PRESIDENT’S REPORT

Dear BPNA members

On your behalf, I took over the reins as President from Peter Baxter in January 2012, following the Annual Conference at London, hosted by Nottingham and Leicester.

Peter Baxter has been an able and dynamic leader. I thank him for his boundless energy and industry committed to the stewardship of the BPNA over the past 2 years. He has expanded the BPNA’s reach and influence nationally and internationally.

The annual conference in January 2012 was high in quality and educational content. Well done to the organising committee from Nottingham and Leicester.

The BPNA AGM has voted for going back to having our annual conference at different centres around the UK, from 2013. The next meeting is at Manchester between 23-25 January 2013.

Safe & Sustainable Paediatric Neurosurgery service review by Steers and Stower was published and recommended that units performing children’s neurosurgery should organise themselves into operational networks, guided preferably by geographic adjacency. The BPNA supports this model as collaborative working across a clinical network mean safe clinical practice, improving standards and good patient outcomes.

The report recommends that children with neurological problems should be under the care of appropriately trained and experienced consultant paediatric neurosurgeons. The standards document suggests that a consultant paediatric Neurosurgeon (PNS), should have at least 50% of the work load as paediatric neurosurgery and he/she should be involved in around 80 operations on children per year. This is requirement is likely to have significant implications on future paediatric neurosurgery services. It is probable that it will lead to contraction in the number of paediatric neurosurgery centres in England with inevitable withering of the full complement of services available in some of our current regional neuroscience centres. It is likely that the membership of the BPNA would be divided on whether this is desirable or not, with a probable majority opposing it.

Currently in-patient acute neurological care for complex patients, including those who may need neurosurgery is provided by paediatric neurologists at regional Children’s neurosurgical centres (CNCs) and some other larger specialist centres. There are very few stand alone Children’s neurological centres without children’s neurosurgical provision. The BPNA considers co-location of children’s neurological and neurosurgical expertise to be vital for accurate diagnosis and optimal management of children who require neurosurgery.

The recommended ‘Network model’ of organisation and delivery of care is potentially beneficial for paediatric neurology services as well in the future. From the BPNA perspective, it is a matter of regret to report that a performance review of a consultant paediatrician was undertaken recently by the paediatric neurology CSAC of the RCPCH. One is reminded of a previous such performance review from Leicester in 2003, highlighting many areas of concern in epilepsy care of children and young people. To me this emphasises the need for cordial and robust links between paediatric neurology centres and district level services within a clinical network for optimal patient outcomes.

(Continued on page 2)
National commissioning of paediatric resective epilepsy surgery came into being for the whole of the UK on 1 April 2011. The DCOH designated the following four centres for England and Wales, to begin new work from November 2012:

- Great Ormond Street Hospital and King’s College Hospital consortium
- Birmingham Children’s Hospital
- North Bristol NHS Trust and University Hospitals Bristol NHS Foundation Trusts
- Alder Hey Children’s Hospital NHS Trust and Central Manchester University Hospitals NHS Foundation Trust consortium

Current tertiary neuroscience centres hitherto offering paediatric resective epilepsy surgery for intractable epilepsy in England and Wales have to link up with geographically adjacent nationally designated centres in a clinical network and have regular multi-disciplinary meetings to discuss all children from infancy up to and including 16 years of age with drug-resistant epilepsy and who may be potential epilepsy surgery candidates. Children under 6 years of age, deemed suitable for epilepsy surgery must have their resective surgery at the designated centre and those over 6 years can have surgery at their local neuroscience centre after prior consensus. The new service is expected to increase number of operations to around 350 by 2015/16.

For all of Scotland the designated centre is the Royal Hospital for Sick Children, Edinburgh to provide the comprehensive resective paediatric epilepsy surgery.

I welcome this development as it will significantly improve epilepsy outcomes for children and young people.

The Health and Social Care Bill has passed in to law despite considerable misgivings and opposition from a majority of the profession. Responsibility for Health care delivery for geographically defined populations is being taken away from the now abolished Primary Care Trusts (PCTs) and Strategic health Authorities (STAs) to local and regional clinical commissioning groups (CCG), that has a majority of GPs and as well as hospital consultants and senior nursing and allied professionals.

A Paediatric Neurosciences Reference Group has been constituted under the chairmanship of Mr Ian Pople, consultant neurosurgeon from Bristol. It has several BPNA members including myself from neurology, neurodisability and rehabilitation backgrounds. This forum will have responsibility for scoping and recommending delivery of regional neurological, neurosurgical, neurodisability and rehabilitation services for children and young people to the regional CCGs from April 2013.

Rare diseases commissioning is also being devolved from the Advisory Group for National Specialised Services (AGNSS) to the Paediatric Neurosciences Reference Group. The BPNA membership had voted for national commissioning of services for rare diseases including neurotransmitter disorders, rare leucodystrophies, surgical treatment for complex movement disorders and DNA diagnostic services for rare peripheral neuropathies. They will be addressed shortly.

‘Epilepsy 12’ National audit is the first ever UK wide national audit of epilepsy care for children and young people that was commissioned by the Royal College of Paediatrics and Child Health. It critically examines the provision of health care for children and young people (CYP) with suspected epileptic seizures, against 12 standard measures, in the first 12 months following presentation to district level health services. Its origins can be traced back to the National Sentinel Audit on Epilepsy-related Deaths published in 2002 and the enquiry into epilepsy care of children and young people in Leicester performed by the British Paediatric Neurology Association and published in 2003. The findings of these led to widespread concern about the quality of epilepsy services for children with epilepsy and prompted a number of initiatives from the BPNA, including a proposal to audit the quality of epilepsy care for children in the UK.

For this audit, 186 units caring for CYP with suspected or confirmed diagnosis of epilepsy provided data regarding nearly 5,000 children. This was analysed against 12 different measures of optimal clinical care in suspected epilepsy, recommended by the National Institute of clinical excellence (NICE) and Scottish Intercollegiate Guidance Network (SIGN). Most importantly it included feedback from the children and young people themselves and their carers. 82% of CYP and 78% of carers gave positive feedback. Performance in most audit measures appears satisfactory. One area needing improvement is for greater involvement of specialist epilepsy nurses in clinical care. The audit is to be repeated in its present form on two further occasions in the next 24 months to seek consistency and assess improvements.

This is an excellent national initiative from the RCPCH on epilepsy care.

ACCEA 2012 round: Following previously circulated deadlines, a BPNA panel under chairmanship of Peter Baxter was convened in October 2011 and scored applications of members seeking BPNA support. We have already completed due process and will not re-open it. Members applying for a national award must do so via the ACCEA online system and upload their applications by 1 August 2012, so that the BPNA can upload its citation on behalf of the relevant members we are supporting in the current round. The closing date for the online ACCEA 2012 round is 17 August 2012.

Paediatric neurological education: BPNA and its members have been in the vanguard of developing and delivering high value training courses. Over 5,000 attendees have benefited thus far from the PET courses alone. The inaugural Movement Disorders course was oversubscribed. A course on paediatric headaches is coming on stream shortly. The Distance Learning Course in Paediatric Neurology is recruiting actively with increasing enrolment worldwide. I have constituted an ‘Education Committee’ with all the course leaders to oversee the planning, quality monitoring and delivery of our educational courses.

The RCPCH Spring Conference at Glasgow in May 2012 organised by Carlos de Sousa was very successful and the BPNA’s joint meeting with the British Paediatric Metabolic Disease group was well attended. The personal practice session on ‘Management of Paediatric Movement Disorders’ run by Paul Eunson had standing room only.

The BPNA is a robust and diverse group with 375 members. We are committed to developing service specifications, standards of clinical care and training in paediatric neurology and related disciplines and for the continuing education and support of our members.

V Ramesh
BPNA President
As an organisation we continue to grow both in membership year on year and in the range of educational activities provided by the BPNA. We are thankful to all members who contribute their valuable time and effort towards the organization and its activities.

Colin Ferrie will be continuing for the second term as National Training Advisor. The following have been elected as Deanery Advisors until December 2014: Cheryl Hemingway (North London), Elizabeth Wraige (South London, 2nd term), Saleel Chandratre (Oxford), Anirban Majumdar (South West), Neti Gayatri (Yorkshire, 2nd term). Congratulations to all the new post holders.

The demands on the Secretariat have been increasing and in order to ensure provision of a good service to BPNA members and customers we have redefined roles and employed an additional member of staff. This takes the number of staff employed for the BPNA to five, although the hours equate to 2.25 WTE.

Elaine Livesey, who will be familiar to many from PET2 courses and the conference, has moved into the newly created position of **BPNA Membership Secretary**. The purpose of this new position is to provide a more comprehensive service to BPNA members including supporting Executive members, course committees and special interest groups of the BPNA. Elaine also performs the accounts function at the Secretariat. Please contact Elaine about membership queries, room bookings for committees, circulating emails and adding information to the members’ only area of the website.

Email: Elaine@bpna.org.uk  
Hours of work: Monday, Wednesday afternoons & Friday mornings

Judith Newton, who has been with the BPNA since 2007, is now the Course Co-ordinator for 2-day courses (PET2, PET3, PET EEG, movement disorders). Judith is responsible for advertising courses and ensuring that attendees and faculty members receive a good service both before and during the course.

Email: Judith@bpna.org.uk  
Hours of work: Tuesday afternoon & Thursday morning

We welcome Sara Rowan to the BPNA Secretariat staff as the **Course Co-ordinator for 1-day courses** (PET1 & Headache). Sara will work with PET1 hosts to ensure their courses are fully booked and that attendees and faculty members receive a good service both before and during the course.

Email: Sara@bpna.org.uk  
Hours of work: Tuesday 10am-3pm, Friday 10am-3pm

Diane Rodie, **Distance Learning Course Co-ordinator**. Diane answers new enquiries about the Distance Learning course and supports enrolled students. Additionally Diane supports the Trainees meeting and DL study days.

Email: Diane@bpna.org.uk  
Hours of work: Monday, Wednesday and Thursday afternoons

Philippa Rodie, **Executive Manager**, is responsible for managing the Secretariat and all its activities, and for supporting development of BPNA initiatives.

Email: philippa.rodie@bpna.org.uk  
Employed full time
The UKCNRC is now three! At the beginning of the year I took over from Mike Pike as the Chair of Trustees, and this has been a useful period of strategic review. We have much to celebrate in what we have achieved in a short time, and have ambitious plans for the future.

As a Registered Charity, the main aim of the UKCNRC is of course to improve the lot of children with neurological disease through high quality medical research. I want to emphasise however that the UKCNRC is an organisation run by members of the BPNA, for members of the BPNA who of course share this aim. As the practitioners at the front line we see daily the need for such research, and are ideally placed to identify priority research questions. We want to help the paediatric neurology community become as research-active as some other specialties such as oncology, fully recognising the much greater challenges that we face in this area.

The UKCNRC will not be a “major league” primary funder of medical research for the foreseeable future. At present we see our role as a research idea “incubator”, using the resources we do have to help you develop initial research ideas to the point where they can be submitted as competitive grant applications. The primary resources at our disposal currently are the free and expert advice of the Research Design Service, John Coleman’s availability to support project development work in kind, and some very limited “pump priming” grant development funding for particularly promising ideas.

In achieving our vision our first step has been to establish the Research Design Service. This is an immensely valuable resource: please use it! A panel of the most research active paediatric neurologists in the UK supported by expert statistical and epidemiological advice, giving their time gratis to comment and improve upon initial research ideas. I urge would-be researchers not to see this as a problem (“another committee to get my research idea past”) but an immensely valuable opportunity.

It’s heartening to see the interest in research skills amongst trainees, and this year’s Trainees’ Day will in fact be devoted entirely to research methods and related topics, with an expert faculty largely drawn from the UKCNRC research panel.

We have ambitious plans to build on the UKCNRC’s capacity to support research in a number of ways, which we hope we will be able to bring to fruition and announce in coming months.

These are of course challenging financial times for any fledgling charity. We have been privileged to be supported by The Roald Dahl Foundation (now Roald Dahl’s Marvellous Children’s Charity) and this has made an immense difference to our ability to progress UKCNRC work. This funding ends in 2013 and we are actively alternative support.

In the meantime we would strongly encourage BPNA members to raise awareness of the UKCNRC’s work particularly with any families who may be expressing an interest in raising funds to support paediatric neurology research. If you have any such contacts please do not hesitate to contact me (rob.forsyth.newcastle.ac.uk) or the UKCNRC’s fundraiser donna.treanor@ukcnrc.co.uk.

Rob Forsyth

ROALD DAHL’S MARVELLOUS CHILDREN’S CHARITY

RCPCH Annual Meeting - Glasgow, May 2012

This year’s RCPCH Paediatric and Child Heath Annual Conference was held for the first time at the Scottish Exhibition and Conference Centre in Glasgow, from 22-24 May 2012. The BPNA hosted a joint session with the British Inherited Metabolic Diseases Group around the theme of neurometabolic disorders in childhood. The session was very well attended and we were fortunate in having a number of very high quality Guest Lecturers, as well as good platform presentations and a large number of posters.

The session was chaired by Carlos de Sousa from the BPNA and Peter Robinson from the BIMDG. Chris Verity from Cambridge began the session with an excellent overview of: Inborn errors of metabolism causing progressive neurological deterioration – lessons from the PIND study. He was followed by Manju Kurian from ICH, London, who gave a really good and brilliantly illustrated talk about: Genes, metabolism and dystonia in childhood. Mike Champion, from the Evelina Hospital, London presented an evidenced-based and practical: Approach to the diagnosis of inherited metabolic disease in children with neurodevelopmental disorders. Shamima Rahman from ICH, London, presented an exciting and wide ranging update about: Diagnosis and management of mitochondrial disease in childhood. The session closed with another excellent and relevant presentation from Evangeline Wassmer from Birmingham: Leucodystrophy - Identifying and treating inherited metabolic diseases of the white matter.

All in all, a very good afternoon which succeeded in covering a diverse range of topics in a way which was accessible to those from neurology, metabolic and general paediatric backgrounds. The success of the session and the good attendance emphasise the importance of continuing with these sessions at future RCPCH Annual Meetings.

Carlos de Sousa
Great Ormond Street Hospital, London
Website: those of you who are regular visitors to the BPNA website will have noticed that it has had a redesign. However, we have now reached the stage where a major overhaul of the functionality ‘behind the scenes’ of the website is needed as the association has developed and become more complex. Fortunately Philippa Rodie, our Executive Manager, has already been very proactive about this, and work is about to begin. The additional developments on the site will improve sharing of information, and in due course allow electronic payments of membership fees, conference fees, and the various courses run by the BPNA. The plan is for this additional functionality to go live from later this year. We will keep you updated as the work is completed.

Manpower Survey: As you will know the BPNA undertakes a Manpower Survey every two years. I undertook this at the end of December 2011/beginning of January 2012, and presented the initial data at the AGM in January. A special thanks needs to be given to all the Regional Advisors for providing the data which I have since compiled into a report that will be placed on the BPNA website in the Membership area. There is a lot of detailed information there but the key points can be summarised as follows:

- There are 96 whole time NHS consultant paediatric neurologists in the UK (defined as ≥ 7 NHS PAs), 7 part time NHS consultant paediatric neurologists (defined as ≤ 6 NHS PAs), and 16 academic posts at consultant level in paediatric neurology. Overall, there are approximately 106 whole time equivalent NHS consultant paediatric neurologists in the UK. There are fewer part time NHS posts in this survey than in the past, but this is likely to be secondary to a more explicit definition of part time working in this survey.
- The total number of whole time NHS Consultants has increased over time from 61 in 2002, to 95 in 2010, and to 106 in 2012.
- The total number of consultant in paediatric neurology posts, which includes whole and part time NHS and academic posts has increased from 67 in 2002, to 115 in 2010, and to 119 in 2012.
- It was estimated that NHS work equivalent to the activity of 9 additional whole time consultants was being performed without being funding.
- There were 2 consultant paediatric neurology posts funded but unfilled at the time of the survey.
- It is anticipated that 7.5 consultants will be retiring by the end of 2015. Over the same time period it is anticipated that 12 posts will become available at consultant level in paediatric neurology (appointment to posts following retirement and new posts). This indicates an average of 3 new appointments per year in paediatric neurology at consultant level over the next 4 years.
- 25 trainees are expected to gain CCT in paediatric neurology by end of 2015, an average of 6 per year. This indicates a surplus of 3 trainees with CCT each year for the number of consultant paediatric neurology posts becoming available each year over the same time period.
- A slight surplus of trainees over available posts is desirable to develop a flexible workforce allowing part time working/job sharing arrangements, appointment to posts that may not be filled because CCT holders are unable to relocate for personal reasons, and because CCT holders may choose to take up permanent positions outside the UK (4 since January 2010).

Next Assistant Secretary

My term in this elected post expires after a 3 year stint in January 2013. It has been a pleasure serving on the Executive and in being involved with the decisions taken by our association.

Please start thinking about applying for this post, about which I am happy to be contacted for further information. Your personal statement will be circulated in the autumn newsletter.

Jayesh Patel, Bristol
Jayesh.patel@uhbristol.nhs.uk
TREASURER’S REPORT

I have now been in the post of Treasurer for a full year and I am only just beginning to understand the complexities of the BPNA.

The final figures for the financial year 2011-12 are still not finalised but we anticipate an overall operating surplus in the region of £33,000. Full details will be available in the annual report, which will circulate with the winter newsletter.

Income from membership subscriptions was £51,770, which is down from £57,263 in 2009-10, such that activities arising from membership led to a net deficit of £431 without inclusion of indirect Secretariat costs. The direct costs include contributions to the Joint Neurosciences Council (JNC), the Committee of National Advisors, and the Neurological Alliance. The BPNA made a contribution of £5,000 to the JNC in support of its eBrain e-learning resource, which will be an asset available to BPNA members in the future. The number of ordinary members has fallen slightly, from 308 in 2010 to 299 in 2011.

During the past year, the Secretariat staff has expanded to a total of five people, with one full-time and four part-time members of staff constituting whole-time equivalents of 2.25 staff. Their functional roles have been redefined as: Executive members of staff constituting whole-time equivalents of 2.25 total of five people, with one full-time and four part-time.

Any intervention by the BPNA will be but a drop in the ocean. But perhaps the model that has been so successful in the UK can be adapted to be suitable for the developing world?

The challenge will be to design a framework that will neither simply be a one-off course nor set up a structure that will be reliant on UK BPNA input in perpetuity. We would wish to build “sustainability” into any course from the beginning such that, over time, the course is handed over to local clinicians trained and experienced in the PET ethos.

PET courses remain a large part of BPNA activity and require substantial support from the Secretariat. Commercial sponsorship for PET courses has steadily declined - from £40,500 to £37,500 to £34,000 over the past three financial years - and we have not as yet secured any commercial sponsorship for the current financial year. There are new opportunities in the development of iPET, the international PET courses.

Income from distance learning courses has grown steadily, with actual values of £28,283 and £44,078 in 2009-10 and 2010-11, respectively, and with an estimated value of £60,662 at the end of the financial year 2011-12. Direct costs have grown also, but there has been a steady growth in surpluses from these courses, which we estimate will be £22,344 during 2011-12.

We have introduced the first of our new Advanced Paediatric Neurology (APN) courses with the Movement Disorders course that was presented in November. The course made a surplus of £4,464, including £3,000 from commercial sponsorship that is being used to meet the costs of further course development.

Despite a small decrease in ordinary membership and the anticipated challenges of securing commercial sponsorship in a stressed financial and economic climate, the BPNA is proving to be a robust and resilient organisation, in large part due to the excellent support of its dedicated Secretariat staff, and we anticipate another financial surplus at the end of 2011-12. With so many creative ideas for new courses, and the popularity and expansion of the distance-learning courses, we should be set for sustainable and healthy growth.
Applications are invited for the MacKeith Prize. Self-nominations or nominations by any member of the Association are invited. The constitution states: Nominees should have made a significant contribution to Paediatric Neurology as judged by published work and be under the age of 40 years or within 5 years of obtaining a CCST, whichever is later, at the time of the next Annual General Meeting. The prize winner is decided by a panel convened by the Secretary and is invited to attend the next Annual Meeting as a guest of the Association where they present a paper and receive a prize of £500.

The process which will be followed will be as follows:

(i) Nominations should be accompanied by:
   a) A brief statement making the case for the candidate to be considered
   b) Copies of three papers on which the candidates contribution may be assessed
   c) References to two additional ‘back-up’ papers to be read should there be difficulty in making a decision on the first three papers.
d) A statement by the nominee indicating the nature of his/her contribution to the work described in these papers.

(ii) These should be sent electronically to secretary@bpna.org.uk. If this is difficult, please discuss with the secretary, Dr Sunny Philip, at the email address below or by post to BPNA Secretariat, Bridge House, Harrow Road, Bolton, BL1 4NH.

The closing date for applications to be submitted will be 31 August 2012.

(iii) A committee to consider the applications will be approved by the Executive. A decision should be arrived at before the end of October.

Sunny Philip
BPNA Secretary
Sunny.philip@bch.nhs.uk

Trainees’ Notes

The BPNA conference always marks a change of Trainee Reps. I am pleased to have the opportunity in the Spring Newsletter to thank the outgoing Deputy Rep Tony Hart for all of his support and hard work in the past year. The success of the 2011 Trainees meeting was in no small part down to Tony’s efforts, particularly in securing a number of the speakers for the day. Tony has been a vocal advocate for the trainee cause, with a clear commitment to ensuring that children receive care from Paediatric Neurologists with the best training possible for the role. Unfortunately Tony will not be able to continue on as Trainee representative due to his recent success in securing a consultant post (which I’m sure you’ll agree is a good excuse!). We wish him all the best in his new role. Taking over from Tony is Marjorie Illingworth, currently training at Great Ormond Street Hospital, whom I’m sure will be well known to many of you.

This year’s trainee meeting will be a departure from the normal format. I am frequently approached by other trainees looking for advice and guidance about how to get involved in research. Paediatric Neurology is by its nature a very academic specialty, although it often seems like there is a lack of guidance as to when and how to start to develop your research career, particularly for trainees early on in their training. In response to this the UK Children’s Neurological Research Campaign (UKCNRC) has developed an interactive day long seminar which will be hosted at this year’s trainee meeting, Saturday 6 October (booking form can be downloaded here: http://bpna.org.uk/pr3ss/wp-content/uploads/2012/04/2012Traineesmeetingform.pdf). The research day will combine personal accounts from a number of eminent researchers in the field of paediatric neurology, workshop sessions based around a practical research question and lectures addressing key themes (e.g. funding and support, ethics, data analysis and dissemination of results). It has been an exciting process developing this training day, and I would like to thank Richard Chin and John Coleman of the UKCNRC for their enthusiasm and commitment to championing involvement in research for all trainees, not just those on formal academic training pathways.

This summer will see a strategic review meeting for the BPNA council and I am very pleased that our new president, Venkateswaran Ramesh, has included training issues as a key part of this review process. You will all be aware of the substantial changes underway to the delivery of care in the UK. Over the next few years we are likely to see a substantial shift from the traditional model of Consultant Supervised Care (CSC) to models based more on Consultant Delivered Care (CDC). In many respects this will be less of a change for those of us working in the delivery of care to children, as a much greater proportion of care is already delivered directly by Consultants in comparison to our colleagues working in adult care. The Royal College of Paediatrics and Child Health (RCPCH) has already undertaken a body of work into CDC, which concluded that children would benefit from 24/7 consultant delivered care in the acute setting (http://www.rcpch.ac.uk/news/247-consultant-delivered-care-‘must’-effective-nhs-says-new-report). To what extent this can or should be extrapolated to the Paediatric Neurosciences remains to be seen, but the challenge facing the BPNA is how the Consultant Role (be that Neurology or Neurodisability) will evolve over the next few years, and how to prepare trainees for their future employment. I firmly believe that as the professionals to whom these changes will apply, it is essential that the views and opinions of trainees are sought, and I would welcome any comments you may have.

Finally, following the AGM in January a new category of Trainee Membership of the BPNA has been created, with the reduced rate of £50 (not including subscription to Developmental Medicine and Child Health which is an additional £86). Trainee membership is open to doctors working in posts prior to consultant appointment. To benefit from reduced costs of the Trainees days and the annual conference Trainees must be members of the BPNA. An application form can be found http://www.bpna.org.uk/pr3ss/wp-content/uploads/2012/03/applicationform.doc

Daniel Lumsden
BPNA Trainee Representative
traineesrep@bpna.org.uk
In the UK, there are currently many Consultant Paediatric Neurologists who are supervisors for the distance learning course, some within the same region. After looking at various worldwide models of supervision, we would like to move to a system in the UK where each region has a named supervisor. We would also like to provide supervisors for specific units who offer support via an online forum.

The distance learning course was developed initially in recognition of the reduction in working time for junior doctors, to ensure that trainees covered all areas of paediatric neurology in a structured way. The course is clinically-based learning, reinforcing a theoretical base but using the work-setting as the spring-board for this.

Student feedback praises the excellent materials and references, good theoretical background and systematic presentation of material, and high applicability of the material to the clinical setting. Students also comment that the material covered in the course often goes beyond that found in textbooks. The material and references are updated every three-years, and they provide excellent summaries of topics and guidelines for investigations and management.

We appreciate that the course has been felt to be too time consuming and over-burdensome and we are currently addressing this issue in each unit.

We believe that Tutors are pivotal in motivating and enabling participants to gain the most from the course. We would like to raise the recognition of the role of the Tutor. We hope that centres will support one colleague fulfilling this role and that Trusts will understand the importance of the role, enabling participants to complete the course and enhancing their training towards appointment as Consultant Paediatric Neurologists.

Why might you want to be a Tutor?

- Free access to the course material (it is an excellent resource for Consultants)
- Recognition as a Distance Learning course Tutor
- Belonging to a Faculty of writers and tutors, who have an annual meeting with speakers, gaining CPD
- Investing in the next generation of clinicians and academics with first class teaching and supervision

We are holding a meeting at RCPCH London on Friday 28 September 2012 to provide an opportunity to meet with other potential / current tutors and to explore the materials and feedback and establish the way forward in the UK.

Please contact Louise Hartley (lmhartley@gmail.com) or Philippa Rodie (info@bpna.org.uk) if you are interested in attending the Faculty meeting and being the DL Tutor for your region or are interested in being an online supervisor for a specific unit.
PET update

PET courses are running successfully throughout the UK, with continued good feedback. A steady state of attendance appears to have been reached with around 10 PET1 courses/year, and 6 PET2, days 1&2 and 3&4. A model running PET2 days 1-4 in parallel appears to lead to greater attendance. PET2 days 3&4 has recently been updated and ran successfully for the first time in Leicester in May. More emphasis has been placed on co-morbidities, pragmatics of drug treatment and therapeutic options for drug-resistant epilepsies. (Thanks to, Katharine Anderson, Sarah Aylett, Celia Brand, Krishna Das, Colin Dunkley, Sunny Philip, Sheila Puri, Steve Warriner and Cathy White).

PET3 ran successfully again this year in March, held in Edinburgh with key topics IGE, benign epilepsy syndromes, neurobiology, pharmacology, trials and epidemiology. Our keynote speakers included Dale Hesdorffer (USA), Amy Brookes Kayal (USA), Mark Richardson (Kings College, London) and Munir Pirmohamed (Liverpool). The workshops were highly interactive and debates lively. Targeted at Consultant Paediatric Neurologists, attendance was down on previous years, which may have been related to timing and proximity to other courses. We have reviewed possible reasons for this, and as a result will be surveying the BPNA membership in the near future to obtain their views. Thanks to the steering committee Ailsa McLellan, Sophia Varadkar, and Deb Pal, particularly Ailsa who steps down this year after 6 years in the role.

The first PET EEG courses for paediatricians ran successfully in Birmingham at the end of April. Although a one-day course, two courses were run on consecutive days to optimise use of faculty and review course material. Feedback was overall excellent. Participants benefited from small group teaching as well as lecture format. Further courses after review of material are planned for the end of the year. Many thanks should go to the development committee (Sunny Philip, Sushma Goyal, Zenobia Zaiwalla, Stewart Boyd, Krishna Das, Lesley Notghi and Arnie Shahwan) who have worked so hard to make this happen.

Further standards with regard to those who teach on the courses have been set. These include that all teachers should be members of the BPNA, they should have all attended a BPNA Train the Trainers or Generic Instructor Course, and should show continued commitment to teaching on the courses doing so at least once every two years. It however is recognised that especially course directors would benefit from further training or update, and therefore such will be arranged on an annual basis, likely to follow the Train the Trainers course. As you will see from the separate report, International PET is also now well into discussion with a pilot planned for the end of this year in Qatar, and another next year in Nepal.

Foundation PET is proceeding, seen as a series of lectures for non-health professionals delivered by epilepsy specialist nurses. Colin Dunkley is establishing closer work with ESNA to take this forward towards a pilot. Thanks to Frances Gibbon, Geoff Lawson and Margaret Wilson who have developed the material so far.

I will take this opportunity to thank all those who continue to be involved, both in course development and delivery of courses throughout the year.

Helen Cross
Chair, PET Steering Group

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**PAEDIATRIC headache training**

This new BPNA course has been designed to improve knowledge and skills amongst health professionals who care for children and young people with headache. Course content has been developed by Ishaq Abu-Arefeh, Mukhlis Madlom, Ravi Singh, William Whitehouse, led by Rachel Howells.

In 2013 this one-day course will be supplemented by a second one-day course for health professionals who require more in-depth training in headache management, eg paediatric neurologists. Day 1 will need to be completed prior to attending day 2.

Anyone interested in joining the faculty for Headache courses, please contact Rachel Howells (rachel.howells@nhs.net).

The first course is being held on Friday 9 November 2012, at the Aston Business School, Birmingham.

By the end of the course, participants will be able to:

- Take a headache-focussed history and undertake a relevant examination
- Classify headache based on this information alone (reducing reliance on investigation)
- Learn about pathophysiology of headache
- Know which elements of the history/examination mandate brain imaging or other tests
- Diagnose and manage migraine, migraine variants and other primary headache types
- Diagnose secondary headaches and take initial steps in their management
- Know how to set up a local headache service

This one-day course will be delivered by paediatricians and paediatric neurologists with expertise in headache. Please go to www.bpna.org.uk/headache to see the full programme and download a booking form. The course fee is £189.00.

For further information please email Sara Rowan at sara@bpna.org.uk or telephone 01204 492888.
National Grid Interviews

These were held at the RCPCH on 22 November 2012. The interview panel comprised Peter Baxter, Ruth Williams, myself and Dr Helen Goodyear who was our independent chair. Dr Goodyear is a paediatrician from Birmingham. We shortlisted 12 candidates and, based on the most recent BPNA Manpower Survey, hoped to appoint 7. Seven centres submitted training programmes. As ever those applying to the Grid were varied in their training backgrounds, experience to date and motivations to be paediatric neurologists. The candidates were assessed and scored using a combination of their application forms, a presentation given to the committee the title of which was only given to them on the day of the interview and on their response to questions put to them at the interview. The committee is tasked both with assessing if each individual candidate is considered suitable to train in paediatric neurology and, if they are, to rank them against the other candidates. The committee only scored 5 of the candidates as being suitable for training in the subspecialty. All 5 were subsequently placed in training programmes. Inevitably both unsuccessful candidates and centres which had submitted training programmes to which no candidate was matched were disappointed. However, maintaining appropriate standards is crucial to the future well-being of paediatric neurology. Our independent chair was particularly supportive of not appointing if candidates were not considered of sufficient calibre. An important challenge for the BPNA in the years ahead is how to ensure we attract bright trainees into paediatric neurology.

The paediatric neurology CSAC, with the support of the BPNA and the neurodisability CSAC, asked the RCPCH to consider merging the interviews for the Neurology and Neurodisability Grids. This is seen as the first step in the possible merging of the two CSACs and CCTs. The proposal was accepted and will be implemented for the next round of grid interviews. For now, candidates will still apply for either neurology or neurodisability (or both) and appointments will be to either neurology or neurodisability.

Penultimate Year Assessments (PYAs)

These are being held on 23 May 2012 at the Royal College of Physicians and Surgeons of Glasgow. The committee will comprise Venkateswaran Ramesh, Alice Jollands and myself. There are 5 trainees nearing the end of their training whose progress to date will be scrutinized, hopefully identifying any problems in sufficient time to allow them to be remedied. Previous experience is that there are no difficulties with most trainees but each year potentially significant problems are identified. The CSAC then works with the relevant training centre and deanery to find solutions.

The Joint Neurosciences Council (JNC)

I continue to represent the BPNA on the JNC as well as being its Honorary Secretary and acting Treasurer. My time in office as secretary has expired and I am hoping someone else will be appointed to this role soon. The JNC is now registered as a not-for profit Company Limited by Guarantee (previously it was an Association). This change protects individuals from liabilities connected with the JNC and was necessary given the potential for the JNCs distance learning programme. A management board is now overseeing the further development and marketing of their distance learning programme.

New Courses

Part of my role is the development of new courses. The first Movement Disorder Course, developed by a superb team led by Alasdair Parker, was held in Cambridge in November 2011. It was a great success and will be repeated this year. Its format is similar to the PET 2 courses.

Rachel Howells is leading the development of the Headache Course, the first of which is due to held in Birmingham this November.
Young Epilepsy (the new name for The National Centre for Young People with Epilepsy) and the Neurosciences Unit of UCL of UCL, Institute of Child Health have now held 3 annual meetings on the cognitive and behavioural problems of children with epilepsy. These have investigated providing an integrated service for children with epilepsy and which recognizes that at least 50% have multiple impairments and that the majority of these needs are not met. Much of this arises from the way in which paediatric and paediatric neurology services have been set up in the UK with CAMHS services being part of child and adolescent psychiatry services. There are initiatives to help and the 3rd of these meetings was held on 8 March 2012, which included an account of a new initiative for behaviourally disturbed children in Chesterfield.

The 3rd meeting was on behaviourally disturbed children. The target audience was for paediatric neurologists, paediatricians, child and adolescent psychiatrists, therapists, social services, nurses and carers.

**The speakers included:**

**Dr Michael Morton** (Child Psychiatrist) explained the interplay of illness, treatment, developmental, psychological and social factors in the mind and brain. The implications of the clinical manifestations require a specific epilepsy diagnosis, the impact of anti-epilepsy drugs on brain and behaviour and the educational and social implications of the illness. He recognised that current models of care are not always suited to the needs of children and young people with epilepsy.

**Professor Eric Taylor** (Professor of Child & Adolescent Psychiatry) on the contribution of ADHD in children with epilepsy is based upon a careful recognition of a behavioural style of chaotic activity which induces impulsiveness and inattention. In severe cases, medication can be very helpful with or without epilepsy.

**Professor Christopher Gillberg** (Professor of Child & Adolescent Psychiatry) examined the contribution of Autistic Spectrum Disorder and that as many as 40% of children with epilepsy have ASD but very commonly associated with cognitive impairment, ADHD and movement disorder. These produce a range of problems for the children which require specific techniques for management.

**Dr Paramala Santosh** (Reader in Developmental Neuropsychiatry & Psychopharmacology) spoke about the pharmacotherapy for difficult and violent behaviours explaining the need for individually designated but coherent treatments.

**Beth Irwin** (Epilepsy Nurse Specialist) maintains the UK Epilepsy and Pregnancy Register and contributed new data on the effects of AEDs on pregnancy.

**Dr Rod Scott** (Reader in Paediatric Neuroscience) was able to find only a small number of papers summarising the effect of brain dysfunction and concentrated on the animal models of early dysfunction particularly using fluothane.

**Professor Francesca Happé** (Professor of Cognitive Neuroscience) and Liz O’Nions (PhD student) are conducting a study of Pathological Demand Avoidance Syndrome. They were able to give us progress on the first of these studies which suggest that the condition may have features not always identified within the Autistic Spectrum Disorder model. These particularly include manipulative behaviour.

**Dr Heather McAlister** (Consultant Learning Disability Psychiatrist) described how she is working within a multidisciplinary Learning Disability Child and Adolescent Mental Health Services (CAMHS) team at Chesterfield which is actively supporting staff dealing with difficult behaviour. This involves medical, educational and parental needs and looks to be one of the first of such initiatives though further are planned and beginning to appear.

**Dr Lisa Rippon** (Consultant Psychiatrist) gave her experience of the legal issues from a clinical standpoint.

**Dr Mike Kerr** (Professor Learning Disability Psychiatr) spoke about very difficult behaviour in children with epilepsy as they approached transition emphasising the need to examine discreet mechanisms.

**Dame Philippa Russell** (Chair of the Standing Commission on Carers) completed the day with an account of how her life had developed to meet the changes that had arisen in her life. She was able to relate this to her and others predicaments.

**The Outcomes**

We need to recognise the multiple routes that lead to difficult behaviour and that they continue to require diagnostic and management skills. Few of those presenting with such a problem with epilepsy have a single pathway and they often require re-evaluation medically and therapeutically.

Epilepsy and difficult behaviour require management together by a team with one taking the lead.

We need better studies on the clinical manifestations of this group of children.

We await the final results of the Pathological Demand Avoidance Syndrome study.

The initiative in Chesterfield was most encouraging and I will follow up this initiative.

The predicament of parents, particularly of the young, can be extremely severe with doctors denying responsibility for the problem. A key worker to help the family with appropriate resources seems essential. Only a small proportion of families get the help they need and this must impact upon the final outcome.

**Brian Neville**
Emeritus Professor of Childhood Epilepsy
bneville@youngepilepsy.org.uk
GENERAL INFORMATION
This annual practical Movement Disorders course is aimed at consultant and trainee paediatric neurologists, and specialists involved in either the diagnosis or management of these interesting disorders.

The course has been developed by an expert steering group: Martin Smith, Birmingham (chair); Manju Kurian, London; Mary King, Dublin; Lucinda Carr, London; Jean-Pierre Lin, London; Alasdair Parker, Cambridge; Arni Majumdar, Bristol and Colin Ferrie, Leeds.

There will be particular emphasis on:
- How to assess these children in practical terms that can guide the clinician in a busy clinic
- Diagnostic issues from simple home videos through to biochemical and genetic analysis
- Classification of common movement disorders and identification of rarer ones
- Practical difficulties with their management in terms of state of the art drug and therapeutic input, acute issues, as well as more practical issues around multi disciplinary and allied health professional support

The format of the course will be immediately familiar to anybody who has attended the PET courses. A mixture of both workshops and lectures, with interactive sessions will allow attendees to bring their own clinical experience to the group’s attention. Attendees will need to participate in the interactive and debate format of the course.

This course complements the BPNA distance learning course Unit 4 ‘Central motor deficits; congenital and acquired spinal cord disorders’ which is available to study online. For further details of this please go to: www.bpna.org.uk/DL.

DATES AND LOCATION
This two-day course is being held at Wolfson College, Cambridge on 10-11 September 2012.

COURSE PROGRAMME
Please go to:
www.bpna.org.uk/movement-disorders for the full programme.

COURSE DINNER
The course dinner will be held on Monday evening at one of the splendid colleges situated along the river. Depending on the weather, we will arrive by punt.

ACCOMMODATION
Accommodation is available at Wolfson College at £70.00 B&B per night.

COST
Course fees:
- BPNA members £300.00
- Trainees £300.00
- Non members £330.00

Course dinner: £35.00
Accommodation: B&B per night £70.00

FURTHER INFORMATION
Please email Judith Newton at:
Judith@bpna.org.uk or telephone 01204 492888.