



RESOURCE CENTRAL

Vagus Nerve Stimulation for Epilepsy

Most insurers will pay for implantation of the VNS for intractable epilepsy, including Medicare and Medicaid. Because insurance companies may have different requirements, people interested in the VNS should inquire directly with their insurance provider. In addition, the VNS Therapy Access Program, sponsored by Cyberonics (cyberonics.com; 888-867-7846) provides information and assistance regarding insurance such as prior authorizations, letters of medical necessity, additional information about VNS, and assistance with appeals and denials. A nurse case manager can be reached at 877-610-1180.

If you are interested in participating in a clinical trial, discuss this possibility with your neurologist. One study, currently recruiting patients at Dartmouth Hitchcock Medical Center, in Lebanon, NH, and University Hospital, in Ghent, Belgium, is trying to determine which electrical stimulation settings of amperage, duration, and frequency are best for seizure control. The study is recruiting people with at least one seizure a month with alteration of consciousness, taking at least one antiepileptic drug, and who are 16 years or older. More complete information regarding this study (NCT00782249) is available at clinicaltrials.gov.

Cyberonics is sponsoring a health outcomes study to evaluate the effect of the VNS on quality of life as measured by the Quality of Life in Epilepsy (QOLIE-89) questionnaire, as well as seizure control and adverse events. This study is open to patients 16 years or older with intractable epilepsy. People interested in this study should contact Cyberonics regarding clinical trial NCT00522418.

Financial assistance to travel to an epilepsy center that can provide the VNS may be available from the Epilepsy Foundation. For more information, contact the Epilepsy Foundation national office at 800-470-1655, x3726.

Caregiving Resources

The Alzheimer's Association and Alzheimer's Foundation of America (see next column) provide information for Alzheimer's disease patients and caregivers.

Elder Rage

elderrage.com/Links.asp

Alzheimer's resources from caregiver advocate Jacqueline Marcell.

American Stroke Association

strokeassociation.org

For general stroke info.

National Association of Area Agencies on Aging

n4a.org

This organization helps older people who have disabilities to live at home.

National Institute on Aging: Alzheimer's Disease Education & Referral Center
nia.nih.gov/alzheimers

National Stroke Association

stroke.org

For general stroke info.

Veterans-Express

veterans-express.com

This organization helps seniors and veterans with benefits and assisted living.

Well Spouse Association

wellspouse.org

This nonprofit supports and educates spousal caregivers.

Assistance Directory

For a full listing of patient organizations, go to neurologynow.com

HELP FOR ALL

NEUROLOGICAL DISORDERS

American Academy of Neurology Foundation
aan.com/go/foundation
1-800-879-1960

TheBrainMatters.org
AAN patient website
thebrainmatters.org

National Institute of Neurological Disorders and Stroke
ninds.nih.gov

ALZHEIMER'S DISEASE

Alzheimer's Association
alz.org
1-800-272-3900

Alzheimer's Disease Education and Referral Center
alzheimers.org
1-800-438-4380

Alzheimer's Foundation of America
alzfdn.org
1-866-232-8484

AUTISM

Autism Society of America
autism-society.org
1-800-3AUTISM (1-800-328-8476)

Autism Speaks, Inc.
autismspeaks.org
212-252-8584

Global and Regional Asperger Syndrome Partnership
grasp.org
1-888-474-7277

BRAIN TUMOR

American Brain Tumor Association
abta.org
800-886-2282

Children's Brain Tumor Foundation
cbtf.org
1-866-CBT-HOPE (228-4673)

National Brain Tumor Society
Braintumor.org
1-800-934-2873

CEREBRAL PALSY

United Cerebral Palsy
ucp.org
1-800-872-5827

DYSTONIA

Benign Essential Blepharospasm
Research Foundation
blepharospasm.org
409-832-0788

Dystonia Foundation
dystonia-foundation.org
1-800-377-DYST (1-800-377-3978)

National Spasmodic Dysphonia
Association
dysphonia.org
1-800-795-6732

Spasmodic Torticollis
spasmodictorticollis.org
1-888-445-4588

EPILEPSY AND SEIZURES

Citizens United for Research
in Epilepsy (CURE)
CUREepilepsy.org
312-255-1801

Epilepsy Foundation
epilepsyfoundation.org
1-800-332-1000

HEADACHE / MIGRAINE

National Headache Foundation
headaches.org
1-888-NHF-5552 (1-888-643-5552)

Migraine Research Foundation
migraineresearchfoundation.org
212-249-5402

HUNTINGTON'S DISEASE

Hereditary Disease Foundation
hdfoundation.org, 212-928-2121

Huntington's Disease Society of America
hdsa.org
1-800-345-HDSA (1-800-345-4372)

HYDROCEPHALUS

Children's Hydrocephalus Support Group
hydrosupport.org
425-482-0479

Hydrocephalus Association
hydroassoc.org
1-888-598-3789

National Hydrocephalus Foundation
nhfonline.org
1-888-857-3434

MULTIPLE SCLEROSIS

MSFriends
msfriends.org
1-877-MSFRIENDS

MSWorld
msworld.org

Multiple Sclerosis Association of America
msassociation.org,
1-800-532-7667

Multiple Sclerosis Foundation
msfocus.org
1-800-225-6495

National Multiple Sclerosis Society
nationalmssociety.org
1-800-FIGHT-MS (1-800-344-4867)

MYASTHENIA GRAVIS

Myasthenia Gravis Foundation of America
myasthenia.org
1-800-541-5454

NEUROMUSCULAR DISEASES

ALS Association
alsa.org
1-800-782-4747

Charcot-Marie-Tooth Association
charcot-marie-tooth.org
610-499-9264
1-800-606-CMTA (2682)

Kennedy's Disease Association
kennedysdisease.org
559-658-5950

Moebius Syndrome Foundation
moebius syndrome.com
1-660-834-3406

24/7
MS Telephone
Peer Support
1-866-673-7436
Staffed by Volunteers
Living with
Multiple Sclerosis
who understand
and care about
you!

MSFriends
www.msfriends.org



Muscular Dystrophy Association
mda.org
1-800-FIGHT-MD (1-800-344-4863)

Neuropathy Association
neuropathy.org
212-692-0662

Spastic Paraplegia Foundation, Inc.
sp-foundation.org
1-877-773-4483

PAIN

American Pain Foundation
painfoundation.org
1-888-615-PAIN (1-888-615-7246)

National Foundation for the
Treatment of Pain
paincare.org
713-862-9332

PARKINSON'S DISEASE & MOVEMENT DISORDERS

American Parkinson Disease Association
apdaparkinson.org
1-800-223-2732

International Essential Tremor Foundation
essentialtremor.org
1-888-387-3667

Lewy Body Dementia Association
lbda.org

Michael J. Fox Foundation
for Parkinson's Research
michaelfox.org
1-800-708-7644

National Ataxia Foundation
ataxia.org
763-553-0020

National Parkinson Foundation
parkinson.org
1-800-327-4545

Parkinson's Disease Foundation
pdf.org
1-800-457-6676

Society for Progressive
Supranuclear Palsy
curepsp.org
1-800-457-4777

WE MOVE (Worldwide Education &
Awareness for Movement Disorders)
wemove.org
212-875-8312

SLEEP

National Sleep Foundation
sleepfoundation.org
202-347-3471

STROKE

American Stroke Association
strokeassociation.org
1-888-4-STROKE (1-888-478-7653)

Give Me Five For Stroke
giveme5forstroke.org

National Aphasia Association
aphasia.org
1-800-922-4622

National Stroke Association
stroke.org
1-800-787-6537

TOURETTE SYNDROME

Tourette Syndrome Association
tsa-usa.org
718-224-2999

TRAUMA

Brain Injury Association of America
biausa.org
1-800-444-6443

Brain Trauma Foundation
braintrauma.org
212-772-0608

Expressions of Courage

For people living with epilepsy, art can be a self-expressive, visual demonstration of how it feels to live with this serious neurological condition.

Expressions of Courage® is a national contest for people with epilepsy. The contest will be open for entries from May 11, 2009, through August 28, 2009. A panel of epilepsy advocates, art industry representatives, and healthcare experts will serve as contest judges and announce the winning artwork in November. Entries are judged based on creativity and the ability to bring to life the experiences of living with epilepsy.

Artwork may be created in ink, pencil, crayon, paint, or a combination of these materials, and must be on paper or board no larger than 8 by 11 inches. Contest entries will be categorized into three age groups: children ages 12 years old and younger; teens ages 13 to 17; and adults 18 years of age and older. Multiple submissions will be accepted.

Winners will be highlighted on the Expressions of Courage® Web site. A few winning pieces will also be chosen by curators from the Society for the Arts in Healthcare for display in a traveling art exhibition comprised of more than 20 winning entries from the past seven contests. Please send original artwork and a completed entry form to:

Expressions of Courage®, 389 Pittstown Road, Pittstown, NJ 08867

To download the Expressions of Courage® entry form and review the rules and regulations, go to expressionsofcourage.com/rules/rules.html or call the Contest Help Line at 800-224-4935 with questions.

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