



EPILEPSY
FOUNDATION®
END EPILEPSY® TOGETHER

DELAWARE

Strategic Plan
2021-2024
Board approved 6/17/21

Executive Summary

The Epilepsy Foundation of Delaware has adapted, just like organizations around the world, to the new reality we live in during the Covid-19 pandemic. We moved many of our programs to a virtual format and offered fun and informative events in safe and new ways. As we are transitioning out of the pandemic, we've used the opportunity to reevaluate how we reach Delawareans and how we can more efficiently use our resources. This was top of mind in the creation of 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 also came to realize that we need to do a better job of not only acknowledging and respecting diversity, but also to make sure our programs are inclusive and accessible to all. This is also reflected in this strategic plan.

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.

Be Seizure Smart for Teens- Through this education program offered in high school health classes, we seek to both eliminate stigma and increase knowledge of epilepsy for all teens in

Delaware. Since its inception fourteen years ago, this program has reached more than 60,000 high school students. This program is in the process of being revamped.

Law Enforcement Training- In partnership with the National Foundation and the CDC, 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.

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.

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.

Project UPLIFT and PACES- These programs provide valuable life skills AND an opportunity for people with epilepsy to find commonality with others. Each program is an intensive, 8 week over the phone program open to adults with epilepsy.

Organizational Description

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

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 SWOT analysis and stakeholder survey.

Strategy 1: Enhance and expand community impact.

1. Goal: Define Community Educator/Outreach Position.
 - a. Action Item: Define job description to include diverse communities, determining types of outreach (schools, virtual vs. in person), increase social activities by March 2022.
 - b. Design and present job description to board, keeping in mind the financial impact of this position June 2022.
2. Hire and Onboard Community Educator
 - a. Publicize and interview potential candidates by August 2022.
 - b. Create and implement an onboard and training program for the new position by August 2022.
3. Create sustainability plan for Community Educator position and current positions
 - a. Sustainability: Utilize program efficiency measures and apply them to future positions and programs while still providing quality programming by December 2022.
 - b. Expansion: Evaluate positions and programs to gauge stability and explore growth opportunities June 2023.
4. Community relationship building
 - a. Assessing needs of diverse communities: Assess community needs through surveys, stakeholders, focus groups etc. by December 2023. **Utilize new community outreach position to assess these needs.**
 - b. Kent/Sussex relationship building: Implement a new event in Kent/Sussex County by May 2022.
 - c. Health system relationships: Identify a community liaison/contact in every health system in Delaware by December 2022.
 - d. Communication: Assess use of technology to provide maximum program reach while still meeting clients where they are and reassess every six months.

Strategy 2: Provide current and cutting edge programs.

1. Programmatic Expansion
 - e. Seizure First Aid Certification: We will increase the number of Delawareans certified by 2% each year by June 2024.
 - f. Seizure Safe Schools: Engage the local legislature to champion this act to ensure all educators are trained in seizure first aid in Delaware by June 2024.
 - g. New diagnosis support and resources: Engage the PAB to enhance our effort to reach those newly diagnosed and provide relevant and helpful resources by March 2022.

Strategic Analysis Data:

Prevalence

- 3.4 million US residents have epilepsy.
- Epilepsy by age: 3 million adults and 470,000 children.
- In Delaware, 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

- Adults on medicaid have a higher prevalence of epilepsy.
- Children with seizures are more likely to live in poverty than children without seizures.
- 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.
- Epilepsy is the costliest chronic condition for children and adolescents in terms of academic and health outcomes.

Program Efficacy

- Self management programs increase the quality of life for people with epilepsy.
- 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., & Maijoié, 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.

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 2021-2024:

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 Analysis:

SWOT Themes from input from board members:

<https://www.surveymonkey.com/stories/SM-DTCGQVQ2/>

Strengths

- Increased Virtual Presence
- Strong Supportive Community (staff, board, epilepsy community)
- We teach Seizure First Aid
- We use our limited budget efficiently for maximum programmatic impact

Weaknesses

- New diagnosis support
- Concern with new programs because of limited budget
- No community outreach/educator position
- Schools have been more difficult to get into (in general and because of COVID)
- Not enough social activities for people with epilepsy

Opportunities

- Strengthen relationships with health systems
- Hire a part time community educator
- Engage with legislators about Seizure Safe Schools

Threats

- We don't know the needs of all the diverse communities we serve in Delaware (define diverse)
- Reduction in training programs for groups who can't or won't use technology
- Losing access to patients without technology

Stakeholder Survey Results:

There were 39 participants in this survey. This was sent to all on our mailing list including clients, donors, community members and board members. See the results here:

<https://www.surveymonkey.com/stories/SM-MX3JWRXD/>