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## **Managing Anti-seizure Medications**

## **Medication Reminder Apps**

- Nile: The epilepsy management app: https://www.nile.ai/app/
- Other Medication Reminder apps: https://www.goodrx.com/healthcare-access/digital-health/medication-reminder-appa/

## Information on Assistance Programs and Discount Cards

- https://www.bigapplerx.com/
- https://newyorkrxcard.com/
- https://www.needymeds.org/
- https://www.pparx.org/
- https://www.rxassist.org/
- https://www.goodrx.com/

## Non-profit or Low-Cost Pharmacies:

- https://rxoutreach.org/
- https://www.markcubancostplusdrugcompany.com/
- https://www.blinkrx.com

### Help for specific populations:

- Infantile Spasms Financial Assistance
  - o Call 844-762-9237
  - https://enroll.tafcares.org/TAF\_ProgramInformation?Id=pyxlzfpc4X91Q54iPf7AVFt0JJmvpo7UOjebTDWGcqNRTebQ%2FDlmFupc6GHDBmSc/
- Lennox-Gastaut Copay Assistance Program
  - Call 855-864-4028 or email: lgsseizures@rarediseases.org
  - https://rarediseases.org/patient-assistance-programs/financial-assistance/
- Veterans
  - o https://www.va.gov/resources/can-i-get-free-health-care-and-prescriptions-as-a-veteran/

## **Specific Medication Programs:**

- Brivaracetam https://www.ucb-usa.com/Patients/Financial-Assistance
- Cannabidiol https://www.epidiolex.com/savings/
- Carbazepine ER https://www.helpathandpap.com/
- Cenobamate https://www.sklsinavigator.com/
- Clobazam\_https://www.lundbeck.com/us/about-us/lundbeck-in-the-us/patient-assistance/
- o Clobazam oral films https://www.sympazan.com/patient/savings-card/



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- Diazepam nasal spray https://www.myneurelis.com/
- Divalproex/Divalproex ER https://www.abbvie.com/patients/patient-support/patientassistance/eligibility-criteria.html#myabbvie/
- Eslicarbazepine https://www.sunovionsupport.com/
- Ethosuxumude https://www.pfizerrxpathways.com/
- o Felbamate https://www.viatris.com/en-us/lm/united-states/patient-assistance-program/
- Fenfluramine https://www.fintepla.com/cost-and-copay/
- Lamotrigine https://gskforyou.com/
- Levetiracetam dissolving tablets https://spritam.com/saving-program/
- o Midazolan nasal spray https://www.ucb-usa.com/Patients/Financial-Assistance/
- o Oxcarbazepine XR https://www.supernus.com/commercial-products/
- Perampanel https://www.fycompa.com/savings-card-program/
- Topiramate https://www.topamax.com/coupon.html
- o Topiramate XR https://www.supernus.com/commercial-products
- Vigabatrin https://amneal.com/vigabatrin/
- Vigabatrin oral solution https://vigadrone.com/savings-and-support/

## **Coping with Stress**

#### Mindfulness and Progressive Muscle Relaxation (PMR) Resources:

- PMR instructions https://www.va.gov/WHOLEHEALTHLIBRARY/docs/Progressive-Muscle-Relaxation.pdf
- Mindfulness Tips https://www.mountsinai.org/files/MSHealth/Assets/HS/Patient%20Care/Service-Areas/Occupational%20Medicine/Mindfulness.pdf
- Guided Mindfulness Meditation https://youtu.be/CdbzDMSGsyg
- Guided PMR https://youtu.be/Z21Xslddz3Y
- New York Wellness Information https://omh.ny.gov/omhweb/resources/publications/
- Mount Sinai Calm for Self-Care and Stress Reduction https://www.mountsinai.org/about/wellness/ms-calm

#### Finding a Therapist

- https://www.psychologytoday.com/
- https://helloalma.com
- https://www.zocdoc.com



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#### **Fitness Resources**

- ShapeUpNYC Free Zumba, yoga, circuit training classes through NYC Dept of Parks https://www.nycgovparks.org/events/shape-up-nyc
- Silver Sneakers Program for seniors 65+ https://tools.silversneakers.com/
- Epilepsy Foundation https://www.epilepsy.com/lifestyle/diet-exercise/fitness/

#### Staying Safe and Fit

- Seizure ID program: Receive a coupon to purchase a Seizure ID wristband: https://epilepsyallianceamerica.org/programs-services/seizure-id-program/
  - How to put your Medical ID on your phone's lock screen: https://www.stroke.org.uk/blog/smartphone-feature-case-emergency-ice
  - Get a free bike helmet: https://portal.311.nyc.gov/article/?kanumber=KA-02574

## Sleep

- https://www.epilepsy.com/complications-risks/sleep
- https://www.cdc.gov/sleep/about/index.html
- https://sleepeducation.org
- Mount Sinai Integrative Sleep Center: 212-979-4775
  https://www.mountsinai.org/locations/respiratory-institute/treatments/sleep-disorders

## **Epilepsy Self-Management Support Programs**

- https://www.epilepsy.com/stories/support-resources-epilepsy-mental-health
- https://managingepilepsywell.org

### **Epilepsy Support Groups**

- https://www.epilepsy.com/programs/family-services
- https://epilepsyallianceamerica.org/programs-services/support-groups/
- Mount Sinai Support Group
  - o Call 212-523-8502
- Epilepsy Caregivers Online Support Group by Mount Sinai
  - Registration form: https://docs.google.com/forms/d/1rgKTnGb6gmbewKbrakgGvc-7NarzzOnqoYJ6GPNN94U/viewform?edit\_requested=true

## **Volunteer Opportunities**

- https://www.nycservice.org/search
- https://www.volunteermatch.org/search

#### **Helplines**

Epilepsy 24/7 Helpline: Call 1-800-332-1000 (en español): 1-866-748-8008



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- Use the online form:
  - https://na0.icarol.com/pub/SurveyForm.aspx?org=72318&key=7c5f7179-4183-47bf-b079-b1b9b727c11c
- Find a resource online:
  https://na0.icarol.info/PublicResourceDirectoryFrm.aspx?org=72318
- Suicide & Crisis Lifeline: Dial or text 988
- Crisis Text Line: Text "Got5" to 741-741
- New York State Domestic Violence Hotline: 1-800-942-6906
- OASAS HOPEline: New York State's 24/7 problem gambling and chemical dependency hotline. For Help and Hope call 1-877-8-HOPENY or text HOPENY

## **Education and Work**

#### School

- Preparedness: https://www.epilepsy.com/preparedness-safety/schools
- Bullying: https://www.stopbullying.gov/
- Legal Rights:

https://www.epilepsy.com/sites/default/files/atoms/files/Legal%20Rights%20of%20Children%20with%20Epilepsy%20in%20School%20and%20Child%20Care.pdf

Seizure action plans: https://www.epilepsy.com/preparedness-safety/action-plans

#### Childcare

- Early intervention: https://www.nyc.gov/site/doh/health/health-topics/early-intervention.page
- Child Care Voucher: https://www.nyc.gov/site/acs/early-care/apply-child-care.page

#### College

Scholarships: https://www.epilepsy.com/parents-and-caregivers/work-college/scholarships

### **Vocational Rehab Programs**

- https://www.acces.nysed.gov/
- Epilepsy Foundation Metro New York: 212-677-8550

## Accommodations And the American Disability Act (ADA)

- Your Legal Rights.pdf
- FMLA for intermittent leave: https://www.dol.gov/agencies/whd/fmla
- Tips to help with reasonable accommodations:
  https://www.epilepsy.com/sites/default/files/atoms/files/How%20to%20Help%20Patients%20with%20Reasonable%20Accomodations.pdf



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- Job Accommodation Network: https://askjan.org/disabilities/Epilepsy-Seizure-Disorder.cfm
- Commercial driving: https://www.fmcsa.dot.gov/sites/fmcsa.dot.gov/files/2024-07/NEW%20Seizure%2007082024.pdf
- Airline Pilots: https://www.faa.gov/ame\_guide/media/Seizures\_Epilepsy.pdf
- Military service: https://www.epilepsy.com/lifestyle/employment/military-service

#### **Legal Assistance**

- Jeanne A. Carpenter Epilepsy Legal Defense Fund: https://www.epilepsy.com/legal-help
- Epilepsy Foundation Information and Referral Service: (800) EFA-1000
- US Equal Employment Opportunity Commission (ECOC)
  - o Call: (800) 669-4000 (voice) or (800) 669-6820 (TDD)
  - Visit https://www.eeoc.gov
- <u>EEOC's Epilepsy in the Workplace and the ADA: https://www.eeoc.gov/laws/guidance/epilepsy-workplace-and-ada</u>
- New York State Division of Human Rights:
  - o Call: (888) 392-3644
  - Visit: https://dhr.ny.gov/complaint

## **Hormones and Intimacy**

- Women & Epilepsy | Epilepsy Foundation: https://www.epilepsy.com/specific-populations/women
- Men & Epilepsy | Epilepsy Foundation: https://www.epilepsy.com/specific-populations/men
- Seizures and Epilepsy in the LGBTQ+ Population: https://www.epilepsy.com/specificpopulations/lgbtq
- Reproductive Health Access Project | Contraception for Patients with Disabilities: https://www.reproductiveaccess.org/resource/contraceptive-pearl-contraception-for-patients-with-disabilities/

## Other Resources to Help Manage Epilepsy

### **Resource Databases**

- Epilepsy Foundation Online Resource Database: https://prd.icarol.com/landing.html?token=cf741f09-1ef4-4d4b-9d0a-2c37e652a388&cssMode=Publish&orgNum=72318&db=72318
- Findhelp Portal: https://www.findhelp.org

#### **Camps**

- https://epilepsyallianceamerica.org/programs-services/camp-programs/
- https://www.familyresourcenetwork.org/campnova/
- https://comfortzonecamp.org/

#### **Clinical Trials**



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- http://clinicaltrials.gov
- https://www.mountsinai.org/clinical-trials

#### **Diet (Low Carb)**

- http://www.charliefoundation.org/
- http://atkinsforseizures.com/

### **Disability Resources**

- https://www.nyc.gov/site/mopd/resources/resources.page
- https://www.justicecenter.ny.gov/disability-resources
- https://nacdd.org/
- https://ncil.org/

## **Driving Laws**

• http://www.epilepsy.com/driving-laws

### **Finding Epilepsy Care**

- https://www.aesnet.org/for\_patients/find\_a\_doctor
- http://www.naeclocator.org/locator/default.asp

#### **Pets**

- https://pawsny.org/additional-services/
- https://www.animalalliancenyc.org/need-help/vetcare/

#### **Pregnancy**

- National Maternal Mental Health
  - o Hotline: 1-833-TLC-MAMA
  - o https://mchb.hrsa.gov/
- https://epilepsypregnancy.com/
- https://www.aedpregnancyregistry.org/
- https://mothertobaby.org/

## Respite care

- https://www.nyconnects.ny.gov/
- https://archrespite.org/ta-center-for-respite/state-respite-coalition-contacts/
- https://rarediseases.org/patient-assistance-programs/caregiver-respite/

## **Seizure Monitoring Device**

- https://www.empatica.com/embrace2/?msclkid=25d51e82a54d11ecb5aba1914f96ba17
- http://smart-monitor.com/
- http://www.samialert.com/
- http://www.dannydid.org/



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## **Seizure Diary Apps**

- https://www.epsyhealth.com
- https://www.nile.ai/app/
- https://seizuretracker.com

## **Specific Populations**

- Aging: https://aging.ny.gov/
- Aicardi: https://aicardisyndromefoundation.org/
- Angelman: https://cureangelman.org/
- Angioma (cavernous malformation): https://www.alliancetocure.org
- Autism: https://autismsociety.org/
- Brain Injury: https://biausa.org/brain-injury
- Brain Tumor: https://www.abta.org/
- Cortical malformations: https://www.cortfoundation.org
- Doose: https://doosesyndrome.org/
- Dravet: http://www.dravetfoundation.org/
- Dup:15q https://dup15q.org/
- Hydrocephalus: https://www.hydroassoc.org/
- Hypothalamic hamartomas: https://www.hopeforhh.org/
- Lennox-Gastaut: https://www.lgsfoundation.org/
- Neurofibromatosis: https://nfnetwork.org
- Sturge-Weber: https://sturge-weber.org/
- Tuberous Sclerosis: http://tsalliance.org/
- Undocumented: https://www.informedimmigrant.com/

## **Talking To Kids About Seizures**

- https://catalystpharma.com/patient-engagement/medikidz/
- http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/GetGoingGang\_Coloring-Boo.pdf
- http://mommyifeelfunny.com/
- https://www.epilepsy.com/parents-and-caregivers/talking-kids-about-epilepsy

### **Transportation**

https://access.nyc.gov/programs/access-a-ride/



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- https://www.health.ny.gov/health\_care/medicaid/members/medtrans\_overview.htm
- https://www.dot.ny.gov/511NY?mode=Public%20Transportation&type=Paratransit%20Services

## **Advanced Epilepsy Care at Mount Sinai Epilepsy Center**

Visit: https://www.mountsinai.org/care/neurology/services/epilepsy-center

## Mount Sinai Hospital (Level 4 Epilepsy Center)

- Visit: https://www.mountsinai.org/care/neurology/services/epilepsy-center
- Call: 212-241-2627
- Address: 1468 Madison Avenue Annenberg, 2nd floor, New York, NY 10029

## Mount Sinai West (Level 4 Epilepsy Center)

- Visit: https://www.mountsinai.org/locations/west
- Call: 212-241-2627
- Address: 1000 Tenth Avenue, New York, NY 10019

## Mount Sinai Kravis Children's Hospital (Level 4 Epilepsy Center)

- Visit: https://www.mountsinai.org/care/pediatrics
- Call: 212-241-2401
- Address: 1184 Fifth Avenue Fourth Floor, New York, NY, 10029

#### **Mount Sinai Union Square**

- Visit: https://www.mountsinai.org/locations/union-square
- Call: 212-241-2401
- Address: 10 Union Square East, 5<sup>th</sup> floor, New York, NY 10003

#### **Mount Sinai South Nassau**

- Visit: https://www.southnassau.org/sn
- Call: 516-632-4590
- Address: One Healthy Way, Oceanside, NY 11572

## **Mount Sinai Brooklyn**

- Visit: https://www.mountsinai.org/locations/brooklyn
- Call: 718-951-3024
- Address: 3201 Kings Highway, Brooklyn, NY 11234



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### **Mount Sinai Queens**

- Visit: https://www.mountsinai.org/locations/queens
- Call: 718-808-7300
- Address: 31-60 21st Street (21st Street and Broadway), Astoria, NY 11106