## Report of the Trustees and

**Unaudited Financial Statements for the Year Ended 31 March 2020** 

for

**British Paediatric Neurology Association** 

	ļ	Page	e
Report of the Trustees	1	to	20
Independent Examiner's Report		21	
Statement of Financial Activities		22	
<b>Balance Sheet</b>		23	
Cash Flow Statement		24	
Notes to the Cash Flow Statement		25	
Notes to the Financial Statements	26	to	44
<b>Detailed Statement of Financial Activities</b>	45	to	48

The trustees present their report with the financial statements of the charity for the year ended 31 March 2020. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

#### President's Report

I am pleased to introduce our annual report for the financial year 1 April 2019 to 31 March 2020. This has been another highly successful but challenging year in which we have successfully fulfilled our charitable aims in the fields of education, research and professional support and continue to do so despite the advent of the coronavirus pandemic.

Our educational programme continues to run successfully with paediatric epilepsy training (PET) courses, and courses in neonatal neurology (NeoNATE) and children's headache (CHaT). The epilepsy courses have been delivered both in the UK and internationally and the course has been translated into Spanish in preparation for roll-out in South America. Translation into French has started, in preparation for courses in francophone countries in Africa. We have forged a constructive partnership with the International League Against Epilepsy (ILAE) to facilitate the international delivery of PET. In addition to our ongoing courses, we have completed the development of a new course dealing with the management of disorders affecting muscular tone and we are developing a new course on the management of acute and emergency neurological problems in children.

From a research perspective, we continue to support a PhD fellowship programme in conjunction with Action Medical Research. We have also embarked on a research priority setting project with the help of the James Lind Alliance to help clarify what areas of research in child neurology are considered most important to address by ourselves and our stakeholders.

It is important that the BPNA both supports its membership and reflects their concerns. We continue to run a professional mentoring scheme and have initiated an annual survey of paediatric neurology centres to detail comprehensively both workforce and service delivery on a national scale. Our membership have been particularly concerned with training opportunities for our trainees and there has been active discussion about the need for paediatric neurology to be recognised as a specialty in its own right in order to safeguard the quality and length of training. These discussions will continue and we will explore options with the Royal College of Paediatrics and Child Health.

There have been specific challenges that the Association has had to meet this year. The first concerns the issue of the use of unlicensed cannabis based medicinal products in childhood epilepsies. The Association, at the request of the Chief Medical Officer and NHS England, conducted a review of the clinical and scientific evidence in this area and published interim guidelines for clinicians. They also actively participated in the development of NICE guidelines in this area. Both guidelines have emphasised the need for further research and the BPNA were actively involved in submitting applications for funding from NIHR for research trials.

The second challenge concerns the advent of Covid-19 that has impacted much of our activity. The BPNA acted quickly, cancelling face to face educational events from late February 2020 and adapting to delivering education online. We also quickly recognised that coronavirus resulted in a significant increase in demand for professional support: Covid-related clinical guidance; personal support; and meeting the needs of trainees, whose access to training were limited as an unintended consequence of the NHS response to Covid-19. To meet these needs BPNA has developed Covid-19 paediatric neurology guidance, increased mentoring capacity and provided additional resources to Special Interest Groups and additional training resources to Trainees. We continue to meet our charitable aims despite the difficulties imposed by the global pandemic.

All our activities are underpinned by the activities of our secretariat and the voluntary participation of our members who give their time enthusiastically and generously. We are so grateful to them all.

Professor Finbar O'Callaghan BPNA President (2018-2021)

#### **OBJECTIVES AND ACTIVITIES**

## Objectives and aims

The British Paediatric Neurology Association (BPNA) is a charitable incorporated organisation registered with the Charity Commission for England and Wales on 6 November 2014 with the charity number 1159115.

The objectives are to promote the health and well-being of children with neurological disorders through:

- · The training and education of professionals working in the field of paediatric neurosciences;
- The promotion of research into the causes, effects and treatments of neurological disorders affecting children and young people;
- The improvement of knowledge of professionals, the public and patients and their families through scientific and educational meetings; and
- The provision of professional support to members to facilitate the delivery of the above objectives and work with health service planners and providers to achieve this aim.

### Main activities undertaken in relation to the purpose

Please see full details of each activity provided in 'Achievement and performance'.

- 1. Training the next generation of paediatric neurologists in the UK.
- 2. Educating professionals in the diagnosis and management of:
  - Epilepsy, through provision of Paediatric Epilepsy Training (PET) and Expert to Expert: Epilepsy courses:
  - Movement disorders, through provision of Expert to Expert: Movement Disorders;
  - Headaches, through provision of Children's Headache Training (CHaT) courses;
  - Neonatal neurology (NeoNATE) courses; and
  - Children with any type of neurological condition through its comprehensive online distance learning course.
- 3. Improvement of knowledge of professionals, the public and patients through the annual scientific meeting held in January.
- 4. Promotion of research through:
  - · British Paediatric Neurology Surveillance Unit (BPNSU); and
  - · Paediatric neurology research fellowship.
- 5. Provision of professional support through:
  - Mentoring;
  - Team support;
  - · Special interest groups; and
  - Clinical governance

### **Public benefit**

The trustees have had regard to the Charity Commission's guidance on public benefit in considering activities during 2019-20. They sought to meet the public benefit of promoting the health and wellbeing of children with neurological disorders in the UK and globally through the initiatives and projects listed in the section 'Main activities undertaken in relation to the purpose'.

#### Grantmaking

The first fellowship was awarded to Dr Apostolos Papandreou, who works at University College London, who completed his fellowship in September 2019. During the year the charity continued to provide a research training fellowship, jointly funded with Action Medical Research. A second fellowship to commence September 2019 was not awarded and the total cost in 2020 was £Nil (2019 - £30,000).

#### ACHIEVEMENT AND PERFORMANCE

### Charitable activities

#### 1. Training

#### 1.1 - Paediatric Neurology Sub-specialty Training

The BPNA continues to have responsibility for training paediatric neurologists in the UK with BPNA members serving on the Royal College of Paediatrics and Child Health (RCPCH) College Specialist Advisory Committee (CSAC) for neurology. The committee is Chaired by the BPNA President.

The BPNA and neurology CSAC remain concerned about the impact of the GMC Shape of Training (SoT) plans on paediatric neurology training. In January 2020, the BPNA conducted a vote to assess views of how best to support paediatric neurology training in the future. Consultant paediatric neurologists and paediatric neurology trainees members were eligible to vote and there was an 80.4% turnout. 93.4% voted to pursue GMC specialty status for paediatric neurology rather than maintaining the status quo of subspeciality status under the parent specialty of paediatrics. At the request of the membership, the BPNA and CSAC have asked RCPCH to support us in progressing GMC specialty status and await their response.

#### 1.2 - New curriculum

Trainees and their educational supervisors are becoming more familiar with the level 3 neurology 'Progress' syllabus, which was launched in August 2018. The BPNA Training Guide to Neurology which is published on the RCPCH website, continues to provide more specific and structured information on how to achieve the learning objectives and capabilities for level 3 neurology (grid) training. The CSAC are exploring the possibility of refining the Progress Curriculum to incorporate more of the detail of the training guide to enhance trainees ability to evidence their training on the e-portfolio.

## 1.3 - Appointment of new Grid trainees

11 applications were received for the 2020 grid training programme. There were 5 grid training schemes available, but only 2 candidates were deemed suitable for appointment after interview in November 2019. A further trainee, already successful in their appointment as an academic clinical fellow, met the criteria for grid appointment and has taken up a post in London. It is disappointing, at a time when we are struggling to fill consultant paediatric neurology posts, not to optimise training opportunities. The BPNA and the trainee representatives have been looking at further strategies to encourage junior doctors to consider a career in paediatric neurology, with initiatives to aid prospective trainees in making successful applications.

### 1.4 - Assessment and Support for Existing Trainees

23 trainees received face-to-face CSAC progression interviews in the last year, 17 at the annual trainees meeting in May 2019 and the remainder at the annual BPNA meeting in January 2020. All were deemed to be making good progress towards achieving their competencies and we were pleased to hear that all grid training centres were providing excellent training opportunities. There are challenges for some trainees to access outpatient activities in specific centres and we will support the local teams to address this.

## 1.5 - Special Interest (SPIN) module in Epilepsy

The number of people undertaking SPIN in Epilepsy has increased during 2019-20

#### 1.6 - Assessment of Equivalence in Training

The neurology CSAC has a role in evaluating training for those who have not followed a UK grid training programme. Dipak Ram, the CSAC assessment advisor, takes a lead in this activity, essential for maintaining the integrity of neurology training.

A doctor can request entry on the specialty register via the GMC CESR route if part of the training has been done overseas. If their initial application is deemed suitable by the adminstrators at the GMC, then the CSAC will review the neurology component of their training and determine whether it has been equivalent to that of a grid trainee in the UK. Only training in the 5 years prior to the CESR application can be considered and, if successful, the applicant will be entered on to the specialty register.

If a trainee cannot apply for CESR accreditation, they can apply to the CSAC to determine whether their training has been 'equivalent' to that of a UK grid trainee. Given the difficulty in adequately assessing training via the generic NHS shortlisting programme and /or during a brief interview, this is a more robust method of supporting the RCPCH representative at appointment advisor committees in ensuring that candidates applying for a consultant paediatric neurology post are suitably trained to fulfil the role. This 'service' offered by the neurology CSAC was presented to the RCPCH AAC representative in 2019. The RCPCH were supportive of this initiative and several other CSACs have expressed an interest in following this strategy. Of note, a 'CSAC approval of training' in those NOT in an establish UK grid training post or applying for CESR, does not allow entry on the specialty register.

In 2019-20, the CSAC received 8 requests to assess a doctor's neurology training. Of these 3 were approved. In the majority, their training was judged not to be of the standard required for a grid trainee at the end of their neurology training.

#### 1.7 - Approval of New Posts

Job plans for all new consultant paediatric neurologist posts submitted by hospitals to the RCPCH for approval are reviewed by the neurology CSAC. The Generic Guide to Consultant Paediatric Neurologist Job Planning published by the BPNA in 2018 has been invaluable in supporting centres in ensuring their jobs are sustainable and will allow new consultants to meet the needs of children and young people with neurological disorders. Final approval for consultant paediatric neurology jobs is given by the RCPCH officer.

#### 2. Education

346 BPNA members directly contributed to the development and delivery of courses during 2019-20. This is 70% of UK ordinary members and 43% of overseas members. This demonstrates the strong motivation and engagement of members, and the trustees wholeheartedly appreciate this commitment to teaching and training.

## 2.1 - Paediatric Epilepsy Training (PET)

PET teaches safe standard epilepsy practice to clinicians, using consensus-based, peer-reviewed, standardised materials linked to internationally recognised clinical guidelines. Introduced to improve standards of care of children with epilepsy, we aim to deliver courses throughout the UK every year: 10 x PET1 (1-day course), 6 x PET2 (2-day course) and 6 x PET3 (2-day course).

Since 2005 to 31 March 2020, 10,415 UK clinicians have attended a PET course (689 in 2019-20; 822 in 2018-19; 704 in 2017-18), contributing to improving the standards of diagnosis and management of children with epilepsy in the UK. The number of attendees in 2019-20 was reduced due to the cancellation of several courses following the government restrictions secondary to the COVID19 outbreak. In response to the outbreak we have introduced an online version of PET1 (one course with 36 attendees ran in June 2020). In the future, we plan to develop these educational courses further, to offer the association flexibility in options for course delivery in a post-COVID19 era.

The PET123 course materials were updated by a team of international clinicians in 2018. The updated materials were used in the UK from 2019. A Consultant Paediatrician with a special interest in epilepsy is employed for 4-hours per week to manage course development.

#### 2.2 - Children's Headache Training (CHaT)

This one-day course is delivered by paediatric neurologists and paediatricians with an expertise in the management of headache. The purpose of CHaT is to improve knowledge and skills amongst health professionals who care for children and young people with headache.

CHaT course materials were updated by a UK team in 2018.

Four CHaT courses run per year around the UK and are extremely well received. Since 2012, 1,045 clinicians have attended CHaT (137 in 2019-20; 139 in 2018-19; 160 in 2017-18). During 2019-20 CHaT welcomed international attendees from Iraq, Italy, India and Romania.

## 2.3 - Neonatal Neurology Assessment and Treatment Education (NeoNATE)

Infants born at term or prematurely are susceptible to neurological conditions whose long-term outcomes can be much improved by effective early recognition and intervention. This practical 2-day course was introduced in 2014 to provide training for paediatricians and neonatologists caring for newborn infants in district general hospitals. It is delivered by paediatric neurologists and neonatologists, and this unique course gives a complementary perspective on a wide range of neurological conditions.

NeoNATE course materials were updated by a UK team in 2018.

Since 2014, 556 clinicians have attended NeoNATE (94 in 2019-20; 142 in 2018-19; 96 in 2017-18). To meet demand, in 2018-19 the number of NeoNATE courses was increased from two to three annually, however due to coronavirus restrictions only two courses ran during 2019-20. During 2019-20 NeoNATE welcomed international attendees from Australia, Argentina, Belgium, Estonia, Hong Kong, Italy, Mexico, Netherlands, Portugal, Saudi Arabia and Singapore.

#### 2.4 - Expert to Expert

International keynote speakers and UK faculty deliver an annual 2-day course, providing continuing professional development for Consultant Paediatric Neurologists from the UK and globally. On alternate years, the course focuses on Epilepsy or Movement Disorders.

Expert to Expert: Epilepsy took place in Manchester on 28-29 November 2019, with 28 attendees. International delegates attended from Canada, Egypt, France, Italy and Malaysia.

Expert to Expert: Movement Disorders - the next course was planned for autumn 2020 however, due to coronavirus restrictions, has been postponed to spring 2021.

## 2.5 - Approaching Children's Tone (ACT)

Children with abnormal muscle tone deserve prompt recognition and timely access to appropriate investigation and treatment, particularly with the availability of new therapies for neuromuscular conditions and cerebral palsy. In view of this, during 2019-20 the BPNA has developed a new BPNA short-course on tone management in children called 'Approaching Children's Tone' (ACT). The first course should have been delivered in May 2020, but this has been postponed due to coronavirus restrictions.

## 2.6 Acute Paediatric Neurology

It is estimated that about a third of all paediatric emergencies are neurological and about a quarter of all admissions to PICU are primarily neurological (not counting the large number of PICU patients that develop a neurological complication of a non-neurological disorder). In addition, a significant number of PICU admissions are the result of medical complications of neurological disability" (Generic guide to consultant paediatric neurology job planning. BPNA, 2018).

BPNA and APEM agree there is a need for education on children presenting with acute neurological problems. We are aware of the volume of children attending emergency departments with neurological presentations, and of the anxiety this can create for the receiving paediatricians and trainees, who often feel inadequately trained in acute paediatric neurology. In 2019, the BPNA committed to developing an acute neurology course for emergency department staff. This course will be jointly supported and endorsed by the Association of Paediatric Emergency Medicine (APEM).

## 2.7 Fetal Neurology

Counselling of families whose fetus has a neurological abnormality is a complex area of medicine, involving a wide range of conditions, difficult ethical and legal issues. Families have a right to receive the best information they can at this stressful time. In 2019, the BPNA committed to developing a Fetal Neurology course aimed at neonatal, paediatric medical staff, obstetricians and midwives. The aims of this course are to: improve training for anyone involved in caring and counselling a family whose fetus has a neurological abnormality; promote collaboration between obstetric, neonatal, neurological and neurodisability colleagues; stimulate research and collaboration between these professional groups. A multi-disciplinary team has been convened to write the course content.

## 2.8 - Distance Learning in Paediatric Neurology

Distance Learning (DL) provides systematic and comprehensive learning, delivered online for trainee paediatric neurologists, paediatricians and established specialists. The course covers the whole of paediatric neurology and participants may enrol for one unit or the whole course. DL fees are differentiated by country according to the World Bank economic classification to widen access to doctors worldwide, in line with BPNA charitable aims. A Consultant Paediatric Neurologist is employed for 4-hours per week to direct and oversee the revision and rewriting process. The Distance Learning steering group has been reconvened with one or two BPNA expert members overseeing each unit.

A total of 571 doctors have enrolled for the whole course since 2004 (2019-20, 30 enrolments; 2018-19, 46 enrolments; 2017-18, 43 enrolments;). During this year, there have been 130 enrolments on individual distance learning units, by 121 people from 29 countries. The highest proportion of enrolments are from the UK, 45% (59 of 130).

Following analysis of students enrolling on DL, we have been revising the content material in line with the needs o of the students. We found students are working in both high and low & middle income countries, and are mainly consultant and trainee paediatricians, with only 8% of this year's enrolments being paediatric neurology trainees. In addition, most students have also attended at least one of the BPNA face-to-face courses (PET, CHaT, NeoNATE). Unit 6 (Epilepsy) and Unit 3 (Neurodevelopment and Neuropsychiatry) have been rewritten during 2019-20. £14,116 was allocated from BPNA reserves to fund updating DL course materials, of which £6,000 has been used during this financial year.

Distance Learning complements BPNA short-courses, providing depth and extending the knowledge gained at a one and two day course. Working with respective short-course development teams, explicit links are being provided in DL units to reinforce the learning provided the related short-courses. Thus we encourage attendees at PET to study Unit 6 (Epilepsy), NeoNATE attendees to study Unit 2 (Neonatal Neurology), CHaT attendees to study Unit 12 (Headache) and attendees at the new ACT (Tone course) to study Units 4 and 5 (Neuromuscular and Central Motor Disorders).

We are indebted to the Consultant Paediatric Neurologist volunteer tutors globally, who give their time to tutor trainees through the course, together with all those Consultants of varying subspecialties who have so generously contributed by speaking at study days.

Following a survey of DL students, the Executive committee has agreed to pursue making the whole course an MSc, accredited through a UK university. This aim was not able to be pursued during 2019-20 due to the redirection of resources to respond to issues related to cannabis based medicinal products. It is hoped to pursue the MSc during 2020-21.

#### 2.9 - International Short-Courses

A 4-year partnership was established between the BPNA and the International League Against Epilepsy (ILAE) to facilitate the roll-out of PET worldwide. The initial memorandum of understanding is for 4-years (2018-2021) to a value of £161,156. The second year of the partnership has been very successful.

Roll-out is achieved through a healthcare partnership with the national paediatric or epilepsy organisation. A UK faculty team delivers a 3-day launch programme in-country to faculty teams recruited locally, who commit to delivering a minimum of one PET1 per year for 5-years. The purpose of launch is to train the local team to deliver PET1 locally without any external faculty members being required in future.

Trustees are cognisant of the need to ensure international launch and delivery of courses is sustainable and that all courses meet our defined quality standards.

The total number of attendees outside the UK and Republic of Ireland is 4,141 (PET1 = 3,335; PET2 = 367; PET3 = 165; iPET = 274; Trained as faculty = 160).

## 2.9.1 - Middle East & North Africa (MENA)

A trained committed faculty from Qatar, United Arab Emirates, Sudan and Egypt work together to deliver PET with support from the UK.

Middle East: The total number of attendees in the UAE and Qatar since 2012: PET1=156; PET2=119; PET3=71; PET EEG=32. During 2019-20, a memorandum of understanding with the UAE Ministry of Health and Prevention has been signed to deliver courses in the UAE.

North Africa:

Sudan: The total number of attendees in Sudan since 2014: PET1=289; PET2=109.

#### 2.9.2 - Sub Saharan Africa

South Africa in partnership with the Paediatric Neurology Development Association of Southern Africa. During 2019-20, 2 PET1 courses were delivered. Since 2015-16, the total number of PET1 attendees is 324 (2019-20, 42 attendees; 2018-19, 119 attendees; 2017-18, 27 attendees).

Ghana in partnership with the Paediatric Society of Ghana. During 2019-20, 1 PET1 course was delivered to 47 attendees. Since 2018, the total number of PET1 attendees is 180 (2019-20, 47 attendees; 2018-19, 133 attendees).

Kenya in partnership with the Kenya Paediatric Association. During 2019-20, 1 PET1 course was delivered to 30 attendees. Since 2017, the total number of PET attendees is 201 (2019-20, 30 attendees; 2018-19, 120 attendees; 2017-18, 51 attendees).

Tanzania in partnership with the Paediatric Association of Tanzania. No courses were delivered in Tanzania in 2019-20. Since 2018, the total number of PET1 attendees is 110 (2018-19, 110 attendees)

Uganda in partnership with the Uganda Paediatric Association. During 2019-20, 1 PET1 course was delivered to 35 attendees. Since 2018, the total number of PET1 attendees is 127 (2019-20, 35 attendees; 2018-19, 92 attendees).

Faculty from South Africa also delivered PET1 in Mauritius and Namibia.

Mauritius: During 2019-20, 1 PET1 course was delivered to 27 attendees.

Namibia: During 2019-20, 1 PET1 course was delivered to 16 attendees.

Faculty from Brazil also delivered a PET1 in Angola.

Angola: During 2019-20, 1 PET1 course was delivered to 34 attendees

#### 2.9.3 - Asia

India in partnership with: Raindrops Children's Foundation. PET1 was launched in northern India in 2014 and southern India in 2016. Following an initially very high number of courses being delivered in India (2015-16, 13 courses; 2016-17, 16 courses) the number has fallen in 2017-18 to 8 courses and in 2018-19 to 1 course. In 2019-20, 1 PET1 course was delivered to 47 attendees. The reasons for the drop in the number of courses continue to be explored.

Total PET1 attendees in India since 2014: 1,499 (2019-20, 47 attendees; 2018-19, 24 attendees; 2017-18, 289 attendees).

Myanmar: PET1 was launched in Myanmar in 2014. Since then, 314 people have attended PET1 (2018-19, 72 attendees; 2017-18, 70 attendees; 2016-17, 52 attendees). No courses were held in 2019-20 due to coronavirus restrictions.

Singapore in partnership with KK Women's and Children's Hospital. PET1 and PET2 were due to be launched in Singapore in February 2020. This was postponed due to coronavirus restrictions.

## 2.9.4. Central & South America

Brazil in partnership with Liga Brasileira de Epilepsia. Throughout 2016, a team of 3 paediatric neurologists in São Paulo translated PET1 into Portuguese. In 2017, a UK faculty travelled to Brazil to undertake the back-translation and develop a project plan to roll-out PET1 throughout Brazil. PET1 launched in São Paulo in June 2018. During 2019-20, 2 PET1 courses were delivered to 41 attendees. Since 2018-19, PET1 has been delivered to 122 attendees (2019-20, 41 attendees, 2018-19, 81 attendees).

Central & South America: During 2018-19, PET1 was translated into Spanish for roll-out in Central and South America. A launch for Colombia, Chile and El Salvador planned for May 2020 has been postponed due to coronavirus restrictions.

#### 2.9.5 - Australasia

New Zealand in partnership with the New Zealand League Against Epilepsy and the Starship Foundation. PET1 and PET2 were launched in Auckland, New Zealand in May 2017. During 2019-20, 2 PET1 courses, 2 PET2 courses and 1 PET3 course were held.

PET1 attendance since 2017: 243 (2019-20, 45 attendees; 2018-19, 109 attendees; 2017-18, 89 attendees). PET2 attendance since 2017: 139 (2019-20, 38 attendees; 2018-19, 40 attendees; 2017-18, 61 attendees). PET3 attendance since 2018: 94 (2019-20, 33 attendees; 2018-19, 61 attendees).

#### 3. Annual Scientific Conference

Oversight of the scientific content of the annual meeting, including abstract scoring and awarding of the MacKeith Prize, rests with the Research Committee.

The 46th annual scientific meeting was held in Belfast, January 2020, with 427 attendees (2019 Liverpool, 391; 2018 London, 479; 2017 Cambridge, 383). Opportunities to learn were provided by: 23 oral presentations, 156 posters, all selected from the 189 abstracts submitted; 6 keynote lectures; 5 clinical practice sessions; and 3 sponsored symposiums.

Prizes were awarded to:

Dr Richard Rosch (Kings College London) The Ronnie MacKeith Prize. Awarded to the person who has made the most significant contribution to paediatric neurology as judged by published work and who is <40 years old or within 5-years of obtaining CCT.

Dr Dora Steel (UCL Great Ormond Street Institute Of Child Health, London) Best oral presentation by a trainee.

Dr Michael Eyre (Great Ormond Street Hospital, London) Best poster presentation by a trainee.

Dr Mario Sa (Evelina London Children's Hospital) BPNA "BAFTA" Award for Fabulous Trainee Action. Awarded to the trainee who has best contributed to service improvement which significantly impacted on their local and/or national practice or any other innovative contribution.

Miss Emily Blackburn (UCL, London)

Best medical student presentation.

The BPNA indirectly facilitates the dissemination of information to children and young people with neurological conditions, their families and their carers, through its members, regionally and locally. The trustees are considering opportunities to develop teaching to be delivered directly to children and young people with neurological conditions, their families and their carers.

#### 4. Patient and Public Involvement

We were delighted that 17 paediatric neurology related charities attended the conference and took up the opportunity to have an exhibition stand to easily engage with BPNA members and the other attendees.

During the conference, the BPNA hosted the first Paediatric Neurology Charities Meeting, with 20 charities in attending. The purpose of this one-day meeting was to provide the opportunity for paediatric neurology related charities to share information about their work, learn from each other and identify opportunities to work together to improve the lives of children with neurological disorders. A number of helpful links were forged between charities and BPNA special interest groups. BPNA look forward to hosting the meeting again at the 2021 conference.

In November 2019, BPNA hosted a meeting of 8 epilepsy charities and paediatric neurologists to discuss the cannabis based medicinal products guidance and discuss potential clinical trial designs. The epilepsy charities provided very helpful input into the clinical trial design before submission to the National Institute for Health Research (NIHR) grant call.

The BPNA indirectly facilitates the dissemination of information to children and young people with neurological conditions, their families and their carers, through its members, regionally and locally.

The trustees are considering opportunities to develop teaching to be delivered directly to children and young people with neurological conditions, their families and their carers.

#### 5. Research

The BPNA research committee has a remit for oversight of the annual scientific meeting as outlined above, as well as for the speciality paediatric neurology session at the annual Royal College of Paediatrics and Child Health meeting. The research committee also oversees the development of research within the organisation to the benefit of children with neurological disease.

Professor Manju Kurian was appointed as the Trustee with responsibility for Research in January 2019 and has appointed a gender-balanced BPNA Research Committee. Members have a wide range of clinical and scientific expertise, and come from a broad range of UK and Irish Paediatric Neurology Centres. The research committee has been working to develop the agreed research strategy of the BPNA, focused on building research capacity within paediatric neurology and promoting research training within the paediatric neurology trainee community.

## 5.1 - British Paediatric Neurology Surveillance Unit (BPNSU)

In 2006, the BPNA set up the BPNSU to target surveillance of rare neurological conditions in a cost-effective and efficient manner with the sample population being UK consultant members of the BPNA. Since 2006, there have been 28 studies conducted using BPNSU.

During 2019-20, seven studies collected data through the BPNSU, none of which were completed in the year. Despite the lack of completion of studies, two publications have arisen at an average impact factor of 5.86 (see below) reflecting the high quality studies that can be achieved through the BPNSU.

- Chitre M, Nahorski MS, Stouffer K, et al. PEHO syndrome: the endpoint of different genetic epilepsies. Journal of Medical Genetics. 2018; 55: 803-813. http://dx.doi.org/10.1136/jmedgenet-2018-105288 (Impact Factor 4.943)
- Wadon ME, Winter M, Peall KJ. Internet-based cognitive behavioural therapy programme as an intervention for people diagnosed with adult-onset, focal, isolated, idiopathic cervical dystonia: a feasibility study protocol. Pilot Feasibility Stud. 2020; 6:100. https://doi.org/10.1186/s40814-020-00641-x (Impact Factor 6.782)

The BPNSU email list is continually reviewed and updated to optimise returns.

## 5.2 - Paediatric Neurology Fellowship

Voluntary donations of members and income generated from sponsored symposia at the annual conference fund this fellowship.

A partnership was established in 2015 with Action Medical Research (AMR) to jointly fund a 3-year AMR-BPNA Research Training Fellowship. In 2016, the first fellowship was awarded to Dr Apostolos Papendreou (University College London). He is dedicated to helping children suffering from BPAN (beta-propeller protein-associated neurodegeneration. This project was completed in 2019.

The Trustees are pleased to report that the partnership with AMR will continue for a further 3-years, to fund a second AMR BPNA Research Training Fellowship from September 2020-23.

This second fellowship has been awarded to Dr Michael Eyre. His 3-year fellowship was due to commence in September 2020, however the start date has been deferred to March 2021 due to Covid-19. In his project, 'Developing magnetic resonance measures of neurobiological dysfunction in early recovery from NMDAR-antibody encephalitis', Michael will investigate if advanced MRI techniques can help predict recovery from NMDAR-antibody encephalitis in children and young people, paving the way for new treatment approaches for the condition in future.

#### 5.3 - Priority Setting Project

The BPNA has committed £50,000 to undertaking a research priority setting project (PSP) in paediatric neurology, facilitated by the James Lind Alliance. This project commenced October 2019, aiming to complete September 2020, however due to Covid-19, the project has been extended to March 2021.

The PSP enables clinicians, patients and carers to work together to identify and prioritise evidence uncertainties that could be answered by research. The outcome of the project will be a top 10 list of jointly agreed research priorities.

"Priority Setting Partnerships enable clinicians, patients and carers to work together to identify and prioritise evidence uncertainties that could be answered by research.

Focussing on specific conditions or healthcare settings, the JLA facilitates priority setting partnerships which:

- Bring patient, carer and clinician groups together on an equal footing;
- Identify evidence uncertainties;
- Work with all groups to joint prioritise identified uncertainties;
   Produce a final (top 10) list of jointly agreed research priorities, publicise them widely and make sure that other
- · uncertainties are recorded and available for research and research funders to access; and
- Provide a rare and valuable opportunity for patients and clinicians to shape the health research agenda"

- James Lind Alliance website

## 6. Professional Support

#### 6.1 - BPNA membership



#### 6.2 - Mentoring and Team Support

In 2015-16 Trustees identified a need for members to have access to mentoring services, and it was agreed that the BPNA should contribute to fulfilling this need. This initiative began in 2016 and continued to develop during 2019-20. At 31 March 2020 there are 26 BPNA members volunteering as mentors and 16 mentees.

## 6.3 - Special Interest Groups (SIG)

## 6.3.1 - British Paediatric Epilepsy Group

The interest of this group is in the clinical area of childhood epilepsy, and members have particular expertise in this aspect of paediatric neurology. The group meets 3 times a year with a focus on the development and implementation of guidelines for epilepsy in children, to share updates in audit and research and to discuss anonymised complex and educational cases. The chair of the group contributed to the BPNA guidance in relation to cannabis based medicinal products, and represented the BPNA at the valproate stakeholder's network meeting both of which are important issues for children with epilepsy and their families.

A presentation regarding the work of the group was made at the BPNA 2020 Paediatric Neurology Charities' Meeting, which provided the opportunity for charities representing childhood epilepsy to discuss how we may work together for the further benefit of patients.

#### 6.3.2 - Cerebrovascular Special Interest Group

This group's interest is in the clinical area of neurovascular disorders, such as paediatric stroke and other vascular disorders affecting the central nervous system. The group members meet 3 times a year.

The cerebrovascular SIG has been supporting paediatric neurologists and paediatricians across the country with the implementation of the RCPCH Childhood Stroke Guidelines. As a priority, the group members have been working towards the development of a National Childhood Arterial Ischaemic Stroke Database. As part of this process, members have been engaging with stakeholders and charities to provide a funding stream for this project. In January 2020, the cerebrovascular SIG presented this idea to multiple charities present at the BPNA 2020 Paediatric Neurology Charities Meeting. The SIG anticipates that this database will provide valuable information about childhood stroke in the UK and how services could be enhanced in future.

In terms of improving education on childhood stroke, the SIG members have recently rewritten and updated the Cerebrovascular Unit of the BPNA Distance Learning Programme. Plans are also in place for an International Paediatric Neurovascular Study Day in the spring of 2021.

### 6.3.3 - Children's Headache Network (CHaN)

This group's interest is in the clinical area of primary and secondary headache disorders in children and young people. The group aims to bring together professionals who are members of the BPNA to come together to advance the clinical management, education and research in primary and secondary childhood headache disorders. The group meet twice per year.

## 6.3.4 - Fetal & Neonatal

The Fetal and Neonatal Specialist Interest Group aims to fulfil the BPNA's aims with a focus on the fetus and neonata. The group provides education on neonatal neurology via the BPNA NeoNATE course. We have also organised 1-2 additional educational meetings on relevant topics; for example, in late 2019 we organised a training day on fetal neurology and antenatal counselling in Southampton that was attended by over 100 delegates.

We have been granted permission to develop a BPNA fetal neurology course and have established a multi-disciplinary team to write the content. The COVID19 pandemic has prevented us from meeting to start developing the course, but we hope to begin the process in 2021.

We have been collaborating with other organisations to improve health care professionals' knowledge and management of neonatal neurological conditions, including a project writing a guideline with the British Academy of Perinatal Medicine (BAPM) on the prevention and management of inpatient neonatal falls and drops. We are currently responding to their recent draft document on the management of neonates with encephalopathy to ensure neurological aspects are included.

Members of the SIG are collaborating on small research projects on common neurological problems, including a project on the current UK management of raised muscle tone in neonates. We hope this will lead on to a formal national guideline or a research project to compare the effectiveness of different medications.

## 6.3.5. Inherited White Matter Disorders (Leukodystrophies) special interest group

In November 2019 a joint meeting with the adult neurologists was hosted in Queens Square. This was well attended by both paediatric and adult clinicians and representatives from the new leukodystrophy charity ALEX TLC. The meeting provided an overview of the clinical approach to diagnosis and presented a selection of diagnosed and un-diagnosed cases for discussion. The afternoon finished with a presentation on BMT as a treatment and a brief discussion of other pending treatments. The general view was that the joint meeting worked very well and we agreed that this should become a yearly event.

The most important news is that the proposal to establish a National IWMD service was approved by NHSE in January 2020. This is very good news coming after 10 years of protracted negotiating, consultations and drafting and redrafting of the Service Specification. The specification includes funding for a IWMD disease registry and we have been working on this with NHSE throughout the lockdown. The aim would be to have this up and running at the same time as the new service commences in 2021. It is hoped that the procurement process will start in the autumn and the aim still is for the service to commence by April/May 2021.

Once the service starts regular multicentre MDTs will be taking place and an educational programme will be developed so the role of the SIG will be superseded. In the run up to this we will continue to hold meetings which members, especially trainees, are encouraged to attend.

## 6.3.6 - British Paediatric Movement Disorder Special Interest Group

The British Paediatric Movement Disorder Group focuses upon children and young people with Movement Disorders in childhood.

The group held physical meetings in London in September 2019, and in Belfast in January 2020. Due to coronavirus restrictions, the group has been hosting 4-6 weekly virtual meetings since March 2020.

In the period 2019-2020, the group has:

- Supported the education and training of professionals in paediatric neurosciences through:
  - o Regularly hosted meetings open to anyone with an interest in movement disorders
  - o Representation of several members in the core group undertaking development of the "Approach to Childhood Tone" (ACT) course
  - o Representation on the Distance Learning Course Steering Group
- The promotion of research into the causes, effects and treatments of neurological disorders affecting children and young people through:
  - o Supporting the Priority Setting Project led by the BPNA, with representation of several members of the group on the steering group of this project
  - o Promotion through the group of research projects recruiting children with movement disorders in the UK (including commercially supported drug trials)
  - o Interactions with multiple patient support groups at the BPNA 2020 Paediatric Neurology Charities Meeting
- The provision of professional support to members to facilitate the delivery of the above objectives and work with health service planners and providers to achieve this aim through
  - o Providing a platform for the regular discussion of complex clinical cases involving children in the UK
  - o Support for members in developing pathways in response to current pandemic conditions (eg provision of botulinum toxin injections)
  - Ongoing development of clinical networks and pathways for children with movement disorders in the UK (eg provision of neurosurgical interventions for disorders of posture, tone and movement)

#### 6.3.7 - Muscle Interest Group

The muscle SIG works closely with the neuromuscular charities, in particular the Muscular Dystrophy UK (MDUK), Action Duchenne, Duchenne UK, SMA UK, DMD HUB. These partnerships have helped accelerate research - funding research fellow posts, access to clinical trials, improved staffing at peripheral sites for trial set up and supported meetings to improve standards of care and data collection and dissemination.

This year key involvements have been with SMA UK and MDUK in helping to implement the Nusinersen MAA (managed access agreement) programme agreed by NICE and NHSE in July 2019, for delivery from October 2019.

From the Northstar group; Ataluren MAA - data cut March 2020 for NICE and NHSE after 4 years.

HUB DMD; funding at 5 sites for 10 posts at Oswestry (RJAH), Oxford, Evelina, Manchester and Glasgow. This enable further trial recruitment and set-up. In November 2019 they hosted the 'Gene therapy ready' study day; looking at all the institutions in the UK and what was needed to deliver gene therapy safely.

The charities sponsor the muscle group's main annual meetings such as the British Myology society, Translational research meeting UK, Northstar and SMA REACH meetings within the UK. They work together with the clinicians on various patient initiatives; patient leaflets, e-learning modules, patient days, children's transition days and camps; and support the various neuromuscular teams in their individual areas; such as NM networks, local educational meetings and trial set ups.

## 6.3.8 - Trainees' Special Interest Group

The BPNA trainees' special interest group (SIG) is a group of all the BPNA trainee members and those interested in paediatric neurology training in the UK. This group meets twice a year, once at the BPNA conference, normally held in January, and once at a 2 day educational trainees' meeting normally held in May. Due to Covid 19, the 2020 trainees' meeting has been postponed and will be rearranged for later in the year.

In December 2019, the trainees' SIG carried out a national survey of paediatric neurology grid trainees and consultants about their views on how paediatric neurology training in the UK should be structured. In March 2020, the NHS response to the Covid-19 pandemic resulted in changes to working rotas for trainees. The unintended consequence of this was limiting access to teaching for trainees. In response, the Trainees' SIG set up the BPNA trainees' paediatric neurology teaching network. This project shares weekly free-to-join video-based paediatric neurology teaching from UK paediatric neurology centres. Sessions are primarily aimed at paediatric neurology trainees and are open to all BPNA members.

## 6.3.9 - UK-Childhood Inflammatory Demyelination

This group's interest is in the clinical area of acquired inflammatory white matter diseases (such as paediatric onset Multiple Sclerosis, MOG and AQP4 antibody driven disorders, the autoimmune mediated encephalitides) as well as other inflammatory brain conditions.

The UK-CID has continued to promote the health and wellbeing of children with inflammatory brain disorders across the UK over the past 12 month. We have worked together with UK charities including the MS Society, MS Trust and Shift MS to produce both written educational material and patient videos. With the support from the charities, healthcare professionals have hosted support forums for children with relapsing demyelination. We have also worked hard with the charities to ensure a smooth transition process for these individuals as they move on to adult services.

The UK-CID has also met formally as a group of interested healthcare professionals every 2 months to update specific guidelines and discuss new research plans as well as complex cases. We have established collaborations with the National MS Society in USA, to enhance this professional network. These meetings not only supports excellent patient care by providing expert input to aid in diagnosis and management, but also serve as an outstanding educational forum for physicians in training. This collaborative network, as part of the meeting, has time dedicated to producing guidelines and supporting research initiatives. Over the past 12 months, a number of major awards (funded from eg MRC, NIHR, Innovate and Action Research) have been granted to individuals from the network. These awards will continue to enable high quality research into inflammatory brain disorders in childhood.

### 6.3.11 - UK Neurorehabilitation Special Interest Group

This group's interest is in the clinical area of acquired brain injury, acquired spinal injury and neurorehabilitation. The purpose of the group is to provide opportunities to: share updates in clinical developments: new research, new treatment options, newly published guidelines etc; discuss implementation of clinical guidelines and identify challenges; identify opportunities for research; discuss anonymised complex and educational clinical cases. The group meets twice per year.

During the year three meetings were held (Bristol and Belfast). The main agreed objectives are to: streamline Units' data collection measurements to enable sharing a common dataset and to write a paediatric Neuro-Rehabilitation guideline in presence of COVID 19.

34 members from a variety of specialty groups (neurology, neurodisability and rehabilitation, therapist and psychologists) attended the Bristol meeting. 16 of 17 Units presented Unit profiles; strengths and areas for development. Assessment methods for disordered levels of consciousness in children and young people with acquired CNS injuries were discussed. Discussion around developing a proposal for a BPSU study followed.

The Belfast meeting was largely attended by Paed Neurology / Rehab Disability BPNA members. The agenda focused on data collection and update from the CRG Neurosciences relating to their prioritisation of Paed neurorehabilitation on their work programme.

## Nottingham

This agenda was dictated by the paed. neurorehabilitation impact of COVID 19 - around 50 interested SIG members attended a virtual meeting with representation from all units apart from Belfast. The meeting agreed to consider to write a consensus guideline on the subject which has now been ratified by BPNA in the June meeting.

#### Plan

- Share collecting a common dataset
- Write a Paed Neuro-Rehabilitation guideline in presence of COVID 19
- Next meeting 1 10 20

#### 6.4 - Clinical Governance

BPNA has been consulted by NHS NICE to comment on guidelines and quality standards and by NHS England to comment on the new drug treatments. The following is a brief summary of the important consultations:

- 1. Prescribing valproate to female patients under 18-years of age. Guidance published 15 April 2019 jointly with Royal College of Paediatrics & Child Health.
- 2. Suspected neurological conditions: recognition and referral. NICE guideline [NG127] published 1 May 2019.
- 3. Nusinersen for treating Spinal Muscular Atrophy. Technology appraisal guidance [NICE TA588]. BPNA input was provided by the neuromuscular special interest group. Published 24 July 2019.
- 4. BPNA Interim guidance on the use of cannabis-based products for medicinal use in children and young people with epilepsy. Produced at the request of NHS England. Published 31 October 2019.
- 5. Cannabis-based medicinal products. NICE clinical guideline (NICE NG144]. Published 11 November 2019.
- 6. Cannabidiol with clobazam for treating seizures associated with Dravet syndrome [NICE TA614]. To appraise the clinical and cost effectiveness. Published 18 December 2019.
- 7. Cannabidiol with clobazam for treating seizures associated with Lennox-Gastaut syndrome [NICE TA615]. To appraise the clinical and cost effectiveness. Published 18 December 2019.
- 8. Fenfluramine for treating Dravet syndrome. [NICE ID1109]. To appraise the clinical and cost effectiveness. In development. Expected publication date: 21 April 2021.
- 9. Epilepsies in children, young people and adults. [NICE GID-NG10112]. In development. Expected publication date: 16 November 2021.
- 10. Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management [to update CG102]. Invitation to guideline scoping. Expected publication date: 8 June 2022.
- 11. NHS England consultation. Stroke thrombectomy service for acute ischaemic stroke. [Service specification 1868].

## Internal and external factors

The trustees maintain a risk register. We have currently identified the following factors as being the main risks to the BPNA:

Pressure from NHS Trusts on BPNA members to increase the number of clinics/patients and limit other
activities. This has the potential to impact on the voluntary time given by BPNA members to lecture, tutor and
mentor at short-courses, distance-learning, and mentoring. Our consultant members have remained robust and
enthusiastic in this support and we hope that this will remain the case, but it is clear that the BPNA would be
unable to continue in delivering education without this generously donated time. This is being monitored by
Education, Quality & Standards committee and Professional Support Committee.

#### FINANCIAL REVIEW

## Financial position

The balance sheet position shows net current assets of £469,421 (2019 - £391,923), resulting from a significant increase in the cash at bank to £512,618 (2019 - £428,541). This has been accompanied by a slight increase in debtors to £72,633 (2019 - £59,995), and creditors to £132,177 (2019 - £104,739).

At the year end the charity has unrestricted freely available current reserves of £431,801 (2019 - £391,923) which excludes tangible fixed assets of £12,568 (2019 - £7,414). Given the charity's current levels of expenditure this would allow for approximately just over five months (2019 - five months) of trading without further freely available reserves becoming available.

## Principle funding sources

The BPNA raises funds mainly through payments received for its educational activities, which include short-courses, annual conference, online distance-learning course; membership subscriptions; and sponsorship. We have also raised money through the voluntary contributions of members.

Total incoming resources for the year have decreased to £958,667 (2019 - £999,753). This decrease has arisen mainly from the decrease in short courses to £313,020 (2019 - £369,659). This is directly attributable to cancellation of courses due to coronavirus restrictions.

Donations and legacies have increased in the year to £326,807 (2019 - £315,269). In particular the charity obtained significant grant funding in the year amounting to £63,575 (2019 - £87,650), sponsors of its annual conference symposiums generating funds of £30,000 (2019 - £20,000), and generating annual conference sponsorship income of £83,000 (2019 - £71,800). See "Note 4 Donations and Legacies" within the notes to the financial statements for a detailed breakdown of income received in the year.

#### Investment policy and objectives

The policy of the BPNA is to invest its reserves in the further development of its charitable aims. In particular, in 2015-16 it committed a total of £90,000 over a 3-year period to the support of an education and research fellowship co-funded by Action Medical Research. In the current year the charity was unable to find an applicant and therefore no costs have arisen in the year. The prior year the charity spent £30,000 as budgeted. The Action Medical Research BPNA Research Training Fellowship is funded through members' donations and sponsorship. BPNA currently has £58,350 committed from reserves.

The BPNA has also committed reserves to the sustainability and further development of both the distance learning and short courses. In 2019, BPNA committed reserves to developing new courses in Acute Paediatric Neurology (£12,230) and Fetal Neurology (£12,230). The development of the new Approaching Children's Tone course has been funded through educational grants. In 2018, BPNA committed £50,000 to the Paediatric Neurology Priority Setting Project. Due to complete March 2021.

As a result of recent financial performance, derived from additional incoming resources, the current level of reserves the BPNA holds cash balances amounting to £512,618 (2019 - £428,541) and is exploring investment opportunities for the reserves. Any interest earned will be utilised for research projects and other activities in line with the BPNA charitable objectives.

### Reserves policy

The total funds held at the year end were £481,989 (2019 - £399,337) and of which £11,613 (2019 - £nil) is maintained within restricted funds for their detailed purposes as described in the notes to the financial statements. Further details of restricted funds are included within the notes to the financial statements.

Overall the financial position of the charity remains healthy, though the trustees continue to pay close attention to the mix of activities in order to ensure that in trying to achieve its objectives it does not lead to deterioration in the financial stability of the charity.

A substantial proportion of the reserves in the balance sheet are represented by the cash at bank and in hand totalling £512,618 (2019 - £428,541) in order to facilitate the continued activities of the charity by holding highly liquid assets.

#### FINANCIAL REVIEW

The trustees regularly review the finances, budgets, and cash flows to aid effective stewardship of the charity.

The trustees recognise that the level of reserves fluctuates during periods of investment by the charity and ensure an adequate reserve is maintained. To this end, in 2019-20 the trustees increased the unrestricted contingency fund to £180,000 (2019 - £150,000) which is held in order to mitigate the risk of liquidity concerns. The trustees have agreed the level of funds held in this account based on the equivalent of six month's Secretariat salaries plus one-year London office rent. This policy is reviewed every 12-months.

#### Funds in deficit

There were no funds in deficit as at the financial reporting date or the comparative financial reporting date.

#### **FUTURE PLANS**

The BPNA is an agile charity that is responding quickly to the coronavirus situation.

Coronavirus restrictions prevent delivery of BPNA face-to-face courses both in the UK and internationally, potentially significantly negatively affecting BPNA income and its ability to meet its educational charitable aims. BPNA has acted quickly to introduce Weekly Paediatric Neurology Webinar Lectures, which are free and open to all, adapt its course delivery model, and maximise use of its distance learning course to ensure continued delivery of its educational charitable aims.

Coronavirus has resulted in a significant increase in demand for Professional Support: Covid-19 related clinical guidance; personal support; and meeting the needs of trainees, whose access to training were limited as an unintended consequence of the NHS response to Covid-19. To meet these needs BPNA is developing Covid-19 paediatric neurology guidance, increasing mentoring capacity, providing additional resources to Special Interest Groups and additional training resources to Trainees.

BPNA has also implemented a variety of cost cutting measures including accessing the Government furlough scheme.

During 2020-21 BPNA will be introducing an Invited Review service.

## STRUCTURE, GOVERNANCE AND MANAGEMENT

#### **Governing document**

The BPNA is governed by its constitution, approved on 3 December 2014 and amended at the AGM on 23 January 2019.

## Method of appointment of trustees

The management of the Association is ultimately the responsibility of the trustees who are elected by BPNA members and appointed under the terms of the Constitution.

## Organisational structure and decision-making

The trustees meet five times per year (January, April, June, September, November) when strategic decisions and business matters are discussed. Monthly telephone conferences are also held.

Council is a larger body that meets twice per year (January and June). During 2018-19, Council was expanded to include representation from every UK paediatric neurology tertiary centre and the Chairs of the special interest groups together with the representatives co-opted from related organisations. The purpose of Council is to ensure a good exchange of information and ideas related to the care of children and young people with neurological conditions and paediatric neurology education and training between Centres and other key organisations.

## STRUCTURE, GOVERNANCE AND MANAGEMENT

## **Members of BPNA Council Serving During 2019-20**

Members of BPNA Council Serving During 2019	-20	
Executive	<u>Name</u>	Term Expires
President	Prof Finbar O'Callaghan	January 2021
President Elect	Dr Alasdair Parker	January 2021
Treasurer	Dr Sandeep Jayawant (2nd term)	April 2023
Secretary	Dr Andrew Mallick	January 2022
Professional Support Officer	Dr Ailsa McLellan	January 2022
National Training Advisor	Dr Anne-Marie Childs	January 2021
Chair, Education Quality & Standards	Dr Michael Griffiths	January 2022
Chair, Distance Learning	Dr Louise Hartley (2nd term)	January 2023
Chair, Research	Prof Manju Kurian	January 2022
Chair, International Education	Prof Martin Kirkpatrick	January 2022
Executive Director	Philippa Rodie	Ex-officio
Paediatric Neurology Centers	Representative	3-year term
Belfast	Dr Sandya Tirupathi	December 2020
Dundee	Prof Martin Kirkpatrick	December 2021
Edinburgh	Dr Kenneth McWilliam	December 2021
Glassgow	Dr Iain Horrocks	December 2021
Newcastle-upon-Tyne	Dr Anna Basu	December 2020
Liverpool	Dr Ram Kumar (2nd term)	December 2021
Manchester	Dr Gary McCullagh (2nd term)	December 2022
Preston	Dr Christian De Goede	December 2021
Leeds	Dr Helen McCullagh (2nd term)	December 2022
Sheffield	Dr Archana Deskurkar	December 2021
Nottingham	Dr Manish Prasad (2nd term)	December 2022
Leicester	Dr Nahin Hussain	December 2021
		December 2023
Birmingham	Dr Ratna Kumar (2nd term)	
Cambridge	Dr Manali Chitre (2nd term)	December 2022
Oxford	Dr Sithara Ramdas	December 2021
Bristol	Dr Sam Amin	December 2020
Swansea	Dr Cathy White (2nd term)	December 2022
Cardiff	Dr Johann te Water Naude	December 2022
Southampton	Dr Georgina Bird-Lieberman	December 2020
London: Great Ormand Street Hospital	Dr Sanjay Bhate	December 2021
London: Chelsea & Westminster Hospital	Dr Naila Ismayilova	December 2021
London: Imperial College NHS Trust	Dr Sushil Beri	December 2021
London: The Royal London	Dr Louise Hartley	December 2021
London: Evelina London Children's Hospital	Dr Ming Lim (2nd term)	December 2021
London: St George's Hospital	Dr Antonia Clarke	December 2021
Special Interest Groups	<u>Chair</u>	3-year term
British Paediatric Epilepsy Group	Dr Sarah Aylett	May 2022
Cerebrovascular	Dr Dipak Ram	December 2021
Children's Headache Network	Dr William Whitehouse	December 2021
Fetal & Neonatal Neurology	Dr Anthony Hart	May 2022
Inherited White Matter Disorders	Dr John Livingston	TBA
British Paediatric Movement Disorders	Dr Daniel Lumsden	May 2022
Muscle Interest Group	Dr Tracy Willis	TBA
UK Neurorehabilitation	Dr Peta Sharples	February 2021
UK-Childhood Inflammatory Demyelination	Dr Cheryl Hemmingway	May 2022
Trainees' Chair	Dr Mark Atherton	July 2022
Trainees' Deputy Chair	Dr Eusra Hassan	July 2022
		•

## **British Paediatric Neurology Association**

Report of the Trustees for the Year Ended 31 March 2020

#### STRUCTURE, GOVERNANCE AND MANAGEMENT

Co-optedRepresentativeEditor DMCNDr Bernard Dan

British Paediatric Neurosurgical Group Rep
Chair, Disability CSAC
Paediatric Neuroscienses CRG
Neuropsychiatry
PET Course Development Manager

Mr Dominic Thompson
Dr Katherine Martin
Dr Anita Devlin
Dr Ashley Liew
Dr Colin Dunkley

BPNA 2021 Oxford Organising Team Dr Martin Smith January 2021

## **Key management remuneration**

Total remuneration paid to key management personnel during the financial year included wages and salaries amounting to £74,995 (2019 - £74,592) and contributions to defined contribution pension schemes of £2,792 (2019 - £902).

## Risk management

The trustees have assessed the major strategic, business and operational risks to which the Association is exposed, and are satisfied that systems and procedures are in place to monitor and control those risks in order to mitigate any impact they might have on the Association. A risk register is maintained and updated regularly.

## REFERENCE AND ADMINISTRATIVE DETAILS

#### **Registered Charity number**

1159115

## Principal address

The Coach House Rear of 22 Chorley Road Bolton Lancashire BL1 4AP

#### **Trustees**

Dr L Hartley
Dr S Jayawant
Professor M Kirkpatrick
Professor F J K O'Callaghan
Dr A Childs
Dr M J Griffiths
Professor M Kurian
Dr A McLellan
Dr A Mallick
Dr A Parker

## **Independent Examiner**

Jonathan Ward ACA FCCA ICAEW and ACCA HSA & Co Chartered Accountants Lewis House Great Chesterford Court Great Chesterford Essex CB10 1PF

## **British Paediatric Neurology Association**

Report of the Trustees for the Year Ended 31 March 2020

## REFERENCE AND ADMINISTRATIVE DETAILS

**Executive Director** 

Philippa Rodie

**Bankers** 

Barclays Bank PLC 15 Bene't Street Cambridge CB2 3PZ

## EVENTS SINCE THE END OF THE YEAR

Information relating to events since the end of the year is given in the notes to the financial statements.

Approved by order of the board of trustees on  $\frac{21}{12}$   $\frac{2020}{2020}$  and signed on its behalf by:

Dr S Jayawant | Trustee

## Independent examiner's report to the trustees of British Paediatric Neurology Association

I report to the charity trustees on my examination of the accounts of British Paediatric Neurology Association (the Trust) for the year ended 31 March 2020.

## Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

#### Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of ICAEW and ACCA which is one of the listed bodies.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
- 2. the accounts do not accord with those records; or
- 3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Jonathan Ward ACA FCCA

ICAEW and ACCA

HSA & Co

Lewis House

Great Chesterford Court

Great Chesterford

Essex

CB10 1PF

Date: 22/12/2020

# Statement of Financial Activities for the Year Ended 31 March 2020

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
INCOME AND ENDOWMENTS FROM Donations and legacies	4	263,232	63,575	326,807	315,269
Charitable activities	6				
Annual conference		166,079	-	166,079	153,776
Short courses		313,020	_	313,020	369,659
Distance learning courses		71,969	-	71,969	81,085
International short courses		12,226	-	12,226	33,959
Research activities		800	-	800	800
EPNS recharges		48,722	=	48,722	44,117
Professional support		17,325	-	17,325	-
Investment income	5	1,719		1,719	1,088
Total		895,092	63,575	958,667	999,753
EXPENDITURE ON					
Raising funds	7	316	-	316	286
Charitable activities	8				
Annual conference		180,631	6,943	187,574	180,862
Short courses		348,892	20,138	369,030	342,486
Distance learning courses		75,040	6,943	81,983	73,141
International short courses		34,891	6,943	41,834	175,534
Research activities		22,623	3,860	26,483	41,323
Membership and professional support		98,365	6,943	105,308	80,006
EPNS recharges		47,398	-	47,398	41,444
Professional support		13,948	-	13,948	-
Governance Costs		2,141	-	2,141	8,715
Total		824,245	51,770	876,015	943,797
NET INCOME		70,847	11,805	82,652	55,956
Transfers between funds	18	192	(192)	-	-
Net movement in funds		71,039	11,613	82,652	55,956
RECONCILIATION OF FUNDS					
Total funds brought forward		399,337	-	399,337	343,381
TOTAL FUNDS CARRIED FORWARD		470,376	11,613	481,989	399,337

## **CONTINUING OPERATIONS**

All income and expenditure has arisen from continuing activities.

The notes form part of these financial statements

## **British Paediatric Neurology Association**

# Balance Sheet 31 March 2020

	Notes	Unrestricted funds	Restricted funds	2020 Total funds £	2019 Total funds £
FIXED ASSETS	notes	L	£	L	£
Tangible assets	13	12,568	-	12,568	7,414
CURRENT ASSETS					
Stocks	14	16,347	_	16,347	8,126
Debtors	15	72,633	_	72,633	59,995
Cash at bank and in hand		501,005	11,613	512,618	428,541
		589,985	11,613	601,598	496,662
CREDITORS		(100.1)		(122.1==)	(10.1 = 20)
Amounts falling due within one year	16	(132,177)	-	(132,177)	(104,739)
NET CURRENT ASSETS		457,808	11,613	469,421	391,923
TOTAL ASSETS LESS CURRENT LIABILITIES		470,376	11,613	481,989	399,337
EIABIEITIES		470,570	11,013	401,707	377,337
NET ASSETS		470,376	11,613	481,989	399,337
FUNDS	18				
Unrestricted funds Restricted funds				470,376 11,613	399,337
TOTAL FUNDS				481,989	399,337

The financial statements were approved by the Board of Trustees and authorised for issue on  $\frac{21/12}{2020}$  and were signed on its behalf by:

S Jayawant - Trustee

## **British Paediatric Neurology Association**

# Cash Flow Statement for the Year Ended 31 March 2020

Notes	2020 £	2019 £
Cash flows from operating activities		
Cash generated from operations 1	91,711	12,182
Net cash provided by operating activities	91,711	12,182
Cash flows from investing activities		
Purchase of tangible fixed assets Interest received	(9,353) 1,719	(489) 1,088
Net cash (used in)/provided by investing activities	(7,634)	599
Change in cash and cash equivalents in the reporting period Cash and cash equivalents at the	84,077	12,781
beginning of the reporting period	428,541	415,760
Cash and cash equivalents at the end of	512.619	120 511
the reporting period	512,618	428,541

The notes form part of these financial statements

1.	RECONCILIATION OF NET INCOME TO NET CASH FLOW	FROM (	OPERATING AC	CTIVITIES
			2020	2019
			£	£
	Net income for the reporting period (as per the Statement of Final	ancial		
	Activities)		82,652	55,956
	Adjustments for:			
	Depreciation charges		4,199	2,471
	Interest received		(1,719)	(1,088)
	Increase in stocks		(8,221)	(6,070)
	(Increase)/decrease in debtors		(12,638)	44,293
	Increase/(decrease) in creditors		27,438	(83,380)
	Net cash provided by operations		91,711	12,182
2.	ANALYSIS OF CHANGES IN NET FUNDS			
	At	t 1/4/19	Cash flow	At 31/3/20
		£	£	£
	Net cash			
	Cash at bank and in hand	428,541	84,077	512,618
		120 5 1 1	94.077	512 (10
	<u>-</u>	428,541	84,077	512,618
	Total	428,541	84,077	512,618
	=			

The notes form part of these financial statements

#### 1. PRESENTATION CURRENCY

The presentation currency of the financial statements is the Pound Sterling (£).

#### 2. ACCOUNTING POLICIES

#### Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

#### Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

#### **Income from grants and donations**

Donations and grants are recognised when they have been communicated and received in writing with notification of both the amount and settlement date. In the event that a donation or grant is subject to conditions that require a level of performance before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that those conditions will be fulfilled in the reporting period.

#### **Income from membership subscriptions**

Membership subscriptions are initially recognised in the period that the member pays the subscription to the charity. Membership subscriptions received in the year relating to the period after the reporting date are recognised as deferred income.

#### Income from sponsorship agreements

Sponsorship income is initially recognised when invoiced in line with the terms of the sponsorship agreement. Income received or invoiced in the year relating to the period after the reporting date are recognised as deferred income.

#### **Income from conferences**

Income in relation to conferences is initially recognised in the period in which the attendee pays the attendance fee. Income received for conferences taking place after the reporting date are recognised as deferred income.

#### **Income from courses**

Income in relation to courses is initially recognised at the point which the attendee has booked and paid for their attendance on the course. Income received for courses taking place after the reporting date are recognised as deferred income.

#### **Income from EPNS recharges**

Income in relation to EPNS recharges is initially recognised at the point which the EPNS is invoiced for the costs incurred by BPNA. Income not invoiced as at the reporting date is recognised as accrued income within the financial statements.

#### 2. ACCOUNTING POLICIES - continued

#### **Expenditure**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Grants offered subject to conditions which have not been met at the balance sheet date are noted as a commitment but not accrued as expenditure.

#### Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Plant and machinery - 25% on reducing balance Fixtures and fittings - 25% on reducing balance

The tangible fixed assets of the charity are reviewed by the charity's executive director and the trustees for impairment on a regular basis and during the preparation of the financial statements.

#### Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

#### Taxation

The charity is exempt from tax on its charitable activities.

## **Fund accounting**

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

#### Foreign currencies

Assets and liabilities in foreign currencies are translated into sterling at the rates of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into sterling at the rate of exchange ruling at the date of transaction. Exchange differences are taken into account in arriving at the operating result.

#### Hire purchase and leasing commitments

Rentals paid under operating leases are charged to the Statement of Financial Activities on a straight line basis over the period of the lease.

#### Pension costs and other post-retirement benefits

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

#### **Financial instruments**

A financial asset or a financial liability is recognised only when the entity becomes a party to the contractual provisions of the instruments.

#### 2. ACCOUNTING POLICIES - continued

#### **Financial instruments**

Basic financial instruments are initially recognised at the transaction price, unless the arrangement constitutes, in effect, a financing transaction, where it is recognised at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Debt instruments are subsequently measured at amortised cost.

Other financial instruments are initially recognised at fair value, unless payment for an asset is deferred beyond normal business terms or financed at a rate of interest that is not a market rate, in which case the asset is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument. Financial assets that are measured at cost or amortised cost are reviewed for objective evidence of impairment at the end of each reporting date. If there is objective evidence of impairment, an impairment loss is recognised in profit or loss immediately.

Any reversals of impairment are recognised in profit or loss immediately, to the extent that the reversal does not result in a carrying amount of the financial asset that exceeds what the carrying amount would have been had the impairment not previously been recognised.

## 3. CRITICAL ACCOUNTING JUDGEMENTS AND KEY SOURCES OF ESTIMATION UNCERTAINTY

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for revenues and expenses during the year. The nature of estimation means that actual outcomes may however differ from those original estimates.

The trustees do not deem there to be any judgements, apart from those otherwise disclosed in the accounting policies or notes to the financial statements, which require highlighting to the readers as a result of having had a critical effect on amounts recognised in the financial statements.

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#### 4. DONATIONS AND LEGACIES

	2020	2019
	£	£
Donations	5,521	4,334
Grants	63,575	87,650
BPNA members subscriptions	85,754	84,485
Gift aid	1,752	-
Membership donations	12,600	13,000
Annual conference symposium sponsorship	30,000	20,000
Annual conference sponsorship	83,000	71,800
Short course sponsorship	44,000	34,000
Miscellaneous income	605	=
	326,807	315,269
	===	=======================================

## 4. DONATIONS AND LEGACIES - continued

Grants received, included in the above, are as follows:

	2020 £	2019 £
International League Against Epilepsy (ILAE)	38,575	33,915
Department for International Development (DFID) via the Tropical Health	-	53,735
and Education Trust (THET)		
Development of Approaching Children's Tone course	25,000	-
	63,575	87,650

Income received for the Development of Approaching Children's Tone course has been received from the follow: Avexis (£5k), Biogen (£5k), Roche (£5k), PTC (£5k), Sarepta (£5k).

Sponsorships received, included in the above, are as follows:

Company name	Course sponsorship £	Conference sponsorship £	Sponsored symposia £	2020 Totals £	2019 Totals £
Actelion	-	-	-	-	5,000
Avexis	3,000	10,000	10,000	23,000	5,000
Biocodex	-	4,000	-	4,000	3,000
Bial	=	4,000	=	4,000	-
Biogen	-	4,000	10,000	14,000	5,000
Biomarin	3,000	4,000	-	7,000	5,000
Colonis Pharma	-		-	-	3,000
Destin	30,500	4,000	-	34,500	32,000
Eisai	-		-	-	3,000
Ephypharm	-	4,000	-	4,000	-
GW Pharma	=	6,000	10,000	16,000	-
Ipsen	=	4,000	=	4,000	-
Livanova	=	4,000	-	4,000	3,000
Martindale Pharma	-	-	-	-	3,000
Neurodiem	=	4,000	=	4,000	-
Novartis	3,000	4,000	=	7,000	-
Novartis Neuroscience	=	-	-	-	3,000
Novartis Oncology	-	-	-	-	5,000
Nutricia	=	=	=	=	3,000
Pharmacomedics	=	-	-	-	3,000
Proveca	=	4,000	=	4,000	3,000
Retrophin	-	-	-	-	3,000
Roche	-	4,000	-	4,000	-
Sanofi	-	-	-	-	5,000
Santhera	-	-	-	-	3,000
Sarepta	-	4,000	-	4,000	13,000
Takeda	-	4,000	-	4,000	-
UCB Pharma	-	4,000	-	4,000	3,000
Zogenix	-	4,000	-	4,000	13,000
Non-pharma stands	-	-	-	-	1,800
<b>Total Sponsorship</b>	39,500	80,000	30,000	149,500	125,800

5.	INVESTMENT INCOME				2020	2019
	Deposit account interest				£ 1,719	£ 1,088
6.	INCOME FROM CHARITA	BLE ACTIVIT	TIES			
			Annual conference £	Short courses £	Distance learning courses £	International short courses £
	Conferences and symposiums		166,079			
	Short courses		100,079	313,020	- -	-
	International short courses		-	-	-	12,226
	Distance learning		-	-	71,969	-
	EPNS recharges		-	-	-	-
	Professional support BPNSU fee income		<del>-</del> -	<del>-</del> -	<del>-</del> -	-
			166,079	313,020	71,969	12,226
					2020	2019
		Research	EPNS	Professional	Total	Total
		activities	recharges	support	activities	activities
	Conferences and	£	£	£	£	£
	symposiums	_	_	_	166,079	153,776
	Short courses	_ _	- -	_ _	313,020	369,659
	International short courses	-	-	_	12,226	33,959
	Distance learning	-	-	-	71,969	81,085
	EPNS recharges	-	48,722	-	48,722	44,117
	Professional support	-	-	17,325	17,325	-
	BPNSU fee income	800	-	-	800	800
		800	48,722	17,325	630,141	683,396

7.	RAISING FUNDS			
	Raising donations and legacies			
			2020	2019
			£	£
	Charity web hosting		100	70
	JustGiving fees		<u>216</u>	216
			316	286
8.	CHARITABLE ACTIVITIES COSTS			
			Support	
		Direct	costs (see	
		Costs	note 10)	Totals
		£	£	£
	Annual conference	117,474	70,100	187,574
	Short courses	193,617	175,413	369,030
	Distance learning courses	12,031	69,952	81,983
	International short courses	14,073	27,761	41,834
	Research activities	9,068	17,415	26,483
	Membership and professional support	53,239	52,069	105,308
	EPNS recharges	45,225	2,173	47,398
	Professional support	13,948	<del>-</del>	13,948
	Governance Costs	90	2,051	2,141
		458,765	416,934	875,699
9.	GRANTS PAYABLE		2020	2010
			£	2019 £
	Research activities		£	36,000
	Research activities		==	====
	The total grants paid to individuals during the year was as follows:		2020	2019
			£	£
	Dr Apostolos Papandreou - via Action Medical Research		-	36,000
	1 1			=====

During the year the charity continued to provide a research training fellowship, jointly funded with Action Medical Research. However there were no applicants in the current year with a cost of £Nil (2019 - £36,000). The first fellowship was awarded to Dr Apostolos Papandreou, who works at University College London.

10.	<b>SUPPORT</b>	COSTS

		Information	Human
	Management	technology	resources
	£	£	£
Annual conference	2,164	2,552	43,116
Short courses	4,521	5,341	108,663
Distance learning courses	12,880	1,278	44,906
International short courses	393	680	24,391
Research activities	197	233	16,499
Membership and professional support	1,081	1,278	38,970
EPNS recharges	393	250	1,323
Governance Costs	2,051	=	-
			-
	23,680	11,612	277,868
		Governance	
	Other	costs	Totals
	£	£	£
Annual conference	20,147	2,121	70,100
Short courses	51,874	5,014	175,413
Distance learning courses	9,827	1,061	69,952
International short courses	1,911	386	27,761
Research activities	486	-	17,415
Membership and professional support	9,679	1,061	52,069
EPNS recharges	207	-	2,173
Governance Costs	-	-	2,051
	94,131	9,643	416,934

Support costs, included in the above, are as follows:

Support costs, included in the a	Annual conference	Short courses £	Distance learning courses £	International short courses £	Research activities £
Trustees' remuneration etc	1,008	2,107	12,303	183	92
Meeting costs	-	2,107	-	-	-
Trustee accommodation	609	1,272	304	111	55
Accommodation and dinner	547	1,142	273	99	50
Trustee elections	-	, -	-	=	-
Trustee training	-	-	-	-	_
Software subscriptions	581	1,217	291	106	53
Computer repairs	184	385	92	67	17
Website hosting	39	83	20	14	4
Website development	878	1,837	440	320	80
Computer upgrades	79	164	39	29	7
Depreciation of tangible					
fixed assets	791	1,655	396	144	72
Employment costs	32,001	83,905	38,422	20,622	14,015
Social security	2,702	6,599	2,182	1,702	1,263
Pensions	1,131	2,935	662	744	559
Staff costs	815	1,703	407	148	74
Carried forward	41,365	105,004	55,831	24,289	16,341

## 10. SUPPORT COSTS - continued

SUPPORT COSTS - continu	ed				
	. 1	G1 ·	Distance	International	D 1
	Annual	Short	learning	short	Research
	conference £	courses £	courses £	courses £	activities £
Brought forward	41,365	105,004	55,831	24,289	16,341
Staff training	525	1,097	262	95	10,341
Recruitment costs	666	1,390	332	121	60
Casual staff	5,276	1,390	2,639	959	480
Rental costs	8,465	21,548	4,233	939	460
Business rates	176	452	4,233 89	-	-
Water rates	93	236	46	-	-
Gas and electric	831	2,113	415	-	-
Waste	261	663	130	-	-
				-	-
Telephone	700	1,785	351	-	26
Office insurance	287	601	144	52	26
Data protection costs	53	124	26	10	-
Health and safety costs	102	211	51	18	9
Legal fees	4.072	- 0.722	- 2.072	-	-
Marketing	4,873	8,622	2,062	750	375
Office repairs and renewals	103	262	52	-	-
Photocopier	836	2,125	417	-	-
Postage	122	311	61	-	-
Printing and stationery	201	2,596	87	-	-
Indemnity insurance	444	929	222	81	40
Printing, postage and phone	1,791	4,231	895	325	-
Bank charges	210	496	105	38	-
Bad Debt	-	3,260	141	-	-
Travel insurance	-	-	-	513	-
Miscellaneous	63	134	32	12	6
Computer and internet	85	180	43	31	8
Staff welfare	111	232	56	20	10
Copyright licence Depreciation of tangible	207	487	103	37	-
fixed assets	133	276	66	24	12
Auditors' remuneration for					
non audit work	2,121	5,014	1,061	386	-
	70.100	175 412	(0.052	27.761	17 415
	70,100	175,413	69,952	27,761	17,415
				2020	2019
	Membership and				
	professional	EPNS	Governance	Total	Total
	support	recharges	Costs	activities	activities
	£	£	£	£	£
Trustees' remuneration etc	504	183	_	16,380	16,400
Meeting costs	-	-	1,711	1,711	6,658
Trustee accommodation	304	111	-,, -	2,766	3,247
Accommodation and dinner	273	99	_	2,483	979
Trustee elections	213 -	-	_	2,703	960
Trustee training	-	-	340	340	540
Carried forward	1,081	393	2,051	23,680	28,784
Carriod for ward	1,001	373	2,001	23,000	20,707

## 10. SUPPORT COSTS - continued

SUPPORT COSTS - continue	ed			2020	2010
	Manalanalain			2020	2019
	Membership and				
	professional	EPNS	Governance	Total	Total
	support	recharges	Costs	activities	activities
	£	£	£	£	£
Brought forward	1,081	393	2,051	23,680	28,784
Software subscriptions	291	106	2,031	2,645	3,266
Computer repairs	92	100	_	837	894
Website hosting	20	_	_	180	444
Website development	440	_	_	3,995	9,436
Computer upgrades	39	_	_	357	4,284
Depreciation of tangible	3)	_	_	337	7,207
fixed assets	396	144		3,598	2,113
Employment costs	31,431	177	_	220,396	221,561
Social security	2,714	_	_	17,162	16,550
Pensions	1,185	-	-	7,216	2,331
Staff costs	407	148	-	3,702	2,634
Staff training	262	95	<del>-</del>	2,384	3,482
Recruitment costs	332	121	<del>-</del>	3,022	
Casual staff	2,639	959	<del>-</del>		1,034
Rental costs	·	939	-	23,986	5,080
Business rates	4,233 89	-	-	38,479 806	7,875 789
Water rates	46	-	-	421	402
		-	-		
Gas and electric	415	-	-	3,774	3,691
Waste	130	-	-	1,184	1,242
Telephone	351	- 52	-	3,187	3,097
Office insurance	144	52	-	1,306	1,233
Data protection costs	26	10	-	239	239
Health and safety costs	51	18	-	460	482
Legal fees	2.062	-	-	10.744	1,200
Marketing	2,062	-	-	18,744	10,216
Office repairs and renewals	52	-	-	469	1,220
Photocopier	417	-	-	3,795	2,124
Postage	61	_	-	555	969
Printing and stationery	222	- 01	-	2,884	1,859
Indemnity insurance	222	81	-	2,019	2,172
Printing, postage and phone	895	_	-	8,137	6,683
Bank charges	105	-	-	954	897
Bad Debt	80	-	=	3,481	4,989
Travel insurance	-	-	=	513	-
Miscellaneous	32	12	=	291	255
Computer and internet	43	-	-	390	-
Staff welfare	56	20	-	505	-
Copyright licence	103	-	-	937	-
Depreciation of tangible		• •		-04	<b>4.</b> - c
fixed assets	66	24	-	601	358
Auditors' remuneration for				2 - 1 -	
non audit work	1,061	-	-	9,643	9,452
	52,069	2,173	2,051	416,934	363,337
	======	=====	<u> </u>	<del></del>	303,337

# 11. TRUSTEES' REMUNERATION AND BENEFITS

	2020	2019
	${\mathfrak L}$	£
Trustees' salaries	11,199	10,832
Trustees' social security	355	332
Trustees' pension contributions to money purchase schemes	245	96
	11,799	11,260

Remuneration paid to the trustees noted above was paid to Dr L Hartley for services rendered in relation to the development and provision of distance courses.

# Trustees' expenses

•	2020	2019
	£	£
Trustees' expenses	6,698	13,109

Within the expenses noted above are expenses paid to the following trustees in respect of direct charitable activity costs ie travel expenses teaching at courses, undertaken on behalf of the charity in the year:

	2020	2019
	£	£
Dr M Smith	-	98
Dr F Gibbon	-	222
Dr L Hartley	190	1,298
Dr S Jayawant	66	-
Prof M Kirkpatrick	364	4,158
Prof M Kurian	219	-
Dr A Parker	396	-
Dr A Mallick	-	15
Dr A McLellan	607	1.924
Dr M Griffiths	275	178
Dr A Childs	-	76
	2 117	7.060
	2,117	7,969

Within the expenses noted above are expenses paid to the following trustees in respect of support costs undertaken on behalf of the charity in the year:

	2020	2019
	${\mathfrak L}$	£
Dr F Gibbon	-	347
Dr L Hartley	168	128
Dr S Jayawant	-	90
Prof M Kirkpatrick	1,879	3,171
Prof F O'Callaghan	410	210
Dr A Parker	43	-
Dr A Mallick	535	-
Dr A McLellan	950	236
Dr M Smith	-	464
Prof M Kurian	274	-
Dr A Childs	322	494
	4,581	5,140

# 11. TRUSTEES' REMUNERATION AND BENEFITS - continued

## 12. STAFF COSTS

	2020 £	2019 £
Wages and salaries	269,692	268,777
Social security costs	51,584	20,741
Pension schemes	9,009	3,034
Total	300,285	292,552

Included within creditors as at the reporting date is £1,327 (2019 - £nil) in relation to unpaid pension contributions.

The average monthly number of employees during the year was as follows:

Management Support staff	2020 4 8	2019 4 7
	12	11

The number of employees receiving gross remuneration, inclusive of the value of benefits-in-kind, greater than £60,000 per annum and to whom retirement benefits are accruing under defined contribution pension schemes were:

£60,000 - £70,000	2020	2019
Total employees	1	1

13.	TANGIBLE FIXED ASSETS			
			Fixtures	
		Plant and	and	
		machinery	fittings	Totals
	G 0 G 77	£	£	£
	COST	20.505	2.462	24055
	At 1 April 2019	20,595	3,462	24,057
	Additions	8,030	1,323	9,353
	At 31 March 2020	28,625	4,785	33,410
	DEPRECIATION			
	At 1 April 2019	14,258	2,385	16,643
	Charge for year	3,598	601	4,199
	At 31 March 2020	17,856	2,986	20,842
	NET BOOK VALUE	<del></del>		
	At 31 March 2020	10,769	1,799	12,568
	At 31 March 2019	6,337	1,077	7,414
		<del></del>		
14.	STOCKS			•040
			2020	2019
	g. 1		£	£
	Stocks		16,347	8,126
15.	DEBTORS: AMOUNTS FALLING DUE WITHIN ON	IE YEAR		
			2020	2019
			£	£
	Trade debtors		52,806	45,239
	Other debtors		57	7
	Prepayments and accrued income		19,770	14,749
			72,633	59,995
			<del></del>	

## 16. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020	2019
	£	£
Trade creditors	41,858	13,200
Social security and other taxes	5,418	7,429
Other creditors	63,337	-
Deferred income	5,596	71,629
Accrued expenses	15,968	12,481
	132,177	104,739

The deferred income balance above includes income relating to training courses amounting to £5,571 (2019 - £71,164), membership subscriptions received in advance amounting to £25 (2019 - £465).

2020

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## 17. LEASING AGREEMENTS

Minimum lease payments under non-cancellable operating leases fall due as follows:

	2020	2019
	£	£
Within one year	38,000	38,000
Between one and five years	30,000	68,000
	68,000	106,000

During 2019-20 the BPNA established a London office at 2 St Andrews Place, Regent's Park, London, on the Royal College of Physicians campus. The initial lease will be for 3-years.

During the year the charity incurred expenditure under cancellable and non-cancellable operating lease agreements relating to office rental amounting to £38,479 (2019 - £7,875).

18.	MOVEMENT IN FUNDS				
		At 1/4/19 £	Net movement in funds £	Transfers between funds £	At 31/3/20 £
	Unrestricted funds	~	~	~	~
	General fund Contingency fund Distance learning development fund Research training fellowship fund Priority Setting Project	169,470 150,000 14,117 15,750 50,000	35,458 (6,000) 42,600 (754)	(54,268) 30,000 - -	150,660 180,000 8,117 58,350 49,246
	Acute Neurology course development Fetal Neurology course development	- -	(457)	12,230 12,230	11,773 12,230
		399,337	70,847	192	470,376
	Restricted funds				
	Development of Approaching Children's Tone course	-	11,805	(192)	11,613
	TOTAL FUNDS	399,337	82,652		481,989
	Net movement in funds, included in the above	are as follows:			
			Incoming resources £	Resources expended £	Movement in funds
	Unrestricted funds				
	General fund		848,492	(813,034)	35,458
	Distance learning development fund Research training fellowship fund		42,600	(6,000)	(6,000) 42,600
	Priority Setting Project		4,000	(4,754)	(754)
	Acute Neurology course development		-	(457)	(457)
			895,092	(824,245)	70,847
	Restricted funds ILAE grant fund		0,0,0,2	(021,210)	70,017
	Development of Approaching Children's		38,575	(38,575)	-
	Tone course		25,000	(13,195)	11,805
			63,575	(51,770)	11,805
	TOTAL FUNDS		958,667	(876,015)	82,652

# Comparatives for movement in funds

		Net	Transfers	
		movement	between	At
	At 1/4/18	in funds	funds	31/3/19
	£	£	£	£
Unrestricted funds				
General fund	126,511	94,856	(51,897)	169,470
Contingency fund	150,000	-	-	150,000
Distance learning development fund	19,100	(4,983)	-	14,117
iPET Myanmar fund	1,540	(3,245)	1,705	-
Research training fellowship fund	14,750	1,000	-	15,750
ACT course development	-	(192)	192	-
Priority Setting Project	-	-	50,000	50,000
	211 001	07.426		200 227
D (1.10 )	311,901	87,436	=	399,337
Restricted funds				
ILAE grant fund				
	9,505	(150)	(9,355)	-
THET grant fund	11,975	(21,330)	9,355	_
F. Hoffman-La Roche AG grant fund	10,000	(10,000)	-	-
	31,480	(31,480)	<del></del>	-
TOTAL FUNDS	343,381	55,956		399,337
	====			====

Comparative net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
General fund	875,103	(780,247)	94,856
Distance learning development fund	-	(4,983)	(4,983)
iPET Myanmar fund	-	(3,245)	(3,245)
Research training fellowship fund	37,000	(36,000)	1,000
ACT course development	, <u>-</u>	(192)	(192)
	912,103	(824,667)	87,436
Restricted funds			
ILAE grant fund			
	33,915	(34,065)	(150)
THET grant fund	53,735	(75,065)	(21,330)
F. Hoffman-La Roche AG grant fund	-	(10,000)	(10,000)
	87,650	(119,130)	(31,480)
TOTAL FUNDS	999,753	(943,797)	55,956

A current year 12 months and prior year 12 months combined position is as follows:

		Net	Transfers	
		movement	between	At
	At 1/4/18	in funds	funds	31/3/20
	£	£	£	£
Unrestricted funds				
General fund	126,511	130,314	(106,165)	150,660
Contingency fund	150,000	-	30,000	180,000
Distance learning development fund	19,100	(10,983)	-	8,117
iPET Myanmar fund	1,540	(3,245)	1,705	-
Research training fellowship fund	14,750	43,600	-	58,350
ACT course development	-	(192)	192	-
Priority Setting Project	-	(754)	50,000	49,246
Acute Neurology course development	-	(457)	12,230	11,773
Fetal Neurology course development	-	-	12,230	12,230
	311,901	158,283	192	470,376
Restricted funds				
ILAE grant fund				
	9,505	(150)	(9,355)	-
THET grant fund	11,975	(21,330)	9,355	_
F. Hoffman-La Roche AG grant fund	10,000	(10,000)	-	_
Development of Approaching Children's		, ,		
Tone course	-	11,805	(192)	11,613
	31,480	(19,675)	(192)	11,613
TOTAL FUNDS	343,381	138,608		481,989

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	1,723,595	(1,593,281)	130,314
Distance learning development fund	-	(10,983)	(10,983)
iPET Myanmar fund	-	(3,245)	(3,245)
Research training fellowship fund	79,600	(36,000)	43,600
ACT course development	-	(192)	(192)
Priority Setting Project	4,000	(4,754)	(754)
Acute Neurology course development		(457)	(457)
	1,807,195	(1,648,912)	158,283
Restricted funds			
ILAE grant fund			
	72,490	(72,640)	(150)
THET grant fund	53,735	(75,065)	(21,330)
F. Hoffman-La Roche AG grant fund	-	(10,000)	(10,000)
Development of Approaching Children's Tone course	25,000	(13,195)	11,805
Tone course		(13,173)	
	151,225	(170,900)	(19,675)
TOTAL FUNDS	1,958,420	(1,819,812)	138,608

#### Contingency fund

The contingency fund is held to support the staffing cost of running the BPNA Secretariat for a period of approximately six months (2019 - six months) should there be any contingency that might lead to a significant reduction in BPNA operational activities, this equates to £180k (2019 - £150k).

#### Distance learning development fund

The distance learning development fund is a designated fund set up by the trustees in order to preserve the anticipated level of funding incurred for distance learning course development in the foreseeable future. This funding is provided from transfers from the general fund.

## Approaching Children's Tone (ACT) Course Development

The ACT course development fund is a restricted fund set up by the trustees to fund development a new 2-day course designed to teach paediatricians and allied health professionals to recognise abnormal tone in children, so that they will ensure timely referral to specialists and access to appropriate investigations and treatment. Funding has been provided through educational grants.

#### Acute Neurology

The Acute Neurology course development fund is a designated fund set up by the Trustees to fund development of a new 1-day course designed to teach paediatric emergency medicine staff, paediatricians and trainees to recognise acute neurological conditions and manage appropriately. This funding is provided from transfers from the general fund.

#### Fetal Neurology Course Development

The Fetal Neurology course development fund is a designated fund set up by the Trustees to fund development of a course designed to improve training for anyone involved in caring and counselling a family whose fetus has a neurological abnormality. This funding is provided from transfers from the general fund.

## International League Against Epilepsy (ILAE) grant fund

This fund represents the residual grant funding received from the ILAE, less expenditure incurred, that has restrictions placed upon it for the performance of delivering and developing international PET courses as agreed in a memorandum of understanding between the two organisations. The performance of these objectives are expected to take place between the period of 2018 to 2021 for which the organisations shall share the budgeted expenditure incurred by BPNA.

#### Tropical Health and Education Trust (THET) grant fund

This fund represents the residual grant funding received from the Department for International Development (DFID) via THET, less expenditure incurred, that has restrictions placed upon it in relation to the provision of training 24 paediatricians from four countries to deliver PET courses in their home countries, contribute to the development of PET courses in the UK, deliver PET courses for the first time in four African nations, and provide continuing education for African faculty.

## Roche grant fund

This fund represents the residual grant funding received from F. Hoffman-La Roche AG, less expenditure incurred, that has restrictions placed upon it that restrict the use of the funds to supporting the running and development of distance learning courses.

## **Priority Setting Project**

The BPNA has committed significant resources to undertaking a research priority setting project in paediatric neurology, facilitated by the James Lind Alliance. This project will run from 2019-20. Priority Setting Partnerships enable clinicians, patients and carers to work together to identify and prioritise evidence uncertainties that could be answered by research. The outcome of the project will be a top 10 list of jointly agreed research priorities, which are publicised widely, and other uncertainties are recorded and available for research and research funders to access.

#### Transfers between funds

The transfers between designated funds and the general fund have been undertaken in order to ensure a suitable level of reserves has been designated as at the reporting date for the purposes of the funds listed.

There have been no transfers between restricted funds and unrestricted funds in the current or prior year.

#### 19. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2020 or the year ended 31 March 2019, except for the transactions with the trustees and remuneration paid to key management personnel as disclosed earlier in these notes.

## 20. POST BALANCE SHEET EVENTS

## **The impact of COVID-19**

On 31 October 2020 the UK Government announced a second national lockdown due to the COVID-19 pandemic, effective from Thursday 5 November 2020. The charity had already taken significant steps to mitigate the impact of a second lockdown. This includes, but is not limited to, providing the majority of their courses online.

Given the charity's contingency planning and other arrangements, the trustees believe the situation can be managed and that the charity remains financially viable through this and a going concern.

#### 21. ULTIMATE CONTROLLING PARTY

The trustees consider there not to be one ultimate controlling party of the British Paediatric Neurology Association in the current or prior year.

# Detailed Statement of Financial Activities for the Year Ended 31 March 2020

	2020 £	2019 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	5,521	4,334
Grants	63,575	87,650
BPNA members subscriptions	85,754	84,485
Gift aid	1,752	12 000
Membership donations	12,600	13,000
Annual conference symposium sponsorship  Annual conference sponsorship	30,000 83,000	20,000 71,800
Short course sponsorship	44,000	34,000
Miscellaneous income	605	34,000
wiiscenaneous income		
	326,807	315,269
Investment income		
Deposit account interest	1,719	1,088
Charitable activities		
Conferences and symposiums	166,079	153,776
Short courses	313,020	369,659
International short courses	12,226	33,959
Distance learning	71,969	81,085
EPNS recharges	48,722	44,117
Professional support	17,325	-
BPNSU fee income	800	800
	630,141	683,396
Total incoming resources	958,667	999,753
EXPENDITURE		
Raising donations and legacies		
Charity web hosting	100	70
JustGiving fees	216	216
	316	286
Charitable activities		
Trustees' expenses	2,117	7,969
Wages	38,097	36,384
Social security	4,067	3,859
Pensions	1,548	607
Developmental Medicine and Child Neurology	·	
(DMCN) Journal	38,708	33,979
Carried forward	84,537	82,798

# Detailed Statement of Financial Activities for the Year Ended 31 March 2020

	2020	2019
Charitable activities	£	£
Charitable activities Brought forward	84,537	82,798
DMCN - other costs	600	3,367
Venue costs	43,327	54,118
Accommodation	63,135	75,746
Catering	120,563	147,997
Courier	5,797	6,188
Short course development manager	8,601	8,304
Course development	20,209	5,661
Course materials	12,521	19,480
Travel	36,674	65,137
AV Hire	4,930	17,418
Conference app	11,945	11,665
Professional support	17,178	1,003
Speakers' Honoraria & Prizes	2,530	3,103
Steering meeting costs	2,742	9,659
Subscriptions	1,075	1,155
Website development	6,640	2,699
Equipment purchases	-	11,339
Other THET costs	_	6,569
Miscellaneous	141	15
BPNSU research	2,449	2,054
Insurance - conference	1,278	1,178
Bank charges	299	353
BPNA newsletter & annual report	215	146
Casual staff	1,617	1,607
BPNA distance learning fees paid		4,320
Website hosting	227	1,091
Meeting costs	3,268	-
Priority setting research	4,754	_
EPNS recharges	1,513	_
AMR BPNA Research Fellowship	- -	36,000
	458,765	580,174
Support costs		
Management		
Trustees' salaries	11,199	10,832
Trustees' social security	355	332
Trustees' pension contributions	245	96
Trustees' expenses	4,581	5,140
Meeting costs	1,711	6,658
Trustee accommodation	2,766	3,247
Accommodation and dinner	2,483	979
Trustee elections	-	960
Trustee training	340	540
	23,680	28,784

# Detailed Statement of Financial Activities for the Year Ended 31 March 2020

	2020	2019
Managamant	£	£
Management		
Information technology	2.645	2.266
Software subscriptions	2,645	3,266
Computer repairs	837	894
Website hosting	180	444
Website development	3,995	9,436
Computer upgrades	357	4,284
Plant and machinery	3,598	2,113
	11,612	20,437
Human resources		
Employment costs	220,396	221,561
Social security	17,162	16,550
Pensions	7,216	2,331
Staff costs	3,702	2,634
Staff training	2,384	3,482
Recruitment costs	3,022	1,034
Casual staff	23,986	5,080
	277,868	252,672
Other		
Rental costs	38,479	7,875
Business rates	806	7,879
Water rates	421	402
Gas and electric	3,774	3,691
Waste	1,184	1,242
Telephone	· · · · · · · · · · · · · · · · · · ·	3,097
	3,187	
Office insurance	1,306	1,233
Data protection costs	239	239
Health and safety costs	460	482
Legal fees	-	1,200
Marketing	18,744	10,216
Office repairs and renewals	469	1,220
Photocopier	3,795	2,124
Postage	555	969
Printing and stationery	2,884	1,859
Indemnity insurance	2,019	2,172
Printing, postage and phone	8,137	6,683
Bank charges	954	897
Bad Debt	3,481	4,989
Travel insurance	513	-
Miscellaneous	291	255
Computer and internet	390	
Staff welfare	505	_
Copyright licence	937	
Fixtures and fittings	601	358
	94,131	51,992

# **British Paediatric Neurology Association**

# Detailed Statement of Financial Activities for the Year Ended 31 March 2020

	2020 £	2019 £
Other		
Governance costs  Auditors' remuneration for non audit work	0.642	0.452
Auditors remuneration for non audit work	9,643	9,452
Total resources expended	876,015	943,797
Net income	82,652	55,956