ILAE STRATEGY 2030

15 January 2021

INTRODUCTION

The purpose of this document is to provide **strategic direction** for the activities for ILAE until 2030.

The Strategy will be accompanied each year by an **Annual Workplan** outlining the specific activities that will be undertaken to achieve the **Goals, Aims and Enabling Objectives** in line with the medium -term focus provided by the **Recommendations**.

The Strategy is underpinned by three important Frameworks: **Risk Management Framework, an Accountability Framework and a Monitoring, Evaluation and Reporting Framework**. These Frameworks will support the ILAE Executive in effectively implementing the annual workplan, in assessing progress towards the Goals and in ensuring that the organization remains true to its **Vision, Mission and Guiding Principles.**

Strategy 2030 is built on the 2009 ILAE Strategic Plan which has guided activities and investments over the past decade. Through a series of strategic retreats in 2020, the core components of the 2009 Strategic Plan have been reviewed. Many elements have been retained; their continuing relevance in supporting our **vision of achieving a world where no person's life is limited by epilepsy** reaffirmed and endorsed. For other elements, the intense work over the past decade has seen us achieve our initial intensions with the need, therefore, to set **new targets.** In other areas though, the immense changes that are taking place around us mean that it is now time to embrace **new challenges.**

Although the aspiration is for the Strategy to remain a guiding document for the next decade, given our rapidly changing environment as highlighted in the **Drivers of Change** section, it is likely that we will need to regularly review and refresh parts of the document as we move towards 2030.

Timeline for the Key Components of Strategy 2030
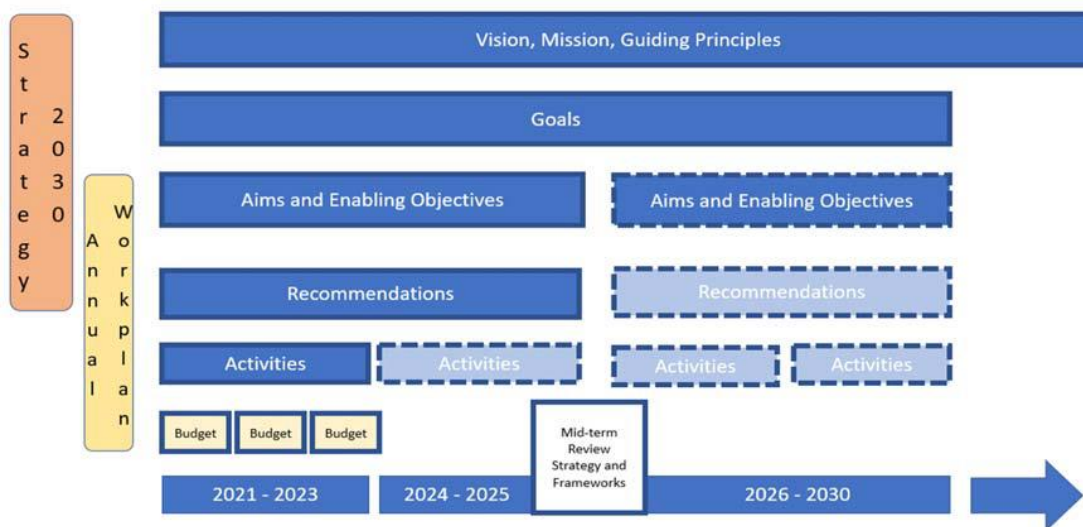
KEY COMPONENTS OF STRATEGY 2030

VISION: Defines where the organization wishes to go. An organizational vision will remain constant for many years providing a clear, superordinate goal.

MISSION: Describes how the organization wishes to achieve its vision. Core elements of the mission will remain constant for many years, adjusting slightly to embrace emerging opportunities that aid the organization to achieve its vision.

GUIDING PRINCIPLES: Provide a broad philosophy to guide the organization and build an ethical and effective culture.

DRIVERS OF CHANGE: A continually moving set of internal and external factors that can impact both positively and negatively on the organization's ability to achieve its vision. Regular evaluation of these drivers helps the organization to anticipate and adjust to changes.

GOALS: Strategic objectives that guide the organization in its journey to achieve its vision. The Goals provide the pillars around which activities and investments are planned for the lifetime of the Strategy (10 years).

AIMS: Statement of what the organization is trying to achieve within a Goal area over the medium (five year) period. The aims will be reviewed and refreshed at the mid-term point of the Strategy.

RECOMMENDATIONS: Within each aim, Recommendations provide a focus for attention over the short to medium term. The recommendations will be reviewed and, if needed, refreshed on a biannual basis.

CROSS CUTTING AREAS: These are specific areas of work that intersect with and support all Goals

ENABLING OBJECTIVES: These provide direction for work within each cross-cutting area and alignment with the respective Goal.

ALIGNED TO STRATEGY 2030

ANNUAL WORKPLAN - ACTIVITIES AND BUDGET: Annual workplan provides details of the planned Activities within each Goal/Aim/Cross Cutting Area (guided, as appropriate, by the shorter-term focus provided by the Recommendations and the Enabling Objectives) and for that year along with the approved budget to support these activities.

FRAMEWORKS TO SUPPORT IMPLEMENTATION

ACCOUNTABILITY FRAMEWORK: Provides details of who is responsible for the oversight and actions required to achieve the Goals within the Strategy. It consists of four key elements:

- ILAE Constitution and By-Laws
- ILAE Executive and Operational Structure
- Code of Conduct based on Mission and Guiding Principles
- Delegation of Authority for the Executive and Directors

RISK MANAGEMENT FRAMEWORK: Provides a structured approach to identify potential threats to the organization and the processes for monitoring and minimizing their impact. It consists of three key elements:

- Risk Statement
- Risk Management Policy
- Risk Management Plan

MONITORING, EVALUATION AND REPORTING FRAMEWORK: Provides a structured approach monitoring and reporting on the availability and use of resources and progress towards achieving the Goals. It also supports regular evaluation of actions and expenditure to support continual learning and improvements.

DRIVERS OF CHANGE

The past decade has seen significant political, technological, and social changes occurring throughout the world that have - and will continue - to have an impact on epilepsy.

The push for access to quality and affordable health services as part of **universal health coverage** (UHC), the acknowledgement that addressing epilepsy, including further research, is a **public health imperative** as well as the development of an **Intersectoral Global Action Plan** on Epilepsy and Other Neurological Disorders (IGAP), open huge opportunities to achieve our vision of a world where no life is limited by epilepsy. ILAE's ability to engage diplomatically and work in partnership at global, regional, and national level in order to implement the IGAP and make UHC a reality for people living with epilepsy has – and will continue - to require significant investment in **advocacy, communications and partnerships.**

However, the critical shortage of health care professionals globally, coupled with specialist skills gaps in epileptology, is a significant barrier to achieving this. Addressing staff and skill shortages, supporting early career professionals, and finding ways to overcome the 'brain drain' affecting many countries requires a complex set of solutions. ILAE has – and will need to continue – to find ways to innovate and expand our **educational, leadership and mentoring programmes**.

Demographic and epidemiological shifts over the past decade have seen a rise in both the incidence of epilepsy and the prevalence of co-morbidities. Given the increasing complexity of clinical practice, the need for high-quality **publications** that include **critical research** and its translation into **practical guideline** as well as **standards** and **evidence of best practice** will continue to be essential.

Protracted humanitarian crises, migration, economic turmoil, increasingly divided populations – these factors, and others, are creating new and growing vulnerabilities. Skills in **adapting guidance to different contexts** as well as strengthening the **sense of community** across our membership will be increasingly needed over the coming decade.

One of the greatest challenges globally has been the COVID pandemic. The sudden, seismic shift in the way in which services are provided, the need for rapid global assessments into the neurological implications and impacts on people with epilepsy, and the psychosocial distress have all necessitated a degree of flexibility not previously experienced. Building **agility and flexibility into our thinking, investing in learning lessons and contingency planning** to prevent negative impacts on research and services in future crises and **strengthening our ability to work as a global network** are – and will continue to be - critical to the success of the organization and advancement of our vision.

Epilepsy is highly preventable and highly treatable, but it is also highly stigmatized. **Intersectoral cooperation** is – and will continue – to be needed to truly address risk factors, and the exclusion and discrimination experienced by people with epilepsy. **Interdisciplinary approaches** that place the person living with epilepsy at the center of care are increasingly needed to maximize the benefits of existing and emerging diagnostic and treatment innovations as well as technological advances such as telemedicine and data analytics. Advancing ILAE's role in within these **collaborations** will need to form an integral part of our work into the future.

VISION, MISSION AND GUIDING PRINCIPLES

Vision

ILAE's vision is a world in which no person's life is limited by epilepsy

Mission

ILAE will ensure that health professionals, people living with epilepsy and their care partners, governments and the public worldwide have the resources and tools needed to understand, prevent, diagnose, and treat epilepsy. ILAE will achieve this by identifying needs, setting standards, providing education, advocating for access to care and treatment and facilitating research.

Guiding Principles

Impact: We strive to achieve international, enduring impact for individuals and communities affected by epilepsy

We recognize that to achieve this we must take a long-term view. We must tackle both the root causes of epilepsy as well as the health and social consequences**.** And we must continually endeavor to be flexible, take appropriate risks and make our actions sustainable.

Cooperation: We collaborate to generate shared outcomes

We recognize that we cannot achieve the impact needed by working alone. We must foster mutual collaborations with health care professionals, individuals and communities affected by epilepsy, the public, governments and other groups**.** And we must continually demonstrate that we value others' ideas, time, needs and goals.

Excellence: We take a holistic and scientific approach to developing best practice

We recognize that to achieve this we must keep ourselves well informed if we are to make the best decisions. We must evaluate ideas in terms of their inherent value not their origin. And we must continually challenge our assumptions and seek out and listen to multiple points of view.

Integrity: We aspire to the highest standards of conduct

We recognize that to achieve this we must communicate honestly, clearly, and transparently. We must be good stewards of our human and fiscal resources. And we must continually hold ourselves to the same standards we ask of others.

Inclusion: We work with <u>all</u> who strive for a world where no life is limited by epilepsy

Above all, we recognize that to stay true to our mission and achieve all that we set out to do, we must ensure that there is no place for bias or discrimination in our organization. There must though be a place for all – as equals, supported and respected.

GOALS, AIMS AND RECOMMENDATIONS

> **Goal 1:** Serve health professionals as the premier international resource for current and emerging standards and best practice

Aim 1.1: Systematically develop our global body of knowledge of best practice in epileptology

Recommendation 1.1.1: Work in partnership with relevant organizations and institutions to **develop standards** and **guidance on best practice** for the prevention, diagnosis, treatment, and care of epilepsy

Recommendation 1.1.2: Work in partnership with WHO and other leading organizations to develop **decisive statements** on critical areas of best practice in line with emerging evidence

Aim 1.2: Disseminate and promote the implementation of international best practice standards for the prevention, diagnosis and treatment of epilepsy and comorbidities

Recommendation 1.2.1: Through ILAE publications, regular literature reviews, Congresses and the ILAE website repository support health professionals' access to a **global body of knowledge** in epileptology

Recommendation 1.2.2: Work as a global network and in partnership with other relevant organizations to **disseminate** and implement **standards and practice**

Recommendation 1.2.3: Work in partnership with WHO and other key stakeholders to incorporate accepted standards of care and best practice into the **Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP)** and to support its use thereafter to strengthen health systems

Aim 1.3: Adapt standards and guidelines to best meet the needs in different epidemiological and socioeconomic contexts

Recommendation 1.3.1: Support health professionals to **adapt best practice guidelines** and the **Intersectoral Global Action Plan** to their epidemiological and socioeconomic contexts using appropriate methodologies including the ILAE's ADAPT approach

Recommendation 1.3.2: Support **multi-lingual translation** of key standards and guidelines

Recommendation 1.3.3: Expand open access and other innovative schemes to increase the access of health professionals in **resource constrained settings** to standards and guidelines particularly those specifically adapted to their working environment

Aim 2.1: Provide world-wide, accessible education and skill development for the prevention diagnosis, treatment and care of epilepsy

Recommendation 2.1.1: Provide **educational resources** of high quality covering all aspects of epilepsy tailored to the needs of health professionals working at all levels and throughout their careers

Recommendation 2.1.2: Enhance educational **needs assessments** and our understanding of the added value of all ILAE educational offerings to develop a **rolling Road Map** to stimulate and coordinate all educational activities

Recommendation 2.1.3: Develop a comprehensive, **financial business** plan to support funding of all educational activities and expansion and outreach to health professionals working in resource constrained settings

Aim 2.2: Achieve and maintain globally recognized status as an accrediting body for Continuing Professional Development and Medical Education in the field of epilepsy

Recommendation 2.2.1: Work towards all significant **educational events and courses** being able to offer globally recognized CPD/CME credits

Recommendation 2.2.2: Take a **stepwise approach** to developing accreditation status for ILAE

Aim 2.3: Enhance the leadership competencies of epilepsy professionals through education, coaching and mentorship

Recommendation 2.3.1 Continue to expand **leadership and management training** particularly for early career professionals

Recommendation 2.3.2: Support the continuation and expansion of the **mentorship programmes** (clinical, management and/or research related) particularly for early career professionals working in resource constrained settings

Goal 3: Advocate for epilepsy as a public health imperative

Aim 3.1: Determine global needs and priorities in epilepsy care, education, and research

Recommendation 3.1.1: Provide updated relevant epidemiological, demographic, and service provision information to inform key documents that serve as **international references on global needs**

Recommendation 3.1.2: Assess and articulate **priority gaps** in epilepsy related **research globally to support achieving the aims of Goal 5.**

Aim 3.2: Interact with stakeholders and governments at global, regional, and national level to promote epilepsy as a public health imperative

Recommendation 3.2.1: Work in partnership with relevant stakeholders at global, regional, and national level to advocate for the implementation of actions in the **Intersectoral Global Action Plan** and incorporation of core elements within regional and **National Health Plans and Budgets**

Recommendation 3.2.2: Work in partnership with relevant stakeholders at global, regional, and national level to advocate for the inclusion of priority epilepsy research in **national and other research specific budgets**

Recommendation 3.2.3: Over the medium term, build specific partnerships to promote **access to essential medicines, diagnostics, and telehealth**

Aim 3.3: Work in partnership with stakeholders, including people with epilepsy, to address stigma, exclusion and discrimination

Recommendation 3.3.1: As part of the development and implementation of the **Intersectoral Global Action Plan,** strengthen action **within the health sector** and in **sectors beyond health**, primarily education and employment, to address discriminatory legislation, reduce stigma and improve inclusion and equal opportunities for people affected by epilepsy

Recommendation 3.3.2: Work in partnership with individuals and communities affected by epilepsy as well as the International Bureau for Epilepsy and other relevant organizations to address **stigma, exclusion, and discrimination**

Goal 4: Promote research and innovation for epilepsy

Aim 4.1: Facilitate scientific and research collaborations in all settings

Recommendation 4.1.1: **Support advancements in research and innovation** for epilepsy prevention, diagnosis, treatment, and care

Recommendation 4.1.2: **Facilitate interaction** between key epilepsy related research institutions and networks to support priority areas of **operational research** particularly in resource constrained settings

Recommendation 4.1.3: Build on the lessons from crises to strengthen the ILAE network's capacity for **agile responses**, rapid **information dissemination and data collection,** and **enhance preparedness** to implement new technologies and continue critical research during crises

Aim 4.2: Develop and promote ethical and scientifically robust methodologies to support epilepsy research

Recommendation 4.2.1: Support the development and implementation of optimal **research standards and methodologies** to enhance epilepsy related research across all relevant disciplines including social, ethical, and legal challenges faced by people with epilepsy

Recommendation 4.2.2: Encourage the development of **specific approaches** that can better support research in low resource settings

Recommendation 4.2.3: Promote and support **specific training programmes** on appropriate epilepsy related research methodologies across all relevant disciplines

Recommendation 4.2.4: Develop programmes to empower and support **individuals and communities affected by epilepsy to engage in research**

Aim 4.3: Embrace digital and technological transformation and the incorporation of relevant innovations into clinical practice

Recommendation 4.3.1: Work in partnership with relevant organizations to support the expansion of the use of **telehealth** in epilepsy diagnosis, treatment, and care

Recommendation 4.3.2: Continue to examine the **optimal use of technology and particularly data and advanced analytics** to accelerate research and innovation, and delivery of health care

Goal 5: Ensure the long term financial and organizational viability of ILAE

Aim 5.1: Strengthen engagement and participation by professionals in ILAE activities and governance

Recommendation 5.1.1: Establish a **Membership Committee** to explore ways to expand global reach, participation, diversity, and engagement of health professionals in ILAE

Recommendation 5.1.2: Continue to support the development of active and effective **Chapters** particularly in areas without current representation and in areas of high need

Recommendation 5.1.3: Ensure the presence and unity of the **ILAE brand** in all (global and regional) activities

Recommendation 5.1.4: Enhance the **recognition** of those who help improve the lives of people and communities affected by epilepsy within ILAE and beyond

Aim 5.2: Ensure effective and efficient management of ILAE activities and resources

Recommendation 5.2.1: Strengthen **regional organizational structure** to ensure it is effectively and efficiently dedicated to fulfilling ILAE mission

Recommendation 5.2.2: Continue to develop and support **effective and efficient ILAE operations**

Recommendation 5.2.3: Continue to strengthen contingency planning, learning lessons from crises to create flexibility within our operations and ensure **effective risk management**

Aim 5.3: Ensure effective financial management including expansion and diversification of income generation and funding

Recommendation 5.3.1: Continue to develop effective **financial management and oversight** processes and structures within ILAE

Recommendation 5.3.2: Establish a **Resource Development Taskforce** to explore expansion and diversification of income generation to support ILAE activities

Recommendation 5.3.3: Minimize **financial barriers** to health professionals' participation in ILAE activities

Goals, Aims, Cross Cutting Areas and Enabling Objectives

Goal 1 Standards and Best Practice	Goal 2 Professional Education and Development	Goal 3 Advocacy	Goal 4 Research and Innovation	Goal 5 Organizational and Financial Viability
1.1 Systematically develop our global body of knowledge of best practice in epileptology	**2.1** Provide world-wide, accessible education and skill development for the prevention, diagnosis, treatment, and care of epilepsy	**3.1** Determine global needs and priorities in epilepsy care, education and research	**4.1** Facilitate scientific and research collaborations in all settings	**5.1** Strengthen engagement and participation by professionals in ILAE activities and governance
1.2 Disseminate and promote the implementation of international best practice standards for the prevention, diagnosis and treatment of epilepsy and comorbidities	**2.2** Achieve and maintain globally recognized status as an accrediting body for Continuing Professional Development and Medical Education in the field of epilepsy	**3.2** Interact with stakeholders and governments at global, regional and national level to promote epilepsy as a public health imperative	**4.2** Develop and promote ethical and scientifically robust methodologies to support epilepsy research	**5.2** Ensure effective and efficient management of ILAE activities and resources
1.3 Adapt standards and guidelines to best meet the needs in different epidemiological and socioeconomic contexts	**2.3** Enhance the leadership competencies of epilepsy professionals through education, coaching and mentorship	**3.3** Work in partnership with stakeholders, including people with epilepsy, to address stigma, exclusion and discrimination	**4.3** Embrace digital and technological transformation and the incorporation of relevant innovations into clinical practice	**5.3** Ensure effective financial management including expansion and diversification of income generation and funding
Cross Cutting: Events and Congresses				
E1 Provide in person and virtual opportunities to develop consensus on best practice and promote guidelines and standards	**E2** Provide in person and virtual opportunities for training, sharing of professional experiences and building professional support	**E3** Provide in person and virtual opportunities to promote messages, and build capacities and connections to support global advocacy	**E4** Provide in person and virtual opportunities for networking, sharing of research and innovative and forward leaning discussion	**E5** Ensure financial viability of in person and virtual events whilst also ensuring high quality, active participation and global reach
Cross Cutting: Publications				
P1 Maintain the position of ILAE journals as leading authoritative sources for dissemination of knowledge, international evidence-based guidelines and standards	**P2** Continue to build the educational content of ILAE journals	**P3** Continue to utilize ILAE publications to increase visibility of ILAE activities as well as articulate needs and advocate for appropriate action	**P4** Disseminate broadly the latest rigorous clinical and basic scientific research, principally through ILAE journals, facilitating the translation of findings into medical care	**P5** Continue to utilize ILAE publications to strengthen internal communication within the ILAE and across the membership
Cross Cutting: Communications				
C1 Use appropriate media to promote standards, guidelines and best practice	**C2** Use appropriate media to promote educational activities and events, and to enhance continual learning	**C3** Use appropriate media and communication partnerships to advocate for action	**C5** Use appropriate media to promote research and innovation and to support digital and technological transformation	**C5** Use appropriate media and communication partnerships to raise awareness about ILAE activities and strengthen our sense of community