



Parkinson's

Companion

Voices of Parkinson's Going Forward

by Robert Grassi, MD

It has been almost 12 years since I put down my stethoscope to deal with the reality of a future encumbered by Parkinson's. There have been many ups and downs during this time; however, we keep going forward. I use the word "we" to indicate the key role my wife has played in my successes and the importance of her support when I have failed.

During my 32 years of medical practice, I never missed a day at work because of illness. Although the consequences of Parkinson's on my profession were soon apparent, the implications for my personal life took some time to be internalized and accepted. After retiring, my wife and I moved to our vacation/retirement home on a small lake in New Hampshire, and I enjoyed being outdoors every day, fishing, landscaping, playing tennis, and taking pictures. The first five years were relatively easy,

and many people did not know about my medical situation.

But the next seven years were more challenging, and I soon made up for my earlier good fortune. I suffered from extensive arthritis in my spine, and opted for intensive physical therapy sessions that rebuilt my strength. I required surgeries for numerous injuries, many related to my favorite outdoor activities. One particular surgery for Achilles tendon repair rendered me non-ambulatory for an extended period. I felt very isolated and alone, but was able to focus on my interest in photography, which has been a lifelong passion.

I refuse to dwell on my medical situation and am determined to maintain a positive self-image, have meaningful activities and exercise every day. But it is important to recognize physical limits imposed by age and

Parkinson's, and to choose activities that can be performed safely, seeking guidance from your physician, physical therapist, and a spouse, family member or friend who has knowledge of your capabilities. Take an active role in working with your physician to assess your needs, establish priorities for addressing them and deal with issues until their negative impact is minimized. Set reasonable goals in your activities, whether writing, painting, walking, or reading stories to your grandchildren, and focus on the positive things you can do. It is important to think of oneself not as a "Parkinsonian" but rather as an individual who can contribute,

Continued on Page 2



Photo by Robert (Bob) Grassi, who has lived in New Hampshire for over 40 years. His work has been displayed at various studios and locations throughout New Hampshire. He is a juried member of the New Hampshire Art Association and has participated in many of their exhibits. You may contact Bob at (603) 569-5802 or his email grassirm@metrocast.net. To view more of his photos, go to rmgrassi.Smugmug.com.

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A Note from the Coordinator **Diane L. Church, PhD**

I am writing these greetings just as a February blizzard is striking the Northeast. From the snowfall predictions, it may be Parkinson's Awareness Month before we have dug out from this storm! Please check the announcements on page 7 for a variety of events in April that will help to educate the Parkinson's

community and the general public about the challenges of this illness and our hopes for the future. This issue of *Parkinson's Companion* features heartfelt pieces contributed by three members of the Parkinson's community, as well as an article on oral health for you to chew on.



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establish relationships and keep going forward. I focus on being the best person I can as a husband, father, friend...and photographer.

My interest in photography has become a very important part of my life, allowing me to share with others my vision of a world reflecting the magnificence of its creator. Recent developments in

digital cameras, such as their computerized programs and higher sensitivity to light, permit most anyone to technically take good pictures, and to "capture the moment" through one's unique composition and vision.

I feel much satisfaction that my pictures allow me to share special moments with grandchildren and family,

encouraging me to acquire skills in matting and framing my pictures, enabling us to enjoy them for years to come. My wife is especially thankful for these accomplishments so she no longer has to give up additional wall space in our house to display all my pictures as they appear to be well received not only by family, but also the public.

I would like to share with you my interpretation of an old saying: "Live, Laugh, and especially Love." Maintain a positive self-image by doing your best in all your endeavors each day, and do some exercise regardless of how tired you may feel. Keep in FOCUS the things you can do and remind yourself: "I AM MY OWN PERSON AND I AM O.K."

SYMPOSIUM SUMMARY: POSITIVE APPROACHES TO PARKINSON'S SERESC CONFERENCE CENTER, BEDFORD, NH | OCTOBER 13, 2012



NAME: Janet Edmunson, MEd, JME Insights

PRESENTED: "Living with Parkinson's: The Importance of Positive Emotions."

This uplifting discussion of new research in positive psychology illustrated how one can flourish emotionally while living with the challenges of Parkinson's disease. Ms. Edmunson provided practical skills to increase positivity in life that can be practiced and learned whether you are by nature an optimist, pessimist or "somewhere in-between." Ms. Edmunson speaks to patient,

family and professional groups across the country and extends her reach by providing health promotion webinars. She is also the author of "Finding Meaning with Charles," "Precious Lessons" (a chapter in "Wise Women Speak: Changes along the Path") and several published articles. More information is available at www.janetedmunson.com.



NAME: Benjamin Wolozin, MD, PhD

PRESENTED: "The Biology of Parkinson's: Mechanisms and Therapeutic Targets."

Dr. Wolozin led us through the complex science behind Parkinson's disease and how it is currently treated. He also provided hope for new treatments in his discussion of potential biological targets revealed through ongoing research. Exciting possibilities include:

- Counteracting mutations in PD-linked genes that disrupt the biological pathways required to keep our mitochondria (which produce energy required for our body's cells) healthy and functional

- Counteracting the effects of PD-causing mutations in the LRRK2 gene associated with familial cases of PD
- Reducing the impact of cellular stress granules on the biology of degenerative diseases like PD

Dr. Wolozin is Professor and Movement Disorders Specialist at the Boston University School of Medicine and the Edith Nourse Rogers Memorial Veterans Affairs Center in Bedford, MA.

THANKS TO ALL WHO PARTICIPATED IN OUR "CREATIVITY GALLERY: ART BY AND FOR PEOPLE WITH PARKINSON'S!"

We were inspired by the wonderful talents on display: photography, water color painting, jewelry, scrapbooking, and quilting. Please see the article on page 1 of this newsletter for Bob Grassi's story about how his passion for his art affects his approach to living with Parkinson's.

Line Dancing? Not Just for Cowboys!

You've probably heard of line dancing and associated it with country music, cowboys and weddings.

Recently this type of dancing has been recognized as a popular form of exercise as well. I am in my early 60s and have had Parkinson's disease (PD) for several years. In my quest to keep moving, I decided to take up dancing. I considered belly dancing but it didn't seem a good fit for me at this time. Line dancing appealed to me because you don't need to have any experience, and you don't need to have a partner. (You don't need cowboy boots either.)

Looking for a class offered locally, I went online, checked out the community billboards and looked through our local newspaper. Finally, in the "Calendar of Events" section of the newspaper, I found a notice of a class starting up. I telephoned several friends who I thought might want to join me, but everyone had something else to do, so I recruited my good-natured husband who agreed to accompany me to the community center.

On a cold January night when it was tempting to curl up on a couch at home, we arrived at the center and tentatively entered, wondering if we would be the only ones there. Gradually, others (mostly women) gathered. Our teacher was Jamie Orr, a well-known local dance instructor who has taught several forms of dancing throughout our area. He told us that he first offered line dancing about six years ago and two people came. The next year only one came! Since then, enthusiasm has built, and that night about 18 of us were lined up to try it.

To accommodate the diversity of talents and experience of the group, Jamie broke the class into segments. In the first segment, the dances were what he



PHOTO BY JAMIE ORR.
Jamie teaches ballroom, swing, Latin and line dance in the Upper Valley of the Connecticut River (NH/VT). Please contact him at www.swingjamie.com or (603) 359-5166.

called "pretty easy." Later segments were for more experienced dancers, and we watched them from the sidelines.

Jamie began with a warm up and then walked us through several common moves like the "swish" and "jazz box." Prior to turning on the music, he cheerfully went over the steps for beginner dances like the "Hustle." If you are not steady on your feet, like many of us with Parkinson's, this could be a little daunting, but I did get the hang of it. Once the music started, Jamie talked us through the steps (e.g., "back 2, 3 to the left 2, 3"), but sometimes you just need to stop and start again, which is not hard since repetition is a major part of this form of dancing.

In line dancing, everyone faces the same direction, but can end up facing any of the four walls in the room depending on how many times the dance sequence changes direction. Mostly, we danced facing the instructor but during one change of direction, I turned and found myself facing everyone. But no one seemed to find that strange. I realized that friendliness and patience must be traits of line dancers because we got lots of encouragement, and slowly, we are gaining skills and are

dancing more confidently.

The music, the enthusiastic instructor, the excitement of an evening out, being able to smile at our mistakes and chat with other dancers, as well as getting in exercise have kept us returning each week.

I found line dancing to be an activity that I can do with Parkinson's. Do you have a favorite activity that helps you work on your balance and flexibility? All of us in the PD community would love to hear what others are doing to keep energized and moving. Please email your experiences to me at gpalazzo@myfairpoint.net so that they can be included in a future newsletter. You will not just be helping those with PD, but also caregivers and all others who seek to age gracefully.

*Gay Palazzo
Lebanon, NH*

This is Gay's second contribution to this newsletter. She began writing after she retired from her job as a resource coordinator. She loves finding ways to get people together and sharing ideas and stories. Gay doesn't have a "bucket list" of things she wants to do, but would rather take it day by day and be open to whatever opportunity comes along. Maybe belly dancing will be next.

PARKINSON'S COMPANION IS A PUBLICATION OF THE PARKINSON'S CENTER AT DHMC

The Parkinson's Center at Dartmouth-Hitchcock Medical Center is an Information & Referral Center of the American Parkinson Disease Association, Inc.

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This newsletter is intended solely to provide you with information on Parkinson's disease. You should not make any changes in your treatment without first discussing them with your health care provider.

Oral Health...What's Parkinson's Got to Do With It?

Oral and dental health is often neglected in those with Parkinson's disease (PD).

The symptoms of PD and side-effects of medications make flossing and brushing more difficult and trips to the dentist a real chore. However, it is very important that this critical aspect of one's overall health not be overlooked. Poor dental hygiene contributes to painful oral conditions, increased risk of aspiration pneumonia, and inadequate intake of food leading to malnutrition, unintended weight loss and frailty.

Remember to discuss oral and dental hygiene with your dentist and doctor, and to enlist your family members and care partners to help you maintain good home care and regular dental visits.



MANAGING YOUR DENTAL VISITS

ACCESS

- Dental office is handicap accessible.
- Time is allowed for patient with slower gait to move to dental office.
- Caregiver assists in transfer of patient to dental chair.
- "Wheelchair dentistry" is very difficult: Transfer to the dental chair is expected.

TIMING OF APPOINTMENTS

- Short & frequent appointments: 45 minutes, every three months.
- Morning appointments are usually better.
- Take PD medication 1-1.5 hour before appointment starts.
- Late stages of PD: dental treatment under general anesthesia is expected.

Your dentist considers **ACCESS, TIMING, COMFORT, & SAFETY** in managing the dental visits of a Parkinson's patient.

COMFORT

- Patient should empty bladder before being seated in dental chair.
- Dentist relieves anxiety by adopting an easy-going "chair-side manner," including:
 - introducing herself/himself each visit,
 - asking questions with simple yes/no answers, and
 - using simple words & short sentences to explain a procedure.
- Caregiver presence can be calming.

SAFETY

- PD patient may be unable to keep mouth open, manage saliva or restrict tongue or head movements. Your dentist might:
 - use a bite prop to keep patient's mouth open,
 - recline dental chair to 45° angle (no lower!) to facilitate patient swallowing,
 - use rubber dam as necessary to protect tongue & prevent aspiration,
 - use high-volume oral suction device to remove excess saliva, or
 - request that dental assistant steady patient's head.
- Dentist raises chair slowly to avoid orthostatic hypotension (drop in blood pressure with change of position).
- Dentist is aware of interactions between PD medications & anesthetics used in dentistry.

FIVE “PROBLEM AREAS” OF CONCERN FOR THOSE WITH PD:

	CAUSES	COMPLICATIONS	RECOMMENDATIONS
<p>POOR ORAL HYGIENE</p>	<ul style="list-style-type: none"> Inadequate brushing & flossing caused by tremor, slowness of movement, muscle rigidity and dyskinesias Behavioral/cognitive symptoms: Apathy, forgetfulness, lack of awareness, missed or hampered visits to the dentist’s office 	<ul style="list-style-type: none"> Tooth decay and loss Gum disease Aspiration of food debris, dental plaque, and/or broken tooth that can lead to pneumonia 	<ul style="list-style-type: none"> Mechanical aids: toothbrush with large handle, electric toothbrush, flossing aids, Water-Pik® Chemical aids: fluoride toothpaste, rinses, & varnishes Caregiver assistance as needed, with written instructions from dentist More frequent visits with dental hygienist/dentist
<p>INVOLUNTARY FACE, TONGUE, & JAW MOVEMENTS</p>	<ul style="list-style-type: none"> Tremor Rigidity & cramping of facial muscles Dyskinesia 	<ul style="list-style-type: none"> Tooth grinding & jaw clenching Mouth, jaw & facial pain Worn, cracked, sensitive teeth/loss of teeth Difficulties in wearing dentures 	<ul style="list-style-type: none"> Medication review by neurologist Tooth guards Replace dentures with tooth implants
<p>DROOLING OF SALIVA FROM CORNERS OF MOUTH (occurs in 75% of people with PD)</p>	<ul style="list-style-type: none"> Inefficient & infrequent swallowing Inability to close mouth fully Forward-leaning posture 	<ul style="list-style-type: none"> Social discomfort Choking sensation Aspiration of excess saliva into the lungs, increasing risk of pneumonia “Angular cheilosis” = redness & cracking at corners of mouth due to persistent moisture/yeast infection or Vitamin B deficiency 	<ul style="list-style-type: none"> Speech therapy to improve swallowing and control of facial muscles Suck on sugar-free candy to increase frequency of swallowing Pay attention to maintaining upright posture Botox injections to reduce production of saliva For angular cheilosis: attempt to keep corners of mouth dry. Apply topical antifungal product. Request nutritional deficiency assessment.
<p>XEROSTOMIA (DRY MOUTH) “The most devastating oral complication from a dental point of view.” Elaine Neal, DMD, PA</p>	<ul style="list-style-type: none"> Symptom of Parkinson’s Side-effect of most Parkinson’s medications 	<ul style="list-style-type: none"> Increased risk of oral infection Tooth decay Periodontal disease Ill-fitting dentures Difficulty speaking and swallowing 	<ul style="list-style-type: none"> Stay well-hydrated: sip water frequently Avoid tobacco and alcohol Avoid mouthwashes containing alcohol, and toothpastes containing peroxide Use mouth moisturizing products Request a medication review from your neurologist
<p>“BURNING MOUTH SYNDROME” (occurs in 25% of people with PD)</p>	<p><i>Cause usually unknown, but possible medical causes include</i></p> <ul style="list-style-type: none"> Dry mouth Nutritional deficiencies Hormonal imbalances (in females) 	<ul style="list-style-type: none"> Depression Difficulty sleeping Difficulty eating possibly leading to nutritional deficiencies Difficulty caring out oral hygiene 	<ul style="list-style-type: none"> Request that doctor rule out possible medical causes See recommendations for dry mouth

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The Ultimate Gift

A STORY OF LOVE AND DEDICATION
by Maureen M. Chamberlain

Parkinson's disease (PD) will change your life. No one would debate that. There are things you can do to help yourself, such as keeping physically fit, eating properly, balancing your medications with your diet, taking your medications on time, joining a Parkinson's support group and maintaining a positive attitude.

And there are times when you need someone to help you to complete simple tasks, like cutting your meat into small pieces, buttoning the collar on a dress shirt, zipping up an outfit with a back zipper, fastening your favorite necklace, holding a hair dryer while fluffing your hair with a brush, tying a knot in your tie, moving quickly out of harm's way or getting out of bed and into a standing position. These are tasks that most people perform automatically and without need for assistance.

Those of us with Parkinson's disease never realized how much we would depend on our spouse, a friend or other family member to assist us with the most ordinary tasks. Each of us has a story to tell about someone who loves us and has made our lives easier, more comfortable or less painful.

Marcia de Sousa was diagnosed with PD in 2007. Marcia and David, her husband of 46 years, educated themselves about PD, reading, attending symposia, joining a support group and scanning the Internet for information. And then Dave's interest was piqued by a website, and he made a life-altering decision.

In his 60s, Dave decided to become a Licensed Massage Therapist (LMT), leaving behind his work as a management



Dave and Marcia de Sousa
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consultant. His focus was on SLM Bodywork, a technique developed by an Australian Massage Therapist, Steve Lockhart. The goal of this unique method is to eliminate or significantly reduce pain. While Dave was learning Steve's method via an online course, he also attended classes at the North Eastern Institute of Whole Health School of Massage Therapy in Manchester, NH. Dave is one of only four licensed massage therapists in the US who are also trained in SLM. Marcia benefited immediately from the massage therapy treatment that Dave had learned. From the beginning of his massage training, Dave knew that he wanted to work with people diagnosed with Parkinson's. Rigidity and pain, including cramps in your legs, feet, or hands and stiffness or aches in your back, shoulders or neck, are common symptoms of the disease that are invisible to others. Massage therapy is especially helpful in relieving these symptoms.

David has successfully obtained his license to practice in the state of New Hampshire. Learning the art of massage therapy requires not only classroom hours but also 125 supervised hours applying and mastering the massage techniques. Dave has over 1,000 hours of training in massage therapy. He reached for the stars and attained his goal, recently opening his business, Relief Bodyworks & Massage in Meredith, NH. Dave will make house calls to serve his clients when necessary. He specializes in working with athletes, those who do physical work and people with Parkinson's disease.

Dave is happiest and finds the greatest satisfaction in relieving Marcia's pain. That is the reason for his career change. He made this decision from his heart. He has given his wife the ultimate gift and is dedicated to lessening her pain. He also knows that he is able to help others, including many within the Parkinson's community.

MEMOS FROM MAUREEN



Our 3rd Annual Walk-in-the-Park for Parkinson's research was held on a perfect autumn day at Greeley Park in Nashua and was well-attended. Our major sponsors generously contributed financially, walked with us at the event, and assisted in numerous ways: hanging banners and balloons to mark the route, registering walkers and teams, distributing T-shirts, painting faces, passing out water and yogurt, and distributing raffle tickets and prizes. The walk has grown in success each year, with over \$6,000 raised for Parkinson's research in 2012. Thank you to our major sponsors, Health South, Northeast Rehabilitation Hospital, G. M. Roth Design Remodeling, and Crowley Associates and to Stonyfield Organic, St. Joseph's Hospital, Elliot Hospital, Laurel Trahan of Age at Home, Bob & Sons Automotive, financial advisor Michael E. Shaughnessy, children's book author Kathy Brodsky, and Bill and Kathryn Flynn of Arrow PC Services

for their generous contributions and advice.

We are grateful to our walkers and teams who raised awareness and dollars for Parkinson's disease. You are the heart and soul of our APDA NH Chapter. Optimism grows because of you. Our support groups and your tax deductible monetary gifts help us "to ease the burden, to find the cure."

Please join the New Hampshire Chapter of the APDA (see form on page 7). Your annual membership supports chapter events, awareness activities and educational forums. Additional benefits include a free walk T-shirt, one free ticket in all raffles, 10 percent discount on all chapter-sponsored social events, and a vote at our annual meeting for election of board officers.

Thank you to everyone who attends our fundraising activities and joins our NH Chapter. Your contributions are tax deductible.

Maureen M. Chamberlain
NH Chapter President, APDA

ANNOUNCEMENTS AND EVENTS

FROM THE APDA PARKINSON'S INFORMATION AND REFERRAL CENTER AT DARTMOUTH-HITCHCOCK MEDICAL CENTER

TUESDAY, APRIL 9, 11:30 AM-1 PM PARKINSON'S EDUCATIONAL PROGRAM AND LUNCHEON

Sponsored by Teva Neuroscience, Fratello's Restaurant, Manchester, NH
Presentation by William Severt, MD, PhD. Registration is required for this free program. Call (603) 434-6252 or (603) 490-5063 to register or for more information.

THURSDAY, APRIL 18, 6-7:30 PM CANDLELIGHT VIGIL TO BRING AWARENESS TO PARKINSON'S DISEASE CONCORD, NH

Join us on the steps of the State Capitol building. 50/50 raffle to benefit the APDA NH Chapter: tickets sold throughout the month of April. Contact: Maureen Chamberlain at (603) 434-6252 or email mchamberlain.apdanh@gmail.com

SATURDAY, APRIL 27 19TH PARKINSON'S UNITY WALK NEW YORK CITY, NY

A gentle 1.4 mile walk in Central Park with informational booths and food trucks; walking optional! Tax-deductible donations to the Unity Walk are distributed to the major U.S. foundations for Parkinson's research, including the APDA. More information at www.unitywalk.org

SATURDAY, APRIL 27 8:30 AM-2:30 PM "OUR JOURNEYS TOGETHER," AN EDUCATIONAL EVENT IN HONOR OF PARKINSON'S DISEASE AWARENESS MONTH DHMC, LEBANON, NH

- Presentations by Caroline P. Moore, MPH and Nancy Sporborg & Pat Piper ("It's Not About the Hike!")
 - Afternoon seated dance workshop with Jenny Gelfan, Dance Instructor
- \$15 per person includes continental breakfast and box lunch. Space is limited. Pre-registration must be received by April 17 but seats may fill sooner.

MONDAYS AND THURSDAYS, JUNE 17-JULY 29, 10-11:30 AM (EXCEPT FOR JULY 4) PLUS PRE- AND POST-ASSESSMENTS SPRING 2013 PARKINSON'S WELLNESS PROGRAM (12 SESSIONS) DHMC, LEBANON, NH

Exercise, balance, gait training, and education program led by DHMC's Rehabilitation Medicine specialists to help those with PD achieve a better quality of life. "Medical Eligibility Form" is required to ensure that the program is appropriate and safe for you. The cost of \$149 (less than \$7.50 per hour for all classes and assessments) includes a Wellness Program Exercise guide. Scholarships are available.

SAVE THE DATES!

SEPTEMBER 2013
DATE AND TIME TO BE ANNOUNCED
4TH ANNUAL WALK-IN-THE-PARK FOR PARKINSON'S RESEARCH
GREELEY PARK, NASHUA, NH
All proceeds are donated to APDA Parkinson's research programs. Contact: Maureen Chamberlain at (603) 434-6252 or email mchamberlain.apdanh@gmail.com

OCTOBER 1-4, 2013
3RD WORLD PARKINSON CONGRESS
MONTRÉAL, QUÉBEC, CANADA
Registration is now open; best rates if you register by July 2
Lodging registration is separate; discounted rates available at website below. October is a busy month in Montréal, so reserve at your preferred hotel before all are booked. Remember: Passport is required for travel between the US and Canada. More information at www.worldpdcongress.org

For information, please contact Diane L. Church at (603) 653-6672 or send email to Diane.L.Church@hitchcock.org or the person noted for a specific announcement.



2013 MEMBERSHIP DRIVE JOIN THE NEW HAMPSHIRE CHAPTER OF THE APDA!

Name _____ Date _____

Address _____

Phone # (____) _____ E-mail _____

Annual Membership (\$20 per household) or Other Donations: \$ _____

Corporate Sponsorship \$25 _____ \$50 _____ \$100 _____ Other _____

____ Yes, I would like to serve on the Chapter Board or contribute my skills, time, and/or resources to the Chapter's efforts.

Kindly complete the form on this page.

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