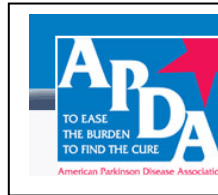


American Parkinson Disease Association, Inc
UTHSCSA – Department of Neurology
8300 Floyd Curl Dr. - MSC 7883
San Antonio, TX 78229-3900



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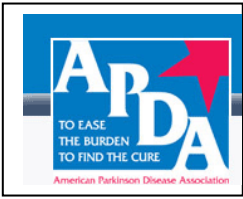
Our Web Site is located at www.aapsq.org
Hosted by PCA Web Design & Hosting in Plano, Texas, Toll Free: 888-229-4747,
E-mail: info@pcawebdesign.com.

**PLEASE NOTIFY US OF ADDRESS/E-MAIL CHANGES OR IF YOU PREFER TO RECEIVE NEWSLETTER
BY EMAIL INSTEAD OF REGULAR MAIL.**

POC: Kim Johnson Vineyard kjv624@yahoo.com 1028 PR 1712, Mico, TX 78056.

We can't get information to you if we don't know where you are living.

See last page for support group information



American Parkinson's Disease Association, Inc
 Alamo Area Parkinson Support Groups
 UTHSCSA – Department of Neurology
 8300 Floyd Curl Dr., MSC 7883 San Antonio, TX 78229-3900
 Phone 210-450-0522, www.aapsq.org
 APDA I & R Center Phone 210-450-0551

Quarterly Newsletter, July 2010

Editors: Dianne Johnson, R.N.

Local News

Executive Board, 2009

| | |
|----------------|------------------------|
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Quote of the Quarter

The way to get started is to quit talking and begin doing - Walt Disney

Parkinson's Disease and the Environmental Toxins: what is the current understanding?

Vikki Alvarez, MD, MAJ, USAF, MC
 Staff Neurologist- Movement Disorders specialist Wilford Hall Medical Center Lackland AFB, TX

Parkinson's Disease or PD is the second most common neurodegenerative condition after Alzheimer Dementia. It is called neurodegenerative because the disease typically gets worse over time. Patients with PD are managed with various medications, but the benefits of these current medications are limited to their symptomatic benefit. To date, there are several medications in the pipeline and their potential role in neuroprotection (in other words, it may help slow down the disease progression) are currently being studied.

The interests in PD are not limited to symptomatic medications, neuroprotection, and even cure, but also to understand and identify its cause. We know that more than 75% of PD is idiopathic, that is part of the brain (substantia nigra which produces dopamine) degenerates. Theories, suggestions, comments, and speculations about the potential role of the environment, particularly environmental toxins, are often the focus of attention. As a neurologist, particularly in a military hospital, I am always faced with questions from my patients regarding the etiology of their PD. Exposure to agent orange, amalgam, fumes, and many other toxins have been asked by many patients if they are the culprit. They frequently bring an article, usually from an internet source or pamphlet type articles. I always give them my honest opinion, while I don't reject the idea, I tell them that the topic is very interesting and various preliminary data are encouraging more investigative study. We need more studies to confirm any of these potential environmental toxins or exposure as a direct culprit to the development of the disease. I would like to share a couple of articles looking at environmental exposure and development of PD.

In June of 2010, several French researchers have looked at pesticide interaction and its potential role in increasing PD risk. They have looked at 101 males with PD and 234 males with no PD, who have been exposed to pesticides (organochlorines). The study showed that those who have PD not only have twice as much exposure to the pesticides, but they also have a distinct gene mutation or variation which is believed to be associated with higher risk of developing PD. They have concluded that patients professionally exposed to organochlorines, if they have some type of genetic variance which prevents clearance of some toxic by-product, may increase their risk for developing PD.

Another interesting article I would like to share was the study looking at consumption of milk and calcium in mid-life and the future risk of PD. If someone only reads the title, that person may stop drinking milk. I hope this is not the case. The authors looked at milk and calcium intake in 7,504 men ages 45-68. Over the next 30 years, 128 developed PD. Risk of PD was more than twice as high among those who consumed more than 16 ounces of milk per day versus those consuming none. The authors state, "Whether [this increased risk] involves constituents of milk other than calcium, alterations in the absorbed nutrients, or contamination of milk by neurotoxins that may promote PD warrants consideration." Clearly, the authors were not stating that a culprit was identified, yet another interesting thought is discovered that needs further understanding.

In this high technology era wired with electronic data, internet, facebook, and web-based support groups, our patients are more educated and informed than ever. As a result, the more we know, the more questions we ask. With regards to environmental toxins and development of PD, I believe that it is quite early and the verdict is not in yet. Preliminary data are a great start to more studies that will have us elucidate the different environmental causes of PD.





Summer Travels



- 1. Carry a spare prescription for any medications you will need regularly.**
- 2. Keep dried fruit, trail mix, granola bars, or other foods in your survival kit that will help stave off the hunger pangs**
- 3. Pack a "survival kit" with your basic needs, information and important supplies, and always keep it in your carry-on. NEVER check this sort of baggage**
- 4. Let your doctor know you are going**, and if you are worried about it, leave a letter in your file giving permission for your doctor to release information or consult on your case while you are gone if you request it. This might be helpful in the event of an emergency and you aren't able to consult doctors in the host country who know anything about your condition.
- 5. Always, always, always travel with medical insurance!**
- 6. If you have medical equipment, like my wheelchair, familiarize yourself with its care and repair.** Consider bringing a repair kit with you.
- 7. Be prepared to be your own best friend** during this trip: Advocate for yourself and your travel needs, and be flexible and adaptable. Don't expect everything to go as planned or even as you need it to go, but instead, think ahead and be willing to consider alternate plans. This sort of attitude goes a long way toward reducing stress and disappointment while putting you in the best frame of mind to totally enjoy yourself!

Travel and Chronic Disease

Chronic disease is not an absolute contraindication to travel abroad. It is; however, wise to seek advice from your general practitioner before travel.

With a little planning, travelling can be possible and even beneficial for those with chronic disease.

Tips:

- Before buying your tickets, discuss your plans with your doctor. He can advise you on appropriate destinations for people with your condition;
- Carry a physician's letter certifying the necessity for any drugs or other medical items (e.g. syringes) carried by the traveler that may be questioned by customs officials
- Any traveler with a chronic illness should carry all necessary medication for the journey and for the entire duration of the trip in their hand luggage
- Travelers are advised to check whether their medication is legal in the destination country with the country's embassy or consulate in prior to departure
- Carry a copy of the prescription, and ensure that both the generic and trade names of the drug are included. .
- Leave all medicine in its original, labeled container to avoid misunderstandings with customs officials.

- Check with your insurance company and know their policies on coverage. If you will not be covered where you are travelling, purchase traveler's insurance.



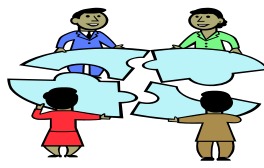
Gene Transfer Phase 2 Clinical Study for Parkinson's Disease

This Phase 2 clinical study delivers neurturin (NTN), a protein related to glial cell line-derived neurotrophic factor (GDNF), to both the putamen and substantia nigra using a genetically engineered adeno-associated virus (AAV) type-2 vector. This compound has demonstrated neuroprotective and neuroregenerative properties in rodent and nonhuman primate models of Parkinson's disease. In previous human studies, AAV2-NTN was found to be safe and well tolerated. The study consists of a 30-day baseline phase, an inpatient hospital stay in which patients are randomized 1:1 to receive the gene transfer agent, delivered via stereotactic neurosurgical procedures to the putamen and substantia nigra, versus sham surgery. Patients are then followed for 36 months. When the first 12 months of the phase 2 study are complete and the blind is broken, patients randomized to sham surgery will be eligible to receive active treatment, if it is found to be safe and effective. There is no cost to the patient for this study.

Key eligibility criteria are:

- Bilateral, idiopathic PD with motor fluctuations despite a robust response to optimized medication therapy
- Bradykinesia and at least one of the following features: resting tremor or rigidity
- Good postural stability in the "on" state
- Age 35-70 years
- Overall good and stable health
- Normal cognitive status and no major affective disorder
- No previous intracranial procedure to treat PD (e.g., pallidotomy, DBS)

The study is being conducted at the University of California San Francisco by Dr. Jill Ostrem and Dr. Nicholas Galifianakis in Neurology and Dr. Philip Starr and Dr. Paul Larson in Neurosurgery. Physicians who require further information or wish to discuss patients who might potentially qualify for this research program should contact Dr. William Marks by email at William.Marks@ucsf.edu.



Sudoku

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|---|---|---|---|---|---|---|---|---|
| | | 8 | | 4 | | 2 | | 3 |
| | 7 | 4 | 8 | 3 | 9 | | | 6 |
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| 1 | | 2 | 4 | 6 | | | 5 | |
| | 5 | 9 | | | | 6 | | |
| | | | | 9 | 2 | 4 | | 1 |
| | 2 | | | | | 7 | | |
| 5 | | | 1 | 7 | 6 | 8 | 9 | |
| 8 | | 7 | | 5 | | 1 | | |



CHEF'S CORNER

Avocado and Romaine Salad

<http://www.qualityhealth.com/recipes/avocado-romaine-salad-6004>

Preparation time: 10 min **Servings:** 4

Cooking time: 0 min

Ingredients:

- 1 lb lettuce
- 1 large avocado, halved, pitted, peeled and sliced crosswise
- 1/2 cup light Italian dressing
- 1 cup seasoned croutons

Cooking Directions:

Combine avocado with lettuce in a salad bowl. Pour dressing over salad and toss with croutons.

Nutrition Facts

Calories 240
 % Calories From Fat 67.5%
Total Fat 18g
 Saturated Fats 3.3g
 Mono-unsaturated Fats 7g
 Poly-unsaturated Fats 5.4g
Cholesterol 0.7mg
Sodium 620mg
Total Carbohydrates 19g
 Dietary Fiber 6.1g
 Sugar 7g
Protein 3.9g



Content provided by Healthwise

Caregiver Tip No. 3: Don't Do It Alone

Some caregivers live under the impression that they are the only available source of help. However, there are often other sources of assistance available that can make your caregiving easier. If you want to be a good caregiver, know where to find help when you need it. The more support you have, the more successful you are likely to be. Services that may be useful to caregivers include the following:

Respite care may be the most important service for caregivers. Respite services provide someone who will stay with the person while you get out of the house for a few hours. If the person you are caring for needs routine medical care, you may be able to arrange to have the person stay in a nursing home for a few days while you get away for a break.

Adult day centers are "drop-off" sites where a person who does not need individual supervision can stay during the day. This service is usually offered during working hours and may or may not be available on weekends. Meals, personal care services, and social activities are provided.

Adult foster care or **board-and-care homes** are private homes where older adults receive around-the-clock personal care, supervision, and meals. Some states require board-and-care homes to be licensed.

Nursing homes generally have two levels of care. Intermediate care includes assistance with using the toilet, dressing, and personal care for people for people who do not have serious medical conditions. Skilled nursing care is usually for people who have just come from the hospital or for others who have medical conditions that require more intensive nursing care. Some facilities have special units for people with dementia.

Hospice programs provide social, personal, and medical services for terminally ill patients who wish to spend their remaining time at home or in a less formal environment than that of a hospital or nursing home.

Support groups give you an opportunity to discuss problems or concerns about caregiving with other caregivers.

To learn whether these services are available in your community, look under "Senior Citizen Services" in the Yellow Pages.



Voice and Speech Disorders in Parkinson Disease: Why They Happen and What You Can Do

By Beth Hannon*+, M.A., CFY-SLP

*National Center for Voice & Speech, Denver, CO and University of Colorado, Boulder, CO
+University of Texas Health Science Center, San Antonio, TX

“What?” “Can you say that again?” “I can’t hear you.”

If these are quotes you commonly hear from your spouse, family members, friends and co-workers you are not alone. Research shows that 89 percent of people with Parkinson disease (PD) have some type of voice or speech disorder, such as soft voice, monotone pitch, hoarse voice quality, breathiness, and imprecise articulation. As a result of these voice and speech characteristics, people with PD say they are less likely to participate in conversation or to have confidence in their voice compared to healthy aging individuals.

Why do these voice and speech problems occur? The reasons for the above-mentioned characteristics are multifactorial. The first reason is related to the disordered motor system in individuals with PD, including rigidity, tremor, and slow, small movements. The reduction and slowness of movement in the arms and legs can also be seen in the speech motor system. Difficulties with muscle activation can result in smaller movements of the respiratory system, larynx (voice box), and articulation, causing reduced breath support, decreased volume, and diminished clarity of speech.

A second cause of the voice and speech difficulties in PD is a sensory system deficit related to speech. Research has shown that PD can affect how your body takes in and understands information around you. This sensory deficit may result in people with PD not being aware that their voice is getting softer and more difficult to understand. Oftentimes this mismatch will cause a person with PD to think that their spouse or close friend is in need of hearing aid rather than thinking they are speaking softly. When asked to speak louder, a person with PD often feels as if they are shouting, even though other listeners perceive their louder voice to be at a normal loudness level.

These motor and sensory speech deficits demonstrate a need for speech intervention, but in the past only about 4 percent of individuals with PD were receiving traditional speech therapy, despite the amount of people who actually were experiencing voice and/or speech difficulties (89 percent). The reason for the lack of speech therapy was a previous consensus that speech therapy did not work. It was not until 1987 when the research and development of an effective voice and speech treatment began. The method of treatment, the Lee Silverman Voice Treatment (LSVT®LOUD), was designed to treat the specific deficits of Parkinson’s patients and has helped many individuals with PD improve their voice and speech problems, and in turn, improve their quality of life.

LSVT/LOUD is administered 4 days a week (one hour per session), for 4 consecutive weeks, making the dosage of treatment more intensive than other traditional speech therapy programs. This intensity, coupled with high effort exercises and activities during treatment, is consistent with theories of motor learning, skill acquisition, and principles of neural plasticity (i.e., the capacity of the nervous system to change in response to signals). The treatment targets both the motor and sensory system, so that following treatment participants know their voice is within normal limits and they feel comfortable using their new voice outside of the treatment room.

For over 20 years, research has been sponsored by the National Institute for Deafness and other Communication Disorders (NIDCD) of the National Institutes of Health (NIH) demonstrating the

effectiveness of LSVT/LOUD for people with PD. Results of the treatment show improvements in vocal loudness, voice quality and intonation, with participants maintaining these improvements for up to two years following treatment. Research into the treatment has also shown a spread of effects from the therapy to improve articulation, facial expression, and certain elements of swallowing.

And the voice and speech research continues! The University of Texas Health Science Center San Antonio (UTHSCSA) is currently running a study to further investigate the effects of certain voice and speech treatments for people with PD. This study focuses specifically on looking into the effects of voice and speech treatments on brain functioning. Participants in the study will take part in voice and speech assessments, undergo MRI and PET scans, and will be randomly assigned to 1 of 3 possible groups: a voice treatment group, a speech treatment group, or an untreated group. All participants in the untreated group will receive treatment at the end of the study. All assessments and treatment are provided at no cost and compensation is provided for the MRI and PET scans.

The UTHSCSA is actively looking for volunteers with PD between the ages of 45 and 85 to participate in the study which began this summer and will continue for the next 12-18 months. All appointments will be at the UTHSCSA Research Imaging Institute. If you are interested in learning more about the study or would like to see if you could qualify, please contact the Research Coordinator, Beth Hannon, at 1-888-838-7329 or pdresearch@uthscsa.edu.

Now that you know why you may be experiencing voice and speech symptoms accompanying your PD, you also know what you can do to help take control of this aspect of your PD. You can talk to your neurologist or primary care physician about receiving LSVT/LOUD treatment or visiting the website: www.lsvtglobal.com and contacting a certified speech-language pathologist. You can participate in a local voice and speech research study to help further develop effective voice and speech treatments for the Parkinson's community. Communication plays a vital role in quality of life and improving or maintaining communicative ability can help individuals with PD remain confident and continue to have a positive self-image as they face other challenges of the disease.

UPCOMING EVENTS:



Symposium is July 10th, 2010

Location: Embassy Suites NW
I-10 in San Antonio

\$10 per person or \$15 per couple

Visit www.aapsg.org for registration form



Current News:

We are now on Facebook www.facebook.com. Join our group to get current news, upcoming events, support group information, etc.

Check out our new blog page at: <http://aapsg.blogspot.com/>

Check out our new and improved website at www.aapsg.org. You can now make donations and pay your dues online.



If you are willing to receive the quarterly Newsletter via email and not through mail, please email Kim Johnson Vineyard at kjv624@yahoo.com to be added to our email distribution list.



AAPSG ANNUAL MEMBERSHIP DUES

Please remember to send in your annual AAPSG membership dues to:

AAPSG
c/o Joan Duval 8507 Chesham San Antonio, TX 78254
\$12 per person or \$24 per family



AAPSG SUPPORT GROUPS



All Support Group Meetings are for PD Patients, their Caregivers, Family and Supportive Friends.

Alamo Area PD Support Group San Antonio

Second Monday every month except Oct, 1 PM. Sunset Ridge Church of Christ, 95 Brees Blvd.

Young-Onset PD Support Group San Antonio

Second Saturday every month, 10 AM. Newforest Estates, a Senior Lifestyle Community, Auditorium, 5034 New Forest Dr.

DBS Support Group “Live Wires”

Fourth Wednesday every month, 11 AM. Location varies; call Dolores Matheny, 830-612-3208, lolamatheny@att.net for current location

Caregivers Only Support Group, San Antonio

Third Tuesday every month, 10 AM. Bob Ross Senior Ctr, 2219 Babcock Rd. POC: Dianne Johnson, 210-450-0551, 651-9835, diannejohnsonrn@aol.com .

Fredericksburg PD Support Group

First Monday every month, 10 AM. Fredericksburg United Methodist Church in a room off the Fellowship Hall, 1800 North Llano Hwy. Coffee, juice and snacks are served. POC Judy Hoopman 830-997-7705 or ralanh@beecreek.net

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