

## **What next for ILAE? Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders and ILAE Strategy 2030 (A Guekht, Treasurer)**

- September/October 2021 – a round of consultations with Health Ministries
- Chapters are requested to advocate on behalf of the IGAP to their MoHs in advance of that
- Revised draft will be submitted for review at the 150<sup>th</sup> session of the WHO Executive Board
- Final draft will be presented to the 75<sup>th</sup> World Health Assembly in May 2022 which will also be preceded by another round of consultation with MoHs
- Actions for Member States:
  - Ensure that PWE are reflected in health policies that will develop/strengthen services and address gender/diversity equality
  - Develop/strengthen legislation for PWE
  - Facilitate community initiatives on epilepsy

## **ILAE Moving Forward (H Cross, President Elect)**

- Evidence: is there a problem? What can make a difference?
- Education: virtual learning. Workshops/webinars/congresses
- Advocacy: Working in partnership with patients/other organisations. Lobbying and discussion with governments/WHO – IGAP
- Tools: Research; Validation
- There is no reason why the IGAP 90-80-70 target cannot be met in the next 10 years
- Strategy 2030 has been developed and is underpinned by
  - risk management, accountability and reporting
  - guiding principles: Impact, Co-operation, Excellence, Integrity and Inclusion
  - 5 goals: (1) Standards & Best Practice, (2) Education and Development, (3) Organisational Viability, (4) Research and Innovation, (5) Advocacy
- 5 Councils have been established to ensure continuity and deliverance of the Strategy:
  - Standards & Best Practice
  - Education Council
  - Global Advocacy Council
  - Congress Council
  - Publications Council
- New Topic Commissions:
  - Equality, Diversity and Inclusion
  - Career Development
  - Big Data
  - Older People
  - Climate Change
- Continuing Topic Commissions:
  - Diagnostics
  - Epidemiology
  - Genetics
  - Medical therapies
  - Neurobiology
  - Psychiatry
  - Paediatrics
  - Surgery
  - Terminology

### **Breakout Group 1: Congresses**

#### Question 1: What is currently good about what we do?

- Communication
- On demand content
- Costs have been lowered
- Courses, interest groups, networking/catching up
- Specialised/novel information

#### Question 2: Where could we improve?

- Increasing accessibility of information.
- Tailoring content to audience/region. More specialized/novel content. Rotate/include new speakers
- Review educational goals to see which served better by virtual or F2F or hybrid
- Facilitated Q&A in longer sessions
- Group delegates by area of interest / more networking
- Subtitles in English. Provide translations for some key take homes/documents
- On-demand content available sooner
- Limit virtual overload and competing with our own events
- Registration process – m-anage system, payment

#### Question 3: Three priorities for the next two years?

- Reviewing offerings, rationale for all events, targeted at the provider level, appropriate time for interaction.
- Collaboration with other international groups
- Language delivery/access
- Review registration fee structure, process
- Make it clear what delegates will get out of sessions/presentations
- Find balance of virtual and F2F. Survey to determine appetite for content
- Build networking strategy

### **Breakout Group 2, Journals: How to get published and supporting more publications from countries facing challenges**

#### Question 1: What is currently good about what we do?

- Implementation of guidelines and reports
- Timeliness of publication
- Availability of three journals with distinct mission, teaching materials etc.

#### Question 2: Where could we improve?

- Communication about availability and missions of journals. Publicise the fee structure better to lower income countries
- Guidelines need to be adapted to resource levels of the different countries. More leniency and inclusiveness
- Clinically important articles representing different regions (both low & high-income countries)
- Improve definition of our journals that aligns with topics/curricular

- More articles about public health issues (IGAP), stigma and advocacy
- Add more categories of materials (videos, electrophysiologic, neuroimaging)
- Have new topic oriented to summarize a new field.
- Wikipedia: creation of taskforce for recognition to those who put effort in it.

Question 3: Three priorities for the next two years?

- Articles that are more regionally representative
- Broaden scope/topics of articles

**Breakout Group 3: Expanding our Education and Training Programme**

Question 1: What is currently good about what we do?

- CME
- Creation of programs / educational activities

Question 2: Where could we improve?

- Assess local needs before creating content for virtual education
- Reduce Congress fees further
- Examine Hybrid meetings for the future
- Tailor to needs of h/care professionals at different levels and disciplines: trainees, nurses, primary care, neurosurgeons, neurologists. Educate teachers in schools e.g. Argentina/Venezuela initiatives
- Electives in medical schools making epilepsy more attractive. Post graduates: provide papers to universities through the ILAE. Neurology residents need to focus more on epilepsy
- Promote education through Chapters / Primary Care
- Homogenous courses/modules that can be used by all Chapters for National Meetings e.g. EEG courses
- Ketogenic diet: using local/regional ingredients/foods
- Address CME requirements in every country

Question 3: Priorities for the next two years?

- CME and Congresses
- Respond to feedback and adapt to local needs
- Outward looking
- Epilepsy Surgery

**Breakout Group 4, Shared Interest Groups: Connecting and Coordinating**

Question 1: What is currently good about what we do?

- ILAE is well organized; structure is well developed
- Focusing on other aspects of epilepsy care through interest groups
- Diversity and popularity of various groups
- The top-down approach has been valuable and has advantages.
- ILAE website is most valuable for identifying specific diagnoses. Great tools on the website
- Communication (email, newsletters, etc.) is helpful re Task Forces, etc.

Question 2: Where could we improve?

- Create more sections and provide sessions at Congresses for them e.g., clinical pharmacology, nurses, technicians with clear definitions so interested parties can join
- Effective communication within and between sections: regular meetings, democratic votes, connecting desires, new graphics e.g., for mental health
- Addressing different language needs
- Commissions: more volunteering, less appointing. More regional balance.
- Be more proactive in requesting input from individuals re open comments on papers, discussion (perhaps region-based).

#### Question 3: Priorities for the next two years?

- Congress sessions and sections for nursing, technicians, neurosurgeons, patient representatives, parents, occupational therapists
- Be more inclusive at the Chapter level. Able to better make recommendations and connections as it relates to operating procedures e.g., presenting Chapters in the ILAE newsletter; highlighting successes
- Strengthening communication of activities and having more regular exchange of ideas/meetings.
- Providing public review process to regions as an opportunity to react in a proactive way. Allowing comments in native languages to improve dialogue and accessibility.

#### **Breakout Group 5, Addressing Stigma, Exclusion and Discrimination**

##### Question 1: What is currently good about what we do?

- Demonstration projects and joint work with IBE
- SUFE, 2019 Global Report and 2022 IGAP
- Patient's Forum and Patient Education
- Stigma Task Force. Four systematic reviews: tools, factors, frequency, intervention

##### Question 2: Where could we improve?

- Conduct a global review and focus on cultural, linguistic and religious factors
- Multi language translation tools
- Address gender related issues for women
- Improve legislation further
- Set up a Stigma Working Group within Advocacy Council
- Education programs for the public and teachers/police/firefighters
- More focused social media

##### Question 3: Priorities for the next two years?

- Advocacy, policy, planning, legislation, service provision, monitoring and research in epilepsy
- Sustained evidence-based strategies with partnership
- Employment Law
- Viral Campaign with celebrities who have epilepsy

#### **Breakout Group 6, Communication**

##### Question 1: What is currently good about what we do?

- Webinars

- Podcast

Question 2: Where could we improve?

- Accommodate languages other than English
- Accommodate more time zones for live webinars especially in Asia which spans 7 time zones
- Dedicated communications for different segments within epilepsy
- Dedicated communications for low resource settings
- More social media posts to promote the webinars. Infographics and videos
- Balance between virtual and F2F meetings

Question 3: Three priorities for the next two years?

- Partnering with other organisations
- Inclusiveness
- Targeted communications for AHPs etc