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ILAE Chapter Convention Report

International League Against Epilepsy

ILAE Chapter Convention 2023

2 September 2023, 10:00-12:00 IST
Convention Centre Dublin, Wicklow Hall 2A

EPI-ACT Plans

Regional breakout groups were asked to consider how best to develop individual Chapter epilepsy action (EPI-ACT) plans to support the implementation of the Intersectoral global action plan on epilepsy and other neurological disorders (IGAP) over the next two years. Groups were also encouraged to address how regional and global support is needed across each of the six main EPI-ACT areas.

Engagement

Engage with governments and partner organizations to agree upon and work towards achieving regionally relevant and realistic targets for the expansion of epilepsy service coverage.

Plans

Develop or revise national health plans and investment for epilepsy services, prevention practices, and research.

Information

Routinely collect information and core data about epilepsy for health service planning and research.

Access

Address access to treatment, including public awareness, medication availability and increased reach.

Care pathways

Build integrated, people centered, and evidence-based care pathways and service models.

Training and education

Identify gaps and expand nation-wide training and education at all levels, from community health to primary and specialist care.

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ILAE-Europe

Group 1	Group 2
Moderator: Matthew Walker **Staff member:** Kathryn Hodgson	**Moderator:** Eugen Trinka **Staff member:** Laurie Beninsig

Engagement

Noted engagement with politicians is challenging due to turnover every four years.

Brainstormed connection strategies, such as through patient organizations and official events (conferences, structure openings), as well as by establishing long-standing relationships with civil servants in the Ministry of Health.

Emphasized the importance of active Chapter involvement, rather than waiting for politicians to act.

Highlighted the amalgamation of engagement, plans and care pathways as interlinked strategies.

Advocated for collaboration with patient groups, acknowledging their influence on government decisions.

Highlighted the potential of utilizing care pathways as a starting point for engagement with the government.

Plans

Highlighted the heterogeneity of healthcare plans among the group.

Cited a best practice example from the Netherlands where education, research and patient care were closely linked in epilepsy centres, initiated by the society, not the government.

Stressed the need to link education, research and patient care to provide an effective plan.

Recognized the difficulty of engaging with governments directly, proposing the use of care pathways to initiate discussions.

Emphasized the importance of collaborating with patient groups, especially those with wider representation like the International Bureau for Epilepsy (IBE), and exploring partnerships with other neurological societies for a stronger voice.

Information

Noted the lack of reliable healthcare data in some European countries.

Highlighted the challenge of GDPR and data protection, suggesting political negotiations or scientific projects to overcome the issue.

Mentioned ongoing projects shedding light on the epidemiology of different countries (Portugal, Turkey, Austria) to contribute to global burden studies.

Stressed the need for resources to examine existing databases and create registries where they do not exist due to a lack of information in many countries.

Recognized the need for assistance from organizations like IBE for accessing resources and enhancing information databases.

Access

Advocated for essential healthcare pathway building for better access.

Cited examples from NASH and EuroNASH studies as starting points for improving access.

Raised issues of diagnostic barriers and the need for reliable data to address disparities in health services.

Noted problems with the distribution and production of medications, suggesting collaboration with industry to encourage local production for improved access.

Suggested setting up hubs in Europe to facilitate access to medicines.

Care Pathways

Stressed the essential triangle between education, clinical service and research to be implemented in all aspects for effective healthcare strategies.

Emphasized the preventability of many epilepsy cases and the importance of early treatment.

Noted brain health as a key message, advocating for early detection of epilepsy through specialized clinics and a focus on prevention.

Proposed the creation of three or four templates, possibly provided by the ILAE, to aid in the development of care pathways.

Training and Education

Recognized challenges in human resources but encouraged seeking structures and asking for resources.

Cited examples from Turkey where clinical practice guidelines on a national basis were implemented, emphasizing the importance of education in building a care network.

Acknowledged the existing curriculum and emphasized the need to implement it in various countries.

ILAE-Africa

Moderator: Jo Wilmshurst
Staff member: Gus Egan

Engagement

Recognized engaging with the government as an ongoing issue.

Explored innovative engagements, such as tapping into infectious diseases resources for better acceptance and capacity.

Gave examples of training workshops as an effective way to engage people, especially those already involved in infectious diseases programs.

Addressed the ongoing barrier of navigating through red tape, not only with politicians but also in engaging with the Ministry.

Plans

Emphasized the need to improve national plans.

Information

Pointed out the absence of helpful, cohesive information on epidemiology across Africa, calling for improvement.

Stressed the need for registries to better understand challenges with access to services.

Highlighted disparities in health services, emphasizing the importance of improving skilled staff, diagnostics and therapeutics.

Access

Identified barriers to accessing diagnostics, including their non-existence, high costs and unreliability.

Emphasized the misconception that metabolics and genetics are unnecessary in the African setting, advocating for equal consideration for children and adults affected by epilepsy complications.

Care Pathways

Acknowledged issues in both diagnostic and treatment gaps, driven by factors beyond facilities, such as financial constraints.

Discussed considerations in scheduling appointments, being sensitive to patients' financial situations.

Training and Education

Highlighted training as a critical issue, advocating for tailored training in Africa that is appropriate to local needs and supports sustainable care.

Encouraged the promotion of regional centres of excellence and collaborative research driven by Africans to ensure broad and accurate data capturing.

ILAE-Latin America

Moderator: Mario Venegas
Staff member: Alicia McNeely

Engagement

Recognized the challenges in dealing with political and economic differences across Latin American countries.

Emphasized the need to engage with Pan-American organizations, national governments, and global entities like the World Health Organization (WHO) to address medication price disparities.

Plans

Highlighted the absence of epilepsy laws in many countries and the importance of establishing and improving them.

Proposed efforts to disseminate information to the general population through web platforms, videos, etc., to raise awareness of regional disparities.

Information

Stressed the importance of sharing information to bridge the medication gap and the need for a collaborative relationship with global organizations.

Addressed the diverse resources and availability for medications across the region, emphasizing the significance of making information accessible to everyone.

Access

Acknowledged the challenges in approaching politicians but highlighted the community’s role in making efforts to address issues.

Advocated for engaging politicians to bridge the gap in medication availability and pricing.

Care Pathways

Mentioned the importance of education, especially for primary care and general practitioners, to enhance knowledge and understanding of epilepsy.

Encouraged collaboration with IBE, recognizing their close connection to society and the potential for a fruitful partnership.

Training and Education

Recognized the lack of epilepsy education for non-neurologists in Latin America.

Emphasized the need to pay attention to education, particularly for general practitioners.

Appreciated the initiative of creating good books for epilepsy for non-neurologists and urged the pursuit of such initiatives.

ILAE-North America

Moderator: Jaideep Kapur
Staff member: Priscilla Shisler

Engagement

Advocated for engaging patient communities as a crucial aspect of epilepsy care.

Highlighted the American Epilepsy Society’s Epilepsy Leadership Council, consisting of 20 patient organizations collaborating for advocacy.

Emphasized the importance of patient engagement in political advocacy, stating that patients can advocate with any politician, irrespective of political affiliations.

Plans

Acknowledged the transient nature of politicians but stressed the enduring advocacy power of patients.

Proposed having at least one epilepsy advocate in each of the 17 Caribbean countries to push forward the IGAP plan.

Recognized the significance of a patient being the face of advocacy efforts before politicians.

Access

Addressed the similarity of access challenges across regions, noting that even in countries like Canada, issues persist if individuals are not working.

Highlighted the need to collaborate on access issues globally, as challenges are comparable in the Caribbean, the US, and other regions.

Care Pathways

Acknowledged the need for adapting care pathways provided by LA (presumably Latin America) for implementation in their region.

Discussed the board’s decision to focus on six topics related to epilepsy care each month for better progress monitoring.

ILAE-Asia and Oceania

Moderator: John Dunne
Staff member: Nancy Volkers

Engagement

Acknowledged the challenges with corrupt politicians in the region but stressed the necessity of engaging with them.

Recognized the political nature of advocating for epilepsy care, noting that politicians like to be seen doing good and cutting ribbons.

Highlighted the potential for engagement with the WHO and emphasized the need for local solutions and state programs, rather than just national plans.

Information

Acknowledged the significance of research output whilst encouraging professionals to value and publish their work seriously.

Access

Addressed the challenges of living in different geographical areas, emphasizing the need for equitable models that enhance accessibility.

Encouraged the use of telephone communication, especially for patients in rural or regional areas.

Stressed the importance of knowledge for optimizing the use of antiseizure medicines, emphasizing that a smaller selection, when used well, can serve the majority effectively.

Care Pathways

Emphasized the patient-centric approach and the importance of having relevant and situation-specific care pathways.

Highlighted the foundational role of clinical diagnosis and engagement with families in treating epilepsy effectively.

Training and Education

Emphasized knowledge as power and identified education, particularly of communities, as the primary focus.

Stressed the importance of educating individuals who may become politicians, primary caregivers, community nurses, general practitioners, paediatricians and neurology trainees.

Urged the promotion of epilepsy as an attractive field, encouraging neurology trainees to consider it as a meaningful career path.

ILAE-Eastern Mediterranean

Moderator: Ghaieb Aljandeel
Staff member: Julie Hall

Engagement

Highlighted the frequent change of politicians in the region every four years, creating challenges in implementing consistent medical plans.

Emphasized the need for dynamic engagement strategies due to the changing individuals involved, making ongoing efforts essential.

Plans

Addressed the need for action despite challenges, emphasizing the importance of not remaining silent.

Acknowledged deficiencies in the history of epilepsy and the need for improvement in proper documentation.

Information

Identified a deficiency in information, particularly regarding the history of epilepsy, creating a problem in understanding the condition comprehensively.

Access

Recognized the availability of drugs but pointed out affordability issues, indicating a gap in providing accessible medication.

Highlighted deficiencies in technology, specifically mentioning the shortage of trained technicians for EEG and video EEG, impacting accurate diagnosis.

Care Pathways

Focused on the diagnostic challenge of determining whether a condition is epilepsy or not, emphasizing the importance of addressing this issue.

Pointed out the deficiency in trained technicians as a critical problem, highlighting the need for training sessions to address the shortage.

Training and Education

Discussed the multifaceted nature of epilepsy, mentioning the involvement of various specialists, with a particular focus on the challenges posed by neurosurgeons.

Emphasized the need for education programs, stating that money should be directed towards educating people rather than solely seeking financial support from external sources.

ILAE-Online

Group 1	Group 2
Moderator: J Helen Cross **Staff member:** Jessica Norvell	**Moderator:** Roberto Caraballo **Staff member:** Alma Paéz Lynch

Engagement

Noted diverse representation from Saudi Arabia, Turkey, Pakistan, Australia, Azerbaijan, the Caribbean (with Trinidad), Romania, Mongolia, Russia, and Colombia.

Highlighted engagement strategies with governments, particularly through the use of non-governmental organizations, and the effectiveness of IGAP as a tool to initiate conversations with ministries.

Plans

Mentioned the abundance of highlighted points across different regions, showcasing commonalities and shared experiences.

Access

Recognized the availability of drugs but pointed out affordability issues, indicating a gap in providing accessible medication.

Highlighted deficiencies in technology, specifically mentioning the shortage of trained technicians for EEG and video EEG, impacting accurate diagnosis.

Care Pathways

Recognized the significance of developing standardized care pathways, indicating their potential as a tool for discussions with governments.

Training and Education

Acknowledged the importance of training, especially online training and webinars, with a noted dramatic increase in participation across different regions.