



DEPARTMENT OF VETERAN AFFAIRS AND APDA



WINTER 2010 PARKINSON PRESS NEWSLETTER

Safe Use Of Dietary Supplements

By Laurel Lindstrom, RN, MS

If it is advertised on the TV or the internet...it must be good – right? WRONG!! When it comes to supplements, you must take the “buyer beware” approach and research the product, what ingredients are in it and what effect they can have on your body.

According to New England Journal of Medicine article by Peiter A. Cohen, M.D., (Contaminated Dietary Supplements, NEJM 361;16, October 15, 2009) the U.S. Food and Drug Administration (FDA) has identified more than 140 supplements that contain a variety of undeclared active pharmaceutical ingredients. And this represents only a fraction of the contaminated supplements on the market. Lack of FDA resources and lenient regulation has allowed manufacturers to introduce new products with effectively no consequences. Manufacturers have been required to report serious supplement related adverse actions to the FDA since 2007, but the majority of the estimated 50,000 adverse events are not reported.

Under the Dietary Supplement Health and Education Act of 1994 (DSHEA), the dietary supplement manufacturer is responsible for ensuring that a dietary supplement is safe before it is marketed. FDA is responsible for taking action against any unsafe dietary supplement product after it reaches the market. Generally, manufacturers do not need to register their products with FDA nor get FDA approval before producing or selling dietary supplements. Manufacturers must make sure that product label information is truthful and not misleading.

“A wide range of dietary supplements have been found to be contaminated with toxic plant material, heavy metals, or bacteria. Of particular concern are the dozens of dietary supplements that
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In Honor of Dr. Paul Maestrone

Last October, 2009, the American Parkinson Disease Association lost its director of scientific and medical affairs, Dr. Paul Maestrone. He served for more than 20 years in this position and his passion and dedication for Parkinson's treatment and research was inspiring. He was instrumental in developing the World Parkinson Disease Association, the largest such grassroots organization, involving 25 countries and serving 1.5 million Americans with Parkinson's. Among his contributions, he was credited with creating the I & R (Information and Referral) concept, a networking program through which people with Parkinson's and their families can find information and support. He was instrumental in securing funding for a \$30 million research program about the disease. It is with great sadness we offer our condolences to Dr. Maestrone's family.

Prescription Assistance Programs Directory

Modified from Salt Lake City, Utah Information and Referral Center Summer/Fall 2009 Parkinson's News.

The programs below offer financial assistance towards the cost of prescription medications. Most of these organizations work on the patient's behalf with the drug companies, and may charge a small fee for their service.

Extra help with prescription drug costs

You must be enrolled in a Medicare Prescription Drug Plan

www.ssa.gov/prescriptionhelp Telephone: 1-800-772-1213 (TTY 1-800-325-0778)

Patient Advocate Foundation – Co-Pay Relief

Helps with co-pay cost for patients with insurance. Limited to specific diseases.

www.copays.org Telephone: 1-866-512-3861

Needy Meds

An information resource to help people who can't afford to pay for their medications.

www.needymeds.org No telephone helpline

Rx Assist

Provides a comprehensive listing of pharmaceutical company Patient Assistance Programs.

www.rxassist.org Telephone: 401-729-3284

Partnership for Prescription Assistance

Provides assistance for low-income uninsured patients to get free or nearly free prescription medicines through existing patient assistance programs

www.pparx.org Telephone: 1-888-477-2669

Rx Outreach

A low-cost, mail-order prescription drug program for low income families

www.rxoutreach.com Telephone: 1-800-7693880

Rx Help

A prescription assistance company that helps qualified patients access and remain in a pharmaceutical Prescription Assistance Program

www.rxhelp4u.com

Telephone: 1-866-960-9497

Rx Hope

A web based assistance program to help patients access pharmaceutical Prescription Assistance Programs

www.rxhope.com

Telephone: 1-877-267-0517



Update on APDA Veteran Services

- The Secretary for the Department of Veterans Affairs has announced that Parkinson's disease will receive a presumption of service connection for disabled Vietnam veterans exposed to Agent Orange who are living with Parkinson's disease. The Secretary also established a service connection for B cell leukemia (such as hairy cell leukemia) and ischemic heart disease. Secretary Shinseki's decision will now follow the rulemaking process. The proposed rule will be published in the Federal Register and then be open for a period of public comment.

You may apply for disability compensation on line at

<http://vabenefits.vba.va.gov/vonapp/main.asp> or call 1-800-827-1000. You can also get help from your service representative.

Go to this website for more information:

<http://www.publichealth.va.gov/exposures/agentorange/benefits.asp>

- The VA is planning to complete the National Vietnam Veterans Longitudinal Study, initiated in 1984, to re-assess Vietnam veterans and identify current prevalence of:
 - PTSD
 - cardiovascular disorders, risk factors, and other stress related syndromes
 - general psychiatric syndromes and behaviors that would constitute significant risk factors for long-term medical care
 - health utilization patterns
- Military to test lifetime EHR in six local communities. The Department of Veteran Affairs is seeking community coordinators to head up as many as six localized health information exchange projects to advance the VA and Department of Defense joint virtual lifetime electronics record project (VLER). VLER was initiated by President Obama in April 2009 according to Government Health IT.

- The Board of Veteran’s Appeals (BVA) has been expanded to include four new Veterans Law Judges. This will enable the board to increase the number of cases being decided. BVA is an appeals body where veterans, their dependents, or their survivors can go when they’re not satisfied with decisions about claims for benefits administered by the DVA. For more information or to download a copy of the “How Do I Appeal” VA Pamphlet 01-02-02A, April 2002, visit VA’s Gateway to VA Appeals webpage at www.va.gov/vbs/bva or send a request for a copy to: **Hearings and Transcription Unit (014HRG)**
Board of Veterans' Appeals
810 Vermont Avenue, NW
Washington, DC 2042
- Looking for an old military buddy? Try finding them with Military.com’s buddy finder. Go to www.military.com and join the website; you can then search using the “buddy finder” feature. Military.com's free membership connects service members, military families and veterans to all the benefits of service — government benefits, scholarships, discounts, lifelong friends, mentors, great stories of military life or missions, and much more. Military.com provides headline news and technology updates and is written in easy to understand language.

What's New???

APDA has published two new Educational Supplements that are available from the center. **Supplement #23** talks about incontinence and Parkinson’s disease. This informational pamphlet defines incontinence and PD’s effects on the bladder. It gives great tips for living with incontinence if that is an issue for you.

Supplement #24 goes over the issues with employment and Parkinson’s disease. It covers the law and disclosure and then goes into disability application and points to consider. This pamphlet was developed by the National Young Onset Center. This center is a great resource for patients with young onset Parkinson’s disease and remembers that “age” is matter of perspective and “young” is defined by **YOU**. We also have a supplement that Check out their website: www.youngparkinsons.org, there you will find educational resources including listening to the speakers from the recent Young Onset Conference held in Dallas. Join the support network work (person to person), consider starting a young onset support group, read inspiring stories from others with young onset PD and learn to live well!

There are a number of other educational supplements available addressing pertinent topics – contact us at the center for a copy. See page 10 for a listing of available supplements.

OOPS - forgot to take your medications? Check out this web based medication scheduler and reminder tool!! www.mymedschedule.com/ask

2009 HOPE conference on Parkinson’s available for viewing on line: [HOPE CONFERENCE 2009](#)

APDA/NPF Young Parkinson Conference, **Now Available Online!** The video of the event is now accessible at: www.youngparkinsons.org. Speakers' presentation slides are also available at link: <http://event.netbriefings.com/event/youngparkinsons/Archives/jointconf1009/>.

View the Movement Disorder Society's webcast for the *Patient and Caregiver Symposium: Nonmotor Aspects of Parkinson's Disease* that was held on October 31, 2009 at http://www.movementdisorders.org/education/patient_education/index.php

Go to WWW.PDCAST.NET to view archived teleconferences on a number of PD topics or register to participate in upcoming live teleconferences. Health care professionals can earn free CME credits.

New Drug Information: Teva Pharmaceuticals today announced the FDA approved newly revised prescribing information for AZILECT[®] (rasagiline tablets) reducing certain food and medication restrictions. This update was based on clinical data that showed AZILECT[®] is a **selective** MAO-B (monoamine oxidase-B) inhibitor at recommended doses. **For patients taking AZILECT[®], this means they no longer need to follow a restriction of ordinary levels of dietary tyramine.** Tyramine is an amino acid found in certain foods and beverages, including some air-dried and fermented meats, some aged cheeses and most soybean products. Non-selective monoamine oxidase (MAO) inhibitors interfere with the breakdown and elimination of tyramine from the body, which can cause a serious increase in blood pressure. In addition, the FDA-approved prescribing information reflects **reduced concerns about the use of AZILECT[®] in combination with amines** contained in medications, including many over-the-counter cough and cold medicines.



Telephone Tip: When calling our office, you can skip listening to our phone message and go directly to leave your message by pressing the # key.

We are working on improving our email communications and saving paper, so please email us or call us with your email address and remember to let us know if it changes. Thanks!

Upcoming Educational Events

“Participating in Parkinson's Clinical Research: The Key to Becoming an Informed Study Volunteer” Webinar featuring Kenneth Getz, MBA

Wednesday, January 14, 2009, at 3:00 PM Eastern Time

To register click link below:

<http://event.netbriefings.com/event/pdtrials/Live/infvol/register.html>

"Parkinson Disease Impersonators (Look-A-Likes) of PSP, CBD & MSA”

Thursday, January 28, 2010 (see times below) Webinar by Dr. Ronald Ziman

Paste the below link into your Web Browser to register:

<https://www2.gotomeeting.com/register/856675715>

Thursday, Jan. 28, 2010 at

8:00 p.m. Eastern Time

7:00 PM Central Time

6:00 PM Mountain Time

5:00 PM Pacific Time

Parkinson’s Action Network 16th Annual research & Public Policy Forum

February 17, 2010, 11:00 a.m.-5:00 pm EST. To register for the Forum at no cost,

Please visit www.thepanforum.org or call (800) 850-4726.

Parkinson’s Disease Foundation, “Understanding Legal Issues for People with Parkinson’s”

February 2010. For more information or to register, visit www.pdf.org/en/expertbriefings.

American Association of Neuroscience Nurses 42nd Annual Educational Meeting

March 20-23, 2010, Baltimore Convention Center, Baltimore, MD. To register go to:

www.aann.org/meeting/2010/

American Academy of Neurology 2010 Annual Meeting in Toronto, Ontario, April 10-17, 2010.

14th International Congress of Parkinson’s disease and Movement Disorders, Buenos Aires, Argentina, June 13-17, 2010.

World Parkinson Congress, September 28-October 1, 2010, Glasgow, Scotland:

www.worldpdcongress.org

7th International Congress on Mental Dysfunction & other Non-Motor Features in Parkinson’s Disease (MDPD 2010), December 9-12, 2010, Barcelona, Spain.

Lending Library

The I&R Center has a lending library which includes books, videos, and DVD’s. A list is available just contact us at the center.

Northern Nevada Support Groups

Contact information: 775-328-1715 or 888-838-6256 ext. 1715

Website: www.reno.va.gov/parkinsons/parkinsons.asp

Carson City	January 12	February 9	March 9
Second Tuesday	Stan Dowdy	Cindy Chorjel	Sheila Young, PhD
2:00 pm	Alzheimer's Disease	Occupational Therapy and PD	Depression and Cognition Issues
Carson City Senior Center 911 Beverly Drive			

Reno	January 8	February 12	March 12
Second Friday	Trace Stiegman	Kerry Seymour	Charles Quaglieri
2:00 pm	PD and Exercise	Nutrition and PD	Medications and PD
Atria at Summit Ridge 4880 Summit Ridge Drive			

Reno	January 19	February 16	March 16
Third Tuesday	Paula Forgy-Gessler	Marie Sterkel	Jane Chan, MD
7:00 pm	PD and Exercise	Speech and Swallowing Update	Neuro-ophthalmic complications in PD
Neuroscience Institute, Suite 325 10085 Double R Blvd Elevator in lobby			

Safe Use Of Dietary Supplements continued from page 1

are contaminated with prescription medications, controlled substances, experimental compounds, or drugs rejected by the FDA because of safety concerns (pg. 1524)". What type of products have these potentially hazardous ingredients been found in? They have been found in supplements marketed for patients with diabetes, high cholesterol, and insomnia but most frequently in products that promise sexual enhancement, optimal athletic performance, and weight loss.

Be sure to inform your Doctor of any and all supplements that you are taking. It is important for physicians to consider side effects, possible adverse reactions, and interactions between prescribed medications and supplements. Physicians, when suspicious of adverse effects from supplements, may have the supplement tested in a clinical lab to detect unreported substances. Physicians should always report suspected adverse effects to the FDA (through MedWatch, www.fda.gov/medwatch/report/hcp.htm).

Several websites are available with FDA to help you make an informed decision about supplements. Go to:

<http://www.fda.gov/Food/DietarySupplements/default.htm> for answers to frequently asked questions about dietary supplements.

<http://www.fda.gov/Food/DietarySupplements/ConsumerInformation/ucm110567.htm> for tips on making informed decisions about supplements.

<http://www.fda.gov/Food/DietarySupplements/ConsumerInformation/ucm110493.htm> to read tips for older dietary supplement users.

So what about some the supplements that those with Parkinson's Disease may take? Things like Coenzyme Q10, Vitamin E, Melatonin, or Cowhage seeds. I will re-cap some information on these supplements from **Natural Standard**. **Natural Standard** was founded by clinicians and researchers to provide high quality, evidence-based information about complementary and alternative therapies.

Coenzyme Q10 is a fat-soluble antioxidant that is produced by the human body and is necessary for basic functioning of cells. It is reported to decrease with age and has been observed to be low in patients with Parkinson's disease. There is promising human evidence for the use of CoQ10 in the treatment of Parkinson's disease. Better-designed trials are needed to confirm these results. The dosage that was most effective in the 16 month clinical trial that was completed, was 1200 mg daily divided into 300mg dose taken four times a day. There are no clear reports of allergy or hypersensitivity to CoQ10 and there are few serious reported side effects of CoQ10. CoQ10 may lower blood sugar levels. Caution is advised in patients with diabetes or hypoglycemia, and in those taking drugs, herbs, or supplements that affect blood sugar. CoQ10 may decrease blood pressure, and caution is advised in patients with low blood pressure or taking blood pressure medications.

Vitamin E is a fat-soluble vitamin with antioxidant properties that exists in eight different forms (isomers): alpha, beta, gamma, and delta tocopherol; and alpha, beta, gamma, and delta tocotrienol. Alpha-tocopherol is the most active form in humans. Vitamin E has been proposed for the prevention or treatment of numerous health conditions, often based on its

antioxidant properties. However, aside from the treatment of vitamin E deficiency (which is rare), there are no clearly proven medicinal uses of vitamin E supplementation beyond the recommended daily allowance. There is ongoing research in numerous diseases, particularly in cancer and heart disease. The scientific evidence is inconclusive for its use with PD. Foods that contain vitamin E include: eggs, fortified cereals, fruit, green leafy vegetables (such as spinach), meat, nuts/nut oils, poultry, vegetable oils (corn, cottonseed, safflower, soybean, sunflower), argan oil, olive oil, wheat germ oil, and whole grains. Cooking and storage may destroy some of the vitamin E in foods. For adults older than 18 years, the tolerable upper limit of dosing for supplementary alpha-tocopherol recommended by the U.S. Institute of Medicine is 1,000 milligrams per day (equivalent to 1,500 IU). Recent evidence suggests that regular use of high-dose vitamin E may increase the risk of death (from "all causes") by a small amount. These conclusions have been criticized by some experts because they are based on re-calculations (meta-analyses) of the results of prior smaller studies, which were of mixed quality, with variable results, and often in patients with chronic illnesses. Nonetheless, this is the best available scientific evidence currently, and therefore chronic use of vitamin E should be used cautiously and high-dose vitamin E should be avoided. Acute overdose of vitamin E is very uncommon. High doses of vitamin E might increase the risk of bleeding and caution is warranted in patients with a history of bleeding disorders or taking blood-thinning drugs such as aspirin, anticoagulants such as warfarin (Coumadin®) or heparin, anti-platelet drugs such as clopidogrel (Plavix®), and non-steroidal anti-inflammatory drugs such as ibuprofen (Motrin®, Advil®) or naproxen (Naprosyn®, Aleve®). Concern has been raised that antioxidants may interfere with some chemotherapy agents and Vitamin E may have additive effects with cholesterol-lowering medications. Large doses of vitamin E may deplete vitamin A stores.

Melatonin is a hormone produced in the brain by the pineal gland, from the amino acid tryptophan. The synthesis and release of melatonin are stimulated by darkness and suppressed by light, suggesting the involvement of melatonin in circadian rhythm and regulation of diverse body functions. Levels of melatonin in the blood are highest prior to bedtime. Synthetic melatonin supplements have been used for a variety of medical conditions, most notably for disorders related to sleep. Melatonin possesses antioxidant activity, and many of its proposed therapeutic or preventive uses are based on this property. Due to very limited study to date, a recommendation cannot be made for or against the use of melatonin in Parkinsonism or Parkinson's disease. Better-designed research is needed before a firm conclusion can be reached in this area. There is strong scientific evidence supporting the use of melatonin for jet lag. There is good scientific evidence supporting the use of melatonin for insomnia in the elderly, sleep enhancement in healthy people, delayed sleep phase syndrome, and sleep disturbances in children with neuro-psychiatric disorders. Based on available studies and clinical use, melatonin is generally regarded as safe in recommended doses for short-term use. Commonly reported adverse effects include fatigue, dizziness, headache, irritability, and sleepiness. Melatonin should be avoided in patients using warfarin, and possibly in patients taking other blood-thinning medications or with clotting disorders. It has been suggested that melatonin may lower seizure threshold and increase the risk of seizure, particularly in children with severe neurologic disorders. Melatonin may cause drops in blood pressure. Caution is advised in patients with diabetes

or hypoglycemia, and in those taking drugs, herbs, or supplements that affect blood sugar. Mild gastrointestinal distress commonly occurs, including nausea, vomiting, or cramping.

Cowhage (*Mucuna pruriens*) seeds have been used in traditional Ayurvedic medicine to treat Parkinson's disease. In a few clinical trials in Parkinson's disease patients, three cowhage treatments yielded positive results. However, more research should be conducted to elucidate which treatment is the most effective. In addition, cowhage seeds have nutritional quality comparable to soy beans and other conventional legumes, but several antinutritional/antiphysiological compounds prevent these seeds from being used as a food source. Avoid if allergic or hypersensitive to cowhage or members of the Fabaceae family. Use cautiously with Parkinson's disease and/or taking levodopa, dopamine, dopamine agonists, dopamine antagonists, or dopamine reuptake inhibitors as cowhage seeds contain the dopamine precursor levodopa. Use cowhage cautiously if taking monoamine oxidase inhibitors (MAOIs) or other antidepressants. Use cautiously if taking anticoagulants (blood thinners) or with diabetes. Avoid with psychosis or schizophrenia. Avoid if pregnant or breastfeeding as cowhage may inhibit prolactin secretion. 15 and 30 grams of cowhage preparation for a week have been used in the treatment of Parkinson's disease; 6 ± 3 sachets (7.5 grams in each sachet) of a derivative of cowhage called HP-200 have also been used. Cowhage can cause acute toxic psychosis (mental disorder), gastrointestinal effects, and pruritus (severe itching).

So, as you can see, there are pros and cons to supplements. You must be an informed consumer and consider the evidence. For more information about a dietary supplement contact us at the center. Be sure and discuss any and all medications/supplements/herbs with your physician.

Available APDA Educational Supplements	
_____	# 4 Keys to Caregiving
_____	# 5 Hospitalization of a Parkinson Patient
_____	# 6 The Living Will & Durable Power of Attorney for Health Care
_____	# 7 Parkinson's Disease and Oral Health
_____	# 8 The Family Unit & Parkinson's Disease
_____	# 10 The Challenge of Parkinson's Disease: Adapting to a Nursing Home
_____	# 12 Re-creation & Socialization in Parkinson's Disease
_____	# 13 Medical Management of Parkinson's Disease, includes Medications Approved for treatment of PD in the USA – November 2008
_____	# 16 When Should PD Patients Go to the Emergency Room
_____	# 17 Neuro-Ophthalmology & PD
_____	# 20 Fatigue in Parkinson's Disease
_____	# 21 Dr. Andrew Weil's Recommendation for Healthy Aging
_____	# 22 Depression and Parkinson's Disease
_____	# 23 Incontinence and Parkinson's Disease
_____	# 24 Employment & Parkinson's Disease

**ALL DONATIONS ARE TAX DEDUCTIBLE – remember the APDA in your giving and help
“to ease the burden and find a cure”**

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