EPILEPSY FOUNDATION

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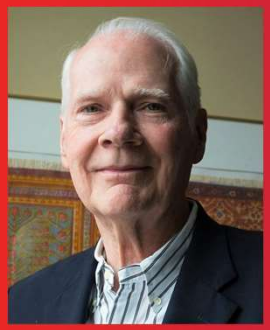
Social Determinants of Health in Epilepsy



MODERATOR

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Executive Director
National Association of County Behavioral Health & Developmental Disability Directors
National Association for Rural Mental Health
Adjunct Professor, Department of Mental Health
Bloomberg School of Public Health, Johns Hopkins University

GUEST SPEAKER

Magdalena Szaflarski, PhD
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The University of Alabama at Birmingham

MISSION STATEMENT

To lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures,
find cures, and save lives.

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Social Determinants of Health in Epilepsy

Magdalena Szaflarski, Ph.D.

University of Alabama at Birmingham

Learning Objectives

- ✓ Describe the social determinants of health framework
- ✓ Define and distinguish health disparities and health inequities
- ✓ Identify the social determinants of health and disparities in epilepsy and epilepsy care
- ✓ Identify strategies to address disparities in epilepsy and epilepsy care
- ✓ Discuss the role of advocacy groups, health care systems, academic institutions, and community partnerships in eliminating disparities in epilepsy and epilepsy care

Social Determinants of Health (SDH)

- The conditions in which people are born, grow, live, work, and age
- Shaped by the distribution of money, power and resources at global, national, and local levels
- SDH are mostly responsible for health inequities – *the unfair and **avoidable** differences in health*
  - Vs. health inequalities or disparities

World Health Organization

Social determinants of health

Commission on Social Determinants of Health, 2005-2008

World Health Organization (WHO)

Examples of SDH

Socioeconomic & Basic Life Conditions

- Socioeconomic status (SES)
  - Income level
    - Poverty
    - Income gradient
  - Educational opportunities
  - Occupation
- Employment status & work safety
- Food insecurity
- Access to housing & utility services

"The Numbers are Staggering: U.S. is 'World Leader' in Child Poverty"

Gender

- Gender economic inequality
- Political/power inequality

Gender Identity

- Gender diversity
- Sexual and gender minorities (SGM)

Race & Ethnicity

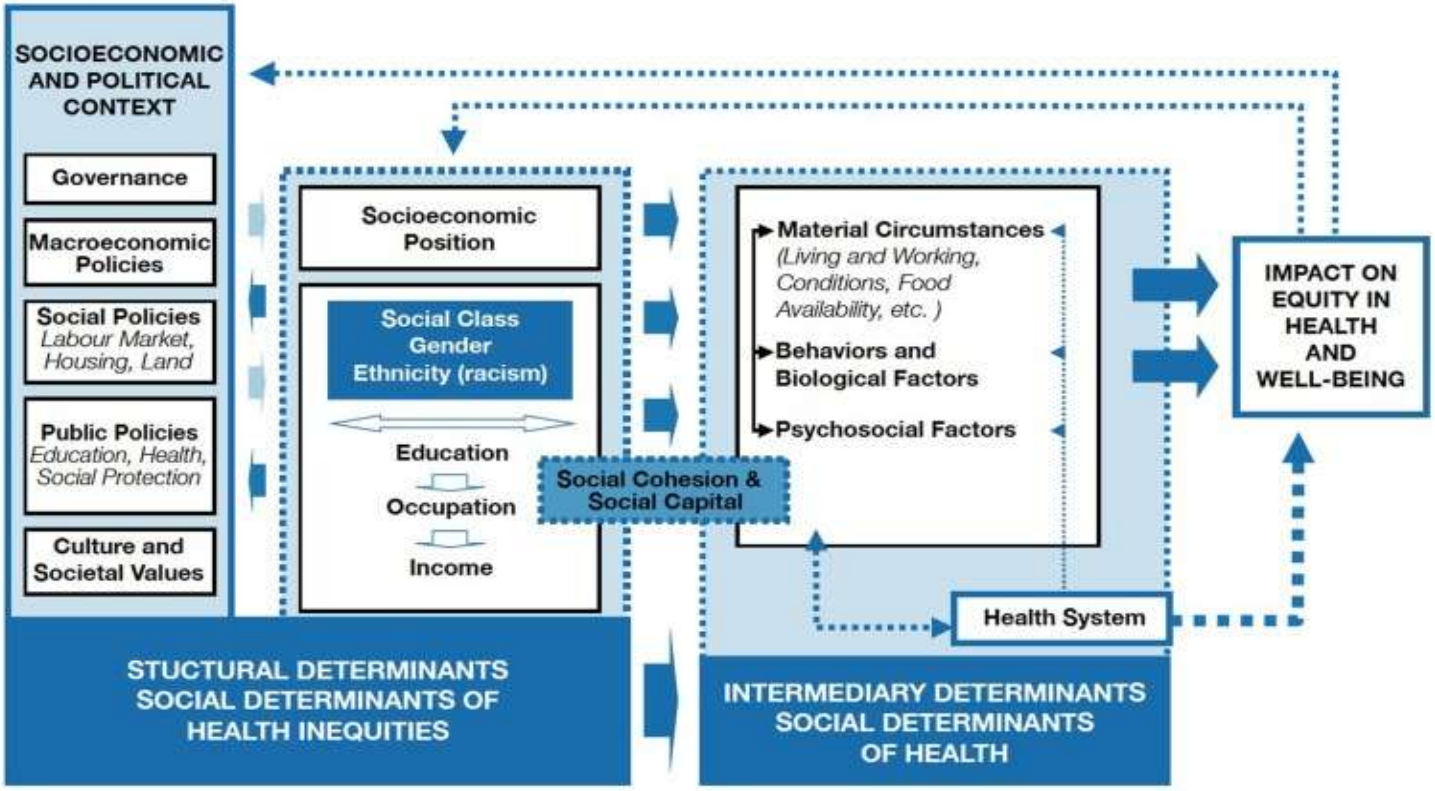
- Racism (overt & implicit)
- Structural racism
- Racial/ethnic segregation
- Immigrant status

Examples of SDH (cont.)

- Socioeconomic status (SES)
  - Income level
  - Educational opportunities
  - Occupation
- Employment status & work safety
- Gender & gender identity
  - Gender inequity
- Race & ethnicity
  - Racism & racial and/or ethnic segregation
- Food insecurity
- Access to housing & utility services

- Early childhood experiences & development => life course
- Social support & community inclusivity
- Crime rates & exposure to violence
- Availability of transportation
- Neighborhood conditions & physical environment
- Access to safe drinking water, clean air & toxin-free environments
- Recreational & leisure opportunities

WHO SDH Framework



WHO 2010

Health Disparities/Inequalities vs. Inequities

- Disparities – broad term, no precise or uniform definition
  - **Unequal distribution of disease and mortality across different groups** (based on SES, gender, race/ethnicity, etc.)
- Social system or disciplinary variations
  - Psychology/medicine approach disparities from the individual perspective
  - Public health/sociology from the social and population-level
- Cultural, regional, and country-based variations
  - Europe – focus on class and SES inequities (unjust & avoidable differences) in health and on equity-building
  - USA – focus on differences in health care and gaps in health status based on race/ethnicity; inequity – not a common term, and equity-building often disputed, controversial

Szaflarski & Vaughn 2014

"Equity isn't just about lifting up the poorest or the bottom, but it's the entire spectrum of disadvantage."

Health Affairs 2020

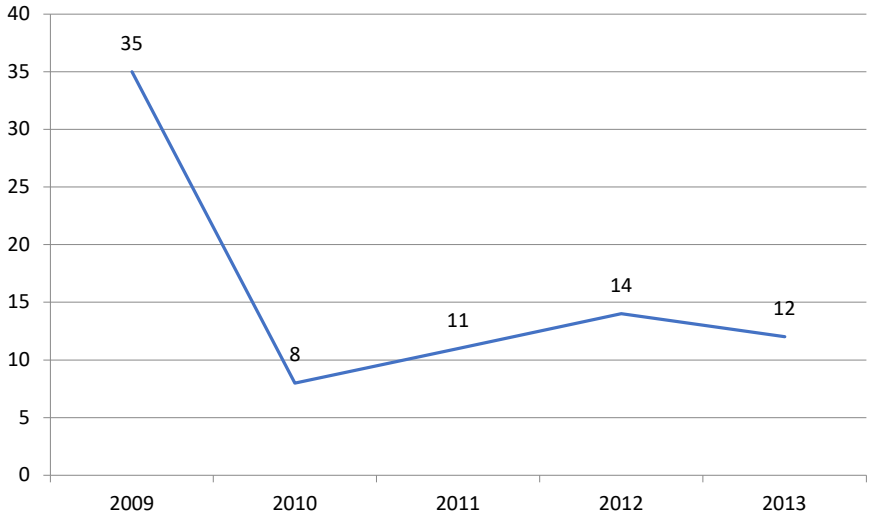
SDH-Epilepsy: Evidence Overview

- SDH
  - Socioeconomic factors
  - Race & ethnicity
  - Age
  - Gender
  - Contextual SDH
- Mechanisms: inequality production/reproduction

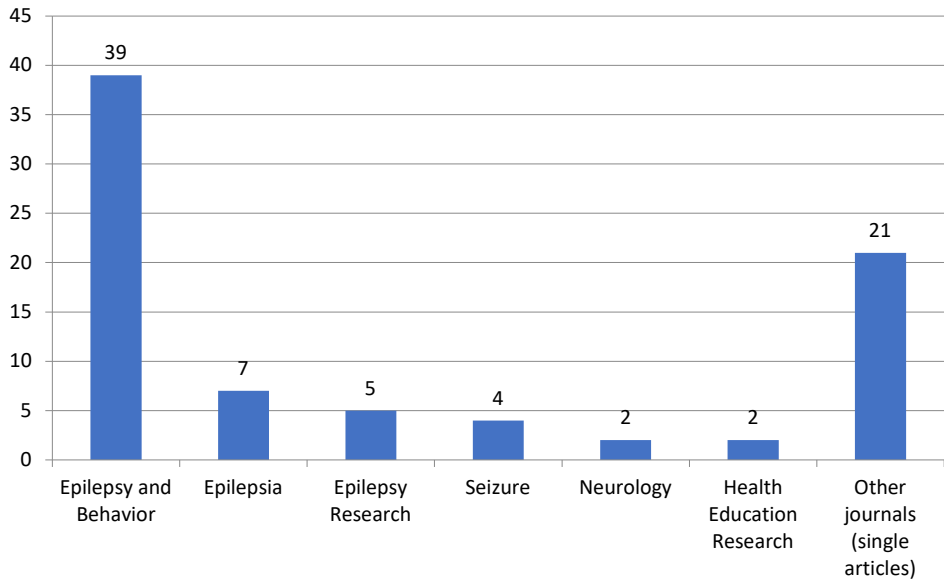
Szaflarski 2014

Relevant Published Evidence: 2009-2014

By Year



By Journal



Socioeconomic Factors in Epilepsy

- Socioeconomic deprivation increases incidence & prevalence of epilepsy
- People living with epilepsy (PWE) have lower education, household income, and health status vs. people who don't have epilepsy
- Finding employment is difficult for PWE

- HOWEVER:
- Inconsistent/mixed findings
- Complex relationships among social factors in epilepsy
- Associations vary by health measures, outcomes, controls
  - Prevalence
  - Antiseizure drug (AES) nonadherence
  - Role of health insurance
  - Health literacy

Race & Ethnicity in Epilepsy

- National adult samples: no race & nativity differences in visits to neurologist and use of AES, but…
- African American PWE shown to have higher rates of acute care, deaths; & less advanced treatments (epilepsy surgery)
- Native American disadvantage in visits to neurologist in some studies
- Hispanic/Latinx and immigrants – cultural and social position-related disparities

Age as a SDH in Epilepsy

- Special needs & vulnerability based on age
  - Children
  - Older adults
  - Working age population
  - Young adults
- Early childhood conditions
- Life course

Gender as a SDH in Epilepsy

- Some gender differences among adults with epilepsy, but not children
- Women shown to have higher use of neurology vs. general practice services
- Quality of life (QOL) may vary among adults based on gender (e.g., childbearing in women affecting QOL)
- Children shown to have same rate of surgery and QOL regardless of gender

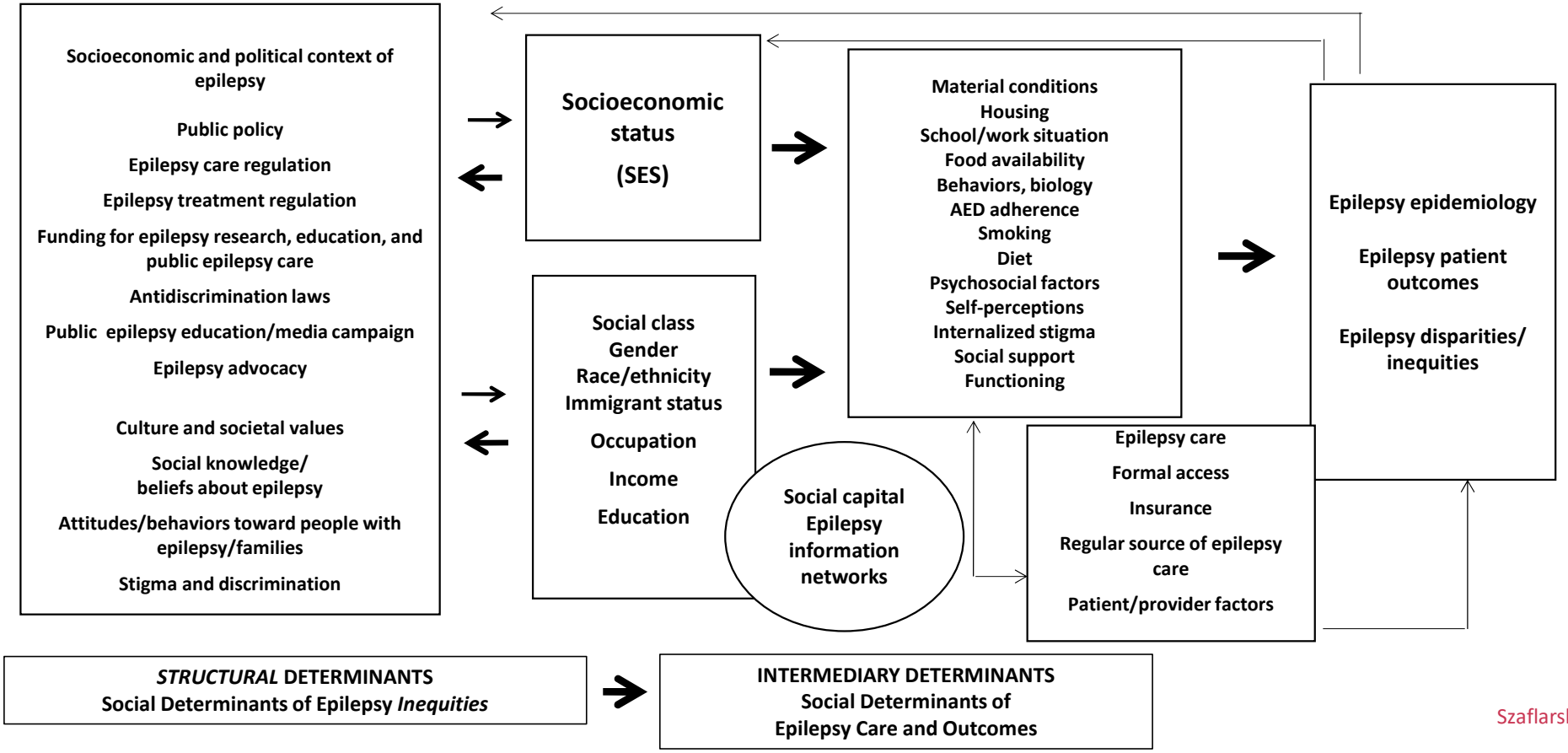
Contextual SDH in Epilepsy

- Neighborhood conditions – PWE reported to assess their neighborhood as safe compared to others
- Urban-rural differences – inconclusive evidence
- Macrostructural conditions: health policies, budgets, health care system/services, treatment regulation, insurance systems
  - Economic burden of epilepsy
- Cultural factors
  - Public awareness and knowledge
  - Attitudes and practices – stigma & discrimination, newly considered fundamental causes of disparities

Mechanisms: How SDH Lead to Inequalities in Epilepsy

- Complexity of associations among social factors and health outcomes in epilepsy
- Limited systematic evidence addressing mechanisms
- Conceptualizing based on the SDH Framework
  - Material conditions
  - Behavioral and biological
  - Psychosocial factors
  - Health system

SDH–Epilepsy: Proposed Framework



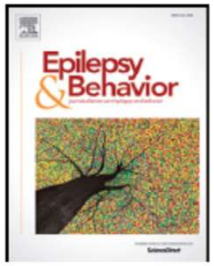
Szaflarski 2014

Epilepsy & Behavior 107 (2020) 107050

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh



Poverty, insurance, and region as predictors of epilepsy treatment among US adults

Magdalena Szaflarski [a,*], Joseph D. Wolfe [a], Joshua Gabriel S. Tobias [a], Ismail Mohamed [b], Jerzy P. Szaflarski [c]

- Lack of insurance and non-Northeastern location key barriers to seeing neurologist
- Poverty key barrier to antiseizure medication use

SDH in Treatment-Resistant Epilepsy

Family income	
<$40 K	22.5
$40 K+	77.5
Financial strain: money situation	
Comfortable with extra	42.5
Enough but no extra	40.0
Have to cut back	11.3
Cannot make ends meet	6.3
Financial strain: food scarcity	
Never	87.5
Sometimes	11.3
Often	1.3
Financial strain: can't afford AEDs	
Never	92.5
Sometimes	7.5
Often	0.0

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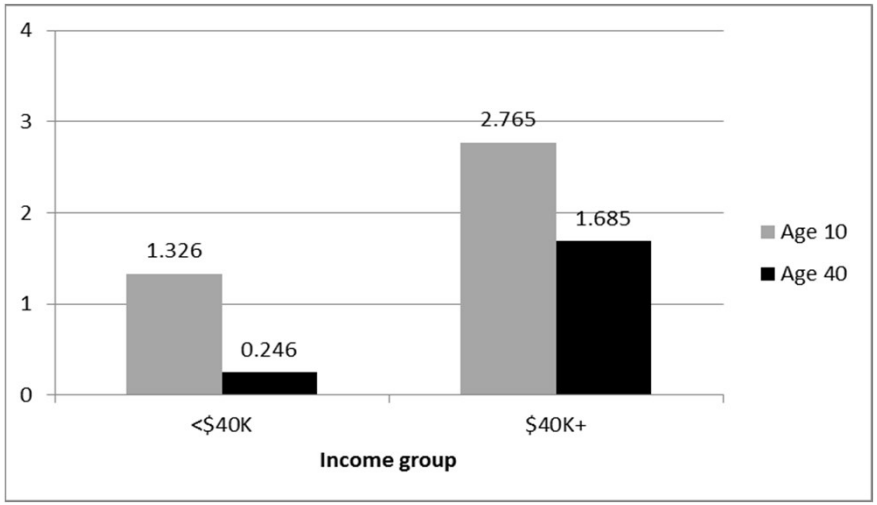
Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Social correlates of health status, quality of life, and mood states in patients treated with cannabidiol for epilepsy

Magdalena Szaflarski [a,*], Barbara Hansen [a], E. Martina Bebin [b], Jerzy P. Szaflarski [b]

Health ratings declined with age & income



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journal homepage: www.elsevier.com/locate/yebeh

Affiliate stigma and caregiver burden in intractable epilepsy

Barbara Hansen [a,*,1], Magdalena Szaflarski [a], E. Martina Bebin [b], Jerzy P. Szaflarski [b]

Health literacy and quality of life in patients with treatment-resistant epilepsy

Brie Scrivner [a,*], Magdalena Szaflarski [a], Elizabeth H. Baker [a], Jerzy P. Szaflarski [b]

Quality of life in adults enrolled in an open-label study of cannabidiol (CBD) for treatment-resistant epilepsy

Tyler E. Gaston [a,b,c,*], Magdalena Szaflarski [d], Barbara Hansen [d,1], E. Martina Bebin [a,b], Jerzy P. Szaflarski [a,b], for the UAB CBD Program

Strategies to Address SDH & Disparities in Epilepsy

- Institute of Medicine (IOM): *Epilepsy Across the Spectrum* (2012)
  - Surveillance of epilepsy including health disparities, service use/cost, quality and access to care, risk factors, and patient-centered outcomes
  - Public health and prevention – health policy, public health system interventions (from national to local)
  - Health care: quality, access, and value
    - Improving access to & quality of epilepsy care
  - Health professional education
    - Attitudes and beliefs (culture)
    - Professional education
    - Role of epilepsy organizations and centers

Strategies (cont.)

- IOM (cont.)
  - Quality of life and community resources
  - Education of patients/families
  - Public education/awareness
- *Healthy People 2020*
  - Objective DH-6: Increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care
    - Measure: visited a neurologist or epilepsy specialist in the past year
    - Progress toward goal: 10% improvement (58% in 2010 to 64% currently)

Role of Various Stakeholders in Combatting Disparities in Epilepsy/Epilepsy Care

- Patients/families
- Advocacy groups
- Health policy makers
- Health care systems
- Academic institutions: education, research, practice, and community and public engagement

Summary

- SDH are responsible for most variation in health status across populations/social groups (production of inequities)
- SDH Framework guides us in efforts to understand what SDH are, how they impact health/health care, and how to develop and prioritize interventions
- SDH apply in epilepsy and must be understood, in order to develop interventions at various social levels, but much work remains to be done on reaching goals
- Stakeholders in these efforts include: providers, patients/families, policy makers, public health officials, researchers, community and advocacy organizations – how much work remains to reach full levels of engagement??

Selected References with Further Sources

Szaflarski, Magdalena, Joseph D. Wolfe, Joshua Gabriel S. Tobias, Ismail Mohamed, and Jerzy P. Szaflarski. 2020. "Poverty, Insurance, and Region as Predictors of Epilepsy Treatment among US Adults." *Epilepsy and Behavior* 2020 107 (June): 107050. DOI: 10.1016/j.yebeh.2020.107050. link

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THANK YOU

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Questions?

Epilepsy Foundation (EF) – Information for Professionals
www.epilepsy.com/learn/information-professionals

Centers for Disease Control and Prevention (CDC)
www.cdc.gov/epilepsy/index.html

CDC Managing Epilepsy Well (MEW) Network
www.cdc.gov/epilepsy/research/MEW-network.htm

American Epilepsy Society (AES)
www.aesnet.org/clinical_resources/practice_tools

International League Against Epilepsy
www.ilae.org/patient-care/mental-health-care-resources

National Association of Epilepsy Centers
www.naec-epilepsy.org

American Academy of Neurology (AAN)
www.aan.com/Guidelines/home/ByTopic?topicId=23

Veterans Affairs Epilepsy Centers of Excellence (VA-ECE)
www.epilepsy.va.org

Epilepsy Foundation 24/7 Helpline
English: 1-800-332-1000
Spanish: 1-888-748-8008

Thank you