The British Association for Paediatric Nephrology

Founded 1972

Annual Report 2011
Welcome from the President

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.

Last year the British Association for Paediatric Nephrology (BAPN), produced its first annual report in this format. We received very positive feedback and so have decided to make this a regular feature. We hope that these reports will keep both our members and others informed of the wide range of activities in which we are involved.

The economic situation and the proposed new Health Bill provide enormous challenges for all of those involved in healthcare. Low volume high cost services such as those delivering care to children with renal disease are particularly vulnerable which is why we believe that our document Improving the standard of care of children with kidney disease though paediatric nephrology networks is very timely and will be an important benchmark against which services can be judged.

I would like to take this opportunity to thank all the members of the Executive committee for the enormous amount of work they have done and help they have given me in the past year to enable the Association to fulfil its duties and move the specialty forward in clinically and in research. You will read further on in this report what they have achieved. Much of this work has been done in their own time and I am very grateful to them for all the support they have given.

Dr Mary McGraw

President BAPN
President’s report

Dr Mary McGraw

I have enjoyed another busy year as President of the British Association for Paediatric Nephrology.

As well as the work I do directly for the BAPN I have responsibilities in as trustee of the Renal Association and member of the RA Executive Committee and Renal Registry Management Board. As well as ensuring that the needs of children are considered in all activities of the Renal Association this has been a real education for me being exposed to the pressures that adult renal services are under, and an insight in what the future might hold for paediatric renal services as we too become forced to be driven by targets, tariffs and delivery of outcome measures. In addition the Renal Association is often consulted on issues that are of importance to the renal care of both adults and children although the BAPN is not independently consulted. This gives the BAPN a national voice as both an advocate and an expert on issues surrounding the care of children with renal disease.

One of the most important pieces of work that the BAPN has completed in the past year has been that of ‘Improving the standard of care of children with kidney disease though paediatric nephrology networks.’ Over the past 18 months I chaired a multi-professional working party that has produced a document which sets standards for the delivery of the care of children through paediatric nephrology networks. This work has been an excellent example of collaboration between the BAPN and the Royal College of Paediatric and Child Health (RCPCH) and we already have other joint work in progress on the production of patient and family information leaflets which we are sure will be equally successful. The criteria of success for this work will now be that very BAPN member uses this document to enhance their local services.

In 2010 there was a major concern amongst the paediatric renal community about the withdrawal of a device for administering one of the commonly used erythropoietin stimulating agents which was a major disadvantage for many of our patients. This episode highlighted the need for much closer scrutiny of pharmaceutical and healthcare product companies’ intentions to modify or withdraw their products. As a result the BAPN has had a far closer link with the MHRA. There have been further concerns this year about companies withdrawing or modifying products which has an impact on the paediatric community. The low volume and high cost of medications and products for children will always make them vulnerable in a financially competitive world especially in economically challenging times. However we believe the role of the BAPN is to be an advocate for our patients and families and raise the profile of the needs of children with kidney disease.

The Advisory Group on National Specialised Services commissions services for rare diseases which it defines as affecting fewer than 500 people. This could include almost all children’s renal diseases. The approach of the AGNSS is that for rare diseases not every centre should treat every condition. The model of services commissioned can vary from those in which a lead centre is consulted only for the initial management of the condition to others where all care is provided by the lead centre. It is clearly important to consider all aspects of care of a particular condition to determine the model.
which would be most suitable. Services commissioned by AGNSS are usually prompted by either individual clinical experts or pressure from lobby group particularly when new or expensive treatments become available. The discovery of Eculizumab and its potential to radically change the way we manage atypical haemolytic uraemic syndrome has led a group from Newcastle to bid for services for atypical HUS to be commissioning nationally. The BAPN have worked closely with the Newcastle team aiming to set a model of service which would most appropriately deliver care for these patients. The outcome of this bid is expected in 2012.

This work is done alongside the more routine work of the Association such as planning meetings, responding to requests for information from both individuals and organisations and providing feedback on consultations from a variety of other organisations.

Time passes very quickly and I will soon complete my term of office as President. It has been an enormous privilege to work with and for such a dedicated and enthusiastic membership and I am sure the Association will continue to grow from strength to strength.

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**Secretary’s report**

**Dr Sally Feather**

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. We are aware that there are some ongoing difficulties with members receiving eNews and votes. We thank members for their patience whilst MCI continue to check their processes and contact details. We would be very grateful if any BAPN members change their contact details if they could keep MCI up to date.

We hope you are enjoying reading eNews. ENews is also available on the BAPN website. Please remember we are happy to advertise any important announcements.

In the last year we have welcomed the following new members to the BAPN:

- Catherine Derry (SPIN)
- Lynn Diskin (SPIN)
- Sheetal Bhojani (trainee)
- Sabani Pahari
- Mona Aslam (SPIN)
- Hitesh Prajapati (trainee)

In addition we have offered honorary membership of the BAPN to Alan Watson, Tim Chambers and Mark Taylor.
Treasurer’s report

Dr Judith van der Voort

Payments from our ring-fenced accounts

We started the year with £31,130.35 in the BAPN ring-fenced account. Our expenditure this year was £3036. We helped with the EWOPA financial shortfall and awarded four travel bursaries. At the end of December 2011, this left £28,094.35 in our account.

Financial arrangements with Renal Association:

Our expenses for the year 2011 included BAPN executive members’ travel expenses, lunch and room hire and came to a total of £1942.36. This amount remains comfortably within the allocated £4000 to the BAPN by the RA.

Our yearly donation to the Kidney Alliance was administered late and will show in the 2012 figures.

We are planning a meeting with the MCI and the Treasurer of the RA to clarify the agreed financial arrangements between the BAPN and RA and the MCI’s role in managing these.

### SUMMARY OF ACTIVITY BAPN 31/12/10 TO 31/12/11

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<th>BALANCE AT 31/12/2010</th>
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<td>PAYMENTS MADE FROM BAPN FUNDS:</td>
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<td>EWOPA Shortfall</td>
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<td>Travel bursaries</td>
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<td><strong>BALANCE OF FUNDS REMAINING 31/12/2011</strong></td>
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<th>BAPN TRANSACTIONS PAID BY RA</th>
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Audit & Registry Committee Report

Chair: Dr Carol Inward

This year with the agreement of the BAPN Executive & the UK Renal Registry Committee, 2 additional ordinary members joined the BAPN Audit & Registry Committee. It is hoped that this will strengthen the links between the registry & the clinical teams. Dr Manish Sinha, Dr Malcolm Lewis and I have been joined by Dr Heather Maxwell, Dr Catherine O’Brien & Dr Yinsent Tse.

Mr Ron Cullen has been appointed as the new director of the UK Renal Registry (UKRR). We welcome him to the post and look forward to working with him. Anna Casula has been assigned to provide the statistical support to the paediatric registry following the retirement of Mr Dirk van Schalkwyck. In collaboration with our colleagues at UKRR the current focus of the Committee’s work is the linking of the paediatric and adult ERF databases and to complete a consultation on the dataset.

The 2009 data was published in two chapters in the 13th annual report from UKRR. There will be a delay in the publication of the 14th report (2010 data) because of changes of personnel & redesign of data handling processes at UKRR. The census date for the 20011 data collection was 31.12.11 with a deadline for data submission of 30th June 2012.

Audit

The BAPN audit of the Management of Blood Pressure in Transplant Patients has been accepted for publication in two reports by Nephrology, Dialysis and Transplantation.

The data collection has been completed for an audit of the managements on Infant on dialysis. We are grateful to the BKPA for providing funding to support this project.

Data collection is in process for an audit of Anaemia in children receiving Renal Replacement Therapy. BKPA has kindly providing funding support this project.

A prospective re-audit of renal biopsy practice is planned with data collection from January to June 2012.

We would like to thank all the BAPN members and their colleagues for their help & support for the audit & registry 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.

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 are 2 Clinical Senior Lecturers (Bristol and London).

Trainee Bursaries

4 bursaries were awarded in September to the value of £500 each, for trainees presenting work at international meetings

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.

A Strategy Document has been discussed and approved to set out the manifesto of the Group

This year there has been an expansion of consumer representation from 1 to 4 members. The Chair will rotate from the end of 2012, and new members are also being sought to replace those who are coming to the end of their term.

Portfolio funded trials include the PREDNOS study; RaDaR; and the HoTKids 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 groups (RDG), aided by substantial new funding from BKPA/KRUK. This year eight new RDGs have been approved and funded by this money, and there will be a further call for new groups in mid-2012.

A new Research Secretary will be appointed in mid-2012
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 meets 4 times a year. The meeting follows on from the BAPN executive meetings as the Chair of the CSAC, the BAPN research secretary and the General Paediatrician with a Special Interest in Nephrology sit on both of these committees.

The CSAC has 9 members comprising of the chair, 2 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 was just one new appointment to the committee over past year - Dr Wesley Hayes replaced Dr Helen Jones as trainee representative.

NTN Grid process 2011 – there were just 2 applicants to the grid this year, both were shortlisted, interviews were held at the RCPCH on 01/12/2011 and 1 applicant was appointed and is due to start on the paediatric nephrology grid training scheme in London (Evelina/GOS) in September 2012.

The total number of current trainees is 13:

9 trainees are in clinical posts.

4 trainees are engaged in research

2 trainees have completed their CCTs, 3 are due to complete their CCTs in 2012, 7 are due to complete in 2013 and 1 in 2014.

There were 2 trainee educational meetings in 2011 - Manchester/January 2011, Nottingham/ July 2011 and 1 trainee educational meeting in January 2012 at the ICH - all 3 meetings were well attended and feedback positive. The CSAC chair attended these 3 meetings and the BAPN Research Secretary attended the most recent meeting to meet up with trainees and potential trainees to assess current progress, training issues and aspirations for future development.

Trainees are now working actively with the CS&G group regarding the development of paediatric renal guidelines building on established guidelines from adult renal care on the Renal Association Website. There are now designated lead paediatric nephrologists identified who are working with trainees to progress these.

There were 3 consultant paediatric nephrology appointments in 2011 – Drs Mc Keever and Convery in Belfast following the retirement of Prof Savage and Dr Belototsky in Hamilton, Canada. There are potentially 3 replacement posts ( + ? 1 new post ) to be advertised in 2012 - in Bristol, London (Evelina) and Glasgow.
The CSAC/BAPN continues to update information regarding future consultant retirements for optimal workforce planning.

The curriculum section in ‘The Framework for competencies for level 3 training in Paediatric Nephrology’ on the RCPCH website has been updated and amended by the CSAC. The proposed document has now been forwarded to the RCPCH training committee for approval with a view to replacing the ‘subspecialty specific conditions in paediatric nephrology’ in that document. The draft document has also been circulated to our current trainees for their information and guidance.

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 CSAC has had a number of interested enquiries. CSAC will need to work with the RCPCH to develop a framework to manage and monitor this process.

3 trainees in paediatric nephrology participated in the ST7A pilot in July 2010. It is anticipated that this exercise will be repeated for paediatric trainees in 2012 and we await further confirmation regarding this from the RCPCH. A working group for our specialty was convened by Dr Larissa Kerecuk which has now submitted a comprehensive number of scenarios directed at paediatric nephrology trainees to be used as a section of the circuit for ST7 paediatric trainee assessment.

**Young Consultant’s Report**

**Dr Simon Waller**

As ordinary member I have attended all executive meetings. I represented the BAPN at Transplant 2013 Parliamentary Reception (solid organ) and at the Launch of NHSBT Strategy for Living Donor Kidney Transplantation. I 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](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). Post taken by Dr Fluck
- An Executive may be appointed to carry out the core work, consisting of a Director, with secretariat support. The previous chair (Fiona Loud) has been appointed as Director.
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.

In comparison to 2010, the year 2011 has been a bit quieter.

Completed items to date

**Standards for renal biopsy:** renal biopsy standards for audit had been placed on the BAPN website by the end of 2010. A UK wide audit against these standards is proposed for 2012.

**Unit assessments:** A document has been placed on the BAPN website for individual units to use as a self-assessment against national standards. This document is based on a peer review document produced and used in the West Midlands.

**Nephrology Networks:** The committee contributed to the development of this document.

**Standards for management of hypertension in transplanted patients:** This documents was published on the BAPN web site and is available for individual units to use.

**Patient information leaflets:** Jan Dudley secured BKPA funding for this 2 year project and David Milford, Leah Krischock and Lyda Jadresic are working with her.

**Growth monitoring in CKD:** The committee was consulted on this document and after revision it has been placed on the BAPN web site for individual units to use for the purpose of audit.

Responses to consultation

**NICE Quality standards on CKD:** After initial resistance there is agreement that paediatric patients will be included.

**PD short guidance:** comments were submitted and the guidance was published in July 2011.

**AKI:** comments were submitted, David Milford and Lyda Jadresic representing BAPN.

**Phosphate and bone metabolism in CKD:** Response to request for comments, Rukshana Shroff accepted to scoping workshop.
On going work

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.

The process by which the guidance is produced is as follows:

- Authors revise adult document
- Draft document presented to CS&G committee
- Authors revise document (if necessary)
- Second draft document published on BAPN web site for comments from membership (1 month)
- Authors revise document (if necessary)
- Final document presented to Renal Association Guidelines Committee and published on BAPN and Renal Association website

The list of topics and proposed authors are:

Haemodialysis – Daljit Hothi
Peritoneal dialysis – Chris Reid
Peritoneal access – Carol Inward, Meeta Mallik
Assessment of potential kidney transplant recipient – Jan Dudley
Anaemia management in CKD – Jonathan Evans
CKD mineral and bone disorders – Rukshana Shroff
Post-op care of the kidney transplant recipient – Heather Maxwell
Communications Officer’s report

Dr Leah Krischock

www.BAPN.org.

A major part of my role as Communications Officer is updating the information provided on our website, including information on the activities of the BAPN, resource materials developed by the subcommittees, and links to other websites and organisations. The website provides 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. Archived editions of the eNews, and now the SPIN newsletters, are kept on the website. The website is also the public face of the BAPN, and has information on each of the thirteen paediatric renal units in the UK. I am always interested to hear comments from members regarding their website, particularly as to whether they think improvements can be made.

I continue to receive requests from families and patients looking for information on renal disease. In my role as BAPN Communications Officer I am a member of the BAPN/BKPA/RCPCH Patient Information Project board (chaired by Dr Jan Dudley) and I hope that in the future the next Communications Officer will be able to direct such enquiries to the extensive library of web based information resources which the Project Board will develop. In the meantime, I can provide draft information leaflets on a number of renal conditions to health care professionals for adaptation to local use. These topics are listed on the website.

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. Our responses to such guidelines and standards documents can be found on the Clinical Standards and Guidelines page of the website, and a list of consultations responded to can be found in the Business and History 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.

The Communications Officer serves a term of three years, and I am drawing to the end of my term. I have very much enjoyed working in this position, and I would like to thank all the members of the Executive Committee, as well as my colleagues at RHSC Glasgow, for their enormous support during my time in office. I am moving to Sydney in May 2012 so will be completing the last few months of my post from Down Under. I step down in October, and encourage applications to this interesting role - IT skills are not essential. I managed very easily to learn how to update the website and have no doubt anyone else will do the same.
**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.

Building on the 2009 survey done on behalf of the BAPN on paediatric renal networking, I was an active participant in the Paediatric Nephrology Networks Project group (RCPCH/BAPN) chaired by Mary McGraw, and the report has recently been published jointly by RCPCH, BAPN and NHS Kidney Care. This, I hope, will be fundamental to the future of paediatric renal networking.

We have recruited a further 10+ new BAPN members specifically designated as “BAPN-SPIN”, and I hope that these numbers will further increase. There are another at least 30 paediatricians with varying degree of “SPIN” (not in the BAPN). This is a heterogeneous group of paediatricians with varying degrees of expertise and work in nephrology. I have recently sent out an e-newsletter, available on the BAPN website, and I hope we will continue to expand our role.

Regarding training, the special training module in paediatric nephrology for level 3 trainees has been available for some time now. However, although there is considerable and recently increasing interest from trainees and from some centres, SPIN training remains relatively informal in practice, and it has been difficult to define the relative roles of deaneries, nephrology centres and local paediatric centres. The BAPN/CSAC has recommended that each nephrology centre has a nominated educational lead for SPIN training, and we are in discussion with the college about further formalization of training and assessment. Other special modules (e.g. neonatal) will have much larger numbers, and the smaller subspecialties may need more special attention.

(A complicating factor now is that the RCPCH has taken up the term “SPIN” to cover all subspecialty special interest training - previously SSM)!

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

Dr Wesley Hayes

Current Trainees
There are currently 15 paediatric nephrology national grid trainees. Seven trainees are currently in clinical training, three are undertaking full time research, two are post CCT, two are newly appointed to start training this year and one is on maternity leave.

Training Events
Two training events were held over the last year, organised by myself and JJ Kim. Both events provided an excellent forum for learning, discussion and networking for both national grid trainees and trainees with an interest in nephrology. The Nottingham event in July comprised a 2 day programme on the theme of transplantation and included a range of excellent speakers and received very positive feedback. This January we met for a further 2 day event at Great Ormond Street on the theme of dialysis. Again a wide range of excellent speakers contributed making this an invaluable training and networking opportunity with feedback to reflect this.

In addition to organised training events trainees continue to contribute to national and international meetings with representation at the ESPN in September 2011 in the form of several poster and oral presentations.

BAPN Trainee Involvement
Sheetal Bhojani took over from JJ Kim as trainee representative on the Audit and Registry Committee this year. In addition to attending BAPN and CSAC committee meetings I sit on the Clinical Standards and Guidelines Committee.

Presentations were given at the BAPN winter meeting in December by Sheetal Bhojani, Akhila Hassan and JJ Kim.

New Developments
A new curriculum for paediatric nephrology is in the final stages of development by Maggie Fitzpatrick and Kay Tyerman. The curriculum reflects new developments in paediatric nephrology and gives clarity to the standards of knowledge and skills expected in subspecialist training. It is expected that the new curriculum will soon be integrated into the RCPCH ePortfolio to guide educational supervision and enable trainees to log progress electronically.