



Paediatric Epilepsy Training Courses: Entry point to knowledge empowerment and practice change



Prof J Wilmshurst

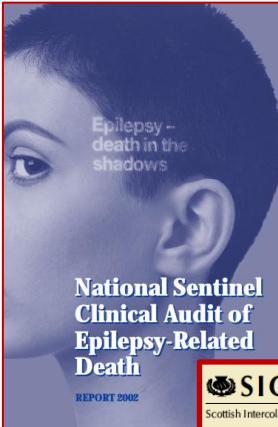


10 February 2026

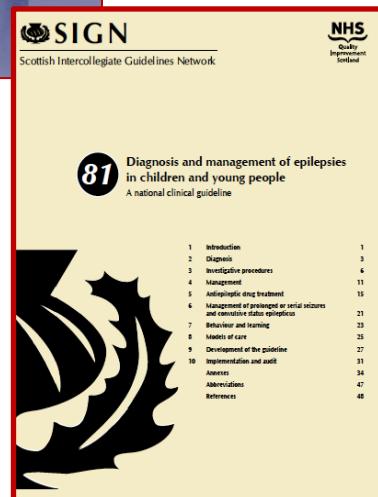
Why did BPNA short courses start?



Concern about standards of care



Need to improve guideline implementation?



Victims misdiagnosed by doctor paid £4m in compensation

The victims of a doctor who reduced children to "zombies" after misdiagnosing them have been paid more than £4m in compensation.

NICE National Institute for Health and Care Excellence

The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care

Issued: January 2012 last modified: December 2013

NICE clinical guideline 137
guidance.nice.org.uk/cg137

BPNA PET cited as exemplar, WHO, 2022



Paediatric Epilepsy Training (PET) aims to improve care worldwide for children and young people with seizures and epilepsies

Uses collaboratively designed educational materials linked to published clinical guidelines

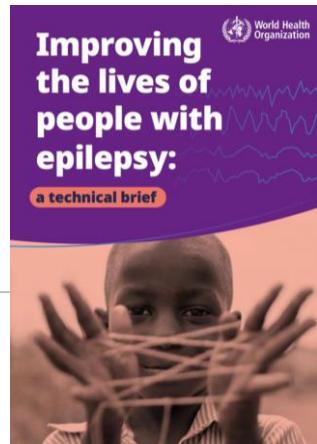


Seeks to embed recommended best, safe practice into local health services

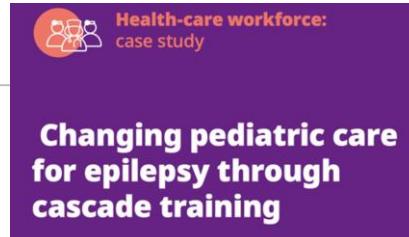
Forming networks!



Working closely with the International League Against Epilepsy (ILAE)



PET 1



Changing pediatric care for epilepsy through cascade training



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PET1 from 2013 to 2025



-  Running regular PET courses
-  PET launch planned
-  PET courses have taken place here

Some 21 000 health workers trained
>350 faculty volunteer

Partnerships with country Paed Assoc
English, Portuguese, Spanish, French

Course Development Teams



• 2004-2015 versions:

- Katharine Anderson, UK
- Richard Appleton, UK
- Sarah Aylett, UK
- Celia Brand, UK
- Helen Cross, UK
- Krishna Das, UK
- Anita Devlin, UK
- Colin Dunkley, UK
- Colin Ferrie, UK
- Elaine Hughes, UK
- Geoff Lawson, UK
- Martin Kirkpatrick, UK
- Ailsa McLellan, UK
- Mary O'Regan, UK
- Alasdair Parker, UK
- Sunny Philip, UK
- Shiela Puri, UK
- Ruby Schwartz, UK
- Stephen Warriner, UK
- William Whitehouse, UK
- Cathy White, UK
- Margaret Wilson, UK
- Zenobia Zaiwalla, UK
- Sameer Zuberi, UK

2019 revision:

- Hadi Al-Malik, UAE
- Dulmini Birkett, UK
- Celia Brand, UK
- Helen Cross, UK
- Colin Dunkley, UK
- Pradnya Gadgil, India
- Mike Griffiths, UK
- Marilisa Guerreiro, Brazil
- Charles Hammond, Ghana
- Richard Idro, Uganda
- Angelina Kakooza, Uganda
- Edward Kija, Tanzania
- Martin Kirkpatrick, UK
- Kyaw Linn, Myanmar
- Finbar O'Callaghan, UK
- Philippa Rodie, UK
- Lynette Sadleir, New Zealand
- Pauline Samia, Kenya
- Steve Warriner, UK
- Jo Wilmshurst, South Africa

2023 revision:

- Jessica Ball, UK
- Francesca Cassidy, UK
- Simone Ardern-Holmes, Australia
- Dulmini Birkett, UK
- Jaime Carrizosa, Colombia
- Chahnez Charfi Triki, Tunisia
- Helen Cross, UK
- Colin Dunkley, UK
- Mike Griffiths, UK
- Samson Gwer, Kenya
- Charles Hammond, Ghana
- Richard Idro, Uganda
- Laura James, UK
- Edward Kija, Tanzania
- Martin Kirkpatrick, UK
- Ann Agnes Mathew, India
- Philippa Rodie, UK
- Lynette Sadleir, New Zealand
- Surekha Tuohy, UK
- Kette Valente, Brazil
- Sophia Varadkar, UK
- Steve Warriner, UK
- Rachael Wheway, UK
- Cathy White, UK
- Jo Wilmshurst, South Africa
- Tong Hong Yeo, Singapore



PET1

Delivers an introduction to the epilepsies and related conditions

Recognition of epileptic events and differential diagnoses

Principles of initial and safe management of children and young people with seizures

Management of children and young people with epilepsies in the acute setting

Inclusive of holistic care and equity rights



DESSCRIBE



D

- Description?

E

- Epileptic, non-epileptic or uncertain events(s)? Epilepsy?

S

- Seizure Type(s)?

S

- Syndrome?

C

- Cause?

R

- Relevant?

I

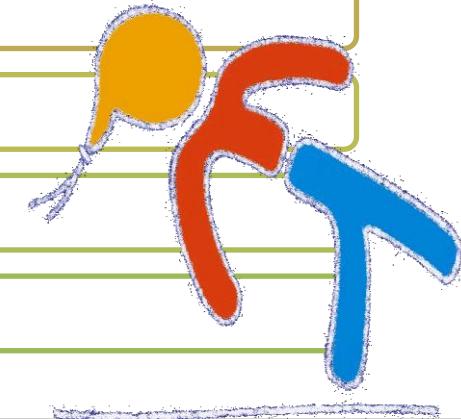
- Impairments?

B

- Behavioural and Emotional?

E

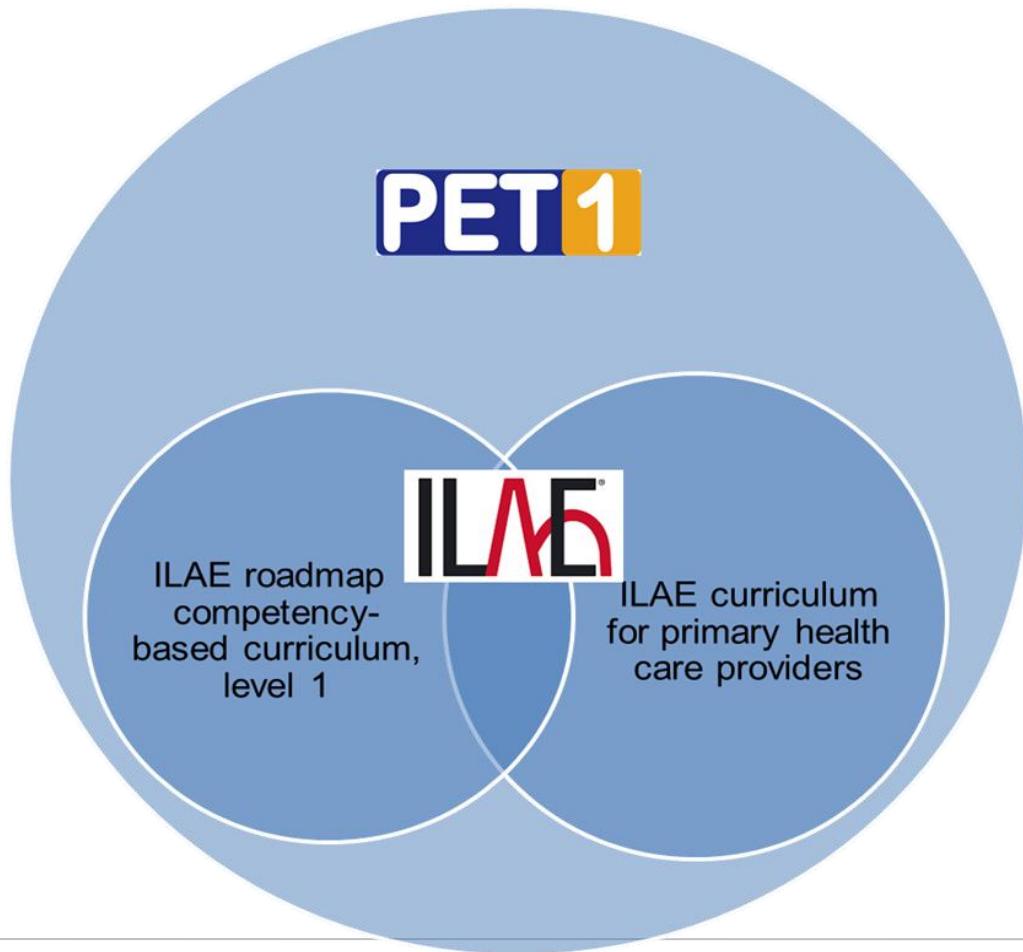
- Educational Issues



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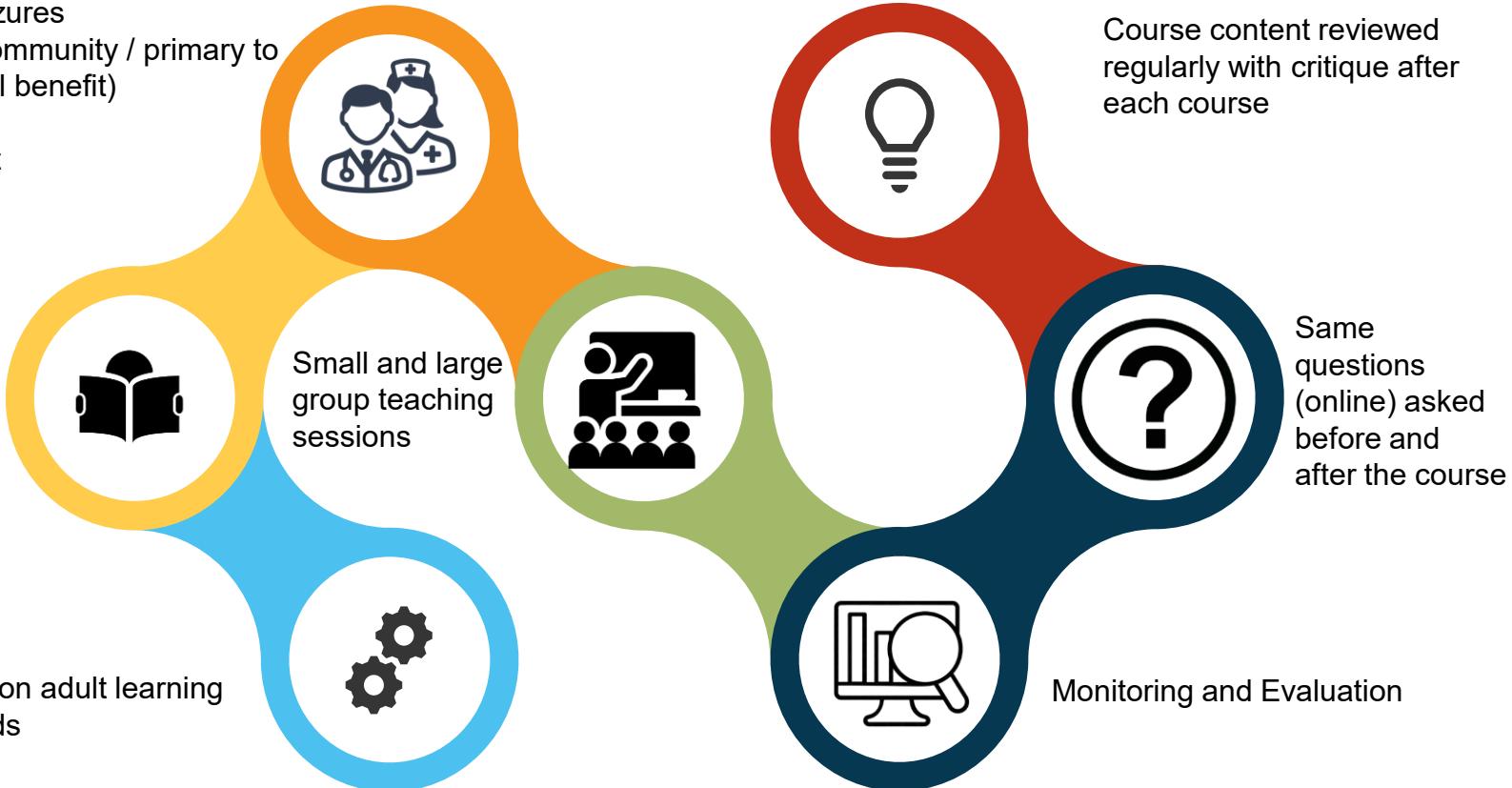
PET1 maps to
"Level 1" ILAE
curriculum for
children and
young people

Ethos of PET



PET is leveled for any healthcare practitioner involved in the care of children with seizures

- Doctors – community / primary to specialist (all benefit)
- Nurses
- Technologist
- Paramedic
- etc



Evidence of Impact of PET



1

Feedback analysed from
>4000 delegates:
• Monitoring of
standards
• Updating courses

2

Measurable
improvements:
• Knowledge
• Attitudes & Practice
survey: 98% tried to
improve their clinical
service for children
following PET

3

75% report improved
history-taking

4

54% use a structured
formulation in clinical
practice

5

30% now use status
epilepticus guidelines
for the management of
prolonged seizures

6

Formal clinical networks
(OPEN) and informal
(WhatsApp groups)
born out of PET



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Evidence of Impact of PET



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ORIGINAL ARTICLE



Reducing epilepsy diagnostic and treatment gaps: Standardized paediatric epilepsy training courses for health care professionals

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Jessica Ball³ | Colin Dunkley⁵ | Ailsa McLellan⁶ | Finbar O'Callaghan⁷ |
Martin Kirkpatrick¹

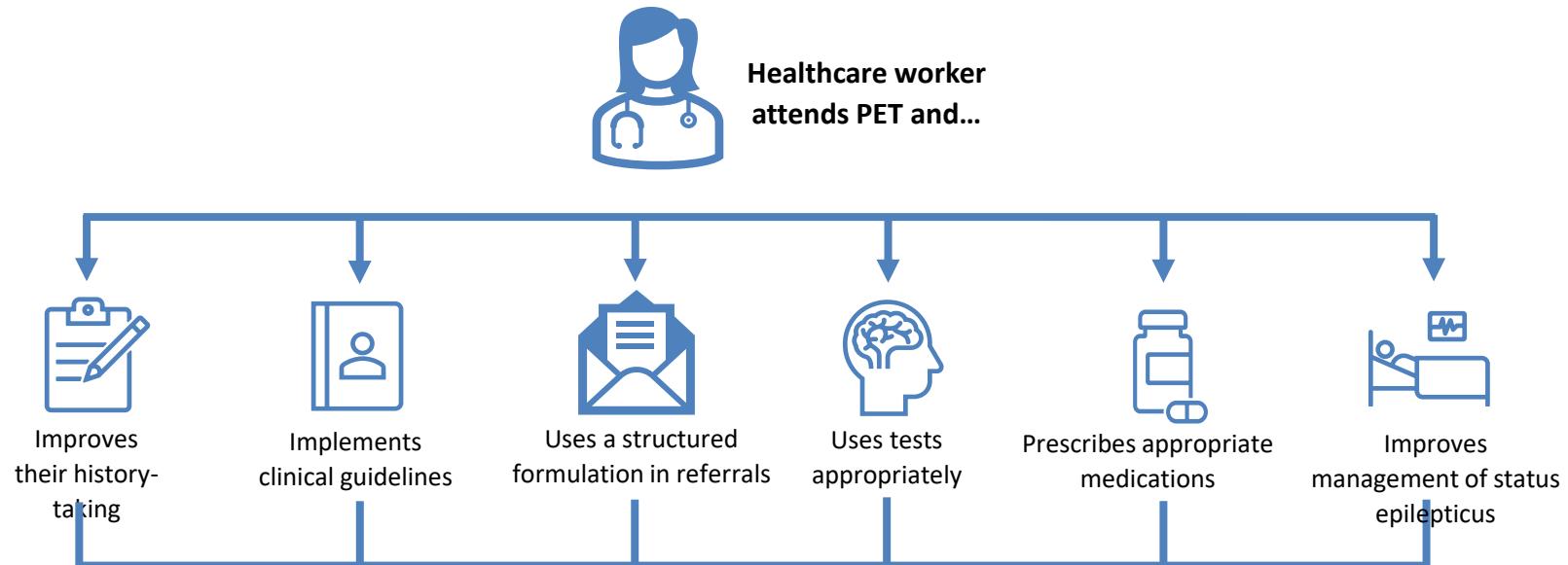


Endorsed and supported by
ILAE International League
Against Epilepsy



rebrand.ly/PET-impact

What Difference has PET made?

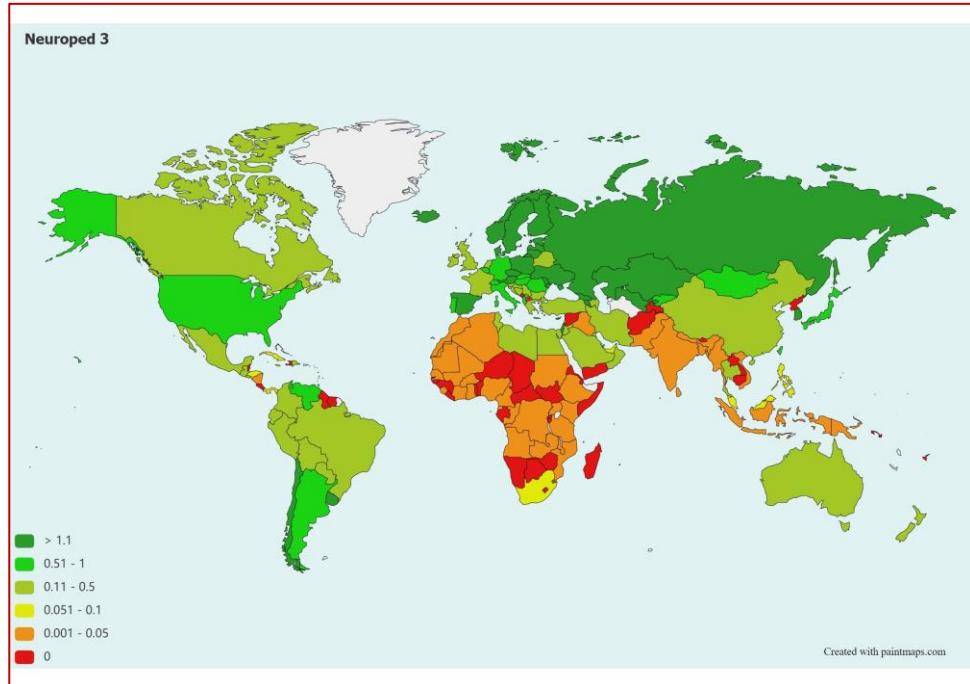


Heat map for number of child neurologists per 100 000 population



- Access to Pediatric Neurology training and services worldwide: A survey by Neurology Association.

Wilmshurst JM, Catsman-Berrevoets C, Gilbert DL, Nagarajan L, Samia P, Serdaroglu E, Triki C, Vidaurre J, Hameed B; for Pediatric Neurology Training study group. *Neurology*. 2023 Jul 25;doi: 10.1212/WNL.0000000000207633.



International PET – Why and How?



THE LANCET



International Demand
- PET1 now global



ILAE endorsement & support



“In the shadow of epilepsy”



Principles:
- Consistent Standards (Curriculum delivery, Faculty Training)
- Sustainability 5 years plus
Quality Assurance

THE LANCET

Volume 349, Number 9069

EDITORIAL

In the shadow of epilepsy

What disease affects 40 million people worldwide, yet three-quarters are untreated? Paradoxically, the same disease, with early diagnosis and treatment, can be controlled in about three-quarters of those affected. The disease is epilepsy, the commonest serious brain disorder in every country in the world.

developed world has around one neurologist per 30-300 000 population, compared with one per 3-10 million in the developing world, where some countries have virtually no specialist epilepsy centres. Adding to this treatment gap is the fact that 80% of the market for antiepileptic drugs is in 15%

“75% untreated, yet 75% are easily treatable”

Day 1 – PET training - local faculty as participants

Day 2 – PET philosophy, “train the trainers”, quality assurance

Day 3 – PET training - Local faculty as trainers



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African Story



PET adapted for relevance to Africa 2015

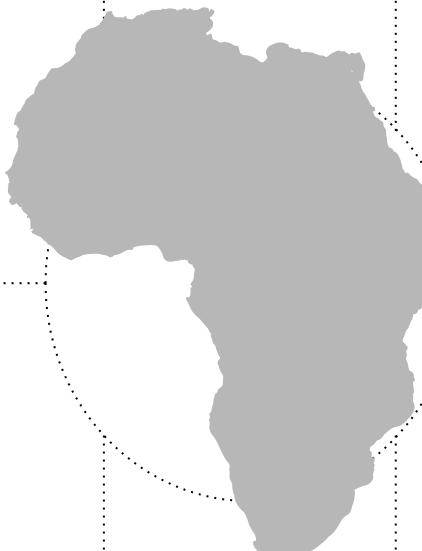
01

Feb 2016: Cape Town – trained 35 African Faculty

02

2016-2019: Multiple courses across South Africa (2-3 per yr)
2017: Kisumu, Kenya

03



2018: Expanded faculty – further 35 faculty
Kenya / Tanzania / Ghana / Uganda

04

2019 Courses:
SA/ Tanzania (African Region funded)
Kenya/ Ghana/ Namibia/ Uganda (African Region funded)
Angola (with Mozambique) (ILAE Ped Comission/ ICNA)

05

2020: COVID-19 Mauritius
2021 – 2025: exponential courses, 2 more country faculties

06





- The established faculties supports the sustainability of the project n=8
 - Reached n=13 countries
- Now available on-line – successful courses in Ghana, Kenya, pan Africa, Mozambique
- 2023
 - PET Faculties Zimbabwe & Zambia
 - Adult adaptation underway (ETAM) pilot Tanzania AND Zim faculty 2025
- 2024 Nov – Tunisia TTT faculty roll-out for Francophile courses



Malawi Experience – 2024 (Blantyre) & 2025 (Lilongwe)



- South African / Tanzanian / Ugandan faculty
- Examples of delegate statements
 - Not aware of infantile epileptic spasms
 - Children frequently excluded from schooling – concern infected or bewitched
 - Treating SFS with phenobarbital
 - No protocol or sustainable approach for status epilepticus epilepticus

In Summary

- Over last 9 years estimated reached over 2000 health care workers in Africa
 - Reaching practitioners who are either institutional leaders or those “at the rock face”
 - Creating a common “language” and approach to children with seizures.
- Next need to measure the clinical impact from the courses.....

