

**American Epilepsy Society (AES)  
Written Comments to  
NINDS Request for Information  
Soliciting Input on Areas of Health Disparities and Inequities  
in Neurological Disease and/or Care in the United States Across the  
Lifespan Notice Number: NOT-NS-20-026**

AES Written Comments were reviewed and approved by the AES Board of Directors.  
Comments were authored by the AES Research & Training Council chaired by Peter Crino MD  
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**Q1: Identify area(s) of health disparity and/or inequity (including race/ethnic, sex/sexual orientation/gender identity, regional/geographic, age, educational attainment, or socio-economic differences) in neurological disease, treatment, care, and/or service in the U.S:**

The American Epilepsy Society (AES) is honored to submit its suggestions for the 2020 NIH RFI on addressing health disparities and inequities in epilepsy research, training, treatment, and outcomes. Our suggestions reflect the integrated viewpoints of the AES, accounting for the basic sciences, translational research, clinical research, and clinical care priorities of our 4500 epilepsy scientists and clinicians.

A major problem in the area of epilepsy is that disparities in epilepsy care have not received comprehensive evaluation. Basic epidemiology must be performed in a comprehensive fashion to adequately address even this first question; approaches may vary depending on major determinants outlined here.

Therefore, the AES has these research recommendations that will accurately lay out disparities in epilepsy care.

- Support epidemiological research in outcomes in epilepsy, with focus on race, ethnicity, sex, gender, geographics, social determinants of health.
- Study access to healthcare and specifically tertiary epilepsy care in inner cities and rural communities.
- Define factors and biases that lead to acknowledged reticence to accept perceived invasive treatments such as intracranial EEG recordings, epilepsy surgery, deep brain stimulation, and responsive neurostimulation among certain patient populations.
- Define specific epidemiological, neurobiological, and molecular factors that lead to differences in epilepsy morbidity in women including hormonal regulation, sexuality, fertility, teratogenicity, and breastfeeding.
- Create initiatives to understand how hormonal changes in transgender individuals undergoing sex reassignment or gender affirming therapies affect seizures.

**Q2: Identify determinants that help explain this/these health disparities and /or inequities**

Only through a concerted research effort outlined above will potential determinants stand out. We anticipate, however, that the following factors affect disparities in epilepsy research and care.

- Race
- Socioeconomic status
- Gender
- Geographic location/access to expertise
- Health care access/payer source

**Q3: Identify evidence-based research strategies, health services, policies, and other interventions that address these disparities/inequities in neurological disease, treatment, service, or care**

The membership of the AES spans all 50 states. The diversity of our American membership informs the below recommendations:

- Support studies across state health systems to link epilepsy care outcomes to systems of supply

Although the “A” in AES stands for “American”, we remain the premier professional organization for epilepsy researchers and clinicians. Fully 28% of our membership consists of those based in other countries, and this multinational diversity informs some approaches to addressing health care inequity.

- Support studies across national health systems to link epilepsy care outcomes to systems of supply

The recent health care crisis arising from the novel corona virus has brought telemedicine into the forefront.

- Support studies of the use of telemedicine health care access, whether clinical or procedural, to optimize access to mitigate geographic location as a source of inequity
- Support patient satisfaction analyses of telemedicine access for “in-home visits” for select patient populations.

Focus across the age spectrum

- Discovery and implementation of optimal interventions during childhood will change outcomes throughout a person’s lifetime
- Support studies of epilepsy causes and treatments in elderly individuals (age >70).

**Q4: Identify knowledge gaps about disparities/inequities in neurological conditions**

The AES notes that the next generation of epilepsy researchers and healthcare providers need fostering. We acknowledge that social and racial backgrounds and economic possibilities to undertake careers in epilepsy are not ideally distributed. This equitable distribution will be one means by which to address inequities in epilepsy care. A vibrant, talented, and diverse neuroscience workforce is dependent on attracting students to neuroscience careers. Increase efforts at the level of undergraduate, graduate and professional levels (“pipeline proposals”) to ensure that promising and diverse trainees consider neuroscience research as an exciting career

- Decentralize high-level training and expertise across geographically distant research centers to increase the quality of training across the country while also creating more opportunities for robust neuroscience research careers in academia. Possible strategies include multicenter institutional training programs that promote collaboration and mentorship across institutions.
- Support for mentors (not just mentees) to dedicate effort to training the next generation is a priority.
- Foster neuroscience training towards non-academic research career paths. For example, develop partnerships between academic centers and industry to develop a workforce dedicated to problem-solving to meet the needs of complex neurological disease.
- Engage school programs to encourage participation in health care and epilepsy research across all levels: physicians, nurses, technologists, and administrators.
- Increase mechanisms to achieve training in design and execution of clinical research.
- Consider additional funding mechanisms for less intensive programs to allow academicians to develop baseline clinical research skill sets, such as 2.0 calendar months x 2 years.
- Establish programs in inner city and rural communities to value neuroscience as a career path.

**Q5: Identify potential approaches for addressing these neurological disparities and/or inequities through ongoing or new research collaborations or interventions**

One approach in tackling disparity is to ensure that the those involved in epilepsy research and healthcare reflect the populations who they serve. We share the NINDS commitment to develop an inclusive and diverse neuroscience workforce. On our end, we are committed to attaining equity and diversity in our research and clinical workforce through our ongoing mentorship programs and committees. We pledge our support of all efforts by NINDS to foster the careers of epilepsy investigators from diverse sub- disciplines, demographics and stages. Our specific suggestions to recruit and retain a diverse workforce are listed below:

- Foster a community of neuroscience researchers that values, nurtures and welcomes diversity, equity and inclusion. Towards this goal, develop diversity and inclusion training programs for all NINDS grantees, their institutional leaders and their professional organizations, similar to that required for the responsible conduct of research training.
- Develop flexible funding programs that would permit all investigators (early career and established) to maintain their research programs during times when their effort needs to be reduced due to medical leave, childcare or other personal/family responsibilities.
- Expand educational NINDS R25 programs to enrich the experiences of diverse researchers to slow or stop the “leaky pipeline” of women and minorities from the research and clinical arena.
- Mitigate perceived barriers and ensure ways by which more at-risk individuals remain eligible and benefit from transition awards.

- Destigmatize perceptions amongst diverse grantees regarding training mechanisms ear-marked for diverse populations through mentoring and educational efforts so that more individuals participate.
- Support for mentors (not just mentees) to dedicate effort to training the next generation is a priority.
- The staff of the NINDS provide instrumental service to the broader epilepsy research community, particularly the extramural Program Directors and Program Officers who support both trainees, new and established investigators. We encourage efforts to recruit, retain and reward excellence in the NINDS workforce commensurate with their efforts to serve persons living with epilepsy and the research community. We also recommend additional resources and support for the NINDS workforce.
- Enhance efforts to incorporate training and inclusion of biostatisticians, epidemiologists and outcome-based researchers to the neuroscience workforce. This might be achieved through funding of core facilities with experts to advise on research design or through direct training/recruitment efforts to bring them into neuroscience field.

The AES remains concerned that access to state-of-the-art treatments and subsequent outcomes are not uniformly available to patients with epilepsy and their families. Access to care varies across factors such as race, ethnicity, socioeconomic status, geographic location, and payer source. We place high priority on research that measures seizure outcomes and quality of life that evaluates differences in terms of

- access to specialized care
- use and reimbursement for telemedicine
- certification for (or lack of) of specialized technical services
- care across the age spectrum. Discovery and implementation of optimal interventions in childhood may change outcomes throughout a person's lifetime.