

Strategic Plan 2025



EPILEPSY
FOUNDATION®
END EPILEPSY® TOGETHER

EPILEPSY FOUNDATION MISSION:

Lead the fight to overcome the challenges of living with the epilepsies and to accelerate therapies to stop seizures, find cures, and save lives.



ABOUT US:

Working with our community and network partners, the EPILEPSY FOUNDATION connects the people, data and resources needed to address challenging health problems associated with seizures and the epilepsies—and promotes education, policy, research and systemic change that will foster measurable and sustainable improvement for all people living with epilepsy.

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EXECUTIVE SUMMARY

We are in a period of tumultuous change throughout society due to the global public health crisis, powerful social movements to eliminate systemic racial and gender-based injustices, and widespread but disparate economic upheaval among Americans. The Epilepsy Foundation is undergoing transformation to meet these challenges, and though our structure and strategies may change, our dedication to serving our community through advocacy, education, direct services, and research endures.

Only a small fraction of the 3.4 million Americans affected by the epilepsies are directly engaged with the Foundation network. People with epilepsy continue to experience stigma around the condition, and diminished opportunities for education and employment. Health disparities and unequal access to care plague our systems. Federal funds appropriated for epilepsy research lag in comparison to other diseases with far lower prevalence. After decades of new therapy development, we are still controlling the symptoms – the seizures – without substantially modifying the course of the disease or preventing it from happening in those at risk. Year after year, we continue to see our loved ones with epilepsy suffer in myriad ways. Lost opportunities, injuries, depression, hopelessness. We lose loved ones with epilepsy, sometimes far too early.

The Foundation must rise to meet the serious challenges we face in a new way, with increased focus, greater scale and efficiency, and stronger partnerships with all organizations in the space that are equally committed to improving the lives of people living with the epilepsies. Here, we lay out a plan to harness the power of collaboration for our work over the next five years to End Epilepsy Together.

The Foundation's strategic vision for 2020 – 2025 has five objectives (the 'Five Pillars'). These Pillars were identified through surveys and collaborative discussions with our stakeholders during 2018 – 2019 and were endorsed by our Board of Directors. They create a bedrock for the structure of our organizational priorities over the next five years. For each Pillar, the Foundation's executive staff leadership defined Key Results that will – if achieved over the five years of this plan – demonstrate dramatic progress toward the goal of Ending Epilepsy Together.

2025 Strategic Plan - Five Objectives ('Five Pillars'):

- 1) Lead the conversation about epilepsy.
- 2) Shape the future of epilepsy healthcare and research.
- 3) Harness the power of our united network to improve lives.
- 4) Expand revenue sources beyond traditional fundraising.
- 5) Become a best-in-class organization leveraging technology and digital assets for greater efficiency & mission delivery.

INTRODUCTION

“Fight for the things that you care about, but do it in a way that will lead others to join you.” - Ruth Bader Ginsburg

It is 2020; this year has brought tumultuous change through a global public health crisis, powerful social movements to eliminate systemic racial and gender-based injustices, and widespread but disparate economic upheaval among Americans. A political transition in the Executive Branch is imminent, which is likely to change the landscape for healthcare (both public and private options) and governmental funding for public health and biomedical research.

The Epilepsy Foundation, too, has undergone a dramatic transformation in this year. As one of the largest and longest-standing non-profit organizations dedicated to improving the lives of people living with epilepsy, the Foundation and its nation-wide network of local offices has long held a leadership role in advocacy, education, direct services, and research related to epilepsy.

But...we know that the organizational model that has supported our work over the last 52 years is not sufficient to meet today's challenges, nor will it thrive over the next 50 years of improving the lives of people living with epilepsy. We are currently comprised of a national organization (EFA) which supports nearly 50 local chapter offices and affiliated local 501c3 organizations. We have been in existence since 1968, and yet there are too many examples of where we are falling short of what the epilepsy community deserves. Only a small fraction of the 3.4 million Americans affected by epilepsy are directly engaged with the Foundation network. People with epilepsy continue to experience stigma around the condition, and diminished opportunities for education and employment. Federal funds appropriated for epilepsy research lag in comparison to other diseases with far lower prevalence. After decades of new therapy development, we are still controlling the symptoms – the seizures – without substantially modifying the course of the disease or preventing it from happening in those at risk. Year after year, we continue to see our loved ones with epilepsy suffer in myriad ways. Lost opportunities, injuries, depression, hopelessness. We lose loved ones with epilepsy, sometimes far too early.

The Foundation must rise to meet the serious challenges we face in a new way, with increased focus, greater scale and efficiency, and stronger partnerships with all organizations in the space that are equally committed to improving the lives of people living with the epilepsies. Here, we lay out the scope of the challenges, the way we see our new role in the landscape, and our strategic vision for our work over the next five years to End Epilepsy Together.

THE SCOPE OF THE CHALLENGES

Epidemiological data indicate that 10% of Americans will suffer a seizure at some point in their lives; 1-2% will have epilepsy. Epilepsy is characterized by re-occurring unprovoked seizures and affects 3.4 million Americans. At least 50% of the total population of individuals with epilepsy will have started having seizures at less than 20 years of age. Compared to the general public, people with epilepsy have higher rates of premature mortality, injury, cognitive impairment, depression, social isolation, and unemployment.

Our scientific understanding of seizures and epilepsy has grown dramatically over the last decades, revealing that epilepsy is not a single disease. Rather, it is a heterogeneous set of disorders with genetic and acquired etiologies better described as “the epilepsies.” There is a wide diversity of seizure types, epilepsy syndromes, outcomes and etiologies. For some, epilepsy is a manageable chronic illness -- affected individuals have risen to the highest echelons of professional success. However, for others, epilepsy is a devastating and progressive disease leading to developmental delay, regression and early death.

Wide variations in epilepsy care delivery and clinical practice may also contribute to poor individual outcomes. Achieving the best possible outcome and highest possible quality of life for every person with epilepsy requires a system with at least four components; high-quality medical care, accessible community services, supportive environments in which to live, learn, work, and play, and an activated individual and family. Unfortunately, today, the health promotion components that support people with epilepsy often do not function as a cohesive system. Healthcare and social support and self-management programs are isolated from each other, making it difficult for anyone to experience truly comprehensive care.

Health disparities create poorer outcomes for some groups within our community, driven in part by social determinants of health. For example, there are racial and ethnic disparities to comprehensive epilepsy care. We know that anyone with a brain can have a seizure or develop epilepsy; the epilepsies affect people of all ages, genders, races, ethnicities, and socioeconomic status. However, the *impact* of an epilepsy diagnosis is not equal.

THE UNMET NEED FOR EFFECTIVE TREATMENTS, PRECISION THERAPIES AND HIGH-QUALITY CARE

Arriving at the correct epilepsy diagnosis is sometimes a complex process, often requiring extensive history, electroencephalogram (EEG) monitoring, neuroimaging, and other diagnostic testing. Having an accurate diagnosis is critical, since the vast majority of current treatments are prescribed based on the type(s) of seizures rather than the cause of the epilepsy. Today’s treatments are effective at controlling seizures in ~60% of people with epilepsy, but adverse effects of therapy are common and impair quality of life. But, even with the availability of many

anti-seizure medications (ASMs), surgical options, dietary therapies, and therapeutic devices, 30-40% of people with epilepsy have seizures that continue to be treatment resistant. There are few or no consensus guidelines on the best practices (e.g., drug therapy strategies) for specific pediatric or geriatric populations, or for other subpopulations defined by seizure type or epilepsy syndrome.

The most common outcome measured in epilepsy care is seizure frequency, which has been repeatedly criticized by advocates as a necessary *but not sufficient* measure of the outcomes that patients and their families prioritize. For example, rare epilepsies are characterized by much more frequent seizures, in which a reduction in seizures could be of limited clinical significance. While seizures are the defining feature of the epilepsies, the broad spectrum of developmental impacts, quality of life, comorbid conditions, and adverse effects of treatment are as much as or more important than the number of seizures remaining. Treatments that both stop seizures AND modify the course of the disease (Disease-modifying epilepsy medications (DMEMs)) are desperately needed.

For example, extensive international consultation with patients with Dravet syndrome and their caregivers has found that across cultures, families and patients have identified seizures as an important outcome but view as equal impacts of the condition the effects on motor skills, expressive and receptive communication, learning, attention, emotional wellbeing, community functioning, daily activities and sleep. Similar themes have been reported by parents of children with other severe early life epilepsies. Measures of seizure frequency or severity alone do not capture the totality of experience for children or families living with the rare epilepsies. Clearly, evaluations in epilepsy must go beyond the number of seizures to incorporate more global measures of functional impact that are meaningful.

Effectively addressing these many challenges will take ingenuity, perseverance, and a willingness to do things differently. The Foundation must maximize its impact for people with epilepsy through strong bi-directional partnerships, technology, innovation and greater scale, and with a singular focus on improving quality of life for all people living with the epilepsies. The Epilepsy 2025 Strategic Plan is our roadmap to get there.

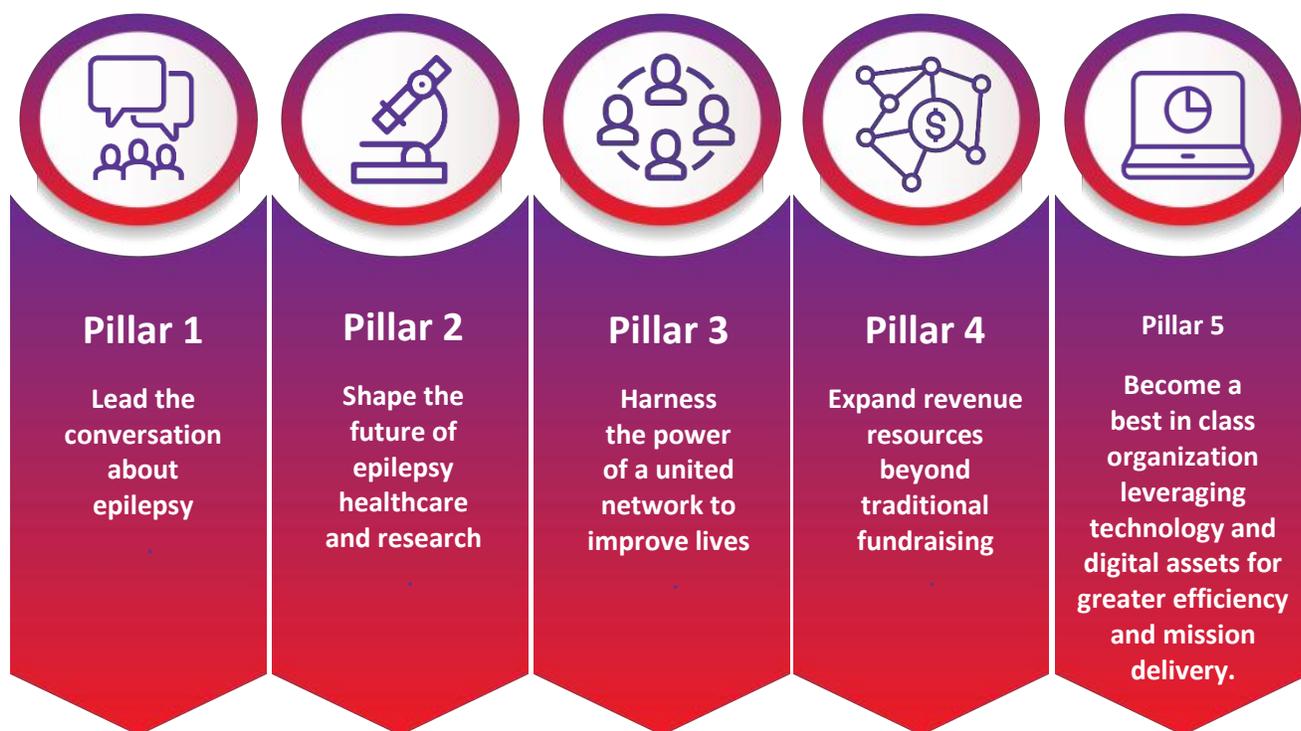
OUR STRATEGIC VISION: END EPILEPSY TOGETHER

The Foundation’s strategic vision for 2020 – 2025 has five objectives (the ‘Five Pillars’). These Pillars were identified through surveys and collaborative discussions with our stakeholders during 2018 – 2019 and were endorsed by our Board of Directors. They create a bedrock for the structure of our organizational priorities over the next five years.

For each Pillar, the Foundation’s executive staff leadership defined Key Results that will – if achieved over the five years of this plan – demonstrate dramatic progress toward the goal of Ending Epilepsy Together.

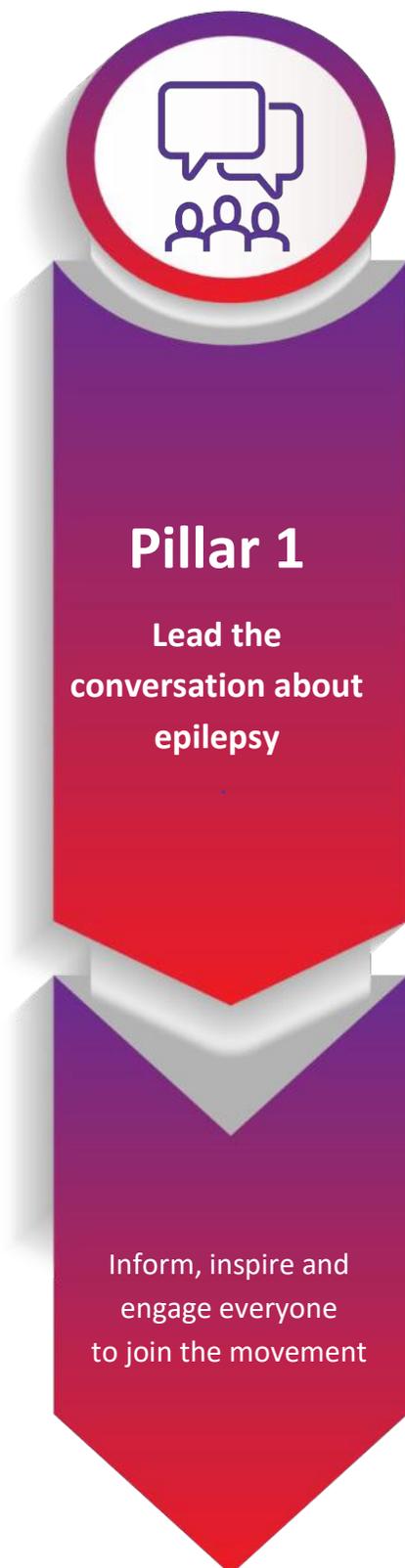
In order to achieve the Key Results, staff leadership will identify specific, measurable, organizational priorities for each year of this plan, and will implement those priorities through the work of its cross-functional teams and partnerships. We will measure and report our progress quarterly, seeking to be transparent with our internal teams and external partners, and to adapt strategies as needed to achieve our goals.

2025 Strategic Plan - Five Objectives (‘Five Pillars’)



OUR FIVE STRATEGIC PILLARS TO END EPILEPSY TOGETHER

The Five Pillars represent how we will create positive impact in the world for people with the epilepsies in pursuit of our vision and mission over the next five years.



Pillar 1

Lead the
conversation about
epilepsy

Inform, inspire and
engage everyone
to join the movement

We will put the brain and stories of people with epilepsy at the center of the conversation. We will ensure that our communication channels provide essential, dynamic and personalized information about seizures and the epilepsies. We will use these channels to educate, connect, and inspire the epilepsy community and increase access to information and news about scientific advances. We will provide more training for seizure first aid through innovative public and private partnerships. We will advocate for legislation to ensure safety, wellness, and access to quality care for people with epilepsy.

5 Year Key Results:

- **Stigma and ignorance about the epilepsies decrease and epilepsy-related discrimination is fought.**
- **Epilepsy.com continues to be the national platform for the epilepsies and is the first stop for the newly diagnosed.**
- **The number of people in the epilepsy community who are engaging with EFA has increased.**



Pillar 2

Shape the
future of
epilepsy healthcare
and research

Accelerate innovation and partnerships in healthcare and research and improve access and care for all people with the epilepsies.

We will build partnerships with key epilepsy centers in the US, and with professional organizations representing the healthcare providers who most often treat people with epilepsy. We will advocate to ensure that every person with epilepsy has health insurance and/or access to the care they need. We will advocate for comprehensive care that treats the whole person, and for behavioral health programs and self-management education. We will partner with our community to leverage data to accelerate personalized treatment and individually optimized management to consistently improve outcomes. We will invest in and support continuous improvement through the Epilepsy Learning Healthcare System (ELHS). We will accelerate innovative epilepsy research in a timeframe that matters.

5 Year Key Results:

- **Accurate diagnosis, effective treatments, and overall outcomes for people with the epilepsies improve by harnessing the power of data and through advocacy and systems change.**
- **Collaborative, physician-directed, person-centered epilepsy healthcare is the gold standard for all epilepsy care and access is improved through public health, education and advocacy.**
- **Innovative epilepsy research that leads to improved diagnosis, treatment, or epilepsy care is accelerated and available in a timeframe that matters.**
- **More new therapies and diagnostics enter the development pathway and the timeline to approval is shortened.**



Pillar 3

**Harness
the power
of a united network
to improve lives**

Improve the lives of people with the epilepsies by activating the field, volunteers and the broader community with the tools, programs and information they need.

We will scale up our network's impact by providing the systems, relationships, tools and information needed to change the lives of greater numbers of people with epilepsy. We will grow and sustain a robust volunteer force. We will empower volunteer leaders with the right information and infrastructure needed to train and support them. We will invest in centralized systems, a unified brand, and best practices across the network for more efficiency and effectiveness at the grassroots level. We will drive change through strategic national and local partnerships, to include affiliated and non-affiliated non-profits, corporate sponsors, healthcare organizations and governmental and philanthropic funders.

5 Year Key Results:

- **More people are engaged on the frontlines of the movement.**
- **Our impact is greater by scaling and standardizing network offerings and tools to extend our reach.**
- **Awareness is increased through strategic national and local partnerships.**
- **A diverse, equitable, and inclusive staff and volunteer base champion change for all people impacted by the epilepsies.**
- **We attract, develop and retain the best talent in our staff, volunteers, board members, and others.**



Pillar 4

**Expand
revenue resources
beyond traditional
fundraising**

Enable more people affected by the epilepsies to engage with us and benefit from our mission by generating new resources, activating new technology and innovations.

We will generate the resources needed to reach, support and engage every person living with epilepsy. We will create and nurture a fundraising culture to fuel fresh ideas about raising awareness and dollars. We will support a robust DIY fundraising platform to drive grassroots funding. We will invest in entrepreneurship to bring breakthrough products to life.

5 Year Key Results:

- **An active fundraising culture is evident by a growing base of staff, volunteer, client and general public fueling fresh fundraising ideas.**
- **Over 500K people are fundraising with us.**
- **Innovative and current development systems, tools, and approaches make fundraising easy and accessible to everyone.**
- **Our revenue portfolio is diversified by growing our fee for service and licensing streams.**
- **We (and partners) are recovering revenue from strategic investments in the epilepsy research and clinical pipeline.**



Pillar 5

Become a best in class organization leveraging technology and digital assets for greater efficiency and mission delivery.

Improve overall outcomes for people with the epilepsies by developing a data infrastructure and cutting-edge technology that utilizes the data for self-monitoring and management, advancing research, identifying patient cohorts for clinical trials.

We will create an innovative, collaborative culture of agile leaders. We will attract, develop and retain the best talent and invest in building a culture of innovation, collaboration, excellence and diversity. Our new emerging culture will be informed by data and will share best practices network-wide to level up our performance and impact.

We will strengthen our ability to fuel a powerful grassroots movement by making sure that we are reaching, serving, and engaging ALL populations, types of epilepsies and communities with equity, fairness, and access to care and information.

We will invest in new technology and data solutions to get the right information to the right people at the right time. We will apply cutting-edge technology solutions and data strategies that speed access and quality of care, increase education, connect and motivate donors, and inform innovation and research programs.

5 Year Key Results:

- **Customer service provided by network IT, human resources, and finance is timely and high-quality**
- **Technology is leveraged to efficiently and consistently deliver mission directly to the community.**
- **An integrated data ecosystem, leveraging AI, and including digital systems and tools, is developed and activated that allows the broad network and community to efficiently and consistently deliver mission objectives.**
- **Research and new therapies are advanced through robust data sets.**

FY21 ORGANIZATIONAL PRIORITIES AND METRICS

In each year of this Strategic Plan, the Foundation will identify one or more organization-wide priorities for each of the Pillars. Achieving each organizational priority will culminate in achieving our Key Results for the Strategic Plan. The organizational priorities are intentionally cross-functional, requiring teamwork across the Foundation’s departments and with network partners and volunteers.

We will build Epilepsy Foundation 2025 for maximum impact over the next five years with strategic investments and measured progress on each of these critical building blocks.

PILLAR 1) LEAD THE CONVERSATION

Current Organizational Priority: Seizure Safe Nation

FY21 METRIC: Certify 15,000 people in SFA; train 150,000 school staff (nurses and other personnel)

PILLAR 2) SHAPE THE FUTURE OF HEALTHCARE AND RESEARCH

Current Organizational Priorities: ELHS and EDEN

FY21 METRIC: Generate real-world population health data from providers and patients from at least 100 patients for a minimum of 2 specific epilepsies from the Epilepsy Digital Experience Navigator (EDEN) and the Epilepsy Learning Healthcare System (ELHS) platforms

PILLAR 3) UNITE OUR NETWORK

Current Organizational Priority: Volunteer Force

FY21 METRIC: Create scalable, nation-wide volunteer model for program delivery and fundraising that supports a minimum of 1,500 active volunteers

PILLAR 4) DIVERSIFY REVENUE

Current Organizational Priority: Epilepsy Venture Fund

FY21 METRIC: Launch and seed EVF with \$5Million

PILLAR 5) BECOME BEST-IN-CLASS ORGANIZATION

Current Organizational Priority: Epilepsy Digital Engine

FY21 METRIC: Have a formal strategy and workplan to execute on the Digital Engine build