PRESIDENT’S REPORT

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ILAE Executive Committee January 2021
Overview

Organizational-Structural
Engaging our Constituency
Finances
Global Actions-Liaisons
Publications/Communication
Education
Special Projects
Challenges
First Things First – Who actually did the work

Over 40 Working groups
Over 600 top professionals
All over the world
All walks of life
All busy in their own careers and institutions
All volunteers
All can’t be thanked enough
Organizational - structural

Key Achievements

- Congresses, Education, Global Advocacy, Publications
  - Standing entities, Strategic aims
  - Advise the Executive
  - Short and long-range planning
  - Continuity

- A League’s First
  - ‘Working as one’ - Consolidation of staff, finances, accounting, processes, human resources
  - Risk Management
  - Liaisons to other organizations
  - Organizational strategy

- A changing world
  Amendments to reflect:
  Organizational entities, Publications, Membership, New Realities

- Our own company
  Transition from Chancel
  Not only Congresses
  Gained efficiencies

- 10-year plan
  5 Goals
  3 cross-cutting themes
  5 Guiding principles
  3 Implementation Frameworks

- Constitution by-laws

Councils
Ilae secretaria
Executive director
Strategic plan
Constitution by-laws
engagement

Key Achievements

Self-organized groups work!
Global platform for specific groups
Foresee as large growth area
YES, Nursing, Social Work

Next generation

A new way of reaching out
Membership counts
Benefits and responsibilities
Attention to Chapter strengthening

Ilae sections

-reaching out - in

Individual affiliation

-chapters

Young Epilepsy Section YES
-Leadership training
-Mentor-Mentee
-Translation, local courses, Bursaries
-Representation in Boards, Councils, organizational entities
-Regional and country liaisons

-Many epilepsy professionals remain poorly engaged
-Early career professionals have been poorly represented and supported
-Allied Health Professionals are key to epilepsy care, education, research

Our Constituency
-Dedicated support
-Membership staff for chapters and individuals
-Regional support
Global actions – **ILAE-IBE**

**Signed agreements for collaboration**
- Int Neuropsychol Soc
- Int Fed Clin Neurophysiol
- Eur Acad Neurol
- BPNA (PET), J Neurosc Council (eBrain)

**Collaborations**

**Global advocacy council**

**Lancet neurology commission**

**Increased presence**

**Looking ahead in epilepsy**
In progress, focused on future aspects
- Broad ranging

**WHO ILAE-IBE**

**Collaborations**

**Goal 3 of Strategic Plan**
- Close collaboration w IBE
- Subsumed Global outreach TF
- Increasing scope and depth
- Multiple stakeholders and initiatives
- ILAE/IBE well positioned to advocate

**Big Impact Projects**
- Intersectoral Global Action Plan
- Global Report ‘Public Health Imperative’ A first for the WHO
- WHA Side-events
- Joint WHO/ILAE/Russian Federation project

**Lancet neurology commission**

**Increased presence**

**ILAE-IBE**

**Regional WHO meetings**
- Statements by Regional Chairs
- United Nations Side Events
- Emergency response
**Key Achievements**

**Changed Managers in 2019**
- Our Finances are Stable (for now)
- From UBS to Goldman Sachs
- Continue to benefit from *Finance Advisory*

**Cross-cutting theme of strategic plan**
- A New World!
  - Publisher Contract re-negotiation
  - Lower revenue across the board
  - Continue exploring new possibilities

**endowment**
- We are there!!
  - Reached investment goal of $20 Million
  - Began drawing $ to support initiatives ($600K/year)
  - Helped us survive Calamitous COVID!

**Advisors & portfolio**
- Goal 5 of Strategic Plan
  - Financial viability
  - Effective and Efficient management of resources
  - Growth requires resources

**Money person**

**journals**

**congresses**
- Tough year!
Key Achievements

- A Major Organizational Entity
  - Goal 2 of Strategic Plan
  - Advise the Executive, Continuity
  - Short and long-range planning
  - Education, Translation, Organization, etc

- Major step in education
  - Competency based - Translated
  - Epileptology – 3 levels
  - Primary Care – ready for consultation
  - All ILAE courses to be aligned with objectives

- New Omnibus Platform
  - Case-based learning
  - F2F and web-based, tutor and self-paced, VIREPA
  - Adaptive Learning
  - Numerous educational resources being produced in line w curriculum

- Approved by Executive Committee
  - ILAE as CME accrediting body
  - Will make us competitive
  - Broader audience

- In the works
  - Exam for level 1 being developed and tested
  - State of the art method (certainty based)
**Special projects**

- **Finding our way in the Data Maze**
  - Acknowledge this is here to stay
  - Neuropathology ontology done/validating
  - Working on Imaging and linking with other ontologies

- **Tele-medicine**

- **Big data**

- **Open data**

- **Covid-19**
  - A Necessary but Huge Task
  - Used by most electronic health records
  - Poor epilepsy coding
  - Complex, will take time/resources

- **snomed**

- **Letters to ministers**
  - Ad-Hoc Urgent Task Force
    - International representation
    - Responsive to changing landscape
    - Resources: Clinicians, Researchers, Patients
    - Surveys, Publications, Guiding principles
    - COVID Symposium & microlearnings

**Highlighting our Chapters**

- Letters written to ministers of health of all ILAE chapters
- Some responses
- Need to persist
Publications and guidelines/consensus

Key Achievements

**journals**
- Growing!
- Increased Impact Factor
- Increased submissions
- Sharper focus of some journals
- Streamlined editorial positions
- Renegotiation of contracts

**Guidelines-consensus**

**Area of Major Importance**
- Goal 1 of Strategic Plan
- ILAE expected to provide guidance
  - Requires Methodological expertise, coordination of numerous initiatives
  - New Best Practice Council
  - Creation of Best Practice Council
Next generation task force – a crucial part of our membership

Key Achievements

- **Young epilepsy section**
  - Growing!
  - Over 400 active members
  - Participate in many ILAE leadership groups
  - YES Webinars
  - Regional and Country liaisons
  - Create educational materials and translations

- **Leadership course**

- **Mentor-Mentee Programme**
  - Continue during face to face congresses

- **On track for International and Regional Congresses**
  - Planning an online offering

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some practice/recommendation papers

- **4 position papers on Epilepsy Syndromes**
  - Neonates and Infants
  - Children
  - Adolescent, adults and variable ages
  - Idiopathic Generalized Epilepsies

- **Guidelines**
  - Automated seizure detection using wearable devices (guideline)
  - Minimum standards for long-term Video-EEG monitoring
  - Treatment of Depression in Adults with epilepsy

- **Reports, Recommendations**
  - Nomenclature of ASMs (in progress)
  - Definition of disease modifying interventions
  - Lamotrigine black box
  - Referral for presurgical evaluation
  - Indications and expectations for neuropsychological assessment in epilepsy surgery in children and adults
  - Management of epilepsy in pregnancy:
  - Novel study design to assess the efficacy and tolerability of antiseizure medications for focal-onset seizures in infants and young children 2019
  - Recommendations for the use of structural magnetic resonance imaging in the care of patients with epilepsy
  - Psychological treatments for adults and children with epilepsy
  - Epilepsy Stigma assessment (wip)
  - Epilepsy Stigma interventions (wip)
  - What is a guideline? (wip)

- **Numerous educational papers aimed at curricular objectives**
Some Challenges ahead

- COVID-19
  - Personal losses
  - Congresses, Meetings, Finances
- Engaging basic science researchers
  - Goal 5 of Strategic Plan – Research/Innovation
- Engaging chapters and improving support
- Regional strengthening and self-determination
- The brave new world of publications and revenue loss
- WHO IGAP: development and implementation
- Wikipedia
- Engaging Industry
- Educational offerings
- Resource/Fund development