



**EPILEPSY  
FOUNDATION®**  
MASSACHUSETTS, RHODE ISLAND,  
NEW HAMPSHIRE & MAINE  
*Not another moment lost to seizures®*

## ***Resource Guide***

*Since 1983, the Epilepsy Foundation Massachusetts, Rhode Island, New Hampshire & Maine, Inc. has been making a difference for people with epilepsy, as well as educating the community and developing support networks for families and friends.*

### **Mission**

The mission of the Epilepsy Foundation Massachusetts, Rhode Island, New Hampshire & Maine (EFMARINHME), is to ensure that people with seizures are able to participate in all life experiences and to work toward prevention, control and a cure for epilepsy through advocacy, education, research and support services.

**540 Gallivan Boulevard, Boston MA 02124**  
**617-506-6041 888-576-9996**  
**Fax: 617-506-6047**  
**[www.efmarinhme.org](http://www.efmarinhme.org)**  
**Office Hours: 9:00 am to 5:00 pm - Monday thru Friday**

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## Epilepsy Facts

**What Is It?** Epilepsy is a disturbance in the electrical activity of the brain. It is a common neurological disorder that affects more than 136,000 persons in Maine, Massachusetts, New Hampshire and Rhode Island.

**Prevalence:** Epilepsy is most prevalent among the very young and the very old, although anyone can develop it at any age. In the U.S. epilepsy affects more than 326,000 children under the age of fifteen and more than 90,000 of these children have severe seizures that cannot be adequately controlled.

The number of cases in the elderly is beginning to soar as the baby boom generation approaches retirement age. Currently more than 570,000 adults age 65 and older in the U.S. have epilepsy.

**Mortality:** The mortality rate among individuals with a seizure disorder is two to three times higher than the general population and the risk of sudden death is 24 times greater.

This year, another 200,000 people in the U.S. will be diagnosed with epilepsy and an estimated 25,000 to 50,000 will die of seizures and related causes, including status epilepticus (non-stop seizures), and sudden unexpected death in epilepsy (SUDEP).

**Traumatic Brain Injury:** About 25% of people with “closed-head” injuries will develop post traumatic epilepsy (PTE). Between 48,000 and 169,600, of the soldiers serving in Iraq and Afghanistan are expected to develop PTE.

**Cost:** Epilepsy costs the nation \$15.5 billion in associated health care costs and losses in employment, wages, and productivity.

### A Worldwide Problem

- The World Health Organization estimates there are 40 to 50 million people with epilepsy throughout the world. The annual incidence in third-world nations is twice that of the United States (2/100 compared to 1/100). In many countries the condition remains a stigmatizing condition surrounded with mystical beliefs and social taboos. On a global basis, an astonishing three fourths of people with epilepsy receive no treatment for their seizures.

**Impact:** Epilepsy treatment is also affected by a mood disorder, and people with a history of depression have a 3 to 7 times higher risk of developing epilepsy. Choice of medication, recreational options and other employment decisions must be considered in relation to an individual's abilities and challenges.

Of major chronic medical conditions, epilepsy is among the least understood even though one in three adults knows someone with the disorder. Some people with epilepsy do not even know that they have it, having been told they have a "seizure disorder" instead. This unfortunate euphemism arose because of the historical stigma associated with epilepsy, which the Epilepsy Foundation and others are fighting to dispel.

Lack of knowledge about proper seizure first aid exposes affected individuals to injury from unnecessary restraint and from objects needlessly forced into the mouth.

The leading non-medical problem confronting people with epilepsy is discrimination in education, employment, and social acceptance.

**Related Disorders:** Epilepsy is prevalent in other disability groups including autism (25.5%), cerebral palsy (13%), Down syndrome (13.6%), and mental retardation (25.5%). For people with both cerebral palsy and mental retardation, the prevalence is 40-50%.

The association between epilepsy and depression is well documented. More than one of every three persons with epilepsy

#### By the Numbers

- Epilepsy is the third most common neurological disorder in the US after Alzheimer's and stroke. More people have Epilepsy than Parkinson's, Multiple Sclerosis and ALS combined.
- The term Epilepsy covers over 40 syndromes and affects almost 3 million people in the US alone. It affects more than 50 million people world-wide.
- The cause of epilepsy cannot be determined in 70% of individuals diagnosed.
- Unemployment in the epilepsy community is 6% higher than the national average.

## Causes and Treatment

### **Causes:**

- **Brain tumor, stroke, and dementia.**
- **Head trauma:** Especially from automobile accidents, sports accidents, falls and blows to the head at work or in the home. **The more severe the injury, the greater the risk of developing epilepsy.**
- **Poisoning:** Including alcohol and drugs. More than 5,000 persons each year are reported to suffer seizures caused by alcoholism.
- **Infection:** Meningitis, and viral encephalitis,
- **Maternal injury, infection, or systemic illness:** Affecting the developing brain of the fetus during pregnancy.
- **Heredity:** In some forms of epilepsy and in some families, genetic factors play a major role. The genetic factor may be greater when no specific cause can be identified.

### **Treatment:**

- **Medication:** Major form of treatment is long-term anticonvulsant drug therapy. Some 20 antiepileptic drugs are currently in use. While multiple-drug therapy is sometimes necessary, single-drug therapy is more common. One third of epilepsy cases proves to be incompletely managed with medications alone, these cases are considered medically refractory.
- **Surgical:** Most common form of surgery takes place when the tissue causing seizures is confined to a small focal area of the brain which can be safely removed without damaging personality or function. Surgery can be considered if medications do not control the seizures.
- **Dietary:** The **ketogenic diet** is a doctor-prescribed, high fat, low carbohydrate, reduced calorie diet. This diet may succeed in some childhood cases when standard treatment fails.
- **Medical Devices:** **Vagus Nerve Stimulation (VNS)** a device that sends small pulses of electrical energy from an implanted battery to the vagus nerve in the neck. Successful VNS therapy reduces the number of seizures people have and sometimes, how long they last. It is unlikely to stop seizures completely. Vagal nerve stimulation may help when medications prove inadequate. Other brain stimulation methods are currently being tested in experimental trials.

**Epilepsy Foundation,  
Massachusetts, Rhode Island, New Hampshire  
& Maine, Inc. Staff**

| <i>Title/Name:</i>  | <i>Extension/Email:</i>                 |
|---|---|
| <b>President &amp; CEO</b><br>Leslie G. Brody, Ph.D                 | ext 14<br>lbrody@efmarinhme.org         |
| <b>Director of Operations</b><br>Charlene Sturgis                   | ext 16<br>cstugis@efmarinhme.org        |
| <b>Director of Programs</b><br>Susan Welby                          | ext 19<br>swelby@efmarinhme.org         |
| <b>Events &amp; Special Projects<br/>Manager</b><br>Shamera Simpson | ext 12<br>ssimpson@efmarinhme.org       |
| <b>Community Education<br/>Coordinator</b><br>Lynn Dann             | ext 11<br>ldann@efmarinhme.org          |
| <b>Program Manager</b><br>Julie Silverstein                         | ext 15<br>jsilverstein@efmarinhme.org   |
| <b>Field Service Coordinator</b><br>Kristine Binette                | 207-730-0500<br>kbinette@efmarinhme.org |

***For more information on:***

Community & Professional Education,  
Legal Issues, H.O.P.E. program, School  
Nurse Training, Take Charge of the Facts  
Speak Up, Speak Out

Support Groups, Parent and Family  
Support Network, Camp Wee-Kan-Tu,  
You Are Not Alone: Parenting Your Teen  
with Epilepsy (YANA), Youth In Transition (YIT)  
Project Access, Website Listing, Volunteer

Dinners, walks, special events

Advocacy, Government Issues,  
Resource development, CEU programs

***Contact:***

*Lynn Dann*

*Susan Welby*

*Shamera Simpson*

*Les Brody*

## Programs and Services

**Support Groups:** Provide local community access to educational programs and peer-to-peer networking for teens and adults.

**Community Education:** Speakers are available through the **H.O.P.E.** program to meet with schools, hospitals, senior citizens, civic groups, and community groups to disseminate accurate information about seizure recognition, impact and first aid. One day seminars are held each year in different regions of Massachusetts and Rhode Island covering a variety of epilepsy related topics.

**School Nurse Training** is available as well as continuing education for psychologists, social workers & counselors. **Take Charge of the Facts** epilepsy awareness program for teens, **You Are Not Alone: Parenting Your Teen with Epilepsy** and **Youth in Transition** programs target teens and parents.

**Information & Referral:** This service provides people with epilepsy, their families, care providers and the general public with accurate information and referrals to appropriate services.

**Parent & Family Support Network:** Provides parents, siblings and other family members opportunities to network through e-mail and phone contact, regional meetings, educational programs and social gatherings.

**First Responders:** The Epilepsy Foundation recognizes the growing need to arm First Responders with the information they need to recognize and respond appropriately to calls related to epileptic seizures. Focused primarily on Law Enforcement and Emergency Medical Services, the goal is to increase the officer's understanding of the causes and effects of seizure disorders, improve the officer's decision making in regard to the call and provide easy-reference information and tools necessary to react. There is a Program that focuses mainly on EMS and public safety personnel, and works with a curriculum based mainly on a Trainer's and Participant's Guide and includes a DVD.

## Programs and Services Continued

**Camp-Wee-Kan-Tu:** An overnight camp for children living with epilepsy ages 8-17. Located in Massachusetts on the grounds of a host camp, this program offers children a week of typical camp activities including: arts & crafts, games, basketball, soccer, swimming, paddle boats, a rock climbing wall and camp fire circle. Staffed by camp counselors, EFMARINHME volunteers and medical volunteers from area epilepsy centers.

**Pathfinders:** As children with epilepsy become adults the camp atmosphere is no longer appropriate in enhancing the abilities and resources of these individuals. In order to better serve these young adults, the Epilepsy Foundation has started Pathfinders. Pathfinders programs are designed to help the participants in skill building, self awareness, self confidence, problem solving, and how to manage stress and conflict. These meetings will also consist of a recreational component each day that allows the participants to use their new skills via entertaining and fun activities.

**Scholarships:** EFMARINHME was the first group to offer financial assistance to students with epilepsy continuing their education or vocational training. EFMARINHME has provided over \$50,000 in scholarship grants over our 27 year history. Applications are due July 15th and awards decisions are made by September of each calendar year.

**Dr. Ed Bromfield Camp Week-Kan-Tu Endowment Fund:**  
The purpose of the Dr. Ed. Bromfield Camp Wee-Kan-Tu Endowment Fund is (a) to provide scholarships, camperships, awards, or other financial support for campers, staff and volunteers with epilepsy to participate in activities of the Camp with preference shown for qualified individuals who have been associated with the Camp for at least two years, and (b) to support the planning and operation of the Camp, and to support activities and programs consistent with the goals and purposes for which the Camp was established.

## Neurology & Epilepsy Centers

— Maine —



### **Maine Medical Center:**

Neuroscience Institute  
22 Bramhall Street  
Portland, ME 04102  
(207) 662-6924  
[http://www.mmc.org/neurto\\_body.cfm?id=4743](http://www.mmc.org/neurto_body.cfm?id=4743)



### **Maine Neurology:**

Services for Adults and Children  
49 Spring Street  
Scarborough, ME 04074  
(207) 883-1414  
[http://www.mainemedicalpartners.org/mmp\\_neurology.cfm?id=6547](http://www.mainemedicalpartners.org/mmp_neurology.cfm?id=6547)



### **Neurology Associates of Eastern Maine**

498 Essex Street, Suite 105  
Bangor, ME 04401  
(207) 947-0558  
<http://www.neurologyeasternmaine.com>



### **Central Maine Neurology**

10 Minot Avenue  
Auburn ME 04210  
(207) 795-2927  
<http://www.cmmc.org/info.html>

#### Famous People with Epilepsy



**Vincent Van Gogh**

#### Famous People with Epilepsy



**Bobby Jones**

*Neurology/Epilepsy Centers (continued)*

**— Massachusetts —**



**Bay State Neurology:**

3300 Main Street, Suite 3C & D  
Springfield, MA 01199  
(413) 794-7033  
Fax: (413) 794-7297

**Baystate Pediatric Neurology:**

3300 Main Street, Suite 4C  
Springfield, MA 01199  
(413) 794-0814



**Beth Israel Deaconess Medical Center:**

*Comprehensive Epilepsy Center*  
330 Brookline Avenue  
Boston MA 02215  
(617) 632-8930  
[www.bidmc.harvard.edu](http://www.bidmc.harvard.edu)



**Boston Medical Center:**

Pediatric Neurology

771 Albany Street  
Dowling 3 South  
Boston, MA 02118  
(617) 414-4501  
[www.bmc.org](http://www.bmc.org)

Adult Neurology

720 Harrison Avenue  
Suite 707  
Boston, MA. 02118  
(617) 638-8456

*Website for parents: [www.specialkidsspecialhelp.org](http://www.specialkidsspecialhelp.org)*



**Brigham and Women's Hospital:**

*Edward E. Bromfield Comprehensive Epilepsy Program*

75 Francis Street  
Boston, MA 02118  
(617) 732-7547  
Attn: Division of Epilepsy/EEG  
[www.brighamandwomens.org/neurology/epilepsy/default.aspx](http://www.brighamandwomens.org/neurology/epilepsy/default.aspx)

**Neurology/Epilepsy Centers (continued)**

 **Children's Hospital (Boston):**  
**Epilepsy Center**

300 Longwood Avenue  
Fegan 9  
Boston MA 02115  
(617) 355-7970  
[http://www.childrenshospital.org/clinicalservices/Site1549/  
mainpageS1549P0.html](http://www.childrenshospital.org/clinicalservices/Site1549/mainpageS1549P0.html)

Lexington  
482 Bedford St  
Lexington MA 02420  
781-672-2100

Waltham  
9 Hope Avenue  
Waltham MA 02453  
781-216-2297

Wilmington  
Family Medical Center  
500 Salem St. Route 62  
Wilmington MA 01887  
978-988-6246

 **Massachusetts General Hospital (MGH):**  
**Epilepsy Center - MGH Epilepsy Service**

Department of Neurology, Epilepsy Service  
Wang Ambulatory Care Center  
Floor 7, Suite 720  
55 Fruit Street  
Boston MA 02114  
(617) 726-3311  
[http://www.massgeneral.org/neurology/services/  
treatmentprograms.aspx?id=1104](http://www.massgeneral.org/neurology/services/treatmentprograms.aspx?id=1104)

**MGH Pediatric Epilepsy Service**

(617) 726-6540  
[http://www.massgeneral.org/neurology/services/  
treatmentprograms.aspx?id=1167](http://www.massgeneral.org/neurology/services/treatmentprograms.aspx?id=1167)

**MGH Webpage: Growing Up With Epilepsy**

<http://www2.massgeneral.org/childhoodepilepsy>

***Neurology/Epilepsy Centers (continued)***

 **Lahey Clinic**

Dept. of Neurology, 7 West  
41 Mall Road  
Burlington, MA 01805  
781-744-1270

 **Mount Auburn Hospital**

*Division of Neurology*  
300 Mount Auburn Street, Suite 316  
Cambridge, MA 02138  
(617) 499-5047  
[www.mountauburnhospital.org/body.cfm?id=55](http://www.mountauburnhospital.org/body.cfm?id=55)

 **New England Neurological Associates**

*Lawrence MA, Nashua NH, Lowell MA, Haverhill MA,  
Newburyport MA*  
Riverwalk, 354 Merrimack Street  
Lawrence, MA 01843  
(978) 687-2321

 **Newton-Wellesley Hospital**

*Neurology Services*  
2000 Washington Street, Green 567  
Newton, MA 02462  
(617) 243-6566 toll free: (866)- 694-3627  
[http://www.nwh.org/medical-surgical-departments/medicine/  
neurology/](http://www.nwh.org/medical-surgical-departments/medicine/neurology/)  
*Pediatric Neurology*  
Off-site appointments- (781)-769-6654 or (781)-416-1919  
(located in Norwood & Wellesley)  
[www.nwh.org/medical-surgical-departments/pediatrics/  
pediatric-neurology](http://www.nwh.org/medical-surgical-departments/pediatrics/pediatric-neurology)

 **UMass Memorial Medical Center (Worcester):**

|                      |                     |
|----------------------|---------------------|
| University Campus    | Memorial Campus     |
| 55 Lake Avenue North | 119 Belmont Street  |
| Worcester, MA 01655  | Worcester, MA 01605 |

Neurology Department: (508) 334-2527  
[www.umassmemorial.org/medicalcenterip.cfm?id=1719](http://www.umassmemorial.org/medicalcenterip.cfm?id=1719)

Pediatric Neurology Department: (508) 856-3279  
To book an appointment: (774) 442-5695  
<http://www.umassmemorial.org/MedicalCenterIP.cfm?id=2250>

***Neurology/Epilepsy Centers (continued)***

**— New Hampshire —**



**Southern New Hampshire Medical Center:**

280 Main Street, Suite 210A  
Nashua, NH 03060  
(603) 577-5300  
<http://www.snhmc.org/practices/foundationneurology/index.htm>



**Dartmouth-Hitchcock Medical Center:**

One Medical Center Drive, Lebanon, NH 03756  
Phone: (603) 650-5000  
[www.dartmouth-hitchcock.org](http://www.dartmouth-hitchcock.org)

***Epilepsy Program***

Adults: (603) 650-8309  
Pediatrics: (603) 653-9669

\*note: need a referral from a physician before enrolling in this program



**Pediatric Neurology:**

Dartmouth-Hitchcock  
25 S River Road # 3110  
Bedford, NH 03110  
Phone: (603) 695-2572  
[www.dartmouth-hitchcock.org](http://www.dartmouth-hitchcock.org)



**Hood Center for Children and Families:**

HB 7465, Department of Pediatrics  
Dartmouth Medical School

Dartmouth Hitchcock Medical Center  
Lebanon NH 03756  
Phone: (603) 653-0777  
Fax: (603) 653-0790  
E-mail: [Hood.Center@Dartmouth.edu](mailto:Hood.Center@Dartmouth.edu)  
<http://hoodcenter.dartmouth.edu>

*The Epilepsy Open Access project, at the Hood Center for Children and Families, Dartmouth Medical School, is working to integrate education, community outreach, transition planning, and seizure co-management to facilitate communication across those systems.*

**Neurology/Epilepsy Centers (continued)**



**Coastal Neurology Services Inc:**

113 New Rochester Road  
Dover, NH 03820  
(603) 749-0913



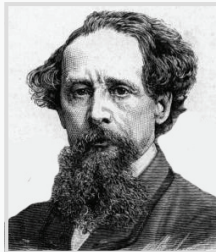
**Upper Valley Neurology Neurosurgery:**

106 Hanover Street  
Lebanon, New Hampshire 03766  
(603) 448-0447      Toll-Free: (888) 391-9737  
Fax: (603) 448-0019  
Email: info@uvnn.com

**Find a Primary Care Provider Line: (603) 653-3211**

This program of Dartmouth-Hitchcock can help adults and children who need a family doctor (primary care provider, or PCP). The service explains which physicians are accepting new patients, and who may be right for you and your family. Have your health plan insurance card available when you call. Note: we recommend that you call the Find a Primary Care Provider Line before contacting your insurance company.

**Famous People  
with Epilepsy**



**Charles Dickens**

**Neurology/Epilepsy Centers (continued)**

**— Rhode Island —**



**Rhode Island Hospital**

*Comprehensive Epilepsy Program at R.I. Hospital*

593 Eddy Street

Providence, RI 02903

(401) 490-0496

<http://www.lifespan.org/rih/services/neuro/epilepsy/>



**Hasbro Children's Hospital**

Neurology and Neurosurgery

(401) 444-4345

To make an appointment: (401) 444-9317

<http://www.lifespan.org/hch/services/neuro/>



**R.I. Neurology Group, Inc.**

*(Private Practice of Dr. Dennis Aumentado)*

1065 Mendon Road

Woonsocket, RI 02895

(401) 762-0170

Fax: (401) 762-3774

<http://www.rineurologygroup.com>



**Neurology Foundation Inc.:**

450 Veterans Memorial Parkway, Building #15

East Providence, RI 02914

(401) 431-9017



**Eastside Neurology, Inc.:**

450 Veterans Memorial Parkway, Building #15

East Providence, RI 02914


(401) 431-1860


## Essential Resources


 **Regional- Social Security Administration**  
(800)- 772-1213


### — Rhode Island —


 **Rhode Island Department of Human Services**  
Office of Rehabilitation Services  
40 Fountain Street  
Providence, RI 02903  
(401) 421-7005                      (401) 421-7016 (TDD)

 **DHS Office of Rehabilitation Services (ORS)**  
Provides Rhode Islanders who have disabilities with a comprehensive program of rehabilitation, social and independent living services. Its mission is empowering individuals with disabilities to choose, prepare for, obtain and maintain employment, economic self-sufficiency, independence and integration into society.  
[www.ors.ri.gov](http://www.ors.ri.gov).

 **Vocational Rehabilitation (VR)**  
Assists individuals who have a disability to choose, prepare for, find and maintain employment.  
<http://www.ors.ri.gov/VR.html>

 **Disability Determination Services (DDS)**  
Determines the medical eligibility of children and adults with disabilities who are applying for cash benefits under the federal program for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).  
DDS web site: <http://www.ors.ri.gov/DDS.html>

 **Prescription assistance:** (patient assistant programs database)  
[www.rxforri.org](http://www.rxforri.org)    (877) 743-6779

 **The Matthew Siravo Memorial Foundation, Inc.**  
Epilepsy awareness, Resource Center, scholarships and Matty's Run.  
10 High Street  
Wakefield, RI 02879  
(401)-789-7330  
<http://www.mattyfund.org/foundation.htm>

## *Essential Resources (continued)*

### **— New Hampshire —**



#### **Office of Medicaid Business & Policy:**

129 Pleasant Street (street address: 115 Pleasant Street)

Concord, NH 03301-3857

(603) 271-3770

Toll Free: (800) 852-3345 x3770

[www.dhhs.state.nh.us/dhhs/specialmedsrvcs/default.htm](http://www.dhhs.state.nh.us/dhhs/specialmedsrvcs/default.htm)



#### **The Governor's Commission on Disability:**

57 Regional Drive, #5

Concord, New Hampshire 03301

(603) 271-2773



#### **The Client Assistance Program (CAP):**

CAP helps persons with disabilities receive the vocational services they need from the Vocational Rehabilitation (VR) system. Its staff can explain how the VR system works, advise about personal rights and responsibilities, suggest ways to work successfully with a counselor, and help prepare for any appeals or hearings.



#### **New Hampshire Vocational Rehabilitation (NHVR):**

An agency that helps persons with disabilities help themselves to get a job, keep the job, and develop a life-long career. NHVR has seven regional offices throughout the state designed to assist persons who have physical, mental, emotional and learning disabilities.



#### **NH Vocational Rehabilitation:**

21 South Fruit Street, Suite 20

Concord, NH 03301

Phone: (603) 271-3471 Toll-free: (800) 299-1647

Fax: 603-271-7095

<http://www.education.gov/career/vocational/index.htm>



#### **Special Medical Services:**

97 Pleasant St.

Concord, NH 03301

(603) 271-4488 TDD (800) 735-2964

<http://www.dhhs.nh.gov/DHHS/SPECIALMEDSRVCS/default.htm>

**Healthy Kids Gold:**

1 Pillsbury Street Suite 300  
Concord, NH 03301  
(603) 228-2925  
[http://www.nhhealthykids.com/programs\\_gold.php](http://www.nhhealthykids.com/programs_gold.php)

**New Hampshire Family Voices:**

129 Pleasant Street, Thayer Building  
Concord, NH 03301  
(603) 271-4525 TOLL FREE: (800) 852-3345 ext 4525  
<http://www.nhfv.org>

**Bureau of Developmental Services:**

105 Pleasant St  
Concord, NH 03301  
(603) 271-5034  
<http://www.dhhs.state.nh.us/dhhs/bds/default.htm>

**Parent to Parent of New Hampshire:**

12 Flynn Street  
Lebanon, NH 03766  
(800) 698-5465  
<http://www.p2pnh.org>

**New Hampshire Partners in Health:**

*(A division of The Hood Center for Children & Families)*  
1 Medical Center Drive  
Lebanon, NH 03756  
(603) 653-1483 TOLL FREE: (800) 656-3333  
<http://www.nhpih.dartmouth.edu/>

**Parent Information Center**

P.O. Box 2405  
Concord, NH 03302  
(603) 224-7005 V/TDD  
(800) 947-7005 (N.H. only)  
(603) 224-4365 (FAX)  
<http://www.parentinformationcenter.org>

**Council for Children & Adolescents with Chronic Health Conditions:**

21 South Fruit Street, Suite 22  
Concord, NH 03301  
(603) 271-7045  
Fax: (603) 271-1156  
Email: [dbrewitt@ccachc.org](mailto:dbrewitt@ccachc.org)  
<http://www.ccachc.org/>

*Essential Resources (continued)*

— Massachusetts —



**Disability Info:**

Contains a wealth of information for people with disabilities, their friends, families and the people who serve them. Information within this site focuses on Massachusetts.

New England INDEX  
Eunice Kennedy Shriver Center  
University of Massachusetts Medical School  
200 Trapelo Road  
Waltham, MA 02452  
(781) 642-0248      Toll Free: (800) 642-0249  
TTY: (800) 764-0200  
E-mail: [info@disabilityinfo.org](mailto:info@disabilityinfo.org)  
<http://www.disabilityinfo.org>



**Disability Determination Services:** (617)-565-2881



**Disabled Persons Protection Hotline:** (800) 426-9009



**MA Network of Information Providers for People With Disabilities:** (800) 642-0249



**Mass. Office of Disability - Client Assistance Program (CAP):** (617) 727-7440 or (800)- 322-2020  
1 Auburn Place Rm. 1305  
Boston MA 02108



**www.massmedline.com:**

A free, confidential service available to all Massachusetts residents. Patients can receive general information about their medications and side effects. Callers to the help line can also be evaluated for eligibility in the many private, state and federal programs that provide free, low cost or discounted medications (including the Medicare Drug Benefit and various patient assistance programs sponsored by members of the pharmaceutical industry) and then guided through the enrollment process.

Toll Free Help Line: (866) 633-1617 Monday-Friday, 8 a.m.–6 p.m.



**Partnership for Prescription Assistance of Massachusetts:**

A nationwide program bringing together America's biopharmaceutical research companies, healthcare providers, patient advocacy organizations, and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them. Patients will be assisted in enrolling in patient assistance programs to access medicines for free or nearly free. and learn how to contact government programs such as Medicaid and Medicare.

(888) 477-2669

<http://www.pparxma.org>



**MassResources:**

A free online resource for Massachusetts residents in need of housing, food, health care, and other basic services. It provides information on what benefits are available, how to apply, eligibility requirements and benefit amounts.

<http://www.massresources.org>



**Home Care Assistance Program: (617) 204-3853**



**The Massachusetts Rehabilitation Commission (MRC)**

Administrative Offices

27 Wormwood Street

Boston, MA 02210-1616

(617) 204-3600

Toll Free: (800) 245-6543

Fax: (617) 727-1354



**Community Services Consumer Involvement, Independent Living, Turning 22, Housing and Supported Living Programs**

(617) 204-3851

Toll Free: (800) 245-6543



**BenePlan**

UMass Medical School Center for Policy & Research

333 South Street

Shrewsbury, MA 01545

Toll Free (877) 937-9675

Benefits Specialists assigned by county.

## *Essential Resources (continued)*

### **--Maine--**



#### **211 Maine:**

Grants access to Maine's health and human services directory. You can find help with community services such as counseling, substance abuse, health care, crisis intervention, disability services, children's services, Volunteer opportunities, and more.

E-mail: [info@211maine.org](mailto:info@211maine.org)

<http://www.211maine.org>



#### **Office of Elder Services, Maine Health and Human Services:**

11 State House Station

32 Blossom Lane

Augusta, Maine 04333

(207) 287-9200

(800) 262-2232

<http://www.maine.gov/dhhs/oes/aboutus.shtml>



#### **Pharmacy HelpDesk:**

MaineCare

(866) 796-2463

<http://www.mainearepdl.org>



#### **State Health Insurance Assistance Program (SHIP):**

(877) 353-3771      TTY: (800) 750-5353

<http://www.maine.gov/dhhs/beas/hiap>



#### **Disability Rights Center**

Legal representation and advocacy of individuals

P.O. Box 2007

Augusta, ME 04338

(207) 626-2774

Toll Free: (800) 452-1948

Fax: (207) 621-1419

E-mail: [advocate@drcme.org](mailto:advocate@drcme.org)

<http://www.drcme.org>

## *Essential Resources (continued)*



### **MaineHealth:**

*Learning Resource Center (East Tower)*

22 Bramhall Street  
Portland, ME 04102  
(866)-609-5183

[http://www.mainehealth.org/mh\\_body.cfm?id=5276](http://www.mainehealth.org/mh_body.cfm?id=5276)



### **Maine Parent Federation, Inc.:**

*Case Management Services*

(207) 623-2144

Toll-Free: (800) 870-7746 (Maine only)

#### **Programs:**

Information & Referral

Workshops

Quarterly Newsletter

Family to Family

Parent/School Partnerships

Case Management

Lending Library

Public Policy

Website

Home Visiting

Post-School Opportunities

#### Available to families who:

- 1) Live in Kennebec & Somerset counties
- 2) Have children between ages 5-20 who have a diagnosis of autism, mental retardation, pervasive developmental disorder, asperger syndrome, and/or developmental delay
- 3) Receive or qualify for MaineCare

12 Shuman Ave., Suite 7 (physical address)

Augusta, ME 04330

P.O. Box 2067 (mailing address)

Augusta, ME 04338-2067

E-mail: [parentconnect@mpf.org](mailto:parentconnect@mpf.org)

<http://www.mpf.org>



### **Learning Disabilities Association of America**

A nonprofit organization dedicated to providing information and advocacy for children and adults with learning disabilities.

(412)-341-1515

<http://www.LDAmerica.org>

## *Essential Resources (continued)*



### **Tri-Country Mental Health Services:**

24-hr emergency services: (888) 568-1112

#### **Services:**

|   |                          |
|---|--------------------------|
| Procare Clinic  | Emergency Services       |
| Deer Run - Crisis Residential                               | Substance Abuse Services |
| Elder Mental Health Care                                    | Child & Family Services  |
| Thrive  | Child Case Management    |
| Employee Assistance Programs                                | Outpatient Services      |
| Community Integration Services                              | Residential Services     |
| Mental Retardation/Developmental Disability/Autism Programs |                          |

#### **Network of Care:**

Online information source/ web-based community for individuals, families, and agencies exploring mental, physical, and emotional wellness.  
<http://www.tricounty.me.networkofcare.org>

1155 Lisbon Street  
Lewiston, ME 04241  
(207) 783-9141      Toll-Free: (800)-787-1155  
<http://www.tcmhs.org>      E-mail: [info@tcmhs.org](mailto:info@tcmhs.org)



### **Maine's State Department of Education**

[www.maine.gov/education/speced/](http://www.maine.gov/education/speced/)



### **Maine's Child Development Services**

[www.maine.gov/education/speced/cds](http://www.maine.gov/education/speced/cds)



### **Speaking up for US of Maine:**

*Maine's Self-Advocacy Network* (Irene Mailhot, Regional Director)  
PO Box 2007  
August, ME 04338  
Toll-Free: (877) 207-4077  
[www.sufumaine.org](http://www.sufumaine.org)      E-mail: [sufucentral@sufumaine.org](mailto:sufucentral@sufumaine.org)



### **MPower: Maine's Adaptive Loan Fund**

Through **mPower**, Maine residents can borrow up to \$100,000 to purchase the equipment, renovations, or technologies needed to achieve greater independence and productivity.  
(800) 640-7200 (V/TTY)  
<http://www.mpowerloans.org>

## *Essential Resources (continued)*



### **Children's Center:**

A nonprofit organization providing programs which encourage the individual growth and development of children of all abilities, creating nurturing environments where children are embraced as unique and valued individuals.

1 Alden Avenue  
Augusta, ME 04330  
(207) 626-3497  
<http://www.childrenscenteraugusta.com>



### **Community Health and Counseling Services:**

Combined home health and mental health organization to provide "The healthy link between People, Family, and Community"

#### **Children's Services**

Treatment Foster Care  
Group Care  
Family-Centered Services  
Assessment and Crisis Group Care  
Assertive Community Treatment  
Targeted Case Management

#### **Adult Mental Health Services**

Community Integration Services  
Assertive Community Treatment  
Housing Options  
Therapy Services  
Psychiatry Services  
Specialized Groups  
Skills Teaching  
Elder Services



### **Crisis Service**

24/7 community based crisis intervention for adults, children, adolescents & their families

#### **BANGOR LOCATION:**

Offering home health & hospice, adult mental health, & children's services

42 Cedar Street  
Bangor, ME  
(207) 947-0366  
<http://www.chcs-me.org>

## ***Essential Resources (continued)***



### **Spurwink Services**

A nationally accredited organization providing behavioral health and educational services to meet the needs of individuals and families facing emotional, behavioral, and developmental challenges.

899 Riverside Street  
Portland, ME 04103  
(207) 871-1200 Fax: (207) 871-1232  
<http://www.spurwink.org>



### **Child Development Services, Cumberland**

A statewide network of services of Maine families and children (0-5 years) with developmental delays & disabilities (based out of Augusta, ME Dept. of Ed.)

50 Depot Road  
Falmouth ME 04105  
(207) 781-8881 Toll-Free: (866) 781-8881  
<http://www.cds-cumberland.org>



### **Morrison Center**

60 Chamberlain Road  
P.O. Box 1539  
Scarborough, ME 04070-1539  
(207) 883-6680 Fax: (270) 883-6695  
Contact: Mary Beth Caron, Preschool Coordinator  
[mbcaron@morrison.pvt.k12.me.us](mailto:mbcaron@morrison.pvt.k12.me.us)  
<http://www.mdcmaine.org>



### **Southern Maine Parent Awareness**

*Serving Families with Children with Special Needs*  
886 Main Street, Suite 303  
Sanford, ME 04073  
(207)-324-2337 toll free (800)-564-9696 (Maine only)  
<http://www.somepa.org>



### **The Parent Resource Center**

B Street Community Center  
57 Birch Street, Suite 204  
Lewiston, ME (207) 783-3990  
<http://www.advocatesforchildren.net/index.php/programs/the-parent-resource-center>

**Essential Resources (continued)**



**G.E.A.R. Parent Network (Gaining Empowerment Allows Results)**

Provides critical support to parents and families that may otherwise be isolated and overwhelmed in dealing with their children's behavioral and emotional disabilities that are often misunderstood. GEAR empowers parents and families by offering parent-to-parent support, advocacy, education, and meaningful participation in all aspects of the services children and families receive.

Contact: Judy Somers, Regional Parent Support Coordinator  
Penobscot, Piscataquis, S. Aroostok & Washington Counties  
jsomers@crisisandcounseling.org  
(207) 943-0908 Toll-Free: (800) 264-9224  
<http://www.gearparentnetwork.com>

G.E.A.R. is a program of:

**Crisis & Counseling Centers:**

32 Winthrop Street  
Augusta, ME 04330-5624  
(207)-626-3448 Toll-Free: (888) 568-1112  
<http://www.crisisandcounseling.org/>

**Famous People  
with Epilepsy**



**Budd Abbott**

## Service Dogs

Dogs that may be helpful to people living with epilepsy are being trained under programs named Seizure Response Dogs, Seizure Assistance Dogs and Seizure Assistance Dogs with Facilitated Alert Training. The listed organizations train the dogs under their own guidelines and have differing criteria for eligibility for a service animal. Contact them to find out about their programs and requirements.



### **AWARENESS K-9 FOUNDATION**

*Dogs trained for people with epilepsy or diabetes*

P.O. Box 1325

North Falmouth, MA 02556-1325

(508) 292-7977

E-mail: [marie@awarenessk9foundation.org](mailto:marie@awarenessk9foundation.org)

[www.awarenessk9foundation.org](http://www.awarenessk9foundation.org)



### **4 Paws for Ability, Inc.**

*Dogs trained for children and young adults with epilepsy*

253 Dayton Ave.

Xenia, OH 45385

Main: (937) 374-0385      Cell: (937) 768-9098

Training Center: (937) 376-2781

E-mail: [karen4paws@aol.com](mailto:karen4paws@aol.com)

[www.4pawsforability.org/seizuredogs.html](http://www.4pawsforability.org/seizuredogs.html)



### **PAWS With a Cause**

*Seizure response dogs, social support dogs*

4646 South Division

Wayland, MI 49348

[www.pawswithacause.org](http://www.pawswithacause.org)

(800) 253-7297



### **Canine Assistants**

*Service dogs for adults and children with seizures*

3160 Francis Road

Milton, Georgia 30004

(770)-664-7178

(800)-771-7221

fax: (770)-664-7820

## **Driver Licensing Laws**

### **Massachusetts**

|   |  |
|---|--|
| Seizure-free Period                                 | 6 months; less with doctor's statement |
| Periodical Medical Updates Required after Licensing | At license agreement                   |
| M.D. required to report Epilepsy                    | No                                     |
| DMV Appeal of License Denial                        | Within 14 days                         |

### **Rhode Island**

|   |   |
|---|---|
| Seizure-free Period                               | 18 months; less at discretion of DOT    |
| Periodic Medical Updates Required After Licensing | At discretion of Medical Advisory Board |
| M.D. required to report Epilepsy                  | No                                      |
| DMV Appeal of License Denial                      | Within 10 days                          |

### **Maine**

|   |                      |
|---|----------------------|
| Seizure-free Period                               | 3 months or longer   |
| Periodic Medical Updates Required After Licensing | At discretion of DMV |
| M.D. required to report Epilepsy                  | No                   |
| DMV Appeal of License Denial                      | Within 10 days       |

### **New Hampshire**

|   |                                  |
|---|----------------------------------|
| Seizure-free Period                                 | 1 year or less at discretion DMV |
| Periodical Medical Updates Required after Licensing | No                               |
| M.D. required to report Epilepsy                    | No                               |
| DMV Appeal of License Denial                        | Yes                              |

**\*\* First Aid for Seizures \*\***

**For Convulsive Seizures**  
(generalized tonic-clonic, grand mal)

**Symptoms:**

- Loss of consciousness
- May fall, stiffen, and make jerking movements
- Difficulty breathing may cause the person to turn pale or bluish, the person may drool or become incontinent

**Care:**

- Cushion the head
- Remove glasses and loosen any tight neckwear
- Turn person on side and keep airway clear
- Track time, check for epilepsy or seizure disorder I.D. Call for EMS if seizure lasts more than 5 minutes.

**DO NOT:**

- Put anything in the mouth
- Panic
- Give oral medication during the seizure
- Restrain
- Give food or drink until the person is fully conscious

**Aftercare:**

- Do reassure the person
- Allow to rest if necessary
- Stay with the person until fully awake and reoriented

**For Non-Convulsive Seizures**  
(complex partial)

**Symptoms:**

- Blank staring, aimlessness
- Chewing motions or lip smacking
- Often mistaken for drunkenness, drug abuse or mental illness; unable to interact appropriately

**Care:**

- Do not restrain, stay calm and keep track of time
- Redirect from hazards or remove hazards
- Do not agitate the person (speak calmly and don't grab)

**Aftercare:**

- Stay with the person until recovered, reassure and reorient
- Don't offer food or drink until the person is fully conscious
- Allow to rest if necessary

## **Be Careful When Switching Medications**

You want to count on your antiepileptic medications to act in the same exact way in your body no matter which manufacturer's version of the drug you use.

### **Preventing Problems with Pharmacies Changing your Medication:**

1. Tell your pharmacist you do not want your medication switched without your doctor and your consent, and ask him or her to put a note in your electronic record explaining that you take antiepileptic medications for seizures and not to switch you.
2. If you have had unusual side effects or unexpected seizures within 4 to 6 weeks of a switch in the formulation of your medication, immediately call your doctor to let him or her know, inform the FDA at 1-800-FDA-1088, and let the foundation know by calling the information and referral line at 617-506-6041.
3. File a complaint with your State Board of Pharmacy if your pharmacy, pharmacy staff or mail order pharmacy did not inform you and/or inform your doctor of an intended medication switch.
4. Join the Epilepsy Foundation's eCommunities and let people know what you think or how you've been effected by medication switching. Please send EFMARINHME a brief narrative of your experience.
5. Be familiar with what your epilepsy medication looks like, how it is prescribed and take it as directed.

# Your Helping Hands Make the Difference

In August of 2009, EFMARINHME partnered with Savers and started The Epilepsy Foundation New England Donation Center (EFNEDC). Soon thereafter, in November, the Donation Center opened its first attended donation site (ADS) in Wilmington, MA. Through the Donation Center, members of the community can donate clothing, household items, miscellaneous goods and furniture, seven days a week. The Donation Center has representatives available to assist community members with curbside pickups. EFNEDC makes it easy for you to donate goods.

In an effort to expand our donation program we have placed “attended donation sites” and clothing donation bins in a wide variety of locations. Please visit our Web site at [www.donateneuengland.org](http://www.donateneuengland.org) to find the location nearest you.

You can help support the Epilepsy Foundation in one of the following ways: sponsor a bin, sponsor an attended donation site, sponsor a neighborhood clothing drive or donate your clothing and household items. Please do not hesitate to contact our marketing coordinator at (888) 322-8209.

**Your generous donation will enable the Epilepsy Foundation Massachusetts, Rhode Island, New Hampshire, & Maine to assist individuals living with epilepsy by providing support programs, services, advocacy, and Camp Wee-Kan-Tu, an overnight camp for children with epilepsy.**



*Epilepsy Foundation New England Donation Center  
357 Middlesex Avenue  
Wilmington MA 01887  
Phone: (888)-322-8209  
[www.donateneuengland.com](http://www.donateneuengland.com)*



The Epilepsy Foundation Massachusetts, Rhode Island, New Hampshire & Maine is proud to serve the community for over 27 years. Our mission in **education, service, advocacy and research** is continually being achieved with the help of volunteers, staff, donors and the epilepsy community.

**YOUR**

**SUPPORT**

**MAKES A**

**DIFFERENCE**

Your contribution to the foundation's **MAJOR GIFTS CAMPAIGN, ENDOWMENT and ANNUAL APPEALS** will assure the future of programs and services. Contact our office for ways that you can help at 617-506-6041 x14.

