



Parkinson UPDATE

Providing Help and Hope to the National Capital Area Parkinson Community

7913 Westpark Drive, Suite 101 • McLean, VA 22102 • 703-891-0821 • www.parkinsonfoundation.org

Spring 2006

Happenings

Community Lecture Series

Held at the Epiphany Byzantine Church, 3410 Woodburn Road in Annandale, Va

Doors open at 6:30, program begins at 7:00.

This is the only written notice—please mark your calendars!!

April 12, 2006

Topic: Occupational Therapy & PD: Skills for the Job of Living
Speaker: Connie Ten Eyck, Dir. of Occupational Therapy Virginia Hospital Center's Outpatient Rehabilitation Center

May 10, 2006

Topic: Exercise and PD: The Key to Functional Fitness
Speaker: Cheryl Bartholomew Seniors 'N Sync, LLC

June 14, 2006

Topic: Metro is Accessible Outreach Project
Speaker: Rikki S. Epstein, ADA Project Officer, Washington Metropolitan Area Transit Authority

July 12, 2006

Topic: PD & DBS: Panel of Patients (*Surprise special guests possible. Come see!*)

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Studies Hint at Placebos' Potential

By Melanie Leitner

Note: Reprinted with permission of the Dana Foundation. This article appeared in the January-February, 2006 issue of BrainWork: The Neuroscience Newsletter.

Researchers have often viewed the placebo effect as a confounding factor in clinical trials, and thus have tried to minimize it. Now some are taking the opposite approach and studying how the placebo effect occurs and could be harnessed to help with treatment.

The placebo effect is a beneficial health effect experienced by an individual that appears to occur because of the individual's beliefs or expectations, rather than by effecting chemical or biological changes. Trust in caregivers and faith in the medical process, for example, can help a patient benefit from a pill or a procedure that should not make a difference on its own.

In the past few years, neuroimaging researchers have identified significant changes in the brain's activity resulting from placebos. Others, studying the brain chemistry, have also begun to unravel the placebo response. At the conference, researchers discussed recent findings regarding what is happening in the brains of individuals experiencing the placebo effect, focusing in particular on studies of placebo responses in Parkinson's disease, depression, and pain conditions.

Fabrizio Benedetti, a neuroscience professor at the University of Torino Medical School in Italy, presented the results of several studies aimed at dissociating a given treatment's biological effects from its psychosocial context: the words of a patient's doctor, the hospital environment, and a patient's expectations of improvement, for example.

Benedetti and his colleagues showed that in some patients with Parkinson's

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Parkinson Foundation of the National Capital Area

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The goal of the *Parkinson Update* is to report medical information to the general reader in a timely and accurate fashion, as well as to provide information about our organization and its activities. *Parkinson Update* content is not intended to provide medical advice, which should be obtained directly from a physician or medical professional. We enjoy providing information for you to further investigate and interpret. Thanks for reading.

Open Call for Submissions

PFNCA invites and encourages its readers to submit articles, announcements and other items to the *Parkinson Update*. Submissions can be mailed to the above address, emailed to info@parkinsonfoundation.org, or faxed to (703) 891-0824. PFNCA reserves the right to refuse to print submitted items or to edit them as necessary.



Co-Chair's Message Hail & Farewell

By Alice Gross

We are thrilled to welcome two new talented board members, Ted Halpern and Bert King. Their expertise and experience will provide PFNCA with much needed financial advice as well as experience in board development.

For the last 14 years, Ted has been an investment advisor who runs his own incorporated company. A graduate of the University of Maryland with dual degrees in finance and economics, Ted has had experience with a wide variety of investment products and has brought to the board's attention several fundraising approaches that have not previously been considered. We are delighted that he has time for us, as his almost three-year-old twins keep him and his wife Bethe extremely busy.

Bert King works from his home as a commercial mortgage banker for a company based in New York City which provides financing to build or acquire apartment buildings, nursing homes, housing cooperatives and low income housing. Bert is the third generation in his family to be involved in the real estate business. Currently Bert is on the board of directors of Yachad, the DC Jewish community development organization; he has served on the board of his synagogue and recently chaired its capital campaign. Bert lives in Bethesda with his wife Susan and has two grown children. Though not a board requirement, Bert is a great baker and an avowed chocoholic.

Having Ted and Bert join us has been fortuitous because two board members have had to resign because of poor health. We hope that they gain strength and are involved in the Foundation in any way they can. We will miss them.

Jannie Roher left us after one year. Elected by the membership, she was a significant help last year in getting attendees for the 2005 car show. We will remember her for the colorful hats that she often wore to the board meetings. Jannie hopes to continue to the co-chair the Sibley support group.

Glenn Lawrence, a three-year board member has also resigned. Known to a lot of people because of his work as coordinator for the Community Lecture Series, he also founded the Great Falls support group, was an important member of the Foundation Bylaws Committee as well as a contributor to the development of the Five-year Strategic Plan. Slowed down by a spinal injury, he is temporarily confined to his home and has turned over the running of the Great Falls group to John Lawrence.

We will miss the contributions of both of these talented people.

To fill out our roster as required by the Bylaws, we are holding a "by mail" election for the Community Member. This important person ensures that the voice of those immediately involved in Parkinson affairs is heard. Elsewhere in the newsletter is information about the candidates for this two-year board position. Please take the time to read about them, mark your ballot and send it to the office. We need your vote.

Ed. Note: Just as the Update was going to press, Ken Chen and Karla Hoffman, Ph.D. were also elected to the Board. Congratulations to both of them! We'll report more about Mr. Chen and Dr. Hoffman in our next issue.

Meet The Candidates *and Vote!*

During the month of April an election will be held to elect a "Community Member" to sit on the Board of Directors of the Parkinson Foundation of the National Capital Area. This Community Member will serve for two years. The duties and responsibilities of this person will be 1) to keep in touch with the community of people with Parkinson's disease and their families so that he/she can understand and represent their perspective on issues affecting the Foundation and its constituency; 2) to report to the community about Board activities; and 3) to participate in fundraising efforts that allow the Foundation to serve the community. The Board of Directors meets every other month, with committee meetings called by the committee chairs as needed. Those running for the Board of Directors are: Mike Epstein, Sharon Meliker and Bill Robbins. Their photos and statements as to why they want to be on the PFNCA Board appear in this issue. We hope you will get to know them. They all have worked hard for our organization in many different capacities.

If you have received this *Parkinson Update* newsletter then you are eligible to vote. **All voting will be done by mail.** Please cut out the ballot below, vote for **one** person, and return the ballot in an envelope addressed to: PFNCA, 7913 Westpark Drive, Suite 101, McLean, VA 22102 , Attn: Nominating Committee - to be **received no later than April 30, 2006.** This ballot may not be copied. Only original newsletter ballots will be counted. The name of the winner will be announced on May 10, 2006 at the Community Lecture Series meeting, will appear on the website, and will be sent to all support group leaders by email.



*Exercise your prerogative
and vote for the candidate
of your choice! They will
represent YOU!*



Ballot

1. Please print your name here:

2. Circle One (1) Name:

Mike Epstein

Bill Robbins

Sharon Meliker

**3. Please mail your
ballot to:**

**Attn: Nominating Committee
PFNCA
7913 Westpark Drive
Suite 101
McLean, VA 22102**

* *Only original ballots cut from
the newsletter will be accepted.
No photocopies.*

Meet the Candidates



Michael J. Epstein: Accomplished Fundraiser

By Mike Epstein

Thirteen years ago, I was diagnosed a Parkinsonian. At the time I had little or no knowledge about what that meant.

Being an inquisitive person, I secured many publications and articles on the disease to get a perspective on what it is like and how it might affect me. I was alarmed and had no idea of what was likely to happen. I found out that people who suffered from Parkinson's disease varied in symptoms, and treatment was designed with the particular patient in mind. Since then I have exchanged information with many other sufferers, especially through my weekly support group.

I would like to use my work experience in telemarketing fundraising through the non-profit Public Information Resources, and my development of clientele as a stockbroker with Dean Witter to assist PFNCA. I have also done telemarketing for Media General Cable where I was in the top 10 percent of producers.

My masters of business administration from Pace University with a concentration in finance might also benefit our organization along with my communication techniques.

But the most relevant aspects of my character are honesty, openness, hard work, and devotion to the organization. I am a quick learner and would venture to say that I could pick up skills in which I am lacking.



Sharon Meliker: A Vote for a Brighter PFNCA Future

By Sharon Meliker

When meeting someone for the first time, I usually talk about where I grew up (in Pittsburgh, Go Steelers!), that I now live in Bethesda with my husband Michael (from Baltimore) and two daughters, Jillian, 17 and college bound and Marissa, 13 and looking forward to high school. If asked, I may mention that I collect vintage cookie jars, most of which I buy on ebay, or talk about my varied work history as a retailer (managed 20 person sales department), trainer (developed and conducted technical training), meeting planner (coordinated conference logistics), and now, a web designer.

About six years ago, my family and I noticed that I was moving slowly and with increasing difficulty. I went to a neurologist, hoping that I didn't have PD, MS, or ALS. That's when I found out that I had Parkinson's disease. I came home and spent the night feeling sorry for myself and surfing the internet for information about PD.

I didn't know anyone who had Parkinson's disease. To help me come to terms with my diagnosis, I sought volunteer opportunities in the PD community. When I learned about the Foundation and its plans for their first Gala fundraiser, I immediately joined the auction committee. I had a lot of experience doing fundraising activities for my daughters'

elementary school and my women's civic organization. What a great way to meet others with PD and at the same time raise money for PFNCA!

Since that first Gala, I have met many others who have Parkinson's disease or are caring for someone with PD. I joined an early-onset support group and continue to attend fundraisers, symposiums, and other PD events. As I continue my involvement with the Foundation, I hope to take my commitment to a new level by serving on the PFNCA Board of Directors. I think my fundraising, event planning, and management skills will be an asset to the Foundation.



A Vote for Me Is a Vote for Positive Progression

By Bill Robbins

Hi – I am Bill Robbins, and I want to represent you as a Board Member of the Parkinson Foundation of the National Capital Area (PFNCA). I want to help make the PFNCA the very best that it can be. I am prepared to help identify and cultivate Foundation funding sources, vital if PFNCA is to survive. I feel that I am very knowledgeable of the environment in which the Foundation exists. I've had PD for 10 years, and although it has slowed me down, I am determined not to let it knock me down. NOW, let me give you a snapshot of my recent PFNCA activities.

- Support Group Leader. Expanded

a group of 6 to 15-20 in less than a year.

- Initiated a Parkinson's online chatroom support group, allowing those who cannot attend a regular meeting, the opportunity to communicate with others.
- I am the chair of the PFNCA website committee, responsible for the maintenance of the website. I think that we have given it a more professional look, and added new features.
- I am a regular contributor to the PFNCA newsletter.
- My family and I raised over \$3000 in the 2004 Baltimore Running Festival, with all

proceeds going to the National Parkinson Foundation, for continued PD research.

Yes, I am active in fighting this terrible disease, but I think that I can do more. I feel that my previous experience on the board of the American Medical Technologist (AMT) will help me to be an effective PFNCA board member. AMT is a recognized certifying agency for allied health professionals (30,000). I served them in the offices of treasurer, vice-president and president, with an operating budget of \$2 million.

On the personal side, I have been

married to the same wonderful woman, Lola, for 45 years, have three great sons, and five wonderful grandchildren. I get much pleasure from watching them grow up.

I retired from the Central Intelligence in 1992, after 31 years of loyal service. No, I wasn't a spy, but worked in the Office of Medical Services as a physician's assistant (PA). Boy, what a ride!

I have given you only a sketch of the salient points covering my candidacy. Will you afford me the opportunity to serve you on the PFNCA Board? Thank you for your support.



Ask the Doctor

Gastrointestinal Dysfunction: Constipation

By Linda Sigmund, MD

A majority of patients with Parkinson's disease experience gastrointestinal dysfunction. The topic in this column is constipation. Constipation occurs earlier in the disease process and affects a greater number of patients with Parkinson's disease than does swallowing difficulties. In fact, constipation actually can precede the motor problems seen in Parkinson's disease and can occur prior to the time of diagnosis.

The basis of constipation is reduced motility of the colon due to decreased dopamine in the nervous plexus supplying the colon. It can result in very serious problems such as bowel obstruction which can lead to perforation of the

colon. Constipation is exacerbated by poor fluid intake, poor diets, lack of exercise, and even some anti-Parkinson medications.

The basic treatment for constipation is aimed at increasing stool bulk by adding more fiber to the diet, and must be done in conjunction with increased fluid intake or the constipation can worsen. It is best to increase fiber by natural means such as increasing raw vegetables and fruits and eating a high fiber or bran cereal. If the stool is particularly hard, stool softeners such as Docusate sodium are quite helpful. Stool softeners can be used once to twice a day but should not be used in combination with daily laxatives. In fact, the long-term use of laxatives

should be avoided if possible. If the patient has not had a bowel movement in two or three days, then the doctor may recommend glycerin suppositories and over-the-counter oral laxatives, or as a last resort, a fleet enema. If constipation becomes a severe problem, the patient should obtain a gastroenterology consultation. Oftentimes, the doctor of those patients who are having chronic, severe problems may recommend daily medications such as lactulose, MiraLax, or cisapride. In summary, the best approach to constipation is preventative therapy such as daily exercise, lots of high fiber foods, and an adequate amount of fluids.

Can caregiving and happiness co-exist?

By Susan Hamburger

The answer to this question lies within each of us. Nobody else can answer it for you. I will give you my personal answer later but first I think it might be a good idea for each of us to look at our own situation and decide if we are happy or if we know how to be happy. Becoming a caregiver often has resulted from sadness – usually advancing Parkinson's Disease in someone we love. Can happiness be found in that kind of a situation? Do we have a right to be happy when we are not the ones with the disease? Will our current happiness begin to disappear as the disease progresses in our loved ones? The caregiving experience can include anger, frustration, and guilt as well as sadness. Can happiness be part of the equation?

'Finding happiness is like finding yourself. You don't actually find happiness, you make happiness. You choose happiness! Self-actualization is a process of discovering who you are, who you want to be and paving the way to happiness by doing what brings YOU the most meaning and contentment to your life over the long run.' (David Leonhardt, *The Happy Guy*)

If we accept this definition of happiness, is there anything in it that would preclude a caregiver from creating happiness? Everybody has constraints within their lives – something they would like to change – something that is difficult to deal with. Finding our own happiness does not have to be hindered by the caregiving experience because it is an

internal choice that each of us has to make.

Sometimes, we develop habits that work against us. Our own actions or personal attitude may be keeping happiness out of reach. One thing to think about is to keep yourself from doing 'it all': When you do it all, you rob others of the opportunity to grow. As a result of 'being a good' caregiver; you rob your Parkinsonian of the opportunity to know independence and the success such independence breeds; and you rob yourself of the opportunities to take time off and away from an exhausting role.

What are we expecting? Maybe we need to redefine our idea of happiness: In our youth, happiness may have seemed to be a new car, a new outfit, a lot of money, or a great date. As we grow older, happiness might have become a caring spouse, healthy children, or a secure job. As caregivers, no matter what our age, our idea of happiness may have to be revised occasionally. Take some time to revisit your definition of happiness. When are you happy? And, how can you increase those moments of happiness?

On a caregiving website, I found some suggestions related to learning the art of happiness and I want to share them with you:

It is OK to want to be happy. It is not unduly selfish, or materialistic, or self-centered. Wanting to be happy is normal. It does not mean that you take anything away from your person with PD if you want to be happy.

To pursue happiness is an inalienable right - to be happy is not.

Some people seem to believe that they have a right to be happy, that other people should make them happy, that when they are not happy they have a right to complain about it and that complaining will cause them to be happy. All three premises are false.

No one owes you happiness. We are all adults, so our happiness is not anyone else's problem. If you are a person who spreads happiness, then others will probably want to contribute to your happiness. This is their choice, not your right.

Happiness comes from attitude, from within. We become happy when we cultivate an attitude of appreciation and gratitude, when we focus on the good in our lives – not always thinking about what we do not have or what we cannot do because we are caregivers. Try to get in the habit of looking for what is good everyday instead of the opposite. You might have to start out by writing it down every day – like a happiness or gratitude journal.

Happiness is more a process than it is a goal. When I get... when I reach... when I am... we may think that happiness is something that will come, or will happen, one day. Eventually, we will find out that happiness is the journey, and that if we focus only on the destination we will never get there. So, don't waste the journey. Find your happiness every day.

Talking about unhappiness does not make you happy. It is true that we all need to vent at times. The purpose of venting is to express our

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My Miracle Man

By Marilyn Morabito

September 13, 2005, 6:00 pm, Peter and I were enjoying a relaxing time in the pool after a hectic day of gardening on the hillside. Peter decided to work his way down to the deep end of the pool where I watched him bobble up and down in the water. Having next to no buoyancy, he dropped to the bottom, some 9 to 10 feet, where he lay in a prone position, face down. I quickly realized that he was in trouble when his head did not reappear. Thoughts ran through my head such as, do I save him and get my hair wet which he never liked, do I become a rich widow, do I no longer have to be a caretaker—but the answer was a given. My husband was and is worth every effort I could make. Five to six times, I dove to the bottom of the pool, never having the strength or breath to bring him to the top. Each time I rose to the surface, I screamed for help. Finally, my housekeeper heard my screams and came to the pool. I climbed out of the pool, hyperventilating, and claiming exhaustion. Maria kept screaming at me to try one more time, refusing to go into the water herself since she was not a swimmer. I finally listened to her, dove one more time from the deck of the pool, grabbed Peter, held onto the pole Maria was holding and was dragged to the side of the pool. When I ultimately was able to get Peter's head out of the pool, he was not breathing. A neighbor finally came to our aid along with a roofer who was working on his house. Thank God for Alan, the roofer, as he was able to perform CPR, which seemingly cleared Peter's lungs and helped him to breathe once again. Some twenty-five minutes later, the 911 rescue squad arrived along with a fire truck

and three police cars. It was determined that Peter was in critical condition and needed to be rushed to the hospital. Arriving in the ambulance with my critically diagnosed husband, I was quickly taken to a family private waiting room where I was told to call other family members. This was definitely not a good sign. Peter had aspiration pneumonia, but the greater fear was brain damage due to the lack of oxygen to his brain.

Within an hour, three of my five children arrived, one still to come from Pennsylvania and the oldest vacationing in Rome, not able to return immediately. The doctors explained that Peter was in critical condition, placed a breathing tube in his mouth, kept him sedated, and sent us home at one in the morning. When we arrived back at the hospital Wednesday morning, Peter was on the critical care floor with one nurse per two patients. This was not a good sign, either. Niles, Peter's Parkinson service dog, and I arrived in the room to find Peter without the breathing tube which he had somehow extracted from his mouth even though his arms were immobilized. Instead, he had another breathing mask which gave him oxygen while allowing him to talk. However, as the day progressed, the nurses removed this oxygen mask and inserted a device in his nose which also gave him oxygen. Peter, amazingly, was cheerful, free of Parkinson medication and ready to go home. Thursday morning when we returned to the hospital, the doctor said that after he ate, walked, and appeared on the road to recovery, we could take him home. You know he's better when



his first solid food was hospital spaghetti and he ate it all, even though it was not his wife's homemade pasta.

Four o'clock, Thursday afternoon, Peter was released from the hospital, came home to cocktails and a gourmet dinner, slept through the night and a good portion of the next day. Friday evening we did our usual movies and dinner out. Saturday, Mass and dinner, and Sunday, family dinner with twenty-two of the twenty-eight children and grandchildren present.

The ironic part of this entire story is Peter's Parkinson's symptoms. He now takes seven Sinemet pills a day instead of fifteen, no longer takes Sinemet CRs and takes his medication every three hours instead of two. He has lost his Parkinson mask, now smiles and laughs with us, improved his walking and balance tremendously, shows little tremor, improved his bladder problems and most importantly, speaks so that we can hear him. Could it be from the prayers of the Pope with whom my son had just had an audience? Could it be from the Jewish roofer who performed the CPR and had his congregation pray for Peter? Or was this, in fact, one of God's miracles? I vote for the latter. If that is not the case, I promised Peter that I will drown and revive him once a month in order to improve his life and mine.

Heartfelt Thanks

The Parkinson Foundation of the National Capital Area gratefully acknowledges the following gifts recorded between 12/08/2005 and 03/03/2006. These contributions will help provide programs and services to improve the lives of people with Parkinson's disease and their families and help support research designed to find more effective treatments and a cure for Parkinson's disease.

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In honor of

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Mrs. Jannie Roher

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Ms. Amelia W. Wilkinson

In honor of

Dr. Linda Sigmund

Mrs. Ruby Bolster

Drs. Russel and Mary Libby

In honor of Peter Sterrett

Mrs. Sabyna S. Sterrett

In honor of Mr. Dick Sundin

Ms. Nancy Shalloway

In honor of the staff of PFNCA

Mr. and Mrs. Harry K.

Tebbutt

In honor of

Cdr. James Victor

Capt. Harry Bishop

Ms. Jacqueline D. Marini

Do you know what your gift provides our Parkinson community?

- Significant research funding to find the cure for PD
- Extensive support-group network in DC, MD, and VA
- Weekly therapeutic exercise classes, led by a certified fitness instructor
- One-on-one consultation with our staff psychotherapist
- Betty R Fuller patient assistance fund
- Free educational material
- Quarterly newsletter
- Free lending library of 200 books and videos
- Information hotline
- Educational symposia featuring leading authorities on PD
- Speakers bureau
- Member-to-member community connector

*These services would not be possible but for your contributions. You make a difference in the lives of special people. **Thank you.***

In memory of

Mrs. Shirley Andary

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Mr. and Mrs. Glenn E. Cartledge
Ms. Sally S. Dellinger
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Mr. and Mrs. Jonathan E. Harmon

Ms. Stacy D. Harrison
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Mr. Stuart Barber

Mrs. Anna L. Barber

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Mrs. Sue W. Barnard

**In memory of father of
Bill Beveridge**

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Mr. John Seelous

Ms. Maureen E. Ewadinger

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Mr. and Mrs. Ted Curtis
Mr. and Mrs. James Hogan
Thomas and Rebecca L. Kurtz
Mr. and Mrs. Larry Taylor

In memory of

Mr. Morton M. Smith

Ms. Suzanne B. Smith

Please note that all names have been carefully reviewed. Nevertheless, errors or omissions may occur. If your name has been misprinted or omitted, please accept our apologies. Questions or corrections should be directed to Banu Luu at the Parkinson Foundation at 703-891-0821.

In memory of
Mr. George B. Sowa
The Bartholomews
Mr. and Mrs. Jerrold Mink
Mr. and Mrs. Justin Mink
Lois Reeves

In memory of
Mr. Douglas H. Stephens
Ms. Pamela L. Stephens
Mr. Victor Matsuo

In memory of
Mr. Harold Suskin
Mrs. Beatrice S. Suskin

In memory of
Mr. Charles A. Thomas
Mrs. Brenda Thomas

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Mr. David G. Carpenter
Ms. Roberta Hinebaugh
Ms. Elizabeth Kriskie
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Mrs. Grace Woodbridge
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Allison
Mr. and Mrs. Mark T. Gibson

In memory of
Mrs. Laura Wruk
Mr. Ray Wruk

(Caregiving — Cont. from pg 6)

dissat-atisfaction with something so that we can move on. If we vent just to let others know how badly used we feel or how awful something is, nothing new will happen. If we keep our mental attic filled with unhappy stuff, there will be no room for anything else. We need to get rid of it so we have room for the happy thoughts that we want to move in.

Memories of happy times can be stored up for retrieval during the bad times. Very few of us will never feel unhappy, especially when one is caregiving. It is a roller coaster journey with good and bad times. A major help is to remember the times when we are happy. They are a part of us. They can remind us that we are capable of happiness, and that the world is not always

so difficult to deal with. When you are happy, consciously store up the memories - they will serve you well.

Happiness comes from sharing happiness. There are few joys as complete as those that involve bringing joy to someone else. Happiness defies the laws of economics in that it is not something that we have less of when we give it away. It is something that grows greater for the giver as it is given. The more you give, the more you have.

And so my friends, there is a lot to think about. Many things can bring us moments of happiness, but to be really happy may take some work. We need to be aware of our own needs and what makes us happy. Ultimately happiness comes from self-fulfillment in the grandest sense of the word. I think we need to do

the things we love, try to stay positive and resume the things that made us who we are. Have we decided that we have had all the fun we are going to have in our lives? Not for a moment, I hope!!! Get back in the game. Choose to be happy and do the things that make the journey to happiness easier. You are the only one that can do that for yourself.

And my answer to the question is yes. I have chosen happiness for myself. There are bad times occasionally when I don't feel happy but I try to put things in perspective and realize that this is a journey and not a destination, that every journey has twists and turns, and that if I work at it, I can regain my positive thinking and do the things that make me happy. At the end of each day I can say that I did my best and that I am a happy person.

World Parkinson Congress 2006

By Banu Luu

The World Parkinson Congress was held February 22-26, 2006 at the Washington Convention Center. For people with Parkinson's, the WPC was not only a new source of hope and excitement for the future, but a unique and practical opportunity to participate hands-on in the global fight against Parkinson's. The Congress featured an extensive program of plenary sessions, symposia, and workshops with presentations and discussions devoted to established and best treatment options, quality-of-life and care delivery issues, and the latest scientific research from around the world. In many ways, it was the world's biggest support group for all involved.

PFNCA was designated the local patient host group in charge of recruiting and coordinating volunteer efforts at the Congress. Thirty-nine volunteers devoted over 400 man-hours to evaluation distribution and collection, caring for people in need of a little extra assistance, and running errands as needed. The volunteers displayed really impressive team work, and we all—PFNCA staff, board members, and volunteers, alike—had a great time. We are so happy to have been part of this event. The next Congress will be held in June, 2009 in Paris. Start saving now!

A Hitchhiker's Guide to the Ritz

by Dottie Aukofer Peet

I took a chance and stuck out my thumb (a check)-and pulled out a plum.

Top prize in the PFNCA's October Golf Fundraiser was four nights at any one of about 30 different Ritz Carlton Hotels, along with American Airlines tickets to get there and back. Roger and I hitched a ride on the right golf ball; our dimpled darling dropped closest to the cup and the prize was ours. (I don't want to be greedy, but do we get to keep the ball? We've dubbed ol' dimples, Richie Rich.)

Anyway, to get back to a plum of a story, the nights at the Ritz weren't just for a room, it was for a suite-and it was sweet. We opted for the Ritz Carlton on the North Shore of Maui, Hawaii, getting there by way of Kua'ai and the Big Island. Our suite included a large bedroom, living

room, dressing room and two (count them, two) full baths. A lanai stretched the full length of the bedroom and living room, overlooking the ocean, palm trees and other tropical greenery.

The package included taxes, a lavish breakfast buffet (\$25 per person if we'd had to pay for it), free use of the spa facilities, and anytime use of the three-level pool-towel service included.

The Ritz also provided us with a wheelchair, which eased the trek (276 steps one way-the Ritz is a small palace, not a small place) from the lobby to our room. And although parking was free, we opted to pay the \$15 a day for valet parking-worth every penny for the convenience. After the first day, most of the staff recognized us and would just bring the car when we came outside.

The American Airlines tickets were for the contiguous U.S., but we could upgrade them for \$125 per person, round trip, to add the 2,800 mile, five-hour leg to Hawaii.

This Hawaii trip was special for us. We'd broken the "curse." We visited Hawaii in 2001, but Roger got sick the second day there. He had emergency surgery while we were on the Big Island, and developed complications. The surgeon put Roger on an air ambulance and sent him to Queens Medical Center in Honolulu. Roger spent 10 days in intensive care and another ten in rehab. We stuck around for two days after he was released to make sure he was ok before heading directly back home.

Not much of a trip. We've make up for it. In style.

So when's the next fundraiser???

WANADA VIP Gala and Autoshow: Fun and Funds for the Foundation!!

PFNCA turned out 509 attendees to the Washington Auto Show Congressional Gala and Charity Benefit held on January 25th. This event ended our annual end-of -the-year campaign that earned the Foundation \$153,850!!

Our staff and board members, dressed in formal evening wear, greeted people on behalf of our organization. We posted signs at the check-in tables thanking our supporters for assisting our program and briefly described our mission in the Auto Show program booklet .



Though most attendees focused on the new, shiny autos, and the music and food, the reason that they came was to benefit PFNCA. We are very grateful for their financial support and that of WANADA. The evening provided an opportunity to call attention to our service to the PD community in the Washington area, and earned the Foundation the capital to continue this service. Thank you to all who made it a success!

Fundraising for the Foundation While You Shop for You

For products and services you would buy online anyway, please consider beginning your shopping at [BuyForCharity.com](http://www.buyforcharity.com) (www.buyforcharity.com). At no extra cost to you, up to 35% of every purchase you make automatically goes to the PFNCA! Look for the Parkinson Foundation of the National Capital Area under Disabilities and Diseases. Some of the brand name retailers who participate are Amazon.com, Dell, J. Crew, Martha Stewart, Gap, L.L. Bean, 1 - 8 0 0 - F l o w e r s . c o m , OfficeMax.com and more than 350 others. What a great way to spend that tax refund!!

Happenings

(Continued from page 1)

Girl Scout Gold Award Project Educates the Public

Lital Shair, teenage grandniece of board co-chair Sue and Stan Hamburger, made sure that, at least, her family and friends were informed about PD. As a project to qualify for the Girl Scout Gold Award, she advertised and organized a dinner in early January focusing on Parkinson's disease. Though the night was cold, the spirit of the evening at Temple Shalom in Chevy Chase was warm and inviting. Purple, gold and orange balloons decorated the tables and formed a backdrop for approximately 150 guests. We were treated to vegetarian chili, slabs of corn bread and green salad while we listened to Lital explain PD, the search for a cure, and her Uncle Stan, a PD patient for many years. At each plate was an informative flyer from PFNCA. In addition, each attendee was able to choose a souvenir ceramic plate made by Lital or her friends with Parkinson Foundation written on it. Although not intended as a fundraiser, Lital donated to the Foundation all funds collected above those needed to defray expenses. Lital's capability illustrates the potential of teenagers in our fight against PD. We wish we had more like her.

Young Onset Parkinson's Disease Conference coming in July

The PFNCA is very proud to be a part of the National Parkinson Foundation Young Onset Parkinson Network Conference coming July 6-8th to the Hyatt Regency at Reston Town Center, in Reston, VA. Our own Angela and Karl Robb are the local

coordinators of this event and are promising a stellar list of speakers, as well as entertainment and fun for all. Mark your calendars, now, and look for more info on our website at www.parkinsonfoundation.org or NPF's website at www.parkinson.org as the event draws nearer.

University of MD Hosting a Patient Seminar

UMD is hosting a patient seminar on Saturday, May 13 from 8:30-2:30 at the Bethesda North Marriott Hotel & Conference Center, 5701 Marinelli Road in North Bethesda, MD. The cost is only \$20 and includes the seminar, parking, continental breakfast, and lunch. In addition to the usual fine faculty from the UMD School of Medicine, the guest speaker will be the Honorable Harry Hughes, former governor of MD, who will speak on "Stem Cells: the Politics." For further information, call 1-800-492-5538.

Companies with a Conscience

Brian Morabito's Companies with a Conscience Program continues to grow and benefit the Foundation and the community we serve. As you may remember, companies who choose to participate in this program save on credit card fees and Brian donates a portion of his commission to the Foundation.

We thank the following civic-minded companies who are making a difference in the lives of people with PD and their families and hope that you will patronize their businesses whenever you can: A B Chelini Company, LLC, Bikes @ Vienna, Taqueria Poblano, Taqueria El

Poblano of Arlington, Cafe La Ruche, Foong Lin Restaurant, Jhoon Rhee Taw Kwon Do, Rheemax Inc, Capri Ristorante, Trattoria Renato, William Penn House, Jins Tailor, Hunter C Bell, DDS, William W Babington DDS, Capital Carpet Cleaning, Original Pancake House (I, II, & III), McLean Hardware, Carpet and Vacuum Expo, Dr Rena Vakay, Peter L Passero DDS & Assoc PLC, Umbertos Italian Restaurant, J S Ackerman, DDS, La Miche.

Golf Tournament Update

The Parkinson Foundation Tournament for Hope Golf Classic sponsored by Russ Holmes and his family netted \$13,292.70 for the Foundation. We sincerely thank Russ and the team he put together to bring this event to our community. We also thank Scott DeBergh for his creativity and innovations. Be sure to read Dottie Aukofer Peet's article elsewhere in this issue about the trip to Hawaii she and Roger took as the golf ball raffle winners.



The Baltimore Running Festival

Run or walk? Long distance or short? Serious performance or just for fun? Sponsor or participant? It's time to begin deciding what your involvement will be in the Baltimore Running Festival being held on Sat. Oct. 14th. This event will raise funds for both patient services and research, so we hope that you will support this important event and have a lot of fun doing so. As more information becomes available, we will post it on our website: www.parkinsonfoundation.org.

(Placebos — Cont. from page 1)

disease, merely expecting to benefit from treatment could induce changes down to the firing of a single brain cell, and these changes in firing correlated with improvement in both the patient's subjective experience of muscle rigidity and a clinicians' assessment of Parkinson's symptoms. Not all patients responded to the placebo treatment, and those who were placebo nonresponders failed to show changes in either neuronal firing rates or in muscle rigidity.

To further isolate the role psychosocial context plays in mediating therapeutic benefit, Benedetti and his team used computers to administer actual treatments that are known to alleviate symptoms. However, patients were unable to detect when they had received treatment, as there were no obvious indications (no nurse appearing at the bedside to administer an injection, for example).

The researchers found that the hidden therapies were significantly less effective in patients with Parkinson's or pain than open or expected therapies, even though the actual treatments were the same. These studies indicate that expectation is a major component of therapeutic benefit, even with real drugs, and that placebos may benefit patients for the same reason.

Preliminary research from Benedetti's team suggests that when expectations are reduced, as occurs in people with dementia, the effects of treatment may also decrease. This finding, if confirmed in larger studies, could hold important implications for treatment approaches in diseases such as Alzheimer's.

Other researchers have used positron emission Tomography

scanning to make sense of the role of the placebo effect in treating depression. Helen Mayberg, a professor of psychiatry and neurology at Emory University, found that placebos caused changes in brain activity similar to those observed when patients took antidepressant drugs, and that these changes were very different from the changes that occurred following cognitive behavioral therapy. Her studies show that antidepressant drugs and cognitive behavioral therapy, each of which relieves depression in some individuals, appear to operate via different brain circuits.

Mayberg stressed that although there were similarities between placebo and drug induced brain changes, the changes in the brains of those who responded well to the drugs were over and above those seen with placebo.

Imaging studies conducted by Tor Wager, an assistant professor of psychology at Columbia University, have examined the brain circuits involved in placebo-induced alleviation of pain. His group found that areas involved in generating expectations, particularly areas of the prefrontal cortex, showed increased activity following placebo treatments. These findings indicate that changes in subjects' anticipation of pain are an important part of the placebo effect.

Wager's team found that treatment with a placebo also lowers activity in brain areas associated with the actual subjective experience of pain, such as the insula. "A placebo treatment can change how your brain processes pain while it's happening," Wager said.

Christian Stohler, dean of the school of dentistry at the University

of Maryland, and Jon-Kar Zubieta, associate professor of psychiatry and radiology at the University of Michigan, took a different approach. Their research team explored whether expectations of pain relief from placebo treatment caused the brain to release its own antipain chemicals, known as endogenous opioids or endorphins.

Their team found that placebo treatment did indeed appear to cause increases in endorphin release, as detected by positron emission tomography scans. Stohler and Zubieta conclude that placebos exert at least part of their pain-relieving effects by increasing opioid release in the brain. The brain areas where endorphin release was greatest corresponded with the areas Wager's group found to be active in the functional imaging studies of placebo-mediated reductions in pain.

Major challenges lie ahead in this relatively young field, the researchers agree. Future studies must examine other conditions and identify the differences between placebo responders and nonresponders.

"The meaning ascribed to an event has important health implications," Wager said. "Your expectations can have profound impacts on your brain and on your body....We are just beginning to learn how that process works in the brain. We also have much to learn about what kinds of placebo treatments produce neurobiologically meaningful outcomes."

Placebos' promise, Zubieta emphasizes, lies in their potential to be used with other drugs—not instead of them.

"It is an additive effect, not a substitutive effect, in many ways," he said.

Support Groups

In the National Capital Area

PFNCA Community Lecture Series

2nd Wednesday monthly at 6:30 pm
Epiphany Byzantine Church,
3410 Woodburn Road, Annandale, Virginia

Chatroom/Online Support Mondays, 8:00 PM

Join: get id and password – <http://www.iVillage.com/support/free/0,,qk3h,00.html>
Log on to chatroom:<http://www.Ivillage.com/support/free/0,,qk38,,html>
Contact: Bill Robbins, 703-830-3823 or wbr_yanks@hotmail.com

Sometimes circumstances require that groups or classes change their meeting dates or places. Please call the listed contact to verify the group's schedule if you have not attended recently.

Maryland

Annapolis, Severna Park

4th Tuesday Monthly at 12 Noon
Elks Lodge in Severna Park
Truck House and Jennings Road
Contact: Tom Mislan, (410) 729-3461

Baltimore Group

2nd Thursday monthly at 2 PM
Johns Hopkins at Greenspring Station
10753 Falls Road
Contact: Becky Dunlop RN, (410) 955-8795

Baltimore Caregivers Group

1st Thursday monthly at 10 AM
Johns Hopkins at Greenspring Station
10753 Falls Road
Contact: Becky Dunlop RN, (410) 955-8795

Baltimore Young Onset Group & Deep Brain Stimulation Group

2nd or 3rd Saturday every other month at 10 AM
Johns Hopkins Outpatient Center
601 North Caroline Street, Suite 2140
Contacts: Sandy Pollock (410) 315-9953;
John Kellerman (410) 494-0398; Bill Innanen (410) 997-2195

Parkinson's Exercise Class at Whitley Park

Mondays, Wednesdays, & Fridays at 1PM
5450 Whitley Park Terrace, Bethesda, MD

Chevy Chase Carepartners Group

Mondays at 11 AM
Speak to Leon if interested in joining
Chevy Chase Presbyterian Church
1 Chevy Chase Circle
Contact: Leon Paparella, (202)966-4450

Chevy Chase Exercise Group

Mondays, Wednesdays, Fridays at 11 AM
Chevy Chase Presbyterian Church
1 Chevy Chase Circle
Contact: Susan Hamburger, (301) 654-5572

Chevy Chase Young Parkinson Network

3rd Thursday monthly at 7:30 PM
The Carlton Condominium
4550 North Park Avenue
Contact: Perry Cohen, (202) 686-9430

Easton Group

2nd Tuesday monthly at 1:30 PM
Talbot Hospice House, 586 Cynwood Drive
Contact: Ann Fischer or Becky Dunlop RN
(410) 820-2927 or (410) 955-8795

Frederick Group

3rd Wednesday monthly at 1 PM
Mt. Pleasant Ruritan Club, Crum Road
Contact: John Kraft, (301) 845-6514

Gaithersburg Exercise Group

Mondays & Wednesdays at 1 PM
Asbury Methodist Village, 409 Russell Avenue
Contact: Judy Cooper, (703) 299-0518, or Jerry Hart, (301) 987-6169

Harford/ Bel Air Group

1st Thursday monthly at 2 PM
William McFaul Activities Center
525 West Mc Phail Rd., Bel Air
Contact: Becky Dunlop RN, (410) 955-8795

Howard Co. / Columbia Group

3rd Wednesday monthly at 7 PM
Brighton Garden by Marriott, 7110 Minstrel Way
Contact: Becky Dunlop RN, (410) 955-8795

LaPlata Civista Group

4th Saturday monthly at 2 PM
Civista Medical Center Cafeteria
701 East Charles Street
Contact: Michele Santiago, (301) 609-4415

Oakcrest Group

3rd Thursday monthly at 10:30 AM
Oakcrest Retirement Community, Walthur Blvd.
Contact: Susan Grossman, (410) 663-3015

Rockville Exercise Class

Mondays, Wednesdays, & Fridays at 1 PM
Call for quarterly fee amount
Saint Mark Presbyterian Church
10701 Old Georgetown Road, Rockville, MD
Contact: Susan Hamburger, (301) 654-5572

Silver Spring

2nd Tuesday monthly at 1:30 PM
Leisure World on Georgia Avenue, Clubhouse 2
Contact: Babs Koch, (301) 598-7840

Silver Spring Holy Cross Exercise Group

Mondays and Wednesdays at 11:30 AM
Support Group only on Monday
Call for session dates & fees
Holy Cross Senior Source, 8580 2nd Ave.
To register, call (301)754 8510

Silver Spring Manor Care House Group

1st and 3rd Fridays at 3:00 PM
2201 Colston Drive
Contact: Chris Graham, (301)854-0921

Silver Spring/Riderwood Support Group

1st Thursday monthly at 9:30 AM
Renaissance Building, 3128 Gracefield Road
Contact: Beverly Gershon, (301)572-1633

Silver Spring/Riderwood Exercise Class

Fridays at 10:30 AM
Renaissance Building, 3128 Gracefield Road
Contact: Beverly Gershon, (301)572-1633

Takoma Park Yoga Class

Sundays, 12 -1:15 PM
Willow Street Yoga Center
Register online at www.willowstreetyoga.com or call (301)-270-8038

University Park PD Support Group

4th Thursday monthly at 7 PM
Riverdale Presbyterian Church
6513 Queens Chapel Road, Rm #1
Contact: Steve Andrews, (301) 864-5298

Westminster Senior Center Support Group

4th Tuesday monthly, 2-4 PM
Carroll Co. Bureau of Aging/Westminster Senior Center, 125 Stoner Avenue
Contacts: Becky Dunlop, (410) 955-8795 or Phil Luster, (410) 875-9898

PSGW Sponsored Groups in MD

Kensington Exercise and Support Groups

Fridays at 10 AM
Heavener Hall, St Paul's Methodist Church
10401 Armory Avenue (Mitchell St. entrance)
Contact Gabriele Rosenberg, (301) 384-9670 for PD Group and Exercise Group info
Contact Ann Jeseloff, (301)946-5468 for Carepartners Group info (*meets only 1st Fri. monthly*)

Laurel Exercise Group

Tuesdays at 10:30 AM
Laurel Regional Hospital
Contact: Sally Heckendorn, (301)776-3426 or Diana Hamilton at (301)952-1990

Gaithersburg/Upper Montgomery County Exercise Group

Wednesdays at 10:30 AM
Fellowship Hall, Covenant United Methodist Church, Intersection of Montgomery Village Ave. and Wrightman Road
Contact: Donna Dorros, (301)840-5973

(Continued on page 16)

(Support Groups, Cont. from page 15)

Virginia

Alexandria

1st Wednesday Monthly at 2 PM

Hollin Hall Senior Center

1500 Shenandoah Road

Contact: Stephen Rosenfeld, (703) 836-0485

Ashburn Support Group

1st Tuesday monthly at 1:30PM

20903 Runnymede Terrace

Contact: Dotty Koyles (703) 723-6805

Arlington Cherrydale Parkinson's Group

Tuesdays at 10 AM

Speak to Leon if interested in joining.

Cherrydale Baptist Church, 3910 Lorcom Lane

Contact: Leon Paparella, (202) 966-4450

Arlington Cherrydale Carepartners Group

Tuesdays at 11 AM

Speak to Leon if interested in joining.

Cherrydale Baptist Church, 3910 Lorcom Lane

Contact: Leon Paparella, (202) 966-4450

Wilbur McBay Exercise Program/Arlington

Tuesdays and Thursdays at 11AM

Cherrydale Baptist Church, 3910 Lorcom Lane

Contact: PFNCA Staff, (703) 891-0821

Fairfax City PD Support Group

2nd Monday monthly at 7 PM

Green Acres Community Center, Rm 116

4401 Sideburn Road

Contact: Karl Robb, (703) 277-9666

Fairfax Little River Glen Exercise Classes

Weekday Mornings – Call for Class Schedule

Little River Glen Senior Center

4001 Barker Court

Contact: LRG Senior Center, (703) 503-8703

Fair at Fair Oaks Group

4th Saturday monthly at 10 AM

Sunrise at Fair Oaks,

3750 Joseph Siewick Drive

Contact: Glenn Smith, (703) 590-4850

Falls Church Evening PD Carepartners

2nd Thursday monthly at 7 PM

Tysons-Pimmit Regional Library

7584 Leesburg Pike

Contact: Angela Robb, (703) 277-9666

Great Falls

4th Tuesday monthly at 7:30 PM

St. Francis Episcopal Church

9220 Georgetown Pike

Contact: Glenn Lawrence, (703) 406-2732

Springfield Greenspring Village Group

4th Thursday monthly at 1:00 PM

7400 Spring Village Drive

Town Center Building, Music Room

Contact: Michel Margosis, (703) 569-2630, or

Mitch Mills, (703) 913-0270

St. Elizabeth Ann Seton PD Group

3rd Tuesday monthly at 2:00 PM

St. Elizabeth Ann Seton Catholic Church,

Music Room

12805 Valleywood Drive, Lake Ridge

Contact: Jill Walton, (703) 580-9450

Vienna Exercise Class

Call for session dates and fees

“Heart and Sole” Chair Exercise Program:

Tuesdays or Fridays, 12:30 PM

“Balance and Beyond”: *Wednesdays, 1:15 PM*

Vienna Community Center, 120 Cherry St. SE

To register, call (703)-255-7801

Contact: Cheryl Bartholomew, (703) 281-1560

Westminster at Lake Ridge Group

4th Wednesday monthly at 2:00 PM

Westminster at Lake Ridge Retirement Community

12191 Clipper Drive

Lake Ridge, VA 22192

Contact: Jean, (703) 494-0117

Washington DC

Georgetown Group

3rd Monday monthly at 2 PM

Georgetown University Medical Center

Lombardi Cancer Center,

Martin Marietta Room

3800 Reservoir Road, NW

Contact: Leon Paparella, (202) 966-4450

IONA Parkinson Group

Fridays at 11 AM

Speak to Leon if interested in joining.

IONA Senior Services,

4125 Albermarle Street, NW

Contact: Leon Paparella, (202) 966-4450,

or Christine Jackson, (202) 966-1055

Methodist Home

4th Wednesday monthly at 11 AM

4901 Connecticut Avenue, NW

Contact: Diane Yagmur, (202) 966-7623

Sibley Group

2nd Thursday monthly at 4 PM

Sibley Memorial Hospital

Renaissance Building, 1st Floor Meeting Room

5255 Loughboro Road, NW

Contact: Honora Dent, (202) 364-7618 or

Jannie Roher, (202) 966-5544

Parkinson Foundation **of the National Capital Area**

7913 Westpark Drive, Suite 101

McLean, VA 22102

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