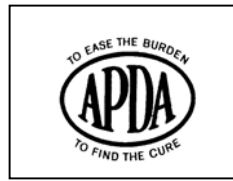


American Parkinson Disease Association, Inc  
5368 Fredericksburg Rd, Suite 200  
San Antonio, TX 78229-6108



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AAPSG Calendar, October 2004 - December 2004

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

-- **Alamo Area Parkinson's Support Group**

Second Monday every month, 1 PM

Sunset Ridge Church of Christ, 95 Brees Boulevard

11 Oct – **NO MEETING CHURCH HOLIDAY**

8 Nov – Dr Pappert & General Discussions

13 Dec – Christmas Party - Bring a \$5 gift per  
person.

-- **Young-Onset Parkinson's Support Group**

Second Saturday every month, 10 AM

Thornton Elementary School, 6450 Pembroke

9 Oct – General Discussions

13 Nov – Dr Pappert & General Discussions

11 Dec – Christmas Party – Bring \$5 gift per  
person.

**DBS Support Group “Live Wires”**

Fourth Saturday every month, 10 AM - Location  
varies; call Sandra Farris, 830-257-3811

[sandyfar@omniglobal.net](mailto:sandyfar@omniglobal.net) or Judy Hoopman 830-  
997-7705 [ralanh@ktc.com](mailto:ralanh@ktc.com) for current location.

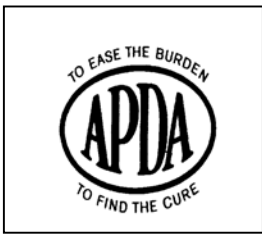
**PD Support Group of Lower Rio Grande Valley**

Third Tuesday in Sept–Nov, & Jan-May, 2:30 PM,  
at the Golden Palms Retirement Center.

2101 Treasure Hills Blvd, Harlingen, TX. Call  
Pauline and Bill Frink at 956-421-3360 for info.

**PD Support Group Poteet Texas**

Second Saturday every month, 11 AM – 1 PM  
Poteet Grange Hall, bring a covered dish. For  
more info call 830-276-4824.



American Parkinson's Disease Association, Inc  
 Alamo Area Parkinson Support Groups  
 5368 Fredericksburg Rd, Suite 200, San Antonio, Texas 78229-6108  
 Phone 210-344-8828, [www.aapsg.org](http://www.aapsg.org)  
 APDA Information & Referral Center  
 Phone 210-567-6688

## Quarterly Newsletter, October 2004

Editor: Dianne Johnson

Publishers: Carla & Doak Walker

### Local News

#### Executive Board, 2002-2004

President	Fred Dyas
Vice President	Cliff Hall
Secretary	Joan Duval
Treasurer	Shirley Knothe

You may leave a message for any AAPSG Officer at 210-344-8828

**It's a little early, but let us be the first to wish all of you and your families a Happy Thanksgiving and a very Merry Christmas.**

#### Success

Our 12<sup>th</sup> Annual Symposium was a tremendous success. Abraham Lieberman, MD, Parkinson's Disease Movement Disorder Specialist, from "Ask the Doctor" and the National Parkinson Foundation, was the primary speaker (sponsored by GlaxoSmithKline). He is actively searching for the cause of PD and has asked us to have everyone take the test at the end of this newsletter. He wants to know if the cause of PD is "under our nose". See the test and you will understand. Please take a few minutes and complete it as soon as possible. You might help find the cause of this disease.

#### Upcoming Elections

In the near future we will be having elections for the four positions on the Executive Board. The term of office for the current Executive Board members expires this year. If you want to run for one of the positions or want to nominate someone for a position contact Joan Duval at 210-680-8286 or Fred Dyas at 210-561-5120.

**PLEASE NOTIFY US OF YOUR MAILING OR E-MAIL ADDRESS CHANGE.** To Doak Walker shalom5@earthlink.net, 210-674-3013, 7650 Hwy 90W #40, San Antonio, TX 78227.

#### PD Glossary

The PD Glossary in this newsletter is adapted from *HAPS Happenings*, the newsletter from the Houston Area Parkinson's Society (HAPS). 2700 SW FRWY #284 Houston, TX 77098 713-626-7114



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**Our Web Site [www.aapsg.org](http://www.aapsg.org).**

## A Parkinson's Disease Glossary

**Akinesia [A kih NEE zee uh]:** Absence of body movements. A decline in motor performance with complete loss of the ability to initiate voluntary movement and loss of automatic movements, such as blinking.

**Amantadine (Symmetrel):** A drug that improves some symptoms by stimulating the release of available dopamine in the brain.

**Anosmia:** Loss of smell.

**Anticholinergic Parkinson's Drugs (Artane, Cogentin):** The specified drugs may help reduce rigidity, tremor, and drooling.

**Apomorphine:** A derivative of morphine and a dopamine agonist. An under the skin injection short term treatment for under medicated or a frozen state in PD. Results last from 45 to 60 minutes.

**Ataxia:** Loss of balance

**Athetosis:** Slow involuntary movements of the hands and feet.

**Basal Ganglia:** Several large clusters of cells deep in the brain, concerned with normal movement and walking. It includes the striatum and the substantia nigra.

**Bilateral:** Occurring on both sides of the body.

**Blepharospasm:** Spasmodic blinking or involuntary closing of the eye lids; a type of dystonia.

**Blood-Brain Barrier:** The protective membrane that separates circulating blood from the brain. For PD medicines to be effective they must be able to pass through this barrier.

**Bradykinesia [bray dee kih NEE zee uh]:** Slowing down of a movement. Involves slowness of initiating and executing movements, especially fine motor and repetitive movements.

**Bradyphrenia [bray dee fre NEE uh]** Slowness of thinking.

**Carbidopa:** The ingredient in Sinemet that prevents the breakdown of levodopa in the body before it can reach the brain.

**Catechol-Ortho-Methyl Transferase (COMT):** One of the two main enzymes, responsible for the metabolism of levodopa in the blood. COMT converts levodopa to 3-O-methyldopa, which decreases the amount of levodopa available for absorption in the brain.

**COMT Inhibitors:** Drugs that block COMT in the gut and periphery resulting in an increased amount of levodopa delivery through the blood brain barrier to the brain.

**Comtan:** A COMT inhibitor.

**Central Nervous System (CNS):** Consists of the brain and spinal cord.

**Cerebellum:** Part of the brain that is involved in coordination.

**Cerebral Cortex:** The largest part of the brain; responsible for thought, reasoning, memory, sensation, and voluntary movement.

**Chorea:** A type of dyskinesia (abnormal movement), characterized by continuing, rapid, dance-like movements. It may result from high doses of levodopa and/or long term levodopa therapy.

**Cogwheel Rigidity:** Stiffness in the muscles, with an intermittent resistance or jerky quality when arm and leg joints are repeatedly moved.

**Corpus Striatum (Also known as the striatum):** The largest part of the basal ganglia. This area receives information about the position and movement of the body from several different parts of the brain and transmits it to the substantia nigra. (The globus pallidus forms part of the corpus striatum.)

**Dementia:** A disorder where brain cells die more quickly than in ordinary aging, resulting in memory loss and confusion. Although affecting different cells to those affected with PD, some, especially elderly, patients with PD, experience it.

**Deep Brain Stimulation (DBS):** An operation which involves implantation of an electrode (a thin, straight, insulated wire) into the brain that continually stimulates a specific area in order to prevent the brain from generating electrical impulses. It helps tremor.

**Deprenyl (Eldepryl, Selegiline):** A drug that slows the breakdown of chemicals, like dopamine, by inhibiting the action of certain enzymes. It increases effects of dopamine in the brain.

**Dopa Decarboxylase Inhibitors:** Drugs that block the conversion of levodopa to dopamine outside the brain. These include carbidopa and benserazide.

**Dopamine:** A chemical produced by the brain; it assists in the effective transmission of electrochemical messages from one nerve cell to the next. It is deficient in the basal ganglia and substantia nigra of a person with Parkinson's. Dopamine governs actions of movement, balance and walking.

**Dopamine Agonist:** Drugs that mimic the effects of dopamine and stimulate the dopamine receptors.

**Dopaminergic:** An adjective used to describe a chemical, a drug, or a drug effect related to dopamine.

**Drug Holiday:** A 3 to 14 day withdrawal of a drug after long term treatment when side effects outweigh benefits; rarely done today because of the severe effects of drug withdrawal.

**Drug Induced Parkinsonism:** Parkinson's symptoms that have been caused by illegal drugs or drugs used to treat other conditions. It is usually reversible.

**Dysarthria:** Speech difficulties caused when the muscles associated with speech are affected.

**Dyskinesia [dis kih NEEZ ee uh]:** Abnormal random involuntary movements.

**Dysphasia [dis FAY gee uh]:** Difficulty in swallowing.

**Dystonia [dis TOH nee uh]:** Painful involuntary spasms of muscle contraction that cause abnormal movements and postures. May appear as a side effect of long term drug treatment and may worsen in response to stress.

**Entacapone:** A COMT inhibitor.

**Festination:** Walking in rapid, short, shuffling steps.

**Flexion:** A bent, curved posture.

**Freezing:** Temporary involuntary inability to move.

**Free Radicals:** Toxic substances that are continuously produced by all cells of the body; their concentrations are high in the substantia nigra. They may be involved in the loss of nerve cells that characterizes PD.

**Globus Pallidus:** A small part of the corpus striatum that is destroyed during pallidotomy. It regulates muscle tone needed for specific body movements.

**Hoehn and Yahr Stage Scale:** A five-point rating scale used to describe and assess a patient's disability in relation to PD.

**Idiopathic:** An adjective meaning "of unknown cause". The usual form of PD is idiopathic.

**Levodopa:** Natural substance found in a number of plants. It is the precursor to dopamine and is currently the best treatment for PD; it is the active ingredient in Sinemet.

**Levodopa-Induced Dyskinesias:** A side effect of medication which may occur with prolonged use. These abnormal, involuntary movements may be alleviated by reducing the amount of medication.

**Lewy Body:** Microscopic abnormalities seen, at autopsy, in the brains of PD patients.

**Livido Reticularis:** A purplish or bluish mottling of the skin seen usually below the knee and sometimes on the forearm in persons under treatment with the drug amantadine (Symmetrel).

**Micrographia [my KRO graf ee uh]:** Small handwriting due to difficulty with fine motor movements.

**Mirapex (Pramipexole):** A dopamine agonist.

**Monoamine Oxidase B (MAO-B):** Enzyme that breaks down dopamine.

**Monoamine Oxidase Inhibitors (MAO-I):** Drugs (e.g. selegiline) that block MAO-B resulting in prolonged availability of dopamine in the brain.

**Motor Control:** A patient's ability to control movement.

**Motor Fluctuation:** Variations in motor control.

**MPTP:** A toxic chemical, exposure to which can lead to Parkinson's.

**Myoclonus:** Jerking involuntary movement of arms and legs, usually occurring during sleep.

**Nigrostriatal Degeneration:** Degeneration of the nerve pathways from substantia nigra to the striatum. These pathways are normally rich in dopamine and are those affected in PD.

**On-Off Fluctuations:** Fluctuations that occur in response to levodopa therapy in which the person's mobility changes suddenly and unpredictably *from* a good response (on) to a poor response (off).

**Orthostatic Hypotension:** A sudden drop in blood pressure during rapid changes in body position (e.g., from sitting to standing); may result in fainting. May occur spontaneously in PD or be related to certain drugs.

**Pallidotomy:** An older surgical operation in which surgeons destroy small areas of the globus pallidus in order to alleviate tremor.

**Paraesthesia:** Sensations, usually unpleasant, arising spontaneously in a limb or other part of the body, variously experienced as "pins and needles" or a feeling of warmth or coldness (thermal paraesthesia).

**Parkinson Plus:** A group of diseases also referred to as "atypical parkinsonism".

**Parkinson Masked Facies:** A stolid mask-like expression of the face, with infrequent blinking; characteristic of PD.

**Parkinsonism:** A clinical state characterized by tremor, rigidity, bradykinesia, stooped posture, and shuffling gait. The more common causes of Parkinsonism are Parkinson's disease, striatonigral degeneration, and a reversible syndrome induced by major tranquilizing drugs.

**Parlodel (Bromocriptine):** A dopamine agonist useful in treating all of the primary symptoms of Parkinson's. It may be used alone or with other anti-Parkinson medications.

**Permax (Pergolide):** A drug similar to Parlodel but more potent.

**"Pill Rolling" Movements:** A rhythmical movement of the thumb upon the first two fingers of the hand. A classic sign of tremor in PD. It derives from the method that apothecaries used to make round pills.

**Postural Deformity:** Stooped posture.

**Postural Instability:** Difficulty with balance.

**Postural Tremor:** Tremor that increases when hands are stretched out in front.

**Progressive Supranuclear Palsy (PSP):** A degenerative brain disorder sometimes difficult to distinguish from PD especially in the early stages. PSP symptoms are rigidity and akinesia, difficulty looking up and down, speech and balance problems. Tremor is unusual. Those with PSP often have poor response to anti-Parkinson medications.

**Propulsive Gait:** Disturbance of gait typical of Parkinsonism in which, during walking, steps become faster and faster with progressively shorter steps that passes from a walking to a running pace and may precipitate falling forward.

**Range of Motion:** The extent that a joint will move from being fully straightened to completely bent.

**Receptor:** A sensory nerve ending that responds to a stimulus.

**Requip (Ropinirole):** A dopamine agonist.

**Resting Tremor:** Shaking that occurs in a relaxed and supported limb.

**Retropulsion Gait:** Suddenly walking backwards.

**Rigidity:** A type of muscular stiffness encountered when examining people with PD. It is characterized by a constant, even resistance to passive manipulation of the limbs.

**Seborrhea:** Increased discharge of the oily secretion sebum from the sebaceous glands of the skin.

**Seborrheic Dermatitis:** Inflammation of the skin sometimes associated with seborrhea.

**Shaking Palsy:** Old popular term which James Parkinson employed to designate the specific disorder we now call Parkinson's.

**Shy-Drager Syndrome:** This is a condition in which the symptoms are the result of abnormalities in motor function and problems in the autonomic nervous system. A person with Shy-Drager Syndrome has Parkinsonism, extremely low blood pressure which worsens upon standing, bladder problems, severe constipation, and decreased sweating. This condition is quite rare.

**Siallorhea:** Drooling of saliva.

**Sinemet:** Trade name for the anti-Parkinson drug that is a mixture of levodopa and carbidopa.

**Sinemet CR:** Controlled-release Sinemet. Levodopa with Carbidopa in a capsule contained in a matrix which releases the drug more slowly in the body. It allows for prolonged, steady absorption of levodopa into the bloodstream.

**Stem Cell:** Stem cells are the universal cells from which all other cells are derived, with the potential to become any kind of cell in the body.

**Stereotactic or Stereotaxic Surgery:** A surgical technique that involves placing a small electrode in an area of the brain to destroy a tiny amount of brain tissue. Surgeons use three dimensional co-ordinates to locate specific areas of the brain. Pallidotomy and thalamotomy use stereotactic techniques to locate the globus pallidus and thalamus.

**Striatum:** Area of brain controlling movement, balance, and walking. Connects to and receives impulses from substantia nigra. It requires dopamine to function.

**Substantia Nigra [sub STAN shuh NIGH gruh]:** A small area of the brain containing a cluster of nerve cells that produce dopamine which is then sent to the striatum. The loss of these dopamine-producing cells triggers PD symptoms.

**Thalamotomy [THAL um of o mee]:** An older operation in which a small region of the thalamus is destroyed to block tremor impulses.

**Thalamus [THAL uh mus]:** A section of the brain where the loss of dopamine signals may produce tremor.

**Tremor:** Rhythmic shaking and involuntary movement of part(s) of the body as a result of sequential muscle contractions.

**Unified Parkinson's Disease Rating Scale (UPDRS):** An overall assessment rating scale that qualifies all the motor and behavioral aspects of PD.

**Unilateral:** Occurring on one side of the body. Parkinson's symptoms usually begin unilaterally.

**"Wearing Off" Phenomenon:** Waning of the effect of the last dose of levodopa associated with abrupt reduction or loss of mobility.

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### **Sleep Problems - When to Seek Help**

If you're having trouble sleeping, talk to your neurologist or movement disorders specialist immediately. He or she can determine whether your PD is being treated appropriately at nighttime. If not, your doctor can adjust your medications to better manage your symptoms during the evening. If after these and the natural methods listed below have been tried and you still are unable to get a good nights sleep, it's time to visit a sleep disorder specialist. Ask your neurologist for a referral.

So while you may have grown tired of chasing sleep, that elusive dream, don't give up just yet. Explore these and other options and maybe you'll be able to read the morning paper without drifting off or stay awake for your favorite evening television program. As many PWP have discovered, little things can make a big difference.

### **Getting a Good Nights Sleep**

- Maintain regular rise and bed times - choose a tolerable hour and get up and go to bed at the same time every day.
- Get plenty of bright light exposure - especially natural daytime light.
- Decrease fluid intake four hours before bedtime. Go to the bathroom just before bed.
- Reserve the bed only for sleeping and sexual activities. Reading, watching TV, eating, etc.,

confuse the mind about what is expected when you get into bed.

- Set the thermostat for a slightly cooler bedroom temperature for sleeping.
- Maintain a regular, relaxing bedtime routine; we are creatures of habit.
- Lie down to sleep only when sleepy. If unable to fall asleep after 15 minutes, get out of the bed and engage in a relaxing activity (listening to music, meditating) until sleepy.
- Minimize light and noise when trying to sleep. Sleep as much as needed to feel refreshed but avoid excessive time in bed.

### **Enemies of Restful Sleep**

- Alcohol, caffeine, nicotine and other stimulants.
- Heavy late-night meals (although a light snack at bedtime may be helpful).
- Heavy exercise within 6 hours of bedtime.
- Thoughts or discussion about topics that cause anxiety, anger or frustration before bedtime.
- Looking at the bedroom clock.

by Leah Galle, From Medtronic's "Activa Therapy New Hope for Parkinson's" On-line Newsletter.

### **DON'T GIVE UP**

**If you are not exercising daily, you are surrendering to your disease and it will progress faster.**

**DON'T GIVE IN TO IT WILLINGLY**

## Memorials

**In Memory of Rev Charles L Myers.**  
Mr & Mrs Paul Deppert

**In Memory of Wilma Clipper**  
Vicki L Williams

**In Memory of Mary Charlene Mims**  
Charlotte Kimmel

**In Memory of Frank Fallon**  
Robert & Ellen Burg

**In Memory of Hazel Lalley**  
Mr & Mrs John B Glaze

**In Memory of Doyle Morgan**  
EB & Marjorie Stull  
Jane S Yury  
Virginia & Ed Fortin.

**In Memory of Cyril Aelvoet**  
Mr & Mrs Philip Persyn  
Marvin & Cheryl Dziuk  
Evelyn Burns  
Katie, Jaclyn & Travis Bonner  
Erma Dixon  
Roylee Buppert  
Helen Garza  
Leon & Genny Tshirhart  
Paul & Pat Ott  
Rene DeWinne  
Annie Halabardier  
Randy Wauters  
Dennis Burrell  
Rene VanDamme  
Norman & Norma Verstuyft  
Robert & Keith Schneider  
Diane & Tom Purdy  
Lillian Kunkel  
Louise Verstuyft  
Geraldine Dausin

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Charlotte Kimmel

**In Memory of Frank Fallon**  
Robert & Ellen Burg

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Virginia & Ed Fortin

## Help the Search for the Cause

Dr Lieberman, National Parkinson Foundation, is trying to determine the cause of Parkinson Disease. **Is the Cause of PD as plain as the NOSE on your face?**

The cause of PD is unknown. It could be genetic, environmental, or viral. For an environmental toxin or virus to cause PD, it must enter the brain. The nose, through the olfactory nerve, provides direct access to the brain. In addition there are rich connections between the blood vessels of the nose, the lungs, and the brain. It's why certain drugs when applied inside the nose, or inhaled through the nose, act so quickly.

In PD, 50% of patients lose their sense of smell. It's as though something entered the nose and traveled to the brain. Smoking cigarettes may protect you against PD. It's as though cigarette smoke "killed" a toxin. [NOTE: Smoking is not a cure for PD, SO DON'T START.]

Each of us inhales 2500 gallons of air a day. In a year all of us inhale 10,000,000 gallons of air. If there's a toxin, or a virus that causes PD, a concentration of one part per million, means all of us inhale 10 gallons of it each year.

Why don't all of us get PD? Perhaps not all of us are exposed; perhaps some of us have worse filters, or broken filters such as a broken nose or a deviated septum. An important way foreign material (bacteria, toxins, viruses) can get into the nose and perhaps the brain is through picking the nose. The above are some reasons as to why some questions were put on the survey.

In light of the above, I'd like you to take the TEST. For each person with PD who takes the TEST, I'd like you to provide a "control": a spouse, a partner, a friend, or someone your age who doesn't have PD.

Dr Lieberman, NPF

## HELP FIND THE CAUSE OF PD PLEASE COMPLETE THE FOLLOWING

\_\_\_\_\_ I am the patient  
\_\_\_\_\_ Male  
\_\_\_\_\_ Female

Check either Yes \_\_\_\_\_ or No \_\_\_\_\_

1 Yes \_\_\_\_\_ No \_\_\_\_\_ Have you had a broken nose? Or a deviated septum? Or surgery on your nose?

2 Yes \_\_\_\_\_ No \_\_\_\_\_ Do you often have sinus infections? Or a stuffed nose? Or a running nose?

3 Yes \_\_\_\_\_ No \_\_\_\_\_ Have you had MANY episodes of flu?

4 Yes \_\_\_\_\_ No \_\_\_\_\_ Have you lost your sense of SMELL?

5 Yes \_\_\_\_\_ No \_\_\_\_\_ Have you had YEARS of being exposed to fumes? Gases? Smoke? Or vapors?

6 Yes \_\_\_\_\_ No \_\_\_\_\_ Have you had YEARS of working in a mine? Or a petroleum field? Or an oil refinery? Or a fertilizer plant? Or a blast furnace? Or as a welder?

7 Yes \_\_\_\_\_ No \_\_\_\_\_ Have you been EXPOSED to Agent Orange? Or had the Gulf War Syndrome?

8 Yes \_\_\_\_\_ No \_\_\_\_\_ Does your Nose EASILY burn or blister in the sun?

9 Yes \_\_\_\_\_ No \_\_\_\_\_ Have you smoked cigarettes? Or cigars? Or other weeds?

10 Yes \_\_\_\_\_ No \_\_\_\_\_ Do you often pick your nose?

11 Yes \_\_\_\_\_ No \_\_\_\_\_ Do you often have nose bleeds?

12 Yes \_\_\_\_\_ No \_\_\_\_\_ Do you often use nose drops? Or nose sprays? Or nose swabs? Or sniff drugs into your nose?

**Please complete the TEST and send to  
Ask the Doctor: Abraham Lieberman MD  
c/o National Parkinson Foundation  
1501 NW 9th Avenue, Miami Florida 33136**

\_\_\_\_\_ I am the control  
\_\_\_\_\_ Male  
\_\_\_\_\_ Female

Check either Yes \_\_\_\_\_ or No \_\_\_\_\_

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