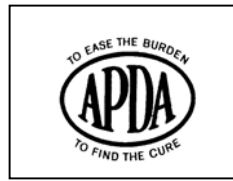


American Parkinson Disease Association, Inc
5368 Fredericksburg Rd, Suite 200
San Antonio, TX 78229-6108



NON-PROFIT ORG
U.S. POSTAGE
P A I D
San Antonio, Texas
Permit No. 3999

RETURN SERVICE REQUESTED

AAPSG Calendar, July 2004 – September 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
12 July – **NO MEETING DUE TO SYMPOSIUM**
24 July -- **Annual Symposium**
9 Aug -- General Discussions and Bingo
13 Sep – Info on new Medicare Drug Card

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

Second Saturday every month, 10 AM
Thornton Elementary School, 6450 Pembroke
10 July – **NO MEETING DUE TO SYMPOSIUM**
24 July – **Annual Symposium**
14 Aug – General Discussions
11 Sep – General Discussions

DBS Support Group “Live Wires”

Fourth Saturday every month, 10 AM - Location
varies; call Sandra Farris, 830-257-3811
sandyfar@omniglobal.net or Judy Hoopman 830-
997-7705 ralanh@ktc.com for current location.

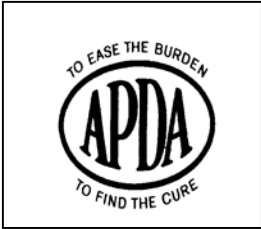
PD Support Group of Lower Rio Grande Valley

Meets Second Tuesday in Sept–Nov, & Jan-May.
2:30 PM, Golden Palms Retirement Center,
2101 Treasure Hills Blvd, Harlingen, TX

**PLEASE NOTIFY US IF YOUR LOCAL
ADDRESS OR E-MAIL ADDRESS CHANGE**

To Doak Walker shalom5@earthlink.net, 210-
674-3013, 7650 Hwy 90W #40, San Antonio, TX
78227.

VETERANS SEE THE LAST PAGE



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
 APDA Information & Referral Center
 Phone 210-567-6688

Quarterly Newsletter, July 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

At-Large Members

Brad Sledge	Roger Johnson
Mark Doherty	Amelia Nieto-Duval
Rob Rodriguez	Isabel Fears
Johnny Jackson	Melinda Rodriguez
Carol Bertsch	Carolyn Deel
Kip Morrison	

You may leave a message for any AAPSG Officer or Board Member at 210-344-8828.

IMPORTANT DATE

The 12th ANNUAL SYMPOSIUM will be held July 24th at the San Antonio Airport Hilton, 10:30 am – 2:30 pm. Lunch will be served. Abraham Lieberman, MD, Parkinson's Disease Movement Disorder Specialist, from "Ask the Doctor" and the National Parkinson Foundation, will be the primary speaker (sponsored by GlaxoSmithKline). Dr Faber will present a presentation on Sexual Problems and PD. Cost is \$15 per person or \$25 per couple. Send a check made out to AAPSG Symposium, with names of attendees and a daytime address & phone number to Shirley Knothe, 107 Mountain View, Boerne, TX 78006-6228 For more info call Dianne Johnson at 210-567-6688. If you have a question you would like Dr Lieberman or Dr Faber to answer, mail them to Dianne Johnson UTHSC-Dept of Medicine, Division of Neurology-MSC 7883, 7703 Floyd Curl Dr, San Antonio, TX 78229-3900.

Walk-A-Thon

We raised \$ 2422.50 at this years APDA Stamp Out PD Walk-A-Thon. A special thank you goes out to all the walkers, and to our Walk Sponsors including SAS

Shoes, Alterra Sterling House, Access Quality Therapy Services (POP Center), Senior 2000, Choice 1 Medical, and Culligan Water.

Our Web Site www.aapsg.org

developing creativity

The AAPSG web site development and hosting is donated by The James Company.

The James Company was founded with the desire to develop creative solutions for business needs. From beginning to end, The James Company combines a passion for technology with an eye for creativity to bring you innovative and customized solutions.

The James Company services include:

- web site design/development
- web site hosting
- custom programming/e-commerce
- small business consulting/solutions

Please visit our web site at: www.thejamescompany.com

This newsletter is provided for informational purposes only. The material should not be used for treatment purposes without discussing it with your Doctor. Products, businesses, services, or websites are not endorsed by APDA, or AAPSG

PD Research

1. The Pentagon has announced a \$240,000 grant to a university in Sweden to fund stem cell research related to PD. The Pentagon sees PD as a model for neurological disease that can also be caused by toxic substances in military contexts. Associated Press

2. An anonymous donor has given the University of Texas Health Science Center at Houston its largest gift ever, \$25 million, to boost its stem cell research program. University officials will use the gift to hire a top stem cell researcher. UT-Houston is one of many institutions to work with stem cells, a promising but sometimes controversial building block of life. Because of their ability to grow into almost any cell in the body, scientists believe stem cells have virtually limitless medical potential. The funding will allow the scientist to bring an entire team of junior researchers and buy new equipment.

UT-Houston has announced they have received approval from the USFDA to inject adult stems cells into patients with severe heart failure. UT-Houston researchers are also working to develop stem cells that won't be rejected by the body and are developing techniques to control the differentiation of a basic stem cell into other cell types, such as heart and lung cells.

ERIC BERGER Copyright 2004 Houston Chronicle
Medical Writer

Curvature of the Spine

A curved spine will make walking difficult and increase balance problems. Keeping the spine straight, preventing the spine from being bent, preventing the posture from becoming stooped is an important exercise: An exercise that must be worked on all the time to keep the spine straight:

- 1. Learn to stand with your hands on your hips. This forces your shoulders-up and forces you to stand straight. Every time you stand, place your hands on your hips-- make it a habit.
- 2. Learn to sit with your elbows on the table. This also forces your shoulders up and forces you to sit straight, with head-up-- make it a habit. It's not what your mother taught you, but she didn't know about PD.

- 3. Every day, in the morning as soon as you get up, and in the evening before you go to bed, face a mirror, raise your hands above your head-- as high as you can reach, your elbows as straight as you can make them. Keep your hands above your head and elbows straight until you slowly count to ten. Then rest your hands at your side and repeat the exercise 20 times. Each time you should feel a pull of the muscles of your upper back. If you don't feel such a pull, you aren't reaching high enough. **NOTE: If you have a balance problem don't try this alone.**

www.parkinson.org/curvature

***** A.S.A.P. *****

There's work to do, deadlines to meet;
You've got no time to spare,
But as you hurry and scurry-
ASAP - ALWAYS SAY A PRAYER

In the midst of family chaos,
"Quality time" is rare.
Do your best; let God do the rest-
ASAP - ALWAYS SAY A PRAYER.

It may seem like your worries Are more than
you can bear.
Slow down and take a breather-
ASAP - ALWAYS SAY A PRAYER

God knows how stressful life is;
He wants to ease our cares,
And He'll respond to all your needs
A.S.A.P. - ALWAYS SAY A PRAYER
God bless and have a nice day!

Vitamin B2 and PD

A study revealed that Parkinson patients have deficiency in vitamin B2 (riboflavin) and consume high amounts of red meat or pork. Including vitamin B2 and excluding red meat and pork were two small changes in the diets of 31 PD patients which resulted in visible benefits. Those patients, under treatment in the Hospital do Servidor Publico Municipal, Brazil, verified not only the stagnation of the disease but also its regression. With only 3 months of treatment (30mg B2 three times a day) and diet, the patients showed an average recovery of the

physical capabilities from 44 to 70%. The best results were found in patients in the first phase of the disease. However, some persons being conventionally treated for a long time also presented improvements of the physical functionalities from 15 to 90% after starting the new treatment.

Animal fat versus meat

Generally, medical information points out that the consumption of animal fat is one of the main factors contributing for the development of PD. However, the neurosurgeon Cláudio Corrêa, says that this information is questionable since no studies could prove that link. On the other hand, he says that there are some studies confirming the direct link between the consumption of meat and the production of neurotoxins. It is already known that red meat produces a substance called hemine, which is extremely toxic for the human cells, generating the production of free radicals. To be eliminated, these free radicals need a substance called glutathione, which, after being consumed, can only be recovered with vitamin B2. In fact, the lack of glutathione is the first neuro-chemical change present in the brain cells that are degenerating with PD.

Therefore, with the increase of vitamin B2, the researcher and Dr. Cicero Coimbra expected to stop the progression of the disease.

Nevertheless, the results were even more promising: the disease started to regress. The explanation for the phenomenon is still not completely understood but it should be related with: 1) the neurogenesis (process of formation of the nervous system); or 2) the recovery of nervous cells, which were not functioning but were still alive in the black substance of the encephalon (main region affected by the degeneration).

In conclusion, Dr. Coimbra believes that the lack of vitamin B2 in the patients may result from a problem that affects 15% of the population: the malfunctioning of an enzyme called lavoquinase, responsible for the absorption of the vitamin B2.

The results of these studies were reported in the 6th International Conference of Alzheimer and Parkinson Diseases, Sevilha, Spain (May 2003).

NOTE: Vitamin B2, 30 mg tablets, are extremely hard to find. I am breaking two 50 mg tablets and estimating three 33 mg tablets. If you find a source of 30mg tablets let me know and I'll pass it on to everyone.

Young Onset PD

Approximately 5% of all people with PD have Young Onset Parkinson Disease (abbreviated YOPD). YOPD is defined as onset at 40 years or younger. In the US there are approximately 50,000 people with YOPD. In some PD referral centers, as many as 10 - 15% of PD patients are YOPD. The incidence of new PD cases per year for all ages is 50,000 of which 5% or 2500 have YOPD. Except for age of onset YOPD resembles adult PD. Motor fluctuations: "wearing-off" and "on off" and dyskinesias may be more common in YOPD. They usually occur within 2 - 6 years of starting levodopa. Fluctuations may be more common because YOPD people tend to use higher doses of levodopa and take it more frequently as they try to continue working, raising a family, and leading a "normal" life. Unlike adult PD, YOPD people do not get drowsy on levodopa nor do they develop mental changes: delusions, hallucinations, paranoia. The drowsiness and mental changes usually limit the intake of levodopa in adult onset PD because they're more likely to be evolving a dementia. YOPD people are usually started on dopamine agonists such as Mirapex, Permax, and Requip because they are less likely to result in fluctuations and dyskinesia.

Freezing episodes, difficulty with balance, and dementia are uncommon in YOPD. However, these symptoms do appear as the disease progresses especially after 10-15 years. Anxiety, depression, and panic attacks may be more frequent in YOPD. In part this may reflect the greater stress or guilt people with YOPD face in finding a spouse, getting pregnant, raising a family, continuing to work, becoming disabled, and passing PD on to their children. YOPD are often easier to treat because they have fewer age-related diseases such as arthritis, diabetes, dementia, high blood pressure, heart and lung disease.

Does YOPD Progress Slower? In YOPD as in adult PD symptoms start insidiously and progress slowly over several years. Progression in YOPD is usually slower. The average age of onset of adult PD is 60 years. PD increases with age, thus 1% of people over 60 have PD and 2% of people over 70 have PD.

Tremor in YOPD Tremor is the most common initial symptom in YOPD, occurring in 70% of patients. In some patients it's present all the time, in some it's present only during times of stress or fatigue. Tremor usually starts in the thumb, or the wrist on one side. This is unlike the tremor of Essential Tremor (ET) that usually starts in both hands at the same time. In PD the tremor, when it spreads, spreads to the leg on the same side and then to the hand on the opposite side. This is unlike the tremor of ET that when it starts in one hand then spreads to the opposite hand. Occasionally the tremor in YOPD may start in or involve the jaw. Rarely the tremor of YOPD may involve the head and neck. Head and neck tremors are more common in ET and in patients with dystonia (a disorder separate from the dystonia that may appear in PD). When tremor is the initial and only symptom, it may be difficult to distinguish YOPD from ET.

Dystonia in YOPD Dystonia is a common initial symptom in YOPD but not in adult PD. Dystonia may appear as an aching pain in the shoulder or upper arm (where it's often mistaken for arthritis) or a cramping pain in a calve or foot (where it's often mistaken for a muscle ache related to sports). On examination, however, the aching of the shoulder or upper arm may be associated with a decreased arm-swing on walking. The cramping of the leg may be associated with curling, or bending of the foot. The aching or cramping may be associated with symptoms such as coldness or tingling. These symptoms often wax and wane, increasing with exercise or fatigue, decreasing with rest.

AskTheDr, NPF

Life Expectancy with PD

Before levodopa and the dopamine agonists the life expectancy of people with PD was 10-20 years from diagnosis. Patients who had PD for

10-20 years died from the complications of being immobile. These included pneumonia, urinary tract infections, and infected bedsores. Since the introduction of levodopa and the dopamine agonists the life expectancy of people with PD is almost the same as for people without PD. Several symptoms, however, only rarely seen before the introduction of effective PD drugs are now more common. Some of the symptoms including dementia (disorientation, confusion, memory loss), lack of balance (freezing and falling) and autonomic nervous system insufficiency (drop in blood pressure on standing, impotence, sweating, swallowing difficulty, shortness of breath, urinary difficulty). These symptoms do not result from PD drugs but from the increased life-span of people with PD, a life-span that allows the underlying disease to progress. Some of the symptoms, however, result from a combination of the underlying disease and the drugs. These symptoms include hallucinations, paranoia, delusions, and dyskinesia (involuntary movements).

AskTheDr, NPF

The Cause or Causes of PD

The cause of PD is unknown. Evidence exists for both genetic and environmental causes. In as many as 15-20% of patients there is a family history of PD. However, whether this is related to a shared gene (or genes) or to a shared environment risk is unknown. In people with adult onset PD who have a relative with PD, usually only one or two relatives in a single generation are affected.

Rarely are more than two relatives in a single generation affected, or more than one relative in several generations. Because only 15-20% of people with PD have a family history of PD while 80-85% of people with PD do not, this has led to the belief that adult onset PD is NOT an inherited disease. However, the absence of a family history doesn't mean that PD isn't an inherited as most people in America are unable to trace their family history back more than 3 generations. Thus in Iceland where most people can trace their family back 10 or more generations, it's been found that everyone with PD is related

when their families are traced back 6 generations. AskTheDr, NPF

WEB Page

Try this one. It has many useful links.
www.firstgov/topics/seniors.shtml

Keep Living

You must simply keep living. Embrace whatever God sends your way either sorrow or joy. Trust that you are not here by accident. Every moment, every event in your life has a purpose for the welfare of eternity if you love God
Jerusalem Vigil, Brock & Brodie Thoene

Motorized Scooters vs. Power Wheelchairs & User Safety

The National Institute for Rehabilitation Engineering (NIRE) is a non-profit organization which operated clinics to design, dispense and fit customized assistive equipment from 1967 through 1996. Working with disabled people and their own doctors and therapists, these NIRE clinics assisted hundreds of people having severe and permanent motor impairments. The NIRE pioneered the development and use of power wheelchairs and motorized scooters. During these years, a great deal was learned concerning user safety. This information is for people using, or considering the use of a motorized scooter as an alternative to a power wheelchair. It is said that "knowledge is power" and this is especially true for electric scooter users because of the safety issues. The user who knows about and understands the various safety issues will enjoy more varied uses of his scooter, and more peace of mind, than the person who must limit his uses out of fear of being injured. Motorized scooters are seen by some people as offering advantages over power wheelchairs. This may be true for some people - but not for others. Serious safety questions must be considered in choosing one or the other.

MOTORIZED SCOOTERS vs. POWER WHEELCHAIRS

Comparisons are between "light, foldable power wheelchairs" and "motorized scooters." Both have small wheels in front - the typical wheelchair has two small casters in front, on opposite sides - the typical scooter has one small, steerable wheel centered in front. Both have similar outdoor-use limitations Heavy duty outdoor, stand-up, and stair climbing wheelchairs cannot be compared with any type of motorized scooter.

Comparative Costs: Motorized Scooters typically cost less than light-weight, foldable, Power Wheelchairs. The scooter may cost up to 20% less. Maintenance costs are about the same for both.

Transportability & Storability: Both types of vehicles can be partially disassembled and folded for storage, or transportation in the trunk of a car. Scooter and wheelchair weights may be comparable or the wheelchair may be slightly heavier depending on its construction. Both carry a storage battery. Only the wheelchair can be transported in a van with the user seated in it. This is not feasible for a scooter.

Appearances: Scooters appear quite different than Power Wheelchairs. The scooters are usually smaller and lighter-weight. Scooters may be favored by some people because they look, to others, more like recreational vehicles than medical equipment. Some people, with mild disabilities, have the option of choosing either one. Those with more severe disabilities must pass on the scooter for a wheelchair.

Comparative Features: Most power wheelchairs have at least four wheels. Some have small wheels in front and large wheels in back. These are better suited for indoor use. Others have large wheels in front and smaller ones in back. These are better suited for outdoor use. The wheels are widely spaced, opposites usually being on opposite sides of the wheelchair. This gives the wheelchair increased stability and safety, lessening the likelihood of rollover accidents. Motorized scooters often lack this stability.

Most power wheelchairs are propelled by 2 motors, 1 on each side. One motor drives one wheel and the other motor drives the other wheel. Power wheelchairs are steered by the user, using his fingers to move a small control stick forward, backward, left, or right to control speed and direction of travel. People so severely disabled that they cannot reliably operate the small joystick control can be fitted with high-technology (quadriplegic) controls that sense changes in breath or eye movements to steer and control the wheelchair. Special controls require intensive mobility and safety training and are available for power wheelchairs, only. Power wheelchairs can be dispensed with electric user-controlled leg rests, back and

head supports not available on scooters. Wheelchairs often feature removable sides to facilitate side-ways transfer in and out, via a transfer board. The use of 4 wheels stabilizes the wheelchair to make such transfers safe for the wheelchair user. Scooters often have only 3 wheels and lack such stability. Most scooters have 3 wheels and use mechanical steering. The typical design has 2 widely spaced wheels in the rear, across from each other. A single or double-width wheel is in front, attached to a tiller, handlebar or steering wheel. The entire scooter looks a little like a child's tricycle - a major difference being that the scooter has smaller wheels. The scooter has a larger seat which gives much more support than a saddle seat on a tricycle. The scooter seat may or may not have armrests and/or a back support. Often, the seat has to be customized for a particular user. If possible, order a scooter offering 4-wheel stability. Some are available. The scooter's handlebar, tiller or steering wheel is used for manually steering the scooter. Because the scooter has only 3 functional wheels, it can turn over if the user leans heavily forward and/or to one side. This can happen while riding, especially if a tilted or uneven incline is encountered. Or, the scooter can fall over when stopped, when the user transfers in or out. These characteristics of the scooter limit its safe use to people with full use of at least one arm and hand, who have strong trunk muscles and can sit upright with little body support, and who can efficiently and safely transfer in and out of the scooter's seat. Scooter users can include people in early stages of PD who have mild impairment.

Necessary HAND & ARM MOBILITY for Safe Scooter Use - Many motorized scooters are mechanically steered using a handlebar (two hands required) similar to a bicycle. Braking while driving is mechanical, usually requiring the user to squeeze one or two braking handles. The parking brake, a necessity for safety, is also mechanical and requires at least one normal arm and hand. Safe operation of some models may require normal mobility of BOTH arms and hands. Other models use a steering "tiller" or "wheel" which can be operated with one good arm and hand. Note: If the free arm and hand are disabled, then braking and other controls must be on the tiller or steering wheel so all are operable with the hand and arm used to steer the scooter.

Necessary BODY STRENGTH and MOBILITY for Safe Scooter Use - The first need is for a user to be able to safely transfer in or out of the scooter seat alone and unaided. To do this, the person must be able to walk unaided, or to walk with a walker, cane or crutches. A second need is stability while sitting on the scooter seat for long periods of time and while bouncing and tilting as one drives. A third need is for sufficient body mobility and flexibility to maintain balance as the scooter tilts and bounces on outdoor sidewalks and pavements. Scooters are not safe to use on soil or grass.

Where Can Motorized Scooters be used safely? INDOOR TRAVEL is safest, with flat and level floors. **NOTES:** Deep-pile carpets can present immediate mobility and safety problems and can, sometimes, cause equipment problems due to carpet fibers entering the wheel bearings, gears or pulleys. Low-cut carpets and rugs usually cause no problem except that they can be stained by oil or dirt falling from the scooter. Scooters usually travel well in malls, public buildings, food stores, etc. - and in any and all indoor areas having flat, level and hard floors. **OUTDOOR TRAVEL requires caution.** Generally, travel is safe on outdoor sidewalks and pavements provided the small front wheel of the scooter does not encounter raised slabs, potholes or debris, and the sidewalk or pavement does not tilt to the left or right (which could cause the scooter to roll over). **NOTES:** Know how steep a grade your particular scooter can safely traverse, up and down, with the particular user's height and weight. Then, safely ride up or down inclines within these limits but always directly UP or DOWN an incline - NEVER across an incline! Grass and soil are not good places to be on a scooter because (a) you are more likely to fall and be hurt, and (b) grass and soil can damage the equipment and can damage rugs and floors when brought home. WET grass and soil are especially dangerous - and it is a good idea to NOT use a scooter outdoors in rain, snow or ice.

CAUTIONS: Most scooter manufacturers and vendors are honest, caring and reputable. They know their products and are needed for ongoing maintenance and technical support. However, they do not have the

training and experience of physicians and occupational therapists. Hence, help should always be sought from these professional resources before a disabled person buys a motorized scooter or wheelchair.

RECOMMENDED SCOOTER PROCUREMENT PROCEDURES

Have medical screenings for eyesight and seizures. Be sure your corrected vision is 20/40 or better, in one or both eyes. If not, then obtain glasses or other correction before using any motorized vehicle. If subject to unexpected fainting or seizures, do not drive any powered vehicle. Know your medical diagnosis and prognosis. You need this information for your ongoing safety. Your functional condition, today, may be compatible with safe use of a motorized scooter. But, how long will this last? When will the scooter become unsafe for your use? If the prognosis is for rapid disability progression, it may be better to obtain a power wheelchair not a motorized scooter. If the scooter is safe for you to use, how often do you need to be re-evaluated by a physician or therapist to ensure it continues to be safe? Are you willing to stop using the scooter when your worsening condition makes it unsafe for you?

Do research and obtain product literature on the various make and model scooters available in your area. It is better to consider only those products sold and serviced by medical equipment dealers or manufacturers' representatives in your area. **DO NOT BUY FROM THEM, YET.** Only get literature at this time. Rule out products lacking local support. **DO NOT buy by mail!**

Contact a **Local Registered OCCUPATIONAL THERAPIST (OTR)**, preferably in the Rehabilitation Department at a hospital or rehabilitation center near you. Plan on and discuss your need for 2 or 3 appointments: (a) for a preliminary wheelchair clinic evaluation for a motorized scooter or for a power wheelchair. Ask that they have both on hand for you to try. Most of the testing will be by an OTR, under medical supervision by a physician who specializes in rehabilitation medicine. (b) the same OTR should be asked to schedule a home visit to inspect the premises for equipment suitability and user safety. This can be without any equipment - or, it may be with a scooter brought by the OTR - or, the OTR may request a local vendor to bring a particular model scooter for on-site testing and user training. If this on-site equipment testing is not done on the 2nd appointment, then a 3rd appointment (c) should be made with the OTR and the vendor for these purposes. It is strongly recommended that the final trials, before ordering, be done in the user's home with both the OTR and the sales person present. If done at and in the residence, outside test driving should also be done by the user in the actual scooter to be ordered to assure safety and compatibility with the nearby pavements and sidewalks. When a scooter is being ordered, be certain that one person is designated in writing, to be responsible for the overall fit of the equipment, including all prescribed modifications, adjustments and accessories (such as special grips, handles or reaching tools, etc.) Usually, the responsible person is the local vendor. Sometimes, however, it is the clinic or therapist rather than the vendor. This must be defined and detailed in writing. For user safety and comfort, we recommend several **VISION AIDS**: (a) One or two rearview mirrors are recommended. For scooters having a handlebar, it is simple to buy and attach two inexpensive clamp-on rear-view bicycle mirrors. One or two mirrors can usually be attached in some way to a scooter having a tiller or steering wheel. (b) In bright sunny climates where a lot of outdoor daytime use is planned, we recommend that scooter users wear gradient-tinted sunglasses, prescription or plain, as the eye doctor recommends. The graduated tint (darker at top and lighter going down the lens) is best colored gray or brown. Greens, blues and reds are best avoided.

When the motorized scooter has finally been ordered and is to be delivered, the user may be asked to visit the vendor's shop for final adjustments. This is fine. However, it is recommended that final delivery be at the user's residence with both the OTR and the vendor present. This facilitates final adjustments, any additionally needed user training especially outdoors, and also needed technical training. A family member, neighbor or friend, should be shown - with the user - how to assemble and disassemble/store the scooter; how to adjust everything; how and how often to recharge the battery; how and when to perform equipment inspections and maintenance.

SCHEDULES: A schedule should be agreed upon for professional inspections and services by the

vendor. If the user has a progressive disability, a schedule of periodic re-evaluations by the OTR should be agreed upon. These might be once every 3-6 months or once a year as the OTR feels best. Personalized equipment adjustments should have been made by the vendor, with the knowledge and approval of the OTR. Actual settings should be recorded in a log, with dates, for future reference. These settings would include these items, plus others: (a) height of seat to place user's legs at correct height for the foot rests; (b) height of manual steering control; (c) location of hand braking control for driving; (d) locations of hand parking brake levers; (e) location of seat rotation locking mechanism; (e) location of controls for parking brakes, if any; (f) locations of rear-view mirrors; etc. It is important to keep written records of all user-settings so that any that become altered can be easily restored. Sharing scooters is risky, at best, for all parties unless use of the shared scooter is limited to strictly indoor use - and with other people present. If used by just one person, always adjusted optimally for that person, the scooter can be used with the least possible risk, indoors or outdoors. Unfortunately, when two or more people share a scooter, then the settings are not optimized for each user. This can lead to fatigue while riding, or even to falls or injuries. For this reason, we recommend against sharing unless there are only two people and both are the same size and weight, and both use all the same adjustment settings. For additional information or free technical support, please email: nire@theoffice.net or contact us by regular mail or telephone. The National Institute for Rehabilitation Engineering Box 1088 - Hewitt, NJ 07421 U.S.A. Tel. (800) 736-2216 Copyright 2003 by The National Institute for Rehabilitation Engineering (The N.I.R.E. is an IRS 501(c)3 organization helping people with disabilities).

Loneliness

Learn the benefits of solitude by undertaking some of its more active forms, such as journal writing, letter writing or reading. Such activities contribute to your sense of personal strength and your level of awareness, and enhance your sense of creativity. These are vital contributions, since low esteem is a central factor in loneliness. It's important to learn the positive benefits of being alone; it's a mistake to spend time with people to cope with feelings of emptiness. Surrounding yourself with people you don't like is just as bad as stuffing yourself with food in order to cope with loneliness. They are narcotics, not solutions to the problem of the void you feel. Remember that the way in which you perceive being alone is the decisive factor in whether you feel lonely. People who equate loneliness with being alone are the ones who end up actually feeling lonely in solitary circumstances. There are, after all, many people who have been living alone all their lives, yet are among the least lonely people. Consider how to establish meaningful ties with other people. This is, above all, the prime factor in avoiding feelings of loneliness. Such feelings reflect that you have insufficient or inadequate personal ties in your life. Abstracted from the Vermont Parkinsonian, January 2004.

Memorials

In Memory of Gloria Mathis

Alton & Sarah Thurman
James & Sharon Lemon
Mr. & Mrs. Fred Cox
Mrs. Virginia Piper

In Memory of Dorris Poppell

Lou Ann Varnell
Ruby & Steve Griffiths
Alma Blaker
Mark, Terri & Claire Luensmann
Bernice L. Robinson
Bud Co Ltd & Employees

In Memory of Cyril Aelvoet

Shirley Verstuyft

In Memory of Joseph F. Rinehart

Mr. & Mrs. Mitch Morgan
Mr. & Mrs. Herschel F. Morgan

In Memory of Bonnie Miller

"The Wet and Wonderful Women of Canyon
Lake"

**VETERANS
Military Data Base**

The Parkinson's Action Network (PAN) is establishing a Military Data Base in an effort to see if there is a common thread in military service that might lead to Parkinson's Disease. If you have served in the military please complete this form and send it to PAN at the indicated address. No one has ever tried to determine on such a large scale whether military service is tied to developing PD.

Parkinson's Action Network (PAN)

Veterans Special-Action Group, Personal Information

Date _____ 2004

Last Name _____ First Name _____ Middle _____

Street Address _____ City _____ State _____

Zip+4 _____

Mailing Address (if different) _____

Phone () _____ Fax () _____ Email _____

Special Capabilities or Interests that could help this PAN Vets Group

1. Branch of Military Service: ___ Army, ___ Navy, ___ Air Force, ___ Marine Corps, ___ Coast Guard,
Other: _____

A. Active Duty Dates of Service (mo/yr) Begin _____ End _____

Inactive Duty Dates of Service (mo/yr) Begin _____ End _____

B. What is your current military status? ___ Retired, ___ Discharged, ___ Currently Serving _____

C. Do you now have an official service-connected disability rating? ___ Yes ___ No, ___ %, ___ DOD ___ VA

D. Are you currently enrolled in VA Medical system? (i.e. hold "Veterans Universal Access ID Card") ___ Yes ___ No

2. What Military Service factor(s) do you feel might have contributed to causing your Parkinson's disease? List: _____

3. Where did you serve? ___ Vietnam, ___ Gulf/Middle East, ___ Other _____

Mark Here _____ if continued on reverse side or on an additional page

Please Mail to: Sue Laux, PAN Illinois Advocacy Coordinator, 3009 Roberts Dr., Woodridge, IL 60517-1519
or Email to: Panvets@aol.com or fax to: 1-630-241-0973

When form is received by Sue, an email response (if I have your email address) or postcard will be sent notifying you that your information has been entered into the database.

Davis Brown - PAN Contact
707-538-4952
www.parkinsonsaction.org