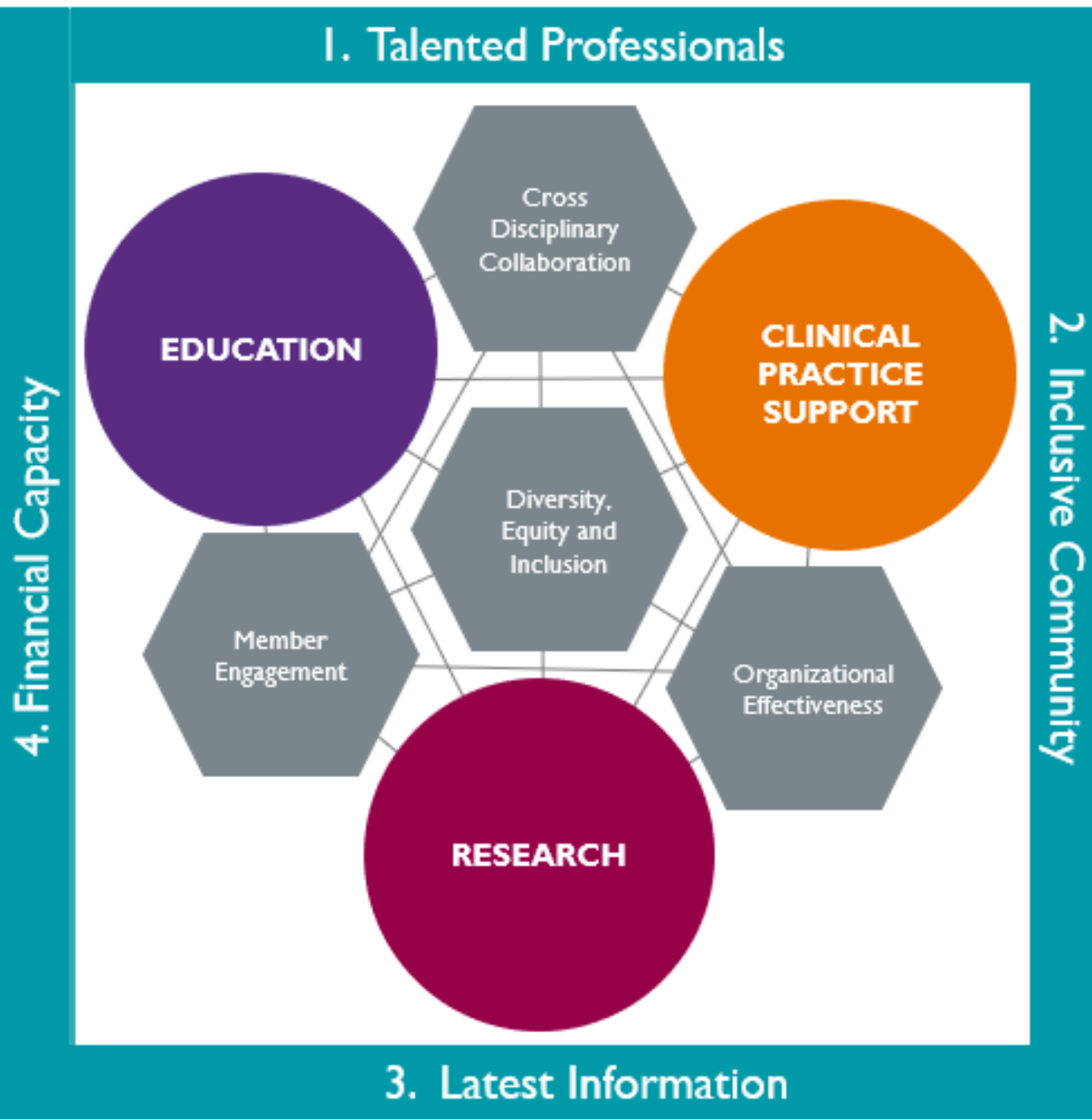


American Epilepsy Society ICARE Update

05/21/2021

Eileen M. Murray, MM, CAE
Executive Director







Objectives for Goal #1 – Talented Professionals

Attract, develop, retain, and enhance the careers of diverse and talented professionals in epilepsy.

- A. Expand trainee and early career investigator programs to continue to attract, develop and retain early career professionals and encourage them to engage in AES and the profession.
- B. Strategically and proactively ensure full diversity in the specialty from a variety of professional and personal backgrounds.
- C. Create focused resources to develop and retain mid-career professionals, inclusive of providing opportunities for professional collaboration and actively cultivating leaders.
- D. Provide career development opportunities that are appropriate for all professionals within the epilepsy ecosystem.



Objectives for Goal #2 – Inclusive Community

***Nurture
inclusion across
the AES
multi-
disciplinary
community.***

- A. Remove barriers and improve access for all members to programs and volunteer pathways through policies, procedures and practices that create a more inclusive society.
- B. Create cross-disciplinary programs that appeal to all audiences.
- C. Effectively incorporate the patient voice in AES' work.
- D. Define and foster successful collaboration with the patient advocacy community and other epilepsy-related organizations.



Objectives for Goal #3 – Latest Information

Enable all engaged in epilepsy to effectively understand and apply the latest information to improve best practices.

- A. Create meaningful cross-disciplinary interactions between researchers and clinicians to drive innovation.
- B. Continuously identify gaps in knowledge and practice and sharing evolving information and guidance in these areas as evidence becomes available.
- C. Leverage all avenues of communication, including digital platforms and social media, to reach a broader community with the latest knowledge and discoveries.
- D. Identify and implement tactics that convert evidence-based guidance into practice by delivering them in compelling new ways.

AES Research Programs



Beyond Grants

Setting research direction

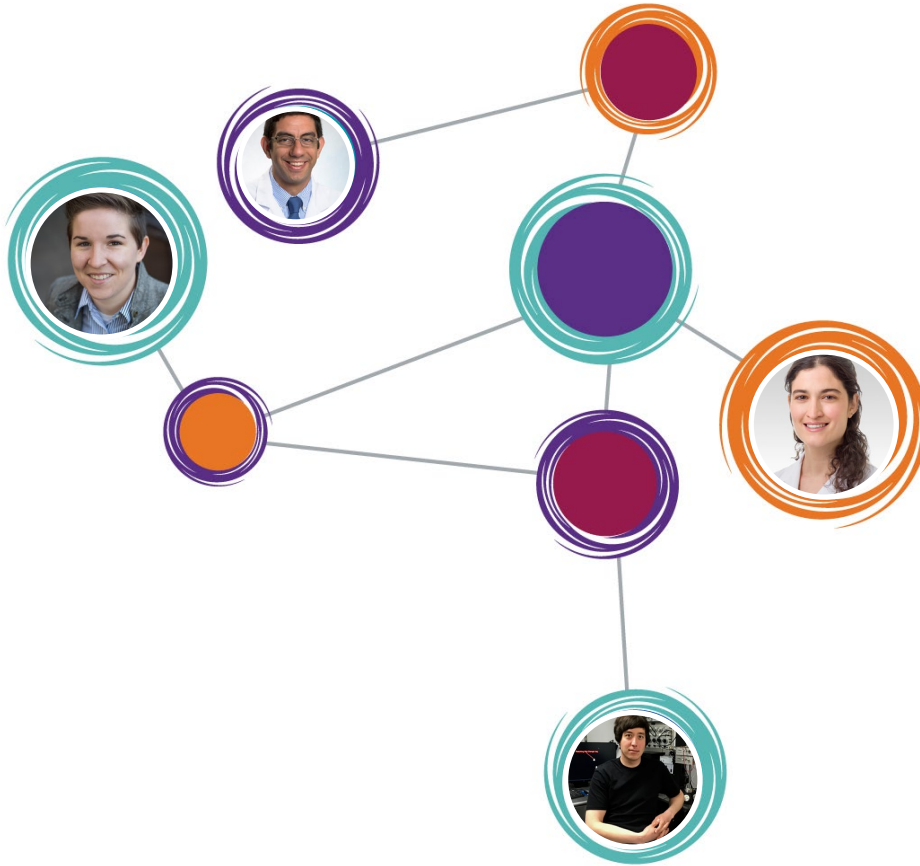
- Epilepsy Benchmarks Stewards
- Translational Research Symposium & SIG
- Investigator Workshops at Annual Meeting
- ILAE/AES Joint Translational Task Force
- Dialogues in Epilepsy session

Leading collaborations and partnering

- Epilepsy Leadership Council, PAME, partnering on granting and other

Training programs & career development

- Fellows program at Annual Meeting, including junior investigator roundtable, career pathways, & mentorship
- EpiPORT content in clinical research
- Basic Science Skills Workshops
- New proposals coming forward from DEI Committee



AES Takes Pride in Supporting the Epilepsy Talent Pipeline

- ~85% of AES grants support early-career scientists
- **Seven** funding programs
- All fields of epilepsy research welcome
- Specific fields eligible for partner funding



2020 - Awarded \$1.09M in Early Career Grants





Current and Recent Funding Partners

AES Partners contribute full or partial support for proposals that align with their priorities



SUPPORT FOR SCIENTIFIC INNOVATORS

- **Infrastructure Grants:** Up to \$50K to facilitate the creation of multicenter research programs
- **Seed Grants:** Up to \$20K for established investigators
- **Research and Training Workshop Grants:** Funding for scientific conferences and workshops focused on epilepsy research and training

The Benchmarks: Progress and Emerging Priorities in Epilepsy Research

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This issue of *Epilepsy Currents* includes 4 reviews reflecting progress in epilepsy research in the 4 benchmarks areas ("Benchmarks") of the National Institute of Neurological Disorders and Stroke (NINDS)/American Epilepsy Society (AES) Benchmarks Stewards Committee. Here, we provide historical context for the formal organization of research priorities related to epilepsy. We review the benchmark areas and the processes through which the Benchmarks will continue to evolve to reflect scientific advances and community research priorities over time.

Origins of the Current Benchmarks

The NINDS at the National Institute of Health (NIH) sponsored the first Curing Epilepsy conference in 2000 in partnership with nongovernmental organizations and other Federal agencies following an executive order from President Clinton. The goal was to shift the focus of epilepsy research from treating seizures to finding cures—in other words, to better understand the cause(s) of epilepsy to inform the development of more effective treatments. At that time, there were many anti-seizure medications on the market, but many had significant side effects and were, and continue to be, ineffective for approximately one-third of individuals with epilepsy. The NINDS then sponsored a conference in 2007 called Curing the Epilepsies (in recognition of the fact that there are many different types and causes of epilepsy) to assess the state of epilepsy research, identify research priorities shared by the research community, and collectively propose new directions. Participants in the first conference in March 2000 were eager to identify a way to evaluate progress resulting from this historic event, and a session was added to the conference in 2007 to "benchmark" the outcomes. The NINDS subsequently worked with more than a dozen Epilepsy Research Stewards—established leaders in the field of epilepsy research—to define a series of goals for the field that could serve as a research agenda.¹ The NINDS and the Stewards developed a series of Epilepsy Research Benchmarks based on the 3 major topic areas of the 2000 Conference: (1) interrupting and monitoring epileptogenesis, (2) genetic

strategies, and (3) developing new therapies. The Benchmarks were subsequently revised and updated in 2014^{2,3-9} following

the Curing the Epilepsies focused on epilepsy-related research. The Benchmarks have been used at NIH, as well as at epilepsy research. Subsequent conference in 2000 with the development of causes of epilepsy and Major NINDS initiative large-scale studies such as Project and Epi4K and focused on sudden unexpected death on epilepsy-related vas-

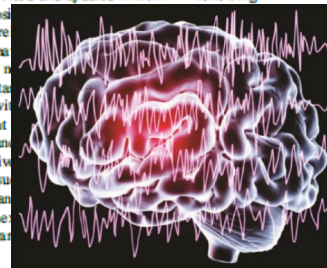
Current Benchmarks

The reviews in this issue of *Epilepsy Currents* are each series of reviews.

Epilepsy Benchmarks the Epilepsies and Epilepsy and Somatic Conditions. Discovery of genetic epilepsies, new discoveries as well as these causes. Emerging causes of epilepsy-related

The review on Epilepsy and Its Progress standing several factors exciting emerging progressions that can be defined

the onset of epilepsy (eg, some cases of tuberous sclerosis complex), providing an opportunity for intervention. In parallel, emerging treatment strategies from drug repurposing to gene therapy are also considered. There is clearly substantial additional research required to better understand who is at risk for epilepsy due to various causes of epilepsy, including



Curing the Epilepsies 2021

January 4 - 6

NIH National Institute of Neurological Disorders and Stroke



Welcome

Agenda

2020 Epilepsy Research Benchmarks

Registration

Contact Us

Curing the Epilepsies 2021: Setting Research Priorities

Virtual Conference



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