



## CFMC Grant Application

# COMPLETE THIS APPLICATION FOR FUNDING REQUESTS FOR THE Community Foundation of Middlesex County Competitive Cycle.

**Instructions:** Complete the application on the website. You may "Save and Continue Later" - the site will email you a link which is active for 30 days. Review instructions document for full details before completing. Complete all questions.

**Section V requires certain documents to be uploaded to the form - see the Application Instructions Document for a list of the required items. All items must be uploaded as PDF Files. The CFMC Budget Summary form is available on the website in Word. This document must be submitted as PDF file as well.**

### I. Application Information

**Legal Name of Organization**

Epilepsy Foundation of Connecticut

**Division or Department Name (if applicable)**

**Other Tax Exempt Entity?**

**Are you a 501(c)3 Organization**

Yes

**EIN #**

22-2535999

If your organization is not a 501(c) 3 tax exempt entity or division/department of a 170(c)1 government agency or religious organization, please contact Thayer Talbott, 860.347.0025, for further information before completing the application.

**Total Cost associated with request \$**

22,856

**Dollar Amount Requested \$**

5,000

**Summary Statement**

Our HOBSCOTCH (HOMe Based Self-management and COgnitive Training CHanges lives) program is a behavioral curriculum designed to address memory and attention problems for individuals living with epilepsy. This problem-solving therapy is specifically designed for adults with seizures as a guide to manage and cope with memory problems and mental health disorders common in this disease.

## II. Funding Request Information

### 1. Proposal / Purpose

Challenges The Epilepsy Foundation of CT faces in Middlesex County, CT:

Our Foundation serves all residents in CT living with epilepsy--those diagnosed with the disease and the caregivers whose lives have changed overnight. But in Middlesex County, presently we are serving zero clients. As 1 in 26 individuals live with epilepsy we know there residents in this region that need our help. One to do is with HOBSCOTCH.

Our HOBSCOTCH (program explained below) clients are presently referred by their epileptologist or neurologist from Epilepsy Centers in CT. As these centers are located in the cities of CT and epileptics, our clients tend to be from New Haven and Hartford Counties and tend to be linked more to cities than to suburban and rural areas. Our goal with funding from Community Foundation of Middlesex County is to implement an outreach initiative and build partnerships with other nonprofit agency such as members of the Middlesex Chamber of Commerce and to directly contact residents in your region.

We do know there are more than 36,000 individuals in CT (<https://www.cdc.gov/epilepsy/data/index.html>) living with epilepsy (LWE). With your support, we would expand our outreach in your service region by not only attending community events, sharing on your newsletter, and being part of a podcasts but also working with direct client services.

Needs/issues to be addressed. So, what is epilepsy?:

The International League Against Epilepsy (ILAE) defines epilepsy as a disease of the brain characterized by any of the following conditions: at least two unprovoked (or reflex) seizures occurring >24 h apart; one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60 %) after two unprovoked seizures, occurring over the next 10 years; diagnosis of an epilepsy syndrome

(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8746065/#B1-jcm-11-00267>;

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8746065/#B2-jcm-11-00267>).

What's a seizure:

A seizure is **a sudden, uncontrolled burst of electrical activity in the brain**. It can cause changes in behavior, movements, feelings and levels of consciousness.

(<https://www.mayoclinic.org/diseases-conditions/seizure/symptoms-causes/syc-20365711>) According to the National Center for Biotechnology Information (NCBI), the overall lifetime prevalence of epilepsy worldwide is 7.6 per 1000 members of the population. The incidence and prevalence are slightly higher in men than in women.

(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8746065/#B3-jcm-11-00267>)

People with epilepsy (PWE) are also exposed to many other health problems that occur often. For many people, co-morbidity is more burdensome than the seizures themselves. Epileptic seizures can cause both morphological and functional changes in the brain, manifesting as cognitive and neuropsychological disorders.... If the epileptic seizures are not properly treated and controlled, they can lead to permanent cognitive dysfunction

(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8746065/#B9-jcm-11-00267>). Finally, the difficulty with **cognition** is one of the most common problems in PWE; **however, it is often overlooked**. Some studies suggest that between 60% and 70% of people with chronic epilepsy have cognitive impairment

(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8746065/#B10-jcm-11-00267>).

The cognitive skills in PWE may be fully affected or partially affected in individual areas, e.g., mild aprosexia (sustained attention deficit disorder), memory impairment, impaired executive function, slowed psychomotor speed, impaired naming ability and impaired visual-spatial abilities (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8746065/#B11-jcm-11-00267>;  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8746065/#B12-jcm-11-00267>).

Although epilepsy presently has no cure, there are proven, beneficial programs. One we offer is called HOBSCOTCH.

So what is HOBSCOTCH?:

HOBSCOTCH (HOMe-Based Self-Management and COgnitive Training CHanges lives) is a behavioral program that targets memory and attention problems in adults with epilepsy by using psychological strategies to improve memory function. The program, while not intended to “cure” patients’ memory problems, has been shown to help adults with epilepsy or seizure disorders develop skills to manage and cope with memory challenges in order to lead happier, more productive lives.

HOBSCOTCH is delivered in 8 sessions that last approximately 45-60 minutes each. The first two sessions typically take the longest due to the amount of material covered. In each session, participants/clients learn new skills, then practice and apply these skills and problem solving techniques in everyday situations between sessions. Ideally, sessions occur weekly, with the entire program spanning 8 weeks. However, due to unexpected scheduling issues and forgotten appointments, this is not always possible. The program has run longer--up to 12 weeks which increases staff time and overall cost. Also, when greater time elapses between sessions, participants sometimes stop completing homework assignments and are unable to keep up with program expectations. As such our staff are trained on an annual bases to be licensed in providing this program.

Before this program, participants often report feeling as if they have lost control over their own lives due to their epilepsy and seizures. What this program does is teach participants how to problem solve solutions to their own unique challenges and to use compensatory skills to regain some of that control. Our goal is to help PWE feel like they are satisfied with and in control of their life by improving how they feel about themselves and how to cope with their own cognitive challenges.

As stated above, we are not reaching Middlesex County to our best potential and therefore the needs of PWE. Funding from Community Foundation of Middlesex County will allow EFCT to expand awareness of epilepsy, our Foundation and our clinically proven successful HOBSCOTCH program to all members regions of Middlesex County. Through word of mouth and goals mentioned above and below, we will connect with individuals living with epilepsy. Although specific data on the number of people living with epilepsy in Middlesex County is not presently available, studies do show that 1 in 26 individuals live with epilepsy. And that 1 in 10 will have a seizure in their lifetime.

With funding from Community Foundation of Middlesex County, our Foundation would prioritize specific outreach to community members to initiate a data base, determine the number of PWE in Middlesex County and by end of grant funding period initiate the coverage of two Middlesex County residents LWE into our successful HOBSCOTCH program.

## **2. Sustainability and Assessing Impact**

Proof of Success:

Presently and moving forward, our Foundation will measure success through our pre and post surveys and review with client their “Memory Toolbox” (available upon request and described in detail below). Sustainability will be measured by number of Middlesex County residents reached monthly, bi-annually and annually.

Also, as part of our three-year Strategic Plan, we will develop podcasts with partner organizations such as Middlesex County Chamber of Commerce and with businesses in downtown Middletown where our main office is located. Here, we will measure the number of touches made in Middlesex County and specifically those living with epilepsy. Finally, through our data system management, our website and social media platforms, we will be able to measure and share with funders, the number of individuals reached to specific ads.

Finally, we are connecting with state legislatures representing to PWE in Middlesex County, expansion of outreach and marketing through feedback and storytelling from clients, networking with more Middlesex County residents and chamber members, Middletown city events, collaboration with Middlesex Hospital, churches, soup kitchens, etc. As all of this is measured at our Foundation on a monthly bases, we will use each to measure the success of outreach into Middlesex County.

As stated above, we will use our successful pre and post surveys that are based on Quality of Life Measure (QOLIE-10-E). This measurement is a brief survey of health-related qualities of life. There are ten specific questions to mental health and well-being. The survey questions are measured on a "strongly agree vs strongly disagree" basis with four open questions at the end.

Also, our “Memory toolbox” as shared above offers practical strategies such as remembering names, keeping a schedule of appointments, using reminders to take medicine on time, or finding ways to limit distractions at work or in social settings. The

“memory toolbox” also provides helpful strategies for setting up reminders which our trained staff member provides to each client.

According to CDC,

<https://www.cdc.gov/epilepsy/communications/success-stories/hobscotch.htm#:~:text=In%202016%2C%20Jobst%20and%20her%20colleagues%20conducted%20a,HOBSCOTCH%20showed%20a%20decline%20in%20quality%20of%20life:>

“Overall, HOBSCOTCH has four measurable components: 1. Education about epilepsy, memory and attention problems, and the factors that influence them; 2. Training in self-awareness and relaxation; 3. Training in the application of memory strategies; 4. Problem-solving therapy. This program is specifically a problem-solving therapy that gives people skills to systematically work through any cognitive-related difficulties they have so that they can better approach day-to-day problems.”

HOBSCOTCH has been successfully proven throughout the nation, and specifically here in CT with clients our Foundation serves.

### **Proof of Success:**

In 2016, there was a randomized clinical trial of HOBSCOTCH. They found that this program greatly improved quality of life and cognition in adults with epilepsy. Study participants who did not receive HOBSCOTCH showed a decline in quality of life. The Dartmouth team then studied HOBSCOTCH in a larger population, enrolling adults with epilepsy and cognitive problems at four centers in northern New England.

That study found the same results—“a significant impact on both quality of life and memory perception,” states [one program specialist, Dr.] Kiriakopoulos. “It was exciting to see the benefits of the program replicated across different epilepsy centers.”

## **III. Grant Program / Project Information**

### **Organization Area of Impact (choose ONE)**

Community Health (Health/Medical/Hospital Care)

### **Grant Type (choose ONE)**

General Organization Support/Improvement

### **Target Demographics (Select all that apply):**

- Adults
- Young Adults (ages 18-25)
- Parents / Guardians
- Retirees
- Students
- Veterans
- Women and Girls
- At Risk Boys and Young Men
- LGBTQIA+
- BIPOC

### **Geographic Area(s) Served By This Application:**

- Chester
- Clinton
- Cromwell
- Deep River
- Durham
- East Haddam

- East Hampton
- Essex
- Haddam
- Killingworth
- Middlefield
- Middletown
- Old Saybrook
- Portland
- Westbrook

**Total Number of People in Middlesex County Personally Impacted**

50 annually but not yet by HOBSCOTCH

**IV. Organization Information**

Board of Directors / Trustees Information

**Percent (%) of Directors/Trustees who contribute annually to Operations**

75% or more

**Total Number of Directors/Trustees:**

13

**Average number attending in person:**

10

**Total Number of Board meetings held last year:**

4

**Year of Return:**

2022

**Date most recent IRS Form 990 was filed:**

2022

**Organization's Total Operating Budget**

858000

**Organization's Fiscal Year**

Jan 1 - Dec 31

**Division Operating Budget Information**

**National Organization Chapter Information**

3

**Did you RECEIVE a competitive process grant in the:**

**Brief Background Statement of the Organization:**

EFCT is a non-profit affiliate of the Epilepsy Foundation of America (EFA). We were founded in 1982 as the Epilepsy Support Group of Greater Hartford by a small group of concerned parents who were unable to find adequate resources for their children diagnosed with epilepsy. In 1990, after satisfying requirements, the Epilepsy Foundation of Greater Hartford was awarded full affiliation and granted a change of name to what we are today. Now, EFCT is the leader in education, advocacy, support, information, and recreation for an estimated 36,000 people in Connecticut who have epilepsy. Our mission is to support people impacted by epilepsy through advocacy, education, programs, and connections to ensure that they can live their best lives.

## V. Additional Information To Be Included with the Application

**Please Note: Additional information requested below MUST be uploaded in PDF files. Other document formats will not be accepted by the application form. Attempts to upload other file formats could result in a loss of all application data entered.**

### A. Current Organization Operations Budget (Required)

- FINAL\_EFCT-Budget-FY-2024\_Board-Approved.pdf

### B. Board of Directors and Officers List (Required)

- Board-of-Directors-List-February-2024.pdf

### C. IRS Tax Exempt Determination Letter

- 501C3-Tax-exempt-form.pdf

### D. For Program/Project Requests only - CFMC Budget Summary Form:

- Grant-Evaluation-Budget-to-Actual-Summary-Form.pdf

### E. Organizations serving a region greater than Middlesex County - county-based budget summary:

### F. America Rescue Plan Act (ARPA)

No

### ARPA Funding detail

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**Additional financial documentation, including the organization's most recent audit, annual report, and IRS Form 990 may also be required. Only provide this information if requested.**

For programs or projects which are collaborations among two or more organizations or where an organization provides in-school or after-school programming for schools, the Community Foundation requires a list of organizations or schools partnering with your organization as well as Letters of Support.

For the purposes of this application, collaborations are defined as partnerships where two or more agencies are committed through staffing, funding, and resource allocation to the goals and objectives of the program described. Because the nature of the collaboration requires two or more entities to work together, for the purposes of funding, only one organization may complete the application, and in doing so, accepts responsibility for all evaluative and fiduciary reporting.

For all collaborations, the Community Foundation requires letters of support from the non-applicant organization(s) and/or from the school(s) and school district(s) at which the applicant organization is the program.

**Is this application in collaboration with a School(s) or School District(s)?**

No

**Is this application a collaboration of two or more nonprofit organizations (NOT schools)?**

No

**If this is an On-Going Collaboration, how long has the collaboration existed?**

**If Yes, is this a New or On-Going Collaboration?**

On-going

**List of Collaborators**

**Letters of Support (if a collaboration with schools or other nonprofits))**

## VI. Organization Contact Information

### Are you a new nonprofit applicant to the Community Foundation?

Yes

#### Title

Executive Director

#### Executive Officer's Name

Cherie Poirier

#### Executive Officer Email

[cherie@epilepsyct.com](mailto:cherie@epilepsyct.com)

#### Phone

(860) 346-1924

#### Title

#### Contact Person

#### Application Contact Email

[cherie@epilepsyct.com](mailto:cherie@epilepsyct.com)

#### Phone

#### Mailing Address

386 Main Street  
Middletown, Connecticut 06457  
United States

#### Street Address

Connecticut  
United States

#### Website

[www.epilepsyct.com](http://www.epilepsyct.com)

#### Social Media Channels

<https://www.facebook.com/epilepsyfoundationct>;  
<https://www.linkedin.com/in/epilepsy-foundation-of-connecticut-16b170103/>

## VII. Non-Funding Needs

Assistance in sharing who we are and what we do; breaking down the stigma of epilepsy and the social barriers of PWE; mental health awareness; pod-casts; connecting to service care facilities, particularly regarding housing for special needs.



## **VIII. Marketing and Public Relations**

Organizations receiving grants from the Community Foundation of Middlesex County must promote their funding awards according to the marketing and public relations guidelines established by the Community Foundation. By signing the application below, the CEO/Executive Director understands the Community Foundation's marketing and public relations requirements if awarded a grant. The Community Foundation will host a seminar on marketing guidelines and tips for grantees annually. The Community Foundation's Grantee Communications Kit may be downloaded on our website in the Nonprofit Resources section, [middlesexcountycf.org/nonprofits/resources/forms-pr-guidelines/](http://middlesexcountycf.org/nonprofits/resources/forms-pr-guidelines/).

## **IX. Tax Exempt Standing and Use of Grant Funding Certification**

By signing this application, the CEO/Executive Director/Board President is certifying that your organization is a qualified 501c3 organization or other charitable organization recognized and currently in good standing with the IRS, or 170(c)(1) governmental agencies. Should a grant be approved by the Community Foundation of Middlesex County, these funds may only be used for the purpose outlined in your original application; you must notify us if you are unable to do so. If grant funding is provided, you may only use these funds for charitable purpose as described in Section 170(c)2 of the IRS code, and funds may not be used for any political or lobbying activity. In addition, no tangible benefits, goods or services may be received by our donors or by staff members of the Community Foundation of Middlesex County in exchange for grant funding.

### **Signature Certification**

I certify that my printed name as stated and assigned below constitutes my signature and may be accepted as such.

**Title**

Executive Director

**Printed Name**

Cherie Poirier

**Date**

03/06/2024