

IBRO-ARC joint ILAE-IBRO epilepsy IGAP workshop
2023 July 3-9th



Workshop justification and background: Epilepsy is a brain disease that accounts for a significant proportion of the world's burden of disease and can affect any individual irrespective of age, race, sexual, social or geographical boundaries. It is estimated that up to 80% of the 50-70 million people with epilepsy (PWE) worldwide live in low- and middle-income countries (LMICs) such as is found in Africa. In the Africa region, PWE often go undiagnosed and untreated due in part to shortages of trained health workers, social stigma, limited resources and infrastructure.

It is important that the future of tomorrow, the young researchers, are equipped with the knowledge and skills to understand these challenges and create innovative ways to circumvent them in their respective contexts. Training on the key updates on Epilepsy care and management by Africans for Africa is among the many ways to tackle this concern.

As evidenced by previous workshops the collaborations between IBRO and ILAE have been most productive, relevant and exciting (eg IBRO/ILAE Epilepsy school in Cape town, South Africa in 2015; IBRO/ILAE School on Epilepsy and Parasitosis in Dakar, Senegal,2017). With the passing by the World Health Assembly (WHA) of the Intersectoral Global Action Plan for epilepsy and

other neurological disorders (IGAP) Africa especially is in a unique position to upskill its capacity to understand and improve on the management of people with epilepsy.

The critical elements of training in the African setting must encompass translation from the basic science research through to the clinical implications.

In line with this the ILAE Africa proposed to coordinate a series of schools aligned with key Neuroscience activities eg SONA (2023) and rotating across strategically located settings in Africa for the subsequent 2 years, inclusive of the 2025 African Epilepsy Congress.

Current project

School Title: Implications and implementation of the Intersectoral Global Action Plan for Epilepsy and other Neurological Disorders from basic science to translation into clinical practice.

Organisation name / details: ILAE Africa commission

Venue: Neuroscience Institute, University of Cape Town, AND Red Cross War Memorial Children's Hospital, Cape Town, South Africa

Duration: 7 days 3-9th July (10th July travel Johannesburg for SONA)

Abstract and purpose of school

The aim of the school was to upskill and inspire a group of early career neuroscientists and clinicians from Africa in the translational elements of basic science study for epilepsy and the implications for clinical practice with especial focus on the content of the IGAP. To attain by the end of the course an understanding of how to work in a laboratory based setting and what can be achieved. To be current with key updates in epilepsy terminology in-line with the ILAE recent updates from the nosology commission, as well as exposure to focused teaching via a Paediatric Epilepsy Training (PET) course. To provide direct clinical knowledge through clinical exposure and contributing to grand round discussion as well as observing real time an Electroencephalography (EEG) unit in practice and attending a dedicated Epilepsy clinic. To gain confidence and insight into protocol development via tutor based support of diverse study designs completed and facilitated within small working groups.

Detailed program description and thematic and practical aspects

Day 1: The school started with a **welcome and orientation** session enabling the faculty and students to be familiar with their background experience as well as their scientific and clinical interests and goals. The themes and daily activities of the workshop were explained, the faculty introduced themselves and then each delegate explained who they were, where they were from, their areas of interest and why they wanted to attend the workshop. (they were also invited to tell the group something personal about themselves eg they have children, like football, cooking etc)

The morning followed with the first **conventional didactic lecture** which was delivered by Prof Marc Blockman – head of research and ethics committee for the Faculty of Health Sciences and also a pharmacologist. Prof Blockman addressed the theme of **Research Ethics** – this was highly interactive and led to extensive discussion from the group as many critical ethics and research related activities were relayed and explored with him. After coffee the group were taken through the **relevance of the IGAP** by Prof Wilmshurst – this enabled them to understand the relevance of the program but also to consider how this relates to their projects they were allocated to over the week. After this the **projects were explained** and how the groups would work together, what resources they had access to and what the expectations for the reports would be (as attached). After lunch the group joined an online meeting APFP EEG on the neuroChat platform. The activity occur biweekly via Red Cross Children’s Hospital. With colleagues mainly from Kenya (Nairobi) but also other African countries real time clinical patients are discussed in-line with their EEG findings. Trainees in paediatric neurology at either site (SA and Kenya) critique the clinical information and EEG findings, assimilate a diagnosis and recommend a conclusion / management plan. The delegates enjoyed the session and joined in the discussions and had views on the EEG findings. There was also extensive discussion on the clinical descriptors and interpretation of clinical information in this setting. After this session the **small tutorial groups** (balanced for neuroscientists and clinicians) met with tutors (3-4 each group) and discussed their allocated a **projects**. The tutors facilitated them developing their protocol ensuring that group had access to literature searches, often downloading and sending on key publications and provided guidance on the development of a successful project design. The students had guest access to the UCT library and internet facilities.

Day 2: This was more focused on **basic sciences**, also at the Neuroscience Institute. The day started with a lecture from Prof Joe Raimondo on how to set up and run a **basic science laboratory** and then he was followed by a presentation by Dr Alina Esterhuizen on setting up **genetic studies** and the challenges with bioinformatics interpretation especially in our setting. The groups then met with their tutors again before lunch to discuss and work on their projects further. After lunch they spent the afternoon **in the laboratory** with Prof Raimondo **taking part in experiments** (they really enjoyed this).

Day 3: The group came to Red Cross War Memorial Children’s Hospital. They were shown the **typical hospital layout** and access to care pathways. They were taken to the neurology ward and sat in on the “**grand round**” discussions. Because the group was too large to have on the clinical ward, the families with permission, came to the ward meeting room and described to the group the clinical history and course affecting their child. This was facilitated by the clinicians caring for the children. The group were able to ask the parents questions and gained great insight into caregiver burdens, pressures, challenges accessing health care support and concern over the ongoing health of their child. After this session the group returned to the teaching area at the hospital for 2 special lectures. Colleagues from Oxford University who are part of the EplnA project underway in Africa were visiting UCT and offered their services to deliver talks aligned with the workshop themes. Dr Sloan Mahone presented on the importance of the **oral history** when engaging with our families in healthcare. She eloquently demonstrated the difference between this form of interaction compared to a standard clinical clerking and how this open approach often results in additional and important information being relayed which would not normally be identified. This talk was followed by a presentation by Dr Tim Denison who presented on the

roles of **artificial intelligence (AI)** in potentially enhancing diagnostics in regions lacking specialized resources. He demonstrated his **mobile EEG head set** that he is consistently evolving and how this could be used in the community setting with raw data fed through to central readers but also how algorithms could be developed to aid early interpretation at the entry point to care. The group spent the afternoon rotating between the epilepsy clinic (sitting in on patient reviews) and the neurophysiology lab (seeing EEGs being performed, facilitated by Ms Veena Kander). The day ended with a typical overview of some of the children referred into the service for **epilepsy surgical work-up**. Three typical cases were presented by Prof Wilmshurst, taking the group through referral and presentation features through to assessment and EEG monitoring (often invasive) and finally the surgical interventions and outcomes.

Day 4: This day was fully committed to the **Paediatric Epilepsy Training course**, also at the teaching resource at Red Cross (2nd floor ICH). This is an internationally accredited teaching course, developed by the British Paediatric Neurology Association and accessible for all clinically applied practitioners who would benefit from entry level knowledge in the care of children with seizures and epilepsy. The teaching is based on models of adult learning and provides a certificate of completion. Whilst targeted at paediatrics, the methodology of the teaching and the evidence based approach to care is translatable into other settings and provides a useful starting point for extended care practice. The group were joined by colleagues from the clinical services in the Western Cape – mainly paediatric registrars, APFP fellows, medical officers. The group for this expanded to 35 and was divided onto 5 tutorial groups. 6 faculty were specifically allocated to cover the didactic lectures and small group tutorials – Dr Ndondo, Dr Riordan, Dr Raga, Prof Scher, Prof Wilmshurst, Dr Asikule and Dr Kandawasvika. Dr Asikule was one of the delegates but as she is also a PET faculty teachers she was recruited to join the teaching for the course. The group did very well and completed a pre and post course knowledge quiz. Results are with the BPNA.

Day 5: The students were taken through the ILAE Classification of the Epilepsies (Prof Wilmshurst), Management of epilepsies (Dr Parbhoo), the co-morbidities of epilepsy (Dr Riordan) and epilepsy surgery in resource limited settings (Prof Feiggen). By now they were highly interactive and responsive with multiple questions regardless of main field of practice.

Day 6: Saturday morning was a **networking activity** with students and faculty on the Red Bus – this went around the beautiful peninsula of Cape Town and stopped off for fish and chips in one of the harbor locations. The afternoon was focused on final project presentation preparation.

Day 7: On Sunday the three groups presented (summaries attached) – each project was aligned with one of the IGAP strategic goals using epilepsy as an entry point. Each member of the groups took turns presenting and answering questions from the faculty. Whilst all of the groups were superb assessing for viability, relevance and merit the group allocated to S03 (prevention and promotion) were considered to have the strongest proposal and given a small prize.

Day 8: the group had open access to the Neurosciences facility and wrote up their projects

Day 9: The group departed for the SONA congress in Johannesburg.

Delegate breakdown:

57 applicants were eligible for the course. Based on funding places were offered to 20. After issues with visa, challenges booking flights and ill-health for one, the final number who managed to attend was 13. In addition trainees within the paediatric and adult neurology service, as well as those affiliated to the Neurosciences Institute were able to join the big group sessions.

Final student breakdown

5 were basic scientists and 8 were clinically based across diverse areas. 8 countries were represented. 8 of the group were female.

Name	Country	Clinical (field) / Basic Science	Male / Female
1. Nouran Farag	Egypt	MsC – interdisc, omics and epilepsy	F
2. Mahamadou KOTIOUMBE	Mali	Adult neurology senior reg (interest neurogenet)	M
3. Foutsop Fossueh Aurélien	Cameroon	PhD candidate – animal antiepi models - ethnopharm	M
4. Selam Kifelew	Ethiopia	MD – assistant prog – ep monitoring unit	F
5. Eman Khalil	Egypt	PhD neuroscientist (animal neurotoxicity studies)	F
6. Essoin-De Souza Ahya Nancy Tanya	Cote d'Ivoire	Paediatric Neurologist	F
7. Fils Armand Ella	Cameroon	Post doc PhD - ethnopharmacology	M
8. Mundih Njohjam	Cameroon	Medic (epilepsy clinic) – pending PhD	F
9. Seblewongel Seyoum	Ethiopia	MD –assistant prof – masters in Public Health	F
10. Ceick AbdelKader Cisse	Mali	Neurology trainee and lab assistant	M
11. Adwoa Ansomaa Gyamera	Ghana	Psychiatrist	F
12. Melody Asikule	Zambia	Adult neurologist	F
13. Abbas Nasidi	Nigeria	MSc – masters on IGAP related topic	M

Faculty

Tutorial group balances for tutors – basic science and clinical

Theme / Specialty	Name	Local / base	Role / topics
Basic Science	Joseph Raimondo	UCT / Neuroscience Institute	<ul style="list-style-type: none">• Epilepsy lab models• tutor
Basic Science	Hayley Tomes	UCT/ Neuroscience Institute	<ul style="list-style-type: none">• co-organiser• Epilepsy lab models• tutor
Basic Science	Adhil Bhagwandin	UCT/ Neuroscience Institute	<ul style="list-style-type: none">• Epilepsy lab models

			<ul style="list-style-type: none"> tutor
Basic Science	Alina Esterhuizen	UCT/ Neuroscience Institute	<ul style="list-style-type: none"> Epilepsy genetics setting up NGS tutor
Clinical	Jo Wilmshurst	UCT/ Red Cross	<ul style="list-style-type: none"> co-organiser Broad epilepsy clinical overviews – neonatal classification / treatment / Research in Africa on Epilepsy <i>PET faculty</i> tutor
Clinical	Serini Murugasen	UCT/Red Cross	<ul style="list-style-type: none"> co-organiser
Clinical	Gillian Riordan	UCT/ Red Cross	<ul style="list-style-type: none"> Co-morbidities of epilepsy <i>PET faculty</i> tutor
Clinical	Alvin Ndondo	UCT/ Red Cross	<ul style="list-style-type: none"> <i>PET faculty</i> tutor
Clinical	Kaajal Parbhoo	Nelson Mandela Children's Hospital, J'burg	<ul style="list-style-type: none"> Management lecture tutor
Clinical	Gail Scher	J'burg Gen, J'burg	<ul style="list-style-type: none"> Tutor <i>Pet faculty</i>
Clinical	Veena Kander	UCT/ Red Cross	Chief clin tech EEG – lab teaching / exposure
Clinical	Gwen Kandawasvika	Harare, Uni Zim – current RX paed neuro trainee	<i>PET faculty</i>
Clinical	Graham Fieggen	UCT / Neurosurgery	<ul style="list-style-type: none"> Epilepsy surgery themes Tutor
Clinical	Zeinab Kone	Mali	<ul style="list-style-type: none"> Tutor

Support for delegates:

A detailed Welcome pack was put together by Hayley Tomes (information but also buffs, water bottle and some UCT memorabilia). She also arranged for Guest access to venues and for internet and to enable library resources. Hayley set up a

series of whatsapp groups with students and faculty and used these to prepare everyone and answer questions before and during the school. The students whatsapp group now remains a group for them to stay in touch. Dr Serini Murugasen coordinated the major role for logistics – namely accommodation, transfer, catering etc. Accommodation was booked at Fuller House linked to UCT. Transfers arranged for to and from airport, to and from the teaching venues and pick up and drop off for Saturday outing. Catering over the week fully covered. Guest access for internet and to enable library resources. Gus Egan from ILAE supported with visa letters and advise about reimbursement for flights (to be claimed after the course). Both Hayley and Serini provided acute contact issues during the week of the workshop. The tutors remain a direct contact point for specific learning objective questions and career guidance questions. Talks were saved onto central resource along with the project uploads.



Programme for IBRO-ILAE workshop: 3-9 July 2023

Date	Mon 3 rd	Tues 4 th	Wed 5 th	Thurs 6 th	Fri 7 th	Sat 8 th	Sun 9 th	Mon 10 th
Venue	NI	NI	ICH	ICH	ICH	NI	NI	
8.30-10.00am	08:30-9:30 Welcome /orientation / intro – JW/HT/SM 9:30 Lecture on research ethics – MB	Setting up a successful and relevant basic science lab – JR Challenges to setting up a Genetics service - AE	08:30-09:00 – Tour of RXH - SM 09:00 Neurology clinical grand round (E floor seminar room)	PET course (GR, JW, AN, GS, SR, MA) GR as faculty chair	Classification of the epilepsies – JW Management of epilepsy – KP	Shuttle to pick up delegates at 9am from accommodation and take to Kirstenbosch to meet Red Bus	Project presentations - Faculty to be present	SONA group stays – to use time to write up project reports for submission to organizing committee Non-SONA group departs
Coffee – 10.00-10.30am								
10.30am-12pm	Overview of iGAP – JW Project overview and allocations - JW/SM/HT	Tutorial group – planning projects Project preparation	Platform Science and Ecosystems: Strategies for Designing Bioelectronic Systems – Tim Denison Oral History and the Social Life of Persons living with Epilepsy – Sloan Mahone	PET course (GR, JW, AN, GS, SR, MA)	Epilepsy surgery in practice - GF Epilepsy and neurobehaviour – GR	Morning Red Bus tour, including lunch at Hout Bay	Project presentations - Faculty to be present Close and summations	
Lunch 12-1pm								
1-4pm	1-2pm EEG case discussion via APFP EEG Neurochat – VK 2-4pm Meet your tutor and plan group projects	1-3pm NI lab tour –JR and HT 3-4pm Tutorial group project preparation	1-3pm EEG - VK / epilepsy clinic – AN/SM 3-4pm Epilepsy surgery case examples - JW	PET all day (GR, JW, AN, GS, SR)	Tutorial group – Project preparation	Shuttle to pick up delegates at 2pm at Kirstenbosch and take to NI Project preparation at NI from 3-5pm		
Emergency contact	Hayley – +2773 213 3794	Hayley – +2773 213 3794	Serini – +2773 163 7700	Serini – +2773 163 7700	Serini – +2773 163 7700	Hayley – +2773 213 3794	Serini – +2773 163 7700	

Appendix 1:

IGAP project framework

3 themes based on using epilepsy as an entry point

Strategic Objective 1: Raise policy prioritization and strengthen governance

- **Global target 1.1:** 75% of countries will have adapted or updated existing national policies, strategies, plans or frameworks to include neurological disorders by 2031.
- **Global target 1.2:** 100% of countries will have at least one functioning awareness campaign or advocacy programme for neurological disorders by 2031.

Strategic Objective 2: Provide effective, timely and responsive diagnosis, treatment and care

- **Global target 2.1:** 75% of countries will have included neurological disorders in the UHC benefits package by 2031.
- **Global target 2.2:** 80% of countries will provide the essential medicines and basic technologies required to manage neurological disorders in primary care by 2031.

Strategic Objective 3: Implement strategies for promotion and prevention

- **Global target 3.1:** 80% of countries will have at least one functioning intersectoral programme for brain health promotion and the prevention of neurological disorders across the life course by 2031.
- **Global target 3.2:** The global targets relevant for prevention of neurological disorders are achieved, as defined in:
 - the NCD-GAP;
 - Defeating meningitis by 2030: a global road map; and
 - Every newborn: an action plan to end preventable deaths.

Strategic Objective 4: Foster research and innovation and strengthen information systems

- **Global target 4.1:** 80% of countries routinely collect and report on a core set of indicators for neurological disorders through their national health data and information systems at least every three years by 2031.
- **Global target 4.2:** The output of global research on neurological disorders doubles by 2031.

Suggested approach:

1. Agree on target question / objective / proposal theme
Break up into Work Packages e.g.
2. Current situation / existing literature (WP1) – *enables justification of the topic*
 - a. Decide target need / priority / question to be answered
3. Develop approach to address target need / priority / question to be answered (WP2)
4. Propose process for implementation and building in sustainability (WP3)
5. Monitoring and evaluation (WP4)

E.G. These are just suggestions! (try to accommodate for stigma too / 3,4 & 5 think lab too!)

SO 1: Raise policy prioritization and strengthen governance

1. Does the national body have a policy for epilepsy?
2. What legislation is in place to promote the access to healthcare for people with epilepsy.
 - a. Target need to assess the limitations of current or absence of legislation for access to healthcare of people with epilepsy
e.g, could pick a sub area such as access to reliable supply of ASMs, Generic switches, or ensure access to special school education, balance of community epilepsy care support v tertiary state of the art.. etc
3. What should the legislation consist of? Who are the stakeholders?
4. How should the lobbying and advocacy for passing of legislation and inclusion in national policy be undertaken? How can it be effectively sustained and rolled out?
5. How would you analyse the outcomes (M&E)

SO2: Provide effective, timely and responsive diagnosis, treatment and care

1. Epileptic spasms
2. What is known in South Africa, Africa and globally about presentation, diagnosis and epidemiology. Recommended treatment ..
(evidence)
 - a. How can the care be improved in South Africa for affected patients – it is relevant / justified for the use of the resources
3. Develop approach to early diagnostics tools / treatment – multicentre / national / single centre – decide. Who is in the team
(stakeholders)? Ensure regulatory body approval. Statistician. Methodologist etc
4. Pilot trial to assess data captured (REDCAP?) – tools for pick up eg video links of events, remote EEGs.
5. Monitoring and Evaluation..

SO3: Implement strategies for promotion and prevention

E.G. training school teachers ?? task shifting for CHWs? Stigma ..

SO4: Foster research and innovation and strengthen information systems

e/g. How to set up / optimise an epilepsy research environment in the African setting from bench to clinic, African relevant diseases.

Hand in presentations Saturday pm – deadline 17.00pm

Expected outcomes:

- Presentation 30 mins + 10 mins questions
 - Powerpoint, should be more than speaker
 - Acknowledgement of roles played in project work
- Report – final write up (about 1500 words, ref in addition)

Appendix 2 PROJECTS

SO2

Improving diagnostic capacity of Infantile Epileptic Spasm Syndrome among primary health care providers in African low-income countries

Strategic objective 2 of IGAP: To provide effective, timely and responsive diagnosis, treatment, and care.

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July 2023

[Acknowledgement](#)

We would like to acknowledge our tutors Dr Jo Wilmshurst, Dr Kaajal Parbhoo, Dr Hayley Tomes and Dr Graham Fieggen for their unwavering feedbacks and support. We would also like to give our gratitude to International League Against Epilepsy, International Brain Research Organization and Neurosciences Institute for all the support.

All the team members contributed equally.

[1. Introduction](#)

Infantile epileptic spasm syndrome (IESS) is one of the most catastrophic epilepsies if untreated. It faces a diagnostic challenge given the subtle nature of its clinical manifestations (1). It is a rare form of epilepsy that typically begins in the first 24 months of life. It is however the most prevalent seizure type in the infantile period. IESS is characterized by brief, but frequent, flexion, extension or mixed epileptic spasms which occur in clusters. Early diagnosis within the first three weeks of infantile spasms lead to better management, thus minimizes developmental delays and provides better prognosis. On the other hand, delayed treatment or lag in an intervention results in long term brain damage (2). From this point, early recognition of the subtle signs of IESS can be challenging. It may be mistaken as the movements for normal infantile reflexes or other benign conditions. Encouraging caregivers to be vigilant and report any unusual movements or behaviors to healthcare professionals is crucial (3). In many low- and middle-income countries, including those in Africa, there is limited access to healthcare resources, including specialized training for primary caregivers. This can result in a deficit of knowledge regarding the recognition and management of IESS. Thus, providing caregivers with access to support groups, educational materials, and resources specific to infantile spasms can be beneficial where these resources can offer emotional support, practical advice, and information on the latest research and treatment options (3,4,5,6). The diagnostic gap is defined as the proportion of persons in a population who fulfill the definition of epilepsy but have not been diagnosed with epilepsy (7). Diagnostic gap of 38% was identified in a study done in southeast Nigeria (8). Among the list of reasons given for leading causes of epilepsy treatment gap according to J H Chin, is the lack of primary health workers trained to diagnose and treat epilepsy (9). Diagnostic gaps are identified more in those patients presenting with non-motor symptoms. (10,11)

1.1. Background

Infantile epileptic spasm syndrome (IESS) is a convulsive disease characterized by brief, symmetric/asymmetric axial muscle contraction (neck, trunk, and/or extremities) (12). It is usually followed by developmental delay or regression. IS often occurs during the first year of life and has an incidence of approximately 2 per 2000-4000 live births. Early diagnosis and management of IESS result in better seizure control and long-term neurodevelopmental outcomes (13;14). The diagnosis of IS is often made by a clinical examination having as objective the identification of its characteristic seizure type. EEG (presence of hypsarrhythmia) is often used to confirm the clinical diagnosis, and in case any structural abnormality is suspected, neuroimaging (especially MRI) is used as a diagnostic/confirmation test. Finally, in case clinical examination or EEG raises suspicion of genetic disorder, a target genetic testing is used (15). These facilities and degree of expertise are however lacking in developing countries. The paucity of pediatric neurologists and the presence of insufficiently trained healthcare givers are reported challenges in these countries. Ultimately, Challenges with the management of infantile Spasms in developing countries are lack of awareness and accessibility to adequate diagnosis tools (13). In order to meet up with this gap, scientists and clinicians have developed strategies to provide better management of IESS. One of the first strategies was the implementation of strict interprofessional communication. As such, coordination between general pediatricians, pediatric neurologists, nurses, pharmacists, and therapists was established, parental education (including nursing) was also initiated (12). In addition, parents and caregivers are increasingly encouraged to capture videos of spasm related behavior so as to ease accurate diagnosis (16). There is also a gap in accessing definitive data on infantile spasm diagnosis and treatment regarding Africa. The lack of information is not only for infantile spasms but also for other childhood epilepsies.

2. Aim and objectives

2.1. Aim:

This proposal aims to facilitate point of entry diagnosis for infantile epileptic spasm syndrome by primary health care providers including training and support related to early diagnosis and pathways to care

2.2. Objectives:

1. Increasing the capacity of primary care providers in recognizing infantile epileptic spasms at an early stage.
2. Raising awareness for primary care providers in the community on infantile epileptic spasms.
3. Developing an interdisciplinary care system for infants with infantile epileptic spasms
4. Develop the framework to capacitate point of entry for infants with epileptic spasms to receive early and targeted intervention

3. Integrated care pathways

Proposed Actions:

We have divided our proposed actions into three phases. The first phase is using education to address the gap. The next two phases will focus on how we can improve and precisely tackle the gap with the latest inventions the world has to offer.

3.1. Combining Several Levels of the Health and Social Care System (17)

- Training medical professionals to provide care in the community and to increase access to epilepsy services is highly valued where task-sharing methods can be used to maximize the usage of the workforce when resources are limited.

- in order to find chances for implementing prevention, early diagnosis, and the treatment of infantile epileptic spasms, integrating education on infantile epileptic spasms
 - During immunization visits,
 - Other outpatient visits
 - High risk clinics or neonatal follow up clinics,
 - Midwives, primary health care workers or traditional midwives

The STOP toolkit that was designed for community awareness in 2019 on infantile spasm awareness week (ISAW2019) can be adopted for educating parents during these mandatory immunization visits or wellness check visits and high risk neonatal follow up clinics. We can also make use of the video images as health education tool at the waiting areas of these clinics.
- Using interdisciplinary care teams, medical health records, and referral systems.
- Integration of the training into standard existing teaching framework such as IMNCI (Integrated management of neonatal and childhood illness) and continuous professional developments.

3.2. Recommended Teaching Tools:

1. Introducing mini course on infantile epileptic spasm diagnosis in primary healthcare training program:(small group discussions based on videos)
 - a. Recognizing symptoms and diagnosing infantile epileptic spasm
 - b. What to do next: referral to a set up where infantile epileptic spasms needs to be treated

The training materials are to be prepared by Pediatric neurologists and health education experts. Training can be done by specialists initially and as the project is rolled out to the vast professionals, training trainers can be considered.
2. Creating interactive blogs or websites, and you tube videos
3. Creating Chat groups (Facebook, WhatsApp) for discussions. Making use of a formal plat form for communication either with parents to health professionals or health professionals to specialists such as vcreate.tv can be adopted for the project.
4. Teleconsultation with either specialist (pediatrician, neurologist or pediatric neurologists for consultation on difficult cases (availability of appropriate green numbers).

3.3. Expanded Opportunities to involve the rest of our community

Since it is beyond the scope of this project, we recommend community awareness deliberations on infantile epileptic spasms by using:

1. Community talks (regular awareness programs in internet-deprived areas, educating parents)
2. Working with community leaders, religious leaders, village chiefs, media influencers (make it viral on the internet)
3. Radio shows/ Newspapers
4. Early morning or late-night TV shows with endorsement by ministry of health: getting a parent with infants treated/untreated for epileptic spasm to tell their story.
5. Celebrity ambassadors for the cause

3.4. Artificial Intelligence and Computational Approaches for infantile epileptic spasms syndrome (18)

We are unable to connect neuronal activity to more advanced physiologic and pathologic behavior because of our incomplete understanding of how networks in the nervous system operate hence artificial intelligence and computational approaches will provide us this technology. Hence, in our study we classified this approach into two classes which are:

A. Digital Health Solutions B. Neuroinformatics

3.4.1. Digital Health Solutions

- Expanding and implementing digital health solutions, mainly epilepsy bed sensor, wearable sensors, videos cameras
- Use of non-invasive mobile EEG and portable EEG as a seizure monitoring tool in infantile epileptic spasms.

One of the problems we should pay our attention to is making digital health 'solutions' sustainable in health care system where the Sustainable Healthcare National Health Service (NHS) England team's change strategy does this by incorporating four pillars of insight **(19)**.

Pillars of Insight

1. Clinical understanding is the first of these foundations. The ultimate goal is to assist the provision of improved healthcare to the purpose; changes that do not advance this goal or that obstruct it won't last in the long run.
2. Behavioral understanding is the second pillar. In order to comprehend how people may react to new services or technology, this draws on a variety of disciplines, including psychology, sociology, and data sciences. As a result, "behavioral derisking" can be used to anticipate implementation issues by taking end users' feedback into consideration during the early stages of design.
3. Engineering of processes is the third pillar. Here, it's important to make the process of implementing new technologies or services as clear, uncomplicated, and understandable as feasible. People can be sure that if they adhere to the process phases, they will frequently produce the desired results. Additionally, it aids in directing context adjustments to ensure that a new technology or service may be offered successfully.
4. Finally, knowledge management offers important insight into the facts supporting the need for change and the most effective ways to implement it.

B- Neuroinformatics

A new digital modeling tool called personalized virtual brains uses MRI data to map the brain network of an epileptic person and it will enable us to personalize and individualize therapy. With the help of this method, seizures and brain imaging signals can be simulated on a computer. The extent and organization of the epileptogenic zone can be estimated using virtual brains in combination with machine learning. In the future, virtual brains may be utilized for clinical decision-making, to increase seizure localization accuracy, and for surgical planning **(20)**.

3.5. Basic Research in tackling infantile epileptic spasms syndrome (21)

- Customized Kits for evaluating Blood-Based Brain biomarkers
- Customized Kits to test whether those children will propose to have Drug-resistant epilepsy based on the mutations known for certain population

4. Target area of the project:

- Piloting will be done where there is a committed team that is inclusive of clinicians, educational experts, statisticians and ministry of health. The whole project envisions all capable countries to be involved.

5. Stakeholders

- 1- Education tool implementation: pediatric neurologists, neurologists, pediatricians, health education experts, social scientists to navigate community culture and how to address different communities.
- 2- Methodology and data analysis to be done by statisticians or public health experts.
- 3- For the project to be equally and equitably executed nationwide the Ministry of Health is a vital asset.
- 4- Since the project if done properly directly meets the strategic objectives of IGAP, the World Health Organization is another strong arm to implement this project.
- 5- Organizations with main focus of brain health such as International Brain Research Organization will play a major role in realizing this project.
- 6- Organizations with main focus of supporting epilepsy awareness and care worldwide such as International League Against Epilepsy are invaluable to implement this project.

6. Limitations

- We might face difficulty in teleconsultation in those areas with unreliable networks.
- The need to have a formal platform for case discussions due to data privacy, accountability and consistent monitoring.
- The responsiveness of specialists for the consultations they might get should be clearly communicated not to miss the time window
- Monitoring depends on the meticulousness of health information recording system which may be lacking in most African setting
- Phase 2 of the project needs dedicated specialized human resource and technologies which may be expensive
- This project focused on the early diagnosis, treatment and care. We believe that promoting awareness in the community specifically parents should be worked on hand in hand with equipping the primary health professionals to ultimately fill the delay gaps in every step.

7. Ethics compliance: Informed and written consent according to Helsinki, for data collection and sharing

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IBRO-ILAE WORKSHOP REPORT

STRATEGIC OBJECTIVE 3: TO IMPLEMENT STRATEGIES FOR PROMOTION AND PREVENTION

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Sharp Minds: Breaking Stigma and Promoting Brain Health among Adolescents with Epilepsy in Africa

1. Definitions

- **Stigma:** Negative social attitude attached to a characteristic of an individual that may be regarded as a mental, physical, or social deficiency.
- **Brain Health:** State of brain functioning across cognitive, sensory, social-emotional, behavioral, and motor domains, allowing a person to realize their full potential over the life course, irrespective of the presence or absence of disorders.
- **Target population: Adolescents (Teenagers)**

Adolescence is the phase of life between childhood and adulthood, from ages 10 to 19. It is a unique stage of human development and an important time for laying the foundations of good health. Adolescents experience rapid physical, cognitive, and psychosocial growth.

2. Current situation

2.1. Burden of epilepsy – globally, sub-Saharan Africa

Epilepsy is a neurological disorder characterized by recurrent unprovoked seizures. It affects more than 50 million people worldwide with 80% living in low- and middle-income countries (LMICS) (Stelzle et al., 2022). In Africa, more than 25 million people have epilepsy and have the largest treatment gap (Nicholas, 2023). Health, sociocultural, economic, and psychological consequences increase this burden (Agbetou et al. 2023). 2

2.2. Epilepsy and Stigma in Africa

Epilepsy remains a stigmatized disease, stemming from traditional African beliefs which view epilepsy as a spiritual disease. Lack of information and illiteracy has also been implicated. Due to its chronic nature and associated taboos, people with epilepsy (PWE) frequently experience stigmatization, marginalization, and overprotection (Magnerou et al., 2023, Agbetou et al., 2023). Epilepsy becomes a social condition due to family and social isolation. In Africa, levels, and types of stigma vary among countries. Stigma against PWE can be found in various situations (Figure 1).

Figure 1: Where do we find stigma? (Adopted from the International Bureau Against Epilepsy Advocate's Toolkit for Reducing Epilepsy Stigma in Africa).

The epilepsy treatment gap is largest in Africa, and this problem is compounded by the ongoing social stigmatization of PWE, making it difficult for them to find work, have relationships, or feel appreciated. Stigma has psychological consequences as well as serious repercussions on the quality of life of patients.

2.3. The impact of stigma among adolescents with epilepsy (AWE)

AWE experience unique challenges:

Education: AWE start attending school late, miss more school days, repeat more classes, don't progress beyond their entry classes, or never attend school at all.

Social life: AWE have reduced self-esteem, tend to be overprotected leading to reduced social 3

interaction with peers and increased vulnerability for physical and sexual abuse. They are also excluded from reproductive health education and services.

Mental health: They face comorbid mental health conditions associated with epilepsy itself or the anti-seizure medication such as learning difficulties, memory deficits, and behavior and mood disorders.

3. Strategies for preventing stigma and promoting brain health among adolescents

Implementation of the following strategies may aid in preventing stigma and promoting inclusivity among AWE:

3.1. Establishing Support Networks

Development of comprehensive educational programs to increase public understanding of epilepsy. Campaigns should debunk myths, provide accurate information about epilepsy, and emphasize that epilepsy does not define a person's capabilities or worth (WHO, 2022).

3.2. School-based initiatives

Schools play a vital role in fostering an inclusive environment. It is essential to educate teachers, students, and staff about epilepsy, dispel myths, and promote empathy and acceptance. Organization of training programs to teach students how to respond appropriately during a seizure and address bullying. Additionally, it is essential to conduct extensive future surveys in educational institutions to evaluate the impact of the academic setting on how children with epilepsy perceive stigma (Vinayan, 2006; Adewuya, et al., 2006; Kirabira et al., 2020, 2018).

3.3. Individual empowerment

Encouragement of active participation in managing their condition by healthcare professionals. Teaching self-advocacy skills and building self-confidence by schools, health services and epilepsy advocacy groups. Access to information about available opportunities such as for 4

training and employment, and inclusion in social and professional activities (Caraballo and Fejerman, 2015).

3.4. Media Campaigns

Social media epilepsy awareness groups created and monitored by epilepsy advocacy groups. Creating radio and TV content tailored to adolescents' needs. Celebrity endorsements and use of digital technologies e.g., mobile apps for epilepsy education and monitoring (WHO, 2022).

3.5. Active involvement of Healthcare Professionals

Promote training of healthcare providers in epilepsy matters. Addressing misconceptions, promoting epilepsy awareness and destigmatization efforts. Supporting AWE and families in managing psychosocial effects. Build regional and international clinical networks to exchange expertise and provide support, particularly for cases of rare types of epilepsy (WHO, 2019).

3.6. Deliberate Governance and policy frameworks

Develop protocols for the integration of epilepsy care for AWE. Review of legislation, policies, and institutional practices, for delivery of first aid, social inclusion, gender equity, and human rights. Create dedicated governmental budgetary allocations for AWE and provide consistent funding for hard-to-reach populations. Promote local research into traditional medicine and practices for epilepsy (WHO, 2015).

4. Our Project: A school-based initiative - BRAINY DAY

- Brainy Day - an epilepsy and general brain health information day to be held during or around International Epilepsy Day or alternatively incorporated into the Brain Awareness Week.
- A four-country collaboration involving Cameroon, Côte d'Ivoire, Egypt, and Zambia.
- The initial pilot project will be held at two schools per country: 1 urban and 1 rural.

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Aim: To design a unique and fun school-based epilepsy information day that will appeal to the adolescent population. If feasible and acceptable, can be hosted annually and expanded, or incorporated into other neurological disorder awareness days/ weeks.

4.1. Objectives

1. Raise awareness and understanding of epilepsy among adolescents, families, and communities.
2. Correct misconceptions and myths about epilepsy in the community
3. Encourage openness, self-advocacy, and empowerment among adolescents.
4. Promote brain health and general well-being among AWE.
5. Strengthen support networks and community involvement in the care of AWE.

4.2 Proposed timeline and project workflow

Duration to event

Duration to event	Activities
12 months	Stakeholder Engagement Establish collaboration with ILAE and IBE country chapters. Meet Government Health and Education directors, teachers, and parents. Assess knowledge and attitudes. Select pilot schools
4 months	Pre-Event Training Epilepsy training workshops for teachers and selected learners at pilot schools. Assess target learners' knowledge and attitudes.
2 months	Event promotion Event promotion through radio, TV, social media, posters, skits by school drama clubs

Day 0
2 months
12 months

BRAINY DAY
Event Evaluation
Handbook and
Toolkit

Several activities
Post-event knowledge and feedback questionnaires from pilot schools.
Development of handbook and awareness day toolkit

SO4



IBRO-ILAE school: Integrating and understanding the IGAP in relation to epilepsy care in Africa

SO4: Foster Research and Innovation and Strengthen Health Information System



PED-R

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