



CATALYST

Growing Funds for Parkinson's Research

The Parkinson Alliance Quality of Life Scale (PAQLS)

by Jeffrey Wertheimer, Ph.D

Deep Brain Stimulation (DBS) has emerged as an effective and promising therapy for Parkinson's disease (PD) and typically results in an improvement in health related quality of life (QoL) (Benabid et al., 2005). Prompted by our previous research (Tuchman et al., 2004; Wertheimer et al., 2004) and limitations of existing PD-specific QoL measures, The Parkinson Alliance designed a QoL survey with the intention of creating a unique and comprehensive self-report measure of QoL in PD patients, The Parkinson Alliance Quality of Life Survey (PAQLS). In the paragraphs that follow, we have provided a brief summary of our initial results.

Let us first introduce the PAQLS. It is comprised of three sections. The first section assessed self-reported motor and non-motor symptoms related to PD. The second section assessed psychosocial factors associated with QoL, including interpersonal relationships, recreation, occupation, independence, and other variables. The final section of the survey assessed satisfaction with DBS therapy, including overall effect of DBS, adjustments and follow-up treatments, changes in symptoms after surgery (i.e., motor and non-motor symptoms), expectations of medication reduction, complications after surgery, among other factors.

As in our previous research, a mail-survey was used to collect information. The participants included 94 individuals with PD who underwent DBS and a comparison group of 86 individuals with PD without DBS. The participants represented a broad geographical range, with a total of 33 states represented. Both genders are

equally represented for each group. Most of the participants were married and not working. The DBS group's disease duration was nearly twice that of the non-DBS group (16 years vs. 8 years). *All analyses took into account disease duration to minimize potential group differences that would be attributable to disease duration.*

Our initial results found that there were no significant differences between the DBS and non-DBS groups on the following motor symptoms: bradykinesia, stiffness, freezing, dystonia, and number of falls. In contrast, there were significant differences between groups on the following symptoms: poor balance, gait disturbance, dyskinesia, and tremor. Specifically, individuals with DBS reported less severe tremor and dyskinesia than the non-DBS group, but they reported more severe gait disturbance and poor balance. Regarding the relationship between motor symptoms and QoL, as expected, regardless of whether or not the person has had DBS, motor symptoms were significantly negatively related to overall QoL. Overall, in this sample, worse motor symptoms were associated with poorer self-reported QoL.

Non-motor symptoms were categorized into four areas, psychological distress, speech, cognition, and sleep. Consistent with previous research, the variables of psychological distress, speech problems, cognitive and sleep symptoms were all significantly negatively associated with QoL. Overall, a large percentage of both groups were experiencing problems with non-motor symptoms, which highlights the importance of investigating and treating non-motor symptoms in PD.

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There was not a significant difference between emotional/distress variables and sleep-related variables between groups. However, the DBS group reported significantly worse speech problems, including low volume, slurred speech, and speech articulation. There was an absence of differences with regard to perceived problems with concentration, word-finding problems, trouble thinking clearly, difficulty planning/organizing, slowed thinking, and impulsivity.

Regarding the DBS-specific portion of the PAQLS, the vast majority (94%) of DBS participants reported being

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Jeffrey Wertheimer, Ph.D.

Message from the Executive Director, Carol J. Walton



In February I attended the Parkinson's Action Network annual public policy forum and the World Parkinson Congress in Washington DC. In speaking with patients and advocates, it seemed to me that half the people I spoke with already had Deep Brain Stimulation (DBS); the other half were considering this surgery.

For the "right candidate," we believe that DBS is a wonderful therapy to help enhance the quality of life for people with Parkinson's. For those who may not be aware, Margaret Tuchman, President of The Parkinson Alliance, had DBS surgery in December of 2000. In 2001 she created a website—DBS-STN.org. We are committed to helping improve the quality of life of DBS-STN patients and their caregivers. Through patient and caregiver surveys, we are not only asking questions but providing answers that will assist in educating about this therapy.

After having DBS surgery a major challenge is to assure you have a seasoned programmer to adjust the stimulators. In an effort to meet this challenge The Parkinson Alliance, in partnership with Medtronic, contracted with WE MOVE—the Internet's most comprehensive resource for movement disorder information. WE MOVE recognized that there is no cookie-cutter approach to DBS programming and in general, the more experienced programmer, the better the result for the patient. The solution was to provide a place on the WE MOVE website where novice programmers could post questions and get feedback from more experienced programmers—in short, to accelerate the learning curve and improve outcomes for patients living with Parkinson's disease.

If you've had DBS, next time you go in for a program adjustment, ask your programmer if they are aware of this website. To make this easy, go to our website: DBS-STN.org and click on the button (DBS/STN Programmers Forum) under the picture of Margaret Tuchman at her computer. We also encourage you to visit our website and forum with any questions, and please feel free to call us at 1-800-579-8440. ☺

Message from the President, Margaret Tuchman



Many of you participated in The Parkinson Alliance Quality of Life Survey during the past 8 months. The report of the results will be arriving in your mailbox (if you are one of the 180 survey participants). The rest of you will have the opportunity to study the results on our website (www.parkinsonalliance.org and www.DBS-STN.org).

We took a bold step and decided to design our own survey. We used the information you provided from the prior 3 surveys. I want to offer you assurance that we listened and learned a great deal about your daily triumphs and recognized the area where you need help.

We believe that by having both DBS-STN and non-DBS-STN individuals answer common questions, we created a more realistic world where a PWP and caretaker are facing the DBS decisions: Should I have the surgery? When would be the best time to have it? And, of course, where to go for the surgery?

We took advantage of an opportunity to enlarge our circle of regular contributors by asking fellow PWP (non-DBS-STN) Ram Chandran to add to our experience of traditional medicine a balanced mix of alternative and complementary therapies. This combination of medical approaches is being called "Integrative Medicine" and may include the use of herbs, vitamins, yoga, tai-chi, homeopathy, biofeedback and many other lines of therapy. Ram will introduce this vast topic in this issue of the Catalyst, but will continue to bring news of clinical research and results appearing on The Parkinson Alliance website (www.parkinsonalliance.org). I urge everyone to read, learn and check with their doctor about safety in mixing PD drugs with any of the therapies discussed in the Catalyst.

The topic of integrative medicine can be discussed on our Forum, www.DBS-STN.org. This is one of the family of websites that is offered as an information/education segment of The Parkinson Alliance. ☺

Roberta Rubin Greenberg Launches New Nursing Specialty

by Roberta Rubin Greenberg

Roberta Rubin Greenberg, RN, CNOR, RNFA, has launched what may be the nation's first specialized private practice in programming for movement disorder patients who have undergone Deep Brain Stimulation surgery.

Working with Dr. James P. Sutton at Pacific Neuroscience Medical Group in Oxnard, California, she will be heading up the facility's new Neurotechnology Clinic, in which she will fine-tune the programming of implanted neurostimulators for each patient, a service generally performed in hospitals by nurses and others who do this among numerous other daily duties. With a national reputation as one of the leading programmers, she is becoming what may be the nation's first exclusive specialist in this area.

Following Deep Brain Stimulation surgery, in which electrodes are implanted in the brain to help control Parkinson's disease tremors and dystonia symptoms, the implanted neurostimulator, or generator, that controls the electrical pulses must be programmed to suit each patient. Few programmers go beyond the basics in setting the devices, few receive special training, and fewer still are involved in the actual implant surgeries.

By contrast, Roberta - known for her humorous approach and willingness to "color outside the lines" - has been one of the leading innovators in the programming of neurostimulators, giving her a reputation as one of the best in the nation. Her unique "perioperative" approach to patient care, working with patients each step of the way before, during and after surgery, has enabled her to know and respond to patients' needs on an individual basis.

Dr. James Sutton says: "Roberta's active participation in the intraoperative neurophysiological evaluation of hundreds of patients has given her remarkable insight into the intricacies and subtleties of deep brain stimulation."

Carol Walton, Executive Director of The Parkinson Alliance, Princeton, NJ said: "Roberta's skills, knowledge and creativity—combined with her intense desire to make every single patient as good as they can be—make her one of the best nurses/programmers in this country, maybe in the world." Patients have come to her from hundreds or even thousands of miles away, to avail themselves of her expertise and knowledge.

From Feb. 2000 through March 2006 Roberta was the clinical supervisor and head nurse of the California Neuroscience Institute at St. John's Regional Medical Center in Oxnard, California. She has been on staff at some of the most progressive neurosurgical centers in the country, including the New England Medical Center in Boston, Barrow Neurological Institute in Phoenix, Cedars Sinai Medical Center in Los Angeles and Hoag Memorial Hospital Presbyterian in Newport Beach, Calif., and has been instrumental in creating movement disorder surgery programs at each of them.

In 2005, Roberta also joined the WEMOVE faculty for the DBS-STN Discussion Forum. *Roberta Rubin Greenberg* Among her other professional credits, she regularly contributes expert advice to online DBS forums at Yahoo and DBS-STN (links at www.brainnurse.com/Links.htm) and provides consulting and training services to DBS centers nationwide. Information about Roberta and her work is available at her new web site, www.brainnurse.com. ☺



How to Make a Good Product Great

by Dan Stark

It's hard to be helpful without people becoming suspicious. I hope the good people at Medtronic know that I am not being critical. I had Deep Brain Stimulation a few months ago, and I have four pieces of your hardware in me: two electrodes in my brain, and two battery pack/control units in my chest. That's not counting the wires that run just under the skin between brain and chest. They are all working fine, thanks.

That's not to say they are perfect, however. Consider the following suggestions as a small down-payment of the debt of gratitude I owe you for help restoring my life from the ravages of Parkinson's disease. I figure you are the same as everyone else - sometimes you keep your head down and are just too darn busy working on trees to see the forest. Here are some ideas that can make your products so attractive that even those who don't have Parkinson's will want them implanted!

1. License Rolex' Kinetic Energy Technology

Your batteries wear out rather quickly. If I last more than three to four years, I am likely to require additional surgery to replace the old batteries with new ones. As one who has had his share of surgery, permit me to tell you that stinks! Here's a better idea. Go to a good jewelry store and look at a Rolex watch. Guess what, it has no battery. If you wear it regularly, it will run forever. It generates the power it needs using kinetic energy from bodily movements.

This seems a perfect solution. The DBS electrodes are not electricity hogs. Even if they were, the average user of your product, even post surgery, moves around a lot more than the average Rolex customer. One good bout of dyskinesia and we could charge the apparatus for months. If you feel your batteries are running low, you could just pop a few extra pills. By the time you stop shaking you are fully charged and ready for action!

2. License the Nano from Apple

No offense, but your apparatus are really kind of big. I assume mine were correctly installed where they are supposed to be, but they poke out of my chest, still under the skin, but honestly making me look a bit freaky.

The size of these reminds one of consumer electronics a few decades ago. One of the great advances of modern engineering has been miniaturization.

To catch up, simply license the iPod technology from Apple Computer. iPods are adding functionality all the time, yet they are both small and elegant. Imagine if the Medtronic product were no bigger than the Nano. It could easily be implanted into the chest without protruding in the

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Integrative Medicine

by N.S. Ramachandran

During my work career I wanted to be a Mover and Shaker. I got my wish. I was diagnosed with Parkinson's disease (PD) in 2002, officially that is. So the moral of the story is "be careful what you wish for." In retrospect I had many symptoms of PD several years prior to my diagnosis but did not make the connection. I am sure many of you have similar stories where you have experienced some of the symptoms of what was later diagnosed as Parkinson's.

A year prior to my diagnosis I experienced episodes of freezing and the feeling of walking in quicksand, especially when I walked to my car at the end of a long day at work. I attributed it to work related stress, or possibly problems with my hip, which was replaced a year earlier. After being in denial for a year I finally got the "tough love" intervention talk from my family. I went to the neurologist and was told that I had a "movement disorder problem" called Parkinson's disease. I was immediately put on a "dopamine receptor agonist" with the assurance that the agonist would solve my movement problems for at least eight to ten years before I would have to go on something stronger like Sinemet. The reality was that I had to go on Sinemet within 6 months. It was the beginning of my saga of dealing with this insidious disease and all its side effects. This was followed by more pills to treat the side effects and even more pills to deal with the side effects of the side effects. Sound familiar?

Mainstream healthcare has three primary approaches to treat diseases — prescribe drugs which are often toxic or replete with side effects, radiation of the disease and its attendant side effects or finally, when these approaches do not work, excise the disease surgically. Some drugs have the dubious distinction of suppressing your immune system completely leaving you vulnerable to any and all viral and bacterial invaders. Believe me, I have experienced all three modalities, the best that the world's leading nation's healthcare system has to offer. Each of them has taken their own toll over the years.

To a large degree, doctors just treat symptoms and practice "crisis intervention" medicine. Until recently drugs were used in "shotgun" mode and not only targeted diseased cells but also healthy cells. This was the collateral damage one had to settle for — the price of modern medicine. Fortunately, that paradigm is changing and some of the newer pharmaceuticals are more precisely targeted. However, many drugs continue to treat symptoms. Our language to deal with illness and disease uses words like killing the diseased cells, fighting diseases and eradicating viruses, etc. It has all the elements of a war footing and a fighting stance against our own body. It is not surprising that even as we deal with many traditional diseases like cholera, malaria, polio, TB, etc., we are still struggling to battle conditions which are chronic, long lasting, and progressively debilitating — physically, emotionally, and mentally.

Healthcare costs are continuing to rise. Current solutions to the healthcare crises end up shifting the cost burden increasingly to the individuals and their families and to tax relief programs, like

healthcare savings accounts, for those who can afford them. It just seems like we are rearranging the deck chairs on the Titanic. We are practicing health crisis management, not health care management. Have we resigned our efforts to providing symptomatic relief instead of finding genuine prevention or cure?

This scenario is similar to the times when people believed that the earth was the center of the universe. Ideas to the contrary ensured one a one-way trip to a bonfire, where you were the main act, or a full spinal stretch at the local inquisition spa.

Well, times have changed. We have known for some time now that, for the time being anyway, the sun is the center of our universe, if not the universe. No great cosmic upheaval or a cataclysmic event. Just a shift in perspective.

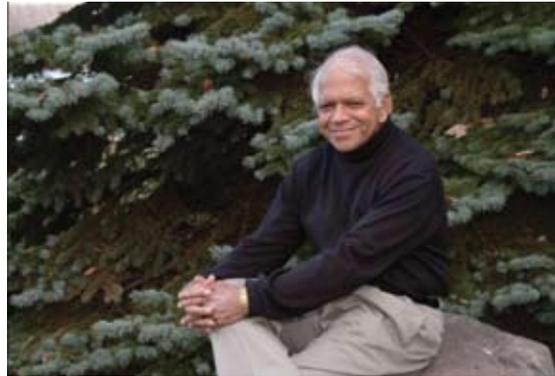
Similarly, for healthcare, the current paradigm is "disease centric" where the focus of therapies is to deal strictly with the disease at hand and its attendant side effects as they emerge. The new paradigm is to look at therapies, which are "patient centric," and takes a holistic view of the patient as being made up of Body, Mind, and Spirit. While spirit is not in the realm of modern medicine, the point is that the patient is treated as an "integrated whole" of body/mind/spirit instead of a fragmented entity.

So for the new healthcare worldview, the shift in perspective is to look to Complementary and Alternative Medicine (CAM). What does it include? The National Institutes of Health (NIH) defines CAM as "a group of diverse medical and health care systems, practices and products that are not presently considered to be part of conventional medicine." As some of the CAM therapies become effective and are considered safe, they become adopted into the conventional health care mainstream. Shades of eminent domain!

In fact NIH considers this important enough to have a separate center, National Center for Complementary and Alternative Medicine (NCCAM), which focuses on the whole arena of CAM. NCCAM is the Federal Government's lead agency for scientific research on CAM and, in the context of rigorous science, dedicated to exploring complementary and alternative healing practices, training CAM researchers, and disseminating authoritative information to the public and professionals.

What types of therapies does CAM encompass? For research purposes NCCAM has identified four "domains" of interest, which are Mind-Body Medicine, Biologically Based Practices, Manipulative and Body Based Practices, and Energy Medicine. In addition they plan to explore "whole medical systems" alternatives such as Homeopathy, Traditional Chinese Medicine and Ayurveda for treatments of selected health conditions.

You probably will recognize some of these CAM therapies and may well be using them in your day-to-day living. They include such things as taking herbs and vitamins, getting acupuncture



N.S. Ramachandran

treatments, chiropractic or osteopathic adjustments, massage, and naturopathic medicine. What you may not know is that it also includes exploring healing methods such as meditation, energy therapies such as bio-electromagnetic based therapies and bio-field therapies.

So what do we expect CAM to do for us Movers and Shakers — the PD community? Let me put this in perspective. Life is too short. As a wise old sage said “life is a parenthesis in eternity.” Most people have 24x7 hours a week to be on purpose and learn and enjoy their time on earth. But the PD patient has an even smaller window. Between “off time,” “on-time,” and the time to get prepared for the coming ON and going OFF, and scheduling the drug cocktails we are lucky to get 15 minutes each day of quality time — no tremors, no dyskinesia, no freezing, no falling or getting ready to fall, and above all being pain free.

This means we cannot just accept symptomatic relief with its many side effects of conventional medicine. We need to reach for cures and prevention of the dis-ease that comes with Parkinson's. It is estimated that there are a million of us in the United States. This population is likely to increase as more of the baby boomers cross the magic threshold of the mid-fifties and become candidates for Parkinson's or one of the other menu choices — diabetes, cancer, heart problems, or Alzheimer's. We are living longer. But it cannot be for 15 minutes a day.

We are making great and significant strides in discovering the root causes for Parkinson's. The compelling, long-term vision should be to discover some type of vaccine and prevent Parkinson's from happening. This is for the future. For those of us who already have it, we should be looking, at a minimum, for symptomatic relief without side effects. The progression in therapy should be to arrest any further deterioration. Finally, we need to discover ways to regenerate, at a cellular level, the body's own immune system to reverse the tide of debilitation and the chronic condition.

Complementary and Alternative Medicine and therapy offer the promise to have no or minimal side effects. Its focus is on activating the body's own immune system to perform the healing. The paradigm shift will also require us to take more responsibility for our own healing. This will require integrating the medicine cocktail or DBS adjustments with positive changes in our mind set towards dealing with Parkinson's.

Unlike our ancestors who had to migrate from an earth-centric to a sun-centric worldview, conventional medicine and CAM will likely co-exist and provide for integrative medicine that combines mainstream medical therapies and CAM therapies for which there is some high-quality scientific evidence of safety and effectiveness.

There are a number of studies and clinical trials that have been spawned by NCCAM in the domains of interest that include: Alternative Medical Systems, Mind-Body Interventions, Biologically Based Therapies, Manipulative and Body-Based Methods, and Energy Therapies.

We will be monitoring the research directions and clinical trials for CAM. Through this newsletter and our website, DBS-STN.org, we will provide you our assessment of the progress of these trials and also links to relevant information for your review and consideration. ☺

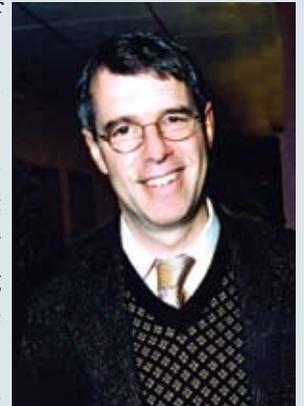
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least. You could have two of them as before, and no one could tell.

In fact, why not just license the Nano? It's programmable, and with a little ingenuity, likely could do everything your current device can do in a much smaller package. You could load your software onto it and implant it rather than your current product. This will open other doors as well. Remember that the wiring under the skin goes from chest and wraps around the ear on its way to the brain. Perfect! You could implant the iPod's smallish headphone cord at the same time as the cord you now use, and just drop it off at the ear. That way those of us with DBS would be able to listen to music on demand, right in our own heads!

3. Go Wireless

I don't know who the industry leaders are in wireless technology but you have only to look around you to see that you don't really need wires to get from point A to point B. You could eliminate the need for wires altogether with off the shelf expertise from someone who has it, both for your own products and for the Nano – implant version. It then becomes a smaller leap to allow the units to communicate not only with the electrodes in your brain but with other people having the appropriate apparatus to receive signals from you.



Dan Stark

Think “out of the head,” and you may come up with something so nifty that even those without Parkinson's will want it. Once again, however, we will be the lucky ones. Given that even your unimproved products cost about one hundred thousand dollars to have installed, we may – assuming insurance will not cover those who want this done for other than therapeutic reasons – be the only ones able to afford it.

You're welcome. ☺

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satisfied or very satisfied with the overall effect of DBS. DBS participants were also generally satisfied with the programmer, post-surgical follow-up, and medication reduction expectations. The variables that many DBS participants reported being dissatisfied with were the distance they have to travel to meet with a programmer, speech problems, and weight following surgery (most often weight gain). There were many DBS variables that were related to QoL, including satisfaction with DBS over time, stability of improvement, the reduction of On/Off episodes, reduction of medications, the programmer, speech, post-surgical follow-up, and one's weight.

The aforementioned summary provides only a glimpse into many of the interesting findings from our recent survey. A more extensive summary of our initial findings and conclusions can be found on our website (www.DBS-STN.org). ☺

Parkinson's Unity Walk — "Unity" is our middle name

By Trina Stokes, Event Director



Team: "Full of Schmidt"

The word Unity means oneness or the state of being in harmony. This definition may come as no surprise to many but to the participants of Parkinson's Unity Walk it goes deeper—it's a way of being connected for one purpose and that's to help find a cure for Parkinson's disease.

Parkinson's affects all walks of life, and people from across the United States and the World want to feel like they are doing something to help eradicate this debilitating disease. We share in a common defense which incorporates a balance between self-interest and shared-interests. Subsequently, we take ownership of this disease by increasing awareness within our local communities by way of education, support groups and raising donations for Parkinson's research. Parkinson's is a giant but together we have the power to affect tremendous change through engagement and the Parkinson's Unity Walk is a useful source.



Founder, Margot Zobel

The Walk is the largest grassroots fundraiser in the country, and it takes into account many entities to ensure success. The participants coordinate walks, golf tournaments, concerts, social events, and sale merchandise such as candles or wrist bands and send the proceeds to the Walk. Not everyone can attend the Walk in Central Park but this does not stop them from being involved. Anyone can raise funds no matter where they live.

We pull out all the stops and this begins to change the way we view the disease. There is a realization that this disease doesn't have to hinder one's hope for a life of achievement. Our participants prove this each year and we have come a long way! In 1994 we had 200 walkers and raised \$16,000; in the year 2005 we had 8500 walkers and raised over \$1 million dollars in less than 12 months! A full 100% of donations raised are designated for Parkinson's research.



Volunteers: Marie-Nella Giordani,
Marie Muscat, Debbie Unger

These efforts and those of the supporting Parkinson's foundations have made a significant impact on Parkinson's research. The aim is to fund the most promising research to get us closer to a cure. Each year the contributions are committed to the American Parkinson's Disease Association, National Parkinson Foundation, Inc., Parkinson's Action Network, Parkinson's Disease Foundation, The Michael J. Fox Foundation for Parkinson's Research, The Parkinson Alliance and the Parkinson's Institute.

We all have a common denominator and we will continue to fight in the name of Unity. After all, Unity is our middle name.

To receive more on Parkinson's disease and the Parkinson's Unity Walk, please visit www.unitywalk.org or call 1-866-PUW-WALK (789-9255). ☺



Parkinson's Summit at the National Parkinson's Foundation January, 2006

left to right: Jose Pedrosa (NPF), Ronnie Todaro (PDF), Maryann Sprinkle (NPF), Debbie Brooks (MJFF), Ruth Hagestuen (NPF), Amy Comstock (PAN), Monica Billger (PAN), Carol Walton (PA), Joyce Oberdorf (MJFF), Pam Olmo (NPF), Robin Elliott (PDF), and Joel Gerstel (APDA)

Why did I get involved with Team Parkinson and why do I continue fundraising for the group?

By Aaron Moretzsky

When I was diagnosed with Parkinson's I was devastated. What did the future hold in store? What would be the quality of my life? What would happen to my wife and me? The questions and fears rolled over and over. I was lucky to become a patient of Dr. Bronstein at UCLA who managed to put my fears and questions to rest and to provide me with the professional support to continue living as best as I could ... But I had to do something to help myself ... and as I thought about what I could do, a letter arrived from Cedars Sinai regarding a program sponsored by Team Parkinson



Aaron Moretzsky

to raise money for research via the L.A. Marathon. I called the listed number and the second most important person in my life,

relating to Parkinson's, answered and I was hooked. Edna Ball enthusiastically accepted an idea I had to raise funds and the rest is history.

How does one sum up the impact of Edna, John and Carol ... it is in the following words my son has displayed in his home:

Some people come into our lives and quickly go. Some people move our Souls to dance.

They awaken us to new Understanding with the Passing whispers of their Wisdom.

Some people make the Sky more beautiful to gaze upon. They stay in our lives For awhile, leave footprints On our hearts and we are Never, ever the same.

– Anonymous

The Success of Team Parkinson is a "Team" Effort

By John and Edna Ball

The City of Los Angeles Marathon takes months of preparation for everyone involved. But sometimes all the preparation in the world can't prevent injuries and I went down with back spasms just five days before the race. I couldn't recover in time, so my string of consecutive LA finishes is broken at ten.

Nonetheless, the weekend was a big success! Team Parkinson (TP) met or exceeded every one of its goals. We had our biggest group of athletes ever - with over 150 participants in LA and 45 more at a satellite walk in Orange County. We had our most successful carbo dinner with over 135 team members, family and guests attending. Thanks to Norm Reeves Superstore for sponsoring the dinner. Featured speakers, Drs. Oleg Kopyov and Jeff Bronstein were both informative and optimistic about the future of PD research and treatment. And we exceeded even our most optimistic estimates in fundraising. With one event still on our calendar (our upcoming 1st Annual TP Golf Tournament in May) we just passed the \$200,000 mark for the fiscal year!

This huge success would not have been possible without the dedication of many people. The list of those contributors stretches from coast to coast. It starts in NJ with Carol Walton, Trina Stokes, and the staff of The Parkinson Alliance who provide us with direction and support of the highest order. The support of our premier sponsor Novartis has been invaluable. Additional help came from Ruth Hagestuen of NPF, Robin Elliott of PDF and Amy Comstock of PAN in their efforts at the World Parkinson Congress to make TP a visible player in the world of patient advocates. Particular thanks to Carol and Robin for their efforts to get us attention in the national media, which helped us so much this year.

The same is true on the local level. We are blessed to have some very special volunteers work for TP. May May Ali, Justine Lassoff, Laurence Cohen and Jennifer Cody have worked diligently to keep us visible in the media. The doctors, researchers and staff at USC have been extremely supportive. Thanks to Drs. Jakowec, Petzinger and Welsh for being such great friends. Special thanks to Novartis rep Athena DiLeva for always showing up.

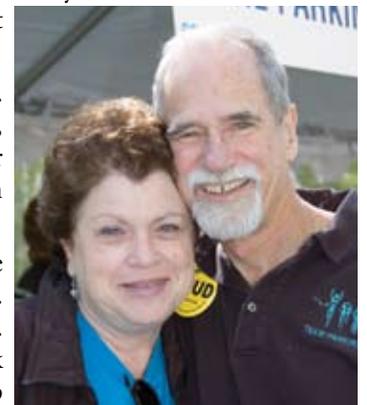
With over 100 athletes participating in the 5K, I got to witness that sea of blue shirts and it was impressive! We had two trophy winners as Ruth Cole took second in her age group and Jerry Woudenberg finished third in his. At the same time in Orange County, a group of 45 walkers were led by cousins Ethan and Erin, just 13 and 12 years old!

The bike ride was once again too early in the morning for me to see, but I do know that we were well represented by Bill Curry and his son Todd, and Ted Bean and his daughter Dana. Newcomer Gregory Wilson was also riding for TP in honor of his father, Neal.

The marathon was exciting, even as a spectator. This year I got to root for our team members as they passed by our cheering station. We had a special treat as David James Elliott, who played "Harm" on the popular TV show JAG, wore our shirt in the marathon and finished in around 4 hours. Our fastest runner this year was Eric Kramer, who ran in honor of his dad, Rick, and finished in 3:46.3. Other sub 4-hour runners included Avery Abernathy and Kin Kui. Avery, a PD researcher at USC, finished in 3:51:39. Others with personal records included Mimi MacGlashan, David Ball, Stacy Palenbaum, Chris Barthell and Dan Kiefer. Dan is the tenth member in the last seven years to finish the marathon in spite of PD!

Top fundraiser was Aaron Moretzsky with over \$15,000. Aaron's Angels took top honors in the team competition, followed by Dan's Bradykinesia Bunch, Team Albert, For Uncle Ron, and the Super N's. The team competition added a new dimension to our fundraising.

One final note: None of this success would be possible without the tireless efforts of my wife and co-chair, Edna. She is the true star of this show we call Team Parkinson. Her dedication makes all the rest possible. We also thank my sister Kippi Stolz who came in from Denver to help out, my parents, Betty and Bill Ball, and our children, David and Sarah. ☺



Edna & John Ball

Upcoming Events - 2006

- May 24th **Putting for Parkinson's Golf Outing**—West, Napa Valley, CA
July 30th **Team Parkinson at the San Francisco Marathon**, CA
Sept. 19th **Putting for Parkinson's Golf Outing**—East, Jamesburg, NJ
Sept. 30th **Carnegie Center 5K & Fun Run**, Princeton, NJ

John Wherry has Parkinson's disease and is a member of our Parkinson Alliance research team. His photo to the right was displayed at the 1st World Congress in Washington, D.C. John grew up in Northern Ohio and attended Hiram College, obtaining a degree in psychology. His interests include writing, digital photography, bridge, and the Internet.



The Parkinson Alliance Welcomes New Board Member Micky S. Landis



Micky S. Landis

The Parkinson Alliance is proud to welcome Mr. Mitchell (Micky) S. Landis to its Board of Directors.

Mr. Landis is the Senior Vice President and Regional Manager of the Princeton office of Boston Properties, a Real Estate Investment Trust (REIT). He is responsible for overseeing development, leasing and property management for the Carnegie Center and Tower Center assets and for the pursuit of new business opportunities in the New Jersey and Pennsylvania region. Mr. Landis joined Boston Properties in June 1998 when the assets of The Landis Group, for which he was Chief Operating Officer, were acquired. For 19 years prior to that, he owned and operated Landis Food Services, a restaurant franchiser in the Northeast United States and

Canada. Mr. Landis received a BS degree in Economics from New York University in 1973 and completed coursework toward a master's degree in Economics in 1975.

In addition to The Parkinson Alliance, Mr. Landis serves as a Director on several local charitable Boards including Raritan Valley Workshop (a division of Easter Seals), Prevent Child Abuse – NJ, Jewish Social Services Committee of Middlesex County.

Mr. Landis currently serves as the Chairman of the Highland Park Redevelopment Agency, following 2 years as a founding Director of Main Street Highland Park.

He lives in Highland Park with his wife Linda and their four children, ages 1 through 9. ☺

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The Parkinson Alliance
Post Office Box 308
Kingston, NJ 08528-0308

1-800-579-8440
609-688-0870
fax: 609-688-0875

www.parkinsonalliance.org
e-mail:
admin@parkinsonalliance.org

Designer/Editor
Gloria Hansen

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100% of net proceeds from all events goes directly to Parkinson's research.

For the latest news on upcoming events,
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