EPILEPSY
FOUNDATION®
END EPILEPSY® TOGETHER

DELAWARE

Strategic Plan
2024-2027
Board Approved 9.24

Executive Summary

The Epilepsy Foundation of Delaware has undergone dynamic changes during the past strategic plan. We created a new position, our Community and Outreach Coordinator, to enhance our services to the community while spreading awareness about epilepsy throughout the state. We have diversified and enhanced our fundraising efforts to make sure we have enough resources to continue to serve our community. We strive to continue this growth in this strategic plan.

In the process, we asked our staff, board of directors and stakeholders to look critically at the programs we provide and the manner in which we provide them. This information was critical in shaping the strategies of this plan. We held key informant interviews to make sure we captured the diversity of our stakeholders. Our board was instrumental in this process at every step of the way as they are the driving force of our organization.

With renewed vigor comes the commitment to continued growth as a viable and sustainable community-based organization that is ever responsive to the changing needs of the community. The Epilepsy Foundation's success is inextricably connected to the support from our community, our dedicated, talented and caring staff and board members along with our generous partner organizations. We look forward to working with you, the community, as we move ahead to achieve our goals.

History of Organization

For over 50 years Epilepsy Foundation of Delaware has been providing support, advocacy and education services throughout the state of Delaware. Originally known as the Delaware Epilepsy Association, the organization was formed by members of the Easter Seals Society who were physicians and lay people directly concerned with the problems of epilepsy. Incorporated in 1964 with an independent board of directors established in December 1983, the Delaware Epilepsy Association became a full affiliate of the Epilepsy Foundation of America in December 1984 and officially changed its name to the Epilepsy Foundation of Delaware in 1996.

Description of Services

Training and Outreach Programs:

Seizure First Aid Certification- This program debuted in April of 2020 on a national level and the Epilepsy Foundation of Delaware was one of the first affiliates to have staff as trained instructors. This program is ideal for school personnel, the general public and other groups. After completion of the course and test, each participant is given Seizure First Aid Certification for two years. This program has expanded to certify the following groups with tailored information for each group:

Seizure Training for Healthcare Professionals – This training was developed for family physicians, nurses, and other medical and behavioral health professionals who will have contact with patients with seizure disorders.

Law Enforcement Training- This education and outreach program is implemented in Delaware to educate and train law enforcement officers, police cadets, and emergency response personnel to increase their recognition of seizures and promote safe and appropriate intervention practices for persons with seizure disorders. This program seeks to reduce inappropriate arrests and improve access to timely and appropriate medical intervention. It is offered to all three police academies, probation and parole officers and correctional officers.

School Nurse Training – In partnership with the National Foundation and the CDC, this training provides school nurses with information, strategies, and resources to better manage students with seizures. The program helps nurses to recognize seizures and their effects, know current treatment options and their side effects, know appropriate first aid, develop a seizure action plan for a student with epilepsy, and provide training for other school personnel on appropriate care for students with seizures.

Outreach and Awareness Events- We bring materials and resources to health and community fairs in communities across the state, spreading awareness about what we do as an organization.

Information and Support Programs

Direct Support/Resource Linking- Accurate information for individuals with epilepsy and their families and skills development in self-management are essential components for helping individuals become better partners in managing epilepsy. Parents of children newly diagnosed with epilepsy need information about the disorder and available support resources. The information priorities for adults can range from healthcare access and employment to accessing transportation or medication management. This program provides services as an adjunct to medical treatment.

Support Groups- Monthly groups in Kent and New Castle County. Each group is open to anyone affected by epilepsy and opens a short discussion on a topic pertaining to epilepsy followed by open discussion driven by the group.

Self Management Programs- These programs provide valuable life skills AND an opportunity for people with epilepsy to find commonality with others. Project UPLIFT is an 8 week, over the phone course that focuses on mindfulness and coping skills for living with epilepsy. Chronic Disease Self Management Program (CDSMP) is a 6 week phone/zoom course teaching nutrition, stress relief, communication skills and more for people with epilepsy.

Delaware Epilepsy Conference- This annual conference provides information for the epilepsy community in Delaware. Local experts educate on a variety of topics that change each year according to the surveys of participants from the year before.

Professional Advisory Board Programs- The PAB leads programming for professionals and for patients in the form of Ammon's Horn's education for professionals and art classes and shows for patients.

Organizational Description

Mission (National) : Improve the lives of people affected by epilepsy through education, advocacy, research, and connection.

Mission (Internal): To identify, reach and support all people impacted by seizures and epilepsy, reduce stigma, increase community awareness and access to care, while leading efforts to facilitate the management of epilepsy throughout Delaware.

Vision: A caring Delaware community strengthened with various possibilities for all people impacted by seizures and epilepsy.

Values: The Epilepsy Foundation's core values are forged by passion to serve people impacted by epilepsy. These core values guide our behavior, judgments and how we accomplish our mission:

1. **Collaboration:** We are better together. We encourage strategic collaboration to bring out the best solutions and strengthen the fabric of our communities.
2. **Excellence and Learning:** We challenge ourselves to do great work. We actively seek feedback and believe continual learning is essential for adaptation, innovation, resilience and relevance.
3. **Impact:** We make a difference. We focus on results that matter to our community and people living with epilepsy.
4. **Service:** We are responsive and flexible. We build relationships. We meet people where they are, developing experiences, content, and outcomes that positively impact the lives of people living with epilepsy.
5. **Stewardship:** We are effective stewards of the financial, human, and natural resources. Service Area: Our geographic service area encompasses the entire state of Delaware. This includes 3 counties, and an area of over 2900 square miles.
6. **Diversity and Inclusion:** EFDE is committed to cultivating and preserving a culture of inclusion. We strive to listen, include and celebrate all communities. We are stronger in our programs, advocacy and community engagement because of our commitment to diversity and inclusion.

Strategic Initiatives

Our strategic initiatives are guided by our organizational values and information received from stakeholders from our survey, key informant interviews and focus groups.

Strategy 1: Invest in the board, staff and community

1. Goal: Recruit new board members from the following areas: Behavioral Health, Women's Health and a Community Member at Large.
    a. Action Item: Survey current board members and other community contacts for appropriate referrals by December 2024.
    b. Action Item: Connect and meet with potential new board members by March 2025.
    c. Action Item: Bring new potential board members to a vote on membership by June 2025.
2. Goal: Explore and implement staff health benefits.
    a. Action Item: Identify at least two viable options for health benefits for staff by October 2024.
    b. Action Item: Bring best option to vote by December 2024.
    c. Action Item: Include costs for the program in the budget process by March 2025.
    d. Action Item: New benefits to be voted upon by the board by June 2025.

Strategy 2: Expand and enhance programs.

1. Goal: Enhance social activities in programming options.
    a. Action Item: Create a line item in the budget to allow for more robust social activities by September 2024.
    b. Action Item: Survey participants about what activities they prefer and try at least two of these by August 2025.
    c. Action Item: Create a yearly (flexible) outline for these activities to inform the yearly budgeting process by December 2025.
2. Goal: Explore a caregiver or mentor program.
    a. Action Item: Create and implement a survey to gauge interest in a caregiver/mentor program by September 2025.
    b. Action Item: Outline new program, assess feasibility and funding options by June 2026.
3. Goal: Transportation program.
    a. Action Item: Create outline of a transportation program by November 2024.
    b. Action Item: Apply for funding by March 2025.
    c. Action Item: Create a program coordinator position for this program by June 2025.
    d. Action Item: Hire coordinator by September 2025.

    e. Action Item: Program details finalized by September 2025.
    f. Action Item: Begin program implementation by December 2025.

Strategy 3: Enhance Funding sources

1. Goal: Increase individual donations by 10% by January 2027
    a. Action Item: Make thank you calls every quarter (ongoing).
    b. Action Item: Increase donation promotions on social media to twice per month by January 2025.
    c. Action Item: Include donor names in monthly newsletter. (ongoing).
    d. Action Item: Start yearly day of giving by February/March 2025.
2. Increase grant applications by January 2027
    a. Apply for two more grants than the previous year by January 2027 (ongoing).
    b. One of the two grants should be program specific (ongoing).

Strategic Analysis Data:

Prevalence

- 3.4 million US residents have epilepsy.
- Epilepsy by age: 3 million adults and 470,000 children in the US.
- In Delaware in 2015, the prevalence for epilepsy is estimated to be 1300 children and 8400 adults.
- 1 in 26 people will develop epilepsy in their lifetime.

Zach, M. M., & Kobau, R. (2017). National and state estimates of the numbers of adults and children with active epilepsy-United States, 2015. *Morbidity and Mortality Weekly Report: 66* (31), 821-825.

Comorbidity

- Those with epilepsy often have multiple comorbid conditions including: stroke, heart disease, depression, developmental delay, autism, head trauma, cerebral palsy.
- These conditions make life and dealing with epilepsy difficult and often leads to early mortality.

Economic Impact/Social determinants of health

- Adults on medicaid have a higher prevalence of epilepsy.
- People with epilepsy who are in poverty are more likely to report taking their prescribed epilepsy medication.
- Children who have seizures are more likely to have parents who are food insecure.
- Yearly healthcare costs for people with epilepsy range from around $10,000-$48,000 and are higher for those with uncontrolled seizures.
- People with epilepsy are more likely to delay medical care due to a lack of transportation.
- Epilepsy is the costliest chronic condition for children and adolescents in terms of academic and health outcomes.

Elliott, J. O., Lü, B., Shneker, B. F., Moore, J. L., & McAuley, J. W. (2009). The impact of 'social determinants of health' on epilepsy prevalence and reported medication use. *Epilepsy Research*, *84*(2–3), 135–145. https://doi.org/10.1016/j.eplepsyres.2009.01.010

Tian, N., Kobau, R., Zack, M. M., & Greenlund, K. J. (2022). Barriers to and Disparities in Access to Health Care Among Adults Aged ≥18 Years with Epilepsy — United States, 2015 and 2017. *Morbidity and Mortality Weekly Report*, *71*(21), 697–702. https://doi.org/10.15585/mmwr.mm7121a1

Program Efficacy

- Self management programs increase the quality of life for people with epilepsy and help with side effects of ASDs.
- Folks with chronic health conditions who are restricted from social activities are more likely to have increased hospitalizations and physician visits.
- Using multimedia in training about epilepsy and seizures increases the level of knowledge of the participants and decreases stigma in those same participants.

Leenen, L.A.M.; Winjen, B.F.M.; Kessels, A.G.H.; Chan, H.; de Kinderen, R.J.A,; Evers, S.M.A.A.; van Heugten, C.M., & Maijoie, M.H.J.M. (2018). Effectiveness of a multicomponent self-management intervention for adults with epilepsy (ZMILE study): A randomized controlled trial. *Epilepsy and Behavior: 80,* 259-265.

Roberts, R.M, & Farhana, H.S.A. (2010). Effectiveness of a first aid information video in reducing epilepsy-related stigma. *Epilepsy and Behavior: 18* (4), 474-480.

Meek, K. P., Bergeron, C. D., Towne, S. D., Ahn, S., Ory, M. G., & Smith, M. L. (2018, January 19). *Restricted social engagement among adults living with chronic conditions*. International journal of environmental research and public health. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5800257/#:~:text=On%20average%2C%20participants%20who%20reported,physician%20visits%2C%20and%20overnight%20hospitalizations.

Key Demographics:

In our ever evolving society, we need to take a critical look at the folks we are serving now and how that might and should change. Here is a list of key demographics for our programs to reach from 2024-2027:

People with epilepsy- This is central to our mission. We need to address the needs of people living with epilepsy including resources, group support, mental health, medication support, etc.

Friends/Loved ones of someone with epilepsy- Caregivers of people with epilepsy are often burdened with stress of caring with someone with a chronic condition. This is a group we should support.

Folks who work with those with epilepsy: Medical providers, teachers, law enforcement, early childhood educators, general public, people who work in device or pharmaceutical arenas- Our community trainings and outreach programs are centered on this group. We want to continue to make sure they have the information needed to support people with epilepsy.

Donors- We need to make sure our donors are being thanked and able to choose from different giving opportunities to match how they like to give.

Delawareans statewide- Our presence should be felt statewide and folks from across the state need to know how to access services.

Communities of Color- We need to do a better job of reaching communities of color in Delaware. Our core values dictate that we make this a priority.

Virtual vs. In Person- The ability to provide programming virtually has opened up the doors for so many Delawareans to access services. However, we need to be aware that some groups either do not have access to virtual programming or prefer in person programming.

SWOT meeting notes:

SWOT Team Meeting Notes.pdf

Stakeholder Survey Results:

37 participants took this survey which included key informant interviews, community members and some board members:

Needs Assessment Summary 2024