



# BPNA

British Paediatric Neurology Association



**PET** **1** **2** **3**  
PAEDIATRIC EPILEPSY TRAINING

Endorsed and supported by

**ILAE** International League  
Against Epilepsy

## Epilepsy

Epilepsy is a global burden affecting around 50 million people worldwide. It is a chronic neurological, non-communicable disease, characterized by recurrent epileptic seizures. Of these, 80% of people living with epilepsy are in low and middle-income countries (LMIC) where the prevalence is double that of high income countries (4-6/1,000 rising to 8-14/1,000 in LMIC). Epilepsy is often misdiagnosed and/or mismanaged, with consequent significant morbidity and mortality. Most epilepsies can be controlled with relatively inexpensive medication.

Most epilepsies start in childhood. If they are not properly treated, they can:

- Adversely affect intellectual development
- Lead to social exclusion. Stigma is significant, leading to reduced opportunities for education, employment and marriage
- Carry significant morbidity and mortality from burns and accidents, particularly in LMIC
- Adversely affect quality of life
- Increase the risk of sudden unexpected death (SUDEP)

Approximately 75% of epilepsies are treatable, however in LMIC, 50-75% are not properly treated. This is called the 'Treatment Gap'. "Part of this treatment gap is attributable to insufficient recognition of the symptoms of epilepsy"<sup>1</sup>.

In 2015, the World Health Assembly, the decision-making body of the World Health Organisation, adopted the epilepsy resolution, endorsed by all member states. It emphasised the importance of training to reduce 'Treatment Gap'. This landmark resolution makes epilepsy a high-priority and aims to ensure people with epilepsy receive timely treatment and are free from stigma.

Paediatric Neurologists worldwide are motivated to improve standards of care and agree the best way to reduce the treatment gap is by training paediatricians and emergency doctors to improve diagnosis and treatment of epilepsy.

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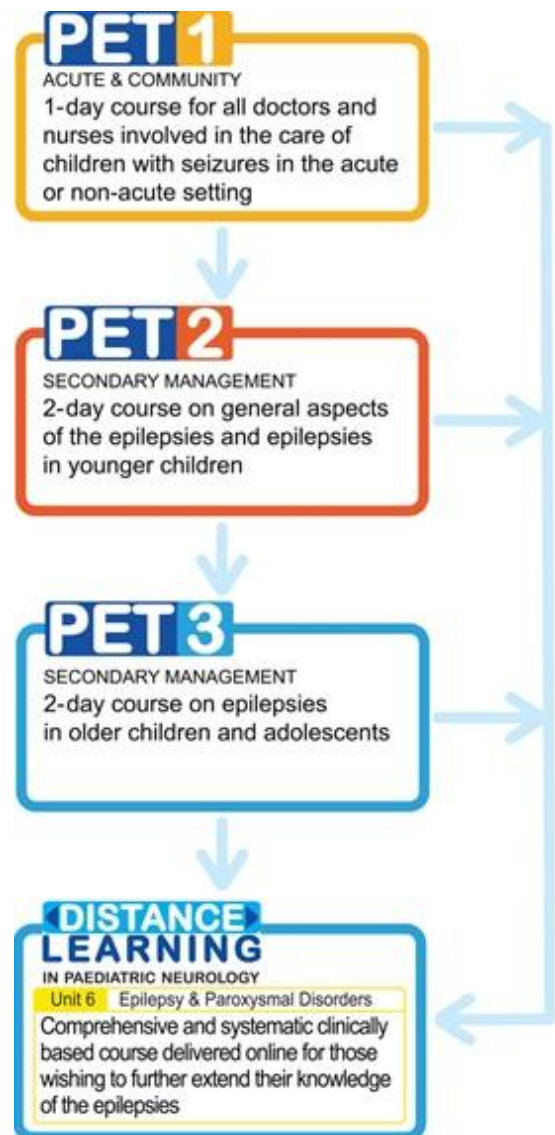
<sup>1</sup> [ILAE/IBE/WHO. Global Campaign Against Epilepsy: "Out of the Shadows". 2003](#)

## Paediatric Epilepsy Training (PET)

Paediatric Epilepsy Training (PET) is a series of face-to-face 1 and 2-day courses developed by the British Paediatric Neurology Association (BPNA) in response to concerns about standards of care for children with epilepsy in the UK<sup>2,3</sup>. PET has been running in the UK since 2005 and is now being established worldwide.

PET is aimed at paediatricians, medical officers and emergency department professionals<sup>4</sup>. It aims to improve the diagnosis of epileptic and non-epileptic events; improve the standard of care; and raise awareness of when to liaise with a Paediatric Neurologist, a children's epilepsy expert.

The International League Against Epilepsy (ILAE) endorses PET. The ILAE identified PET as an effective, sustainable format to teach safe standard epilepsy practice to clinicians across all levels of healthcare. PET has been critically reviewed by Paediatric Neurologists around the world who have concluded that this course teaches "safe standard epilepsy practice to clinicians, applicable to children in all countries" and are "sensible, practical and pragmatic".



<sup>2</sup> Hanna NJ, Black M, Sander JW, et al. National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy – Death in the Shadows. London: The Stationery Office, 2002. This audit reviewed pre-death care and post-death investigations in children and adults over the period of a year. Although the proportion of children that could be reviewed in detail was small, the key findings showed that 77% of children had what would be regarded as substandard care and that 59% of deaths in children were potentially or probably avoidable. Deficiencies identified included inadequate drug management, access to specialist care and investigations, and a lack of holistic management.

<sup>3</sup> White C. Doctor referred to General Medical Council after inquiry into epilepsy diagnosis. *British Medical Journal*. 2001; 323:323. Following this, the Royal College of Paediatrics and Child Health commissioned a report on the care of children with epilepsies in the district general hospital where the paediatrician was employed. The report, published in 2003, found that of almost 2,000 children with a diagnosis of epilepsy, 32% had been misdiagnosed, either because they did not have epilepsy or the type of epilepsy diagnosed was incorrect. There was excessive and/or unnecessary drug treatment in almost one third of children.

<sup>4</sup> Crisp N, Gawanas B, Sharp I; WHO Task Force for Scaling Up Education and Training for Health Workers. Training the health workforce: scaling up, saving lives. *Lancet*. 2008; 371 (9613): 689-691. This report recognises the need for a diversity of levels of health practitioners and that 'High-Level Health Workers' are one of an essential range of personnel for an effective healthcare system.

*“The standardisation of care is already evident in South Africa based on the level of interest and demand for further courses and improved referrals to specialists and identification of affected children” - Dr Jo Wilmshurst, PET Lead, Paediatric Neurology Development Association of Southern Africa & President Elect, International Child Neurology Association*

PET aligns with the 2015 World Health Assembly resolution on epilepsy. PET increases the local workforce capacity, improving access to quality essential health-care services for children, and teaches practical approaches to achieve social inclusion for children with epilepsy.

The ILAE is supporting the delivery of PET throughout the world. PET is being delivered in the following countries<sup>5</sup>:

| Region                            | Country              | PET1 | PET2 | PET3 |
|-----------------------------------|----------------------|------|------|------|
| Australasia                       | New Zealand          | ●    | ●    | ●    |
| Brazil <sup>6</sup>               | Brazil               | ●    |      |      |
| Europe                            | United Kingdom       | ●    | ●    | ●    |
| India                             | India                | ●    |      |      |
| Middle East & North Africa (MENA) | Sudan                | ●    | ●    |      |
|                                   | United Arab Emirates | ●    | ●    | ●    |
| South East Asia                   | Myanmar              | ●    |      |      |
| Sub-Saharan Africa                | Ghana                | ●    |      |      |
|                                   | Kenya                | ●    |      |      |
|                                   | South Africa         | ●    |      |      |
|                                   | Tanzania             | ●    |      |      |
|                                   | Uganda               | ●    |      |      |



**12,131** PET attendees worldwide<sup>5</sup>

**358** PET volunteer faculty worldwide

<sup>5</sup> At August 2018




<sup>6</sup> PET1 has been translated into Portuguese

## PET courses

PET teaches the importance of correct diagnosis of epileptic and non-epileptic events, through improved history taking. 85% of attendees report PET1 has improved their ability to distinguish between epileptic and non-epileptic events; 82% of attendees report they have improved history taking following attendance at PET1<sup>7</sup>.

PET teaches the management of a child presenting acutely with afebrile seizures and principles of acute management of prolonged seizures. Over half (54%) of attendees have introduced changes to services resulting in improvements in prolonged seizure management in their unit within 6-months of attending PET<sup>7</sup>.

PET addresses issues of equality; disability and social exclusion. Many children with epilepsy have disability co-morbidities. Health workers, parents and teachers tend to exclude these children from normal activities, which can include attending school. PET teaches that children with epilepsy are able to participate in usual childhood activities, and how to engage practically with parents, teachers and other society members to enable social inclusion through the use of individual care plans.

|   |   |
|---|---|
|   | <p>1-day course recommended for all doctors and nurses who contribute to the initial or ongoing care of a child experiencing paroxysmal disorders in the acute and community setting.</p>   |
|  | <p>2-day course covers general aspects of epilepsy (history taking, differential diagnosis, investigation etc) and concentrating on epilepsies in infants and young children. Recommended for all doctors and nurses who care for young children with epilepsies.</p> |
|  | <p>2-day course concentrating on the epilepsies presenting in older children and adolescents and transition to adult services. Recommended for all doctors and nurses who care for older children, adolescents and young adults with epilepsy.</p>                    |

Each PET course has short didactic lectures and interactive small-group workshops. There are many opportunities within each course to consider difficult cases, share 'experience in the real world', and debate 'the evidence'. The size of workshops is limited to 8 attendees, to ensure everyone is able to contribute and gain the most from the learning experience.

Each course has standardised course materials that are taught to the same high standard worldwide by a trained local faculty of experienced paediatric neurologists and paediatricians with an expertise in epilepsy. Pre-course reading, and a course handbook are provided to attendees.

<sup>7</sup> 2017 PET1 Outcome Measures Report

## PET teaching materials

PET is evidence based, refers to internationally recognised guidelines, and provide a consensus view for paediatricians. Content is internationally peer reviewed. Course materials are updated every 3-years to reflect:

- Feedback from the teaching faculty at all courses
- Feedback from attendees at all courses
- New developments in epilepsy management, medication, diagnostic techniques etc
- Up-to-date recommendations from organisations such as the UK National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidelines Network (SIGN) and the World Health Organisation
- Changes in terminology and classification from the International League Against Epilepsy

In spring 2018, 21 consultant paediatric neurologists representing 12 countries<sup>8</sup> came together in a collegiate atmosphere to revise PET1. The team agreed PET1 promotes safe, standard practice applicable worldwide and they aimed to revise the course to ensure it meets the needs of doctors in all countries caring for children with epilepsy.

They agreed the fewer differences between country versions, the more consistent the messages worldwide. They aimed to produce one version of the course, with additional slides for specific groups of countries that reflect their differing resources and common problems. The result is one PET1 course with adaptations for specific groups of countries to reflect different drug availability; prevalence of specific aetiologies and syndromes, eg hypoglycemia, acute symptomatic seizures, West syndrome; and different national protocols.

PET2 and PET3 were revised in 2018 by UK and New Zealand paediatric neurologists.

The next update is due in 2021 when it is envisaged that PET Leads from around the world will again come together to revise the materials.

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<sup>8</sup> Brazil, Ghana, India, Kenya, Myanmar, New Zealand, South Africa, Sudan, Tanzania, Uganda, United Arab Emirates and UK

## Outcomes

### 1.1.1. Published evidence of the impact of PET

- In the UK, the annual incidence of a diagnosis of epilepsy declined by 4% per annum between 2001 and 2008<sup>9</sup>. While there may be a variety of possible explanations for this, it may reflect more accurate diagnosis and appropriate cessation of treatment.
- UK national audit data<sup>10</sup> have demonstrated significant engagement of the paediatric epilepsy clinical community some of which is likely to have been engendered through PET attendance.
- A series of Performance Indicators demonstrated good adherence to nationally published clinical guidelines and it seems likely too that PET training has contributed to this<sup>11</sup>.
- There is data to suggest that clinical care provided by a paediatrician “with expertise” in epilepsy who is running a dedicated seizure clinic is superior to that provided by a mixed paediatric general clinic<sup>12</sup>.

### 1.1.2. Course feedback

We routinely collect attendee feedback at the end of each course. PET is rated excellent or very good by 99%<sup>13</sup> of attendees (excellent=61%, very good=39%). 87% report their expectations were exceeded (30.1%) or fulfilled (57.28%). 95% say they will definitely recommend PET to a colleague, 5% that they probably will.

### 1.1.3. Attitudes and practice survey

We routinely survey all attendees 6-months post PET1 to record changes in attendees’ attitudes and practice following attendance. Results from the 2017 PET1 Outcome Measures indicate:

- 85% report they have improved ability to distinguish between epileptic and non-epileptic events
- 82% report they have improved history taking
- 80% report PET has prompted them to try to improve the way clinical services are set up to support children with epilepsy
- 75% report they have made moderate or significant changes to their practice, diagnosis and caring for children and young people with epilepsies

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<sup>9</sup> Meeraus WH, Petersen I, Chin RF, Knott F, Gilbert R. Childhood epilepsy recorded in primary care in the UK. *Archives of Disease in Childhood*. 2013; 3: 195-202

<sup>10</sup> Royal College of Paediatrics and Child Health. [“Epilepsy12” national audit reports from 2009-2014](#)

<sup>11</sup> Kirkpatrick et al. Guidelines, training, audit and quality standards in children’s epilepsy services: closing the loop. *Seizure*. 2014; 23: 864-868

<sup>12</sup> Mar S, Dunkley C, Al-Ansari I, Whitehouse WP. Comparison of a dedicated children’s seizure clinic to mixed general paediatric clinics. *Child Care Health Development*. 2005; 31: 597-602

<sup>13</sup> Feedback from 2018 PET1 courses in India, South Africa, Kenya, Ghana



- 63% report they recognise more quickly when a patient needs to be referred to an expert
- 58% report they always provide first aid advice to parents and care givers
- 57% have made improvements in information sharing
- 54% have introduced changes to services resulting in improvements in prolonged seizure management in their unit
- Many have introduced or improved teaching about epilepsy to parents and families (88%), undergraduates (70%), post graduates (63%), professional colleagues (65%)

#### **1.1.4. PET as a requirement for training**

- To register as a Paediatrician with a [special interest in epilepsy](#), the Royal College of Paediatrics & Child Health require attendance at PET
- Attendance at PET is often a requirement on job descriptions in the UK for Paediatricians who will be managing children with epilepsy
- Whilst PET courses are not mandatory in the UK, they have become the accepted gold standard of epilepsy education. It has become expected amongst paediatricians themselves that anyone working with children with seizures should have attended PET.

## Further information

For further information about bringing PET to your region or are interested in funding PET in a low or middle income country, please contact:

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To book to attend a PET course, please go to: <https://courses.bpna.org.uk/>