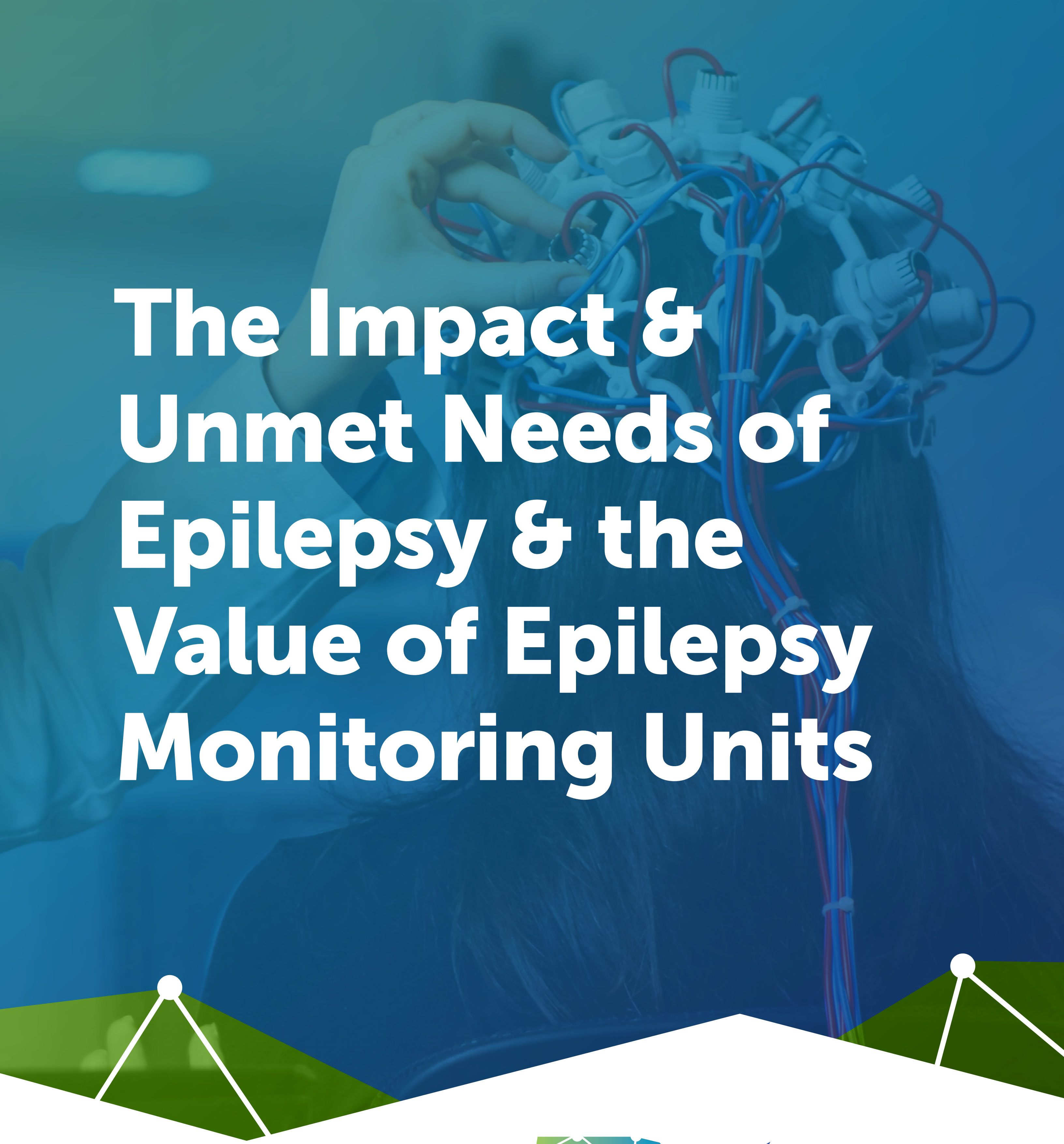


The Impact & Unmet Needs of Epilepsy & the Value of Epilepsy Monitoring Units

A Clinical Proceedings
White Paper
February 2026

Clinical
Neurological
Society of America

CNSA's Clinical Proceedings

The Clinical Neurological Society of America has more than 50 years of experience bringing together leading experts and clinical neurologists for educational programming. CNSA's Clinical Proceedings—a white paper series—are informational resources intended to raise awareness and address unmet needs in neurology. CNSA recognizes the expert panel members who contributed to the development of this white paper.

Daniel Friedman, MD
Chair

Gregory K. Bergey, MD, FAAN, FANA, FAES, FAAAS

Tanya Kehoe, PA-C, OTR/L

Mohamad Koubeissi, MD, MA, FAAN, FANA, FAES

John Stern, MD, MA, FAAN, FANA, FAES

CNSA acknowledges the professional writing assistance of Amy Sullivan, PhD, with Obrizus Communications in the preparation of this document. This Clinical Proceedings white paper was supported in part with funding from SK Life Science.

Table of Contents

Introduction

Approximately 3.4 million people in the United States have epilepsy, making it one of the most common neurological conditions in the country.[1,2] People with epilepsy have seizures causesd by excess electrical activity in the brain. While some types of epilepsy have obvious signs/symptoms, such as irregular movements or convulsions, other types have subtle signs/symptoms, such as brief staring spells or alteration of consciousness. In addition to seizures, epilepsy is associated with comorbid conditions (e.g., depression and anxiety) and activity restrictions (e.g., driving a car, some sports) that can increase the risk of premature death and negatively impact the overall quality of life of patients and their families.

Since symptoms can be intermittent and/or subtle, epilepsy can be difficult to recognize and diagnose. Even when it is diagnosed, a large portion of people fail to respond to anti-seizure medications. To improve care for those with epilepsy, particularly those with difficult to diagnose and drug-resistant epilepsy, patients need more access to specialized care, including epilepsy monitoring units, or EMUs. EMUs are inpatient hospital units that are staffed by epilepsy specialists who can safely record seizures, with the ultimate goal of accurately diagnosing patients and developing appropriate treatment plans. With the ability to promote timely diagnosis and effective treatment, EMUs are important resources for people suffering from epilepsy, with the potential to improve the day-to-day life and outcomes of patients and their families.

What is Epilepsy?

Epilepsy is a neurological disorder that is characterized by the propensity for repetitive seizures. A seizure consists of abnormal electrical activity in the brain that can cause changes in behaviors, movements, feelings, and levels of consciousness. Depending on the type of seizure and the area of the brain affected, the symptoms can vary. They may include:

- Temporary confusion
- Staring
- Stiff muscles
- Uncontrollable jerking movements
- Loss of consciousness/ awareness
- Psychological symptoms, such as fear or anxiety[3]

Such symptoms may last from a few seconds to a few minutes[4] (over five minutes is considered a medical emergency[5]). Seizures can also happen with different frequencies in different people. For example, some people may have seizures once a year while others may have hundreds per day.[4]

If a person has a single seizure, it does not necessarily mean that the person has epilepsy. Seizures may be caused by other factors such as head injuries, infections, metabolic problems, or medications.[4] Epilepsy is defined as having two or more seizures at least 24 hours apart that don't have a known cause.[4]

Epilepsy is common, with 1 in 26 people in the United States developing the condition.[2] It is also known to affect people of all sexes, ages, races, and socioeconomic levels; however, it does not necessarily affect all these groups equally. It has been reported that the prevalences of different types of epilepsy can vary between males and females.[6] In addition, while epilepsy can occur at any age, onset more often occurs at younger and older ages, with those over the age of

60 having the highest incidence of the disease.[3,7] There are also differences in the prevalence of epilepsy among different races. The US Centers for Disease Control (CDC) reported that of the adults with active epilepsy in 2021–2023, 69.1% were non-Hispanic White, 13% were non-Hispanic Black, 12.5% were Hispanic, 1.4% were non-Hispanic American Indian/Alaska Native, and 0.8% were Asian.[8] It has also been observed that epilepsy occurs more often in those of lower socioeconomic status.[9]

> “No group is unaffected by epilepsy.”
>
> **–John Stern, MD, MA, FAAN, FANA, FAES**

> “Epilepsy affects everybody across the spectrum, but the risk is not distributed equally across the U.S.”
>
> **–Daniel Friedman, MD**

Different Types of Seizures

There are two main categories of seizures:[3,5]

Focal Seizures

- Start on one side of the brain
- May cause changes in awareness, behaviors, or sensations
- May cause abnormal movements on one side of the body

Different types of focal seizures:

- Focal aware seizures *(simple partial seizures)*:
  - no loss of awareness
  - emotions and senses may be altered
  - may have involuntary jerking of a body part
  - may experience déjà vu
- Focal impaired consciousness seizures *(complex partial seizures)*:
  - loss of awareness
  - may feel like a dream
  - may stare into space and not respond
  - may have repetitive movements

Generalized Seizures

- Start on both sides of the brain
- Usually affect consciousness/awareness
- May cause abnormal movements on both sides of the body

Different types of generalized seizures:

- Absence seizures:
  - sudden lapses of consciousness
  - may stare into space
  - may have subtle movements, such as eye blinking or lip smacking
  - last 5–10 seconds
- Tonic seizures:
  - muscles stiffen *(usually back, arms, and legs)*
  - may affect consciousness
  - may cause the person to fall
- Atonic seizures:
  - loss of muscle control *(usually legs)*
  - often causes the person to fall
- Clonic seizures:
  - repeated or rhythmic muscle movements *(usually neck, face, and arms)*
- Myoclonic seizures:
  - sudden, brief jerks or twitches *(usually the upper body, arms, and legs)*
- Tonic-clonic seizures *(grand mal seizures)*:
  - sudden loss of consciousness
  - body stiffening, twitching, or shaking
  - may lose bladder control
  - may bite tongue

The Impacts of Epilepsy

Patient burdens

Lower overall health

Epilepsy has a tremendous impact on overall patient health. Indeed, people with epilepsy have higher rates of injury, such as fractures or bruising, due to the seizures themselves.[10] In addition, approximately 50% of people with active epilepsy also have at least one comorbid condition, such as dementia, migraines, heart disease, peptic ulcers, or arthritis.[9,11] Psychiatric conditions, such as depression and anxiety, are also reported in 29 to 40% of people with epilepsy, which is 7 to 10 times higher than the prevalence in the general population.[9] Consequently, 42.6% of US adults with active epilepsy report having fair or poor health, and 38.4% report having a disability.[8]

> “There is a higher incidence of anxiety and depression in people with epilepsy. People talk about depression a lot, but anxiety also occurs in about 30% of patients.”
>
> **–Gregory K. Bergey, MD, FAAN, FANA, FAES, FAAAS**

> “Depression, when it is present, can ruin an epilepsy patient’s quality of life. One study found that the impact of concomitant depression on the quality of life of people with epilepsy is much more than the impact of the seizures themselves.”
>
> **–Mohamad Koubeissi, MD, MA, FAAN, FANA, FAES**

Higher risks of premature death

The risk of premature death in those with epilepsy is, on average, 2 to 3 times higher than what is observed in the general population.[9,12] This is particularly true for those people who have drug-resistant epilepsy. In fact, people who continue to have seizures have an almost 40 times higher risk of mortality than those who have attained seizure freedom.[9] Some reasons for this increased mortality include sudden unexplained death in epilepsy patients (SUDEP), status epilepticus, and injuries/accidents.[12,13]

> “SUDEP—sudden unexpected death in epilepsy—is one of the most common causes of mortality in epilepsy. It scares every patient and physician, and, unfortunately, we deal with it once or twice a year in our clinics, which is really the saddest thing.”
>
> **–Mohamad Koubeissi, MD, MA, FAAN, FANA, FAES**

Suicide also significantly contributes to the increased mortality observed in people with epilepsy.[13] It is estimated that 5 to 14.3% of people with epilepsy either attempt or complete suicide.[9] This is particularly important in the context of comorbid psychiatric conditions because people who have epilepsy without a comorbid psychiatric disorder have a 2 to 3 fold higher risk of committing suicide, but the risk increases 12 to 32 fold for those who do have an accompanying psychiatric condition.[20]

> “Suicide is a consequence of the disease and its related psychosocial impacts. In some studies, people with epilepsy have a 10 to 20 fold increased risk of suicidal behavior and completed suicide compared to the general population.”
>
> **–Daniel Friedman, MD**

Lower quality of life

Epilepsy can have a great impact on quality of life, with those with epilepsy generally reporting a lower quality of life than those without epilepsy.[21] In particular, having seizures that occur with higher frequency, have longer durations, include convulsions, or have an earlier age of onset have been associated with reduced quality of life.[22] Those with drug-resistant epilepsy also carry higher burdens of disease and have lower quality of life than those with controlled epilepsy.[9] Major contributors to the lower quality of life observed are the physical and emotional/mental effects of the seizures themselves as well as the associated comorbidities.[13] Side effects from anti-seizure medications can also contribute to poorer quality of life, particularly for those on a greater number of medications.[13]

Seizure Freedom

> “The rule of thumb is that you don’t consider someone seizure-free until they’ve gone either a year or three times their longest pre-treatment seizure interval without a seizure, whichever is longer. This means that if someone only has a seizure every 6 months, that’s a year and a half of waiting to see if they are out of the woods.”
>
> **–Daniel Friedman, MD**

Sudden Unexpected Death in Epilepsy (SUDEP)

SUDEP is a term used to describe deaths of people with epilepsy that are not caused by injury, drowning, status epilepticus, or other known causes.[14] It most often occurs after a generalized tonic-clonic seizure in bed during sleep, with the person being found face down on their stomach (prone position).[15] However, SUDEP may also be caused by breathing, heart, or other problems that may arise during a seizure.[14] SUDEP is rare, occurring in 1 out of every 1,000 adults and 1 out of 4,500 children with epilepsy.[16] SUDEP rates are higher for those who are not seizure-free, those with intellectual disability, and those with low socioeconomic status.[16–18]

Status Epilepticus

Status epilepticus refers to an instance where a seizure lasts longer than five minutes or when seizures occur back to back with no recovery time in between.[19]

In addition, the constant fear of having another seizure and the embarrassment associated with having seizures can promote anxiety and social isolation.[13,23,24] Furthermore, despite epilepsy being one of the world's oldest recognized conditions, there is still a lot of stigma associated with the disease that can lead to discrimination.[10,25]

For example, someone with epilepsy may be discriminated against in the workplace due to an employer's misunderstanding or fear of their condition, which may be linked to concerns surrounding the potential for a workplace accident.[26] Such treatment can contribute to depression as well as higher unemployment rates and limits to career progression, particularly for those with uncontrolled seizures.[27,28] There may also be difficulties associated with the somewhat hidden nature of the disease in that people with epilepsy look fine as long as they are not having seizures; however, they can be incapacitated at any time when a seizure occurs.

Drug-Resistant Epilepsy

Drug-resistant epilepsy, also known as intractable or refractory epilepsy, refers to epilepsy that does not respond well to anti-seizure medications. More specifically, epilepsy is considered drug-resistant when a person fails to reach seizure freedom after adequate trials of two appropriate anti-seizure medications.[29] About one-third of people with epilepsy will develop drug-resistant epilepsy.[30]

> “There's a lot of anxiety related to epilepsy. There's the fear of the next seizure and not knowing what the future will look like in addition to the stigma and lower self-esteem.”
>
> **–Mohamad Koubeissi, MD, MA, FAAN, FANA, FAES**

> “It's not just the seizures themselves that can have an impact. There are also side effects from medication and cognitive side effects that occur after a seizure that can decrease quality of life.”
>
> **–Tanya Kehoe, PA-C, OTR/L**

> “There is an ongoing issue of how visible the condition is to others. With longer times between seizures or seizures that aren't really obvious to others it can create the question of whether there is really a disability. However, the seizures are often unpredictable and are disabling at the time.”
>
> **–John Stern, MD, MA, FAAN, FANA, FAES**

In addition to the direct physical and emotional/mental effects as well as its comorbid conditions, epilepsy is often associated with restrictions that can limit activities, leading to reduced quality of life. Indeed, some leisure activities, such as swimming, climbing, biking, or some sports, may need to be restricted or avoided because of the increased risk of serious injury in the event of a seizure.[31]

People with epilepsy may also be restricted from driving, which can affect employment, the ability to complete life tasks, such as grocery shopping, and the ability to attend medical appointments and pick up prescription medications.[13,32,33] Such restrictions can be especially difficult in areas without extensive and reliable public transportation systems, like rural areas.[32] People with epilepsy, particularly those with uncontrolled epilepsy, may also be restricted by the types of jobs they are able to pursue because it may pose a risk to themselves or others. Such high-risk jobs may include those in transportation (e.g., pilot, bus/truck driver), those that involve working at heights (e.g., roofer), or those that require work with dangerous construction or industrial machinery. Having epilepsy has also been associated with lower levels of education, which can have broader effects on employment and timely access to epilepsy treatment.[34]

> “People with epilepsy have lower rates of employment, higher rates of disability, lower rates of marriage or being in a stable, long-term relationship, so the disease affects all aspects of life. It’s also much worse for those with treatment-resistant epilepsy.”
>
> **–Daniel Friedman, MD**

> “The inability to drive is going to have a greater impact on those with epilepsy that live in rural areas where they don’t have subway or bus systems readily available.”
>
> **–Gregory K. Bergey, MD, FAAN, FANA, FAES, FAAAS**

Family/caregiver burdens

Lower quality of life

People with epilepsy are not the only ones who are affected by their condition; their families/caregivers (often a parent or spouse) may also experience reduced quality of life. Much of this decrease is due to the worry associated with when the next seizure will happen and whether the person will be sleeping, driving, or alone when it happens.[24]

Depending on the severity and frequency of seizures, caregivers may also have to take on more household and medical responsibilities, including maintaining employment, handling child care, driving to medical appointments, and helping with medication adherence.[35] Families/caregivers may also experience stigma and/or embarrassment associated with the seizures and epilepsy diagnosis that can result in feelings of embarrassment, guilt, social isolation and loss of social support or relationships.[36]

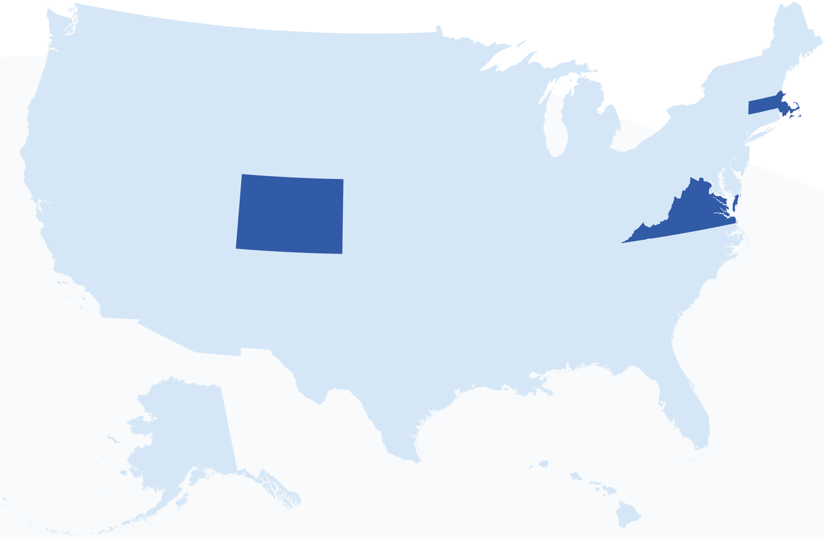
> “What most of us hear from the family member who sees the first seizure is that they thought their loved one was dying, so there’s tremendous trauma from witnessing the seizures and, therefore, a fear of the seizures occurring again.”
>
> **–John Stern, MD, MA, FAAN, FANA, FAES**

> “The state of caregivers of people with epilepsy goes hand in hand with how well the seizures are controlled and how complex the medication management is. You’ll see caregivers are a lot more stressed out if the seizures are increasing.”
>
> **–Tanya Kehoe, PA-C, OTR/L**

Economic burdens

The economic burden of epilepsy is immense, with national direct costs due to epilepsy estimated to be $5.4 billion (2019 U.S. dollars, based on 2010 to 2018 data) per year.[37] Hospitalizations and anti-seizure medications have been cited as the source of most of this expense;[9,38] therefore costs are particularly high for those with drug-resistant epilepsy, those without insurance, and those who experience delays in appropriate treatment.[39–42] In addition to direct medical expenses, families of people with epilepsy also incur a great deal of indirect costs due factors such as more days of missed work (for both the person with epilepsy and the caregiver), higher unemployment rates and higher travel expenses.[9,42,43] This loss of productivity can have further consequences for national social systems because of lost income taxes and increased need for social services, such as disability benefits.

Costs of Epilepsy



A study of all-payer claims data from three US states (Colorado, Virginia, and Massachusetts) found that the estimated healthcare costs for adults with epilepsy ranged from **$28,000 to $34,000** (2021 US dollars) annually, with the costs attributable to epilepsy ranging from **$12,000 to $31,000**, depending on the covariates included.

In contrast, annual healthcare costs for matched non-epilepsy controls were between **$2,900 and $6,300**

Barriers to Timely and Accurate Diagnosis

Lack of seizure recognition

One of the primary reasons that diagnosis and treatment of epilepsy are delayed is the under-recognition of seizures by patients, families, and healthcare workers.[17] While the symptoms of motor seizures are usually more obvious, non-motor seizures often have subtle symptoms that the person isn't aware of and are difficult to detect by others. Notably, one study reported that the delay to diagnosis was ten times longer for those with non-motor seizures than those with motor seizures at epilepsy onset.[45]

> “The average person on the street thinks of a seizure as a convulsion, but the majority of seizures are non-convulsive.”
>
> **–Gregory K. Bergey, MD, FAAN, FANA, FAES, FAAAS**

> “Part of the delay in diagnosis is related to the types of seizures the patients are having. While it's the dramatic convulsions that lead emergency or primary care physicians to an epilepsy diagnosis and referral to neurology, the reality is that these patients have been having smaller seizures, such as focal aware or focal impaired aware seizures, for upwards of several years without anybody recognizing them.”
>
> **–Daniel Friedman, MD**

> “Some patients can be unaware of their own seizures. I had a patient who was living alone tell me for years that she was seizure-free until she had one in the clinic. She had no idea. She didn't know that they were happening, and no one witnessed her seizures.”
>
> **–Mohamad Koubeissi, MD, MA, FAAN, FANA, FAES**

Misdiagnosis

In addition to difficulties initially recognizing seizures, identifying what kinds of seizures a person is having is important for accurate diagnosis and appropriate treatment. For example, it is essential to know whether a person is having focal or generalized seizures because they are treated with different medications.[46] In addition, functional seizures, also known as psychogenic non-epileptic seizures (PNES), are often mistaken for epileptic seizures. Functional seizures look like epileptic seizures in that they are unintentional, with altered consciousness as well as sensory or motor symptoms.[46,47] However, they are not caused by electrical overload in the brain.[46] Instead, they are thought to be psychological in nature and may be triggered by conditions such as post-traumatic stress disorder (PTSD).[48] Due to such differences in etiology, surgeries and anti-seizure medications that work for epilepsy do not work for functional seizures.[46] Therefore, misdiagnosis of functional seizures as epilepsy could result in patients having prolonged symptoms, being subjected to harmful medication side effects and undergoing unnecessary surgical procedures.

> “Non-epileptic episodes and epilepsy are confused a lot.”
>
> **–Tanya Kehoe, PA-C, OTR/L**

> “Of patients with epilepsy, 25 to 30% of them will have co-existing non-epileptic seizures. Sometimes the patient and family can tell them apart and sometimes they can’t, so it’s important to understand which types of seizures they are currently having.”
>
> **–Daniel Friedman, MD**

Lack of education

Another factor that can delay epilepsy diagnosis and treatment is the lack of education about the condition. While a lack of education can delay seizure recognition, it can also perpetuate stigma and fear surrounding epilepsy, which can prevent people from reaching out to a healthcare provider when they start having symptoms.[17] While stigma exists in all areas, the degree of stigma can vary due to factors such as geographic location or cultural background. In fact, some cultures still think that epilepsy is caused by possession by evil spirits, witchcraft, or poisoning and that it is contagious,[49] resulting in more stigma and further isolation of those with the disease. Importantly, it has been shown that improving public awareness and knowledge of epilepsy decreases the amount of stigma,[50] making education an important part of improving epilepsy care and patient/caregiver quality of life.

> “Some of the impact of epilepsy can be cultural. For example, in parts of Asia, there is a very strong stigma associated with epilepsy, so a diagnosis for someone associated with one of these areas may be particularly devastating.”
>
> **–Gregory K. Bergey, MD, FAAN, FANA, FAES, FAAAS**

Appropriate diagnosis and treatment of epilepsy may also be delayed because people having seizures may not know that they need an epileptologist and specialized care.[51] Physicians also may not know what epilepsy resources, such as epilepsy monitoring units and epilepsy centers, are available in their area and when they should be sought out. Indeed, only a small fraction of patients are referred to specialty care within two years of developing drug-resistant epilepsy and it is common to have many years of delay before a referral is made for epilepsy surgery.[52] Therefore, educating both patients and physicians on the specialty resources available for diagnosing and treating epilepsy should improve timely access to appropriate care, resulting in better overall outcomes.

> “Knowing that one could benefit from accessing an expert clinician is a remaining problem because, so often, patients say that they didn’t know that this type of specialty care existed.”
>
> **–John Stern, MD, MA, FAAN, FANA, FAES**

> “Delayed care may occasionally happen because of a patient’s hesitation or non-adherence, but the vast majority of delays are due to the high threshold for physicians to refer to a specialized epilepsy center. It’s not good. It leads to patient mortality.”
>
> **–Mohamad Koubeissi, MD, MA, FAAN, FANA, FAES**

Lack of access to appropriate care

A lack of access to appropriate care can also delay the diagnosis and treatment of epilepsy. There are multiple reasons for such lack of access. Economic constraints may prevent people from seeking care, particularly from specialists. Indeed, socioeconomic disadvantages have been associated with delays in epilepsy diagnosis and care,[53] and patients without insurance are less likely to see a neurologist.[32] Moreover, since many people with epilepsy are unable to drive, medical appointment attendance may be affected by a lack of transportation.[32,54] This is particularly true for those in rural areas who may have to travel to big cities to see a specialist (neurologist, epileptologist), since the majority of neurologists (94.33%) practice in urban metropolitan areas.[51,55,56]

Epileptologist

An epileptologist is a neurologist who specializes in the diagnosis and treatment of epilepsy.

Shortages of neurologists and epileptologists may also be a barrier to access to care. The Association of American Medical Colleges reported that there were 14,765 neurologists in the U.S. in 2023, translating to four neurologists for every 100,000 people nationally.[57] However, these specialists were not equally distributed throughout the country. For example, Western states had two to five neurologists for every 100,000 people, while states in the Northeast had three to ten neurologists for every 100,000 people.[57] Certified epileptologists are even more scarce, with only 2,169 active practitioners in the country in 2024.[56] Similar to neurologists, epileptologists are also not uniformly distributed geographically. For instance, the South had the highest ratio of patients to specialists (1,904 to 1), while the Northeast had the lowest ratio (1,117 to 1).[56] Therefore, having more specialists in more areas of the country and expanding the use of telehealth could lead to a significant improvement in patient access to care, which would speed up the diagnosis and treatment of epilepsy.

> “Epilepsy, particularly for follow-up visits, lends itself to telehealth in many, many patients. The problem, of course, is keeping telehealth a viable alternative in terms of economics and insurance coverage, particularly when the physician is located in a different state than the patient.”
>
> **–Gregory K. Bergey, MD, FAAN, FANA, FAES, FAAAS**

The Value of Epilepsy Monitoring Units (EMUs) in Improving Diagnosis and Treatment

> “If you want to have a true impact on the quality of life of someone with seizures, you make them seizure-free.”
>
> **–Gregory K. Bergey, MD, FAAN, FANA, FAES, FAAAS**

An important specialty resource for epilepsy patients, particularly those with drug-resistant epilepsy, is an epilepsy monitoring unit (EMU). An EMU is an elective, inpatient unit at a hospital where epilepsy specialists can observe and record patients' seizures. When a patient enters an EMU, they are usually there for one to seven days, but it could be longer, depending on the patient. While a patient is in the EMU, they are constantly monitored with a video electroencephalogram (EEG). For a video EEG, a video camera is used to continuously film the patient during their stay, while an EEG records their brain activity via electrodes placed on the scalp. Video EEGs allow epileptologists to compare the video of an episode to the brain activity occurring during the episode to determine whether the person is having an epileptic seizure or a non-epileptic event, such as a functional seizure.

Along with the video EEG, additional diagnostic tests, such as lab work or neuropsychological tests, may also be performed during an EMU stay. The doctor may also order brain imaging studies, such as computed tomography (CT) scans, magnetic resonance imaging (MRI), or single-photon emission computed tomography (SPECT).[58] The results of these tests can provide more detailed information about a person's seizures so that an epileptologist can ascertain what types of seizures are occurring and where they are occurring in the brain. This information is important for determining what anti-seizure medications may be most effective and whether any non-drug treatments, such as diet therapy, devices, or surgery may be appropriate to treat the patient's specific type(s) of seizures.[59]

> “Diagnostic accuracy is crucial. Evaluation at an EMU is the diagnostic gold standard for determining the true nature of epileptic and epileptic-like events, such as functional seizures.”
>
> **–Mohamad Koubeissi, MD, MA, FAAN, FANA, FAES**

> “The value of an EMU is that it can clarify the diagnosis and also determine the type of epilepsy, which is relevant for making care decisions.”
>
> **–John Stern, MD, MA, FAAN, FANA, FAES**

Who needs an EMU?

Not every person with epilepsy needs to go to an EMU. Those people whose seizures are controlled with medication may never need to go to an EMU. However, a person may need to go to an EMU if:

- The diagnosis is not definitive; it is unclear whether the seizures are actually being caused by epilepsy
- The seizures are not being controlled by anti-seizure medications
- Surgery, stimulation devices, or dietary therapy are being considered as treatment options

Levels of epilepsy care

The National Association of Epilepsy Centers (NAEC) has defined 4 levels of epilepsy care.[60]

Level 1 The first level of epilepsy care typically occurs in a primary care physician's office or an emergency room. It consists of an evaluation for epilepsy and may include a prescription for an anti-seizure medication. If seizure freedom is obtained, then no further evaluation may be necessary.

Level 2 The second level of care involves a consultation with a general neurologist. A visit to a neurologist becomes necessary if seizures persist and are not brought under control by the anti-seizure medication prescribed by the primary care physician within 3 months.

Level 3 The third level of care is for patients whose seizures are not responding to standard medical therapy (seizures remain uncontrolled after 12 months of treatment or 2 failed medications) or those who are having persistent medication side effects. This level of care is offered at level 3 or level 4 NAEC-accredited epilepsy centers that provide basic neurodiagnostic evaluations, such as EMUs, as well as medical, neuropsychological, and psychosocial services provided by a team of specialists, including epileptologists, neurosurgeons, neuropsychologists, nurse specialists, EEG technologists and social workers.

Level 4 The fourth level of care is for patients with more complex cases of epilepsy. This level of care is offered at level 4 NAEC-accredited epilepsy centers. Level 4 centers offer all the services offered by level 3 centers but are also capable of providing more intensive neurodiagnostic evaluations as well as more extensive treatment options, including a broad range of surgical procedures, which includes the implantation of neuromodulatory devices.

While it is possible for video EEGs to be performed at home or in outpatient centers, these settings may not be suitable for all patients. For example, if medications need to be lowered to improve the chances of recording a seizure, then, for the patient's safety, the video EEG needs to be performed in an EMU where they are under constant surveillance and close medical supervision. Being in an EMU also enables physicians to safely use seizure-inducing activities, such as hyperventilation, sleep deprivation or flashing lights (photic stimulation), to help the care team get recordings of the patient's seizures. Such information is vital for determining what is going on in the brain during a seizure, which is key for attaining a correct diagnosis and improving the chances of identifying an effective treatment.

> “Home video EEGs can be ordered, but they are limited because you don't adjust meds. It would be unsafe for patients to do that at home.”
>
> **–Tanya Kehoe, PA-C, OTR/L**

EMUs are an essential part of epilepsy care for many patients. While about two-thirds of people with epilepsy are able to manage the condition with medication, the remaining third develop drug-resistant disease that requires more extensive medical and/or surgical interventions to achieve seizure freedom.[32,51] In fact, it has been reported that less than 3% of patients with drug-resistant epilepsy achieve seizure freedom with continued use of multiple drugs.[61] In addition, 20 to 40% of patients that are referred to an EMU for difficult to control seizures end up being diagnosed with functional seizures, not epilepsy.[48] Due to such misdiagnosis, these patients may be subjected to treatments, including medications and, in some extreme cases, surgery, that will never be effective.[46] Therefore, EMUs are valuable resources for patients with seizures because they promote timely and appropriate diagnosis as well as prevent unnecessary treatments, resulting in better quality of life and outcomes for patients and their families.

> “Sometimes we'll see patients come in from community hospitals where they don't have an EMU and will have multiple medications on board. Then, after we capture their episodes in the EMU, we'll find that their episodes are actually non-epileptic, so the medications aren't going to help.”
>
> **–Tanya Kehoe, PA-C, OTR/L**

Conclusion

Epilepsy has great impacts on the overall health and quality of life of not only the millions of Americans affected by the disease but also their families. To minimize the negative effects of epilepsy, educating the public and elevating awareness of the disease is crucial. Such steps will not only reduce the social stigma and discrimination related to epilepsy but will also promote timely recognition of seizures and the prompt use of key specialized medical resources, including EMUs. The use of EMUs is particularly important for those suffering from uncontrolled seizures because they enable early and accurate diagnosis and the identification of appropriate treatment(s) that will minimize the burdens of disease.

About the Clinical Neurological Society of America

Established in 1974, the Clinical Neurological Society of America is a non-profit 501(c)(6) made up of neurologists and other health care professionals practicing in clinical and academic settings. CNSA's mission is to improve clinical practice and patient care through education and thought leadership.

CNSA is led by a volunteer board of directors who, like the society's members, hail from across the country and treat patients with a range of neurologic conditions.

Sarah Zallek, MD, FAAN, FANA, FAASM, DipABLM
President

Amy Brown, MD, MS
President-Elect

David J. Houghton, MD, MPH
Immediate Past President

Kyle Ruffing, MD
Secretary/Treasurer

Garret Conyers, MD
Board Member At-Large

Ashley Ghiaseddin, MD
Board Member At-Large

Sina Linman, CPNP, APRN
Board Member At-Large

References

1. CDC. Epilepsy Facts and Stats. Epilepsy. October 3, 2024. Accessed May 22, 2025. https://www.cdc.gov/epilepsy/data-research/facts-stats/index.html
2. Epilepsy by the Numbers | Epilepsy Foundation. Accessed October 2, 2025. https://www.epilepsy.com/about/impact
3. Mayo Clinic. Epilepsy - Symptoms and causes. Accessed October 2, 2025. https://www.mayoclinic.org/diseases-conditions/epilepsy/symptoms-causes/syc-20350093
4. Seizures - Symptoms and causes. Mayo Clinic. Accessed October 2, 2025. https://www.mayoclinic.org/diseases-conditions/seizure/symptoms-causes/syc-20365711
5. CDC. Types of Seizures. Epilepsy. August 21, 2024. Accessed October 2, 2025. https://www.cdc.gov/epilepsy/about/types-of-seizures.html
6. Samba Reddy D, Thompson W, Calderara G. Molecular mechanisms of sex differences in epilepsy and seizure susceptibility in chemical, genetic and acquired epileptogenesis. *Neurosci Lett*. 2021;750:135753. doi:10.1016/j.neulet.2021.135753
7. Beghi E, Giussani G, Costa C, et al. The epidemiology of epilepsy in older adults: A narrative review by the ILAE Task Force on Epilepsy in the Elderly. *Epilepsia*. 2023;64(3):586-601. doi:10.1111/epi.17494
8. CDC. Data and Statistics on Adults with Active Epilepsy. Epilepsy. April 15, 2025. Accessed May 22, 2025. https://www.cdc.gov/epilepsy/data-research/facts-stats/data-and-statistics-on-adults-with-active-epilepsy.html
9. Ioannou P, Foster DL, Sander JW, et al. The burden of epilepsy and unmet need in people with focal seizures. *Brain Behav*. 2022;12(9):e2589. doi:10.1002/brb3.2589
10. World Health Organization. Epilepsy. Accessed May 22, 2025. https://www.who.int/news-room/fact-sheets/detail/epilepsy
11. Keezer MR, Sisodiya SM, Sander JW. Comorbidities of epilepsy: current concepts and future perspectives. *Lancet Neurol*. 2016;15(1):106-115. doi:10.1016/S1474-4422(15)00225-2
12. Trinka E, Rainer LJ, Granbichler CA, Zimmermann G, Leitinger M. Mortality, and life expectancy in Epilepsy and Status epilepticus—current trends and future aspects. *Front Epidemiol*. 2023;3. doi:10.3389/fepid.2023.1081757
13. Strzelczyk A, Aledo-Serrano A, Coppola A, et al. The impact of epilepsy on quality of life: Findings from a European survey. *Epilepsy & Behavior*. 2023;142:109179. doi:10.1016/j.yebeh.2023.109179
14. CDC. Sudden unexpected death in epilepsy. Epilepsy. February 5, 2025. Accessed October 6, 2025. https://www.cdc.gov/epilepsy/sudep/index.html
15. Devinsky O, Hesdorffer DC, Thurman DJ, Lhatoo S, Richerson G. Sudden unexpected death in epilepsy: epidemiology, mechanisms, and prevention. *Lancet Neurol*. 2016;15(10):1075-1088. doi:10.1016/S1474-4422(16)30158-2
16. Harden C, Tomson T, Gloss D, et al. Practice guideline summary: Sudden unexpected death in epilepsy incidence rates and risk factors. *Neurology*. 2017;88(17):1674-1680. doi:10.1212/WNL.0000000000003685
17. Pellinen J. Treatment gaps in epilepsy. *Front Epidemiol*. 2022;2. doi:10.3389/fepid.2022.976039
18. Wagner AP, Croudace TJ, Bateman N, et al. Clinical services for adults with an intellectual disability and epilepsy: A comparison of management alternatives. *PLoS One*. 2017;12(7):e0180266. doi:10.1371/journal.pone.0180266
19. Wylie T, Sandhu DS, Murr NI. Status Epilepticus. In: *StatPearls*. StatPearls Publishing; 2025. Accessed October 6, 2025. http://www.ncbi.nlm.nih.gov/books/NBK430686/
20. Kanner AM. Suicidality in Patients With Epilepsy: Why Should Neurologists Care? *Front Integr Neurosci*. 2022;16. doi:10.3389/fnint.2022.898547
21. Jacoby A, Baker GA. Quality-of-life trajectories in epilepsy: A review of the literature. *Epilepsy Behav*. 2008;12(4):557-571. doi:10.1016/j.yebeh.2007.11.013
22. Baker GA, Jacoby A, Buck D, Stalgis C, Monnet D. Quality of Life of People with Epilepsy: A European Study. *Epilepsia*. 1997;38(3):353-362. doi:10.1111/j.1528-1157.1997.tb01128.x
23. Fisher RS. Epilepsy from the Patient's Perspective: Review of Results of a Community-Based Survey. *Epilepsy Behav*. 2000;1(4):S9-S14. doi:10.1006/ebeh.2000.0107
24. Stern JM, Penovich PE, Becker DA, Long L, Santilli N, Peck EY. Perspectives on Epilepsy-Related Fears Among Adult Patients Living With Epilepsy, Caregivers, and Healthcare Professionals (1047). *Neurology*. 2020;94(15_supplement):1047. doi:10.1212/WNL.94.15_supplement.1047
25. Addressing Stigma Surrounding Epilepsy | Epilepsy Foundation. Accessed October 6, 2025. https://www.epilepsy.com/stories/addressing-stigma-surrounding-epilepsy
26. Jacoby A, Gorry J, Baker GA. Employers' Attitudes to Employment of People with Epilepsy: Still the Same Old Story? *Epilepsia*. 2005;46(12):1978-1987. doi:10.1111/j.1528-1167.2005.00345.x
27. Chaplin JE, Wester A, Tomson T. Factors associated with the employment problems of people with established epilepsy. *Seizure*. 1998;7(4):299-303. doi:10.1016/S1059-1311(98)80022-8
28. Mar Htwe Z, Lae Phyu W, Zar Nyein Z, Aye Kyi A. Correlation between depression and perceived stigma among people living with epilepsy. *Epilepsy & Behavior*. 2023;146:109372. doi:10.1016/j.yebeh.2023.109372
29. Drug Resistant Epilepsy | Epilepsy Foundation. Accessed October 6, 2025. https://www.epilepsy.com/treatment/medicines/drug-resistant-epilepsy
30. Chen Z, Brodie MJ, Liew D, Kwan P. Treatment Outcomes in Patients With Newly Diagnosed Epilepsy Treated With Established and New Antiepileptic Drugs: A 30-Year Longitudinal Cohort Study. *JAMA Neurol*. 2018;75(3):279-286. doi:10.1001/jamaneurol.2017.3949
31. Staying Safe With Exercise and Sports | Epilepsy Foundation. Accessed October 6, 2025. https://www.epilepsy.com/preparedness-safety/staying-safe/exercise-sports
32. Kamitaki BK, Maniar S, Rambhatla R, et al. Health insurance and transportation barriers impact access to epilepsy care in the United States. *Epilepsy Research*. 2024;205:107424. doi:10.1016/j.eplepsyres.2024.107424
33. Welty TE, Willis SL, Welty EA. Effect of limited transportation on medication adherence in patients with epilepsy. *Journal of the American Pharmacists Association*. 2010;50(6):698-703. doi:10.1331/JAPhA.2010.09081

34. Kobau R, Luncheon C, Greenlund K. Active epilepsy prevalence among U.S. adults is 1.1% and differs by educational level—National Health Interview Survey, United States, 2021. *Epilepsy Behav.* 2023;142:109180. doi:10.1016/j.yebeh.2023.109180
35. Poprelka K, Fasilis T, Patrikelis P, et al. Burden in caregivers of adults with epilepsy: A critical review. *Epilepsy & Behavior.* 2025;164:110260. doi:10.1016/j.yebeh.2024.110260
36. England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: Promoting health and understanding.: A summary of the Institute of Medicine report. *Epilepsy & Behavior.* 2012;25(2):266-276. doi:10.1016/j.yebeh.2012.06.016
37. Moura LMVR, Karakis I, Zack MM, Tian N, Kobau R, Howard D. Drivers of US health care spending for persons with seizures and/or epilepsies, 2010–2018. *Epilepsia.* 2022;63(8):2144-2154. doi:10.1111/epi.17305
38. Vrouchou P, Risi A, Annoni E, Alvarez G, Grovale N. Humanistic and Economic Burden of Focal Drug-Refractory Epilepsy In Europe. *Value in Health.* 2015;18(7):A765. doi:10.1016/j.jval.2015.09.2510
39. Ambrose J, Mahmood N, Campbell CI, Eaton A. Time to evaluation and characteristics of patients evaluated at epilepsy centers within an integrated health care delivery system. *Epilepsy & Behavior.* 2025;164:110256. doi:10.1016/j.yebeh.2024.110256
40. Cramer JA, Wang ZJ, Chang E, et al. Healthcare utilization and costs in adults with stable and uncontrolled epilepsy. *Epilepsy Behav.* 2014;31:356-362. doi:10.1016/j.yebeh.2013.09.046
41. Villanueva V, Girón JM, Martín J, et al. Quality of life and economic impact of refractory epilepsy in Spain: the ESPERA study. *Neurologia.* 2013;28(4):195-204. doi:10.1016/j.nrl.2012.04.012
42. Allers K, Essue BM, Hackett ML, et al. The economic impact of epilepsy: a systematic review. *BMC Neurol.* 2015;15:245. doi:10.1186/s12883-015-0494-y
43. Brook RA, Rajagopalan K, Smeeding JE. Healthcare Costs and Absenteeism Among Caregivers of Adults with Partial-Onset Seizures: Analysis of Claims from an Employer Database. *Am Health Drug Benefits.* 2018;11(8):396-403.
44. Karakis I, Moura LM, Boualam N, Wetzel M, Howard D. The health care costs of epilepsy: Evidence from all-payer claims data. *Epilepsy Research.* 2025;218:107661. doi:10.1016/j.eplepsyres.2025.107661
45. Pellinen J, Tafuro E, Yang A, et al. Focal nonmotor versus motor seizures: The impact on diagnostic delay in focal epilepsy. *Epilepsia.* 2020;61(12):2643-2652. doi:10.1111/epi.16707
46. Epilepsy or Not? PNES Mistaken for More Common Seizure Disorder. Yale Medicine. Accessed May 24, 2025. https://www.yalemedicine.org/news/seizure-epilepsy
47. Epilepsy Monitoring Units (EMU). Accessed May 24, 2025. https://www.hopkinsmedicine.org/neurology-neurosurgery/specialty-areas/epilepsy/emu
48. Huff JS, Lui F, Murr NI. Psychogenic Nonepileptic Seizures. In: *StatPearls*. StatPearls Publishing; 2025. Accessed May 24, 2025. http://www.ncbi.nlm.nih.gov/books/NBK441871/
49. Bone I, Dein S. Religion, spirituality, and epilepsy. *Epilepsy & Behavior.* 2021;122:108219. doi:10.1016/j.yebeh.2021.108219
50. Shi Y, Wang S, Ying J, et al. Correlates of perceived stigma for people living with epilepsy: A meta-analysis. *Epilepsy Behav.* 2017;70(Pt A):198-203. doi:10.1016/j.yebeh.2017.02.022
51. Kreimer S. The State of Epilepsy Care in the US: A New Report from the National Association of Epilepsy Centers. *Neurology Today.* 2022;22(1):1. doi:10.1097/01.NT.0000817616.29163.a7
52. American Academy of Neurology. Epilepsy Update 2017: Quality Measurement Set. Published online 2017. https://www.aan.com/siteassets/home-page/policy-and-guidelines/quality/quality-measures/epilepsy-and-seizures/20180215-epilepsy-measures-final.pdf
53. Hogan RE. Delay of Treatment, After Diagnosis, as a Contributor to the "Treatment Gap" in Epilepsy. *Epilepsy Curr.* 2019;19(6):385-386. doi:10.1177/1535759719874793
54. Tian N, Kobau R, Zack MM, Greenlund KJ. Barriers to and Disparities in Access to Health Care Among Adults Aged ≥18 Years with Epilepsy — United States, 2015 and 2017. *MMWR Morb Mortal Wkly Rep.* 2022;71(21):697-702. doi:10.15585/mmwr.mm7121a1
55. Curtis K, Elrahi S, Bilello J, Rai P. Geographical Distribution of Neurologists in the United States (727). *Neurology.* 2020;94(15_supplement):727. doi:10.1212/WNL.94.15_supplement.727
56. Gotlieb E, Lally A, Blank LJ, Jette N. Geographic Heterogeneity in Epilepsy Specialist Distribution. *Neurology.* 2025;105(6):e214035. doi:10.1212/WNL.0000000000214035
57. U.S. Physician Workforce Data Dashboard. AAMC. Accessed October 9, 2025. https://www.aamc.org/data-reports/report/us-physician-workforce-data-dashboard
58. What to Expect in an Epilepsy Monitoring Unit. Accessed May 24, 2025. https://www.aap.org/en/patient-care/epilepsy/diagnosing-pediatric-epilepsy/what-to-expect-in-an-epilepsy-monitoring-unit/
59. Epilepsy Centers | Seizure Treatment | Epilepsy Foundation. Accessed October 15, 2025. https://www.epilepsy.com/treatment/epilepsy-centers
60. National Association of Epilepsy Centers. What are Epilepsy Centers and How can they Help? Accessed May 24, 2025. https://naec-epilepsy.org/what-are-epilepsy-centers-and-how-can-they-help
61. Spotnitz M, Ekanayake CD, Ostropolets A, et al. Use of Recommended Neurodiagnostic Evaluation Among Patients With Drug-Resistant Epilepsy. *JAMA Neurol.* 2024;81(5):499-506. doi:10.1001/jamaneurol.2024.0551