

The American Parkinson Disease Association

F A L L 2 0 0 3 N E W S L E T T E R

The American Parkinson Disease Association

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by The American Parkinson Disease Association, Inc.

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Complementary Medicine

Complementary medicine treats the individual as a whole person. All aspects of one's lifestyle, environment, diet, mental, emotional and spiritual health are considered alongside the evaluation of physical symptoms.

Practitioners of complementary medicine aim to identify the cause of the symptoms and to apply the specific therapy to promote physical, mental and spiritual balance. An extensive number of complementary therapies is based on the concept that the body strives to maintain a state of balance referred to as homeostasis. Homeostasis is one of the most remarkable and most typical properties of a highly complex open system. A homeostatic system is a system that maintains its structure and functions by means of a multiplicity of dynamic equilibriums rigorously controlled by interdependent mechanisms. Such a system reacts to every change in the environment, or to every random disturbance, through a series of modifications of equal size and opposite direction to those that created the disturbance. The goal of these modifications is to maintain the internal balances. Treatments of complemen-

tary medicine therapies are aimed to stimulate this natural healing ability in the body.



Complementary medicine embraces a wide range of therapies and types of treatment, many of which are gaining popularity and becoming part of traditional medicine. In recent years the concept of integrated medicine has been gaining favor. Integrative medicine is a healing-oriented medicine that draws upon all therapeutic systems to form a comprehensive approach to the art and science of medicine.

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COMMUNICATING WITH YOUR HEALTH CARE PROVIDER

Cathi Thomas, RN, MS,
APDA Coordinator, I&R Center,
Boston University, Boston, MA

In general, a person with Parkinson's disease (PD) visits his or her health care provider three to four times a year. It can be a challenge for a patient to identify targets of therapy, describe responses to medications, and report adverse effects within the limited time of an office visit. Often a patient must communicate his or her progress and concerns to the doctor in between visits, usually by telephone. This article will assist you in determining when you should consult your health care provider and how to do so most efficiently.

Be Prepared

Always have a complete and current list of your medications (not just Parkinson's drugs) available. The list should include names, dosages, and the times you take them. Also, keep a record of each medication that you have previously used to treat your Parkinson's disease. Note name, dosage, how long you have been taking it, and why you stopped taking it. Consider using a binder to maintain long-term records.

Report Symptoms and/or Adverse Effects

When reporting symptoms of Parkinson's disease and/or adverse effects of medication, it is important to understand the difference between the two. For example, tremor is a Parkinson symptom; dyskinesia (abnormal movement) is an adverse effect.

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Complementary Medicine

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Complementary medicine therapies can be classified in five domains:

I Alternative Medical Systems

Alternative medical systems are built upon complete systems of theory and practice. In Western cultures examples include homeopathic medicine and naturopathic medicine. In non-Western cultures examples include traditional Chinese medicine and Ayurvedic medicine.

II Mind-Body Therapies

Mind-body medicine utilizes an array of techniques designed to enhance the mind's capacity to affect bodily function and symptoms. Examples of these therapies include meditation, visualization, mental healing, and therapies that use creative outlets as art, music, dance and drama.

III Biologically Based Therapies

Biologically based therapies utilize substances found in nature. Two primary examples are nutritional therapy and medical herbalism. Nutritional therapy uses diet to treat and prevent illness and to restore the body to its natural, healthy equilibrium. Medical herbalism is the use of plants as medicines to restore and maintain health, relying on curative qualities of plants, flowers, trees and herbs to stimulate a person's healing system.

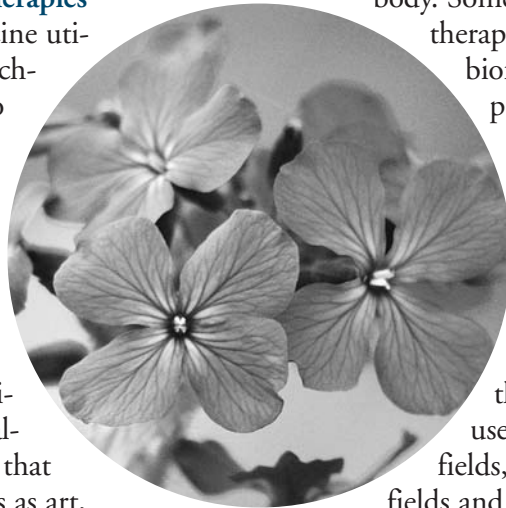
IV Manipulative and Body-Based Methods

Manipulative methods are based on

manipulation or movement of one or more parts of the body. Examples include osteopathy, chiropractic, massage, and reflexology.

V Energy Therapies

Energy therapies involve the use of energy fields. There are two subcategories, which include biofield therapies and bioelectromagnetic-based therapies. Biofield therapies are intended to affect energy fields that surround and penetrate the human body. Some forms of energy therapy manipulate biofields by applying pressure and/or manipulating the body by placing the hands in, or through, these fields. Bioelectromagnetic based therapies involve the unconventional use of electromagnetic fields, such as pulsed fields and magnetic fields.



Being open and receptive to one of the therapies mentioned will promote the patient's willingness to experience, in conjunction with their personal medical diagnosis and prescribed medical treatment, a heightened sensation and awareness of personal inner balance. Each and every individual upon this earth is a vibrant and vital spirit whose energy, presence and mission is unique. May you remind yourself of this and celebrate the gift of life and the spectacular majesty of a single breath. ■

Note: This article was abstracted from the Parkinson's Bulletin, APDA I&R Center, New Brunswick, NJ.

COMMUNICATING...

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They are different and each requires its own interventions.

Identify a “pattern” of change before contacting your health care provider. For example, if on a particular day, your medication wears off at 11 am, it is not necessary to call the provider immediately. Determine if this is a one time occurrence, or if it happens again on the next day, or the day after that. Information about “patterns” that develop is extremely valuable.

Utilize a diary to record mobility, symptoms, and adverse effects. To establish a pattern of activity, more than one 24-hour diary should be completed. It is possible to avoid fatigue from completing the log by skipping a day in between. For example, record your information on Sunday, Tuesday, and Thursday. Send a copy of your observations to your physician for review. Sample diaries are available from your local APDA Information and Referral Center.

Always record and report adverse effects (side effects) from medications when they first appear. A slight adjustment or change of medication by the physician will usually correct the problem.

And lastly, if possible, contact your health care provider early in the day to insure adequate response time.

Ask For Help

If you need assistance with understanding how to fill out a patient diary or formulating the right questions to ask your doctor, do not hesitate to call your local I&R Center. ■

P R E S I D E N T ' S M E S S A G E



Dear Readers,

As APDA plans for the November board of directors meeting, we assess this past year, and look with anticipation to our ambitious plans for the upcoming fiscal year.

As we look back, much has taken place. We have made great strides in a number of areas which will be beneficial to this organization, and significantly help our efforts in the fight against Parkinson's disease.

We have also suffered a heart-rendering loss with the death of Salvatore (Sal) Esposito. Salvatore was secretary and past national president of the American Parkinson Disease Association which was founded by his family in 1961. His vision and steadfastness over the years was a principal drive in the success of the organization. He shall be missed.

One of Sal's hopes, and his dream for this organization, was met this year. We have now completed arrangements, and a ground breaking, for the construction of the APDA's national headquarters on Staten Island. It will be a facility designed to advance all aspects of the association's operations.

In addition, APDA proceeded with extensive research efforts at an invigorated pace. We have again contributed significantly to the search for a cure, and considerably increased the funding of patient support to alleviate the difficulties of those with Parkinson's disease.

The annual APDA National Conference held in Portland, Maine this summer was a success. It was also an opportunity for Chapter Presidents, Information and Referral Center Coordinators and headquarter staff to share information, become better informed and to confer on the important issues facing the organization.

APDA has forged ahead with new initiatives in the corporate development area and looks to continue with these efforts in the new year. We have, in addition, put in place an increased effort in the national public relations area.

APDA continues to evaluate new ways and means to meet the challenge of service and support to all Parkinsonians.

These efforts and goals are only possible with your continuing trust, support, guardianship and perseverance. For these efforts and more, I thank you.

Sincerely,

A handwritten signature in black ink, appearing to read "Vincent N. Gattullo". The signature is fluid and cursive, with a large, prominent initial "V".

Vincent N. Gattullo

SLEEP *and* PARKINSON

Joseph Friedman, MD, Chief, Division of Neurology, Director of APDA I&R Center, Brown University, Providence, RI

Parkinson's disease patients frequently have sleep problems, and, of course, this often translates into problems for other members of the family. Most of the problems are from the disease itself, either directly or indirectly, and some are from other conditions that have nothing to do with Parkinson's disease (PD). The medications for PD also may contribute.

Sleep problems can be broken up into three major categories: **A)** falling asleep, **B)** staying asleep and **C)** excessive daytime sleepiness.

The most common sleep problem for PD patients is "fragmented sleep." This term means that the normal sleep problem is broken up into pieces. In some cases the pieces refer to abnormal sleep patterns in which the sleep isn't as deep as it should be



at various times during the night, so that the patient may actually sleep through the night, but the sleep isn't of the quality that it should be, so the patient awakens in the morning feeling less than fully refreshed. In many cases the fragments are very obvious because the patient is awake during parts of the night. One of the most common problems for PD patients,

once they fall asleep, is an overactive bladder. PD causes the bladder to be hyperactive, meaning that people get the urge to urinate when it is only

partly full, and when they get the urge, they need to get to the toilet quickly to relieve their bladder. This is further complicated by other conditions such as enlarged prostate glands in older men, which keep the bladder from being fully emptied, or fluid retention, as occurs with leg swelling.

Many neurologists are unaware that PD patients may continue to tremor after falling asleep. I was taught and I myself taught others, that tremors and other

movements go away once the patient falls asleep. So, while I knew that tremors frequently interfered with falling asleep, I always explained to my patients, who told me that their tremor woke them up, that really they woke up for some other reason and once awake their tremor restarted. I was wrong. It has been clearly shown that during the light stages of sleep tremors may resume, and can be severe enough to awaken the patient, just as my patients told me. L-Dopa induced dyskinesias can also resume during sleep, but are much less likely to occur as the medication effects wear off.

Staying asleep and falling asleep are often complicated by pain. PD is frequently associated with pain, particularly back and neck pain. These problems, along with stiffness, slowness, and balance disorders, make it very difficult for some patients to find a comfortable position in which to fall asleep. When they awaken, for whatever reason, they then find it particularly difficult to fall asleep again.

Excessive daytime sleepiness, due to several factors, leads to daytime naps.

Since PD patients generally sleep about the same as a person without PD of a similar age over a 24 hour period, the nap time interferes with sleeping through the night. If a person doesn't sleep well at night, he's tired the next day, leading to more napping and an endless cycle. Why do PD patients get sleepy during the



day? Some medications, particularly the dopamine agonists (pergolide, pramipexole, ropinerole), can cause significant sedation. Many PD patients suffer from anxiety, and almost all the medications for anxiety cause sleepiness as a side effect. Some anti-depression, anti-allergy, and a variety of other medications may cause sleepiness. Some PD patients suffer from sleep apnea, a fairly common disorder in the general population, but probably increased in PD. In the general population most patients with sleep apnea are overweight, and many of them suffer from lung conditions caused by cigarette smoking. In the PD patients this is not the case. The PD patients tend to be of normal weight and not to have lung problems. In sleep apnea, patients have occasional long pauses in their breathing. "Apnea" means "not to breathe." In sleep apnea the patients generally snore heavily and will suddenly stop. When they stop, it's often because they're not breathing. They don't die because they awaken to a lighter level of sleep. They may have a sudden body jerk too, which is more likely to awaken the bed partner than the patient.

These people can sleep 10-12 hours at night and seem to sleep like logs, yet when they awaken in the morning, they are not refreshed and need to nap some more. They feel sleepy all the time and fall asleep at the drop of a hat.

Some PD patients may have “restless legs syndrome (RLS).” In this condition, which is fairly common in the general population, people feel restless, particularly at night, and this restlessness is reduced by standing and walking. People describe a sensation like crawling in their legs, relieved by walking. This is worsened by lying down, so it clearly interferes with falling asleep. In addition, many people with RLS also have “periodic leg movements of sleep (PLMS).” These are relatively slow leg movements, bringing both legs up towards the chest and then stretching them out again. That may awaken the patient, the bedmate or both.

As if the above weren't enough, PD patients frequently have bizarre dream problems. For one thing L-Dopa causes “vivid” dreams, meaning that the dreams may be very realistic. This can cause some degree of confusion when a person awakens and thinks a dream actually occurred. For people who already suffer from occasional nightmares, realistic dreams are not good things. It is unclear if L-Dopa and the other PD medications actually cause nightmares. They probably do it occasionally, however, the really interesting problem that occurs in over 15% of PD patients is “REM sleep behavior disorder (RBD).” Most dreams occur during REM sleep. REM stands for “rapid eye movement.” When people dream, they usually have rapid movement back and forth of their eyes, as if they were watching their dream play out. Aside from these eye movements and breathing, they are otherwise paralyzed and can't move. This

is obviously protective since one wouldn't want to act out a dream. However, those who have RBD actually act out their dreams, but only certain dreams.

RBD preferentially affects men and about 80% of people with RBD are men. They act out dreams of violence, most often protecting a loved one, and awaken to screams of their spouse whom they are hitting, kicking or even strangling. One of my patients awoke in the middle of a room throwing a pillow, while in the dream he was throwing a more lethal object. They make noise; they kick; they flail; they jump out of bed; they punch or throw furniture. The spells occur irregularly but cause enough of a problem that bedmates move to other beds or even other rooms. Patients may try to tie themselves into bed to avoid jumping into the wall and injuring themselves. And what amazes me more than anything is that although this affects more than 15% of PD patients, possibly as many as 30%, it wasn't recognized until the mid 1980s.

Most of these sleep problems are difficult to treat and all, except for RBD, involve common sense. Reduce fluid intake after supper; try to nap less during the day; try to stay active so that boredom doesn't translate into sleep; try to reduce sedating medication; take the water pill as early in the day as possible; treat sleep apnea and restless legs syndrome if they are present. RBD, however, which would defy common sense, actually responds in 90% of cases to small doses of clonazepam, a valium like drug that is used to treat anxiety and special types of seizures.

Although PD is a movement disorder, it causes a large number of alterations in behavior. Sleep is one such area and is affected in the majority of patients. ■



SALVATORE J. ESPOSITO, JR.

Time has passed since Sal left us, but his accomplishments will be with us for many years. Our grief for his loss has been mitigated by the many groups and individuals sharing our sorrow here and throughout the country.

Our appreciation for their kind and numerous expressions of sympathy will not decrease with time. Thank you again.

Lillian and the Esposito Family

MEDICATION NEWS

A NEW PD MEDICATION: STALEVO

Novartis Pharmaceuticals Corporation announced on September 17 that a new treatment for Parkinson's disease, Stalevo[®] (carbidopa, levodopa and entacapone) tablets, is now available in U.S. pharmacies. Indicated for patients with end-of-dose “wearing off” symptoms this therapy significantly improves Parkinson's disease patients ability to control body movements and the ability to perform basic functions such as walking and dressing versus previously available forms of levodopa. Stalevo is the first new treatment for Parkinson's disease in three years and the first new form of levodopa in more than a decade. ■

The 2003 APDA Biennial Conference

Lillian Scenna, LSW, Coordinator, APDA Portland I&R Center

This year's American Parkinson Disease Association's Biennial Chapter President and Coordinator Conference, held in Portland, Maine, had memorable moments.

The first was when the national office staff and the executive committee were greeted by Maine's Chapter president, Carl Barker, and a fleet of antique cars for a pre-conference guided tour of Portland. It was a complete surprise! All anyone knew was that Carl had arranged transportation for the tour. We should have had a video of the faces of the people as they stepped out of the hotel lobby!

Another experience, which will long be remembered, was the boat trip (in the pouring rain) to an island in Casco Bay for a taste of that well-known Maine delicacy, lobster. More than 170 hardy souls braved driving, salty breezes and slippery gangplanks to enjoy this Down East ritual. (those APDA umbrellas sure came in handy, too)

But the memorable moments were not confined to only fun and game. The goal of the conference was to help Chapter Presidents and I&R Center Coordinators perform their duties more effectively and efficiently. "Sharing our Knowledge" was the theme of the conference, and the five day meeting presented a series of thought-provoking, educational seminars and workshops on a variety of topics.

The objective was met with flying colors. We are very grateful to those people from the national office and the Coordinators and Presidents who contributed their time and expertise. The "show & tell" type of workshop presentations gave us a way to share our creativeness with each other and learn ways to incorporate new ideas and improve the performance of our

Chapters and I&R Centers.

The conference began officially with a welcome dinner on Thursday night. Vincent Gattullo, President of APDA, expressed his appreciation for all the hard work and devotion of the staff and volunteers affiliated with APDA. Joel Gerstel, Executive Director, updated the participants on the happenings at the headquarter office. Maine Chapter President, Carl Barker, gave a short presentation on the benefits to Parkinson's patients of playing the harmonica: increased breathing volume leading to better voice control and just plain fun with music.

The scientific presentations on Friday morning discussed advances in research into the causes and treatment of Parkinson's disease. Dr. Frederick Wooten gave an overview of the research area with his presentation entitled "Update on Research", followed by Dr. Ray Watts' discussion of "Pharmacological Therapies," and Dr. Malcolm Stewart's presentation of "Strategies in Early Detection." A question-and-answer session completed the morning program.

The afternoon breakout sessions included:

- Building & Educating the Board
- How to Obtain, Excite and Expand your Volunteers
- Health Information on the Internet: "Know Where To Go"
- Writing Parkinson's in Plain Language
- Palliative Care
- Parkinson's Disease & the Art of Moving

A motivational and up-lifting end-note presentation titled, "The More We Get Together" was given by Geriatric Consultant Susan Imke, RN, MS, GNP.

At the Saturday night awards dinner, Dr. Lawrence Golbe, New Jersey School of Medicine, Department of Neurology, was awarded the prestigious Frederick Springer Award, which is given annually to outstanding researchers in the Parkinson's disease area. Dr. Golbe shared some innovative ideas with us in his acceptance speech.

The recipients of the Salvatore A. Esposito, Sr. awards, established to commemorate one of the founders of the association, were William Lear, Barbara Berger, and Robert Dolezal, Chapter Presidents, respectively of New Jersey, Georgia and Arizona and Gina Cici and Linda O'Connor Coordinators respectively of the APDA I&R Centers in Memphis and Los Angeles. Congratulations to all of them on being chosen for this honor.

We are fortunate to have the wisdom and guidance of APDA and its staff who shared many stimulating ideas throughout this conference. Unfortunately Dr. Paul Maestrono could not participate because of health reasons, but he sent his best regards to everybody. Each of us working with APDA has something special and unique to offer, and it is in this diversity that we find new ideas for improving our ongoing service to the Parkinson community.

Our working life takes up much of our time. Our jobs are challenging and tiring sometimes, but also very rewarding in many different ways. The workshops offered at this conference have made our jobs easier and more effective.

Thanks to all who helped make this conference such a big success. We look forward to seeing you all again at our next national conference. ■

SPEECH DISORDERS IN PD

Many individuals with Parkinson's disease (PD) lose their ability to talk with loved ones, to use their voices effectively in daily living, and to interact proactively with society. The loss of this ability to communicate has a significant impact on the quality of their lives.

An effective treatment called "LSVT" has been developed over the last 10 years. It is named for an individual with PD — Mrs. Lee Silverman and was administered to thousands of patients with PD. Individuals who received LSVT improved their speech, vocal loudness, intonation and voice quality and maintained these improvements up to two years after treatment.

Recent research studies, supported by the National Institutes of Health (NIH) have documented, moreover, improvements following LSVT in the common problems of disordered articulation, facial expression and swallowing in individuals with PD.

For optimal treatment results, it is essential for LSVT to be delivered by an individual who is certified in this method. There are over 800 clinicians in the United States who have received the LSVT certification.

The LSVT Foundation has also produced a videotape that individuals may use at home to do voice exercises as part of the LSVT procedure. The viewer is prompted through a series of daily speech exercises that will help the individual maintain and enhance the improvements in the voice after the therapy sessions with a certified LSVT clinician.

Additional information about the LSVT Foundation is available at its web site — www.lsvt.org or by calling 1-888-606-5788. ■

Questions & Answers

Enrico Fazzini, D.O., Ph.D

*Assoc. Prof. Neurology New York University,
New York, N.Y.,*

University of Nevada, Las Vegas, NV,

N.Y. Institute of Technology, Old Westbury, N.Y.

Q: Dr. Fazzini, what is your Web site? Do you receive e-mail?

A: My web site is www.theparkinsonsdoctor.com. Please make sure you type parkinsons not parkinson as this was misprinted in a previous newsletter. You can send me email through a link on this site or directly to enricofazzini@hotmail.com. If you send me an email question, indicate whether it can be used in the newsletter. We will maintain the privacy of all health information transmissions and not publish your name. Keep the questions brief and to the point.

Q: What is Stalevo?

A: Stalevo is a new combination medication which was made available this month by Novartis. This is a combination of Comtan (entacapone) and Sinemet (carbidopa and levodopa). It comes in three strengths: Stalevo 50 (Comtan 200 mg and 1/2 of a Sinemet 25/100),

Stalevo 100 (Comtan 200 mg and a full Sinemet 25/100) and Stalevo 150 (Comtan 200 mg and 1 and 1/2 Sinemet 25/100). This medication is useful for at least three reasons: 1) It decreases the number of pills that you are taking if you are on Sinemet and Comtan. 2) It is easier to swallow than Comtan since it is smaller in shape. 3) It is less expensive than taking Comtan and Sinemet separately. I would like to introduce this medication in patients who are on Sinemet without Comtan and having fluctuations in response to their Sinemet. For example — if you are on Sinemet 25/100 and having too much dyskinesia and too much wearing off, we could exchange the Sinemet with the Stalevo 50, which would reduce the Sinemet by half and add Comtan all in one pill. If a patient is on Sinemet CR and now needs Sinemet immediate release added, then the Stalevo 50 is also useful. If you are on Sinemet 25/100 and having wear-off, then the Stalevo 100 could be given instead of the Sinemet 25/100 and this should decrease the off time. Similarly, the Sinemet 25/250 could be replaced with the Stalevo 150 in order to decrease off time. You may take Sinemet CR and even regular Sinemet along with Stalevo if needed. ■



THE COURAGE TO CLIMB

Patty Gibson, a 45-year old mother of two with young onset Parkinson's disease, recently climbed Mt. Whitney, the tallest peak in the continental United States at 14,491 feet. Patty was diagnosed four years ago, although she first experienced symptoms when she was younger. For her, this was a tremendous personal challenge as well as a golden opportunity to raise funds for the APDA Greater Los Angeles Chapter. Patty became aware of APDA through her neurologist, Dr. Jeff Bronstein, who is the Medical Director for the APDA I&R Center at UCLA. Patty developed a very organized fundraising campaign and through her many friends and family members she raised over \$41,000. She has chosen to devote her free time toward the fight against Parkinson's disease, and has become the newest member of the Greater Los Angeles Chapter. ■

The material contained herein concerning the research in the field of Parkinson's disease and answers to reader's questions are solely for the information of the reader. It should not be used for treatment purposes, but rather as a source for discussion with the patient's own physician.

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Information on Parkinson's Disease

Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling the toll free number 1-800-223-2732 or Fax 1-718-981-4399.

EDUCATIONAL BOOKLETS

1. **Basic Information about Parkinson's Disease**
4 page brochure (English, Chinese, Spanish)
2. **Parkinson's Disease Handbook**
Symptoms, causes, treatment, 40 page booklet (English, German, Italian, Portuguese, Spanish, Russian)
3. **PD "n" Me-Coping with Parkinson's disease**
70 page booklet (English)
4. **Be Active** — A suggested exercise program for people with Parkinson's disease, 25 page booklet (English, German, Italian)
5. **Be Independent** — Equipment and suggestions for daily living activities, 32 page booklet (English, German, Italian, Spanish)
6. **Speaking Effectively** — Speech and swallowing problems in Parkinson's disease, 34 page booklet (English)
7. **Good Nutrition in Parkinson's Disease**
26 page booklet (English, Italian, Swedish)
8. **Young Parkinson's Handbook**
78 page booklet (English)
9. **How to Start a Parkinson's Disease Support Group**
24 page booklet (English, Italian)
10. **Aquatic Exercise for Parkinson's Disease**
A 20 page booklet for patients and their families (English)

EDUCATIONAL SUPPLEMENTS

Hospitalization, Helpful Hints, Living Will, Oral Health Care, The Family Unit, Helping Your Partner, Nursing Homes, Long Term Care Insurance, Recreation and Socialization in Parkinson's Disease, Comtan Questions & Answers, Use of Comtan in the Treatment of Parkinson's disease, PD and The Emergency Room

CARELINK

(A cooperative APDA - GSK project)

You can now contact the APDA Information and Referral Center closest to you by dialing the toll free number 1-888-400-2732

APDA WORLDWIDE WEB SITE

www.apdaparkinson.org for PD I&R Centers, Chapters, Support Groups, Education and Information Material, Meeting Dates, Publications, Medical Abstracts, Video Library, etc.

WORLD PARKINSON DISEASE ASSOCIATION WEB SITE

www.wpda.org/ A weekly updated source of world news