

NEWSLETTER



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EMERGENCY PLANNING IN CASE OF A DISASTER

By Orly Avitzur, M.D.

While evacuations are difficult for everyone, patients with neurological conditions and their caregivers face even greater challenges. Sleep deprivation, missed meals and stress can exacerbate certain conditions like seizures and can place patients at risk for more serious health problems. Here are some ways to be prepared.

Organize a trip bag with a three-week supply of prescription medication, over-the-counter drugs and related supplies. Some insurance carriers are willing to cover the cost of prescriptions for such eventualities in advance. Remember to use airtight,

watertight and light-resistant containers.

MedicAlert, the company that pioneered the bracelet engraved with personal ID number and condition, maintains detailed patient medical files on its secure database for a \$35 membership with annual \$20 renewals. It gives physicians quick access for many patients with seizure disorders, Alzheimer's and Parkinson's. Now, they have released a special USB flash drive for an additional \$50 fee. Patients can work with their doctors to add materials to their comprehensive medical records.

Put aside at least a three day supply of water and food for each person. For example, a 55-gallon barrel of water, canned and dried



food, clothes, blanket, flashlights, generator, radio, extra batteries and a first aid kit.

Patients that depend on electricity should not only have a generator but also battery backups that makes the device portable. It's also a good idea to have cash on hand. Gas, food and shelter are hard to come by otherwise.

Plan a route and destination. Ask your emergency response agency, fire department and other local organizations to help you create an evacuation strategy and practice it.

(excerpts taken from *Neurology Now*—Jan/Feb 06)

RESEARCH UPDATES

Alzheimer's Disease— Myriad reported negative results for Flurizan. It was generally well tolerated but the study failed to meet the primary endpoints of cognition and activities of daily living. Myriad plans to discontinue the development of Flurizan (CWWeekly July 21, 2008)

Dimebon significantly improves the clinical course of patients with mild to moderate AD and demonstrates

increasing benefits over 12 months. Dry mouth and depression were the most common adverse events. Phase III trials are planned (The Lancet/docguide.com-7/23/08)

Elan and Wyeth released mixed results from a phase II trial of bapineuzumab. Non-carriers of the ApoE4 gene showed statistically significant benefits on several endpoints. Treatment was generally well tolerated. Bapineuzumab is currently in

phase III trials (CWWeekly June 23, 2008).

Baxter issued positive results from a phase II trial of Gamma-gard Liquid and Gammagard S/D. Phase III trials are planned (CWWeekly April 28, 2008).

Tagacept and AstraZeneca released negative results from a phase IIb trial of AZD3480. Neither AZD3480 or Aricept reached the primary endpoints. Treatment

Continued pg. 3

Helpful Resources

Centerwatch

<http://www.centerwatch.com>

Alzheimer's Arkansas Programs & Services

www.alzark.org
800.689.6090

National MS Society

www.nationalmssociety.org
501.663.8104

American Diabetes Association

www.diabetes.org
501.221.7444

Epilepsy Education Association of Arkansas

www.epilepsyarkansas.com
501.772.4788

American Parkinson's Disease Association

www.apdaparkinson.org
501.622.3990

7th Annual Caregiver Symposium Hope for the Future

March 20, 2009

Geyer Springs First Baptist Church
Little Rock, AR
7:30am—4:30pm

SPEAKERS:

- Morgan Sauer, MD
- Nancy Pearce
- Victor Biton, MD
- Raymon Harvey

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Registration Deadline
March 13th
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800-689-6090**

EPILEPSY 101

More than 2 million people in the U.S. have some form of epilepsy. Some causes include birth injuries, head injuries, tumors of the brain, genetic conditions, stroke and infectious diseases including meningitis and encephalitis. 7 in 10 cases are unknown causes. Symptoms can vary from a strange feelings, to one side of the body jerking, to a whole body convulsion.

There are 2 types of epilepsy: **partial and generalized**. Partial seizures only affect a specific part of the brain. **Simple partial seizures** may include jerking movement and abnormal sensations. **Complex partial** seizures may include a person losing awareness and unconscious movements. Partial seizures that spread and become generalized are called **partial seizures secondarily generalized**.

Generalized seizures affect the entire brain. **Tonic-clonic** seizures involved the entire body stiffening and jerks and a person loses consciousness, they are also know as **grand mal** seizures. **Myoclonic** seizures are lightning jerks of the muscle, usually on both sides of the body. **Absence** seizures are when a person loses awareness and has a blank stare, they are also known as **petit mal** seizures. **Atonic** seizures cause the body to lose muscle tone with no warning and fall over.

The term epilepsy means that someone has had more than one seizure on more than one occasion. 9 percent of people will have a seizure at some point in their lives, but only 3% will go on to have epilepsy.

To diagnose epilepsy, a doctor will start by taking a medical history, physical and neurological exams. Other test include an electroencephalogram (EEG) which measure electrical impulses in the brain, a MRI of the brain and blood tests.

About 15-20% of people with epilepsy have seizures that are not adequately controlled despite receiving treatment. It is important to take antiepileptic medications (AED's) regularly. In order for the medicine to work, there must be a steady and effective amount in the blood stream and brain. There are several AED's available including Ativan (lorazepam), Depakote (valproic acid), Diazepam (benzodiazepine), Dilantin (phenytoin), Keppra (levetiracetam), Klonopin (clonazepam), Lamictal (lamotrigine), Lyrica (pregabalin), Neurotin (gabapentin), Tegretol (carbamazepine), Topamax (topiramate), Trileptal (oxcarbazepine), Zarontin (ethosuximide) and Phenobarbital.

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- ▲ Have experienced this pain for at least the past 6 months

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Participation is at no charge and compensation is available for time and travel.

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1-888-802-9612

or visit



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Patients that have repeated attacks of identical looking seizures that arise from one part of the brain may be particularly good candidates for surgery. Only patients whose seizures cannot be controlled adequately with AED's should consider surgery. The most common type of surgery performed is the anterior temporal lobectomy, which removes the front part of the temporal lobe.

The ketogenic diet is an accepted form of treatment for epilepsy for selected individuals, especially when AED's fail and surgery is not an option. The diet is most successful for children between the ages of two and five with Lennox-Gastaut syndrome (LGS). The diet does have side effects, and requires careful and significant parental training in meal preparation.

A vagus nerve stimulator (VNS) can also help. It works through a battery implant in the chest that delivers small pulses of electrical energy into the brain. It doesn't work for everyone and it is not approved by the FDA for kids younger than age 12. Brain stimulation technologies and new medications are also in clinical trials.

(WebMD-March/April 08, MINCEP Epilepsy Facts-1995/
Robert J. Gumnit, MD)

RESEARCH UPDATES CONTINUED...

was generally safe and well tolerated (CWWeekly Sept. 29, 2008).

Diabetes & Neuropathy—XTL released negative results for Bicifadine SR. Statistically, the drug had little, if any, therapeutic benefit (XTL Biopharmaceuticals 11/21/08).

Sangamo Biosciences reported positive results for SB-509. It was well tolerated and no drug-related severe adverse events. This trial has been expanded to include a third treatment cohort of a higher dose (CWWeekly Sept. 27, 2008).

Schwarz Pharma released positive results for lacosamide. The mean pain score dropped from 6.5 to 2.5. Treatment was safe and well tolerated. An MAA and NDA are currently under review by the EMEA and FDA (CWWeekly May 12, 2008).

Multiple Sclerosis—Genentech and Biogen released negative results for Rituxan for Primary Progressive MS. They plan to fully analyze the data to determine the best path forward (CWWeekly April 21, 2008).

Acorda reported positive results for Fampridine-SR. The average increase in walking speed was 24.7% compared to 7.7% in the placebo group. Based on the results Acorda plans to file an NDA with the FDA (CWWeekly June 9, 2008).

Antisense Therapeutics and Teva reported positive results for ATL1102. MRI scans showed significant 54.4% reduction in new active lesions. It was also effective in significantly reducing T1-enhancing lesion volume by 84% (CWWeekly July 14, 2008).

A new oral treatment (laquinimod) appears to reduce MRI disease activity and is well tolerated in patients with relapsing-remitting MS. The benefits and risks of laquinimod treatment are now being further assessed in a large-scale phase III trial (The Lancet/docguide.com/7/23/08).

A small pilot study of minocycline in relapsing-remitting MS showed that it was safe and beneficial. The results support further investigation of its efficacy (NIH/University of Calgary/7/23/08).

Opexa released results for Tovaxin. Although a positive trend was seen, statistical significance was not reached. Treatment was safe and well tolerated (CWWeekly Sept. 29, 2008)

Avigen issued negative results for AV650 for MS spasticity. Treatment failed to achieve reduction from baseline compared to placebo and did not reach statistical significance (CWWeekly Oct. 27, 2008).

Parkinson's—Teva and H. Lundbeck reported positive results for Azilect. Subjects showed significant improvement and it was well tolerated. Teva plans to submit these results to the FDA and EMEA (CWWeekly Sept. 2, 2008).

Kyowa Pharmaceuticals reported positive results for istradefylline, a selective adenosine receptor antagonist, for patients treated with levodopa. Results showed a reduction in OFF time and was well tolerated (NIH abstract by Mark Stacy with Duke University 7/23/08).

Epilepsy—Schwarz Pharma and UCB announced that the European Commission has approved VIM-PAT (lacosamide) as adjunctive therapy of partial-onset seizures in patients 16 years and older. It was also submitted to the FDA and is under review (Schwarz Sept. 4, 2008).

The FDA has approved valproic acid (Stavzor) delayed-release capsules in 125-, 250-, and 500-mg strengths for Bipolar disorder, seizures and migraine headaches (docguide.com/7/23/08).

Sepracor reported positive results for eslicarbazepine acetate for partial epilepsy. There was a 35.4% reduction in seizures for the 800mg group and 38.8% reduction in the 1200mg group. Sepracor plans to file and NDA with the FDA (CWWeekly June 30, 2008).

Eisai issued positive results of rufinamide for Lennox-Gastaut syndrome (LGS). Subjects had 42.5% reduction in tonic-atonic seizures. An NDA for rufinamide is currently under review (CWWeekly May 27, 2008)

CURRENT STUDIES

Epilepsy

- Cluster seizures
- Epilepsy—uncontrolled even after years of treatment with AED's (anti-epileptic drugs).

Diabetic Neuropathy

- Type 1 or 2 Diabetes, Pain (tingling, burning, numbness) in your fingers, hands, toes or feet.

Alzheimer's Disease

- Diagnosed with probable Alzheimer's disease, 50+ years of age and may or may not be on medication.

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A research study - ICARA - is now underway to explore a possible new investigational treatment for Alzheimer's disease.

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- Are 50 to 88 years old
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In addition to receiving study-related physical exams and laboratory services at no charge, participants may receive study medication and will be monitored by a medical team, including a nurse or study coordinator and a physician.

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Visit www.ICARASTUDY.com or call 1-888-818-MEMORY for more information

ICARA
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- Stephen Ambrose

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A PERSONAL EXPERIENCE... WITH PARKINSON'S DISEASE

My Husband Jim by Linda Lee Albert

The first seven years after his diagnosis of Parkinson's disease at the age of 58, Jim barely turned a hair. He was at a comfortable plateau in his career and content. Things changed when he started to fill stiff and lethargic in a way he had not previously experienced and his optimism was no longer evident.

Our son-in-law, a clinical social worker, did some research for us and according to what he found, 50 percent of Parkinson's patients will go through clinical depression at some point during their illness. Once armed with this information, we were ultimately able to find a neuropsychiatrist who aided us in understanding what my husband was going through and reassured us that Jim could be helped. The doctor prescribed Wellbutrin, an anti-depressant and encouraged him to get back to living his life as fully as possible.

There were challenges ahead. Jim had retired abruptly from his work, leaving me to handle our personal affairs. His longtime trusted assistant helped figure out

how to sell our investments and close down the business. Jim spent long days just sitting around the house in his bathrobe. I would try to perk him up by encouraging him to think of what still lay ahead—children yet to be married—grandchildren to look forward to—new places to explore. This only seemed to make him feel worse. He felt hopeless, and was ashamed of his inability to improve his spirits.

Then I learned from a course I was taking for spiritual directors, hope it not considered something you can force into being through your own will power. If it is true that we cannot actually will hope, then my efforts to persuade Jim to feel more hopeful were clearly failing for a good reason. If hope could only come as a gift, then there was nothing my husband could do to be hopeful when hope had disappeared. What he could do instead that was still within his power—begin to hope for hope.

That was the beginning of a turning point in our lives; the start of a remarkable journey that has led us to Florida—a place we never expected to be—to a beautiful condominium overlooking a



(© Microsoft Word Clip Art)

beautiful bay, to warmth and sunlight, and improved health and energy for my husband.

What challenges the future will bring, we do not know. Nor can we control the future, much as we might like to. But it is a gift to know that good things can often come out of bad, that surprises and adventures of the best sort may be around a dark and frightening corner, and that even when things seem hopeless, we can always hope for hope.

Linda Lee Albert is a corporate trainer and personal communication and life coach with a Master Certification in Neuro-Linguistics. An author and poet, her work has appeared in many publications including McCall's Magazine and The Wall Street Journal. She is a recipient of the International Merit Award in Atlanta Review's 2007 International Poetry Competition. Linda resides in Longboat Key, Florida with her husband, Jim.

(excerpts taken from her article in *Today's Caregiver Magazine* - Sept/Oct. 2008)