

The American Parkinson Disease Association

S P R I N G 2 0 0 4 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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Virtually everyone is lonely from time to time, but chronic loneliness is a matter of more serious psychological dimension.

Most people have no trouble describing what loneliness feels like. Emptiness, tightness of the throat, anxiety, feelings of "deadness inside" are among the phrases that recur when people talk about their lonely feelings. The trouble people do have is locating the sources of their loneliness.

The most common error is that people who feel lonely blame themselves for their condition. In fact, usually it is some situation or external problem that causes the loneliness, rather than some inner, psychological reason. No one is "genetically lonely" or "naturally lonely."

Social forces have a good deal to do with being alone, the most common cause of loneliness. Being alone is, in good part, the product of the high divorce rate and the fact that wives outlive husbands. It is also a product of our culture's emphasis on "self-sufficiency" and independence.

It is a popular fallacy that old people are the most lonely members of our society. Just the opposite is true. Research shows that young people are most lonely as well as the most unhappy, the most often bored and the lowest in self-esteem of the entire population. Seniors are the least lonely because they

become wiser and psychologically sturdier as they age. It's also possible that the unhappy, lonely people die sooner, leaving the more optimistic, cheerful ones to survive and be counted.

Another fallacy is that women need men more than men need women. Fact: Indications are clear that men tend to be more dependent on women. One reason is that women are far more skilled than men at establishing intimacy and at creating nurturing relationships.



What to do about loneliness.

Some of the means people use to adjust to loneliness can actually exacerbate the problem; solitary drinking, taking tranquilizers or other drugs, or watching television. This is particularly insidious (because ostensibly harmless) such diversions can reduce the capacity to be alone and introspective. It's no accident that in a study of high school students, the ones who had the lowest social status and self-esteem were the ones who watched television most often. Television tends to serve as a substitute for social life, not a route into it.

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STUDY ABOUT CHILDREN OF PARENTS WITH PD

Participants are still being sought for the study "Quality of Life of Children of Parents with Parkinson's." Volunteers will be sent a questionnaire booklet for completion, and asked to return it in a pre-paid envelope. The booklet should take about one hour to complete.

The goals of the study are to collect and provide information for both families and health care professionals, as well as develop strategies to promote a good quality of life for children who have a parent with Parkinson's.

All family members are eligible to participate, including children age 11 or older, as well as grown children who have left home. For more information contact David Morley at The Sobell Department of Motor Neuroscience & Movement Disorders, Institute of Neurology, 8-11 Queen Square, London, WC1N 3BG, United Kingdom; or phone 44207 8373611 ext. 4114; or email D.Morley@ion.ucl.ac.uk. ■

LEARNING AND MEMORY IN PD

Dr. Filoteo of the San Diego VA Hospital is conducting research into Parkinson's disease's impact on learning and memory. He is seeking volunteers who have been diagnosed with Parkinson's disease and have no other neurological problems. Participants will be asked to go to the VA Hospital in La Jolla, Calif. to receive memory and attention tests. There is no compensation for this study. If interested, please contact Dr. Filoteo's lab at (858) 552-8585 ext. 5593. ■

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



Dear Reader,

Spring is finally upon us, though it took a while to make up its mind in the Northeast.

It is no surprise that this season of blossoming flowers and opening windows is the time chosen for graduations, weddings and religious rites of passage. It is an occasion of life, renewal and hope. That is probably why, consciously or not, APDA makes its research grant awards. It is the period of hope and commencement to future success.

APDA received more than 100 applications, the highest number in our history, this year from scientists and researchers committed to finding a cure. Our Scientific Advisory Board has met to review the requests, and the Executive Committee of the Board of Directors will review its recommendations and announce the fellowships and grants soon, always with the hope that among them is the research, which will at least ease the burden and, it is hoped, lead us to a cure.

We are proud to be able to say that APDA has funded every major scientific breakthrough in Parkinson's disease thus far, and continues to seek the most promising research to expedite the eradication of Parkinson's disease. We have contributed more than \$28 million to research and patient services thus far and will continue to raise funds and awareness to fulfill our mission.

We also recognize and applaud the efforts of our national network of 64 Chapters and 57 Information & Referral Centers who celebrated April as Parkinson Awareness Month. Walk-a-thons, proclamations, symposia, conferences, special events and seminars filled the events calendars of newspapers across the country as volunteers and healthcare professionals gave hours of time and an abundance of talent to bring the APDA message of hope and determination to millions of people.

The symbiotic relationship of research for the future and support for the present is one of APDA's greatest strengths, making it unique among other organizations. We are proud of our work, but even more proud of the people who are responsible for it.

In the laboratories, on the dance floor, in the classrooms, in the parks and in the newspapers, our APDA army will ultimately win this war against Parkinson's disease.

Sincerely,

A stylized, handwritten signature in black ink, appearing to read "Vincent N. Gattullo".

Vincent N. Gattullo

Ice packs, hot and cold compresses, medicated baths and other forms of water therapy were mainstays of medicine for centuries.

Today, high-tech medicine has eclipsed water-based treatment, even though hydro therapy is still recognized as effective in several European countries and its use is covered by national insurance programs. These treatments — safe, inexpensive and easy to use — remain valuable tools for easing discomfort caused by common ailments.

Medicated

Baths We all know how relaxing a warm-water bath can be; however, not everyone realizes that even greater benefits can be reaped by adding natural ingredients to the water. Add a cup of apple-cider vinegar to the bath water, and splash a handful over your shoulders, back and chest. That will invigorate you when you're fatigued. It also helps restore the skin's germ-killing natural acidity, which is continually washed away by bathing.

To soothe poison ivy or sunburn, add two cups of vinegar to your bath.

A bran bath eases itching, soothes dermatitis or other skin irritations, and eliminates scaly patches. Sew several handfuls of wheat or oat bran into a cheesecloth pouch. Soak the pouch in hot water for several minutes, then place in a tub filled with tepid water. Squeeze the pouch until the water turns milky.

Pine Extract One cupful of pine extract in a warm bath helps open clogged pores, speeds healing of rashes and relieves muscle fatigue. Be careful not to confuse pine extract with pine cleanser, a detergent, which will irritate the skin.

Salt Massage This energizing technique tones tissues, relieves stress and fatigue, and can help you ward off a cold. Sit on the edge of a tub filled with warm water. Pour salt into a cupped hand. Slowly add water to the salt until you make a thick paste. Using firm, circular motions, rub the paste over your body. Then rinse off the paste with a brief soak in the tub,

or sponge it off with cold water. Be careful not to rub salt on sores, cuts, etc.

Cold-Water

Treading Fill the tub ankle-deep with cold water. Holding onto a firmly

anchored rail, march in place for a few seconds or minutes as long as you can comfortably tolerate. Then rub your feet briskly with a towel. Done twice daily, this technique creates a remarkable sense of well-being and is great for relieving exercise-related leg cramps. Some believe that it builds resistance to diseases as well. Cold-night treading promotes sound sleep, yet it has an eye-opening effect when done in the morning.

Compress To prevent or relieve headache pain, fold a washcloth in half, dip it in ice water and wring it out. Place it on your head or neck. Re-wet it every few minutes to keep it cold.

To relieve a sore throat or laryngitis, fold a cotton cloth in thirds, wet it with cold water and wring it out. Wind it once around the neck and fasten with a safety pin. Over the cloth, wrap a wool scarf. Leave this wrap in place as long as you like. With the cold trapped against the skin by the wool, the body continues to divert more warming blood to the area, helping break up congestion. ■

Abstracted from the Vermont Parkinsonian, Jan '04



Loneliness

Continued from Page 1

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 they enhance your sense of creativity. These are all 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 more intimate 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. ■

Article abstracted from the Vermont Parkinsonian, January 2004.

When the PD Patient Needs Surgery

Michael Rezak, MD, Ph.D., Director APDA I&R Centers, Glenbrook Hospital, Glenview, Ill.

Special consideration must be given to those individuals with Parkinson's disease (PD) who require any type of surgical intervention. The stress that surgical procedures can impose affects PD management, and although most patients with PD will not encounter difficulties, knowledge of potential problems may help to preclude their development. If problems do arise, being forewarned will allow prompt recognition, treatment and resolution.

In the paragraphs that follow, I will address the questions most frequently asked by patients who are about to undergo surgical procedures. These questions (and answers) will also address some of the potential complications seen in PD patients undergoing surgical procedures. I will not address questions related to neurosurgical procedures used to treat PD.

Q) When should PD medications be discontinued prior to surgery and how soon can they be restarted after surgery?

A) It is my practice to encourage my patients to continue taking all PD medications up to 3 hours before surgery. The exception to this is selegiline (Eldepryl®), which I discontinue 2-3 weeks before surgery in order to avoid any possible interaction with certain narcotic analgesics.

PD medications are restarted as soon as the individual can swallow safely. Unfortunately, there are no dopaminergic PD medications that are available for administration via intravenous, intramuscular or by rectal routes. If the patient is recovering from gastrointestinal surgery, I recommend giving the medications through a nasogastric tube which should be clamped for about 30 to 45 minutes after the medicine is delivered to allow absorption. It should be noted that anticholinergic drugs (such as Cogentin®) are currently available in intravenous formulations, and apomorphine (a potent dopamine receptor agonist) should also be available in the near future.

Q) What are the dangers in delaying the restarting of dopaminergic medications?

A) Post-operative recovery can be difficult under any circumstances, however with the additional burden that PD imposes, resumption of optimal motor function as soon as possible is of paramount importance to minimize any of the following potential problems:

First, delay in reinitiating PD medications will compromise motor function, including those of the respiratory (breathing) and pharyngeal (swallowing) muscles. Compromise of respiratory



muscle function can lead to poor cough and restriction of movement of the respiratory muscles (limiting deep breaths). Additionally, swallowing problems can develop or worsen without PD meds, thus increasing the risk of aspiration. These problems, taken together with the decreased ability to move, about, will make the common post-operative complication of pneumonia much more likely without PD medications.

Secondly, the rigidity and bradykinesia brought on by lack of PD medications leads to decreased movement and thereby increases the post-operative risk of developing blood clots in the legs (deep venous thrombosis) related to the sluggish blood flow. Mobilization, a major goal following surgery of any kind, is made considerably more difficult without medication, thus further delaying rehabilitation. Finally, a rare but potentially life threatening condition known as neuroleptic malignant

syndrome (NMS) must be a concern whenever dopaminergic drugs are abruptly discontinued. In NMS, mental status changes, rigidity, tremor, fever, and autonomic instability can lead to a life threatening condition. If recognized early, treatment can be life saving.

Q) Should a PD patient do anything special pre-operatively to maximize the possibility of a good recovery?

A) Of course, obtaining general medical clearance prior to surgery is the standard.

Additionally, I recommend that

some patients undergo a formal video swallowing evaluation as well as obtain pulmonary function tests so that baseline measurements can be obtained and thus appropriate planning for potential postoperative difficulties be instituted. Also, common medications that may alter bleeding need to be discontinued such as vitamin E, aspirin and Ginkgo Biloba. Maintaining good

hydration, appropriate nutritional status and optimizing overall conditioning before surgery maximizes the potential for a good recovery.

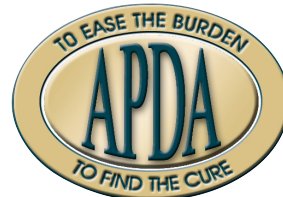
Q) What medications should be avoided following surgery?

A) Needless to say, all drugs that block dopaminergic function need to be avoided. Post-operative nausea is extremely common and medications such as Reglan®, Compazine®, and Phenergan® are often considered first line medications to treat this problem. By their very nature all of these medications will worsen PD symptoms and should therefore be avoided. If treatment of nausea and vomiting is required, the drug of choice for PD patients is Zofran®. Zofran's mechanism of action does not involve altering dopaminergic function, and the drug can be given intravenously as well as orally.

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F.Y.I. is an informational guide to the efforts and success of the hundreds of volunteers and staff who work daily to help ease the burden and find a cure and for millions of PWP and their caregivers across the United States.



FYI EDITOR: K.G. Whitford

SPRING 2004

VOLUME XI NO. II

Parkinson Awareness Month Spurs Events Across the Country

While Chapters, Centers and Support Groups across the country sponsor "Stamp Out Parkinson's Disease," events throughout the year to raise funds and awareness of the disease, numerous groups choose April, which is National Parkinson Awareness Month, for their events.

Last month proclamations, seminars, symposia and walk-a-thons took place from shore to shore.

Richard M. Daley declared April 11 World Parkinson's Day in Chicago by mayoral proclamation.

Mall walks were popular in **Leesburg, Fla.** and **Reno Nev.**, where the Lake County Support Group and Reno/Carson/Tahoe I&R Center sponsored walks. **Atlanta Chapter** also went indoors at the Concourse Office Park for its annual walk-a-thon, which last year raised more than \$35,000 for PD research. the **APDA Support Group of Asheville, NC**, held an afternoon walk.

On April 15, **San Diego's I&R Center**, had its Spring Symposium at the Scottish Rite Center, with the appropriate title, "How to Make PD Less Taxing." The **Lubbock Tex. Center** presented "Coping with Movement Disorders: Treating the Mind and Body," an educational symposium for patients and caregivers, on April

16, in Lubbock, and "Overcoming Obstacles: Living with Movement Disorders," on April 24, in Brownwood, Tex.

On April 17, the **Vermont I&R Center** sponsored an education seminar for PD Awareness, the **Washington State Chapter** conducted "A Dance for Parkinson's Disease Awareness" at the Wintergarden in Bellevue, Wash, and the **Rhode Island Chapter** held a symposium "Living Healthy With Parkinson's," at Memorial Hospital in Pawtucket.

APDA was co-beneficiary of The Young Parkinson Disease Association's (YOPA) "an Evening of Musical Magic," hosted by New York Giant star linebacker Harry

Carson, in Martinsville, N.J., on April 23. The next day the **Minnesota Chapter and Center** hosted a walk in the Como Lakeside Pavilion in St. Paul, while at the Texas A&M University campus in College Station the Brazos Valley Parkinson Association sponsored a 5K run/walk.

Two groups, **Greater Los Angeles Chapter** and **Suffolk County**, opted to utilize their location's natural water sites as settings for their walks. The formers was held in Santa Monica's Palisades Park along the Pacific Ocean and the Long Island, NY group chose Belmont Lake, and expanded the event into a Family Fun Day with Disney characters, face painting, an auction and raffle. ■

APDA Director Appointed to Federal Coalition

APDA executive director Joel Gerstel has been appointed to represent the Parkinson's disease community on the Transportation Security Administration's (TSA) Disability Coalition, a division of the U.S. Department of Homeland Security.

The coalition includes representatives from more than 35 groups and organizations to provide insight into the needs and concerns of persons with disabilities being screened at airport checkpoints while meeting strict security codes. The panel's input will be incorporated in the TSA's Screening of Persons with Disabilities program, policies, procedures and screener training that is given to more than 50,000 screeners nationwide.

Joel has headed the national organization since 1996 and invites input from the APDA's nationwide network of Chapters, Information and Referral Centers and 200 affiliated support groups, the Young Onset Parkinson Association, with which ADPD has an agreement of mutual cooperation, and from PD patients and their families to communicate what persons with Parkinson's disease find a problem. ■

In the East

The University of Pittsburgh's football team is the Beast of the East, and the city is known as the gateway to the West, so we are choosing the former in locating it geographically. More important is that the Chapter had two major events recently. I&R Center medical director Dr. Susan Baser was the keynote speaker at the Parkinson Outreach Program, April 3, at the Boyce Park Ski Lodge. The evening program included her lecture, food and snacks, karaoke, Jugglin' Joe Wagner and a hamster race. Boyce Park was also the site for the national walk-a-thon on May 15.

In the West

The event was called "All That Jazz," but it turned into all that cash for the UCLA Center for Advanced Research in September. Coordinator Susan Daniels reports that the Chapter's first major fundraising event was an evening of dinner and dancing with a live and silent auction at the Long Beach Aquarium of the Pacific, co-sponsored by the Long Beach Yacht Club. Dr. Marie-Francoise Chesselet, the center's director, thought the best part was the check for \$50,000 supporting research being done there to explain the role played by the subthalamic nucleus of the brain in treated and untreated PD. "Clarifying the functional connections among the parts of the brain most affected in PD, could pave the way for the development of new treatments for people with the disease," says Susan. The Chapter has a symposium sched-



Dr. Marie-Françoise Chesselet, center, director of the APDA Center for Advanced Research at UCLA, happily receive the symbolic check representing \$50,000 from (left to right) Susan Daniels, I&R coordinator for Laguna Hills, Fountain Valley, and Long Beach; Karen Sherman, Long Beach Yacht Club; Cecilia Ezekiel and Mike Bell, co-presidents of the Orange County Chapter.

uled for June 19 at the Long Beach Memorial Medical Center. Mark Siegel, acting president of the Greater Los Angeles Chapter, led a group attending the California State Assembly's hearing to create a state Parkinson's registry. The Chapter is also busy getting signatures to qualify the stem cell initiative for the state's November ballot. May 28, is the last day.

In the Northwest

It was a full day for those who attended the Idaho Chapter's annual seminar on April 7, cosponsored by the I&R Center and St. Alphonsus Medical Center in the Boise Holiday Inn, according to coordinator Nichole Whitener. Neurologist Dr. Stephen Asher provided medical and research updates and topics on voice therapy, caregiver support and nutrition preceded lunch. In the afternoon participants had a choice of 45-minute breakout sessions that included biofeedback, therapeutic massage and an introduction to the Chi Gung, the ancient Chinese practice based on gentle movement and natural breathing.

In the Midwest

The St. Louis Chapter saluted board member Debbie Dalin Guyer for developing the "LIL" Monitor to encourage people with PD to speak louder and to continue benefiting from the LSVT voice enhancement program. Because altered loudness perception is a symptom, persons with PD may begin to speak very softly without realizing it.

The monitor is a calibrated, lightweight, portable, battery-operated device about the size of a garage door opener, which is illuminated in response to voice volume. Through a series of lights, which change color from orange to red to green as the user's loudness level increases, the user can visually self-monitor his/her voice volume and adjust it accordingly.



The "Lil" Monitor was developed by St. Louis Chapter member Debbie Dalin Guyer and named in honor of her mother.

Debbie named the monitor for her mother, who has PD. Anyone interested may call her at 1-800-489-1888.

In the South

Lydia Stevens, Arkansas I&R Center coordinator, notes that the April 24th symposium, "Managing Parkinson's Disease Symptoms" in the Rogers Activity Center kept a full house of attendees occupied all day. Presented by the Arkansas

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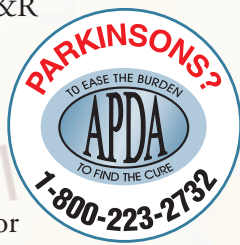
Chapter and St. Mary's Hospital, the day included a continental breakfast, Dr. David Davis explaining "What is PD?" and "Non-surgical Treatments of PD," a luncheon, lectures on diet, exercise, musical therapy, assistive devices, and a silent auction.

The South Florida Chapter and I&R Center filled the Saturday with a picnic, fun walk, prizes, face painting and entertainment at the Tradewinds Park in Coconut Creek, reports Daphne Persaud. Meanwhile the Suncoast Parkinsonians Chapter president Ginny Bernard was leading a similar morning with refreshments, prizes, clowns, face painting and more in Largo's Barrington Senior Living Community Center.



The Yellow Pages want you to let your fingers do the walking, but the Southern Nevada Chapter wants you to let your letters do the PR. Geri Giallanza, Las Vegas I&R Center coordinator, reports that Chapter board member Florence Kunstman suggested developing a small adhesive label that could be applied to outgoing mail thus raising awareness of PD and the APDA where the mail went in the world. The Chapter and I&R Center are offering the eye-catching red, white, blue stickers in full 24-label sheets for \$2.50 for personal or business mail or as gifts.

The labels can be ordered by check or money order payable to APDA at PO Box 81884, Las Vegas, NV 89180-1884. Allow two to four weeks for delivery. ■



Chapters — At the Heart of APDA

When Salvatore Esposito Sr. began his efforts to benefit Parkinson's disease in 1961, he in fact began the first chapter of what would become a national organization. Neither did he realize that by 2004 that organization would have contributed to every pioneering PD research breakthrough and create an unparalleled network of patient and caregiver assistance across the country.

Today APDA's 64 chapters, working cooperatively with I&R Centers and support groups, are at the heart of the national operations, raising funds for research, sponsoring regional conferences and symposia, cooperating with I&R Centers and providing resources for support groups.

All volunteers, chapter members also implement and carry out all necessary reporting and donor acknowledgement functions. Many are or have family members who have PD, but many more, like the founding Espositos, are motivated by the desire to "Ease the Burden and Find the Cure" for the progressive, debilitating disease that afflicts more than 1.5 million Americans.

Chapters work closely with support groups and, in fact, many new chapters have begun as affiliated support groups, though any group that wishes may affiliate as a chapter. The first step is to call the national office and receive the guidelines.

The Chapter and I&R Center relationship is also a close one, with each supporting the other particularly in fund-raising and education efforts.

Symposium Results in Research Collaboration

Anyone who doesn't believe in the positive results of networking might want to talk with Drs. Malcolm Stewart and Michael Rezak, medical directors of the Dallas and Chicago I&R Centers respectively, who met at an APDA symposium last year.

In the course of casual conversation, they began to discuss their individual research objective, to establish markers that will identify those individuals at an increased risk of developing PD in the future, only to learn it was the same. The neurologists invited each other to look at the research to date, and though their centers are separated by almost 1,000 miles, the casual conversation led to formal collaboration.

Their area of research involves screening first generation PD individuals, using the results of a comprehensive battery of blood tests, sleep studies, neuropsychological evaluations and brain scans, genetic tests to establish identification markers, which if the disease occurs, can serve as early indicators for future generations thereby allowing early neuroprotective therapy.

Drs. Stewart and Rezak's collaboration not only avoids duplication, but also provides a larger pool of research subjects. ■

PROFILE:

Paul Maestrone, DVM

What do you call a Fulbright Scholar, inventor with several patents for veterinary medication products, author of 50 scientific papers, and former research leader at a major American pharmaceutical company?

We call him Dr. Paul Maestrone, APDA's director of scientific and medical affairs, who supervises all 57 I&R Centers nationally, is the liaison with the Scientific Advisory Board, and for the past 18 years has edited the quarterly newsletter, and directs the production of all educational materials.

Born in Italy's northernmost lake region, Gianpaolo (Paul) Maestrone was graduated magna cum laude from the University of Milan and at age 23 an assistant professor at his alma mater when named a Fulbright Scholar, which brought him to the United States aboard the Italian liner *Saturnia* in 1953. During the crossing he met Sophia Esposito, who was returning home from an Italian vacation. The meeting became what Dr. Maestrone calls a "48-year-long shipboard romance."

But love wasn't that simple. Paul attended Iowa State University, where he trained in veterinary microbiology, environmental hygiene and diagnosis of viral diseases — all which would serve him well in his future research career. He returned to Italy and asked Sophia to join him to become his wife. She liked the proposal but

had other location ideas.

She won, and they were married on Staten Island in 1956, thus beginning Dr. Maestrone's American research career — first as a research associate at New York City's Animal Medical Center where he established and supervised the microbiology diagnostic laboratory of Speyer Animal Hospital. He moved to E.R. Squibb in New Brunswick, NJ, as senior research microbiologist and from there to Hoffmann-LaRoche's

Animal Science Research Department in Nutley, NJ, where he started as a senior microbiologist and retired 20 years later as research leader to join APDA.



Dr. Maestrone with his Commendatore medal presented by the Italian government in recognition of his international scientific contributions.

Beyond his APDA contributions, he has been a pioneer in international development for PD research, and three years ago was awarded the Italian government's title of Commendatore in recognition of his numerous scientific contributions. Among these is his role in establishing the World Parkinson Organization, which now numbers 25 countries, and his support of the Associazione Italiana Parkinsoniani, which since its founding in 1990 has grown to 18 chapters across Italy and 20,000 members. His knowledge of five languages proves a great resource.

Dr. Maestrone considers himself a jack-of-all-trades and likes to spend his free time reading, pursuing his photography interest and with his family, which includes son Frank, daughters Liz and Elena, and seven grandchildren. There is also the newest family member, Louie, a year-old teacup Yorkshire terrier. ■

Associate Director of Scientific and Medical Affairs Named

Michele Popadyne, RN, MPS, has been appointed Dr. Maestrone's associate. After earning her RN from Kings County Hospital Center School of Nursing and a Bachelor of Science degree from St. Francis College, both in Brooklyn, she was awarded a Master of Public Service from the New School University, Manhattan.

Ms. Popadyne, who was born in Nanticoke, Pennsylvania, has been a pediatric surgery intensive care unit staff and head nurse at Kings County Medical Center where she also served as associate director of quality management. She has held various positions in critical care, research and quality assurance at the Brooklyn Veterans Administration Center, Brooklyn, and was the Department of Medicine administrator at SUNY Downstate Medical Center, Brooklyn, a title she most recently held at North Shore University Hospital, Manhasset, New York. ■



Ms. Popadyne, administrative assistant Heather Duffy, and Dr. Maestrone organize more than 100 fellowship and grant applications.

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: My 72-year-old husband with PD for six years was doing well on Sinemet 25/100 four times a day (at 8 AM, 11AM, 2 PM and 5 PM), but he developed a kidney stone and needed to go into the hospital for removal of the stone. While in the hospital, the Sinemet was given every six hours, and a new doctor added Mirapex. My husband became confused and rigid. The Mirapex was stopped and Requip was added along with Comtan. My husband is even worse. Now he is bloated, not eating, complaining of stomach pain and diarrhea. What do I do? What went wrong? He was mildly forgetful but now he seems demented and his PD has worsened.

A: Another disconnect exists between neurologists who treat many patients with PD and those that do not. By the book — Mirapex and Requip are good dopamine agonists and beneficial in treating PD. By the book — Comtan extends the duration of L-DOPA and is beneficial in treating PD. But a neurologist with a great deal of experience in treating many, many patients with PD would have realized that the hospital was not giving your husband the Sinemet at the three hour intervals that was most effective, that physical therapy and NOT bed rest would have been very important, that Mirapex and Requip have a great deal of hallucination potential in the elderly with dementia, and that Comtan produces many more gastrointestinal side

effects than can be explained simply by its enhancement of the potency of L-DOPA. Put your husband back on his old schedule and get him out of the hospital as soon as possible. If you need to do anything right now, I would suggest to increase the Sinemet temporarily. If he needs any new PD medications, Permax is a dopamine agonist with less hallucination potential than Mirapex of Requip.

Q: In the Winter 2003-04 Newsletter the first question in the Q&A was similar to what my wife is going through, but with some differences. She turns 75 years of age next month and has had Parkinson's disease for about 10 years. She was first placed on Sinemet 25/100 3-times a day, Eldepyrl (Selegiline) 5mg tabs twice a day. She started to have problems again and the medication was changed to Sinemet 50/200 3-times a day. Problems persisted, and her medication was changed to Sinemet CR 25/100 4-times a day. She then began, what I call "dancing-like movements." Medication was added, this time Symmetrel (Amantadine) 100 mg caps and her ankles began to swell, blue splotches appeared all over her legs, her hair began to fall out, her face was flush and she complained of being hot. Her doctor told her to stop the Symmetrel to see if that was the cause. Three days after going off the medication, she fell once a day for 3 days. Her ankles and feet were still swollen. She went back on Symmetrel. The above symptoms returned and her doctor told her to stop taking the Symmetrel. She has now started to

clasp her hands together and at night, shakes so much that I am awakened. She hasn't fallen so far, but she has problems moving to some degree. What can we expect next?

A: Your question demonstrates the disconnect between research on Parkinson's disease and the everyday treatment of patients suffering from Parkinson's disease. Current research is focused on the causes of the accumulation of alpha-synuclein (which seems to be the culprit in causing cell death), methods of delaying the progression of cell death and surgical interventions, which except for subthalamic deep brain stimulation, are experimental, unproven and dangerous. Meanwhile, while waiting FDA-approved therapies that will take many years to get to the local pharmacy, tens of thousands of patients such as your wife are seeking the advices of skilled clinicians to help them to survive in reasonable good shape, until the "cure" is available.

In this case it is obvious that Amantidine helped your wife but she did have side effects from this drug. Many of Amantidine's beneficial effects are due to its action as an anticholinergic drug. Simply reduce the Amantidine to one pill a day, which should reduce the side effects and add a small amount of another anti-cholinergic medication such as trihexane or bentrופן which will have the same beneficial effect of Amantidine without the side effects. If the side effects of the Amantidine persist, you could discontinue it but keep on the other anti-cholinergics. Sinemet may need to be increased, if she worsens. ■

CAREGIVING...

Cathleen Lear, Elizabeth, N.J.

I find caregiving to be one of the highest forms love can take. The general public might look at caregiving as taking care of someone confined to home, bedridden or in the terminal stages of illness. With Parkinson's Disease, (PD) it is not so.

Caregiving for someone with PD is compatible with life. It is the day to day adjustments which are needed, the patience to do all the things necessary to live within the constraints of the disease, the stares of those insensitive souls who seem fixated on the gait, the tremors or some other manifestation of PD, the on-off times, those moments when he/she just can't "kick in," or the other things which must be put on hold because of circumstances we cannot control. Caregiving has to do with sublimating your own needs while taking great care of yourself, doing at least one thing everyday for Y.O.U., educating yourself, being able to find the best doctor who will partner with both of you or having the courage to move on until you do. Being an advocate for both of you, providing the greatest gift your love can give, that of never, ever doing for persons with PD what they can do for themselves. If you allow this to happen because it is easier for you to do it or because it takes less time for you to do it, you are laying the foundation for the one you love to become a victim. Caregiving may be crying rivers for what was, ranting

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It is a good idea to get some training before you begin; ask your local hospital about training classes for:

1. **Transferring** (moving to and from a bed or toilet).
2. **Incontinence** (loss of bowel/bladder control) **management.**
3. **Nutritional needs** (ideas and supplements)

The caregiver's credo should always rule your activities:

- A) I have the right to take care of myself. This will allow me to take better care of my loved one.
- B) I have the right to seek help from others, even though my loved one may object. I recognize the limits of my skills, time, endurance, and strength.
- C) I have the right to take pride in what I am accomplishing, and to applaud the courage it sometimes takes to meet my loved one's needs.
- D) I have the right to reject any attempt by my loved one to manipulate me through guilt, anger, or grief.

Some suggestions follow for specific care needs, such as:

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Dressing:

- Have him or her sit down while you help with dressing.
- Use Velcro-closure sneakers, zippers instead of buttons, and slippers with non-skid soles to make dressing easier.
- Suggest that your loved one wear sweats or other action clothes. They're easy to care for and comfortable.
- Make sure slippers, socks, or shoes are always worn.

Moving:

- Tell your loved one what you're going to do.
- Stand with your feet apart and balance your weight evenly with your knees bent and your back straight.
- Bend and straighten with your knees, not your back; let your legs carry the weight.
- If you turn, pivot — using small steps with your feet; don't twist.

Walking:



- Let your loved one hold onto you. With his or her arm around your waist first, you can offer support by then putting your arm around his or her waist.
- You can offer either your arm to lean on or your hand to hold.
- Encourage your loved one to pick up his or her feet.
- A four-pronged cane works well for support assistance.

Bathing:

- Recognize that your loved one may not need to shower or bathe every day. You can wash parts of the body, as needed.
- If your loved one is unsteady, you

I V I N G

CAREGIVING...

Continued from Page 10

- may want to buy or rent a shower bench or chair. Or install grab bars.
- Keep a sense of humor and an easy-going approach to bathing.
 - Assemble all your equipment first, including a no-tears shampoo. Make sure the water is warm, not hot. Rinse your loved one, gently soap, and rinse again. Have him or her lean forward for a shampoo.
 - Respect your loved one's right to privacy. A towel or robe can be worn until the last minute.



2. Every two hours while lying down.
- Use a mattress cover of sheepskin or eggcrate foam.
 - Use a seat cushion or mattress that contains foam, gel, or air (or, waterbed).
 - Avoid the use of donut-shaped cushions. They can decrease blood flow and cause or worsen an ulcer.
 - Lift, don't drag, the person across the mattress.
 - Ask your pharmacist or doctor to recommend a product for bedsores. Protect the skin with a cream or ointment.

Loss of Bowel or Bladder Control:

- Clean your loved one's skin as soon as it's soiled.
- Use absorbent pads and/or briefs with a quick-drying surface.
- Cover the mattress with a rubber sheet; use a mattress-protecting pad on top of the sheets.

Bedsore:

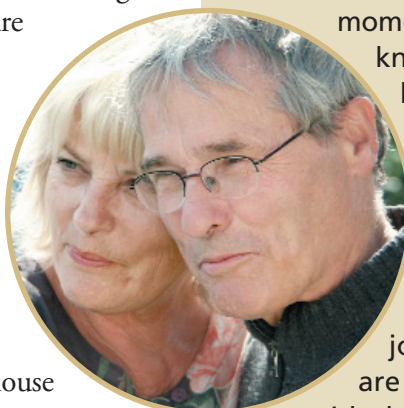
- Bedsore are serious ulcers that begin with reddened skin, but they can eventually penetrate muscle and bone.
- Keep skin as healthy as possible with a good diet.
- Inspect skin at least once a day; bathe when needed for comfort or cleanliness.
- Prevent dry skin with lotion and/or cornstarch.
- Don't massage bony parts of the body; tiny injuries can occur under the skin.
- Don't let body areas rub together (e.g., separate knees when lying on the side with pillows or wedges).
- Change position
 1. Every hour while sitting, (every 15 minutes if the person can't shift weight);

Other Hints:

- Stock a compartmentalized pill-reminder container a week at a time.
- Buy a baby-monitor intercom (you can find one at electronics stores).
- Try headphones for TV or radio listening, especially if your loved one is hard of hearing.

To Preserve Independence:

- You and your loved one can move to a smaller home, apartment, or mobile home.
- Live with assistance from visiting nurses, home healthcare aides, adult day care, meal delivery, transportation, and chore or minor-repair help.
- Home-share with another older person or with a college student.
- Ask a banker about financial options like house sales, leasebacks, and reverse mortgages. ■



and raving at the unfairness of it all, those valleys of despair from which you must climb out, anger at what has been lost and how to deal with the challenges and perhaps even denial of reality.

But it must also include dwelling on the positive: Savoring those little victories that medication was taken on time and worked so that there is little "off" time. It is pulling into a handicapped parking space during peak shopping times when the only parking is miles away. It is the love and respect our children have for their father. It is being able to dance at our children's weddings, watching Bill play with our granddaughters, being part of a support group with others who truly understand. It is the respect of family and friends who realize that there are changes in Bill's body but not in his mind.

It is realizing the importance of laughter in our lives. Laughing at ourselves, watching "Bringing Down the House" again and again, anticipating the laughter that erupts during those outrageous parts of the video. It is being able to meditate to bring calm to an otherwise difficult moment. It is in the knowing what we know that gives us strength and hope and courage to give care.

Caregiving is an evolving learning journey where we are taught to cope with the changes in the fabric of our lives. ■

Foot Note: Abstracted from the Vermont Parkinsonian January 2004

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-APDA (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.apda.org/ A weekly updated source of world news

When the PD Patient Needs Surgery

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Post-operative confusion and agitation is another situation where dopamine blocking agents are often employed. Older neuroleptic drugs such as Haldol[®] and closely related drugs should be avoided. The newer so called "atypical neuroleptics" such as Risperdal[®] and Zyprexa[®] also have a deleterious effect on the motor symptoms of PD. The drugs of choice for the treatment of post-operative delirium are Seroquel[®] and Clozaril[®] both of which are very effective and usually have insignificant negative effects on PD symptoms.

Q Why are so many people with PD confused after surgery?

A Post-operative confusion (delirium) is usually due to a number of factors in the PD patient. Certainly, as the age of the patient increases, post-operative mental status changes become more likely. Additional factors that may play a role in post-operative delirium include pre-existing dementia, anesthetic and pain medications, change in environment, and the unfamiliar medical staff. Optimal management of this situation requires treatment of the delirium without compromising motor function. Thus, as noted above, by using drugs such as Seroquel[®] or Clozaril[®] mental status can often be treated without lowering PD medications which can then preserve motor function. The approach of lowering PD medications to treat post-operative mental status changes usually results in marked worsening of motor status and places the patient at greater risk of aspiration, blood clots, pneumonia and further deconditioning, all of which retard recovery. ■

The material contained herein concerning the research in the field of Parkinson's disease and answers to readers, 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.