

REGISTERED CHARITY NUMBER: 1159115

**Report of the Trustees and
Financial Statements for the Year Ended 31 March 2023
for
British Paediatric Neurology Association**

British Paediatric Neurology Association

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for the Year Ended 31 March 2023**

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**Report of the Trustees
for the Year Ended 31 March 2023**

The trustees present their report with the financial statements of the charity for the year ended 31 March 2023. 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

The BPNA has had another highly productive year. Despite re-organisation of the NHS following the Pandemic, we have continued to grow, bridge, build and innovate. We continue to be a small medical charity hitting well above our weight in terms of research, education, training and professional support.

This occurs across all our diverse communities and we strive to achieve this equitably.

Our international profile now extends from our excellent links with our European colleagues and through research, training and education to all Continents.

It is a challenge for me to direct you the key highlights and as a result I have emphasised the below as these are areas that have been specifically raised by our members as priorities.

- Our Training Team continue to overcome barriers, encourage applications between a Student starting out on their journey, all the way through to those who have almost completed competencies in Paediatric Neurology. This is reflected in much greater numbers of applicants, development and appointments in areas where programmes have previously stopped.

- UK Education continues to get excellent feedback in terms of quality, quantity and reach in terms of accessibility.

- International Education thrives with launches from afar a field as New Zealand/Australia/Sub Saharan Africa and more recently advanced plans for North Africa, South America building on our previous excellent experience elsewhere. Bridging with the International League Against Epilepsy (ILAE) and acknowledged by World Health Organisation (WHO) is likely to be a great benefit to children with Epilepsy across the World.

- Despite the challenges in clinic practice as the NHS "Reboots", professional support has been steady with very positive feedback from centres who have liaised and is likely to be a continuing priority for my successor - who has led this area admirably for a long period.

- We continue to have an extremely active research portfolio across British Paediatric Neuroscience as demonstrated by our very successful 2023 conference and ongoing productive fellowships in partnership with Action Medical Research.

Lastly, if I am to make any criticism of the BPNA, it is that our finances are too good! With hard work of our members, council, executive and secretariat, our reserves have grown steadily despite ongoing investments. We are in a sound financial position and one of the major challenges for the next year will be to identify key areas for investment/reduction of those reserves.

I finish by saying it has been a pleasure and privilege to be President of the BPNA. I am confident we are in a strong position in all senses. I thank all the members, council, executive and secretariat who have worked so hard to support the wonderful children/families we care for.

Yours sincerely

Dr Alasdair Parker
BPNA President (2021-2024)

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, through provision of (NeoNATE) courses
 - Abnormal muscle tone, through provision of the Approaching Children's Tone (ACT) courses
 - Acute neurological disorders through the newly developed course Acute
 - 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

Public benefit

The trustees have had regard to the Charity Commission's guidance on public benefit in considering activities during 2022-23. 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

During 2022-23, the charity provided £41,302 funding the second year for the second joint BPNA Action Medical Research (AMR) fellowship and £41,667 funding the first year for the third joint BPNA Action Medical Research fellowship.

OBJECTIVES AND ACTIVITIES

Volunteers

BPNA faculty in the UK and overseas directly contributed to the development and delivery of courses and distance learning. They also contribute their expertise in the other areas of the BPNA including Professional Support and Research as Chair, Council and Committee members. You can define all these people as volunteers who give their time to the BPNA as a charity. Their contribution is significant to the ongoing activities of the BPNA and the trustees wholeheartedly appreciate this commitment and thank them.

Fundraising

BPNA raises funds through applying for grants from organisations that have the same interests.

The charity has used its own staff for fundraising and not any external fundraisers.

The charity is not a member of any voluntary scheme for regulating fundraising.

All fundraising activities are monitored by the Director and the charity has not received any complaints regarding its fundraising activities.

The charity does not come into contact with vulnerable people as it is not involved with street or door to door fundraising.

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 and includes the BPNA National Training Advisor.

The GMC and RCPCH Shape of Training (SoT) plans on paediatric neurology training are now finalised and will be commencing in August 2023. It has been agreed that neurology GRID trainees will still have up to 3.5 years to meet learning objectives.

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, 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 has developed an Annual Progression Form which incorporates the curriculum and trainees have provided positive feedback regarding this.

1.3 - Appointment of new Grid trainees

For the 2023 paediatric neurology GRID training programme, there were 9 GRID training schemes available. Over thirty applications were received, and 19 trainees were shortlisted for interview. 16 candidates were deemed appointable, and 9 trainees accepted a GRID position. Overall, this is a huge increase in number of trainees applying to the GRID scheme in comparison to previous years.

There has also been a change in number of attempts at GRID applications. Unlimited attempts are now being allowed, provided the trainee has had equivalent training up to the stage of entry, counting a maximum of 12 months of equivalent experience.

In 2020, the BPNA established a Recruitment Working Group to develop strategies to encourage junior doctors to consider a career in paediatric neurology. Various initiatives have been implemented to aid prospective trainees in making successful applications including a careers page on the BPNA website with webinars on applications and interviews and general topics in paediatric neurology. Feedback on these sessions have been very positive overall.

1.4 - Assessment and Support for Existing Trainees

All trainees receive an annual virtual CSAC progression interview. In the past year, most trainees have been making good progress. There are challenges for some trainees to access outpatient activities in specific centres and the Neurology CSAC have been supporting the local teams to address this. A shortage of consultants in substantive posts has impacted on their ability to train in some centres.

1.5 - Special Interest (SPIN) module in Epilepsy

The Neurology CSAC have rewritten the Special Interest (SPIN) Epilepsy curriculum in 2022 and this has now been endorsed and signed off by the RCPCH. The BPNA are looking at more ways to support Trainees taking on SPIN Epilepsy.

1.6 - Assessment of "Non Grid" Training

Doctors who have not completed the UK paediatric neurology GRID training programme, but who can show they have knowledge, skills and experience equivalent to the approved curriculum, can request entry on the GMC specialty register via the Certificate of Eligibility for Specialist Registration (CESR) route, if part of their training was done overseas. The Neurology CSAC has a role in evaluating CESR applications. If the GMC approve the initial application, the Neurology CSAC will review the neurology component of their training and determine whether it is equivalent to that of a UK GRID trainee. Typically, only training in the 5 years prior to the CESR application can be considered and if successful, the applicant will be entered onto the GMC specialist 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 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 on Advisory Appointments Committees (AAC) in ensuring that candidates applying for a consultant paediatric neurology post are suitably trained to fulfil the role. Of note, a 'Letter of Equivalence' does not allow entry on the specialist register.

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 Training Services team.

2. Education

285 BPNA faculty in the UK and overseas directly contributed to the development and delivery of courses during 2022-23. This demonstrates the strong motivation and engagement of faculty, and the trustees wholeheartedly appreciate this commitment to teaching and training.

The BPNA's face-to-face courses were cancelled from March 2020 due to coronavirus restrictions and courses were adapted to be taught in an online, virtual environment. Some courses have started up again to take place face-to-face, with the majority still taking place online. The BPNA are beginning to look at what the best balance is for a mixture of face-to-face and online courses, as remote courses are popular, however, there is still a desire for face-to-face activity.

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.

All PET1, PET2 and PET3 courses took place in a virtual setting again in year 2022-23. Virtual courses have resulted in a reduced number of PET courses compared to when they ran face-to-face pre-pandemic:

- PET1 (1-day) 6 courses (2019-20=10)
- PET2 (2-days) 4 course (2019-20=6)
- PET3 (2-days) 2 courses (2019-20=6)

Since 2005 to 31 March 2023, 12,143 UK clinicians have attended a PET course (2022-23=726; 2021-22=702; 2020-21=300), contributing to improving the standards of diagnosis and management of children with epilepsy in the UK. Feedback from virtual courses has been excellent.

The PET23 course materials were updated by a team of international clinicians in 2018. The updated PET23 materials were used in the UK from 2019. The PET1 course materials were updated by a team of international clinicians in March 2023. The updated PET1 materials were used in the UK from May 2023. 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 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 was adapted for virtual delivery during the coronavirus pandemic. In 2022-23, four virtual CHaT courses were held. Feedback has been excellent, with many attendees preferring virtual. During 2022-23 CHaT welcomed international attendees from Australia, Estonia, Germany, Greece, Indonesia, Norway and United Arab Emirates.

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

Since 2012, 1,498 clinicians have attended CHaT (2022-23=198; 2021-22=138; 2020-21=117; 2019-20=137).

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.

The NeoNATE course was not adapted for virtual delivery and therefore no courses have run since pre-pandemic, in November 2019. In 2022-23, NeoNATE ran two courses with being able to run face-to-face courses. Since 2014, 636 clinicians have attended NeoNATE (2022-23=80; 2021-22=0; 2020-21=0; 2019-20=94). During 2022-23 NeoNATE welcome international attendees from Belgium, Denmark, Egypt, India and Netherlands.

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.

In 2022-23, 39 people attended Expert to Expert: Epilepsy, with international attendees from Malaysia (1), Netherlands (2) and Norway (1).

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, the BPNA developed a short course on tone management in children called 'Approaching Children's Tone' (ACT).

The ACT course was developed for virtual delivery. Since the running of the first course in 2020-21, 222 clinicians have attended ACT (2022-23=94; 2021-22=92; 2020-21=36).

2.6 Acute Paediatric Neurology

It is estimated that about a third of all paediatric emergencies are neurological. 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 view of this, the BPNA in collaboration with the Association of Paediatric Emergency Medicine developed a 1-day course called Acute Paediatric Neurology.

The Acute course was developed for virtual delivery. Since the running of the first course in 2021-22, 126 clinicians have attended Acute (2022-23=91; 2021-22=35).

2.7 Distance Learning in Paediatric Neurology

Introduction

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 or more units. 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. During 2021-22, doctors enrolled from 46 countries.

Distance Learning complements BPNA short courses, providing depth and extending the knowledge gained at a one and two day courses. Working with respective short-course development teams, explicit links are being provided in DL units to reinforce the learning provided in the related short-courses. Thus, we encourage:

- PET attendees to study Unit 6 Epilepsy
- NeoNATE attendees to study Unit 2 Neonatal Neurology
- CHaT attendees to study Unit 12 Headache
- ACT attendees to study Unit 5 Neuromuscular and Unit 4 Central Motor Disorders
- Acute Paediatric Neurology attendees to study Unit 13 Acute Paediatric Neurology

Updating content

A Consultant Paediatric Neurologist is employed for 4-hours per week to direct and oversee the constant revision and rewriting process. The Distance Learning Steering Group, consisting of one/ two experts per unit, meets twice per year.

In 2021-22 £75,000 was allocated to the Distance Learning development reserve to fund development and updating 2021-2024. During 2022-23, Unit 8 Inflammation and infection of the CNS has had a major update and the update of Unit 5 Neuromuscular was completed.

Distance Learning is hosted on the Moodle platform. During 2022-23 the platform was upgraded, resolving security issues and providing access to new functionality.

Enrolments

During 2022-23, there have been 672 enrolments on distance learning units, by 197 people from 40 countries. The highest proportion of these enrolments are from the UK, 53% (358 of 672). Additionally, 184 people enrolled on 'bundles' of units, of which 109 were from high income countries and 75 from low and middle-income countries.

Acknowledgements

We are indebted to the Consultant Paediatric Neurologist volunteer tutors globally, who give their time to tutor students through the course. We give enormous thanks to all those Consultants across the subspecialties who contribute to the course content development, including preparing and giving BPNA webinars.

2.8 - Webinar Lecture Series

Covid-19 led to a change in trainee's working patterns that resulted in them having restricted access to appropriate teaching. In response, the BPNA President launched a free weekly Webinar Lecture Series.

BPNA webinar lecture series was launched as a free weekly virtual learning resource for child health professionals, in particular those working in paediatric neurosciences worldwide.

The first lecture was given on 14 May 2020 and lectures have been delivered weekly up until September 2022, with a couple of short breaks for holidays. From October 2022 to this date the webinar lectures have been delivered on a monthly basis. This would not have been possible without the generosity of BPNA members giving their time. We are grateful to them all for preparing and delivering such excellent lectures on wide range of topics and for remaining until all the questions have been answered. Recordings of lectures are available in the BPNA members' area and are also provided on the distance learning platform for enrolled students to access.

During 2022-23, the webinar lecture series has been attended by both trainees and consultants worldwide. 3559 doctors and allied health professionals from over 82 countries have attended 30 BPNA weekly webinar lectures.

It has been acknowledged that the webinars are a great promotion to the BPNA's brand and charitable objectives and that they should carry on.

2.9 - International Short-Courses

2022-23 saw a beginning of a return to form after the postponement of many activities during the coronavirus pandemic. Due to the lifting of restrictions, PET1 was launched in Colombia and Australia and Face to Face courses around the globe began again. PET is typically rolled out in new countries through a 3-day launch programme, which takes place face-to-face.

This was the first year of BPNA's new four-year partnership (2022-2026) with the International League Against Epilepsy (ILAE), which was formed to facilitate the roll-out of PET worldwide. The initial memorandum of understanding has a value of \$278,844 over that time. 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 BPNA and ILAE share a commitment to improving care for children with epilepsy. In 2005, the BPNA developed Paediatric Epilepsy Training (PET) courses to train healthcare workers to better diagnose and treat children with seizures. PET1 is now attended by almost every paediatrician in the UK and the courses have also been launched overseas, setting a gold standard for epilepsy care around the world. Outside of the UK, the programme currently runs in: Australia, Brazil, Colombia, Ghana, India, Kenya, Myanmar, New Zealand, South Africa, Sudan, Tanzania and Uganda.

PET aligns with the ILAE's Education Council's aim to teach competency in the diagnosis and clinical management of epilepsy, with a focus on non-specialists i.e. paediatricians. It forms part of the portfolio of educational activities that the ILAE aims to develop. It also supports Goal 2 of the ILAE's Strategy 2030: Support health professionals worldwide to enhance their knowledge and skills in the prevention, diagnosis, treatment and care of epilepsy.

The BPNA and the ILAE first signed a partnership agreement in 2018, committing to build on the success of the Paediatric Epilepsy Training courses developed by the BPNA.

The ILAE has agreed to cover 40% of staff costs in the BPNA's International Education team (3 staff members) from April 2022 to March 2026.

The total number of attendees outside the UK and Republic of Ireland is 5,455 (PET1=4,428; PET2=502; PET3=251; iPET=274; Trained as faculty=223).

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: Two virtual courses were run in partnership with the Ministry of Health and Prevention in Sharjah.

PET1 attendance since 2014: 171 (2021-22=15; 2020-21=0; 2019-20=0)

PET2 attendance since 2014: 133 (2021-22=14; 2020-21=0; 2019-20=0)

North Africa:

Sudan: A group of 8 attendees from Sudan joined a virtual course being run in the UK.

PET1 attendance since 2014: 297 (2021-22=8; 2020-21=0; 2019-20=0)

PET2 attendance since 2014: 109 (2021-22=0; 2020-21=0; 2019-20=0)

2.9.2 - Sub Saharan Africa

South Africa in partnership with the Paediatric Neurology Development Association of Southern Africa. One course was delivered by South African faculty in 22-23, for delegates attending in Mauritius. 19 delegates attended the course. Since 2015-16, the total number of PET1 attendees taught by south African Faculty is 398 (2022-2023=19; 2021-22=55; 2020-21=0; 2019-20=42)

Ghana in partnership with the Paediatric Society of Ghana. During 2022-2023, one Face to face course was held, with 33 attendees. Since 2018, the total number of PET1 attendees is 264 (2022-23=33; 2021-22=11; 2020-21=40; 2019-20=47)

Kenya in partnership with the Kenya Paediatric Association. During 2022-23, one PET1 course was held with 48 attendees and one hybrid PET2 course was held with 39 attendees.

PET1 attendance since 2017 = 310 (2022-23=48; 2021-22=11; 2020-21=50, 2019-20=30)

PET2 attendance since 2017 = 19 (2022-23=39; 2021-22=16; 2020-21=3)

Mozambique. During 2022-23, 16 attendees joined a virtual PET1 course run by the team in Brazil aimed jointly at delegates in Mozambique and Angola. PET1 attendance since 2021 = 24 (2022-23=16; 2021-22=8).

Angola. During 2022-23, 16 attendees joined a virtual PET1 course run by the team in Brazil aimed jointly at delegates in Mozambique and Angola. PET1 Attendance since 2019 = 50. (2022-23=16; 2021-22=0; 2020-21=0; 2019-20 = 34)

Tanzania in partnership with the Paediatric Association of Tanzania. One Face-to-face course was run in 2022-23, with 41 attendees. Since 2018, the total number of PET1 attendees is 184 (2022-23=41; 2021-22=0; 2020-21=33; 2019-20=0)

Uganda in partnership with the Uganda Paediatric Association. During 2022-23, no PET1 courses were delivered. Since 2018, the total number of PET1 attendees is 136 (2022-23=0; 2021-22=9; 2020-21=0; 2019-20=35).

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. In 2022-23, one face-to-face course was held with 45 delegates. Total PET1 attendees in India since 2014: 1,634 (2022-23=45; 2021-22=88; 2020-21=0; 2019-20=47).

Myanmar: PET1 was launched in Myanmar in 2014. Since then, 313 people have attended PET1 (2022-23=0; 2021-22=0; 2020-21=1; 2019-20=0). Courses in the country are on hold due to the current political situation.

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, and has continued to be postponed, due to coronavirus restrictions. No courses were held in Singapore in 2022-23.

**Report of the Trustees
for the Year Ended 31 March 2023**

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 2022-23, one face-to-face course was held for 32 attendees. Since 2018-19, PET1 has been delivered to 211 attendees (2022-23=32; 2021-22=40; 2020-21=17; 2019-20=41).

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 was postponed due to coronavirus restrictions. The three-day launch occurred in August 2022. 25 members of New Faculty took part in the launch, with 19 attendees from Colombia joined by colleagues from other Spanish speaking countries in the region, with 1 delegate from each of the following countries: Argentina, El Salvador, Guatemala, Honduras, Mexico and Paraguay. UK Faculty delivered a PET1 and Instructor Training Day to the New Faculty on days one and two, with the new faculty delivering the course in Spanish on day three across two courses to a total of 38 delegates. Since 2022, the total number of delegates taught PET1 in Colombia is 78 (2022-23=63, 2021-22=15).

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 2022-23, three PET1 Courses were held, one PET2 course was held and 2 PET3 courses were held, all face-to-face courses.

PET1 attendance since 2017: 388 (2022-23=83; 2021-22=25; 2020-21=27; 2019-20=45).

PET2 attendance since 2017: 170 (2022-23=32; 2021-22=31; 2020-21=0; 2019-20=38).

PET3 attendance since 2018: 126 (2022-23=54; 2021-22=0; 2020-21=32; 2019-20=33).

Australia in partnership with the Australia and New Zealand Child Neurology Society (ANZCNS), PET1 and PET2 were due to launch in July 2020. This was postponed due to coronavirus and instead occurred in November 2022 with a five-day launch. On day one, UK Faculty delivered PET1 to 23 attendees, on days two and three, PET2 was delivered to 21 attendees. On day four, 12 new faculty were delivered the instructor training day, with two attendees from Singapore, two from New Zealand and eight from Australia. On day five, PET1 was delivered by the New Faculty to 25 attendees. Prior to the launch, Australia also held a virtual PET1 course in May 2022 with a total of 43 attendees.

Since 2021, the total number of course attendees in Australia are PET1 = 107 (2022-23=94; 2021-22=13), PET2= 24 (2022-23=24).

2.9.6 - North America

In 2022, a virtual course was held for Caribbean delegates by UK Faculty. The course, held over two days due to the time difference between the UK and Caribbean welcomed 26 delegates.

2.10 Evaluation of educational activities

BPNA's educational activities are designed to promote the health and well-being of children with neurological disorders. We are committed to evaluating them to ensure that they do so and to adapting them on an ongoing basis. After completion of any of our educational activities, learners are required to complete a feedback form to assess their level of satisfaction with the course. At PET1 courses, learners also complete a pre- and post-course quiz to assess knowledge-gain, and, six months later, a follow up survey to establish the changes that they have made to their clinical practice. These data have been analysed by a group of researchers from the BPNA and the University of Dundee and form the basis of a research paper that we hope will be published in the coming months. Together with the University of Manchester we intend to further refine our evaluation methods for the PET1 course during 2023/4 by using a clinical behavioural-change methodology to further understand the impact of the course. It is hoped that these refined evaluation tools can be adapted and applied to other BPNA short courses.

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 49th annual scientific meeting was hosted by Edinburgh and held as a hybrid event in January 2023. There were 816 delegates from 50 countries. Technology facilitated high delegate numbers (2022=941; 2021=1,134; 2020 Belfast=427; 2019 Liverpool=391) and geographic access. Opportunities to learn were provided by 22 oral presentations and 237 posters (selected from 266 abstracts submitted); 17 keynote lectures; 4 clinical practice sessions; and 6 sponsored symposiums.

2023 Prizes were awarded to:

Dr Sophie Adler
(Research Associate, UCL Great
Ormond Street Institute of Child
Health, 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 Laura Hyrapetian & Dr Dora
Steel
(Royal London Hospital) & (Great
Ormond Street Hospital, London)

Best oral presentation by a trainee.

Dr Emily Lancsatle & Dr Sharmilla
Manivannan
(University of Edinburgh) &
(Addenbrookes Hospital)

Best poster presentation by a trainee.

Dr Shima Abdullateef
(University of Edinburgh)

Best poster audio narrative by a trainee.

Dr Gemma Fisher & Dr Maria
Gogou
(University Hospital Wales) &
(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.

Dr Ramya Ramesh Baby
(Synapse Neurocenter)

Best medical student presentation.

Dr Susan Harvey
(CHI at Temple Street)

A new prize, Development Medicine and Child Neurology (DMCN)
Best Article by a BPNA Trainee Prize was introduced this year.

4. Patient and Public Involvement (PPI)

We had 18 paediatric neurology related charities attended the conference. 13 were able to take up a physical stand and 5 took up the opportunity to have a virtual exhibition stand to engage with BPNA members and the other attendees.

During the conference, a Charity networking session was implemented for the charities who had a stand. The purpose was to meet with other charities to discuss updates, for attendees to go, and have as a place to invite people coming to the conference to meet. The aim was to open up on the opportunity for charities to engage with attendees at the conference and identify opportunities to improve the lives of children with neurological disorders. Each BPNA Conference venue has its challenges of where stand spaces can be located, each year aiming for charities to have as much involvement as possible with their stand location.

Feedback was received for improvement. The BPNA look forward to hosting them again at the 2024 conference.

During 2022-23 eight representatives from 6 epilepsy related charities observed PET1 Virtual and provided very constructive feedback to inform course development. The group highlighted the need for clinicians to understand the holistic impact on families, amongst other important messages. The group will repeat the exercise for PET2 and 3 during 2023-24.

The BPNA worked in collaboration with the Child and Adolescent Psychiatry Faculty of the Royal College of Psychiatrists to produce a 2021 Consensus statement on childhood neuropsychiatric presentations to support its members on 21 April 2021.

Following that a PANSPANDAS Working Group was set up to discuss and liaise with PANS PANDAS UK in producing a PANS PANDAS Working Group Statement with other colleges and groups. This was published in February 2023 and addressed the current variation across the UK in the management of patients presenting with Paediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS).

The BPNA constantly looks to expand the PPI throughout the organisation as part of the charitable aims. Request have been made for PPI representation in the special interest groups, course development and as many other activities as possible. As well as trainees should be facilitated to work with PPI and social media. We proposed increasing this area going forward.

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.

The BPNA Research Committee is chaired by Dr Sam Amin.

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.

There is also BPNA Research Committee representation on the editorial board of Mac Keith Press for the Developmental Medicine and Child Neurology (DMCN) journal. One Research Committee member and one other BPNA member.

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, 27 studies have been conducted using BPNSU.

Dr Sukhvair Wright has taken over from Prof Richard Chin as BPNSU Lead in the Research Committee

During 2022-23, no project was added onto the BPNSU system (2021-22 = 1 2020-21 =1, 2019-20=1; 2018-19=1; 2017-18=3). As of 31 March 2022 one project was active on BPNSU system.

BPNSU fees were increased in 2020-21 to £1,200 for up to 2-years, which is still significantly less than other surveillance studies. Additional years are charged £600 per annum.

The BPNSU website has been redeveloped to provide increased efficiencies and consistency of information. The aim is to have it all inhouse by June 2023 with the purpose of the BPNSU email list continually reviewed and updated to optimise returns by the Membership and Committees Coordinator. Emails are sent out twice a month for notifications of new studies.

In 2020-21, an audit of all past studies was carried out. Since 2014, there have been 15 conference abstracts and 10 peer-reviewed publications resulting from BPNSU studies. Journal publications have been in Developmental Medicine and Child Neurology, Neurology, and Lancet Child and Adolescent Health. One PhD was awarded, and one project reported 4 invited international talks in which BPNSU data were part of the presentation. There were four successful grant applications arising from BPNSU studies, with a total grant income of £1,237,949: 1 MRC Developmental Pathway Funding Scheme award, 1 NIHR/GOSH Clinical Fellowship, 1 KESS2 (Knowledge Economy Skills Scheme) Studentship, and a donation from the Alternating Hemiplegia of Childhood UK Charity. Public engagement varied from parental groups informing study design, results informing genetic counselling for families, to results being presented or planned to be presented.

In view of no project being added in 2021-22, the BPNA reviewed barriers for applications and implemented the BPNSU Grant Award.

It was agreed by the BPNA Trustees to produce a BPNSU Grant Award for up to a 2 year study. This is equivalent to the cost of £1200 which would cover the cost of a study so as to support this charitable aim.

This grant would be eligible for a BPNA member who is otherwise a trainee or newly appointment consultant within 2 years of qualifying.

The purpose of the award is to promote research amongst junior members of the BPNA and to help create future researchers in paediatric neurology.

One of the aims in the last year has been to develop our relationship and try to collaborate with the British Paediatric Surveillance Unit (BPSU) which is part of the RCPCH. This is due to having similar objectives.

5.2 Paediatric Neurology Fellowship

A partnership was established in 2015 with Action Medical Research (AMR) to jointly fund a 3-year AMR-BPNA Research Training Fellowship. Voluntary donations of members and income generated from sponsored symposia at the annual conference fund this fellowship.

The 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.

The third fellowship was advertised and awarded to Dr Jonathon Holland, commencing in Autumn 2022. In his project ; Multiple sclerosis: assessing nerve repair in children to find out if they could benefit from new treatments' Jonathon will aim to find out whether children with MS could benefit from potential new treatments currently being tested in adults.

A fourth Fellowship will be advertised in Summer 2023 with the aim to commence in Spring 2024. The BPNA Research committee has designed a pre-selection questionnaire to support applicants.

Previous AMR BPNA Research Training Fellows:

2016-19 Dr Apostolos Papandreou Neurodegenerative disorders with brain iron accumulation - finding new treatments

5.3 Priority Setting Project

The BPNA committed £50,000 to undertaking a research priority setting project (PSP) in paediatric neurology, facilitated by the James Lind Alliance. This partnership aims to shape future research on paediatric neurological conditions by bringing together patients, their parents and carers and health care professionals to identify and prioritise unanswered research questions around treatments, therapies or procedures. The outcome of the project will be a list of the top 10 jointly agreed research priorities. These priorities will then be promoted to research funding organisations to influence future research.

The PSP commenced October 2019, aiming to complete September 2020, however due to Covid-19, the project was extended to 31 March 2022. During 2020-21, a survey was promoted to clinicians, patients and carers to complete online. The responses were analysed filtered, and a second survey was sent out in 2021-22. It asked them to identify their top research priorities in paediatric neurology from a list of 44 questions. These responses were analysed and filtered and produced a top 26 final list of unanswered questions.

The final prioritisation workshop was held with various stakeholder groups on 30 March 2022 in London, with the objectives to finalise top 10 research questions from the final 26.

The top 10 and the other 16 that did not make the top 10 were published in a final summary document in November 2022 as 'Top Ten UK research priorities for interventions in childhood neurological disorders' and was well received.

The aim now would be looking into how some of these questions can be researched with the support of the BPNA and interested stakeholders.

A Pre-conference Trainees' research network meeting happened at the BPNA2023 Conference with discussion about the AMR Fellowship and Priority Setting Project results, chaired by Dr Sam Amin (Chair of Research) & Dr Robert Spaul (Trainees Rep). Dr Sam Amin will continue to have development meetings throughout the next year.

5.4 BPNA Conference

The BPNA Research Committee review, score and select submitted abstracts, sponsored symposium and the Ronnie MacKeith Prize. Mac Keith Press co support the Ronnie MacKeith Prize and also support and select the Developmental Medicine and Child Neurology (DMCN) Best Article by a BPNA Trainee Prize.

Prizes are also chosen and give by the BPNA for the Best Poster by a Trainee Prize, Best Poster Audio Narrative by a Trainee Prize, Best Oral Presentation by a Trainee Prize and Best Medical Student Presentation.

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5.5 Read of the month and Trainee paper of the month

As part of the BPNA Newsletter, every month, a different member of the BPNA Research Committee will choose a recently published, topical paper relevant to Paediatric Neurology, Neurodisability or Neuroscience, that they think would be of interest to the BPNA membership.

Also every month, a recent publication that has either been led by a BPNA Trainee (or where a trainee has provided significant input) will be highlighted.

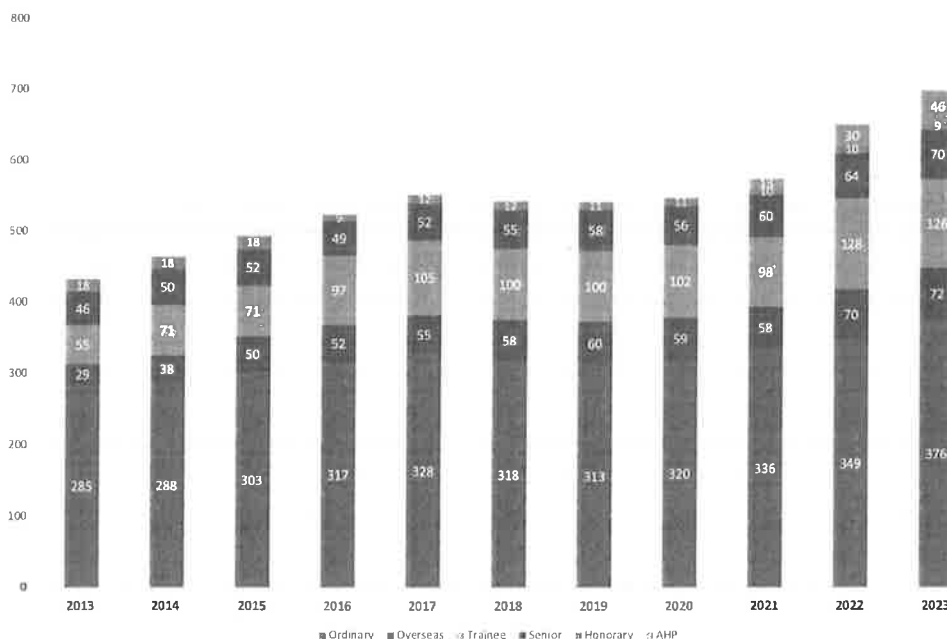
6. Professional Support

Coronavirus 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 has developed Covid-19 paediatric neurology guidance, increased mentoring capacity, provided additional resources to Special Interest Groups and additional training resources to Trainees.

6.1 BPNA membership

Membership numbers have increased steadily during 2022-23, supported by our dedicated Membership Engagement Manager, Philip Levine who was promoted to Interim Director. Following that a new employee joined in January 2023, Katerina Roumelioti as Membership and Committees Coordinator who now oversees BPNA membership. A new category of membership 'Allied Health Professional' was introduced in recent years. This category has minimal subscription fees to encourage engagement and no voting rights. The BPNA also added Medical Student membership with £0 fee to engage with young people with an early interest in Paediatric Neurology. Criteria to be accepted is a confirmation letter from associated University that is resent each year for membership renewal.

BPNA Members at January 2023



Membership Numbers

| Category | 2023 | 2022 | 2021 |
|--------------|------------|------------|------------|
| Ordinary | 376 | 349 | 336 |
| Trainees | 126 | 128 | 98 |
| Overseas | 72 | 70 | 58 |
| Senior | 70 | 64 | 60 |
| AHP | 46 | 30 | 13 |
| Honorary | 9 | 10 | 10 |
| TOTAL | 699 | 651 | 575 |

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. The mentoring programme began in 2016.

During 2020-21 the mentoring programme was expanded to paediatric neurology and Neurodisability GRID trainees within 12 months of CCT to provide additional support through the pandemic. As of 31 March 2023, there are 39 BPNA members volunteering as mentors (2022=38) with 50 mentees (2022=37) with some mentors now taking on two mentees.

In November 2022 BPNA commissioned a Mentor Consultant to deliver a training day for mentors for a third time. The training taught different models of mentorship and was very well received. The aim would be to do this every year.

Invited Reviews

In support of the BPNA charitable aims, BPNA Invited Reviews offer assistance to healthcare organisations in addressing concerns and challenges relating to care for children with neurological conditions.

"The primary purpose of an invited review is to provide expert opinion and external assurance around quality of care that may lead to improvements to patient safety and service provision. Invited reviews are designed to facilitate reflection and learning." - Academy of Medical Royal Colleges 'A framework of operating principles for managing invited reviews within healthcare' (March 2022)

BPNA Invited Reviews are conducted in accordance with the principles set out in the Academy of Medical Royal Colleges (AoMRC) 'A framework of operating principles for managing invited reviews within healthcare' (March 2022).

The BPNA has produced A Guide to BPNA Invited Reviews, available on the BPNA website, which explains the structured, clear and consistent process that we follow.

<https://bpna.org.uk/?page=invited-reviews>

6.3 Special Interest Groups (SIG)

For the Special interest groups hybrid working makes it more accessible for people to join online or in person depending how their meeting is arranged. Some face-to-face meetings happen but due to the size of the groups online meetings are more beneficial for people to attend.

The BPNA also updated their website for each SIG page to inform about Trials and resource documents for their members.

6.4 British Paediatric Epilepsy Group

Members of this Special Interest Group have particular expertise in childhood epilepsy. There are over 100 members which includes paediatric neurologists, paediatricians with an interest in epilepsy and clinical nurse specialists. Three meetings have been held in June and November 2022 and March 2023. The focus of the meetings has been on the development and implementation of guidelines for epilepsy in children, to share updates in audit and research in paediatric epilepsy, to explore opportunities for the professionals to network and to discuss anonymised complex and educational cases.

The BPEG (British Paediatric Epilepsy Group) Chair and members have contributed to the following particular aspects of childhood epilepsy:

Cannabidiol and CBMPs

Ongoing liaison with RCPCH, NHSE and stakeholder charities on issues related to prescription of cannabis-based products for medicinal use in children and young people with epilepsy. BPEG/BPNA have had meetings with APPG chair for prescription of CBMPs and Patient Safety Commissioner to discuss these issues. Regular BPNA CBMP group meetings to review press and media requests about CBMPs.

Sodium valproate

Since the announcement of MHRA statement on new restrictions on the prescription of sodium valproate, we have actively engaged with relevant stakeholders such as epilepsy charities, Association of British Neurologists, and OPEN-UK to discuss potential implications. We have written to MHRA expressing our concerns and potential risks for patients with epilepsy, and requested a meeting with MHRA to discuss our concerns and suggestions for safe implementation of any changes. We have also formed a working group with ABN members to address the issue of changes to sodium valproate prescription.

Stakeholder Charities

Engagement with stakeholder charities, in particular addressing the issues of prescription of sodium valproate and CBMPs.

NHSE Epilepsy Oversight group

Provided oversight on developing national bundles of care for patients with epilepsy as part of CYP Transformation Programme.

Led on development of national bundle of care for transition to adult care for CYP with epilepsy.

Facilitating research in paediatric epilepsy

BPEG provides the platform for colleagues from across the UK to present their research, facilitate collaboration and setting up a dedicated page on BPNA website with information on epilepsy research projects.

Clinical Nurse specialists and paediatric neurology trainees

BPEG have encouraged contribution of clinical nurse specialists and Advanced Nurse Practitioner in childhood epilepsy and requested for representation in the group.

BPEG have encouraged participation of paediatric neurology trainees and epilepsy SPIN trainees and requested for representation in the group.

Additional meetings regularly attended with contributions from BPEG:

Epilepsy 12 Audit programme.

Open UK Network Meeting.

Epilepsy Programme Board (led by RCPCH).

RESCAS.

6.5 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 and has been meeting virtually during the pandemic.

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. The SIG are working on securing a funding stream for this at present after finalising the core dataset required.

The cerebrovascular SIG has also been working with the Stroke Association UK to increase awareness of the new 'Childhood Stroke Support Service'.

Members of the SIG are part of multiple national and international clinical trials, namely the CARE trial for cavernous malformations and PASTA trial for paediatric arterial ischaemic stroke.

The SIG has organised an international neurovascular meeting in 2022 involving clinicians from across the world, which was very well-attended. Feedback from this has been particularly positive.

6.6 Children's Headache Network (CHaN)

CHAN has continued to remain very active over the past year to advance the clinical management, education and research in primary and secondary childhood headache disorders.

Although there is an appetite to resume face to face meeting, we plan to have the next meeting in autumn 2023 as remote/virtual.

There remains a clear structure of the roles within the CHaN network on a national level with dedicated responsibilities to members for providing clinical, research and academic updates.

CHaN also recognises the need to develop national registries for patients with conditions like Migraine/ TACs and uncommon headaches. Specialist groups within CHaN such as IHH SIG group and the CHAT course development network continue to develop educational materials and guidelines (e.g., the paper by Holland et al. on 'How to perform Lumbar puncture in children' and the paper by Dr Prabhakar et al. regarding the 'Assessment and management of children with acute headaches') both recently published in the Archives of Disease in Childhood

Aims for the next year:

- Benchmark the current practice for management of episodic and chronic migraines in the UK with identification of key paediatricians, so that a gap analysis can be made
- Closer and wider engagement with various headache charities (like The Migraine Trust/ The Brain Charity) to fund data bases and educational tools
- Encourage trainees' participation in the distance learning module

6.7.1. Fetal & Neonatal Neurology Special Interest Group

The Perinatal Special Interest Groups has a strong educational theme, and continues to provide educational meetings twice a year in neonatal and fetal neurology. These have been delivered virtually since the COVID pandemic, and draw a range of health care professionals, including therapists and nurses, from around the UK and beyond. Members of the SIG have worked with the BPNA executive to relaunch the NeoNATE course, which was on hold following the pandemic, and two courses are planned in 2023-2024. We are looking to increase our teaching faculty in the coming year. We have had an initial planning meeting for the BPNA Fetal course, which aims to provide educational material on fetal neurological anomalies and antenatal counselling. A preliminary programme has been produced and talks are currently being written. We plan to meet in Autumn to review progress.

Internationally, we have had meetings with perinatal neurology colleagues in the US, and plan to collaborate on education meetings and service recommendations, as well as building our contacts in Europe. Within the UK, we have continued our work with the British Association of Perinatal Medicine on guidelines, on this occasion recommendations for neonatal neuroimaging.

Clinically, the BPNA executive has agreed for us to proceed with an initiative to develop patient information leaflets on a range of fetal neurological anomalies, and a working group is being created. We also intend to discuss how we can collect data on genetic diagnoses and outcomes too, which would inform and improve future prognostication.

Members of the SIG remain research active in a range of ideas, including MRI appearances and neuro-development outcomes following neonatal hypoxic ischaemic encephalopathy, families' views on antenatal counselling, and a new proforma for the neurological examination of the unwell newborn baby.

6.7.2. Inherited White Matter Disorders (Leukodystrophies) special interest group

New National Service for Inherited White Matter Disorders (IWMD) clinical registry

NHS England has recently commissioned a new highly specialised service for Inherited White Matter Disorders (IWMDs) and also a separate National IMWD clinical registry to support this.

NHSE has commissioned 3 paediatric and 4 adult centres to provide the IWMD service. NHSE has also contracted with Evelina London Children's Hospital which is part of Guy's and St Thomas' NHS Foundation Trust, to host the National IMWD clinical registry.

A core element of the registry is the management of an online secure database that contains information about people of all ages with suspected or confirmed IWMD. We aim to use this registry to support the provision of direct patient treatment and care and improvements to clinical care. This will help us to: understand the incidence and prevalence of IWMD in our population, improve our understanding of the natural history of various IWMDs, measure the impact of living with an IWMD for patients and carers and create more awareness of these conditions.

This registry is unique as this is both clinician and patient driven. The primary aim of this registry is for clinical purposes; however, this registry will certainly provide important data for future research for patients within the field of IWMDs.

The registry will work very closely with 3 other paediatric IWMD clinical service centres (Leeds/Manchester- Led by Professor John Livingston/Dr Dipak Ram, Birmingham - led by Professor Evangeline Wassmer and Dr Amitav Parida and London (GSTT and Great Ormond Street) led by Dr Rahul Singh/Dr Cheryl Hemingway) and the adult centre (London, Queen Square Hospital-led by Dr David Lynch) in collaboration with units in the north and Midlands. A formal launch of the IWMD registry service will take place later in the year. The registry is in the pilot phase now and we expect this will be live soon.

We would accept referrals from patients, parents or carers, clinicians involved with the IWMD patients, and from neurologists, paediatric neurologists, geneticists, metabolic physicians, geneticists, paediatricians or any local clinicians involved in the diagnosis or treatment of IWMDs.

Referrals will also be accepted from fetal medicine teams, when there is a strong family history of an IWMD and we will also facilitate rapid diagnosis for conditions where there is a treatment option (e.g. Metachromatic Leukodystrophy).

The charities Alex TLC (www.alextlc.org) and Metabolic Support UK (www.metabolicsupportuk.org) have been closely involved in the development of this registry, will continue to support the registry and will be an integral part of the IWMD registry steering and development committee. We plan that the new service will be fully operational in the coming months.

In the meantime, if you wish to request further information please contact: gst-tr-IWMDR@NHS.Net

6.7.3. British Paediatric Movement Disorder Special Interest Group

The SIG has continued to meet virtually throughout the last year, and have been active in many areas. It has been agreed to continue with virtual meetings for the foreseeable future, with FtF meetings to be opportunistically added to other meetings members may be adding (e.g. the BPNA conference).

Education has remained a major focus of the MDSIG. Work has continued on the entry level Movement Disorder course, chaired by Lucinda Carr. Now named "MovEd", the first course will run Virtually on 5-6th October 2023 (places filling fast at the time of writing). An update on Unit 4 of the distance learning course is underway, which will better align with the MovEd course, and provide an opportunity to build upon the topics covered. Members of the MDSIG continue to support the successful ACT course (which has seen a significant expansion of it's faculty), and contribute to the ongoing BPNA Seminar series. Plans are underway for the inaugural updated Expert to Expert Paediatric Movement disorder course (first date still TBC).

The MDSIG has launched a series of documents on the BPNA website to support members and non-members alike in providing personalised Dystonia Management Plans for children and young people with complex dystonia. Included in the resources section of the website are template forms for completion, and example of a completed form for reference, and a document outlining how these forms can be found completed via bpna.org.uk/?page=resources-documents

Provisional feedback about the utility of these documents has been positive, and a more formal audit is planned for later in the year.

Several of the top 10 priorities emerging from the BPNA PSP related to the working of the MDSIG. The group has decided to focus on one priority to begin with - "Which medications should be used, and in what sequence, in the management of muscle stiffness (hypertonia) in children and young people?". A meeting to begin to plan research opportunities (and challenges!) emerging from this priority is planned for the BPNA Annual meeting 2024.

Several workstreams have been initiated aimed at establishing clinical standards across movement disorders. A working group has been established for the development of consensus criteria for the referral of children for consideration of neurosurgical interventions for the management of posture and tone. A larger body of work has also been started to establish consensus standards for the prescription of pharmacological interventions in the management of dystonia. Finally, some provisional work has begun in conjunction with colleagues with BPEG on exploring how care is delivered to children and young people with Rett syndrome, given the emergence of potential interventions for this condition.

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Transition remains a major concern from the group. Provisional meetings have been held with adult counterparts in neurodisability/neurorehabilitation, which we hope will lead to mutually constructive work moving forward. This will remain a main priority for the MDSIG in the coming year, along with engaging more trainee involvement with the group, and establishing better PPI.

6.7.4. 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, helped coordinate regional neuromuscular networks and upskilling events 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 continue the delivery of the gene therapy programme in SMA, Zolgensma, following approval by NICE and NHSE on 8 March 2021. The last 12 months have been focused on identifying all patients eligible, both those that are incident cases and naive to treatments and those that have had some form of treatment in the past. The infusion sites have now been established and the national MDT running since May 2021, and approx. 90 children have received gene therapy. There has also been continued work on access to Nusinersen and Risdiplam, our 2 other approved SMA treatments.

All the SMA children have been followed up and various webinars and meetings have been held with European colleagues on side effects and problems associated with gene therapy, as well as forum meetings face to face in September 2022.

From the NorthStar group; Ataluren MAA -now extended to January 2023.

HUB DMD; has continued close working with clinicians to enable trial readiness and liaison with the pharma companies to look at what is needed per site to continue trials. Many require MRI both muscle and cardiac and therefore work looking at which sites can offer this has been useful. Trials are now continuing and further set up of sites for new studies have commenced.

As a SIG we have continued in 2022 and 2023 to meet regularly virtually and planned our first standalone full day face to face muscle interest group meeting for June 2023. Both paediatric and adult NorthStar meetings (DMD) and paediatric and adult SMA REACH meetings (SMA) have continued virtually this last 12 months, especially developing the adult SMA REACH, British Myology society was face to face as was the Translational research meeting UK and World muscle society meeting (hybrid). The muscle interest group has met 4 times in total 2 fully virtually and the last 2 meetings hybrid with some face to face for case discussions and topic led presentations over the last 12 months. The RDCN(rare diseases collaborative networks) have also accredited the Juvenile Myasthenia (JMG) Gravis group hosted and designated providers by Oxford and this new group have held 2 virtual meetings for difficult cases with JMG. Myaware also supported the CMS information day last month.

The charities also 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. The meetings also receive unrestricted educational grants from pharmaceutical companies. We 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.

6.7.5. Neurocutaneous Special Interest Group

This group's interest is in the clinical area of neurocutaneous syndromes, such as Neurofibromatosis, Tuberous Sclerosis Complex and Sturge Weber Syndrome. This is a new group who had their first meeting last year and have another planned in a few months' time. We are meeting twice a year which have been virtual and are hoping to have an in-person meeting during the BPNA conference.

The neurocutaneous SIG has been supporting paediatric neurologists and paediatricians across the country with information about the different syndromes. Members have been involved in supporting and giving information to stakeholders and to families at support days hosted by charities like the recent TSC Big Day and upcoming clinic leads meeting, and the Sturge Weber UK family weekend. We are also in the process of carrying out an audit of the use of vigabatrin in TSC with the aim of being able to produce some guidance for its prescribing in the future.

As a group we are keen to discuss and share information about upcoming research and new treatments such as MEK inhibitor Selumetinib for NF1 which we are hoping to hear more about from the national NF clinics in our next meeting.

ACHIEVEMENT AND PERFORMANCE

Fundraising activities

6.7.6. Trainees' Special Interest Group

The BPNA trainees' special interest group (SIG) is a group for all BPNA trainee members and those interested in paediatric neurology training. Currently there are 126 Trainee members, including paediatric neurology Grid trainees, paediatric trainees of different grades and other trainees interested in paediatric neurology. The group meets twice a year, once at the BPNA conference in January and once at a 2-day educational trainees' meeting held in May. In May 2022 our meeting covered Mastering Neonatal Neurology, aiming to educate in areas of examination, assessment, diagnosis and other topics on what is needed as a new paediatric neurology consultant. We had excellent talks from inspiring clinicians at this in-person meeting, with up to 40 attendees present and strong positive feedback. In addition, this is a key opportunity for trainees to meet each other and network with future consultant colleagues, and to encourage and support the next round of applicants with support from CSAC. Recordings of selected sessions are available to watch in the BPNA Trainees' SIG area of the BPNA website.

The SIG also contributes towards the BPNA Recruitment working group aiming to improve recruitment to paediatric neurology specialty training. We continue to run annual pre-application and interview webinars for neurology and neurodisability applicants which have been well-received by both applicants and CSAC interviewers. Recordings of these sessions are available on the BPNA website careers session and will run again for the next round. We have run training webinars aimed at medical students and foundation year doctors to encourage early interest in the specialty, led by a senior registrar and advertised on social media. This work runs alongside efforts to increase medical student involvement in the annual conference. Recruitment into neurology has greatly improved in recent years, in part due to these efforts, and we welcome the new round of specialty trainees starting in September, for whom we will host an evening welcome webinar in the Autumn.

The results of the 2022 paediatric neurology Grid training annual survey were presented at an RCPCH CSAC meeting and an anonymous summary of results was sent to all training centres. Issues highlighted as of particular concern to training include workload difficulties with reduced time in neurology, and lingering impact of the pandemic on training. CSAC have worked on these issues where possible and support individual trainees at and between their annual review meetings. Of note, there is an increasing trend towards trainees working less than full time, and intend to continue this as consultants.

The SIG continues to successfully set up and support study groups for modules of the BPNA Distance Learning. Trainees report these provide excellent support and motivation to complete modules. The groups are open to all trainees and recent groups included neurology specialty trainees, epilepsy specialist interest (SPIN) trainees, trainees from abroad, and recently qualified consultants completing units to complete SPIN accreditation. Many of these groups have very kindly been supported by consultants offering their time to supervise and facilitate the sessions during their weekly meetings.

A more recent focus has been to support trainees interested in research. Working with the research committee we have held a first trainees research network meeting at the January conference, which we plan to re-visit and work towards identifying methods to support this further. Research papers authored by trainees are highlighted as 'Paper of the Month' in the BPNA bulletin, to further raise the profile of paediatric neurology research and the role trainees can have in this.

ACHIEVEMENT AND PERFORMANCE

6.7.7. 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, MOGAD and AQP4 antibody driven disorders and the autoimmune mediated encephalitides) as well as other less common inflammatory brain conditions.

The past 12 months has continued to be a busy for the paediatric neurology acquired and inflammatory white matter group. We have met regularly, as before, every 2 months. The meetings have all been virtual, chaired by Paed Neurologist Cheryl Hemingway and with administrative support provided by the BPNA and hosted on the BPNA Zoom platform. Clinical administrative support has been provided by GOSH PA team. The 6 meetings have been well attended, with around 40- 50 individuals joining, with both national and international representation. The meeting format has continued as before, with the first hour consisting of updates and formal presentations, and the next 3 hours discussing clinical cases. We have discussed on average 8 to 10 cases per meeting. The meeting has been excellently supported by expert neuroinflammatory colleagues around UK and has had expert neuroradiology from Great Ormond Street, and we thank particularly Dr Kshitij Mankad and Dr Asthik Biswas for their time.

We have as before kept the format standard as follows:

- 3rd Friday of every 2nd month
- Time: 1-5pm
- Video-conferencing via Zoom
- First 60-90 minutes involves updates on research/new medications/clinical challenges then
- Brief comfort break
- Next 90 minutes discussion of clinical cases with radiology review and formulation of a suggested investigation and/or treatment plan

The meetings have all been expertly documented by our trainees in neuroinflammation, and I would particularly like to thank Dr Eyre, Dr Abdel-Mannan and Dr Perry.

We have in the meeting had a number of excellent presentations including updates amongst others: i) WGS in the newborn from David Wicks ii) the neuropsychiatric approaches to the behavioural health on children with neuroinflammatory disease from Aaron J Hauptman iii) Encephalitis updates from Ming Lim, iv) updates on the IWMD set up from Cheryl Hemingway and v) Guillain Barre Syndrome from Dr Ramdas. We have also had regular research updates from the fellows in neuroinflammation. From 2023, the talks at the meetings has been recorded and the talks are available on the BPNA website for the SIG members.

In May 2022 Sukhvir Wright hosted the UKCNID/NHS England HSS (Highly Specialised Service) paediatric onset MS meeting at Aston. Alongside the co-organiser of the event, Paediatric Neurologist Evangeline Wassmer, delegates included clinicians, specialist nurses, researchers and NHS managers from Birmingham Children's Hospital, GOSH, Evelina Children's Hospital, Royal Manchester Children's Hospital, Addenbrookes, Alder Hey and NHS England, University of Oxford, and Birmingham University. Researchers attended as part of an effort to set research priorities from cellular mechanisms to patient outcomes. Dan Griffiths-King and Charly Billaud both presented datablitz and poster presentations on their research into acquired demyelinating disease in children.

At this meeting we also distributed within working groups plans to complete disease management guidelines, patient information sheets and disease modifying drug guidelines. These are ongoing and many are completed and hosted on the NHSE platform.

We will continue to meet over the next 12 months, with another face to a face meeting planned for July 2023 and hosted this year by Cambridge.

The next 12 months the dates we are due to meet as follows:

15 September 2023
17 November 2023

ACHIEVEMENT AND PERFORMANCE

19 January 2024
15 March 2024
17 May 2024
19 July 2024
15 September 2023

6.7.8. UK Neurorehabilitation Special Interest Group

The paediatric neurorehabilitation SIG is a multidisciplinary group supported by representatives from England, Scotland, Wales and Northern Ireland.

We aim to:

- Share good practice
- Develop an equitable paediatric neurorehabilitation service nationally
- Support research and improve the evidence base in paediatric neurorehabilitation for acquired CNS injury.
- Link with other groups (third sector) and parents / users affected by acquired brain injury

The SIG continues to be Chaired by Dr Peta Sharples. This year we have continued to work closely with the Paediatric Neuroscience Clinical Reference Group whose agenda priority is currently Paed Neurorehabilitation.

Paed CRG Neurosciences

Each of our meetings has heard updates from the CRG Chair (Charlie Fairhurst) and Anthony Prudhoe (Women and Childrens NHSE Manager) relating to the review of the National Service Specification for Paed Neurorehabilitation. In order for them to be satisfied this specification review will meet the needs of our CYP population they have had significant engagement with our providing teams and visited several units. We await the final consultation.

Meetings

Kings Dec 2022 (Host) - theme paediatric spinal cord injury and the national transformation review. Speakers included Dr A Graham services for CYP with acquired spinal cord injury - several units described their new Children's Spinal Cord Case Manager posts and the London team (speaker Anna Majowska) shared their SCI commissioning strategy.

Oxford March 22 (Host) - theme innovative technology on applied to Acq brain injury, including immersive virtual reality systems. Jill Cadwgan spoke about the Twocan Study - A proof of concept study of using wrist worn accelerometers to encourage affected upper limb movements in children with unilateral cerebral palsy. Information was also shared about the NIHR Innovation Observatory horizon scanning research regarding technology for Paediatric Trauma care and Rehab.

Next meeting Autumn 2023 Date tbc. Areas of ongoing concern (amongst many) being transition with a childhood ABI to adult hood and also the challenge of finding optimal services if sustaining an acquired brain injury between 16-18 .

6.8. 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. If you would like more information about which of these the BPNA have contributed please contact the Director.

ACHIEVEMENT AND PERFORMANCE

Internal and external factors

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 to mitigate any impact they might have on the Association. A risk register is maintained and updated regularly.

Principal risks and uncertainties

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 with the aim to start a faculty retention working group this year to research and review the risks.
- Reputation in being associated with unprofessional or unethical or even criminal activities in the UK/abroad due to disengagement about hot topic issues. This can be highlighted in recent years on cannabis-based medicinal products (CBMPs) and Paediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS). The BPNA has worked hard in engaging with such issues and producing their own or collaboration with other professional colleges to produce working statements. Similar issues will no doubt arise in the future and the BPNA must engage with those groups to be seen as professional and supportive while not putting more pressure on the BPNA members and wider medical professionals in the paediatric neurology community.
- Staff have been overworked in the last year due to the end of the Covid pandemic and the increase of work throughout due to that happening, including more BPNA face-to-face activities. This would produce burnout, reduction of wellbeing and possible loss of the quality staff. Part of 2023-24 operational plan is to recruit more staff to compensate the imbalance.

FINANCIAL REVIEW

Financial position

The balance sheet position shows net current assets of £922,236 (2022 - £801,489), resulting from a significant increase in the cash at bank to £981,135 (2022 - £872,695). This has been accompanied by an increase in debtors to £40,051 (2022 - £36,933), and decrease in creditors to £110,011 (2022 - £123,823).

At the year end the charity has unrestricted freely available current reserves of £909,160 (2022 - £801,489) which excludes tangible fixed assets of £10,402 (2022 - £7,903). Given the charity's current levels of expenditure this would allow for approximately just over ten months (2022 - fifteen 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 increased to £1,154,406 (2022 - £729,064). This increase has arisen mainly from the increase in annual conference to £344,377 (2022 - £136,400). This is directly attributable to courses starting back up after the coronavirus restrictions.

Donations and legacies have increased in the year to £255,960 (2022 - £139,401). In particular the charity had more grant funding in the year amounting to £120,415 (2022 - £39,919), sponsors of its annual conference symposiums generating funds of £66,000 (2022 - £77,000), and generating annual conference sponsorship income of £90,000 (2022 - £33,000). See "Note 4 Donations and Legacies" and "Note 6 Income from Charitable Activities" within the notes to the financial statements for a detailed breakdown of income received in the year.

FINANCIAL REVIEW

Investment policy and objectives

The policy of the BPNA is to invest its reserves in the further development of its charitable aims.

The BPNA has also committed reserves to the sustainability and further development of both the distance learning and short courses.

As a result of recent financial performance, derived from additional incoming resources, the current level of reserves the BPNA holds cash balances amounting to £981,135 (2022 - £872,695) 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 £932,638 (2022 - £809,392) and of which £13,076 (2022 - £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 £981,135 (2022 - £872,695) in order to facilitate the continued activities of the charity by holding highly liquid assets.

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 2022-23 the trustees kept the unrestricted contingency fund to £200,000 (2022 - £180,000) 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

During 2023-24 recruitment to paediatric neurology will continue and relationship with other associations and colleges will continue to develop (RCPCH & Association of British Neurologists).

The Movement Disorder course will launch October 2023 and PET2/3 Update will happen in late 2023.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

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

Method of appointment of trustees

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

When a new Trustee is appointed a procedure is followed under BPNA policies which includes Trustee eligibility declaration, sending a copy of 'The Essential Trustee' guide, Conflicts of Interest policy and Declaration of interest form. They are also offered training.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Organisational structure and decision-making

The trustees meet four times per year (usually January, May/June, September, November) when more in depth strategic decisions and business matters are discussed. Monthly Zoom meetings are also held.

Council is a larger body that meets twice per year (January and May/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. Please see list of BPNA Council members below:

**Report of the Trustees
for the Year Ended 31 March 2023**

STRUCTURE, GOVERNANCE AND MANAGEMENT

Members of BPNA Council Serving During 2022-23

| <u>Executive</u> | <u>Name</u> | <u>Term Expires</u> |
|--------------------------------------|---------------------------|---------------------|
| BPNA President | Dr Alasdair Parker | January 2024 |
| Secretary | Dr Daniel Lumsden | January 2025 |
| Chair, Research | Dr Sam Amin | January 2025 |
| Chair, Education Quality & Standards | Prof Dr Michael Griffiths | January 2025 |
| Chair, International Education | Prof Martin Kirkpatrick | January 2025 |
| Director, Senior Management | Mr Philip Levine | |
| President Elect | Dr Ailsa McLellan | January 2027 |
| Treasurer | Dr Santosh Mordekar | January 2026 |
| Professional Support Officer | Dr Manish Prasad | January 2026 |
| National Training Advisor | Dr Dipak Ram | January 2024 |

Paediatric Neurology Centres

| | <u>Representative</u> | <u>3-year term</u> |
|--|---------------------------------------|--------------------|
| Belfast | Dr Donncha Harahan | January 2025 |
| Dundee | Dr Alice Jollands | January 2025 |
| Edinburgh | Dr Kenneth McWilliam (2nd Term) | January 2025 |
| Glasgow | Dr Sarah Abernethy | January 2026 |
| Newcastle-upon-Tyne | Dr Anna Basu | January 2024 |
| Liverpool | Dr Anil Israni | January 2027 |
| Manchester | Dr Siobhan West | January 2026 |
| Preston | Dr Christian De Goede (2nd Term) | January 2025 |
| Leeds | Dr Lydia Green | January 2026 |
| Sheffield | Dr Archana Deskurkar (2nd Term) | January 2025 |
| Nottingham | Dr Manish Prasad (2nd term) | January 2024 |
| Leicester | Dr Nahin Hussain (2nd Term) | January 2025 |
| Birmingham | Dr Ratna Kumar (2nd term) | January 2024 |
| Cambridge | Dr Deepa Krishnakumar | January 2026 |
| Oxford | Dr Sithara Ramdas (2nd Term) | January 2025 |
| Bristol | Dr Sam Amin (2nd term) | January 2024 |
| Swansea | Dr Gareth Thomas | January 2026 |
| Cardiff | Dr Johann te Water Naude (2nd Term) | January 2026 |
| Southampton | Dr Georgina Bird-Lieberman (2nd Term) | January 2026 |
| London: Great Ormond Street Hospital | Dr Sanjay Bhate (2nd Term) | January 2025 |
| London: Chelsea & Westminster Hospital | Dr Naila Ismayilova (2nd Term) | January 2025 |
| London: Imperial College NHS Trust | Dr Sushil Beri (2nd Term) | January 2025 |
| London: The Royal London | Dr Louise Hartley (2nd Term) | January 2025 |
| London: Evelina London Children's Hospital | Dr Daniel Lumsden | January 2025 |
| London: St George's Hospital | Dr Antonia Clarke (2nd Term) | January 2025 |

Special Interest Groups

| | <u>Chair</u> | <u>3-year term</u> |
|---|-------------------------------------|--------------------|
| British Paediatric Epilepsy Group | Dr Suresh Pujar | June 2025 |
| Cerebrovascular | Dr Jaspal Singh | February 2026 |
| Children's Headache Network | Dr Gautam Ambegaonkar | January 2025 |
| | Dr Anthony Hart (Co-Chair 2nd Term) | May 2025 |
| Fetal & Neonatal Neurology | Dr Brigitte Vollmer (Co-Chair) | May 2025 |
| Fetal & Neonatal Neurology | Dr Rahul Singh | July 2023 |
| Genetic White Matter Disorders | Dr Daniel Lumsden (2nd Term) | May 2025 |
| British Paediatric Movement Disorders | Dr Tracey Willis (2nd Term) | May 2025 |
| Muscle Interest Group | Dr Peta Sharples (2nd Term) | February 2024 |
| UK Neurorehabilitation | Dr Cheryl Hemmingway | May 2023 |
| UK-Childhood Inflammatory Demyelination | Dr Sam Amin (Co-Chair) | August 2025 |
| Neurocutaneous | | |

**Report of the Trustees
for the Year Ended 31 March 2023**

STRUCTURE, GOVERNANCE AND MANAGEMENT

| | | |
|--|----------------------------|--------------|
| Neurocutaneous | Dr Sarah Aylett (Co-Chair) | August 2025 |
| Trainees' Chair | Dr Robert Spaul | June 2024 |
| Trainees' Deputy Chair | Dr Tom Smith | June 2024 |
| <u>Co-opted</u> | <u>Representative</u> | |
| Editor, DMCN | Dr Bernard Dan | Co-opted |
| British Paediatric Neurosurgical Group | Dr Pasquale Gallo | Co-opted |
| Chair, Disability CSAC | Dr Katherine Martin | Co-opted |
| Paediatric Neurosciences CRG | Dr Anita Devlin | Co-opted |
| Neuropsychiatry Representative | Dr Ashley Liew | Co-opted |
| Short Course Development Manager | Dr Colin Dunkley | Co-opted |
| BPNA 2024 Bristol Organiser | Dr Sam Amin | January 2024 |
| Trainee Rep, Neurodisability | Dr James Hammond | January 2024 |

Key management remuneration

Total remuneration paid to key management personnel during the financial year included wages and salaries amounting to £69,547 (2022 - £85,853) and contributions to defined contribution pension schemes of £3,338 (2022 - £3,907).

Pay and remuneration of key management personnel

Permanent staff have yearly appraisals with aims to achieve for the year and are given opportunities to develop themselves with training that the BPNA covers the cost towards. If staff achieve all their objectives they will get a grade increase (2%) until they reach the top band of their pay grade.

BPNA staff positions and pay are reviewed annually and are benchmarked within the recruitment market and similar organisations.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Staff have been overworked in the last year due to the end of the Covid pandemic and the increase of work throughout due to that happening, including more BPNA face-to-face activities.

This would produce burnout, reduction of wellbeing and possible loss of the quality staff.

Part of 2023-24 operational plan is to recruit more staff to compensate the imbalance.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number

1159115

Principal address

2 St Andrews Place
Regent's Park
London
NW1 4LB

Trustees

Dr L Hartley (resigned 16.1.23)
Dr S Jayawant (resigned 16.1.23)
Professor M Kirkpatrick
Dr M J Griffiths
Dr A McLellan
Dr A Parker
Dr D Ram
Dr S Amin
Dr D Lumsden
Dr M Prasad (appointed 1.5.23)
Dr S Mordekar (appointed 16.1.23)

Auditor

DonnellyBentley Ltd
70 Chorley New Road
Bolton
BL1 4BY

Bankers

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

TRUSTEES' RESPONSIBILITIES STATEMENT

The trustees are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

**Report of the Trustees
for the Year Ended 31 March 2023**

TRUSTEES' RESPONSIBILITIES STATEMENT - continued

The law applicable to charities in England and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the board of trustees on 5 December 2023 and signed on its behalf by:



.....
Dr S Mordekar - Trustee

Report of the Independent Auditor to the Trustees of British Paediatric Neurology Association

Opinion

We have audited the financial statements of British Paediatric Neurology Association (the 'charity') for the year ended 31 March 2023 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 March 2023 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other matters

The financial statements for the charity for the year ended 31st March 2022 were not audited. This is because the level of income in the year to 31 March 2022 was below £1 million and therefore an audit was not required by the Charities Act 2011. An independent examination was carried out as required by the Charities Act.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditor thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Trustees' Responsibilities Statement, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditor under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditor that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

We obtained an understanding of the legal and regulatory framework applicable to the charity and the sector in which it operates and considered the risk of non-compliance with applicable laws or regulations.

We determined that the following laws and regulations were most significant: the Charities Act 2011, 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 issued in October 2019, those that relate to health and safety regulations, those that relate to employment law and those that relate to data protection regulations. We designed audit procedures to respond to the risk, recognizing that the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment, for example, forgery or intentional misrepresentations, or through collusion.

We obtained an understanding of how the charity is complying with those legal and regulatory frameworks by making enquiries of the management. We corroborated our enquiries through our review of board minutes.

Our tests also included agreeing the financial statements disclosures to underlying supporting documentation. There are inherent limitations in the audit procedures described above and, the further removed non-compliance with laws and regulations is from the events and transactions reflected in the financial statements, the less likely we would become aware of it. We did not identify any key audit matters relating to irregularities, including fraud.

**Report of the Independent Auditor to the Trustees of
British Paediatric Neurology Association**

We also addressed the risk of management override of internal controls, including testing journals and evaluating whether there was evidence of bias by the directors that represented a risk of material misstatement due to fraud.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditor.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

DonnellyBentley Ltd

DonnellyBentley Ltd
Chartered Accountants
Statutory Auditors
70 Chorley New Road
Bolton
BL1 4BY

Date: 5 December 2023

DonnellyBentley Ltd is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

British Paediatric Neurology Association

**Statement of Financial Activities
for the Year Ended 31 March 2023**

| | | Unrestricted funds | Restricted funds | 2023 Total funds | 2022 Total funds as restated |
|-------------------------------------|-------|-----------------------|---------------------|------------------------|---------------------------------------|
| | Notes | £ | £ | £ | £ |
| INCOME AND ENDOWMENTS FROM | | | | | |
| Donations and legacies | 4 | 158,045 | 97,915 | 255,960 | 139,401 |
| Charitable activities | 6 | | | | |
| Conferences | | 344,377 | - | 344,377 | 136,400 |
| Short courses | | 268,917 | - | 268,917 | 189,455 |
| Distance learning courses | | 71,560 | - | 71,560 | 93,276 |
| International short courses | | 31,156 | - | 31,156 | 13,147 |
| Research | | 1,200 | - | 1,200 | - |
| Membership and professional support | | 109,963 | - | 109,963 | 104,090 |
| EPNS recharges | | 43,728 | - | 43,728 | 50,567 |
| Professional support | | 5,304 | - | 5,304 | 1,703 |
| Invited Reviews | | 19,400 | - | 19,400 | - |
| Investment income | 5 | 2,841 | - | 2,841 | 1,025 |
| Total | | <u>1,056,491</u> | <u>97,915</u> | <u>1,154,406</u> | <u>729,064</u> |
| EXPENDITURE ON | | | | | |
| Charitable activities | 7 | | | | |
| Conferences | | 202,923 | 8,395 | 211,318 | 85,930 |
| Short courses | | 191,670 | 14,280 | 205,950 | 113,995 |
| Distance learning courses | | 80,518 | 9,442 | 89,960 | 79,057 |
| International short courses | | 139,912 | 36,877 | 176,789 | 74,177 |
| Research | | 103,151 | 2,352 | 105,503 | 76,538 |
| Membership and professional support | | 115,454 | 8,160 | 123,614 | 95,988 |
| EPNS recharges | | 40,490 | - | 40,490 | 48,036 |
| Support Costs | | 9,811 | - | 9,811 | - |
| Governance Costs | | 43,079 | 4,362 | 47,441 | 32,095 |
| Invited Reviews | | 19,314 | 970 | 20,284 | - |
| Total | | <u>946,322</u> | <u>84,838</u> | <u>1,031,160</u> | <u>605,816</u> |
| NET INCOME | | 110,169 | 13,077 | 123,246 | 123,248 |
| RECONCILIATION OF FUNDS | | | | | |
| Total funds brought forward | | 809,392 | - | 809,392 | 686,144 |
| TOTAL FUNDS CARRIED FORWARD | | <u>919,561</u> | <u>13,077</u> | <u>932,638</u> | <u>809,392</u> |

The notes form part of these financial statements

British Paediatric Neurology Association

**Statement of Financial Activities
for the Year Ended 31 March 2023**

CONTINUING OPERATIONS

All income and expenditure has arisen from continuing activities.

RESTRICTED INCOME AND EXPENDITURE

Comparatives for income and expenditure

All income and expenditure in 2022 was unrestricted apart from:

| | |
|--|--------|
| | £ |
| Donations and legacies income | |
| International League Against Epilepsy (ILAE) | 39,919 |
| Charitable activities expenditure | |
| Short courses | 5,460 |
| International short courses | 44,583 |

The notes form part of these financial statements

British Paediatric Neurology Association

**Balance Sheet
31 March 2023**

| | Notes | Unrestricted funds £ | Restricted funds £ | 2023 Total funds £ | 2022 Total funds as restated £ |
|--|-------|-------------------------|-----------------------|--------------------------|---|
| FIXED ASSETS | | | | | |
| Tangible assets | 13 | 10,402 | - | 10,402 | 7,903 |
| CURRENT ASSETS | | | | | |
| Stocks | 14 | 11,061 | - | 11,061 | 15,684 |
| Debtors | 15 | 40,051 | - | 40,051 | 36,933 |
| Cash at bank and in hand | | <u>968,059</u> | <u>13,076</u> | <u>981,135</u> | <u>872,695</u> |
| | | 1,019,171 | 13,076 | 1,032,247 | 925,312 |
| CREDITORS | | | | | |
| Amounts falling due within one year | 16 | (110,011) | - | (110,011) | (123,823) |
| NET CURRENT ASSETS | | <u>909,160</u> | <u>13,076</u> | <u>922,236</u> | <u>801,489</u> |
| TOTAL ASSETS LESS CURRENT LIABILITIES | | <u>919,562</u> | <u>13,076</u> | <u>932,638</u> | <u>809,392</u> |
| NET ASSETS | | <u>919,562</u> | <u>13,076</u> | <u>932,638</u> | <u>809,392</u> |
| FUNDS | 18 | | | | |
| Unrestricted funds | | | | 919,562 | 809,392 |
| Restricted funds | | | | <u>13,076</u> | <u>-</u> |
| TOTAL FUNDS | | | | <u>932,638</u> | <u>809,392</u> |

The financial statements were approved by the Board of Trustees and authorised for issue on **..5.December.2023..** and were signed on its behalf by:



Dr S Mordekar - Trustee

The notes form part of these financial statements

British Paediatric Neurology Association

**Cash Flow Statement
for the Year Ended 31 March 2023**

| | | 2023 | 2022 |
|---|-------|----------------|------------------|
| | Notes | £ | as restated £ |
| Cash flows from operating activities | | | |
| Cash generated from operations | 1 | <u>111,568</u> | <u>75,617</u> |
| Net cash provided by operating activities | | <u>111,568</u> | <u>75,617</u> |
| Cash flows from investing activities | | | |
| Purchase of tangible fixed assets | | (5,969) | (1,927) |
| Interest received | | <u>2,841</u> | <u>1,025</u> |
| Net cash used in investing activities | | <u>(3,128)</u> | <u>(902)</u> |
| | | <hr/> | <hr/> |
| Change in cash and cash equivalents in the reporting period | | 108,440 | 74,715 |
| Cash and cash equivalents at the beginning of the reporting period | | <u>872,695</u> | <u>797,980</u> |
| Cash and cash equivalents at the end of the reporting period | | <u>981,135</u> | <u>872,695</u> |

The notes form part of these financial statements

**Notes to the Cash Flow Statement
for the Year Ended 31 March 2023**

1. RECONCILIATION OF NET INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES

| | 2023 | 2022 as restated |
|---|-----------------|---------------------|
| | £ | £ |
| Net income for the reporting period (as per the Statement of Financial Activities) | 123,246 | 123,248 |
| Adjustments for: | | |
| Depreciation charges | 3,470 | 2,636 |
| Loss on disposal of fixed assets | - | 938 |
| Interest received | (2,841) | (1,025) |
| Decrease in stocks | 4,623 | 663 |
| Increase in debtors | (3,118) | (925) |
| Decrease in creditors | <u>(13,812)</u> | <u>(49,918)</u> |
| Net cash provided by operations | <u>111,568</u> | <u>75,617</u> |

2. ANALYSIS OF CHANGES IN NET FUNDS

| | At 1/4/22 £ | Cash flow £ | At 31/3/23 £ |
|--------------------------|----------------|----------------|-----------------|
| Net cash | | | |
| Cash at bank and in hand | <u>872,695</u> | <u>108,440</u> | <u>981,135</u> |
| | <u>872,695</u> | <u>108,440</u> | <u>981,135</u> |
| Total | <u>872,695</u> | <u>108,440</u> | <u>981,135</u> |

**Notes to the Financial Statements
for the Year Ended 31 March 2023**

1. STATUTORY INFORMATION

British Paediatric Neurology Association is a charitable incorporated organisation registered with the Charity Commission for England and Wales. The registered charity number is 1159115 and the principal address is 2 St Andrews Place, Regents Park, London, NW1 4LB.

The charitable incorporated organisation constitutes a public benefit entity as defined by FRS 102.

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.

Going concern

The Trustees have assessed whether the use of the going concern basis is appropriate and have considered possible events or conditions that might cast significant doubt on the ability of the charity to continue as a going concern. The trustees have made this assessment for a period of at least one year from the date of approval of the financial statements. In particular the trustees have considered the charities forecasts and projections and have taken account of pressures on income. After making enquiries the trustees have concluded that there is a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future.

As such the charity can expect to be able to meet its liabilities as they fall due in the period of at least 12 months from the date of approval of these accounts. However, there can be no certainty in relation to these matters.

On this basis the Trustees have concluded that the charity is a going concern. The financial statements do not include any adjustments that would result from the charity not being able to meet its liabilities as they fall due.

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.

2. ACCOUNTING POLICIES - continued

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.

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.

2. ACCOUNTING POLICIES - continued

Debtors and creditors receivable / payable within one year

Debtors and creditors with no stated interest rate and receivable / payable within one year are recorded at transaction price. Any losses arising from impairment are recognised in expenditure.

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.

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.

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.

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

4. DONATIONS AND LEGACIES

| | 2023 | 2022 as restated |
|-------------------------------|----------------|---------------------|
| | £ | £ |
| Donations | 5,245 | 42,561 |
| Grants | 120,415 | 39,919 |
| Gift aid | 1,063 | - |
| Membership donations | 11,950 | 11,850 |
| Annual conference sponsorship | 90,000 | 33,000 |
| Short course sponsorship | 25,500 | 10,500 |
| Miscellaneous income | 1,787 | 1,571 |
| | <u>255,960</u> | <u>139,401</u> |

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

| | 2023 | 2022 as restated |
|--|----------------|---------------------|
| | £ | £ |
| International League Against Epilepsy (ILAE) | 65,915 | 39,919 |
| Pet Grant | 15,000 | - |
| Movement disorder income | 7,500 | - |
| Dundee University Buist Trust | 20,000 | - |
| GW / Jazz Pharma | 12,000 | - |
| | <u>120,415</u> | <u>39,919</u> |

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

| Company name | Conference sponsorship | Course sponsorship | 2023 Totals | 2022 as restated Totals |
|--------------------------|---------------------------|-----------------------|----------------|-------------------------------|
| | £ | £ | £ | £ |
| Biocodex | 6,000 | 3,000 | 9,000 | 3,000 |
| Biogen | 6,000 | - | 6,000 | 3,000 |
| Biomarin | - | - | - | 3,000 |
| Desitin | 6,000 | 14,500 | 20,500 | 13,500 |
| Egetis | 6,000 | - | 6,000 | - |
| GW/Jazz Pharma | 6,000 | 3,000 | 9,000 | - |
| Neuraxpharm UK | 6,000 | - | 6,000 | 3,000 |
| Novartis | 6,000 | - | 6,000 | 3,000 |
| Nutricia | 6,000 | - | 6,000 | - |
| Orchard | 6,000 | - | 6,000 | - |
| Orion Pharma | 6,000 | - | 6,000 | 3,000 |
| Proveca | 6,000 | - | 6,000 | 3,000 |
| PTC | 6,000 | - | 6,000 | - |
| Roche | 6,000 | 2,000 | 8,000 | 3,000 |
| UCB Pharma | 6,000 | 3,000 | 9,000 | - |
| Veriton | 6,000 | - | 6,000 | - |
| Vitaflo | - | - | - | 3,000 |
| Zogenix | - | - | - | 3,000 |
| Total Sponsorship | 90,000 | 25,500 | 115,500 | 43,500 |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

5. INVESTMENT INCOME

| | 2023 | 2022 as restated |
|--------------------------|--------------|---------------------|
| | £ | £ |
| Deposit account interest | <u>2,841</u> | <u>1,025</u> |

6. INCOME FROM CHARITABLE ACTIVITIES

| | Conferences £ | Short courses £ | Distance learning courses £ |
|---|------------------|-----------------------|--------------------------------------|
| Conferences | 278,377 | - | - |
| Short courses | - | 268,917 | - |
| International short courses | - | - | - |
| Distance learning | - | - | 71,560 |
| EPNS recharges | - | - | - |
| Professional support | - | - | - |
| BPNSU fee income | - | - | - |
| Invited Reviews | - | - | - |
| Trainee Fees | - | - | - |
| BPNA membership subscriptions | - | - | - |
| Annual conference symposium sponsorship | <u>66,000</u> | <u>-</u> | <u>-</u> |
| | <u>344,377</u> | <u>268,917</u> | <u>71,560</u> |

| | International short courses £ | Research £ | Membership and professional support £ | EPNS recharges £ |
|---|--|---------------|---|------------------------|
| Conferences | - | - | - | - |
| Short courses | - | - | - | - |
| International short courses | 31,156 | - | - | - |
| Distance learning | - | - | - | - |
| EPNS recharges | - | - | - | 43,728 |
| Professional support | - | - | - | - |
| BPNSU fee income | - | 1,200 | - | - |
| Invited Reviews | - | - | - | - |
| Trainee Fees | - | - | - | - |
| BPNA membership subscriptions | - | - | 109,963 | - |
| Annual conference symposium sponsorship | <u>-</u> | <u>-</u> | <u>-</u> | <u>-</u> |
| | <u>31,156</u> | <u>1,200</u> | <u>109,963</u> | <u>43,728</u> |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

6. INCOME FROM CHARITABLE ACTIVITIES - continued

| | Professional support £ | Invited Reviews £ | 2023 Total activities £ | 2022 as restated Total activities £ |
|---|---------------------------|----------------------|-------------------------------|--|
| Conferences | - | - | 278,377 | 59,400 |
| Short courses | - | - | 268,917 | 189,455 |
| International short courses | - | - | 31,156 | 13,147 |
| Distance learning | - | - | 71,560 | 93,276 |
| EPNS recharges | - | - | 43,728 | 50,567 |
| Professional support | - | - | - | 1,703 |
| BPNSU fee income | - | - | 1,200 | - |
| Invited Reviews | - | 19,400 | 19,400 | - |
| Trainee Fees | 5,304 | - | 5,304 | - |
| BPNA membership subscriptions | - | - | 109,963 | 104,090 |
| Annual conference symposium sponsorship | - | - | 66,000 | 77,000 |
| | <u>5,304</u> | <u>19,400</u> | <u>895,605</u> | <u>588,638</u> |

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

| Company name | Symposia Sponsorship £ | 2023 Totals £ | 2022 as restated Totals £ |
|--------------------------|---------------------------|---------------------|------------------------------------|
| Biocodex | 11,000 | 11,000 | 11,000 |
| Biogen | 11,000 | 11,000 | 11,000 |
| Biomarin | - | - | 11,000 |
| Desitin | 11,000 | 11,000 | - |
| GW/Jazz Pharma | 11,000 | 11,000 | 11,000 |
| Novartis | - | - | 11,000 |
| PTC | 11,000 | 11,000 | - |
| Roche | 11,000 | 11,000 | 11,000 |
| Zogenix | - | - | 11,000 |
| Total Sponsorship | 66,000 | 66,000 | 77,000 |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

7. CHARITABLE ACTIVITIES COSTS

| | Direct Costs £ | Grant funding of activities (see note 8) £ | Support costs (see note 9) £ | Totals £ |
|-------------------------------------|----------------------|---|---------------------------------------|------------------|
| Conferences | 143,119 | - | 68,199 | 211,318 |
| Short courses | 89,935 | - | 116,015 | 205,950 |
| Distance learning courses | 13,257 | - | 76,703 | 89,960 |
| International short courses | 88,809 | - | 87,980 | 176,789 |
| Research | 3,429 | 82,969 | 19,105 | 105,503 |
| Membership and professional support | 57,319 | - | 66,295 | 123,614 |
| EPNS recharges | 40,490 | - | - | 40,490 |
| Support Costs | 3,204 | - | 6,607 | 9,811 |
| Governance Costs | 11,997 | - | 35,444 | 47,441 |
| Invited Reviews | 12,400 | - | 7,884 | 20,284 |
| | <u>463,959</u> | <u>82,969</u> | <u>484,232</u> | <u>1,031,160</u> |

8. GRANTS PAYABLE

| | 2023 £ | 2022 as restated £ |
|---|---------------|--------------------------|
| Research | <u>82,969</u> | <u>41,302</u> |
| The total grants paid to institutions during the year was as follows: | | |
| | 2023 £ | 2022 as restated £ |
| Year 1 of 3 joint research training fellowship with Action Medical Research | 41,667 | 41,302 |
| Year 2 of 3 joint research training fellowship with Action Medical Research | <u>41,302</u> | <u>-</u> |
| | <u>82,969</u> | <u>41,302</u> |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

9. SUPPORT COSTS

| | Management £ | Information technology £ | Human resources £ |
|-------------------------------------|-----------------|--------------------------------|-------------------------|
| Conferences | 1,160 | 2,051 | 51,461 |
| Short courses | 1,973 | 3,489 | 87,535 |
| Distance learning courses | 1,304 | 2,307 | 57,877 |
| International short courses | 1,496 | 2,646 | 66,383 |
| Research | 325 | 574 | 14,415 |
| Membership and professional support | 1,127 | 1,994 | 50,021 |
| Support Costs | - | - | 6,607 |
| Governance Costs | 603 | 1,066 | 26,742 |
| Invited Reviews | 134 | 238 | 5,946 |
| | <u>8,122</u> | <u>14,365</u> | <u>366,987</u> |
| | Other £ | Governance costs £ | Totals £ |
| Conferences | 11,048 | 2,479 | 68,199 |
| Short courses | 18,799 | 4,219 | 116,015 |
| Distance learning courses | 12,426 | 2,789 | 76,703 |
| International short courses | 14,255 | 3,200 | 87,980 |
| Research | 3,096 | 695 | 19,105 |
| Membership and professional support | 10,742 | 2,411 | 66,295 |
| Support Costs | - | - | 6,607 |
| Governance Costs | 5,744 | 1,289 | 35,444 |
| Invited Reviews | 1,279 | 287 | 7,884 |
| | <u>77,389</u> | <u>17,369</u> | <u>484,232</u> |

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

| | Annual conference £ | Short courses £ | Distance learning courses £ |
|---------------------------------------|---------------------------|-----------------------|--------------------------------------|
| Trustees' remuneration etc | 1,160 | 1,973 | 1,304 |
| Trustee training and strategy | - | - | - |
| Loss on sale of tangible fixed assets | - | - | - |
| Software subscriptions | 1,060 | 1,801 | 1,191 |
| Computer repairs | 102 | 173 | 114 |
| Website hosting | 81 | 140 | 93 |
| Website development | 343 | 583 | 385 |
| Depreciation of tangible fixed assets | 465 | 792 | 524 |
| Employment costs | 42,230 | 71,831 | 47,493 |
| Social security | 3,895 | 6,625 | 4,380 |
| Pensions | 2,163 | 3,681 | 2,434 |
| Carried forward | 51,499 | 87,599 | 57,918 |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

9. SUPPORT COSTS - continued

| | Annual conference £ | Short courses £ | Distance learning courses £ |
|---|--|--|--------------------------------------|
| Brought forward | 51,499 | 87,599 | 57,918 |
| Staff costs | 1,595 | 2,713 | 1,794 |
| Staff training & Welfare | 169 | 287 | 190 |
| Recruitment costs | 1,409 | 2,398 | 1,586 |
| Business rates | 53 | 91 | 60 |
| Water rates | - | - | - |
| Gas and electric | - | - | - |
| Waste | - | - | - |
| Telephone | 742 | 1,262 | 835 |
| Office insurance | 183 | 311 | 205 |
| Data protection costs | 34 | 58 | 38 |
| Legal fees | 451 | 768 | 508 |
| Marketing | 504 | 855 | 565 |
| Office repairs and renewals | (19) | (30) | (20) |
| Photocopier | 16 | 28 | 18 |
| Postage | 56 | 96 | 63 |
| Printing and stationery | 134 | 228 | 151 |
| Credit card charges | 1,514 | 2,576 | 1,703 |
| Bank charges | 136 | 232 | 153 |
| Bad Debt | 22 | 38 | 25 |
| Copyright licence | 105 | 178 | 117 |
| London Office Expenses | - | - | - |
| London Rent | 5,802 | 9,871 | 6,526 |
| Bolton Rent | 1,285 | 2,186 | 1,445 |
| Depreciation of tangible fixed assets | 30 | 51 | 34 |
| Auditors' remuneration | 1,285 | 2,186 | 1,445 |
| Auditors' remuneration for non audit work | - | - | - |
| Accountancy and legal fees | <u>1,194</u> | <u>2,033</u> | <u>1,344</u> |
| | <u>68,199</u> | <u>116,015</u> | <u>76,703</u> |
| | | Membership and professional support | Support Costs |
| | International short courses £ | Research £ | £ |
| Trustees' remuneration etc | 1,496 | 325 | 1,127 |
| Trustee training and strategy | - | - | - |
| Loss on sale of tangible fixed assets | - | - | - |
| Software subscriptions | 1,366 | 297 | 1,029 |
| Computer repairs | 131 | 28 | 99 |
| Website hosting | 106 | 23 | 80 |
| Website development | 442 | 96 | 333 |
| Depreciation of tangible fixed assets | 601 | 130 | 453 |
| Employment costs | 54,472 | 11,829 | 41,047 |
| Social security | <u>5,024</u> | <u>1,091</u> | <u>3,786</u> |
| Carried forward | 63,638 | 13,819 | 47,954 |
| | | | 6,607 |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

9. SUPPORT COSTS - continued

| | International short courses | Research | Membership and professional support | Support Costs |
|---|-----------------------------------|--------------------|--|------------------------------------|
| | £ | £ | £ | £ |
| Brought forward | 63,638 | 13,819 | 47,954 | 6,607 |
| Pensions | 2,792 | 606 | 2,104 | - |
| Staff costs | 2,058 | 447 | 1,550 | - |
| Staff training & Welfare | 218 | 47 | 164 | - |
| Recruitment costs | 1,819 | 395 | 1,370 | - |
| Business rates | 69 | 15 | 52 | - |
| Water rates | - | - | - | - |
| Gas and electric | - | - | - | - |
| Waste | - | - | - | - |
| Telephone | 957 | 208 | 721 | - |
| Office insurance | 236 | 51 | 177 | - |
| Data protection costs | 44 | 10 | 33 | - |
| Legal fees | 582 | 126 | 439 | - |
| Marketing | 648 | 141 | 489 | - |
| Office repairs and renewals | (23) | (5) | (17) | - |
| Photocopier | 21 | 5 | 16 | - |
| Postage | 73 | 16 | 55 | - |
| Printing and stationery | 173 | 38 | 130 | - |
| Credit card charges | 1,953 | 424 | 1,472 | - |
| Bank charges | 176 | 38 | 133 | - |
| Bad Debt | 29 | 6 | 22 | - |
| Copyright licence | 134 | 29 | 101 | - |
| London Office Expenses | - | - | - | - |
| London Rent | 7,486 | 1,626 | 5,641 | - |
| Bolton Rent | 1,658 | 360 | 1,249 | - |
| Depreciation of tangible fixed assets | 39 | 8 | 29 | - |
| Auditors' remuneration | 1,658 | 360 | 1,249 | - |
| Auditors' remuneration for non audit work | - | - | - | - |
| Accountancy and legal fees | 1,542 | 335 | 1,162 | - |
| | <u>87,980</u> | <u>19,105</u> | <u>66,295</u> | <u>6,607</u> |
| | | | 2023 | 2022 |
| | Governance Costs | Invited Reviews | Total activities | as restated Total activities |
| | £ | £ | £ | £ |
| Trustees' remuneration etc | 603 | 134 | 8,122 | 11,822 |
| Trustee training and strategy | - | - | - | 9,590 |
| Loss on sale of tangible fixed assets | - | - | - | 938 |
| Software subscriptions | 550 | 122 | 7,416 | 5,063 |
| Computer repairs | 53 | 12 | 712 | 852 |
| Website hosting | 43 | 10 | 576 | 660 |
| Website development | 178 | 40 | 2,400 | 240 |
| Depreciation of tangible fixed assets | <u>242</u> | <u>54</u> | <u>3,261</u> | <u>2,356</u> |
| Carried forward | 1,669 | 372 | 22,487 | 31,521 |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

9. SUPPORT COSTS - continued

| | | | 2023 | 2022 as restated |
|---|--------------------------|-------------------------|--------------------------|--------------------------|
| | Governance Costs £ | Invited Reviews £ | Total activities £ | Total activities £ |
| Brought forward | 1,669 | 372 | 22,487 | 31,521 |
| Employment costs | 21,943 | 4,879 | 302,331 | 233,171 |
| Social security | 2,024 | 450 | 27,275 | 20,041 |
| Pensions | 1,125 | 250 | 15,155 | 11,331 |
| Staff costs | 829 | 184 | 11,170 | 1,926 |
| Staff training & Welfare | 88 | 20 | 1,183 | 5,696 |
| Recruitment costs | 733 | 163 | 9,873 | 17,895 |
| Business rates | 28 | 6 | 374 | 582 |
| Water rates | - | - | - | 229 |
| Gas and electric | - | - | - | 217 |
| Waste | - | - | - | 543 |
| Telephone | 386 | 86 | 5,197 | 1,402 |
| Office insurance | 95 | 21 | 1,279 | 1,255 |
| Data protection costs | 18 | 4 | 239 | - |
| Legal fees | 235 | 52 | 3,161 | 7,618 |
| Marketing | 261 | 58 | 3,521 | 663 |
| Office repairs and renewals | (9) | (2) | (125) | 2,608 |
| Photocopier | 9 | 2 | 115 | (593) |
| Postage | 29 | 7 | 395 | 33 |
| Printing and stationery | 70 | 16 | 940 | 879 |
| Credit card charges | 787 | 175 | 10,604 | 7,627 |
| Bank charges | 71 | 16 | 955 | 954 |
| Bad Debt | 12 | 3 | 157 | 19 |
| Copyright licence | 54 | 12 | 730 | 1,115 |
| London Office Expenses | - | - | - | 610 |
| London Rent | 3,015 | 671 | 40,638 | 31,065 |
| Bolton Rent | 668 | 149 | 9,000 | 10,167 |
| Depreciation of tangible fixed assets | 15 | 3 | 209 | 280 |
| Auditors' remuneration | 668 | 149 | 9,000 | - |
| Auditors' remuneration for non audit work | - | - | - | 8,400 |
| Accountancy and legal fees | 621 | 138 | 8,369 | - |
| | <u>35,444</u> | <u>7,884</u> | <u>484,232</u> | <u>397,254</u> |

10. TRUSTEES' REMUNERATION AND BENEFITS

| | 2023 | 2022 as restated |
|---|--------------|---------------------|
| | £ | £ |
| Trustees' salaries | 7,672 | 11,199 |
| Trustees' social security | 239 | 325 |
| Trustees' pension contributions to money purchase schemes | 211 | 298 |
| | <u>8,122</u> | <u>11,822</u> |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023**10. TRUSTEES' REMUNERATION AND BENEFITS - continued**

Included in the remuneration paid to the trustees were amounts paid to Dr L Hartley for services rendered in relation to the development and provision of distance learning courses.

Trustees' expenses

Expenses paid to the following trustees in respect of direct charitable activity costs i.e. travel expenses teaching at UK and/or International courses, undertaken on behalf of the charity in the year:

| | 2023 | 2022 |
|--------------------|---------------|----------|
| | £ | £ |
| Dr L Hartley | 2,681 | - |
| Dr S Jayawant | 416 | - |
| Prof M Kirkpatrick | 10,719 | - |
| Dr A Parker | 483 | - |
| Dr A McLellan | 45 | - |
| Dr M Griffiths | 427 | - |
| Dr D Lumsden | 195 | - |
| Dr S Mordekar | 139 | - |
| Dr D Ram | 164 | - |
| Dr S Amin | 649 | - |
| | <u>15,918</u> | <u>-</u> |

During the year, in addition to the above, amounts totalling £5,264 relating to executive meeting expenses were paid on behalf of all trustees.

11. STAFF COSTS

| | 2023 | 2022 |
|-----------------------|----------------|----------------|
| | £ | £ |
| Wages and salaries | 345,432 | 292,098 |
| Social security costs | 30,948 | 24,723 |
| Pension schemes | <u>16,993</u> | <u>13,680</u> |
| Total | <u>393,373</u> | <u>330,501</u> |

Included within creditors as at the reporting date is £3,200 (2022 - £1,563) in relation to unpaid pension contributions.

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

| | 2023 | 2022 |
|---------------|-----------|-----------|
| Management | 4 | 4 |
| Support staff | <u>7</u> | <u>6</u> |
| | <u>11</u> | <u>10</u> |

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:

| | 2023 | 2022 |
|-------------------|----------|----------|
| £60,000 - £70,000 | <u>0</u> | <u>0</u> |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

11. STAFF COSTS - continued

| | | |
|-----------------|----------|----------|
| Total employees | <u>0</u> | <u>0</u> |
|-----------------|----------|----------|

Total remuneration paid to key management personnel during the financial year included wages and salaries amounting to £69,547 (2022 - £85,853) and contributions to defined contribution pension schemes of £3,338 (2022 - £3,907).

12. PRIOR YEAR ADJUSTMENT

In the prior year, income was received totalling £77,000 relating to the annual conference symposium sponsorship and £104,090 relating to subscriptions. A prior year adjustment has been made to reclassify this income from Donations to Charitable Activities to ensure the recognition is consistent with the current year. This does not affect the charity's surplus for the prior year.

13. TANGIBLE FIXED ASSETS

| | Plant and machinery £ | Fixtures and fittings £ | Totals £ |
|-----------------------|-----------------------------|----------------------------------|---------------|
| COST | | | |
| At 1 April 2022 | 26,727 | 3,321 | 30,048 |
| Additions | <u>5,969</u> | <u>-</u> | <u>5,969</u> |
| At 31 March 2023 | <u>32,696</u> | <u>3,321</u> | <u>36,017</u> |
| DEPRECIATION | | | |
| At 1 April 2022 | 19,665 | 2,480 | 22,145 |
| Charge for year | <u>3,261</u> | <u>209</u> | <u>3,470</u> |
| At 31 March 2023 | <u>22,926</u> | <u>2,689</u> | <u>25,615</u> |
| NET BOOK VALUE | | | |
| At 31 March 2023 | <u>9,770</u> | <u>632</u> | <u>10,402</u> |
| At 31 March 2022 | <u>7,062</u> | <u>841</u> | <u>7,903</u> |

14. STOCKS

| | 2023 £ | 2022 as restated £ |
|--------|---------------|--------------------------|
| Stocks | <u>11,061</u> | <u>15,684</u> |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023**15. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

| | 2023 | 2022 as restated |
|--------------------------------|---------------|---------------------|
| | £ | £ |
| Trade debtors | 32,977 | 19,471 |
| Prepayments and accrued income | <u>7,074</u> | <u>17,462</u> |
| | <u>40,051</u> | <u>36,933</u> |

16. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

| | 2023 | 2022 as restated |
|---------------------------------|----------------|---------------------|
| | £ | £ |
| Trade creditors | 26,472 | 26,466 |
| Social security and other taxes | 11,904 | - |
| Other creditors | 3,354 | 1,897 |
| Deferred income | 43,761 | 78,393 |
| Accrued expenses | <u>24,520</u> | <u>17,067</u> |
| | <u>110,011</u> | <u>123,823</u> |

The deferred income balance above includes income relating to training courses amounting to £43,631 (2022 - £74,388), membership subscriptions received in advance amounting to £130 (2022 - £4,005).

17. LEASING AGREEMENTS

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

| | 2023 | 2022 as restated |
|----------------------------|---------------|---------------------|
| | £ | £ |
| Within one year | 11,628 | 23,355 |
| Between one and five years | <u>-</u> | <u>23,355</u> |
| | <u>11,628</u> | <u>46,710</u> |

During the year the charity incurred expenditure under cancellable and non-cancellable operating lease agreements relating to office rental amounting to £49,638 (2022 - £41,232).

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

18. MOVEMENT IN FUNDS

| | At 1/4/22 £ | Net movement in funds £ | Transfers between funds £ | At 31/3/23 £ |
|---------------------------------------|-----------------------|----------------------------------|------------------------------------|-----------------------|
| Unrestricted funds | | | | |
| General fund | 271,694 | 99,288 | (22,408) | 348,574 |
| Contingency fund | 180,000 | - | - | 180,000 |
| Research training fellowship fund | 153,604 | 26,044 | - | 179,648 |
| Priority Setting Project | 9,739 | (2,206) | (7,533) | - |
| Fetal Neurology course development | 12,130 | (1,400) | - | 10,730 |
| International Faculty Education Fund | 5,600 | 895 | 3,700 | 10,195 |
| Kenya Fellowship Travel Fund | 1,000 | - | - | 1,000 |
| Fellow Travel Bursary Fund | 6,325 | 800 | - | 7,125 |
| Distance Learning Development Fund | 76,700 | (8,875) | - | 67,825 |
| PET Update Course Development | 30,000 | (4,857) | - | 25,143 |
| PET Hot Topics course development | 12,600 | 5,000 | - | 17,600 |
| Impact & Evaluation officer | 50,000 | - | - | 50,000 |
| Movement Disorders course development | - | 5,222 | 16,500 | 21,722 |
| PET1 International Update | - | (9,741) | 9,741 | - |
| | <u>809,392</u> | <u>110,170</u> | <u>-</u> | <u>919,562</u> |
| Restricted funds | | | | |
| Colombia Launch | - | 13,076 | - | 13,076 |
| | <u>-</u> | <u>13,076</u> | <u>-</u> | <u>13,076</u> |
| TOTAL FUNDS | <u><u>809,392</u></u> | <u><u>123,246</u></u> | <u><u>-</u></u> | <u><u>932,638</u></u> |

18. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

| | Incoming resources £ | Resources expended £ | Movement in funds £ |
|---------------------------------------|----------------------------|----------------------------|---------------------------|
| Unrestricted funds | | | |
| General fund | 891,632 | (792,344) | 99,288 |
| Research training fellowship fund | 109,013 | (82,969) | 26,044 |
| Priority Setting Project | - | (2,206) | (2,206) |
| Fetal Neurology course development | - | (1,400) | (1,400) |
| International Faculty Education Fund | 895 | - | 895 |
| Fellow Travel Bursary Fund | 800 | - | 800 |
| Distance Learning Development Fund | 400 | (9,275) | (8,875) |
| PET Update Course Development | 11,250 | (16,107) | (4,857) |
| PET Hot Topics course development | 5,000 | - | 5,000 |
| Movement Disorders course development | 7,500 | (2,278) | 5,222 |
| PET1 International Update | 30,001 | (39,742) | (9,741) |
| | 1,056,491 | (946,321) | 110,170 |
| Restricted funds | | | |
| ILAE grant fund | 58,791 | (58,791) | - |
| Colombia Launch | 39,124 | (26,048) | 13,076 |
| | 97,915 | (84,839) | 13,076 |
| TOTAL FUNDS | <u>1,154,406</u> | <u>(1,031,160)</u> | <u>123,246</u> |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

18. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

| | At 1/4/21 £ | Net movement in funds £ | Transfers between funds £ | At 31/3/22 £ |
|---|----------------|----------------------------------|------------------------------------|--------------------|
| Unrestricted funds | | | | |
| General fund | 352,714 | 111,160 | (192,180) | 271,694 |
| Contingency fund | 180,000 | - | - | 180,000 |
| Research training fellowship fund | 101,513 | 29,698 | 22,393 | 153,604 |
| Priority Setting Project | 9,200 | (9,461) | 10,000 | 9,739 |
| Acute Neurology course development | 10,937 | - | (10,937) | - |
| Fetal Neurology course development | 12,130 | - | - | 12,130 |
| International Faculty Education Fund | 2,400 | 200 | 3,000 | 5,600 |
| Kenya Fellowship Travel Fund | 1,000 | - | - | 1,000 |
| Fellow Travel Bursary Fund | 6,100 | 225 | - | 6,325 |
| Kenya PET Fund | 150 | (150) | - | - |
| Distance Learning Development Fund | - | 1,700 | 75,000 | 76,700 |
| PET Update Course Development | - | - | 30,000 | 30,000 |
| PET Hot Topics course development | - | - | 12,600 | 12,600 |
| Impact & Evaluation officer | - | - | 50,000 | 50,000 |
| | 676,144 | 133,372 | (124) | 809,392 |
| Restricted funds | | | | |
| Development of virtual Instructor Training Day and PET1 virtual Colombia | 10,000 | (10,124) | 124 | - |
| TOTAL FUNDS | <u>686,144</u> | <u>123,248</u> | <u>-</u> | <u>809,392</u> |

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

18. MOVEMENT IN FUNDS - continued

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

| | Incoming resources £ | Resources expended £ | Movement in funds £ |
|---|----------------------------|----------------------------|---------------------------|
| Unrestricted funds | | | |
| General fund | 617,720 | (506,560) | 111,160 |
| Research training fellowship fund | 71,000 | (41,302) | 29,698 |
| Priority Setting Project | - | (9,461) | (9,461) |
| International Faculty Education Fund | 200 | - | 200 |
| Fellow Travel Bursary Fund | 225 | - | 225 |
| Kenya PET Fund | - | (150) | (150) |
| Distance Learning Development Fund | - | 1,700 | 1,700 |
| | 689,145 | (555,773) | 133,372 |
| Restricted funds | | | |
| ILAE grant fund | 39,919 | (39,919) | - |
| Development of virtual Instructor Training Day and PET1 virtual Colombia | - | (10,124) | (10,124) |
| | 39,919 | (50,043) | (10,124) |
| TOTAL FUNDS | 729,064 | (605,816) | 123,248 |

Contingency fund

The contingency fund is held to support the staffing cost of running the BPNA Secretariat for a period of approximately six months (2022 - six months) should there be any contingency that might lead to a significant reduction in BPNA operational activities, this equates to £200,000 (2022 - £180,000).

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.

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.

18. MOVEMENT IN FUNDS - continued

International League Against Epilepsy (ILAE) grant fund

The BPNA and ILAE share a commitment to improving care for children with epilepsy. In 2005, the BPNA developed Paediatric Epilepsy Training (PET) courses to train healthcare workers to better diagnose and treat children with seizures. PET1 is now attended by almost every paediatrician in the UK and the courses have also been launched overseas, setting a gold standard for epilepsy care around the world. Outside of the UK, the programme currently runs in: Brazil, Ghana, India, Kenya, Myanmar, New Zealand, South Africa, Sudan, Tanzania and Uganda.

PET aligns with the ILAE's Education Council's aim to teach competency in the diagnosis and clinical management of epilepsy, with a focus on non-specialists i.e. paediatricians. It forms part of the portfolio of educational activities that the ILAE aims to develop. It also supports Goal 2 of the ILAE's Strategy 2030: Support health professionals worldwide to enhance their knowledge and skills in the prevention, diagnosis, treatment and care of epilepsy.

The BPNA and the ILAE first signed a partnership agreement in 2018, committing to build on the success of the Paediatric Epilepsy Training courses developed by the BPNA.

The ILAE has agreed to cover 40% of staff costs in the BPNA's International Education team (3 staff members) from April 2022 to March 2026. This equates to a total of \$278,844 over that time.

Priority Setting Project

The BPNA committed £50,000 to undertaking a research priority setting project (PSP) in paediatric neurology, facilitated by the James Lind Alliance. This partnership aims to shape future research on paediatric neurological conditions by bringing together patients, their parents and carers and health care professionals to identify and prioritise unanswered research questions around treatments, therapies or procedures. The outcome of the project will be a list of the top 10 jointly agreed research priorities. These priorities will then be promoted to research funding organisations to influence future research.

The PSP commenced October 2019, aiming to complete September 2020, however due to Covid-19, the project was extended to 31 March 2022. During 2020-21, a survey was promoted to clinicians, patients and carers to complete online. The responses were analysed filtered, and a second survey was sent out in 2021-22. It asked them to identify their top research priorities in paediatric neurology from a list of 44 questions. These responses were analysed and filtered and produced a top 26 final list of unanswered questions.

The final prioritisation workshop was held with various stakeholder groups on 30 March 2022 in London, with the objectives to finalise top 10 research questions from the final 26.

The top 10 and the other 16 that did not make the top 10 were published in a final summary document in November 2022 as 'Top Ten UK research priorities for interventions in childhood neurological disorders' and was well received.

The aim now would be looking into how some of these questions can be researched with the support of the BPNA and interested stakeholders.

A Pre-conference Trainees' research network meeting happened at the BPNA2023 Conference with discussion about the AMR Fellowship and Priority Setting Project results, chaired by Dr Sam Amin (Chair of Research) & Dr Robert Spaul (Trainees Rep). Dr Sam Amin will continue to have development meetings throughout the next year.

Research Training Fellowship Fund

The Research Training Fellowship funds trainee clinicians to complete a research degree (eg PhD) in the field of clinical neurology and/or neuroscience, including neurodisability and neurodevelopment. Fellowship applicants are pre-doctoral trainee clinicians who either already hold a UK or Irish specialist training post in Paediatric Neurology or are planning to apply for a specialist training post in Paediatric Neurology or Neurodisability after completion of their PhD. Both the proposed application and fellowship applicant must meet the BPNA charitable aims.

18. MOVEMENT IN FUNDS - continued

Income to this fund is from members' donations and the income from sponsored symposia at the BPNA annual conference.

Since 2015, the BPNA has partnered with Action Medical Research to fund a joint Research Training Fellowship award. Applications for this joint award are considered in open competition through the Action Medical Research peer review system.

International Faculty Education Fund

To enable Low and middle income country (LMIC) BPNA course faculty to benefit from BPNA education by funding registration fees. The aim is to support faculty to pay for courses that they would otherwise be unable to afford. BPNA Education includes: face-to-face courses and conferences held in the UK, virtual courses or conferences and enrolment on distance learning units. It does not fund travel or accommodation.

Kenya Travel Fellowship Fund

In 2019, the BPNA and Kenyan Paediatric Association established a fellowship for UK paediatric neurologists to go to work in Kenya for a short period. The KPA will pay the UK clinician's salary. This fund is to cover the cost of their return travel expenses.

Fellow travel bursary fund

Bursary fund for UK trainees and fellows

PET1 Development

PET1 was last updated in January 2018. This money will fund the bringing together of an international development team to update PET1 course materials to reflect feedback, updates in research and guidance.

PET Hot Topics Course development

To fund development of a new course designed for those who attended PET2 and 3 more than 3-years ago.

Impact & Evaluation Officer

The BPNA has been running courses since 2005. This money is to fund an Impact and Evaluation Officer to report on the full impact of BPNA courses.

Movement Disorders course development (MovED)

MovED is a 2-day course being developed by Consultant Paediatric Neurologists and Paediatricians in Neurodisability. It will run as a stand alone course, but will develop themes from the Approaching Children's Tone (ACT) course.

This course aims to cover a broad spectrum of movement disorders that are seen in children and will place emphasis on description, diagnosis and initial management of these conditions.

The planned launch is October 2023.

Columbia Launch Fund

In partnership with the University of Antioquia and ASCONI, the Colombian Child Neurology Society, BPNA launched PET1 in Colombia in August 2022.

The Buist Foundation, ILAE South America Region and Jazz Pharmaceuticals have contributed to the Columbia Launch Fund.

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.

18. MOVEMENT IN FUNDS - continued

Transfers between funds - continued

There have been no transfers between restricted funds and unrestricted funds in the current, prior year there was a transfer of £124 from general fund to Colombia Launch restricted fund.

19. RELATED PARTY DISCLOSURES

During the year, Dr L Hartley became director and shareholder of HMLH Consulting Ltd, and during the period that Dr L Hartley was a trustee of BPNA and a director of HMLH Consulting Ltd, BPNA made payments of £1,973 to HMLH Consulting Ltd for the provision of distance learning courses. Dr L Hartley officially stepped down as a trustee on 16 January 2023.

20. 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.

21. CONTINGENT LIABILITY

It is possible that some areas of conference income may be eligible for VAT. The charity will consult an external tax advisor. It is not possible at this stage to quantify the amount of the obligation and the likelihood that BPNA will have a liability is, at this stage, possible rather than probable.

