



# PRESIDENT'S REPORT

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Samuel Wiebe, MD

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

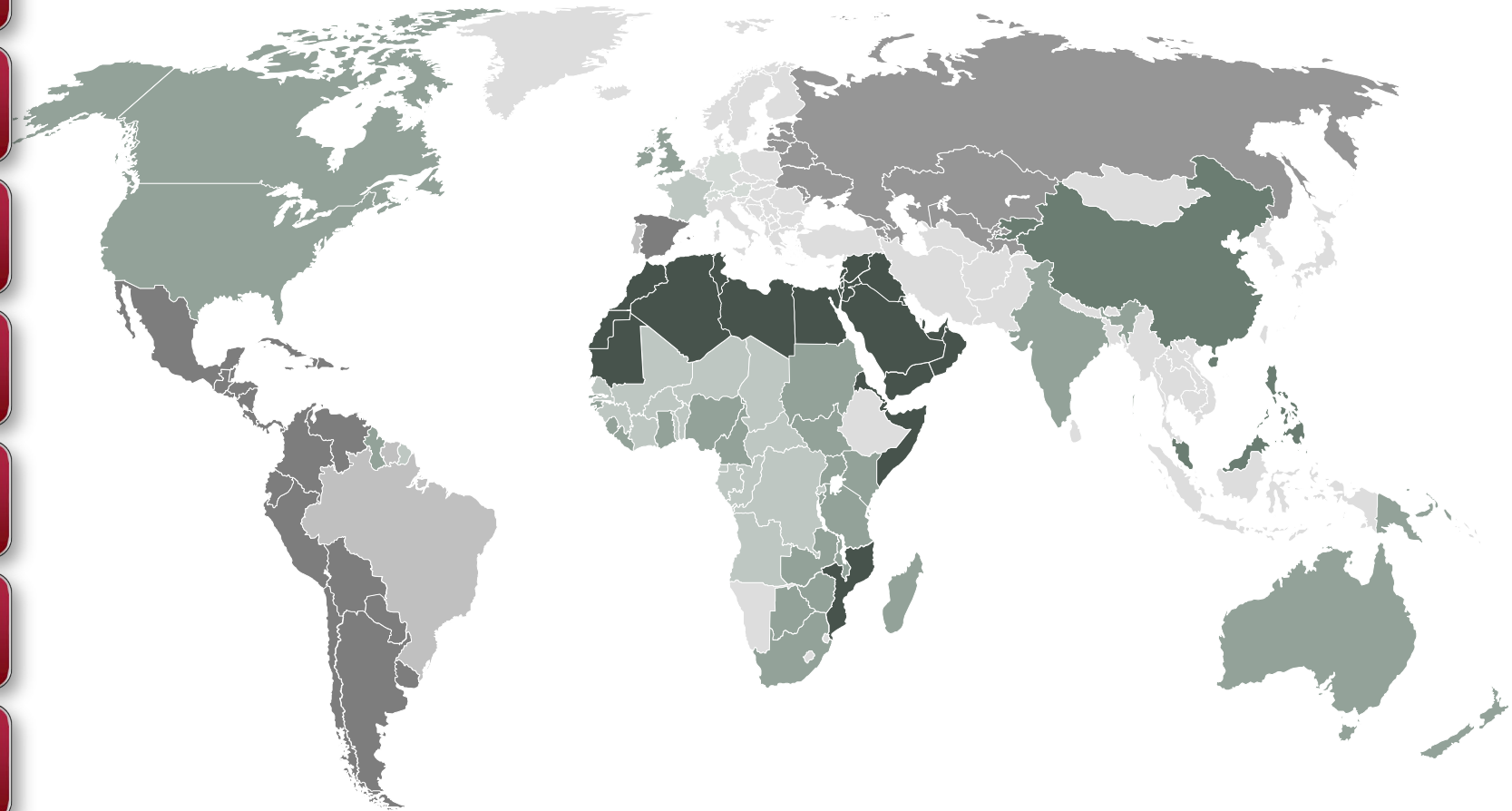
All over the world

All walks of life

All busy in their own careers and institutions

All volunteers

All can't be thanked enough



ARABIAN CHINESE ENGLISH FRANCE GERMAN PORTUGUESE RUSSIAN SPANISH OTHER



# Regional Boards

ILM NORTH AMERICA



Nathalie Jetté

ILM EUROPE



Eugen Trinká

ILM ASIA & OCEANIA



Akio Ikeda

ILM LATIN AMERICA



Roberto Caraballo

ILM EASTERN MEDITERRANEAN



Chahnez Triki

ILM AFRICA



Angelina Kakooza

# Organizational - structural

## Key Achievements

**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

councils

Ilae  
secretaria

executive  
director

Strategic  
plan

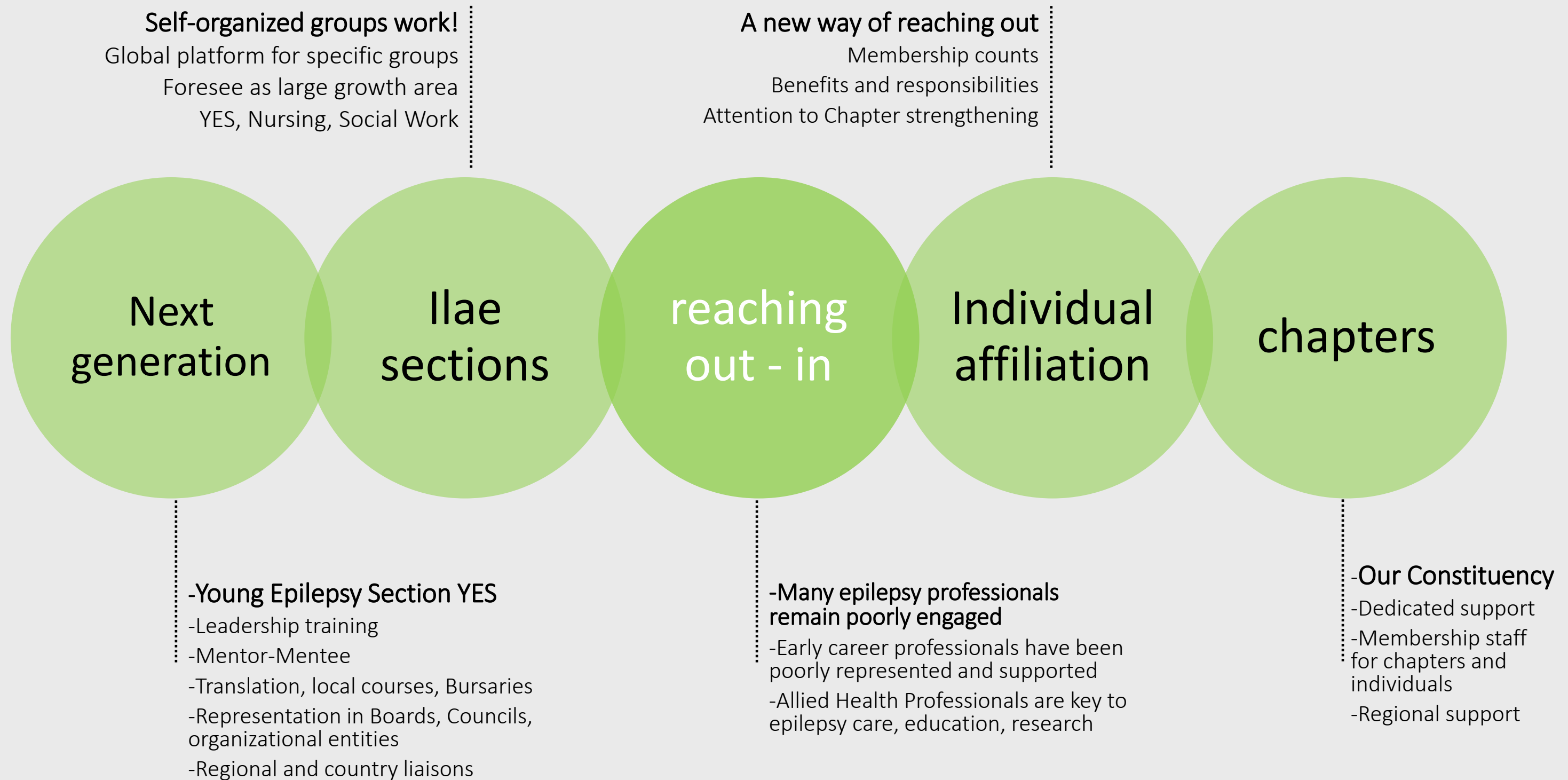
Constituti  
on by-  
laws



- 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



# Global actions – ILAE-IBE

## Key Achievements

Signed agreements for collaboration

Int Neuropsycholo Soc

Int Fed Clin Neurophysiol

Eur Acad Neurol

BPNA (PET), J Neurosc Council (eBrain)

Looking ahead in epilepsy

In progress, focused on future aspects

Broad ranging

WHO  
ILAE-IBE

Collabora  
-tions

Global  
advocacy  
council



Lancet  
neurol  
commissi  
on

Increased  
presence  
ILAE-IBE

-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

-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

-Regional WHO meetings

-Statements by Regional Chairs

-United Nations Side Events

-Emergency response

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

Advisors  
&  
portfolio

Money  
person

journals

congresses



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

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

**-Tough year!**



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

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

curricula

Education  
council



Ilae  
academy



Cme  
credits

Exams &  
certificates

- 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

- In the works
- Exam for level 1 being developed and tested
- state of the art method (certainty based)

# Special projects

## Key Achievements

### -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

### A Necessary but Huge Task

Used by most electronic health records  
Poor epilepsy coding  
Complex, will take time/resources

Tele-  
medicine



Big data  
Open  
data

Covid-19



snomed



Letters to  
ministers



### -Getting started

- Especially relevant during Pandemic
- Initial guiding principles created
- International Task Force assembled to move forward
- Role of ILAE: Standards, collaboration, support, implementation in areas of need

### -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

### 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



On track for International and Regional Congresses

- Planning an online offering

**-Growing!**

-Over 400 active members

Participate in many ILAE leadership groups

-YES Webinars

-Regional and Country liaisons

-Create educational materials and translations

Continue during face to face congresses

# some practice/recommendation papers

## Key Achievements

- **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

## Key Achievements

- 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