

The American Parkinson Disease Association

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by The American Parkinson
Disease Association, Inc.

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Maintaining Hope

By Linda O'Connor, LCSW
Coordinator APDA I&R Center, Los Angeles, CA

In my work as the Coordinator of the Los Angeles APDA Information and Referral Center at Cedars-Sinai Hospital, I have the opportunity to talk with people diagnosed with Parkinson's disease (PD) and their family members every day, and one of the most significant aspects of our contact often centers on the subject of "hope". Sometimes it is spoken, and often unspoken, but the question of hope is always present in some way.

Living with PD is challenging, both physically and emotionally for the person who has been diagnosed, as well as for family members. In difficult times it becomes vital to have something to hold on to, and in my opinion, one of the best things is hope. Because having hope can be such a powerful tool to assist with coping, it is certainly worth further exploration and understanding.

Defining Hope

According to the dictionary, hope is: "A desire accompanied by expectation of or belief in fulfillment; also expectation of fulfillment or success." Richard Lazarus, a psychologist who has done a great deal of study and writing on hope, defines it this way: "To hope is to believe that something positive, which does not presently apply to one's life, could still materialize, and so we yearn for it. Although desire is an essential feature, hope is much more than this because it requires the belief in the possibility of a favorable outcome."

The fact that having the diagnosis of PD brings with it so much uncertainty, and because you don't know absolutely for sure what will happen next, this creates the possibility that something good may happen, and that possibility makes room for hope.

No one's future is absolutely foretold, so while there may be reason to fear, there is also great reason to hope.

Hope as a Coping Process

Maintaining a hopeful attitude can be an extremely helpful coping strategy. First it produces action. Studies have shown that hope can galvanize efforts to seek improvement of an unfavorable situation. Without hope we are unlikely to act on our own behalf. Hope combines yearning for something better with the belief that our actions could help to bring about the outcome we want.

Hope is why people seek information about Parkinson's disease and its treatment. Hope is why people become actively involved in getting the best treatment possible. Hope is why people exercise, concentrate on good nutrition and focus on stress management. Hope is why people connect with each other for support or do advocacy work or enroll in clinical trials. Hope is why people don't give up, even in some of the most difficult situations. It keeps us engaged with life.

The second way that hope aids coping is that it serves as a vital resource against despair. The best defense we have against despair and the depression that accompanies it is hope.

Cultivating Hope

Because hope partly involves our thought process, it is possible to make very deliberate, conscious decision to be hopeful. Now this may not happen overnight, and it may not work every single day, especially if you're having a particularly bad day, BUT... it is worth trying to focus on maintaining an overall hopeful attitude as much as possible. ■

RASAGILINE, A NEW DRUG

Rasagiline is a potent second generation monoamine oxidase-type B (MAO-B) inhibitor, which has been developed by Teva Neuroscience in partnership with Eisai, Inc. This drug acts in a similar fashion to selegiline (Eldepryl) and is anticipated to receive FDA approval and become available in the United States in the near future.

Rasagiline acts by inhibiting an enzyme (MAO-B) that degrades dopamine in the striatum, thereby increasing dopamine function in the brain. In laboratory tests rasagiline is 15 times more potent than selegiline. Several trials make this an appealing Parkinson's disease (PD) drug.

The TEMPO trial looked at 404 patients with newly diagnosed PD. Participants were randomized into two groups receiving rasagiline or placebo for the first six months of the trial. All patients received rasagiline for the second six-month period. At the end of 12 months, patients who were in the early rasagiline group were statistically better on a PD rating scale than those who were on the placebo for the first six months. This study strongly suggests that rasagiline is an excellent drug to use in early P.D. for potential neuroprotective effect and mild symptomatic benefit.

The PRESTO trial showed that rasagiline lessened motor fluctuations and decreased "off" time in patients in mid to later stages of PD.

The LARGO trial included 454 patients on carbidopa/l-dopa who had motor fluctuations. The group treated with rasagiline had significant improvement in their gait (freezing spells), a troublesome symptom of many patients. Moreover, patients on rasagiline also showed significant improvement in tremor, including those with severe tremor. This drug therefore, offers potential benefit in both the early and late stages of the disease.

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



Dear Reader,

It has been the best of times and the worst of times for APDA during the past few months.

Like thousands of Americans, we were affected emotionally seeing the suffering of our fellow citizens as Hurricane Katrina ripped apart the Gulf Coast and hurricane damaged Florida, but were also affected directly, unable to contact or hear anything about our New Orleans I&R Center at the LSU Medical School. After a few days word came from our newest Center at Vicksburg, Mississippi. Though without communications, water or power, it was intact. Meanwhile, Carla Cothran, in Birmingham, Alabama, was aiding in evacuee relief while addressing the exacerbated needs of her regular constituency. We finally learned that Dr. Jayaraman Rao and Maureen Cook were safe and had opened a temporary site in Baton Rouge, La., and that Brenda Allred, of the Vicksburg Center, after locating her patients listed as "missing persons," was distributing flyers and press releases along the Mississippi Gulf Coast, offering assistance for people with Parkinson's.

We are so very proud of our APDA family members who, despite their own obvious personal concerns created by a such an horrific act of nature, never lost sight of their mission to help their Parkinson patients, but also their community.

On a happier note, this year marks the milestone of APDA having its own national headquarters. On September 14, after 39 years of operating from several, and often cramped and inadequate offices, and without any interruption in service, the national staff moved into Parkinson Plaza, its new three-story office building located at 135 Parkinson Avenue on Staten Island, just a short distance from where the first Chapter was founded. Having its own facility will mean a savings of more than \$100,000 each year in rent, and build equity for the organization.

We are most grateful to numerous foundations and individuals who supported us with grants and bequests, especially the Richmond County Savings Foundation, which contributed a lead \$200,000 grant.

We dedicated the building on November 20, following the annual meeting of the national board of directors.

In other action this fall, APDA and the Michael J. Fox foundation (MJF) collaboratively saved the only PD state registry in the country by picking up funding of the Nebraska Parkinson's Disease Registry. The registry was begun six years ago by the Department of Health of the State of Nebraska following the campaign of former APDA Chapter president Bill Kopepski, but the state suspended funds in 2004. APDA's Creighton University I&R Center director, Dr. John Bertoni, has been very involved in the program, and at the recommendation of the Scientific Advisory Board, the executive board voted unanimously to join with MJF to fund the continuation of the registry.

Sincerely,

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

Vincent N. Gattullo
President

DROOLING & ITS TREATMENT

By Daniel Truong, MD

Medical Director

APDA I&R Centers Long Beach, Fountain Valley, Laguna Hills, CA

Drooling, also known as sialorrhea, is a common symptom of Parkinson's disease (PD) occurring in up to 80 per cent of patients. Excessive drooling can be a nuisance to patients, and it is sometimes embarrassing. Apart from this, however, drooling can cause aspiration pneumonia (swallowing of drool into the lungs) or skin irritations or infections if left untreated.



Drooling in PD patients is caused by pooling of saliva in the mouth because of difficulty swallowing due to muscle stiffness. The difficulty in swallowing results from the effects of PD on muscles that are used to move food down into the stomach; it is not caused by the production of increased saliva.

Early in the course of PD the drooling may not be severe and may happen mostly during sleep, in part due to gravity. Later, however, it may become more frequent and may cause more problems.

There are a few treatments options for drooling in patients with PD. One approach is to increase the dose of the anti-Parkinsonian medication that the patient is already taking, in hope that better control of movement will result in less pooling of saliva and less drooling. Another approach is to treat with drugs that block acetylcholine, an important chemical messenger in the brain and body. Increasing medication doses and/or adding

another type of drug, however, can produce side effects. This is especially true when using anti-cholinergic medications in the elderly population. Third, there are non-drug approaches that include changing sleeping position and eating.

A relatively new approach is to use botulinum toxin type A (Botox®). Botulinum toxin blocks the release of acetylcholine, preventing the injected muscle from excessive contraction and movement. Botox has recently received a lot of attention for its use as a cosmetic enhancer, but it has long been used for the treatment of spasticity and other movement disorders.

Botulinum toxin type A has not yet been approved specifically for the treatment of drooling in patients with PD, but several clinical trials have suggested that it may be beneficial. A recent, well-controlled study conducted in Germany compared different doses of botulinum toxin type A and placebo. Injections were given into each parotid gland, one of the glands that produce saliva.

Drooling was reduced by approximately 50 per cent in the patients receiving the high-dose injection.

Overall, two-thirds of patients treated with any dose of botulinum toxin type A improved in terms of the amount of drooling. Because the amount of drooling was very high, the authors note that even a 50 per cent reduction left many patients with considerable drooling and impairment.

More research is being done to determine whether and to what extent botulinum toxin type A might be beneficial for drooling in Parkinson's disease patients.

Another form of botulinum toxin, type B, is also under study as a treatment for drooling in Parkinson's patients.

A recent study by Dr. Ondo and colleagues at Baylor College of Medicine compared the effects of a single dose of type B toxin injections into the parotid and submandibular glands to placebo injections in the same areas on drooling and swallowing.

As was the case for the type A toxin, type B toxin significantly reduced drooling. Most patients in the botu-

linum toxin group rated the improvement as dramatic, marked or moderate, whereas patients in the placebo group generally reported no change.

These findings are promising but difficult to compare to the type A studies because of dosing differences as well as differences in injection location and procedures.

Additional studies will be needed to examine the effects of different doses of type B toxin on drooling and on unwanted side effects. ■



Questions & Answers

Enrico Fazzini, DO, PhD

*Assoc. Prof. Neurology New York University, New York, NY,
University of Nevada, Las Vegas, NV,
N.Y. Institute of Technology, Old Westbury, NY.*

Q: My husband has experienced episodes of fainting lately. His blood pressure is 100/60 in the doctor's office. At times it is higher. No one knows why he faints. He is taking Sinemet 25/100 and Requip 4 mg three times a day. Can you help?

A: It is very common to have widespread fluctuations in blood pressure sometimes leading to fainting. PD may lead to a degeneration in the automatic controls on blood pressure. The medications may drop blood pressure. In a patient with wearing-off or on/off fluctuations, the blood pressure may drop when the medications are working and the muscles are relaxed and rise when the medications are not working and the muscles are rigid. In addition, your husband may be dehydrated. I would try to reduce all medications which drop blood pressure — such as dopamine agonists Requip, Mirapex, and Permax — and try to manage him on controlled release and immediate release Levodopa-Carbidopa preparations. Comtan may also be helpful. ProAmatine and Florinef could be added to increase blood pressure. Remember to monitor potassium levels if Florinef is used. Keep him hydrated. Monitor the blood pressure seated and standing. Try to keep the systolic blood pressure over 100 when he stands.

Q: My wife did very well on Permax and is now fatigued on Mirapex. Her doctor is afraid of using Permax because of the potential of heart problems. Can we go back to using Permax?

A: I have prescribed Permax since 1984 and I have never seen a patient develop heart valve problems. This is a potential effect of the entire class of drugs derived from ergotamine, which includes Permax and Parlodel. As long as she does not have heart valve problems to begin with and an echocardiogram is done periodically, there is much less of a chance of Permax inducing a heart valve problem and she can return to taking this medication. Permax is stronger and has less sedation and psychosis potential than Mirapex and Requip.

Q: My husband has developed a tendency to be obsessed about cleaning the garage and basement. He will be awake during the night worrying about finances even though there is no problem. He is also obsessed with sex and gambling. He is on Mirapex 1.5 mg and Stalevo 100 three times a day. What should I do?

A: Mirapex and Requip cause limbic stimulation, and although they are helpful in elevating mood and motivation, they can cause psychosis. Psychosis includes obsessions, paranoia, delusions and hallucinations. There is also a potential for being easily angered and aggressive. These medications must be reduced and discontinued if necessary to alleviate these symptoms, or they will increase. Seroquel or Clozaril are frequently helpful in reducing the symptoms.

Q: My brother has had PD for seven years. He had recently developed confusion. He sometimes forgets what day it is. He leaves his keys in odd places and cannot find them. He is on Stalevo 150 taken four times a day and Eldepryl. Is this Alzheimer's disease?

A: PD patients can develop dementia. This impairment in cognitive skills such as attention and memory must be distinguished from psychosis. In this case I would discontinue the Stalevo and Eldepryl, use immediate-release Sinemet and place him on either Aricept or Exelon. Namenda could be added as well. He should refrain from driving until his cognitive skills have improved.■

FYI is a guide to the efforts and successes of the hundreds of volunteers and staff who work daily to help ease the burden and find a cure and for millions of persons with Parkinson's and their caregivers across the United States.

GOOD PEOPLE MAKE GOOD THINGS HAPPEN

In 1971, Philip Mayer Good, a joyous 7-year-old who loved to visit Oglebay Park — the nationally famous, city-owned 1600-acre park in Wheeling, WV — died after a year-long illness. His death devastated his parents and two younger brothers, Jay and Paul, but Laurance (Larry) and Barbara Good were determined to turn their loss into a lasting and loving memory of Philip's spirit.

The strength of character and flexibility that brought Larry through Philip's death came to the fore again four years ago when he was diagnosed with Parkinson's. Despite his soft voice and "annoying" gait problems, he has been for the past 10 years the full-time director of development at Wheeling Hospital, a 270-bed acute-care facility; he drives to work, gardens, exercises daily and swims almost every day.

Having had 38 years' experience as the senior vice president of merchandising in a respected 100-year-old retail business, Larry earned his CEBS (Certified Employee Benefits Specialist) and five additional designations including CLU (Certified Life Underwriter) and ChFC (Chartered Financial Consultant), and became affiliated with a prestigious employee benefits firm. This segued into his current work in health-care development.

But Barbara's and his true love — beyond their family itself — is the zoo. In "A Thumbnail Sketch of the History of Oglebay's Good Zoo," Barbara wrote in 1979, "Remembrance of him (Philip) created the spark and the inspiration for this facility — and still



Barbara and Laurance Good look in on newborn naked mole-rats at an exhibit at the Good Zoo in Wheeling, West Virginia.

does."

As a committee member of the esteemed and dynamic Wheeling Park Commission, Larry learned — during Philip's illness — of the plan to build a 10-acre zoo in the next decade. It was then that the Goods committed their resources, their energies and their love. Their funds were magnified by the many memorial contributions made as an outpouring of love at the time of Philip's death. The sum was matched by the Wheeling Parks System Trust Fund and subsequently doubled again by coveted and federal grants awarded by the Appalachian Regional Commission and the Bureau of Outdoor Recreation.

With the site being moved to a larger-than-originally-anticipated 30-plus-acre location, ground was broken and the Good Zoo was off and running. In 1974, Joseph Bissonnette, the former director of the Pittsburgh Zoological Society, joined the staff, as did Penny Miller, who is now director of the only accredited zoo in West Virginia, and who is especially proud of

its endangered species program's success — including the birth of 22 rare red wolf pups.

Barbara remembers how Jay and Paul (both under 10 years at that time) saved their allowance in four Mason jars, dividing their monies among religious school (charity), savings, spending, and the zoo. "The zoo jar always had the most in it at the end of each week," remembers Larry. In Philip's memory more than 6,000 individuals and families added their contributions to the boys' \$34 — the latter being the money

which created Good Zoo Friends, the support arm of the zoo with an initial membership of more than 10,000 people.

To this, Larry and Barbara added another significant contribution which funded several one-of-a-kind exhibits including the incomparable model-train exhibit, the outdoor train which takes zoo visitors on a 2-mile ride through the complex (complementing the 2 miles of walkways throughout). The additional money enabled the zoo to be a year-round facility, inspiring the Benedum Foundation to endow it and establishing it as the Benedum Planetarium Theater whose director, Steve Mitch, has been there since its inception.

In order to document the story of the zoo, Barbara and Larry commissioned the internationally-acclaimed and Wheeling-based filmmaker, Ellis Dungan, to photograph the various stages of its growth and in the late '70s, they co-wrote and produced "Good Zoo and How It Grew", a 12-minute

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In the Northeast



Mark Higgins with his well-earned trophy after completing more than 300 miles on his bike ride from Presque Isle to Falmouth.

Mark Higgins has done it again! The Second Mark Higgins Ride from Presque Isle to Falmouth (Maine), Sept 6 - 10, raised more than \$5,000 for PD research and lots of aware-

ness including television coverage all along the 300-mile route. Averaging about 70 miles a day, Mark, who was diagnosed at age 35, and for the past 16 years has defied his doctor's 5-10-year prediction until total disability, took up cross-county and downhill skiing, kayaking, climbing, hiking and flying ultra-light airplanes. He also hiked 350 miles of the Appalachian Trail three years ago. "He wanted to do the entire 2,160 miles from Georgia to Maine, but his wife Debbie nixed that," reports Falmouth Coordinator Lillian Scenna, "so he settled to stop in Virginia."

Things are busy and productive in neighboring Massachusetts, where more than \$100,000 was realized by three very successful summer events. The annual walk at the Reebok International Headquarters raised \$68,000 in June and two months later the 10th Annual Putt at the Sandy Burr Coun-



Multigenerational walkers circled the Reebok headquarters to raise dollars for PD research.

try Club raised another \$30,000 with the help from NFL, NHL, and American Baseball League celebrities. The "Summer of the Arts Exhibition" rounded out a busy summer for Cathi Thomas and Laura Bridges of the Boston I&R Center, still leaving them time for the Annual Winchester Symposium addressing, "Non-pharmacological Approaches to Caring for PD."

Dr. Cheryl Waters, movement disorder specialist, researcher and author from Columbia University, NYC, discussed "Parkinson's Disease: Exciting Advances & Emerging Treatments" at Connecticut's Lecture/Luncheon Se-

ries and Annual Awards Ceremony last month. The Chapter also awarded Robert Mandelkern its Volunteer of the Year Award and Andrew Spagnolletti the Caregiver of the Year Award during the luncheon.

The Long Island Chapter did it again with a bigger and more successful "Paws for Parkinson's" walk. More than 300 people and 120 furry friends raised approximately \$20,000. President Viginia Cravotta told the New York Times that it was a pet day with talent and dog costume contests and an agility course, and that all participating doggies got a thank-you card afterward.

APDA IS ALL IN THE FAMILY IN MEMPHIS TENNESSEE

APDA is literally a family affair in the Memphis, Tenn. home of Patrick and Gina Cici — and especially 20-month-old Nicolas Cici.

Gina has been the Memphis I&R coordinator since 1998, her husband Patrick has been president of the Mid-South Tennessee Chapter since April and Nicolas has been, since the I&R coordinator conference in Maine in 2003.

According to Patrick, a police officer for Memphis suburb of Bartlett, member of its SWAT team, and vice president of the local police association, he became president in order to see his wife more. Gina, however, reports that there is more to the story.

After the Chapter president resigned and the vice president passed away, it looked as if temporary dissolution was inevitable. But Patrick went to the rescue. "Pat knows a lot of people in the area and asked if he could give it a shot to keep the Chapter alive

until new officers could be enlisted," says Gina. "Of course, we were delighted."

And Nicolas? Well, Patrick was on Naval Reserve duty in Sicily in 2003, and Gina, who had arranged for care of their two daughters, Savannah and Natalie, now 7 and 4 respectively, thought that Maine would be a nice second honeymoon. "Pat flew in from Sicily and met me in Maine and we had a week before the conference." That year Gina returned to Memphis with the Salvatore Esposito, Sr. Award and, unknowingly, the to-be Nicolas.

When Gina announced in October, two months after the 2005 Presidents' & Coordinators' Conference in New York City, that their fourth child was on the way, the obviously question was, another APDA baby? But no, the new Cici is expected May 30, thus post conference. ■



Memphis I&R coordinator Gina Cici only has eyes for Mid-South Tennessee Chapter president Patrick Cici.



A really bonded Parkinson Dutch Lunch Bunch meets for its support group meeting to live up to its name.

In the Southeast

Here is the story of a support group that bonded so well that it created a pre-support group meeting meeting. **South Florida** coordinator Gigi Gilcrease reports that Milton Shapiro founded the "Parkinson Dutch Lunch Bunch" that meets before the monthly meeting wearing their APDA tee-shirts to increase awareness in their community and enjoy good food, good conversation and their long-lasting friendship.

In the Midwest

Welcome to APDA's 61st Chapter located in Madison, **Wisconsin**. Scott Glendenning, is the president.

There were no low-carb fanciers at Dianne Dallmann's Pancakes for the Parkinson's event in New Ulm, **Minnesota** — just lots of dough. Approximately 200 pancake eaters showed up at Applebee's restaurant in New Ulm in June for free pancakes and raised more than \$3,000 for the Chapter. Dianne's husband Gary, a retired college professor and coach, has stayed active since being diagnosed at age 50. Coordinator Paulette Olsen says the syrup on the pancakes was the front-

page coverage in the New Ulm Journal adding valuable publicity about PD. Midwest (**Illinois**) Chapter President Mary Anne Ostrenga is still reveling in the success of the Sept. 10 walk-a-thon that raised more than \$70,000. "We had a spectacular day, with more than 800 participants. What a fabulous

turnout, the spirit of the people attending was fantastic," she reports, and is busy planning next year's event, Sept. 9, 2006.

The 2005 **Chicago** area support group leaders' workshop and luncheon on Halloween addressed "Alternative Medicine: Helpful, Harmful or Hocus-Pocus?" The event, held at the Highland Park Hospital, explored wellness lifestyles and alternative ther-

apies as adjunctive treatment to traditional medical treatments.

St. Louis TV and radio personalities and community volunteers added to the success of the local chapter's "Broadway On The Runway" in September. Coordinator Susan Levin says more than 200 donated items including a handmade Victorian dollhouse made for a very successful silent auction.

In the West

The Los Angeles Chapter's 1920s-themed "Charleston Club and Casino" held at Hollywood's historic Wattles Mansion was a grand success with roaring '20s music and silent auction items including a vacation in France. ■

THE REAL BEAUTY OF THIS SPA DAY IS THAT PD RESEARCH BENEFITS



Last year Carol Lenz of Bellport, New York, entered and won the Ms. Senior New York pageant and went on to be a finalist in the Senior Ms. America pageant in Las Vegas. Carol was diagnosed with PD in 1994 and has dedicated her time, talents and efforts to raise funds for

Parkinson's research and awareness about the disease.

In July, she hosted a Body & Mind Spa Day at her home to benefit APDA research. More than 70 friends and friends of friends spent the beautiful morning learning massage techniques, practicing Yoga, having their tennis techniques evaluated by the Bellport Country Club tennis pro, exercising and learning movement routines before luncheon around the pool.

Above, Carol, center, posed with Ethel Bennett, NY State Pageant Director, Marie Mango, Ms. Senior NY State 2003; Maureen Smith Setton, NYS 2001 and 1st runner up in national competition; Sandy Greco, Ms. Senior America 2003-2004; Terri Stevens, NYS 2002 and Marleen Schuss, State co-director.

On page 8 Carol shares, "one of the most moving moments of my life," during the Senior Ms. America Pageant.

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The Journey of a Dream Realized

By Carol Lenz

The gift of unconditional love has carried me to magical places. Places I could only have dreamed about. With all the love, devotion and commitment of so many cherished friends, my life has been so enriched. I can hardly believe how fortunate I am. With each new experience I feel like a little girl with a basket filled with golden retriever puppies.

This glorious journey began two years ago with an article in the local newspaper about Ms. Senior New York and the exciting opportunities I might experience by entering the state pageant contest. This sounded like a perfect distraction for me at the time. The audition, the rehearsing, the preparation was exhausting but wonderful. I enjoyed every minute of it from the judges' interviews to the actual performance. Meeting and working with all the other contestants was an invaluable experience, and as I stood there among all the other contestants and heard my name called as the winner, I literally floated upstage to be crowned Ms. Senior New York 2004.

Nov. 24, 2004 — The National Pageant in Las Vegas. Unfathomable gowns, stage makeup, rehearsals, galas, dances, dinners, film crews backstage, state sashes, crowns, past queens, state and national directors. What a week!

Can you imagine one day I'm at home, unpacking groceries, picking up the dry cleaning, reading a book for my book club, stopping at the toy store to buy more trucks for my 2-year-old grandson, going to our Friday night movies and making plans for the holidays with our children, and the next moment I'm clicking my heels twice, closing my eyes, and there I am in my white suit,

sash and crown holding the microphone on the plane to Las Vegas singing the medley for the national pageant. Forty dear friends joined me. I called APDA's Las Vegas chapter and they came to add their support. How can it get any better? It can, and it did. National Pageant week with all its scheduled responsibilities was fun, exciting, educational and exhausting.

A typical morning:

Arise at 5:45 - 6:00 a.m. — shower, hair and makeup

7 - 8 a.m. — breakfast with all the state queens

8 a.m. - noon — rehearsals, talent, philosophy of life

Noon - 1 p.m. — lunch. After lunch, competitions, meetings and interviews with judges and alternating talent and philosophy of life.

I was very tired but very happy. My Sinemet and Requip were cooperating

and doing their jobs. The last day of competition, however, as we were lining up for our parade, the Sinemet and Requip suddenly went on strike with no warning and no time for negotiations. They just walked off the job and left me stranded without any dopamine — I froze. Unlike the Titanic, I was surrounded by every one of the state queens telling me in one clear voice, "We will help you. You can do it. It is very important to each and every one of us that you get up, and we'll walk out together." With all their hugs and kisses and prayers, we were on our way: they physically picked me up — two queens in front and two behind — and literally held me up as we got on stage. After awhile, my pills finally kicked in.

The gift of true friendship is that it takes us by the hand and reminds us that we are not alone in this journey of life! ■

Good People Make Good Things Happen *continued from page 5*

documentary narrated by Barbara.

In a recent zoo book entitled *A Guide To America's Best*, Allen Nyhuis calls the Good Zoo one of the top ten children's zoos in the United States.

In 1975, 10 years after the births of their sons, the Goods were blessed with two daughters — Jenny, who resides in Colorado, and Heidi, who lives in New York.

Larry and Barbara bring a thriving 46-year partnership to their new challenges. He lives his active life, and she does likewise. As a professional musician, she has a busy career, performing her popular cabaret shows, doing weddings and parties, being a featured entertainer at Oglebay as well as director of music and cantorial soloist at their congregation, Temple Shalom. Larry

takes tremendous pride and joy in her and her music and says "she is one of the finest cabaret singer-pianists around, with successful shows at The

Kennedy Center, in Paris, and wherever the muse calls." Barbara says that she doesn't see her Parkinson's caregiver role as a new or different role because, "every loving wife is always a caregiver."

Larry, who thinks it's funny that one of his medications directs "shake before taking," continues to beguile people with his sense of humor. With Barbara, their busy, interactive family, their memories and never-ending love of life, he is meeting his PD diagnosis with the same courage and strength with which he has met his other challenges. ■



The Goods enjoy the zoo dedicated as a memorial to their son Philip Mayer Good.

HOSPITAL HAZARDS

Most people make an assumption when they check into a hospital, they can trust its staff to take good care of them. But mistakes do happen, sometimes with serious or even fatal consequences.

A doctor, practicing for 35 years, didn't realize how dangerous hospitals can be until he was hospitalized for an angioplasty three years ago. An artery ruptured during the procedure, and he had to have emergency open-heart surgery to repair it. Then the doctor caught a nasty staph infection from an unsanitary catheter. To top it all off, the doctor developed phlebitis in his arm from repeated needle sticks. The swelling took months to heal.

This experience is not unique. Something similar could happen to you, but you can protect yourself if you know what to watch out for.

1 Identity Mistake. Being mistaken for another patient occurs more often than you might imagine. Once you get your room assignment, ask if another patient in the ward has a last name that's the same as, or similar to, your own. If so, ask to be moved to another ward. Such a request might raise a few eyebrows, but your life may be at stake.

As soon as you move into your room, post a sign with your name and room number directly over your bed. Ask a friend or family member to spend as much time with you as possible throughout your hospital stay, asking questions, insisting that you get proper care, etc. Your "patient advocate" should make it clear that he/she expects to be consulted on all treatment decisions. This persistence could save your life.

If you're having surgery it's not unheard of for surgeons to operate on the wrong side of the body, take out the wrong organ, etc. To avoid such errors, meet with your surgeon the night before surgery. Discuss the procedure in detail, including the exact body part being operated on. For absolute safety: be sure, a few hours before surgery, to use a felt-tip pen to write CUT HERE on the in-



cision site.

2 Catching an Infection. One in five people catches an infection while hospitalized. Each year 80,000 patients die as a result of such nosocomial infections. Staph infections can be deadly, especially if you come down with one of the antibiotic resistant strains.

What is the high incidence of hospital infections due to? Dirty hands and medical equipment are the usual culprits. Only one out of four doctors consistently washes his/her hands between patients. An even smaller portion wash their stethoscopes between patients, so much that the American Medical Association has issued a warning about "Killer Stethoscopes".

Wash your own hands frequently, and insist that all doctors and nurses wash their hands before touching you. Be polite, but don't worry about offending anyone.

Alert the staff immediately if your room seems dirty or if you run out of soap or paper towels. Make sure that any equipment that comes into contact with your skin has been swabbed with alcohol (or covered with a fresh disposable cover shield). This goes for stethoscopes, thermometers, otoscopes, infusion pumps, hemodialysis equipment and urinary catheters.

Because Intensive Care Unit (ICU) beds are so close to one another, infection risk is always greater in an ICU than in a private or semiprivate room.

3 Getting the Wrong Medication. A nurse might inadvertently give you

the wrong drug, or give you the right medicine at the wrong dose, wrong time or by the wrong route.

Each year, tens of thousands of hospital patients die as a result of such medication errors and account for 40 per cent of all adverse drug reactions in U.S. hospitals, according to a Harvard study.

Defense Measures: Learn the names, dosages, and correct administration route of any drugs prescribed for you. Check this information with the nurse each time you're given a medication. Learn the dosing schedule, too. Nurses sometimes fall behind schedule and have to be reminded.

If you're given a pill or liquid (or intravenous fluid) that differs from what you've been getting, double-check with the nurse before taking it.

Alert the nurse at once if you experience any untoward reaction to a drug such as pain or a burning sensation, shortness of breath, dizziness, confusion, tightness in your chest, numbness or itching. If you have any allergies, be sure they're listed on your medical chart.

4 Security. With all the hospital staffers, patients, family members, delivery people, etc., roaming the hospital, it's difficult for hospital security to keep track of everyone.

More than half of all hospital violence occurs in the emergency room (ER). One in three ER patients is armed, one in four is on some kind of illicit drug. While in the ER, don't talk or stare at anyone who is tense, loud or belligerent. Quietly alert a security guard or desk attendant. Hospital parking lots can be dangerous, too. If you feel nervous, ask a hospital security guard to escort you to and from your car. If you're staying in a hospital room, inquire ahead of time about security arrangements. Before going to sleep, make sure that the bathroom light is on and that the nurse call button is within easy reach. ■

Adapted from "How to Get out of the Hospital Alive", published in the December 2001 Issue of the Vermont Parkinsonian.

GETTING OFF TO A GOOD START

Talking with Charlie Lund about his 18 year effort to stay on top of Parkinson's disease brings to mind a sailor charting a course. He sets out on course, knows and applies the rules, makes small changes from time to time, but in the end, he maintains the course!

From the first day Charlie learned he had PD, he embarked on a plan. He reports he was blessed to have a wonderful neurologist to get him off on the right foot, saying with encouragement, "We can treat it!" "He gave me hope!" Charlie exclaims, "and I became his star pupil!"

Charlie says that living well with PD is no secret. It requires a positive attitude, regular exercise, great support, and good management of the medications. Charlie uses a videotape to do a 45 minute daily exercise at home and then rides his bike outdoors, weather permitting. Three days a week he goes to the fitness center to work out on the bike, swim in the pool, and relax in the hot tub.

Charlie feels that exercise is vital. Long ago he heard several physical therapists give a talk on Parkinson's disease. Upon hearing them comment that the people they see in the nursing homes arrive so deconditioned that it is difficult to initiate exercise at that stage, Charlie vowed to stay ahead of the Parkinson's by keeping fit. His daily workouts have kept him going.

Charlie attributes support from many people to his successful life with PD — support from his doctor, from his wife and his support groups. Charlie and Patricia have attended two Parkinson's support groups nearly every month since he attended his first one in December of 1998. Because they are so powerful for him, he even remembers the date when he went to his first group. "I enjoy it!

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Drugs Trials — The Placebo Effect

By J. Stephen Fink, MD, Ph.D.

A medication may have several effects on a patient. Some effects may be directly related to the medication's effect on the body's functions, which is called the pharmacological effect.

Another effect of a medication may not be linked directly to the medicine's pharmacological effect. This is called the placebo effect. A placebo effect can be observed when a pharmacologically inactive substance is administered.

What is the placebo effect, what does the placebo effect have to do with the process of developing new treatments or new medications in controlled clinical trials, what is the importance of the placebo effect for clinical trials in Parkinson's disease?

The word placebo comes from the Latin verb "placere," that means, "to please." Placebo is an inactive treatment and the placebo effect is the effect (usually beneficial) resulting from the administration of an inactive substance. When a patient receives any treatment (whether it is active or not) there may be a beneficial effect experienced by the patient just because there is an expectation of benefit. Placebo effects can result simply from contact with doctors or other health care providers, even in the mere act of interviewing or examining a patient. There may also be beneficial effects of additional treatment or improved care provided during the clinical trial of a new medication.

In addition to expectation of benefit, other contributors to this improvement in patients' symptom scores may include the tendency for patients to enter trials when their symptoms are worse, and

"bias" in the rater's scoring of patients symptoms.

The beneficial effect resulting from the act of receiving treatment may be quite powerful and long lasting. For example, in some studies of asthma and pain, there was improvement of 30-40

per cent in subjects given placebo (inactive) medications. The beneficial effect of receiving any treatment is not limited to medications, as the expectation of benefit alone

may lead to improvement in symptoms after surgical procedures as well.

The placebo effect can interfere with the assessment of whether a new medication or treatment is really beneficial. Therefore, when new medications are tested, they are commonly compared to an inactive treatment (placebo); this is a placebo-controlled trial.

When neither the patient nor the examiner knows whether the patient is receiving active treatment or placebo, the trial is referred to as "double-blind." When the subjects are assigned to active treatment or placebo groups by chance, this is called a randomized trial. Randomized, double blind, placebo-controlled trials offer the most effective way to control for the placebo effect and have become the "gold-standard" in clinical trial design for assessing new drugs or treatments. For a new medication or therapy to be considered effective, it must be shown to be better than a placebo in a double-blind, randomized, placebo-controlled trial. Sometimes therapies that are thought to be effective are no



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better than placebo when tested in this type of trial.

Long lasting placebo effects have been reported in Parkinson's disease. In some medication trials improvement in motor scores of 20-30 per cent in patients assigned to the placebo group has been observed for up to 6 months. Similarly, improvement and deterioration in Parkinson's disease patients have been observed after the introduction and discontinuation, respectively, of placebo medication.

Placebo effects appear to be particularly evident in the clinical trials of surgical therapies. In the double blind, clinical trial of human fetal transplantation in Parkinson's disease conducted by Fahn, Freed and colleagues, the control group received an "imitation" surgical procedure. Several of the patients in the control group rated themselves improved one year later. Similarly, 30 per cent improvement in motor scores in the placebo control (imitation surgery) patients was observed in the double-blind trial of porcine mesencephalic tissue. In this trial, improvement in the control group lasted at least 18 months, longer than had been previously observed in clinical trials of medications, suggesting that placebo effects may be stronger in clinical trials of surgical therapies.

What causes the placebo effect? It is not possible to test adequately for placebo effects in laboratory animal experiments because animals are not known to have responses to placebo. It has been assumed that the placebo

response is not mediated directly through a physical or chemical effect of treatment. However, a remarkable study by Jon Stoessl and colleagues demonstrated that the placebo effect in Parkinson's patients was accompanied by a release of brain dopamine from the remaining midbrain dopaminergic cells. This suggests that the improvement in motor function that is observed in the placebo groups of clinical trials in Parkinson's patients might be due, in part, to actual physiological changes in the damaged brain dopamine nerve cells.

In summary, the placebo effect is important in the testing of new medications for Parkinson's disease. It dictates the design of clinical trials of new medications by the inclusion of placebo groups. The placebo effect might be considered to "benefit" those Parkinson's disease patients who join clinical trials and are assigned to the placebo group, as they may demonstrate improvement in symptoms. Indeed, some of this improvement in symptoms in the placebo group may actually be due to beneficial changes in brain dopaminergic nerve cells.

This perspective underscores the often-spoken adage at Parkinson's disease centers: "One of the best things to do when a patient first learns of the diagnosis of Parkinson's disease is to join a clinical trial." Among the many benefits of such participation may be the placebo effect! ■

Adapted from "The Placebo Effect in Clinical Trials" by Stephen Fink, MD, Ph.D. in the Summer 2005 Young Parkinson's Newsletter.

THE WORLD PARKINSON CONGRESS WASHINGTON, D.C. FEBRUARY 22-26, 2006

Designed to bring the Parkinson's community together, this conference will enable patients and caregivers to:

- meet leading doctors, scientists and researchers from around the world
- talk with PD advocates about new research, clinical trials, coping and how to afford family care
- meet other patients, caregivers and families struggling with PD.

For more information call World Parkinson Congress, at —1.800.457.6676 or go to www.worldpdcongress.org

GETTING OFF TO A GOOD START

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"I learn things!" He feels people who join a support group realize that they are not alone. They learn how to take a positive attitude and to "exercise, exercise, to stay ahead of the disease."

Charlie also "gives back" by being a spokesperson for Parkinson's disease. "I am always willing to help out. I like to move forward, and I make a lot of friends that way."

Lastly, Charlie is inspired by his friends. They meet for coffee every day, take interest in him, and tell him how well he is doing! ■

Originally published in the Fall 2004 issue of the Minnesota Messenger, the APDA Minneapolis I&R Center Newsletter.

RASAGALINE

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For early disease, there is mild symptomatic improvement and neuroprotection, for late disease there is lessening of tremor and freezing spells. ■

Abstracted from the Fall 2004 Parkinson's Source, the APDA Pompano Beach, FL I&R Center Newsletter.



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, Japanese)
7. **Good Nutrition**
20-page booklet (English), new edition
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**
20-page booklet for patients and their families (English)
11. **My Mommy Has PD... But It's Okay!**
20-page booklet for young children.

EDUCATIONAL SUPPLEMENTS

Hospitalization; 34 Helpful Hints; Living Will; Helping Your Partner; Adapting to a Nursing Home; Comtan (Entacapone); The Treatment of Parkinson's Disease: Question and Answers; Comtan: Extending the Benefits of Levodopa; Comtan (Entacapone) Tablets and the Quality of Life in Patients with Parkinson's Disease; Caring for the Caregiver: Body, Mind and Spirit; The Family Unit; The Fine Art of "Recreating & Socialization" with PD; Medical Management of PD; Vision Problems and PD; Mirapex® in the Treatment of PD; Fatigue in Parkinson's Disease.

APDA WORLDWIDE WEB SITE

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

WORLD PARKINSON DISEASE ASSOCIATION WEB SITE

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

IS THE NEW MEDICARE DRUG BENEFIT RIGHT FOR YOU?

Starting January 1, 2006, Medicare will begin offering a new prescription drug benefit (Part D). Medicare prescription drug plans will only be available through private companies. Questions to consider before enrolling in a plan — as well as information about how the new benefit will affect existing coverage — can be found on Medicare Interactive, now available on the American Parkinson Disease Association Website.

Companies have great flexibility in how they can structure individual plan benefits. The monthly premium for the new drug benefit will average roughly \$35. Most plans will have deductibles (ranging from \$0 to \$250) and require members to pay co-payments or coinsurances. With all plans, after \$3,600 has been spent out-of-pocket — including the premium — Medicare will pick up 95 percent of the cost of prescription drugs.

Enrollment has begun and signing up after May 15, 2006 could bring a penalty fee.

Whether you should enroll in the new benefit depends on whether you have prescription drug coverage now, and the quality of that coverage. For more information to help you make an educated decision, go to Medicare Interactive at www.medicareinteractive.org/apda, or call 800 333 4114. ■

Materials concerning the research in the field of Parkinson's disease, and answers to readers' questions are solely for the information of the reader and should not be used for treatment purposes, but rather as a source for discussion with the patient's health provider.