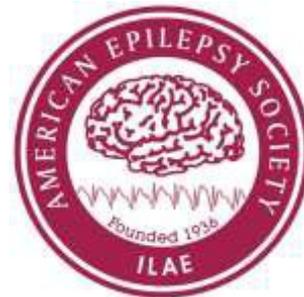


ICARE Membership Report: AES



ICARE Member Report: AES

- Major topics of interest in epilepsy research
 - Basic Science
 - Clinical Science
 - Translational
- Types of research support or other activities (*e.g., training, meetings, networks, resources; please highlight examples of recent/current activities here*)
 - Pre-doctoral and Postdoctoral Fellowships
 - Annual Scientific Meeting
 - Research Grants for mid-level researchers (seed money, Infrastructure support)
 - Support for Workshops
 - Junior Investigator/Abstract Submitter Travel Stipends
 - Advocacy
 - Consensus building

American Epilepsy Society

Mission Statement: The American Epilepsy Society promotes research and education for professionals dedicated to the prevention, treatment and cure of epilepsy.

Anticipated Outcomes

- Closer collaboration amongst research community
- Enticing young basic and clinical science researchers to come into the field of epilepsy
- Patient care: Addressing the issues and gaps raised in the IOM report. Forming collaborations with other organizations to work on specific projects.

INITIATIVE A: Support Excellence in Research and Education

Outcome #1: Take a more active role in advocating for research dollars.
Encompass setting research objectives and working on advocacy.

1. Created a joint Advocacy Committee with EF
 - Research summit
2. Reach out to NIH and NINDS leadership to attract more dollars from other institutes (non traditional for epilepsy)
3. Increased direct advocacy

Outcome #2: Ensure the future of clinical and basic science research.

1. Created a Translational Workgroup-
 - supporting a meeting in London with both AES and ILAE representatives
 - Budget includes proposal to fund (\$40,000) a translational grants program.
2. Active role in planning for Curing Conference 2013.
3. Assess the priorities of the R&T portfolio
 - New models and partnerships.
 - Expand the AES fellows program (aka NEF, Top Scholars)

INITIATIVE A

Outcome #4: AES will expand its educations offerings and products.

1. EpiPort Program. Budget includes a \$40,000 investment in program, plus money allocated in the annual meeting budget for stipends.
2. Supporting Junior Mexican Epileptologists to come to AES in 2012 – no cost, comp registration. Travel covered.
3. Expansion of Telemedicine program: joint effort with NAC/ILAE. \$10,000 over two year period
4. Supported PAME conference 2012, Gordon conference 2012
5. Develop list of educational offerings in collaboration with other organizations to address findings from IOM report.

Outcome #5: AES will grow its official Journal.

1. Epilepsy Currents

- added money to the budget to expand pages and content.
- Considering a mobile app

INITIATIVE B: Enhancing the ability of professionals to provide high quality care to persons with epilepsy

Outcome #1: AES will produce, generate and disseminate policies, guidelines, practice parameters, and checklists to its members and other stakeholders.

1. AES will work with other designated organizations to respond to IOM report
2. AES will conduct an epilepsy specialist program at the AES meeting and at AAN.
3. Look at inventory of programs to improve access to epilepsy information.
 - a. PAME program- jointly funded by several organizations
 - b. EMU safety program - partnership with other organizations

INITIATIVE C: Build a strong financial and programmatic infrastructure to achieve growth and continuous improvement of services

Outcome #1: Develop a sustained capacity to support AES high priority programs.

1. Investigate non-traditional sources of funding
 - a. increase development activity, legacy giving and attracting private foundation grants.
 - b. Create a competitive project system to ensure that AES is supporting the highest priority projects.
 - c. Grow the Lennox and Lombroso Trust to \$10 mm
 - d. Increase the number of AES members contributing to one of the AES endowment funds.
2. Leverage partnerships to increase support for research (EF, CURE, AAN)
3. Identify ways to generate new revenue streams: podcasts, Skills Workshop, look to web site for revenue generation.

INITIATIVE C

Outcome #2: AES will grow and energize talented volunteers and staff leading to a sustained workforce.

1. Conduct an annual leadership program
2. Develop and increase the AES staff competencies

INITIATIVE D: Forging external relationships to raise awareness and in support of research and education in the wide spectrum of epilepsies

Outcome #1: AES will continue to increase its visibility and influence.

1. Revisit the internal and external communications strategic plan in the context of the IOM report.
2. AES will lend its voice to encouraging new treatments for patients.

ICARE Member Report: AES

- Resources available for shared use or other opportunities for collaboration
 - Resources in Epilepsy Research website
 - Partner with Epilepsy Foundation and American Academy of Neurology
 - AES Annual Meeting and repurposed symposia
 - Coordination of Vision 20-20 activities
 - A sponsor of IOM Report on Epilepsy