KRISTINE WALSH

RESOURCE CENTRAL



diagnosis of Alzheimer's can take a toll on a patient's entire family. Fortunately there are numerous resources that offer families support and can also help them to navigate the eldercare system.

- ► The Alzheimer's Association has local offices across the country and offers resources and support groups for families: alz.org
- ▶ Elder Care Online offers both in-person and online support groups for caregivers, including special groups for children caring for their aging parents and adults caring for their spouses: ec-online.net/community/Activists/can.htm
- ► The Family Caregiver Alliance offers online caregiver support groups; caregiver resources; respite options; and workshops, classes and conferences for caregivers: caregiver.org
- The University of Florida offers online support for caregivers who have a loved one with AD: alzonline.phhp.ufl.edu

SUDEP Resources and Advocacy Groups

The group SUDEP Aware promotes understanding and knowledge about SUDEP in Canada and the United States (sudepaware.org). Epilepsy Bereaved in the U.K. (sudep.org) provides support services to affected families and dedicates its research funds to the prevention of SUDEP and other epilepsy-related deaths. Epilepsy Bereaved convened the first international research workshop on SUDEP in 1996, which helped define SUDEP and identified research priorities.

In 2008, Epilepsy Bereaved established the SUDEP Research Initiative, a collaboration with a team of researchers at King's College, University of London, and King's College Hospital National Health Service Foundation Trust.

Topics identified for research include the communication of risk, impact of SUDEP, monitoring of epilepsyrelated deaths, and seizures that occur during sleep. Ongoing studies include research into death after epilepsy surgery, as well as an assessment of SUDEP in patients with refractory epilepsy and vagus nerve stimulation.

Other SUDEP resources include:

- CURE (Citizens United for Research in Epilepsy): cureepilepsy.org
- ► Epilepsy Foundation: efa.org
- Epilepsy Therapy Project:epilepsy.com

Assistance Directory

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

HELP FOR ALL NEUROLOGICAL DISORDERS

American Academy of Neurology Web site aan.com/patients 1-800-879-1960

CaringBridge® (free, personalized Web sites to support your health journey) Caringbridge.org 651-452-7940

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

Well Spouse Association wellspouse.org 1-800-838-0879

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

Association for Frontotemporal Dementias FTD-Picks.org 1-866-507-7222

AUTISM

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

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

RESOURCE CENTRAL

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

BRAIN TUMOR

American Brain Tumor Association abta.org

1-800-886-2282

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

CEREBRAL PALSY

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

The National Amyotrophic Lateral Sclerosis (ALS)
Registry

It's Here!
www.cdc.gov/als
(800)232-4636

U.S. Department of
Health and Human Services
Agency for Toxic Substances
and Disease Registry

Lou Gehight Excessed by the Rip Van Winkle
Enundarian wowl on Gehich rem

DYSTONIA

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

American Headache Society Committee for Headache Education (ACHE) achenet.org 856-423-0043

Migraine Research Foundation migraineresearchfoundation.org 212-249-5402

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

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

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 moebiussyndrome.com 1-660-834-3406

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

PARKINSON'S DISEASE & MOVEMENT DISORDERS

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

Foundation for PSP, CBD and Related Brain Diseases curepsp.org

1-800-457-4777

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

Lewy Body Dementia Association lbda.org 404-935-6444

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

The Parkinson's Institute and Clinical Center thepi.org

1-800-655-2273

STROKE

American Stroke Association: A Division of American Heart Association strokeassociation.org

1-888-4STROKE (478-7653)

National Stroke Association stroke.org

1-800-STROKES (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

A Walking Aid Designed for Neurological Conditions!

"The U-Step is ideal for patients with multiple sclerosis, parkinson's disease, cerebullar ataxia, muscular dystrophy, ALS, stroke and head trauma.

- Pat Casev, MS, OTR/R Department of Neurology at Northwestern Medical Facility Foundation, Chicago, IL

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The innovative braking system is safe and easy to use. Unlike other walkers, the *U-Step* will <u>not</u> roll until the hand brakes are squeezed.

LaserLight™ for Parkinson's

Introducing LaserLight™an exclusive optional feature of the *U-Step*, which is designed specificially to help people with Parkinson's Disease

Optional feature: red button for operating LaserLight"



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- Easy turning in tight areas
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- Heiaht adjustable Folds for transport



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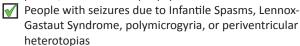
8027 N. Monticello, Skokie, IL 60076 walkers@ustep.com

EPILEPSY PHENOME/GENOME PROJECT

The Epilepsy Phenome/Genome Project (EPGP) is a collaborative effort to understand the causes of epilepsy, why people respond differently to medications, and why some families have several people with seizures.

The study is enrolling:

People with epilepsy who also have a brother, sister, parent, or child with epilepsy -or-



Please join us to unlock the mysteries of epilepsy!

To learn more about epilepsy and EPGP, please go to:

Epilepsy Foundation:

www.epilepsyfoundation.org/research/epgp.cfm

Epilepsy Therapy Project: www.epilepsy.com/articles/epgp



www.epgp.org info@epgp.org Toll-free 1-888-279-EPGP





