

The American Parkinson Disease Association

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The American Parkinson Disease Association

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"What To Do?"

LONG TERM CARE VISITING TIPS

Lillian Scenna, LSW, Coordinator, APDA Information & Referral Center, Scarborough, ME

If your loved one is living in a long-term care facility, spending quality time during visits can be emotional and sometimes stressful. Whether you spend frequent time with your loved one or you're encouraging others to visit, here is a list of ideas that can enhance your visits and prove to be both meaningful and enjoyable for everyone involved.

Attending an activity with a loved one can also encourage an inactive resident to find pleasure in a regularly scheduled event. Your loved one will feel special if a visitor joins in the fun!

Provide your own activity.

What did your loved one like to do before long-term care placement? Go for a walk. Play cards. Throw a ball.

Listen to a ball game. Watch a favorite TV show together.

Have a picnic on the patio. Take along a pet.

Go for a ride.

Residents sometimes have little opportunity to see how the community has changed, to view the scenery, or to see their previous home. Such an outing brings back memories and enlarges the resident's world. Please be sure to clear the outing with the staff and also check with the staff for medication schedules and or transporting suggestions. Always let the facility know when you plan to return and keep the telephone number of the facility available in case of an emergency and in the event you may need staff to assist you.



Celebrate a special event.

A party is always out of the ordinary and fun. Your loved one can be the "guest of honor" for whatever occasion you wish to celebrate.

Go to lunch. Plan your visit around mealtime and enjoy a meal together to socialize while eating. Some facilities can order a guest tray (for a small cost or donation).

Look at pictures. Ask your loved one to identify and explain old pictures. Bring him or her up-to-date by showing and telling about your newer family members. Show your own vacation pictures, too.

Reminisce. Ask about the "old days" and learn something about your roots.

PAIN MEDICATIONS FOR PARKINSON'S PATIENTS

Pain can be controlled by medication, but all medications can have side effects. Narcotic medications like Vicodin (hydrocodone and acetaminophen) and Tylenol 3 (acetaminophen and codeine) can make you sleepy and irritate your stomach. Medications like Motrin (ibuprofen) and other aspirin-like medications can also irritate the stomach.

Many people can relieve the stomach irritation by taking the pain medication with a snack or after a meal. Always take medication with at least a half a glass of water to dissolve the medicine. If the medication still irritates the stomach, you can cut the tablet in half or quarters and take a portion every 20 to 30 minutes to decrease the irritation. Do not, however cut tablets that are designed to be long acting or dissolve over a long period of time. Even if the directions on the label state "take one to two tablets every four to six hours as needed for pain" that doesn't mean they have to be taken as a whole tablet or both tablets taken at the same time, if it irritates the stomach. In fact, it is best to use the lowest effective dose because there is no need to take any more medication than is necessary to control the pain. Since these medications can make you sleepy, they can slow your reaction time driving, and the effects can last for four to six hours. Always read the warning labels on your prescription

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PRESIDENT'S MESSAGE



Dear Readers,

Hope has many faces. Like Janus, the Roman god who guarded the gates of heaven, it must look backwards and forwards at the same time.

Yes, we know of the research breakthroughs that have taken place in recent years and the new medications, were developed and are in the final stages of testing. But where can we turn for hope here and now?

There is Charlotte Sanders, who recently bequeathed more than \$1 million to APDA. Her husband of 62 years, Joseph, died of complications of Parkinson's disease. Her generous gift is one of hope for future generations.

Also, there is 89-year old Belle Englander, president and the only remaining member of the J. Louis Blumberg Chapter in Philadelphia, who single-handedly sends more than \$30,000 to headquarters for PD research each year. Her inspirational dedication to the work of the organization shines like a beacon of hope.

You will notice that there is a new section in this newsletter called FYI. This includes news about the activities of our 63 chapters, 59 Information and Referral Centers, and more than 200-affiliated support groups across the country. This section will be the responsibility of the recently added communications director so that you can learn more about the commitments of these groups and individuals to "ease the burden and find the cure."

Our annual meeting in November was also an occasion of hope. Dr. Jacob Sage of our scientific advisory board, professor of neurology and director of movement disorders at Robert Wood Johnson Medical School, shared some of the research being done in three specific areas. Joel Gerstel, our executive director, announced that we surpassed \$11 million in revenues for the first time this year and a budget of more than \$2.5 for research. Patient support for the coming year was also increased by 10 percent. This represents a steady organizational growth at a time when other health-related charities are suffering a decline in revenue.

With science seeking and finding new medications, procedures and research potentials and people daily committing themselves to raising funds and awareness about Parkinson's disease, we can realistically look to the future with hope.

Sincerely,

Vincent N. Gattullo

“What To Do?”

Continued from Page 1

Use a notebook and record the answers for generations to come.

Share your talents. Are you learning something new? Practice your musical instrument or handiwork, crafts and see if your loved one has comments from one visit to the next.

Show and tell. What is new in your life? Are you excited about a new car, set of tools, dishes or even a new outfit? Take it in to show it off and ask your loved one’s opinion.

Help. Perhaps your loved one needs clothes or belongings marked with his/her identification. Go through the closet and drawers and label where things are kept. Usually closet space is tight; this may be an activity you can do together around the change of season.



Create a feeling. We all respond and do better when we feel approval and caring. Provide an atmosphere of pleasant concern and security. Find some way to give a compliment or something to appreciate. Remind your loved one how special he or she and how much you enjoy his/her company.

Touch. We all need physical contact with other human beings. Use your visiting opportunity to hold your loved one’s hand. Give affectionate and encouraging hugs and pats.

Give attention. Individual attention is a wonderful thing. Make sure your loved one knows that he/she has your

undivided attention. Look at him/her when he/ she speaks.

Be positive. Try to distract a complaining resident by bringing up a cheerful event, telling a joke or recalling a pleasant occasion. Do not get caught up in the negative aspects of residential living. May your visit bring a happy experience. Do not allow yourself to be bogged down with feelings of resentment, guilt or self-blaming. This is not helpful to you or to the resident.

Identify yourself. Sometimes it may be necessary to remind your loved one of your name and relationship with him/her. Even if your loved one has memory loss, he/she may not remember your name, but will always remember their feelings of love toward you.

Adhere to safety rules.

Because of the danger of fire, smoking may not be allowed or only allowed in a designated area. Help the facility to protect your loved one by retaining possession of cigarettes and matches.

Provide a special treat.

Sharing a favorite food is appreciated. But also be respectful for cleanliness and contamination. All foods must be not perishable and be contained in a sealed plastic or metal container if it is kept in the resident’s room. Label all items with the resident’s name and date. Make sure you check with the nurse or dietician for any possible dietary restrictions.

Participate. Consider being a part of the family group while visiting. Respect the new home of your loved one and other’s who live with him/her. If after your visit, you need additional support, visit your local Parkinson’s support group where you can find friendship and guidance. ■

PAIN MEDICATIONS

Continued from Page 2

bottles. The pain medication with least number of side effects for most people is Tylenol (acetaminophen). ■

This article was adapted from an A.G. Hammond, Pharm, D., article published in the PD Association of San Diego’s Parkinson Post, Winter 2003.



USE OF RASAGILINE IN PARKINSON’S DISEASE

Rasagiline is a new potent, second-generation, irreversible monoamine oxidase type-B (MAO-B) inhibitor that blocks the breakdown of dopamine. According to an abstract presented at the American Neurological Association (ANA) annual meeting in San Francisco, Rasagiline added to levodopa at 0.5 and 1.0 mg doses per day significantly reduced the total time when Parkinson’s disease (PD) symptoms were not controlled. The average reduction of “off” time was 1.85 hours daily for 1 mg rasagiline and 1.41 hour daily for 0.5 mg rasagiline, while placebo provided a reduction of 0.91 hours daily.

Rasagiline was well tolerated during the six months of controlled administration. ■

PD PATIENTS' REGISTRY FOR OFF PERIODS

Bertek Pharmaceuticals recently announced the launch of a nationwide registry for Parkinson's disease (PD) patients suffering from the "off" episodes associated with the disease.

There is currently little definite information about "off" episodes, and the establishment of a registry will help in filling a gap in the PD information base. Bertek plans to make the registry available through 500 movement disorders and general neurology clinics across the U.S.

Neurology clinics interested in enlisting in the registry may call 1-877-776-6787. ■

CAPS OFF OCCUPATIONAL, PHYSICAL AND SPEECH THERAPY

APDA was instrumental in President Bush's signing a law on Dec. 8, 2003, removing all caps on occupational, physical and speech therapy for the next two years and one month for all Medicare recipients. The therapy can be administered either at a hospital location or at an outpatient site. ■

NEW YORK CITY UNITY WALK

The 10th Parkinson's Unity Walk will take place in New York City's Central Park, Saturday, April 24, 2004. Click www.unity-walk.org, or call 1-866-789-9255 to sign up for this walk to raise awareness for Parkinson's disease and funds for research. ■

APOMORPHINE

Apomorphine is a drug that has been used in Europe for many years. At the present time apomorphine is being tested in clinical trials in the United States. It has a strong agonist effect, many times greater than the current dopamine agonists. It can be used by subcutaneous injection or infusion route and some studies have tried to use it in a sublingual or an intranasal form. Its maximum plasma level is reached as early as 10 minutes and its half-life is about 35 minutes. The duration of its effect is variable in each patient

but it lasts up to 90 minutes. In patients who have confusion, disorientation and dementia and other neuropsychiatric symptoms, this drug can be used carefully and is very effective for off episodes. It is a rescue drug because it can be dosed as the patient is just going off or is near off. It has its onset of benefit very quickly. It reduces off time and it has been shown to improve activities of daily living and quality of life. The onset of improvement in the UPDRS scores is usually within 10 minutes. In clinical studies it showed that it can be effective as long as 90 minutes in some cases. When clinical trials were done, 95% of the off events were reversed. It is not shown to lose its efficacy with repeated use. Adverse events can be seen and they are usually nausea, vomiting, excessive drooling, rhinorrhea, hypotension, sedation or somnolence and also skin changes. Injections may cause skin bruising and also nodules. There are some rare reported cases of skin necrosis. There is also a contraindication

in patients that are allergic to sulfites. Oftentimes Tigan and in other countries, Domperidone, has to be used for the nausea that occurs with the initial usage of apomorphine. It is usually given three days before at 300 mg t.i.d. and the dosing may be able to be reduced after a number of days. Yawning is also a side effect that occurs as is dyskinesias, since without question with the use of this drug, especially if the patient gets dyskinesias from L-dopa, they will get dyskinesias with the use of apomorphine. Dizziness can occur

and there have been a small number of cases that have chest pain, pressure and angina. Hallucinations and confusion have also been reported.

Subcutaneous apomorphine is very effective in reversing acute off episodes and results can be seen as quickly as in 10 minutes or less. On initiating the treatment blood pressures must be carefully monitored, a 2 mg test

dose is used, and the blood pressure monitored. If patients develop significant orthostatic hypotension with the first test dose of 2 mg, they are not candidates for apomorphine. The drug can be increased in 1 mg increments, but blood pressures should be definitely monitored. The degree of improvement in the Parkinson symptoms or the anti-Parkinson effect is usually equivalent to the benefit of the L-dopa dose that the patient is already obtaining. One of the great benefits of apomorphine may be the ability to delay or avoid deep brain stimulation. ■

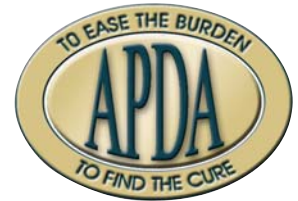
Note: This article by Dee Silver, MD was published in the PD Association of San Diego's Parkinson Post, Winter 2003.



... "It reduces off time and it has shown to improve activities of daily living and quality of life."



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

WINTER 2004

VOLUME XI NO. 1

A PROFILE *Belle Blumberg Englander*

Meet the Philadelphia chapter of APDA. She's just a bit over 5 feet tall, has glaucoma, works from a white plastic milk box in her dining room lined with family pictures, and sends about \$30,000 a year for Parkinson research.

That's right, 89-year-old Belle Englander is the only remaining member of the 42-year-old J. Louis Blumberg Chapter, and blessed with the tenacity of her father in whose memory the chapter was named, she intends to continue to do so for years to come.

Her father died in 1964, never knowing what his disorder was. "Whatever this is that I have, I will never let it be my boss or change my life," were his words to his family, who believes his onset may have been as early as 1950.

"The tremors didn't stop him from continuing his auto-repair supplies company, becoming a Mason and rising to Grand Master. He was never embarrassed. He attended lunches and asked someone to cut his meat.



Belle Englander, Dr. Howard Hurtig, and Pennsylvania State Senator Allyson Schwartz, at a 1992 event at Graduate Hospital, Philadelphia.

He went up the steps in his house skipping one. He only asked his wife of 52 years for help dressing when he could no longer use zippers or buttons on his shirts," Belle says showing the same family pride.

The chapter was started in her father's home in 1965 with her aunt Rebecca as its first president.

(It was Rebecca who had moved to New York and discovered through APDA that her brother's symptoms were those of Parkinson's disease.)

Family members invited everyone who would come, greeting people at the door and offering free refreshments. From about 10 people its number grew to about 50, demanding a move to larger quarters at the William Penn House, where it was given free meeting space. Its final meeting place was Graduate Hospital.

"We never had dues, and everyone was encouraged to come and share experiences," Belle remembers. "I served as public relations person, arranged for speakers, and planned parties and trips. We sold greeting cards to raise funds." Her husband, Horace, was treasurer. With changing times, people moved or passed away and only Belle remained.

Today, she is listed in the Philadelphia telephone book as the Parkinson's disease contact, receives and acknowledges memorial gifts, and offers support to all who call. Her sister, Tossi, who was flower girl at her wedding, assists her, and Tossi's husband, Leon Aaron, volunteers with his computer as treasurer.

"How can I give up?" asks Belle. "How can you give up on something that is so much in your heart? We must all keep working to find a cure." ■

FOUR NEW CHAPTERS LAUNCHED

APDA welcomed four new chapters during 2003, one in Minnesota, one in Tennessee and two in California, bringing the number nationally to 63. The new chapters and the presidents are: Minnesota Chapter in St. Paul, Anita Nessbaum, anita436@yahoo.com; Mid-South Tennessee Chapter in Germantown, Linda Allen, bcsartain@aol.com; Greater Los Angeles, Mark Siegel, markus1952@hotmail.com; and Bay Area Chapter in San Francisco, Thomas O'Brien, bayareaapda@yahoo.com. ■

In the Northwest

Editor's Note: Reporters' names are in bold face type.

Clipping may cost 15 yards on a football field, but it earned dollars for Parkinson research in 57 Great Clips hair salons in Washington Oct. 18-24. **Washington State Chapter** president **Celia Grether** happily announced that this second hair-raising event topped last year's \$12,000 as well as raising awareness about PD.

The chapter's 19th annual Symposium for Persons with Parkinson's attracted more than 250 people to the Shoreline Conference Center on Nov. 1.

In the South

Despite the rain, more than 300 people turned out to hear Dr. Ray Watts, chairman of the University of Alabama's Department of Neurology and APDA Scientific Advisory Board member, speak at the **Birmingham Chapter's** Patient and Family Symposium, Sept. 21, at the university. Chapter president **Paul E. Haynes** reports that following a luncheon, participants benefited from an unlimited Q&A period with a panel of neurologists and research specialists. The chapter's annual fashion show, sponsored by the Newcomers' Club of Birmingham, recorded its 11th annual success on Oct. 10. The fashions from Parisian's Department Store drew "oohs" and "ahhs" from more than 350 people as they were paraded down a runway at the Wynfred Hotel. **Atlanta Chapter** launched its first

"Comic Relief Gala" at the Georgian Terrace Hotel, Sept. 19. Actor, comedian and longtime chapter friend Rob Cleveland gave a special performance and WSB-TV's Monica Kaufman was the MC. **Kathy Edwards** noted that the evening included hors d'oeuvres, a silent auction, and tribute to Dr. Ray Watts, and raised \$9,000 to benefit the chapter's respite program.

Suncoast Chapter president **Ginny Bernard** welcomes anyone visiting the Tampa Bay area this winter to the St. Petersburg Support Group, which meets the 2nd & 4th Monday of each month. With a successful mini-symposium in November, the group is now planning its annual Walk-A-Thon, March 27.

In the Midwest

The Midwest meets the press and looks really good in print. **Maxine Dust**, **Midwest Chapter** president, says response to the three-page Pioneer Press spread has been excellent, and has certainly achieved its purpose of raising pub-

lic awareness about PD and promoting the work of the chapter and I&R center.

The chapter is gearing up for its annual educational symposium March 20, at the Oakbrook, Ill. Marriott, at which APDA Scientific Advisory Board chairman Dr. Frederick Wooten will speak. The theme is "Live Your Best Life." And details are available at 847-724-7087, or cacapda@aol.com.

Meanwhile the **Midwest Regional I&R Center's** Support Group Leader's Conference reached an attendance record Oct. 21, at Glenbrook Hospital. According to coordinator Susan Reese, more than 38 participants heard an update by movement disorders specialist Dr. Kathy Kujawa, and saw a presentation of caregiver respite programs available in Illinois and Indiana in addition to the APDA chapter's program. Presentations from various vendors who offer services for "easing the burden" for patients and families, networking, idea sharing and prizes followed lunch.

St. Louis Chapter has been busy. Even the Aug. 18th blazing sun could not deter Chairman Brook Dubman and his committee Shari

APDA AND YOPA JOIN EFFORTS

APDA and the Young Onset Parkinson's Association (YOPA) have announced an agreement of mutual cooperation in their efforts to fight the degenerative neurological disease that affects more than 150,000 young Americans under age 50.

YOPA, whose mission is to raise public awareness and to offer support to those living with young onset Parkinson's disease, is composed of more than 1,000 young onset patients from across the United States.

The leaders of both organizations expressed hope that their cooperative efforts will aid the younger generation of Parkinson's patients in finding the support it needs. The two groups have joined to hold the second annual Parkinson's Awareness Walk and Symposium in Albuquerque, NM, and are planning a spring gala, April 23, in Martinsville, NJ. ■

Rakestraw, Ed Schneider, Christine Sadler, Lisa Price and Trish Welsh Saleeby from leading more than 100 golfers to the Lake Forest Country Club's links and the annual Nat Dubman Golf Classic and auction. Proceeds benefit PD research at Washington University School of Medicine.

The inspirational life of legendary sports announcer Jack Buck, who had PD but lived his life to the fullest, was the impetus for the APDA Celebrity Fashion Show and Luncheon, Sept. 22, at the Hilton Hotel. While TV and radio personalities and community volunteers graced the runway in today's hot fashions, it was St. Louis Cardinal mascot "Fred Bird" who stole the show to the delight of the more than 600 guests.



St. Louis Cardinal mascot, Fred Bird, parades his finery during the St. Louis fashion show.

Around the World" sponsored by the Dallas Market Center and Market Center Rotary Club, they have already scheduled the 2004 run for Nov. 6. Former FYI editor and APDA director **Fred Greene** notes that the event is made possible by the generosity of supporting sponsors World Savings, KRLD NewsRadio 1080, Presbyterian Hospital of Dallas, Luke's Locker, GlaxoSmith-Kline, Signature Athletic Club, Feizy Rugs, Pfizer, Southwest Airlines, the U.S. Postal Service, RBC Dain

Rauscher, Prestige Lincoln Mercury, Micro Center, D&M Leasing, Medtroic, Novartis, Oggetti Imports and Adolph's Coffee.

The 2004 Greer Garson-E.E. Fogelson Humanitarian Award will be presented to the family of Anne C. Slicker in recognition of the Anne C. Slicker Early Parkinson's Detection Center at Dallas's Presbyterian Hospital, directed by I&R medical director Dr. Malcolm

Stewart. The award will be made at the Greer Garson Gala April 17th at the Fairmount Hotel. The award is named for the actress and her husband Buddy, who died of complications from Parkinson's disease. The inaugural award was presented to former Arizona congressman Morris "Mo" Udall, who remained in Congress while suffering from PD and whose name adorns the Udall Parkinson's Education and Research legislation. Margot and Ross Perot and Bette Perot were honored in 2002 and Nancy Hamon, Ms. Garson's long-time friend who recently made a \$3 million gift to support PD research, was honored in 2003.



Greater Los Angeles may be one of the newest chapters, but it is a busy one. **Chapter President Mark Siegel** reports that the chapter is working to have a bill passed in the state legislature requiring a mandatory registry. For a variation on the lobbying theme, the chapter had LA City Council members join in a "Karaoke for Cure" fund-raiser on Jan. 22.

In the Southwest

Bob Dunagan and the **New Mexico Chapter** enjoyed their second annual Awareness Fund-raiser Walk and Raffle in cooperation with the Young Onset Parkinsons Association as much as raising the \$5,000 for support research. Congressman Tom Udall and about 60 walkers participated in a 1/4 mile or 1K walk on Oct. 11th at Albuquerque's Presbyterian Healthplex. The congressman urged attendees to stay in contact with their public officials regarding PD research.

The **Dallas Chapter and I&R Center** don't sit on their laurels. After a very successful "Run

APDA RECEIVES \$1 MILLION BEQUEST

Charlotte B. Sanders, a former high fashion model, gourmet cook, lavish hostess, and widow of a Parkinson's disease patient, made a testamentary gift of more than \$1 million to the American Parkinson Disease Association (APDA). She was 101 years old at the time of her death, June 12, in her Landsdowne, Pa., home, where she had lived for more than 60 years.

Mrs. Sanders was born in Baltimore, Md., and moved to the Philadelphia suburb with her husband of 62 years, Joseph, who was a boxer and later the owner of an exclusive Philadelphia men's health club. He died of associated complications of Parkinson's disease in 1991.

Together, the Sanders traveled the world, she collecting recipes from internationally renowned chefs and putting them to use in her famous theme parties, which she hosted until late in her 80s. ■

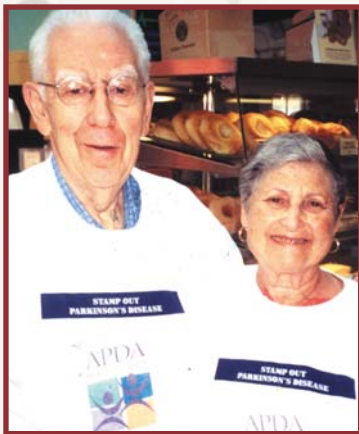
Orange County Chapter's first fundraiser, "All That Jazz," was a sold-out dinner dance event that raised \$80,000 while increasing awareness about PD and APDA. The event was held at the Aquarium of the Pacific in Long Beach on Sept. 20.

In the East

The Salvatore and Elena Esposito Chapter launched the Salvatore J.

Esposito, Jr. Memorial Parkinson's Disease Lecture, Oct. 1, at Staten Island University Hospital, where he served as a trustee. Dr. Allen Perel, the Staten Island I&R center medical director and the hospital's neurology director, was the presenter.

Coordinator Diane Lee says the center intends to make the lecture an annual event for patients and their families. Mr. Esposito was a member of APDA's founding family and served as president and secretary of the board of directors. He



Bob and June Mandelkern begin their lucrative walk to "Stamp Out Parkinson's Disease Walk."

died in August. Wendall Daugherty and his wife, Mil, have taken on the tasks of president and vice president of the **Delmarva Chapter** — ending not just an administration, but an era. **Will Johnston** served as president, vice president and held other chapter offices for the past 12 years. His wife, Mary Margaret, who served as treasurer in recent

years, turned the secretary/treasurer tasks over to Roberta Duffy. The Johnstons will be relocating to Texas. Will, who is also a writer and editor, mailed the 77th edition of The Parkinson's Newsletter of the Delmarva Chapter in November, ending its 11-year circulation.

Canine capers have given a new dimension to the traditional walk-a-thon. **Virginia Cravotta** introduced the Paws for Parkinson walk for the Oct. 26, **Suffolk County**



The dogs of Suffolk County are barking up the right tree — raising funds for PD research.

Chapter event in Marjorie Post Park, Massapequa, NY. Despite the torrential rains, many pooches came in costume, as did

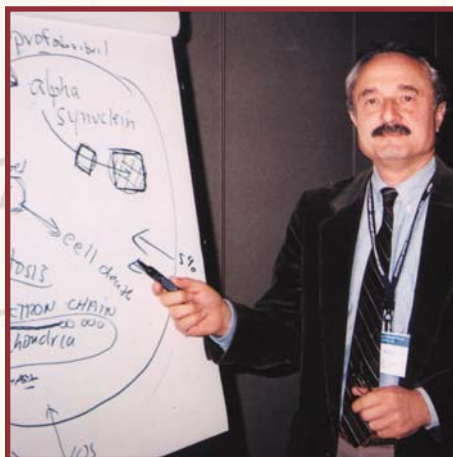
the humans they brought along with them, keeping the Halloween theme. Information tables, demonstrations by guide dogs and rescuer dogs, obedience training and adoptable residents of local shelters all added to the damp but successful day.

Donna Diaz, **Connecticut I&R Center** coordinator, reports that more than 300 participants enjoyed the festivities of the Connecticut chapter's Walk-A-Thon 2003 "Stamp Out Parkinson's Disease Walk," which included health checks, refreshments and door prizes. Among the walkers were Bob and June Mandelkern of West Hartford. Bob embarked on a letter-writing campaign to family and friends and collected more than \$1,300 plus matching funds. ■

ANNUAL MEETING 2003



Director Robert Meeker from Tucson, AZ, and his wife, Dorothy, are ready for the beginning of the morning session.



Scientific Advisory Board member and Robert Wood Johnson Medical School professor of neurology Dr. Jacob I. Sage explains the PD process in the brain.



Director Dorothy Reimers of Chesterfield, Mo., with executive committee member Michael Prietrangelo, Esq. presents a check to President Vincent N. Gattullo during the luncheon.

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 husband has had Parkinson's disease for four years. He is taking Sinemet 25/100 and Permax .25 mg. three times daily. He is beginning to experience a return of tremors and fatigue in the afternoon and evening. What should he do?

A: Your husband is experiencing wear-off periods in which the medications are not sufficient to treat the PD symptoms. This is common because the amount of dopamine production continues to decline as a patient ages. There are many things that can be done to treat this recurrence of symptoms. Comtan can be added, if the patient did not have gastrointestinal problems in the past. Sinemet CR and Eldepryl could be added. I would keep the Eldepryl to one a day, if there is insomnia. I would not increase the Permax dose, if the patient's blood pressure is low unless I planned to add medications to elevate the blood pressure. The present Sinemet and Permax doses could be given four times a day instead of three. Artane or Symmetrel could be added, although these medications can cause blurry vision, urine retention, memory loss, or leg edema. If the patient is otherwise young and healthy, I would probably increase the dopamine agonist, lower the

Sinemet, and add Comtan and Eldepryl. If the patient is older and had numerous medical problems, I would probably just increase the dose frequency. As you can see, there are many answers to your question and the best answer depends on attention to details regarding the patient's past medical history.

Q: My wife was diagnosed with PD two years ago. She is now 78 years old. The neurologist put her on Mirapex. She began to hallucinate and was hospitalized and given Haldol. She then became rigid and withdrawn. She only had a left arm tremor and now she is a real mess.

A: Many physicians attend seminars in which the best way to treat a newly diagnosed PD patient is discussed. The difference in the effects of each dopamine agonist is usually not recognized. Typically we prefer to use dopamine agonists like Mirapex in younger, healthy patients. In terms of hallucination potential, Mirapex has more than Requip, which has more than Permax. In terms of a benefit in mood and motivation, Mirapex has more than Requip, which has more than Permax. In terms of strength per mg. in improvement in motor symptoms, Permax has the most. And most important, it is not stressed that older patients do not tolerate dopamine agonists as easily

as younger patients. Therefore, even though it is correct to start a newly diagnosed patient on Mirapex, it was not correct in your wife's case because this led to hallucinations and psychosis. Your wife should be placed on low dose immediate-release Sinemet given during the day with the last dose in the early evening. Seroquel could be used to reduce any hallucinations.

Q: What are the next new medications to be released for PD treatment?

A: Rasagiline may be the next medications out for PD. It is stronger than Eldepryl (selegiline) and does not break down into amphetamines. As with Eldepryl, it helps to reduce the off periods and may delay disease progression. Sumanitrole is an oral dopamine agonist, which has more physical benefit than Permax, less hallucination potential than Mirapex or Requip and less side effects than Permax. It should be out within two years. I am most excited about the patch. The Rotigotine skin patch seems to be working extremely well in clinical trials and hopefully will be available within three years. This medication is administered in a continuous release form across the skin and is highly effective in reducing the "on/off" fluctuations. I believe it will be the greatest advance in the treatment of PD since the introduction of L-Dopa in the mid-1960's. ■ 9

CHARITABLE GIFT ANNUITIES OFFER FLEXIBILITY AND SECURITY

Charitable giving doesn't have to be a one-way experience, explaining why charitable gift annuities have become increasingly popular with people in a variety of tax brackets.

A charitable gift annuity is a contract between a donor and a charity such as the American Parkinson Disease Association, allowing for a stream of payments to flow back to the donor while generating valuable income tax benefits.

The donor makes a gift with a guarantee of receiving regular, fixed payments for the rest of his/her life and/or the life of another person, usually a spouse or a sibling. The organization receives a substantial gift to support its mission.

The benefits to the donor are numerous:

- Guaranteed established payments to the donor and/or designee for life
- An immediate income tax deduction because the annuity is treated in part as a gift and in part as purchase of an annuity
- Partially tax-free income, in most cases, because the annuity payment is considered a return on principal
- Possible estate tax savings by using what would otherwise be taxable assets to fund the annuity
- Partial capital gains tax savings, if the assets used to create the annuity are appreciated securities such as stocks or bonds

Payments from the annuity can begin immediately or, as many people choose, postponed to begin at the time of their retirement assuring supplemental income to their social security

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Preventing Falls

William Samuel, M.D., Ph.D., Southwest Neurology, Escondido, CA

The likelihood of falls resulting in injury greatly increases with age. Main risk factors for falls include arthritis, poor vision, general frailty, multiple medications, faints and near-faints, and the problems with walking and balance that are so often seen in Parkinson's disease (PD) and other movement disorders.

Both PD, as well as the medications used to treat it, can increase a person's fall risk. Sometimes a new medication is needed to treat a progression in PD symptoms or to address a specific problem such as dizziness when standing up, but all medications can potentially cause unwanted side effects.

When falls have occurred or seem imminent, there are a few practical preventive steps that can be taken:

Suggestion 1. Consider the circumstances of falls (e.g., getting up from low armless chairs) and the possibilities for changing habits to avoid repeat performances.

Suggestion 2. Limit the number of prescription medications to less than 5, and reduce doses of, or discontinue altogether, sleepers, antipsychotics, and antidepressants whenever possible — keeping in mind that medications are generally prescribed to address medical issues, so reducing them may not be so easy.

Suggestion 3. Check vision, at least annually, for correctable decrease in acuity, including cataracts and glaucoma.

Suggestion 4. Ask your primary care physician to look for postural changes in blood pressure, and if present, consider increasing fluid intake, relaxing salt restrictions, using compression stockings, or adjusting medications.

Suggestion 5. Ask your primary care physician for a detailed musculoskeletal exam, or for a referral to a physical therapist for the exam, emphasizing strength and coordination as they affect balance and gait.

Suggestion 6. Ask your primary care physician to consider a referral to a neurologist to look for peripheral neuropathy or signs of unsuspected

strokes, or middle-ear dysfunction.

Suggestion 7. Ask your primary M.D. to consider a referral to a cardiologist to look for faints due to transient irregular heart rhythm, valvular heart diseases, and so forth.

Suggestion 8. Modify your home environment to provide night lights, nonslip bath mats, stair rails, and remove hazards such as loose rugs. The stooped posture characteristic of PD can itself be a fall risk.

Exercises with supervision from a physical therapist may help:

Suggestion 1. Stand with arms behind your back and grab the left wrist with the right hand and pull down to straighten the spine: 20 repetitions, three times a day.

Suggestion 2. Use a chinning bar to pull yourself erect without actually lifting your feet off the floor: 10 reps, two times a day.

Suggestion 3. Consider the use of a shoulder high walking stick instead of a cane to keep the spine straighter, but be careful that this does not worsen your balance.

Suggestion 4. If you use a walker, be sure the handles are high enough to keep the spine straight without compromising your balance.

The tendency for PD patients to "freeze" in certain situations, or at times when their response to medications goes "off", can cause anxiety which only worsens the problem. Here are some tricks:

1. Take a few deep breaths to try to relax when freezing occurs.
2. Try to straighten the spine.
3. Pretend you are stepping across an imaginary line on the floor.
4. Identify settings where freezing occurs, and try to avoid them.

A visit to a neurologist can help rule in or rule out most of the foregoing possibilities, and to review the current mix of medications used to manage Parkinson symptoms. ■

This article was originally published in the Parkinson Post, San Diego, CA, Spring 2003.

Support is Right Around the Corner!

Lillian Scenna, LSW, Coordinator, APDA Information & Referral Center, Scarborough, ME

Parkinson's disease (PD) is one of the most baffling and complex neurological disorders. Afflicting more than 1.5 million people nationally, this progressive disorder of the central nervous system has touched a growing number of lives.

PD becomes evident when the nerve cells in a certain part of the brain die or stop working properly. These cells stop producing dopamine, an important brain chemical responsible for transmitting signals between nerve endings. People with Parkinson's disease do not have enough dopamine, and messages fail to travel across the nerve endings properly. This results in lack of control of everyday movements and/or uncontrollable shaking or tremors.

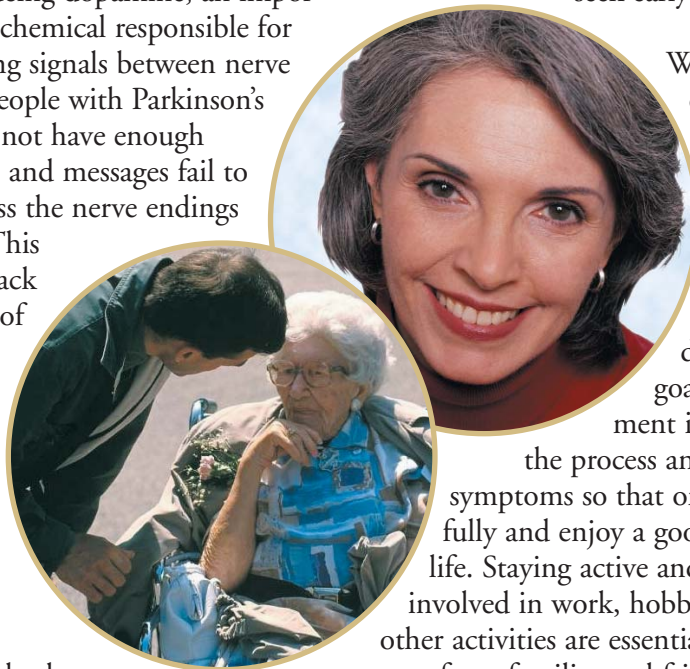
PD affects both men and women, however men have a slightly higher incidence. Although this disease occurs more often in the elderly, 10 percent of sufferers are in their 50s or even younger.

Tremors, rhythmic shaking, muscle stiffness, slow movements and difficulty walking are the major symptoms. Since the symptoms do not follow a natural progression, an accurate diagnosis can be difficult. In the earliest stages of this disease, symptoms may be slight and may even go unnoticed. Additionally, people with PD may show other signs including:

- difficulty with handwriting
- difficulty speaking clearly

- speaking softly
- loss of balance

Although there are no definitive laboratory or other diagnostic tests on for a PD diagnosis, there are some to rule out other diseases. Because this disease can carry both a physical and social stigma in the eye of the patient, neurological degeneration can be made worse by the refusal to seek early help.



What actually causes Parkinson's is still unknown. Because it is a slowly progressive disease, the goal of treatment is to slow

the process and relieve symptoms so that one can live fully and enjoy a good quality of life. Staying active and keeping involved in work, hobbies and other activities are essential. Seek support from families and friends and/or join a support group.

Thanks to the efforts of the American Parkinson Disease Association, Inc. (APDA), we are very fortunate to have the APDA Information and Referral Centers and support groups for families suffering from Parkinson's disease. Each center offers a lending library of books and videotapes, pamphlets, support group information, and a professional coordinator to assist families. If you or someone you know suffers from Parkinson's Disease, call or visit the APDA Information & Referral Center closest to you. It is there for you! 1 (888) 400-APDA (2732). ■

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and retirement payments for life.

The amount of the payments depends on the donor's age. (Because rates are based upon life expectancy, older annuitants will receive higher rates than younger ones.) All charitable organizations are free to set the rates that they offer as long as they comply with any applicable state regulations. The payments are fixed at the time the annuity is created and cannot be changed, and the annuity cannot be revoked once established.

Because the gift annuity provides a reliable income for life, it is a valuable financial planning tool while providing the satisfaction of assisting in the work of a favorite charity.

To obtain a copy of our brochure or for further information, please contact Joel Gerstel, 1-800-223-2732. ■

“FAMILY CAREGIVING IN A CHANGING WORLD”

A conference sponsored by the United Hospital Fund, is scheduled for March 4-5, 2004, at the CUNY Graduate Center, 365 Fifth Ave., New York City. The conference will include first-person accounts by family caregivers, reports about new research from the Fund's Families and Health Care Project, program innovations, a policy roundtable, a theatrical presentation, and other sessions. The conference is designed for family caregivers and professionals. For more information, contact: Hollis Holmes at (212) 494-0761 or hholmes@uhfnyc.org. The fee is \$95. for clinicians, \$50. for caregivers. ■

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 and others

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

HANDBOOK FOR LONG-DISTANCE CAREGIVERS

Family Caregiver Alliance (FCA) has released its new "Handbook for Long-Distance Caregivers," a guide for families and friends caring for ill or elderly loved ones.

According to the FCA Executive Director, "families don't really know where to start when a parent or other family member becomes frail or has cognitive problems from Alzheimer's disease, PD or stroke and it's especially difficult when they live far away.

The Baby Boomers are aging; women are in the workplace and not available to provide daily care as in the past; and a mobile society has left families separated, sometimes by thousands of miles.

Families just need to know where to look. This is where they can start

- assessing the care situation
- developing a care team
- holding a family meeting
- accessing community organizations and private agencies
- balancing work and eldercare
- locating reliable online information on concerns including paying for care, eligibility for public benefits, volunteer help, making decisions about relocation, and dealing with driving and dementia.

The handbook is available free on the FCA website, at www.caregiver.org. It is also available in print from the Family Caregiver Alliance, 690 Market St., Ste. 600, San Francisco, CA 94104. ■

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.

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