcommittee

### Dr David Milford

As chairman of clinical guidelines and standards subcommittee I serve a three year term of office. The committee comprises the Chairman, The Chair of the Registry Committee, the BAPN Communications Officer, two representatives of the membership, a trainee representative and a co-opted member of the Clinical Services Subcommittee. My duties include chairing at least two committee meetings each year, providing a link to the Renal Association Clinical Practice Guidelines Committee, overseeing development of standards and guidelines for all aspects of nephrology and reviewing externally produced documents when requested by the BAPN Executive.



#### *Completed items to date*

Care plans: these documents were developed by NHS Kidney Care but were not published. They cover dialysis, transplantation and chronic renal failure and have been converted into Word files and placed on the BAPN website for members to download and edit to suit local needs.

Patient reported outcome measures for haemodialysis, peritoneal dialysis and transplantation: these documents are published and are on the BAPN website. Individual units are encouraged to use these tools to measure the quality of their service as assessed by patients.

Standards for renal biopsy: renal biopsy standards for audit were approved by the subcommittee and have now been placed on the BAPN website.

Unit assessments: the document will be circulated to the membership of the committee again so that the document can be finalised and published on the BAPN website. The committee agreed that the document is valuable and should be used by units to assess their service.

#### *Responses to consultation*

NICE scoping workshop on immunosuppressant therapy for the treatment of renal transplantation in children (review of TA99): Leah Krischock and Meeta Mallik attended the scoping workshop.

NICE Anaemia management: Committee comments collated and forwarded to RCPCH.

NICE Quality standards on CKD: This was a document for the adult services but it was agreed that a similar document could be valuable for paediatric patients.

EMA consultation: concept paper on the need for guidance on the clinical investigation of medicinal products to slow the progression of renal insufficiency.

UK NSC consultation on screening for glomerulonephritis

Nephrology Networks: comments on document under development by the BAPN

### *On going work*

Self assessment tool: Adaptation of a document produced by the West Midlands Renal Network that allows units to assess their services; originally used to undertake a peer review of Birmingham Children's Hospital Renal Unit.

Hypertension standards: Development of audit standards following a survey by Manish Sinha.

Guideline for growth monitoring in CRF: Developed by Bristol Children's Hospital Renal Unit.

Development of standards and guidelines to match RA topics: This is a task the BAPN hoped to achieve a number of years ago. It is hoped that a renewed effort to identify small groups of clinicians willing to take on this important work will be more fruitful this year.

## **Young Consultant's Report**

### **Dr Simon Waller**

As ordinary member I have attended executive meetings and have represented BAPN at Kidney Alliance (KA) meetings. I was seconded to the KA organising committee for Parliamentary Reception for WKD: <http://www.kidneyresearchuk.org/support-us/world-kidney-day>

Unfortunately the KA is in severe financial difficulties due to lack of industry support. A new structure for the organisation has been approved:

- A board of 6 members - one from each of the primary funding associations.
- A Chair to be chosen from the 6 members (to serve for one year and then to rotate to a different association each year, subject to agreement).
- An Executive may be appointed to carry out the core work, consisting of a Director, with secretariat support.

The current chair has been suggested as a possible Director.



## **SPIN Representative's Report**

### **Dr Peter Houtman**

The duties of the SPIN (special paediatric interest in nephrology) Representative include responsibility to the BAPN/CSAC for the interface between specialist paediatric nephrology services and renal aspects of general paediatrics. I am the first person serving in this capacity.

Much of the work this year has been built upon the recent survey done on behalf of the BAPN on paediatric renal networking.

I have been an active participant in the Renal Networks Project group (RCPCH/BAPN) chaired by Mary McGraw, and I am looking forward to the publication of the relevant report later this year. This, I hope, will be fundamental to the future of paediatric renal networking.

We have recruited 12+ new BAPN members specifically designated as "BAPN-SPIN", and I hope that these numbers will further increase. There are another at least 30-40 paediatricians with varying degree of "SPIN" (not in the BAPN). I am working towards further identifying this group, at present through email, but I hope later with meetings and a more formal structure. I hope that this will complement the Nephrology Networks Project recommendations, particularly for workforce planning.

Regarding training specifically, the RCPCH has now initiated a "pilot" Special Study Module (SSM) in paediatric nephrology, using our recommended framework of competencies and curriculum guidance. I have been engaged in clarifying the pathway and process for this module, particularly the relative roles of deaneries, educational supervision and our CSAC. I have been in contact with several trainees at various stages of Level 2 and 3, both to help them and also further to define and develop this "SPIN" training in general. This is a difficult area that is evolving rapidly.

I have attended all but one BAPN Executive Committee and CSAC meetings during this period.



## **BAPN Trainee Representative Report**

### **Dr Helen Jones**

As trainee representative my roles include

#### *Member of BAPN Executive and CSAC*

I attend meetings four times per year in which I'm able to give any trainee feedback that arises. I also attended the BAPN Winter meeting in which there is an opportunity for 3-4 trainees to present some recent work they have been involved in or part of their research. This year, presentations were given by JJ Kim, Wes Hayes, Ben Reynolds and myself.



#### *Member of the Clinical Standards and Guidelines Committee*

The trainee rep also forms part of the BAPN Clinical Standards and Guidelines Committee, which meets twice a year. From the trainee point of view there is continuing discussion between this committee and the CSAC about guideline production and involving trainees in this and I have been involved in sharing the trainees' points of view and ideas with this committee.

In addition a trainee representative sits on the BAPN Research & Audit Committee. This representative is currently JJ Kim, who attends meetings three times a year at the Renal Registry. This has enabled trainees to become involved in some National Audit Projects.

#### *Educational Meetings*

As trainees we arrange 2 sets of National Grid trainee days per year. Joanna Clothier and I hosted a meeting at the Evelina Children's Hospital in June 2010 (timed to fit with the BAPN Histopathology meeting at Great Ormond Street Hospital) and Deepa Athavale organised the meeting in Manchester Children's Hospital in January 2011. I must also mention we had a meeting in Glasgow in early 2010 arranged by Mairead Convery. All meetings received very positive feedback and we plan to continue this set up of having educational meetings for Grid trainees twice a year at different centres. As part of one of these meetings we are able to meet with the CSAC Chair to discuss any training related issues. The next meeting is to be held in Nottingham in July 2011 hosted by Dr Wes Hayes.

#### *Other Roles*

Other roles include highlighting meetings of relevance to the trainees and being a point of contact for anyone who emails me through the BAPN website. More recently I have been trying to establish a list of those working on the Special Interest in Paediatric Nephrology (SPIN) Module to allow some networking between ourselves as Grid Trainees and the SPIN Trainees at our meetings in the future.