



CATALYST

Growing Funds for Parkinson's Research

\$1,000,000 Raised for Research!

by Trina Stokes, Event Director

We always had dreams that the Parkinson's Unity Walk would make a \$1,000,000 impact on Parkinson's research in one year's time. This dream came true during the 2005 Parkinson's Unity Walk on Saturday, April 16th, in New York's Central Park.

We are making a difference—in total the Walk has raised over \$5,000,000 for Parkinson's research over the past 11 years. Not only is the impact made monetarily—the Walk changes people lives. People leave feeling inspired and full of energy. Participants take advantage of the "Ask the Doctor Booth," they are able to learn about new therapies, clinical trials or locate a support group. It's truly a Community and Education Day!

Personal accomplishments are demonstrated by over 8500 people walking and holding up their signs, that they made at the "Make a Sign

Booth" to honor a friend or a family member. It's inspiring to see a sea of people walking with their signs. We have walkers and/or donors from 50 states and 24 countries. The Parkinson's Unity Walk certainly shows to the world that our community is serious about finding a cure!

From the very beginning, 100% of all the donations raised has been and continues to be designated for research. To read about grants that the Parkinson's Unity Walk has funded through the participating foundations, please visit our web site at www.unitywalk.org.

Donations support research for the following foundations:

- American Parkinson Disease Association
- National Parkinson Foundation
- Parkinson's Action Network
- Parkinson's Disease Foundation
- The Michael J. Fox Foundation for Parkinson's Research
- The Parkinson Alliance
- The Parkinson's Institute

INSIDE

Message from the Executive Director 2

DBS-STN.org Newsletter..... 3-6

The Neural Interfaces Workshop..... 3

The 9th International Congress of Parkinson's Disease and Movement Disorders 4-5

Thoughts on My Upcoming DBS Surgery 6

Past Events 7

Upcoming Events 8

For more information, please call 1-866-PUW-WALK (1-866-789-9255) or visit our web site at www.unitywalk.org.



Belt Eggs Team



Hannah Flynn

Team Parkinson Top Charity at the San Francisco Marathon

Once again, San Francisco not only lived up to its reputation as a top destination city for runners, it exceeded all of our expectations with a super race course, great weather and a lively crowd of race fans on the streets. Team Parkinson was in the city to participate in the newly re-named San Francisco Marathon, now sponsored by Runner's World magazine. Nearly 30 charities chose to participate in Cause to Run, giving the 12,000 participants in the weekend's events a wide variety of charities to support. Over 80 athletes chose to run for Team Parkinson, making us the largest group of committed athletes. Not only was Team Parkinson the largest charity team in the weekend's races, we were also the biggest fundraisers! Team Parkinson raised over \$42,000.

Not all the best races were in the streets, because one of the closest contests of the weekend was to see who would become the top fundraisers for Team Parkinson. The race finished in a flat-out sprint between two new members to the team: Darci



We Made a Difference Then ... We are Making a Difference Now

I remember it clearly: It was the early 1990's when we were trying to get federal legislation passed to increase funding for Parkinson's research. Advocates for Parkinson's research came together and we made a difference. In November 1997, President Clinton signed the Morris K. Udall Parkinson's Disease Research Act. This was the first law to focus entirely on the need to expand the Parkinson's disease research programs administered by the National Institutes of Health (NIH). We were all celebrating, as we thought we had \$100 million dollars for research each year for the next 3 years. It wasn't long until we found out the difference between the two "A" words: authorization and appropriations. We had "authorization," but we did not have "appropriations." In other words, we did not have the money. But we continued to work, making our voices heard, and we made a difference.

In the early advocacy years, NIH was spending less than \$25 per patient per year on Parkinson's research. Today, we are closer to \$250 per person, per year. We have 12 Morris K. Udall Centers of Excellence across the country doing innovative and collaborative Parkinson's research including Duke, Columbia, Harvard and Johns Hopkins—just to name a few (visit www.ninds.nih.gov for a complete list). This took about 5 years. Was it worth the work? Absolutely.

Presently we are advocating to have a bill passed for a Stem Cell Institute that will help advance research in New Jersey. In January 2004, Governor McGreevey signed legislation permitting stem cell research. We thought all the significant bills to move research forward and the institute would be approved and in the budget by June 2005. However, this did not happen.

Instead many changes occurred in New Jersey that prevented these bills from being approved. Governor McGreevey resigned; our acting Governor, Richard Codey, decided not to run for election (resulting in a "lame duck" governor); and there are budget deficits—just to name a few of the obstacles. Rather than giving up, we are refocusing our efforts. We organized a new coalition—New Jersey Citizens Coalition for Cures (NJCCC—www.njstemcell.org). The Coalition represents many different disease groups—and some of the members work gallantly as they fight for their loved ones. We understand the work ahead of us; we understand it will take time; but we are making a difference.

At the federal level, major recent events have helped to increase our push for stem cell research. H.R. 810, The Stem Cell Research Enhancement Act, legislation to expand the President's stem cell policy, passed the House of Representatives on May 24th by a bipartisan vote of 238 to 194. The Senate is slated to take up this legislation when it returns after Labor Day. In addition, on July 29, Senate Majority Leader Bill Frist announced his support for embryonic stem cell research. This all happened because of advocates!

One of the most important things an advocate can do is be visible with a focused message. **Every person makes a difference.** A person who is homebound making phone calls or writing a letter is just as important as the individual going to a meeting in a representative's office. Everyone's voice counts. Contact the Parkinson's Action Network (www.parkinsonaction.org). Find out who your PAN state coordinators are and learn the important issues in your state. There is an unwritten motto in Washington, DC, that says you must stay on your representative's "radar screen." In other words, stay in front of them as much as you can with a clear and unified message: support stem cell research and support Parkinson's research.

Please, do not get discouraged. Our work takes time. We are making a difference. For proof, just look at how far the Parkinson's community has come in the past 15 years.

The hard work was worth it then, it is certainly worth it now.

A handwritten signature in black ink that reads "Carol J. Walton".

Carol J. Walton
Executive Director

The Neural Interfaces Workshop

By Guest Columnist, Jeffrey Wertheimer, Ph.D.

Science continually proves that progress in the treatment of Parkinson's disease isn't just possible, it is inevitable. The Parkinson Alliance recently attended the Neural Interfaces Workshop in Bethesda, Maryland. A significant portion of this conference was dedicated to presenting updates on and introducing rigorous research endeavors that help facilitate the understanding and enhancement of treatment for Parkinson's disease. Although there were many intriguing topics discussed at the conference, only a brief introduction to a few of the themes will be mentioned in the succeeding paragraphs.

To begin the conference, The Parkinson Alliance attended a round-table wherein some of the leaders in Deep Brain Stimulation (DBS) research were in attendance. The "vision" of DBS therapy was discussed, and the intellectual dialogue during this gathering illustrated a universal understanding that optimal outcomes of DBS therapy will most likely ensue when there is 1. appropriate screening procedures, 2. trained professionals performing DBS surgery, 3. clinical trials evidencing the optimal lead location, 4. trained personnel providing DBS programming, 5. access to DBS programming, 6. an interdisciplinary team approach [that effectively communicates with one another], and 7. education to the patients and caregivers to empower them to assist in treatment-related decisions.

Additionally, further discourse in this gathering revealed that ongoing dogma exists as it relates to different approaches when choosing the site wherein to place the lead of the stimulator; specifically, irrefutable evidence that the subthalamic nucleus (STN) is the superior anatomical structure to stimulate over the Globus Pallidus (GP) does not exist at this point in time. Dr. Jerry Vitek from the Cleveland Clinic Foundation stated, "Maybe the STN is the best site out there, but we do not know for sure, yet." In spite of the various opinions about the optimal site to stimulate, everyone exuded enthusiasm about the benefits of DBS. For example, Dr. Dave Heydrick, a neurologist and person with DBS-STN, mentioned how his experience with DBS improved his quality of life immensely, which was exemplified by his statement "To be able to throw a baseball with [my] son again improved my quality of life considerably."

As many clinicians and patients know, although there have been some major advances in our understanding of DBS, the challenges of "programming" can be a difficult and time-consuming process. Hope has arrived, however; a cutting-edge research project was designed to address these issues. Christopher Butson from the Cleveland Clinic Foundation facilitated a marvelous presentation entitled "StimExplorer: Interactive Visualization Software for Deep Brain Stimulation Parameter Selection."

This new software aids in the postoperative programming of DBS-STN. Using a 3-dimensional image, this program customizes the system to an individual patient and can demonstrate and evaluate the effects of electrode location and stimulation parameter settings. The "StimExplorer" calculates and suggests a theoretical optimal stimulation parameter setting for an individual patient. The implications are vast. The benefits include decreasing time and effort needed to adjust the stimulation parameters to achieve acceptable clinical results, assisting in standardizing DBS programming, and providing a teaching tool on the effects of DBS.

As confirmation about and advances toward our understanding of DBS on motor symptoms continues to grow, so does our knowledge about the impact of DBS on cognition, mood, and behavior in PD.

INSIDE

The 9th International Congress of Parkinson's Disease and Movement Disorders.....2-4
Thoughts on my Upcoming Surgery ... 4

One presentation pointed out: 1. DBS-STN does not produce any global adverse effects on cognition, 2. when cognitive decline is documented following DBS surgery, the age of the patients, pre-operative cognitive status, medications, the precise location of the implanted electrodes and parameters used for stimulation may be key factors in explicating these findings, 3. DBS-STN has been shown to produce behavioral features ranging from mania to apathy, hallucinations, and aggression, but most of these effects are transient and only present themselves in the immediate post-operative phase, and 4. for the majority of patients, significant improvement of anxiety, depression, and quality of life has also been reported.

In summary, dedicated scientists, clinicians, advocates, and patients and those who share their lives continue to enhance our understanding of the treatment for PD, which will inevitably lead to progressing towards optimal treatment outcomes. For a detailed review of the conference, please visit our website: DBS-STN.org, where you will find further, more comprehensive descriptions about the round-table, lectures, and poster presentations.



Margaret Tuchman and Jeffrey Wertheimer, Ph.D.

The 9th International Congress of Parkinson's Disease and Movement Disorders

by *The Parkinson Alliance Research Team*

In March of 2005, The International Congress of Parkinson's Disease and Movement Disorders congregated in New Orleans. The Parkinson Alliance attended this top-tier conference, and we are excited to share with you a brief overview of the copious amounts of information that was presented. Topics to report in this synopsis will include the following: Advances in Understanding Parkinson's Disease, Sleep Disorders in Parkinson's Disease, Balance and Gait in Parkinson's Disease, and Programming following Deep Brain Stimulation.

A Brief Overview of Advancements in Understanding Parkinson's Disease:

It was Dr. James Parkinson himself who stated "there appears to be sufficient reason hoping that some remedial process may be discovered, by which, at least, the progress of the disease may be stopped." (J. Parkinson, 1817). These words resonated with the audience as our "current" physicians and scientists further educate and instill hope about the understanding and treatment of Parkinson's disease (PD).

PD is a slowly progressive disorder that affects movement, muscle control, and balance. One variant of PD is often referred to as idiopathic, which means that the cause is unknown. What is known, however, is that PD develops as cells are destroyed in certain parts of the brain stem. The loss of these cells results in the depletion of dopamine, an essential neurotransmitter (a chemical messenger in the brain). This process negatively affects the nerves and muscles controlling movement and coordination, resulting in the major symptoms characteristic of PD (postural instability, rigidity, bradykinesia (slowness of movement), and tremor).

Dr. Heiko Braak shared his insights about the progression of PD. Specifically, he identified 6 major stages. He indicated that there are two stages prior to the onset of the overt physical symptoms of PD. In the pre-symptomatic stages, the idiopathic PD-related pathology remains confined to structures within the brain stem. In stages 3 and 4, the progression of the disease travels its course to the midbrain and slightly beyond and is the focus of initially subtle and, then, severe changes. At this point, the illness reaches its symptomatic phase, meaning that one can begin overtly seeing the cardinal symptoms of PD. In the final stages 5 and 6, the pathological process encroaches upon the cortex of the brain – the outer level of the brain. In the latter stages, idiopathic PD manifests itself in all of its dimensions, causing further impairments in physical, cognitive and behavioral/emotional domains.

The implications of this observation are intriguing. As science continues to advance, there is hope that we can identify PD in the pre-symptomatic stages and hopefully intervene accordingly. As such, expectations for the future include increasing the accuracy in diagnosis of PD and creating interventions that will prevent the progression of the disease before the onset of any overt physical symptoms. Thus, as the aforementioned quote by James Parkinson stated, there is hope that scientific advances will eventually find a way to cease the progression of PD.

Sleep Disorders in Parkinson's Disease:

Between 60 and 98% of people with Parkinson's disease (PD) experience sleep-related disturbances (Partinen, 1997; Tandberg,

1998). For individuals with PD, the most common forms of sleep disturbances include nocturnal sleep disruption and excessive daytime sleepiness, restless legs syndrome, rapid eye movement sleep behavior disorder (aggressive nocturnal behavior during rapid eye movement (REM) sleep), sleep apnea, nightmares, sleep terrors, and panic attacks. Sleep/wake abnormalities are common in the elderly, but are more common and more severe in those with PD. The majority of patients with Parkinson's disease complain of nocturnal sleep disturbances and about 15% report excessive daytime sleepiness (EDS). It is important to note that sleep disorders can be attributable to a number of factors such as movement disturbances that occur during the night and prevent sleep, nocturnal sleep deprivation that causes excessive sleepiness during the day, medications, and/or changes of the brain secondary to the disease process.

Treatment:

When a patient or a family member begins to notice sleep disruption, an evaluation by a specialist is recommended. Treatment for sleep disturbance may not only increase one's physical activity, social activity, and safety while operating a motor vehicle, but it will also improve one's quality of life. Dr. Brad Boeve indicated that a thorough assessment should include complete medical and psychiatric histories, sleep history, and a 1- to 2-week sleep diary or Epworth Sleepiness Scale evaluation (a scale that helps to assess sleep disturbance). Sleep recording devices (polysomnography or actigraphy) may also be indicated. Furthermore, treatment should address underlying factors such as possible depression, anxiety or pain.

Medications may also be having an impact on sleeping habits. It is important to talk to a doctor about any sleep disruption and inquire as to the effects that medications may be having on your sleep, as some medications may quell sleep disturbance issues and others may cause or adversely effect sleep disturbance.

Balance and Gait in Parkinson's Disease:

Among the cardinal features of PD, gait disturbances and falls are a leading cause of disability and functional dependence. Of interest, Dr. Fay Horak cited that PD patients have 3 times the falls and 5 times the injuries when compared to age-matched individuals who do not have PD. Thus, gaining further understanding about gait disturbance and its cause(s) are of great importance.

Dr. Nir Giladi described the relationship between locomotion gait disturbances and the progression of PD. He indicated that in the early stages, gait disturbance manifests itself in decreased arm swing, shorter stride, slower speed, and short and transient hesitation or festination (involuntary shortening of stride and quickening of gait that tend to occur while turning or ambulating through spatially restricted areas – e.g., doorways). In the advanced stages of PD, one is more likely to experience postural instability, akinesia (inability to move the muscles) when off medications, dyskinesia (excessive movement of the body), significant festination, and significantly reduced stride-length and ground clearance (which results in shuffling of feet while walking). Freezing spells were reported to occur in approximately 7% of PD patients within the first year of diagnosis, approximately 26% around 18 months, and over 50% after several years.

Some medications may also affect one's ability to walk safely. Moreover, in the context of gait disturbances in PD patients, medications often have side effects that impact mobility, such as dyskinesia, freezing spells, festination, sudden off periods, light-headedness, and double vision.

Cognition and Gait:

Cognitive inefficiency can impact mobility. Some research has found that as the brain has more to process gait speed is slowed down and gait rhythm is disturbed. Research conducted by Hausdorff and colleagues (2005) indicated that routine walking relies upon higher levels of cognitive abilities called executive function (such as attention, planning, sequencing, organizing, initiating activity, solving problems, etc.). In fact, as these higher-order functions become dysfunctional, gait disturbance and fall risk are likely to result.

Treatment:

Several approaches to treatment of gait disturbances have been demonstrated. Herman and colleagues (2005) examined the effect of intensive treadmill training. Patients walked on the treadmill for 30 minutes each session, 4 training sessions per week, for 6 weeks. The results of the study demonstrated the potential to enhance gait rhythmicity in patients with PD and suggest that treadmill training can be used as a powerful tool to minimize impairments in gait, reduce fall risk, and increase quality of life. Dr. Horak indicated that rehabilitation for mobility and stability improves function, and she stated that exercise may even be neuroprotective. Furthermore, she indicated that rehabilitation earlier in the disease has been found to have better results.

As was mentioned above, cognitive processes are very important in ambulation. There are some medications that may assist in improving gait performance via improving cognition. Uriel and his colleagues (2005) evaluated the impact of a psychostimulant (Methylphenidate, also known as Ritalin) on gait performance. The results of their study revealed that Ritalin was associated with an improvement in attention and other higher order cognitive functions (but not memory) and gait performance.

Dr. Robert Iansek indicated that the use of external cues (e.g., visual cues: lines on the floor to identify/dictate stride length; verbal cues: go ahead and take a step that is 12 inches long) have been helpful in stride length and reducing festination. Additionally, Dr. Iansek described the importance of managing the environment in which patients ambulate. One can maintain an environment at home that eliminates or at least minimizes obstacles that may influence gait disturbance, such as making sure that the areas through which the patient may be walking are spacious and free of hazardous objects on the floor. Furthermore, Dr. Iansek indicated that some medications might be helpful while others may exacerbate gait difficulties. He emphasized the importance of good management of medications and sound assessment of how they affect gait performance.

Programming following Deep Brain Stimulation:

Dr. Michele Tagliati and Dr. Jens Volkmann discussed the Principles of Programming. Drs. Tagliati and Volkmann stated that successful DBS therapy could be achieved by obtaining accurate patient selection, utilizing surgical procedures that allow for proper target and precise electrode placement, accurate medication adjustments, managing side effects, and educating and supporting the patient.

Drs. Tagliati and Volkmann indicated that what currently makes

DBS challenging are multiple anatomical targets (trying to locate the best target for the patient's presenting problems), thousands of parameter setting combinations (12, 964 combinations of Pulse Width, Frequency, and Voltage), numerous contact configurations (65 combinations with unknown stimulation effects), and multiple time-dependent effects of stimulation (the effects of the stimulation can occur immediately or weeks or months later). They also addressed adjustment of medications following DBS therapy. They stated that there is little agreement on how to adjust medications during DBS therapy. The approach of medication modification varies from institution to institution all over the world. For example, one philosophy believes that on the day of the first DBS-STN programming, one can reduce medications or even discontinue them. Other philosophies subscribe to reducing the medications gradually and tempering the reduction via observations of bodily reactions; and others still, do not reduce medications. Furthermore, the question arose, "Which is better, dose reduction or increasing intervals between doses?" Drs. Tagliati and Volkmann reportedly prefer to increase the space between dosages.

In this context, two other important points emerged. First, if levodopa/dopamine agonists are not decreased, additive side effects may present themselves. These side effects include dyskinesia, hypomania (elevated mood, increased activity, decreased need for sleep, grandiosity, racing thoughts, and the like), and/or sedation or confusion. It was mentioned that it is of great import to avoid decreasing the medications too rapidly. The second point emphasized that adverse effects may result from excessively decreasing medication (e.g., apathy, depression, and freezing of gait).

Drs. Tagliati and Volkmann concluded by sharing the following pearls of wisdom:

1. There should be close collaboration between the neurologist and the programmer in adjusting the medications and stimulation.
2. Clinicians should minimize re-programming for short-term exacerbations. It is recommended to work through the short-term changes (wait a few days, as the changes could be due to extraneous variables – e.g., the weather).
3. Follow-up programming visits should include reviewing interim changes (e.g., symptom response, medication changes, and adverse effects), interrogating the device (check the impedance), and assessing the stimulation parameters making sure they are within the therapeutic window.
4. The goal is to maximize the benefit of DBS therapy, not to get the patient off medications entirely.
5. With regard to the course of the stimulation effects, there is quite a bit of variability. Motor symptoms may improve within seconds to minutes after the stimulation is activated, but there may be a delay of hours to days until the therapeutic effects are obvious or maximal. Of note, the stimulation-induced adverse effects are mostly evident immediately.
6. The patients should keep a diary of symptoms and exacerbations.
7. Remember, each patient is different.

For a detailed overview of this conference and to view the list of the references, please visit our website, DBS-STN.org.

Thoughts on My Upcoming DBS Surgery

By Dan Stark, a NJ writer and former Vice President of Law with AT&T

In less than a month I am going to have my head put into some sort of Frankenstein device to hold it steady while a very smart doctor drills two holes in it so that he, in consultation with a very smart Parkinson's specialist, can mess with my brain. I'm not really worried about whether they know what they're doing. They've done this to other people and those patients are alive, even improved. I worry instead about the neurosurgeon sneezing at the wrong moment. Sure you don't hear about it, but it must have happened.

I'm getting Deep Brain Stimulation, or DBS. I am not a medical expert and I don't offer any advice here. I'm going to be one more data point for those interested. I was diagnosed with Parkinson's disease almost seven years ago. While that is not a long time, I seem to be rushing through the early stages of the disease, and sense I am headed for rough waters. I try to "Live Life Large," as I wrote in the Washington Post.¹ I have too much I want to do during my life and I resent a disease that first limits, and then eliminates, my opportunity to do it.

I have been labeled an "ideal" candidate for DBS. When I'm "on" I'm very on, meaning when the medication is at peak effectiveness, I can act very human. It just doesn't last long enough. Hopefully, the surgery will allow me to move my limbs without taking my daily dose of twenty or thirty Parkinson's related pills. Reducing the intake of pills should cure my involuntary shakes, rattles and rolls, side effects caused by too much medicine in the bloodstream.

Hitting a home run would mean being able to do simple things that most of you take for granted, like getting out of bed in less than five minutes, straightening my back before the medications I take kick in, or going to dinner without turning into a whirling dervish who nearly squirms out of his chair. Those simple things would make life so fantastic!

There is one feature of this operation I don't like: you're awake during the entire time they're playing around in your head so they can communicate with you. What fun. Just think, six hours of having to respond to the question, "Can you hear me now?"

Allowing your mouth to stay awake after your discretion and judgment have been put to sleep is troubling. There are some messy thoughts up there that I should have thrown out long ago. It is like inviting someone to your home, forgetting that you hadn't cleaned it since 1965. Who knows what they're going to find!

My plan had been to talk about a safe topic like baseball. It's an old trick used by men when we start thinking about women that we shouldn't be thinking about. Force yourself to think about baseball instead. It never worked, at least for me. The law of averages says it's got to work sometime. I had planned to at least give it a whirl here.

The problem is that my Parkinson's doctor is a Yankees fan and she knows I'm a Red Sox fan. It's not that she would deliberately kill me given that this is not play-off season. But she has threatened to change my allegiances surgically. I thought she was joking until, purely by accident, I found a manual on such a procedure locked with her private things in her desk. (I thought I heard someone calling for help). It's a diabolical book; I'll read you a short excerpt:

"Directions to convert Red Sox fans into Yankees fans: Step 1: Remove and discard a minimum of half the cranial capacity of the patient. Patients with more than half a brain do not like the Yankees. After removal of the first piece, ask the patient a few simple questions. If he exhibits any critical judgment, remove more of his brain. Repeat as many times as necessary to produce a slobbering simpleton with the brain of a tapeworm, able only to mumble, "Did you see Bucky Dent hit that thing?" Then put a beanie on his head and place a can of beer in his hand. Congratulations, you've produced your first Yankees fan."

Deep Brain Stimulation is a much milder procedure by comparison. There's really nothing to remove other than some bone and scalp. They then insert a few wires which shoot impulses which, oh what the hell, I have no idea what they do. I don't really understand how this works. I am like the guy with the salami: I want to eat it because I like the result; I don't want to know how it was made.

I do wonder about one thing. I would like to meet the very first patient who had this done. What would make a patient willing to have holes drilled in his/her head to try

something that had never been tried before? Yes, it had been demonstrated to work and had been approved by the FDA. Lots of things work in theory. I took a long time making up my mind, even knowing this is a proven procedure and that I had excellent and experienced doctors. Someone was willing to take a huge leap of faith that I admire but don't know if I could match. I stand in awe both of a disease that can stimulate that sort of bravery, and the human being that stepped up to the challenge.

I am very lucky. I'm still in pretty decent shape, meaning I can take care of myself. But I also spend a good part of each day out of commission. I do not absolutely require the surgery. I could limp along without it. So why did I choose to do this?

Surviving isn't enough for me. I am doing fine but I want to do better. My experience with Parkinson's instilled in me a zest for life. It made me realize how beautiful life can be. It did so by robbing me of the ability to do many of the things that make life so precious. Reminding you of the wondrous nature of life but then preventing you from enjoying it is one of the cruel ironies of the disease.

I intend to have the last laugh. If we can cure or at least hold the disease at bay, I get to keep my cake and eat it too. I get the wake up call to enjoy the wonders of life, and I also get the time to do it. DBS seems to give me the best chance to do that. Now that I've crossed the bridge and decided to have the surgery, wild horses couldn't keep me away.

My surgery is the first week of October. Given my gratuitous comments on the Yankees, I will not disclose the location. Look, I really don't hate the Yankees that much. There are games where they are playing a team in the National League where I don't actively root against them. You see, I'm coming around. I am even willing to risk emerging from surgery liking them, to get a handle on this Parkinson's thing. That's a lot for a Red Sox fan.

Wish me luck.

¹ WashingtonPostHealth Section, 6/21/05.

DBS-STN.org — The Newsletter

published by The Parkinson Alliance

Post Office Box 308 • Kingston, NJ • 08528-0308 • 1-800-579-8440

www.DBS-STN.org • e-mail: info@DBS-STN.org

Past Events

Putting for Parkinson's Golf Outing — East September 27, 2005

Jamesburg, NJ

It was a record breaking year for the annual Putting for Parkinson's Golf Outing with \$100,000 raised for Parkinson's disease research!

The weather was spectacular for the 132 golfers who participated in The Parkinson Alliance and The Tuchman Foundation combined tournament at Forsgate Country Club in Jamesburg, NJ. After a day on the green, golfers and guests enjoyed a lovely buffet dinner where awards were given and a variety of gift items were raffled. The Grand Prize gift—a three night stay at the Bellagio Hotel in Las Vegas—was won by Art Burns of Interpool, Inc.

Martin Tuchman will personally match the net proceeds of this event; therefore \$200,000 will go to The Tuchman Foundation. The Tuchman Foundation's main objective is supporting The Parkinson Alliance. This matching funds program helps pay the administrative costs for The Parkinson Alliance and provides the Alliance with the unique ability to spend 100% of all individual donations and all net proceeds of events directly on research.



Carnegie Center 5K & Fun Run October 1, 2005

West Windsor, NJ

On Saturday, October 1st more than 300 runners, walkers and volunteers gathered in West Windsor, NJ, for the 6th annual Carnegie Center 5K and Fun Run to raise funds for Parkinson's disease. The event benefits The Parkinson Alliance of Princeton and raised over \$45,000—the largest event to date.

It was an early start, as young runners set off in the one mile Fun Run, while parents and adults tackled the 5K. All child winners received their own runner's trophy while the top men's winner, Michael Daigeaun, with a time of 16:22, and the top women's winner, Tamara Kladt, with a time of 19:13, walked away with a trophy and special prizes.

Prior to the 5K, Full Circle Family Massage & Healing Center gave stress reducing massages. The Honorable Rush Holt (D-12th) addressed the audience and talked about the progress and the importance of Parkinson's research. After the race, enthusiastic volunteers served a spread of drinks, snacks, sandwiches and pizza for the runners to enjoy.

Congratulations to The Hyatt Regency Princeton on being awarded the "King Award" for their support and dedication of this event. This is a special award named after Joseph G. Fennelly for his love of the sport and being a generous philanthropist and long time volunteer. He was an icon in the community as one who cared and wanted to help the cause.

Commercial real estate broker and Race Director Jerry Fennelly, his wife Nancy, and generous corporate sponsors like Yardville National Bank, Interpool, Tyco, Boston Properties, GE Healthcare, Kyowa Pharmaceutical, NRG Energy, Residence Inn at Carnegie Center and Washington Group International helped to make this event another great success. "This gets us one step closer to the cure," says Carol Walton, Executive Director of The Parkinson Alliance.



L to R: Jerry Fennelly, Paul Pisarz – General Manager, The Hyatt Regency, and Gwen Fennelly

December 4, 2005

Team Parkinson at the California International Marathon and MaraFUNrun, Sacramento, CA

March 19, 2006

Team Parkinson at the Los Angeles Marathon, CA

April 2006

Parkinson's Unity Walk in Central Park, NY

Please check the web site www.unitywalk.org in November for the confirmed date.

May 21, 2006

"A Step Ahead: A Positive You" Fashion Show and Luncheon, Princeton, NJ

July 30, 2006

Team Parkinson at the San Francisco Marathon, San Francisco, CA

continued from page 1

www.teamparkinsonla.org

Riecken from Newport Beach, California and Kristin Babington from Mobile, Alabama. Darci ran the half-marathon to honor her brother, and Kristin ran the marathon to honor both her father and father-in-law. In the end, the race for the top spot was won by Kristin Babington and her family. They deserve special recognition for not only being the top fundraisers for the event with over \$8,000, Kristin was also Team Parkinson's top individual performer in the marathon, running a 3 hour 21 minute marathon and securing a second place trophy in her age group. Running with her for Team Parkinson was Lori Thomasson, also of Mobile, Alabama,

who finished in 3:21:26 and finished 4th in her age group.

Other notable performances in the marathon by Team Parkinson members were by Frank Markowitz, finishing in 4:19:31, and Jenice and Kevin Cunningham, finishing in 4:45:41 and 4:48:29 respectively.

Darci Riecken was a close second in the fundraising race with \$7,420. She ran the half-marathon in 2 hours, 23 minutes. Darci was joined by fellow team member Kimberly Blix, who finished in 2:23:39. Not far behind them were Anna-Marie and Margaret Babington, aged 13 and 15, who finished in 2:29:07 and 2:29:08. In the second of the two half-marathons, Jennifer Bugnatto, the San Francisco coordinator for Team Parkinson, missed her bid to improve on last year's time, finishing in 3:00:29.

There are many individuals we should thank for their support, but Rampi Gulati from our premier sponsor, Novartis, deserves some special recognition for the materials and time he dedicated throughout the event. According to Carol Walton, Executive Director of The Parkinson Alliance, "The weekend was a terrific success. This race brought many new faces to Team Parkinson because San Francisco is one of America's favorite cities for runners, and aligning with Cause to Run made it easy for newcomers to find us."

PARKINSON'S

CLINICAL TRIALS

Find out all you need to know about Parkinson's clinical trials at:

www.PDtrials.org

- Learn more about trials that are seeking patients
- Receive regular updates by print and e-bulletin
- Obtain free educational brochures

Or call (888) 823-8889 for a free information pack.



www.PDtrials.org

The Catalyst published by:

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

Board of Directors

Chairman of the Board
Martin Tuchman

President
Margaret Tuchman

Executive Director
Carol J. Walton

Secretary
Lauren Barbero

Treasurer
Kathleen C. Francis

Director
Lynn Fielder



Receive The Catalyst by mail by making a donation of \$25 or more yearly to The Parkinson Alliance.

Updating our Mailing List . . .

If your name or address is incorrect on this newsletter's mailing label, please let us know. If you receive multiple copies of this newsletter, please notify us so that we can correct our mistake. Thank you!

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

For the latest news on upcoming events, please visit our Web site at www.parkinsonalliance.org