



EPILEPSY FOUNDATION

New England

PLAN 2020

Table of Contents

I.	Executive Summary	p.2
II.	EFNE Organizational Summary	p.3-4
III.	A Look Back at the 2016 Plan	p.5-8

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With additional Input from
 EFNE Staff, September 26
 EFNE Board of Directors, September 28
 EFNE Professional Advisory Board, September 29
 2017 Stakeholder Survey

Adopted by the EFNE Board of Directors
 September 28, 2017

www.epilepsynewengland.org



Plan 2020: Executive Summary

In the spring of 2016, Epilepsy Foundation New England's (EFNE) Board of Directors adopted a strategic plan that called for organizational transformation. By summer 2017, the plan's program, staffing, and resource goals were accomplished, almost three years ahead of schedule. Major strategic growth included new executive leadership, refined and expanded programs and services, growth in fundraising and business development, revitalization of the Professional Advisory Board, and rethinking and implementation of the foundation's work across New England. Every major system in the organization has been reviewed and updated, including service delivery, human resources, business operations, financial management, development and fundraising, governance, and communications and marketing.

As a result, the Board convened a strategic planning process in July 2017, which resulted in Plan 2020. The three-year Plan 2020 aims are:

1. EFNE is a model nonprofit organization and is a model epilepsy-serving organization. We are a leader in making progress to advance practical solutions for people living with the challenges of epilepsy, and we do so through a top quality staff, a robust volunteer program, sound day-to-day financial management, growing an endowment, diversified revenue streams, and our network of collaborators and supporters, including our Donation Center.
2. EFNE provides accessible, helpful services for people living with epilepsy that make a measurable impact in all four states we serve.
3. EFNE's effective marketing and communications efforts achieve growing awareness and understanding, acceptance, and support for epilepsy in New England, including Sudden Unexpected Death in Epilepsy (SUDEP); EFNE is known as a resource by the epilepsy community, including providers.
4. EFNE is a leader in advancing support for research into epilepsy, especially in terms of fundraising for research.

Strategic priorities to accomplish these aims are:

1. Build invested leaders who can advance the mission within the Board of Directors and Professional Advisory Board; by developing regional leadership councils in RI, ME, and NH; and through engaging committed corps of advocates and of volunteers.
2. After the 2016-2017 period of dynamic growth, stabilize our core programs and services (i.e., epilepsy walks, support services, camp, public policy advocacy, employment services, education programs, and young adult programs) by implementing evaluation systems to measure impact over time, by developing a vetting process to pilot new program directions through our Board of Directors, and by leveraging the Donation Center to advance our programs and services.
3. After this past year's period of rapid organizational change and development, stabilize organizational systems to reflect best practices in nonprofit management, including supporting our new development team, ensuring the Foundation's organizational culture embodies our stated values, implementing top notch financial management systems, developing our human resource function to nurture staff, ensuring technology keeps pace with EFNE's growth, and being sure that our office space meets EFNE's evolving needs.
4. Building on the basic platforms put in place at the Foundation last year, developing and implementing a strategic framework for marketing and communications to advance EFNE's goals, including leveraging our relationships with EF "national" and with our Donation Center.
5. Build EFNE's programs and services and fundraising to be consistent across the New England region to ensure a balanced regional presence, including expanding staffing to meet the needs of people with epilepsy in RI, ME, NH, and Western MA.
6. Grow fundraising for research in epilepsy by working in partnership with EF "national" to raise at least \$100,000 per year for research by 2020.

Organizational Summary

August 1, 2017

Epilepsy Foundation New England (EFNE) is a 501 c 3 nonprofit organization whose mission is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. EFNE is an independent affiliate of the national Epilepsy Foundation; we serve the approximately 100,000 people in Maine, Massachusetts, New Hampshire, and Rhode Island effected by epilepsy and the people who care for them. Our vision statement is Help for Today, Hope for Tomorrow.



The services we provide are employment services; camp for children and teens; Youth Councils; Helpdesk; Resource Center; retreats for adults; scholarships; emergency financial aid to people in need; community education for children, school personnel, first responders, and employers; conferences for health care providers and for families; public policy advocacy; support groups; bereavement support; community connections; and, public awareness and engagement. In partnership with the national foundation, we raise money for research efforts for the Epilepsy Innovation Institute.

Established in 2009, the EFNE Donation Center is an LLC of EFNE. Thanks to a partnership with Savers, the Donation Center collects clothing and household items that are resold through 15 regional thrift stores. Proceeds fund approximately \$500,000 in EFNE programs and services per year.

EFNE is governed by a 20-member volunteer Board of Directors. A 30-member Professional Advisory Board provides Strategy, Advice, Outreach to EFNE and act as Ambassadors for our mission. ME, NH, and RI Leadership Councils provide leadership for the epilepsy community in their regions and ensure that EFNE is attuned to each area's strengths and challenges. Staffed by regional Field Service Managers, Councils contribute to networking and community-building activities for the epilepsy community in their area; conduct outreach to help build a network of people with epilepsy and their loved ones in their area; select and help run programs and activities that engage and connect people with epilepsy and their loved ones to each other and to the Foundation; support fundraising activities such as our Walk for Epilepsy; act as ambassadors for EFNE; support advocacy work in the region/state; and work as individuals and as a Council to implement strategies that decrease the stigma of epilepsy.

EFNE's FY18 operating budget is \$1.8 million; this is an 80% increase from FY17. The Foundation has invested \$2 million to begin building an endowment.

In spring 2016, the EFNE Board of Directors led a strategic planning process that called for transformational change. A new President/CEO came on board in July 2016, and the Foundation was reorganized in August 2016. Major milestones that mark the resulting transformation are:



Welcoming The Matty Project: In January 2017, The Matty Fund became The Matty Project as an initiative of EFNE. The Matty Fund, established by Richard and Deb Siravo after the passing of their 5 year-old son, Matty, from a prolonged seizure, was a success in its own right, connecting children and their families to epilepsy support and services throughout Rhode Island. Through The Matty Project, we are now able to integrate these invaluable community-focused elements into EFNE programs across New England, including Camp Matty and the "My Friend Matty" curriculum, an epilepsy awareness program for children. For Rhode

Island individuals and families seeking support as children grow into teenagers and adults, EFNE is now a closer resource for services and opportunities.

New Epilepsy Resource and Support Center: “Help” is at the core of EFNE. A 2016-2017 evaluation and rethinking of our resources and supports, coupled with welcoming our new Chief Operating Officer, Dr. Elaine Kiriakopoulos, to our staff (i.e., a neurologist and epileptologist with extensive knowledge and clinical experience), led to a relaunch of the Resource and Support Center in 2017. The new center provides live help desk services alongside a comprehensive library of online tools and resources to educate and support individuals, families, and caregivers. In the 1st half of 2017, we helped more than 1,000 people through the Center.

Growing Young Adult Leaders: Juggling school, work, friends, and growing into one’s own is no easy feat for any young adult. It can be even tougher for those living with epilepsy. That’s why last fall EFNE launched three new programs focused specifically on engaging and empowering young adults. To-date, more than 70 individuals ages 13-29 have gotten involved in our Athletes vs. Epilepsy®, Teens Speak Up®, and Leadership Council programs. We are connecting young people to each other and encouraging our next generation of leaders. In Fall 2017, we hope to expand the Councils to include Boston, Springfield, Providence, and Portland Councils.

Tripled Camp Programs: Over the past year, we have tripled the size and number of our camp offerings, which have been rebranded as The Purple Camp. We believe strongly in providing camp experiences to individuals and families fighting epilepsy because we’ve seen the support it can provide both. Camp affords individuals with epilepsy a chance to have fun in an environment designed for them, to make friends with others like them, and to build their own confidence in their abilities. For families, it brings them together with others connected to epilepsy and provides an opportunity for new experiences with their loved one. Day and sleepaway camps are available for children, families, young adults, and adults.

Expanded Employment Services: In December, we relaunched our Employment Services program. Entering the job market after an epilepsy diagnosis can leave questions for both employers and individuals. Gaps in employment, questions of physical and medical ability, wavering self-confidence, and fear of disclosing an epilepsy diagnosis are all very real concerns. EFNE’s employment services aim to support people in their journey towards gratifying, competitive, and integrated employment. Now serving dozens of people, services include assessment, coaching, workshops, job placement, and more. In June, EFNE was awarded a \$100,000 grant from the Cummings Foundation to establish supported job training based on employee needs and to develop strategic employer partnerships.

Leveraging Our Volunteers: Volunteers truly embody everything that EFNE stands for. From our epilepsy runs and walks to our programming and services, EFNE’s hundreds of volunteers bring passion, optimism, creativity, and experience to our organization. And they bring the human power to make it happen! We are incredibly fortunate to have them. In October 2016, EFNE hired its first Volunteer Coordinator to work hand-in-hand with our volunteers, providing support and leveraging their expertise. Volunteers now approach 200 giving individuals.

Increased Fundraising and Business Development: Running the EFNE organization accounted for 9% of our budget in FY2017. The other 91% of our funds went directly into programs and services for individuals and families fighting epilepsy. Thanks to the kindness of more than 4,500 donors in FY17 – up 60% from the previous year - we were able to increase our services and our impact. In FY18, EFNE is focused on increasing grant-funded and business development opportunities.

The 2016 Strategic Plan

In March 2016, the EFNE Board of Directors authored a 3-year Strategic Plan. As shown in the following pages, almost 100% of the Plan's goals and action items have been achieved.

The Plan called for 10 action steps:

- 1) Complete Search for EFNE CEO by June 2016
Update: Completed. New President/CEO on board on July 5, 2016.
- 2) Fill EFNE Key Open Staffing Positions: Director of Development, Operations Manager...
Update: Completed. 1st Director of Development onboard on July 11, 2016. FY17 included the new position Office Manager, with support from accounting, IT, and communications consultants. On August 28, 2017, the new position of Director of Business and Administration was implemented.
- 3) Outsource support for operational systems, externally facing applications including Social Media...
Update: Completed. EFNE's new President/CEO located external facing applications in her duties. By 10/1/16, EFNE had an active presence on Facebook, Twitter, Instagram, and LinkedIn as well as a weekly e-newsletter. With help from a consulting firm, EFNE's brand (letterhead, business card, logo) were refined; EFNE produced a brand video and stylized marketing materials (e.g., gala invitation) by the end of 2016. On July 31, 2017, a half-time Communications Specialist joined the EFNE team.
- 4) Increase Linkage and Leverage Between NE Donation Center & EFNE.
Update: Progressing. Progress on this action item includes initial assessment of the viability of linkages (e.g., can fundraising efforts cross-pollinate?).
- 5) Revitalize PAB and Link with EFNE Board (Add one or two EFNE Board members to PAB?)
Update: Complete. The 8-member PAB has expanded to 30 members that meet quarterly.
- 6) Build & Drive Leverage with EFA "National"
Update: Progressing. An ad hoc committee of Board members, President/CEO, and Director of Development has met monthly and with national to advance the partnership.
- 7) EFNE Board to Fund Research
Update: Progressing. A March 2017 cultivation event kicked off EFNE's fundraising for research, and another event is planned for March 2018.
- 8) Establish EFNE Standing Investment Committee to Manage Growing Cash Balances

Update: Completed The Committee formed and established an Investment Policy.

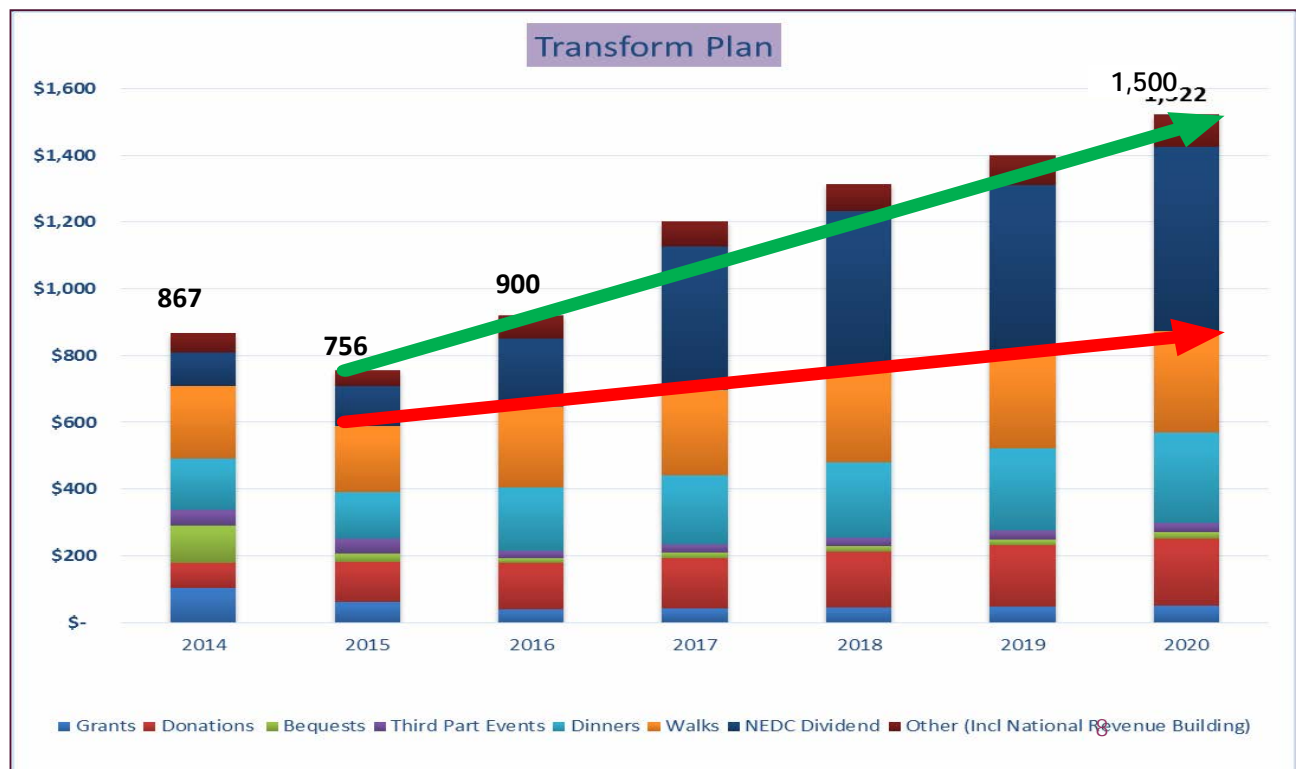
9) Consider Guidelines for Building Long Term EFNE Endowment (Target \$1-2 million by 2020?)

Update: Progressing.

10) Establish Annual Strategic Planning Review each March: What did we say & What did we do?

Update: Completed. Because of the transformational change at EFNE, the Board convened a new strategic planning process that resulted in a new Plan 2020, which follows.

The March 2016 plan provided 3 options for growth, including “modest/maintenance” (i.e., FY17 budget of \$950K to FY20 of \$1M); “growth” (i.e., for FY20 of \$1.3M); and transformative (i.e., toward FY20 of \$1.5M). In September 2016, the Board voted to increase the budget to reflect necessary investments, to \$1.2M. In June 2017, the Board passed a FY18 budget of \$1.8M.



The 2016 Plan called for the following Program Priorities:

Programs:

- These include sessions pertaining to: Seniors & Seizures, School Nurses, School Personnel, First Responders/EMS, Daycare Personnel, High/Middle Schools, and Elementary Schools.

Update: Completed; All curriculum under review; new My Friend Matty curriculum added; Dedicated Director of Community Education

- Camps for Kids and Families.

Update: Completed; Camp programs tripled in 2017, including the addition of a Young Adult Retreat, Adult Retreat, and Camp Matty (2 4-day horseback riding camps)

- E-studios.

Update: Completed

- Information and referral networks

Update: Completed. Development of a new Resource and Support Center, helpdesk, and online resources

- Advocacy

Update: Completed; added a paid intern to support efforts

Employment:

- Materials relating to this program need updating. Clear Program scoping and measurement of outcomes.

Update: Completed; Director of Employment Services onboarded October 2016; Career Resource Specialist onboarded July 2017, funded by a \$100K grant from the Cummings Foundation

Veterans:

- Services for this group involve I+R

Update: An ad hoc committee on Veterans services is launching fall 2017.

- Leveraging CC & Universities, Advocacy & Public Policy

Update: Completed

Support for Research:

- Link & expand impact of Professional Advisory Board

Update: Completed

- Connect & Leverage with National

Update: Progressing

The 2016 Plan called for the following Staffing and Resource Priorities:

- 1) Development Director - Link & Leverage with “National”
Update: Completed.
- 2) Add Technology Resources for Salesforce & Web
Update: Completed. New website; Salesforce Repaired
- 3) Invest in Staff development and training for Sales Force & Technology (shared with Donation Center)
Update: Completed, but not linked with Donation Center.
- 4) Implement Basic Operational Procedures & Controls. Provide Oversight & Enforcement of Procedures
Update: Completed.
- 5) Add Human Resource staff (shared with Donation Center)
Update: Completed. Shared staff for most of FY17; in August 2017, the Foundation added its own HR staff with the Director of Business and Administration.
- 6) Expand use of “self-management” tools & systems from “National”
Update: Completed.
- 7) Add Regional Field Staff, over time with Target model of 1 fulltime & 2 part time staff
Update: Progressing; 3 Field Service Managers are in place with clear goals.
- 8) Expand Camps with Partners in all 4 states for children & families
Update: Completed (camps in 4 states reevaluated).
- 9) Establish a Research & New Therapy Development Conference for/in New England with National
Update: in progress.
- 10) Add Employment Staff/Director
Update: Completed.
- 11) Expand Transportation Services & Resources/Staff
Update: Transportation services reevaluated.
- 12) Provide Board and PAB Development for Foundation & Donation Center Board of Officers
Update: Progressing.