



# CATALYST

Growing Funds for Parkinson's Research

## Walking Towards a Cure—Parkinson's Unity Walk

by Trina Stokes, Event Director

It's more than a beautiful 2-mile Walk that takes place in New York's Central Park one day a year. Participants of the Parkinson's Unity Walk (PUW) go all-out, all year long, to raise donations—no matter what it takes. Parkinson's disease is dealt with daily for those affected and, for the PUW community, fundraising efforts to find the cause and cure to Parkinson's are nonstop.

Many PUW participants care so much about the cause that they begin dedicating time and resources far in advance of the annual Walk. It's becoming the norm for some Teams and Walkers to set new fundraising goals immediately following the conclusion of one Walk and then working throughout the year to reach their goals by the next Walk. The PUW community cares about giving back, and it wants to be certain that future generations do not have to deal with this devastating disease.

*Jenn's Movers and the Shakers*, a team from Pennsylvania, have already hosted two events for the 2005 Walk and have at least two more planned. In the summer they held a bowling tournament where they charged a donation fee to bowl and accepted general donations from those who could not attend. And talk about creativity, they also hosted a *Beef n' Beer* event at their local Hall and charged a general donation ticket price per person. So far they raised over \$2,500!

Ron Hyland, a physical therapist from Toms River, New Jersey, directs an exercise class for people with Parkinson's. In just under three months, he and 90 members of his class coordinated a Walk in September



Trina Stokes

and raised \$15,000. The *Walk at the Shore for Parkinson's* is expected to become an annual event.

In November, Tamra Cantore of *Team Cantore and the Weather Channel* organized the first annual *Countrified Rock for Research* which featured Jeffrey Steele—one of today's hottest songwriter/entertainers in country music. Over 150 neighbors, friends, family members, and colleagues from the Weather Channel attended this Monday evening concert in Atlanta, Georgia and raised over \$30,000 for the Walk.

The greatest news about these events and others that take place throughout the year is that 100% of all donations sent to the Unity Walk go to Parkinson's research.

Since 1994, families, friends, caregivers, and Parkinson's foundations have gathered once a year to unify their collective goal of finding the cause and cure to Parkinson's disease. Every year the Walk grows in attendance, attracting new participants and new Teams. This year, new teams, such as *Team Butterfly* and *I have PD-No Offense to You Charlene*, became involved with the Walk because they want to support their loved ones, have fun, and raise money for much-needed research. While at the Walk, informative Parkinson materials provided by the foundations and sponsors are available to everyone. Participants can talk to a neurologist, find out about new therapies and clinical trials,

locate a support group, and learn how to be a Parkinson's advocate—all in one day!

Tom Gorman of *Team Gorman* who writes a monthly article for the Parkinson Unity Walk web site notes, "people with Parkinson's, their friends and family see Central Park as a sanctuary, the calm 'eye' in their 'hurricane'."

### INSIDE

Message from the Executive Director .....	2
DBS-STN.org Newsletter.....	3-6
DBS	
The DBS-STN Programmers Discussion Forum	
The Future of Neuromodulation	
DBS Programmers Forum	
DBS-STN.org Site Update	
Past Events .....	7
Upcoming Events .....	8

The next Parkinson's Unity Walk is scheduled for Saturday, April 16, 2005. Rain or shine, over 6,000 people and almost 300 Unity Walk Teams are planning to attend. They know Parkinson's does not take a day off, and their sights are set on walking the two-mile Walk and raising awareness and donations for Parkinson's research. For some, it will be a tough walk to finish. But however many steps are taken, the PUW community knows every step matters. Every step taken gets us that much closer to finding the cure to Parkinson's. Come and join us on Saturday, April 16<sup>th</sup>, as we walk towards the cure.

For more information, call toll free 1-866-PUW-WALK (789-9255) or visit [www.unitywalk.org](http://www.unitywalk.org).



Prior to starting the Walk, the crowd gathers in NYC's Central Park to listen to guest speakers



## A New Door Opens to Research

As I was thinking about what to write about for this issue, the telephone rang. It was Joan Samuelson, President and Founder of Parkinson's Action Network telling me she was just appointed a member of the Independent Citizens Oversight Committee for California's Proposition 71, the California Stem Cell Research and Cures Initiative. This committee will govern California's \$3-billion embryonic stem cell research effort. My first thought: What an important step this is for the entire Parkinson's community — it truly provides us with a "seat at the table" in this precedent setting legislation that has the potential to cure many diseases.

In 1997, Congress signed the Morris K. Udall Parkinson's Disease Research Act into law. The Udall Act directed the National Institutes of Health (NIH) to expand and coordinate Parkinson's research with the purpose of finding a cure or treatment.

Today, we have 12 Udall Centers around the country, including Harvard University Medical School and McLean Hospital, Duke University, Johns Hopkins University School of Medicine, and Columbia University — just to name a few (for a complete list, see the website at [www.ninds.nih.gov](http://www.ninds.nih.gov)). Annually, the Director of each Center formally presents their research and conclusions to the other Centers as well as the NIH staff. This meeting develops relationships and fosters collaborations and alliances among the various Centers. This year, the National Institute of Neurological Disorders and Stroke (NINDS) funded a Parkinson's Disease Data Organizing Center to collect information from all Udall Centers, thus allowing for standardized data and resources to be shared widely within the Parkinson's research community.

We just participated in the 6th Annual Udall Centers Meeting in Washington DC. This is my third year and I can safely say this was the best. The Directors are becoming a driving force for developing therapies. It seems every Center is collaborating with at least two other Centers — and even the definition of a Udall Center has expanded. The University of Pittsburgh includes Wake Forest and University of Austin in Texas as part of their Center. If I had room in this issue I could give you examples of at least 15 research collaborations among the Centers. In addition, 12 different NIH institutes and centers fund research on Parkinson's as well as the Department of Defense and the Department of Veterans Affairs.

Twice a month the Executive Directors of the major Parkinson's organizations participate in a conference call to discuss strategies and work together on issues of major importance to the entire Parkinson's community; i.e. advocacy, research and clinical trials. We meet in person at least twice a year to review strategies.

The passing of the Udall Act planted the seeds, which helped the entire Parkinson's community to grow together, work together, and unify our collective goal of curing Parkinson's. Now, with the passing of California's Proposition 71, and with Joan's new role as a Committee member, the Parkinson's community not only has a "seat at the table," but a voice that is loud and strong. Like the passing of the Udall Bill before it, the passing of Proposition 71 opens an important new door to research that will take us closer to finding the cause and cure to Parkinson's.

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

**Carol J. Walton**  
Executive Director

## Where We Are, Where We Need to Go, Challenges We Face

*By Margaret Tuchman*

We achieved our goals for 2004 — Our website, DBS-STN.org has a significant presence on the Internet, WE MOVE launched the DBS-STN Programmers Discussion Forum, and we were welcomed into the homes of 108 post DBS-STN respondents who took part in our latest survey, “Focus 2, Depression and Quality of Life (QoL) for PD Patients Who Had DBS-STN.”

Carol Walton and I called each respondent, and we learned a great deal about post surgery depression and QoL. In addition to the answers to the individual survey questions, we found that patients and their caregivers were desperately seeking answers about how to manage their symptoms at their current post-DBS stage. It was reinforced that adjustments play a significant (50 – 70%) role in the quest for QoL. We found that the success of adjustments and therefore the ongoing daily life of patients was directly correlated with the skill of the programmer/adjuster. Programming can overcome incorrectly placed electrodes. In the right hands, it can find a marriage between choosing to speak intelligibly and walking— or falling, freezing, and having bradykinesia. Yes, I am saying that we can and should ask for the highest level of professionalism in all aspects of our treatment.

In our phone contacts, we found that most patients had obvious problems with speech. Many caregivers had to speak for the patient. Other complaints were balance and gait problems resulting in frequent falls. Although all respondents (except one) were pleased with their decision to have DBS-STN, they intimated that there was a disconnect between expectation, understanding and reality as changes in symptoms emerged. Very few patients really understand that successful DBS-STN provides an additional treatment tool and is not a remedy by itself. PD condition is not static or unchanging; therefore, all the elements that make up a satisfactory QoL need to be constantly adjusted. PD is not a disease that offers the luxury of long range planning.

A Special Edition of the DBS-STN Newsletter that contains the full report analyzing the responses to the Focus 2 Survey is available (if you would like to receive the Special Edition, please contact us for a copy or visit our website).

Based on the success of the phone contacts, we are now focusing on three new goals for the coming year:

- Developing a list of questions which will be collected via telephone approximately every 12 weeks to feed our database with your most current symptoms, changes in medications, whether you feel the need for an adjustment, and other health, psychological, social issues affecting your QoL.

- Putting together a bi-annual topical questionnaire that will explore the issues affecting QoL. For example Focus 2 survey’s lead topic was Depression. Our analysis pointed out some interesting facts, most importantly that our population closely followed the data in research. Please refer to the Focus 2 Report for specifics. There are many topics that merit highlighting.

- Recognizing the yet unmet needs of the general PD community and more precisely of the DBS sector. Our goal is to provide this target group with information to assess their current QoL and suggest tools they can use to make improvements.

Our condition demands that everyone take part in improving our lot.



*Margaret Tuchman,  
President of  
The Parkinson Alliance  
& Founder of DBS-STN.org*

## INSIDE

The Future of Neuromodulation .....	2-3
DBS Programmers Forum .....	4
DBS-STN.org Site Update.....	4

## The DBS-STN Programmers Discussion Forum

In November 2004, WE MOVE ([www.wemove.org](http://www.wemove.org)) announced the DBS-STN Programmers Discussion Forum at [www.mdvu.org/cgi-bin/ultimatebb.cgi](http://www.mdvu.org/cgi-bin/ultimatebb.cgi). The WE MOVE DBS-STN Programmers Forum is for healthcare professionals ONLY. **If you had DBS-STN surgery, we ask that you tell your doctor about this forum to share their experiences.**

DBS-STN Programmers:

Do you have questions about DBS-STN programming? Have you made observations that you would like to share? Would you like to know how experienced programmers approach initial and follow-up programming, medication adjustment, and troubleshooting? There is no “cookie cutter” approach to DBS-STN programming, but sharing information among professionals can be a great help.

To accelerate the learning curve, WE MOVE invites programmers to the DBS-STN Programmers Discussion Forum at [www.mdvu.org/cgi-bin/ultimatebb.cgi](http://www.mdvu.org/cgi-bin/ultimatebb.cgi). The Forum is available 24/7 and enables novice programmers to post questions and receive responses from peers. Experienced programmers may benefit from the strategies for success from their peers. The DBS-STN Programmers Discussion Forum is part of the WE MOVE Parkinson’s Disease Educational Initiative and is funded by educational grants from Medtronic, Inc., The Parkinson Alliance, the Charles & Vivian Sukenik Philanthropic Foundation, and the Evan and Sandra Stern Foundation.

# The Future of Neuromodulation

*by The Parkinson Alliance Research Team*

Neuromodulation is the science of how electrical, chemical, and mechanical interventions can modulate or change central and peripheral nervous system functioning. Because of our interest in deep brain stimulation (DBS), The Parkinson Alliance recently attended an outstanding research conference of the American Society for Stereotaxic and Functional Neurosurgery (ASSFN). Sponsored by the Cleveland Clinic Foundation, Medtronic, and many other institutions and businesses, the meeting was held in a state-of-the-art conference facility at the Cleveland Clinic from October 1st-3rd. By bringing together many of the most creative and productive members of the field, the goal of the conference was ambitious - to effectively define the future of neuromodulation.

The conference agenda was organized primarily by clinical category, with half-day sessions devoted to each of the following topics: movement disorders, epilepsy, chronic pain, neuropsychiatric disorders, and emerging applications. The majority of the research involved deep brain stimulation, but many other neuromodulation methods were discussed, including gene therapy, drug infusion therapy, motor neural prosthesis, brain/machine interfaces, and many others. Because the meeting was relatively small, all of the attendees met in a single conference hall, which was unique and fostered frequent interaction between the audience and the presenters.

During the first half of each session, experts in various areas of neuromodulation presented their work. They were followed by briefer abstract presentations, some of which were unpublished research results. The material covered within each session was impressively diverse and at times highly technical. For these reasons, it is impossible to comprehensively summarize the content of the conference in this brief review. However, a few central themes emerged that we believe are important to consider. We encourage you to explore these themes further by scrutinizing the references and internet links listed below.

The most remarkable and exciting theme, of course, is how effective DBS can be. Dramatic illustrations of this fact were documented by films that showed patients before and after surgery. One film showed a young man who experienced almost complete remission of symptoms of Tourette syndrome following DBS. Other films depicting the effective treatment of Parkinson's disease and obsessive-compulsive disorder were equally noteworthy. Dramatic case-studies, however, cannot serve as the primary evidence for the effectiveness of DBS. Although many outcome studies indicate that DBS for movement disorders is effective for most people and relatively safe, there are very few long-term outcome studies of DBS.

Exactly how DBS works is not fully understood, but tremendous progress has been made in discovering the mechanisms underlying its effects. Of course, the placement of the electrode is critical and many of the presentations discussed the best brain "target" for DBS; that is, the ideal brain region to apply electrical stimulation. DBS of the subthalamic nucleus (STN), globus pallidus, thalamus, hypothalamus, cerebellum, and some cortical regions has been shown to ameliorate

neurologic and psychiatric symptoms. These target brain regions vary in size, and it is clear that the effectiveness of DBS depends upon precise placement of the electrodes. For many disorders, the optimal brain target is not known. For a discussion of the issues related to optimal electrode placement, see Kuncel and Grill (2004).

The paradox of DBS is that electrical stimulation of brain tissue, which presumably induces brain activation, has the same effect as that of a surgical lesion, which effectively destroys brain tissue. The ultimate elucidation of this paradox depends on the nature of the complex and interactive neural connections in the brain that communicate through electrical and chemical processes. Although consensus has not been reached, there is an emerging view that DBS has both excitatory and inhibitory effects on how brain circuits communicate with one another. For a discussion of issues related to how DBS works, see McIntyre et al. (2004) and Breit et al. (2004).

According to Dr. Alim-Louis Benabid, the "founding father" of DBS, for the treatment of movement disorders it is known that high frequency stimulation (100-185 Hz) is more effective than lower frequency stimulation. In fact, stimulation at low frequencies can actually exacerbate tremor in movement disorders. There are many ways to vary the "parameters" of stimulation (e.g., amplitude, frequency, duration, etc.), and each one likely plays a unique role in the patient's individualized response. Although basic guidelines exist for stimulator programming, according to many surgeons and patients the "art" of stimulator programming is alive and well. Interestingly, there was even a lack of consensus about whether or not to turn the stimulator off after surgery, with some surgeons preferring to never turn the stimulator off and others systematically and longitudinally examining the effect of stimulator parameters on symptoms. Unfortunately, there is little methodical research on long-term programming considerations. It may be that greater individualization of stimulator parameters, including relatively frequent re-adjustments, can lead to even better outcomes.

Like most medical procedures, DBS poses risks, and these risks were given adequate attention by the presenters. For example, Dr. Benabid pointed out that although negative side effects of DBS are typically not severe, one consistent finding is that speech may be disrupted by DBS. This observation is supported by other studies as well as our own survey research at The Parkinson Alliance on quality of life in individuals with DBS. Our preliminary results reveal that speech problems are commonly experienced by DBS patients. Our recent review of issues related to speech and DBS can be found on the DBS-STN.org website. This and other side effects are only beginning to be explored empirically. A discussion of the risks of DBS can be found in Piasecki and Jefferson (2004), Rezaei et al. (2004), and Pollak et al. (2002).

In addition to risks, important considerations regarding ethical issues surrounding DBS and neuromodulation were discussed, including conflicts of interest, informed consent, and the relationship between science and industry. One clear

recommendation in this context was the establishment of a national registry of single-case reports. Such a registry would assure that cases in which DBS produced negative results would be published and available to the scientific community for review.

Throughout the conference, fascinating research was presented on the various methods involved in implementing DBS. These topics included, for example, using computer modeling to customize the electrode placement for individual patients, engineering considerations in developing neuromodulation devices, the risks of undergoing an MRI after DBS, and predicting successful response to DBS. Regarding the latter topic, research suggests that younger age, but not gender, predicts positive response to some degree. A history of confusional states, dementia, or other cognitive impairment is also associated with poorer outcome following DBS. The condition of the brain also predicts outcome uniquely; patients with relatively large brain ventricles (fluid-filled cavities in the brain) which are typically indicative of brain atrophy, tend to respond less well to DBS. These and other factors serve as the basis for the recommendation that surgical candidates require a thorough, multidisciplinary evaluation. The field would be served well by the establishment of standards of practice for patient inclusion and exclusion criteria. Much more research needs to be done to more fully determine what physical, psychiatric, neuropsychological, and social factors serve to reduce the effectiveness of DBS.

Following movement disorders, the next most common disease treated with DBS and other neuromodulation techniques is epilepsy. A number of studies were reviewed that showed very significant reductions in seizure activity as a result of DBS treatment. One of the most intriguing developments in the realm of epilepsy was illustrated by a presentation by Dr. Joseph Smith and colleagues at the Department of Neurosurgery at the Medical College of Georgia. These researchers developed and tested a device capable of "responsive neurostimulation." Instead of being applied on a fixed schedule, as in movement disorders, the stimulator is triggered by intrinsic brain activity that typically precedes a seizure. By intervening before a seizure develops, this intervention can help prevent seizures. Although the results are extremely preliminary, they are positive and show that seizures can be predicted by brain activity measured by multiple subdural electrodes. This research serves as an exemplar of the novel technologies that will be developed in the coming years.

The theme of emerging applications was prominent throughout the conference. Now that it has proved effective as a treatment for movement disorders and epilepsy, DBS is being used experimentally in the treatment of pain, stroke, and neuropsychiatric disorders such as Tourette syndrome, obsessive-compulsive disorder, and depression. The study of the effectiveness of DBS for these disorders is in its infancy, with few controlled clinical trials published to date. The patients who have received DBS for these conditions have typically failed all other conventional treatment modalities and undergo a rigorous screening process before surgery. Before conclusions can be made regarding the safe and effective treatment of these

disorders using DBS, a tremendous amount of basic and clinical research needs to be done.

One emerging application that has yet to move from the laboratory to the operating room is examining the effect of DBS on the neuroregulation of feeding behavior. This research has been conducted only in animals, though the potential for DBS in the treatment of obesity and eating disorders was offered as a possibility in the future.

One final emerging application that was particularly captivating was the work of Dr. Gerhard Friehs and colleagues. Dr. Friehs demonstrated that a brain-machine interface can be made. A wide range of computer, technical, and research developments over the past 10 years have enabled the creation of a "prosthesis," by which a monkey (and even a few humans!) can learn to use feedback about their brain activity to control a computer or robotic device. In a brain-machine interface, the brain learns to view and control a mechanical device as it would a natural body part. In other words, in the future it may be possible to control computers and other devices with our minds! For a review of these developments, see Friehs et al. (2004).

Not only is the brain amenable to the beneficial effects of controlled electrical stimulation, but so is the peripheral nervous system. The use of peripheral stimulation is being explored in many peripheral nervous system conditions, including chronic pain, cluster headache, and peripheral nerve stimulation. Vagal nerve stimulation (VNS) is approved by the FDA for the treatment of epilepsy, and the technology was recently nearly approved by the FDA for treatment resistant depression. The field of peripheral nervous system stimulation is expanding rapidly and will undoubtedly lead to effective treatments for a variety of disorders.

These observations capture only a small sample of the voluminous amount of information reviewed and debated during this fascinating and informative conference. Though tremendous advances have been made in the field of neuromodulation, many questions remain unanswered. For example, it is not yet known whether DBS has any neuroprotective effects. Research addressing this and many other important topics is only beginning to be explored.

The ultimate future of DBS and other neuromodulation methods was brought into sharper focus by the end of this conference. The theoretical and technical advances made over the past 20 years bode extremely well for the field to achieve its ultimate goal - to cure disease and relieve suffering. Indeed, there is no question that the future of neuromodulation is bright! The field is on the cutting-edge of developments across a wide range of scientific disciplines and requires the input and support of scientists, patients, industry, government, and education and research organizations such as The Parkinson Alliance. We look forward to sharing with you much more information about future developments in neuromodulation as they emerge.

Complete references for this article are available on the DBS-STN.org website.

## DBS Programmers Forum

By Roberta Rubin, RN, CNOR, RNEA, California Neuroscience Institute

The Parkinson's patient decides to have DBS surgery. Being an experienced and educated consumer, she does extensive research. Who has done the most implants? Which is the highest rated hospital? Do they have the newest technology? Will her insurance cover the procedure?

She identifies the surgeon and facility that meets all of her criteria, and has a smooth and successful surgery. The DBS has been implanted perfectly, and the surgeon's piece is finished.

### *Now what?*

Unlike most surgical procedures, the closing stitch is just the beginning of the DBS journey. Once implanted, the device has to be programmed. DBS programming is a time-consuming and delicate process involving a great deal of interaction and communication between clinician and patient. There are varying levels of experience and training among the facilities associated with the implanting surgeons, and there has been little standardization in the practice of programming.

So, who are the programmers, and how are they trained?

Many of the comprehensive DBS centers have nurses providing the programming, some neurophysiologists program, and most movement disorder specialists have a working knowledge about programming, although the time-intensive nature of the work makes it difficult to integrate into their daily practice. Occasionally, when there are no trained programmers in an area, the local Medtronic representative will provide the service.

Medtronic provides a basic beginners training session, but after that, the programmers are on their own to seek out more advanced training. Some will visit the more established centers to work with experienced programmers, and others do their best to figure it out as they work with the patients.



*Roberta Rubin*

Recognizing this gap in service to the DBS community, Judy Blazer, of WE MOVE, joined forces with Margaret Tuchman and Carol Walton, of The Parkinson Alliance, to

start an initiative for education and information exchange. This has resulted in the programmers forum, a part of MDVU (Movement Disorders Virtual University—see page 1 of this newsletter for more information), providing a place for experienced and novice programmers to exchange information, ideas, and knowledge.

In its infancy, the forum is open only to practicing clinical professionals. Summaries of the programmers forum will periodically be made available on the DBS-STN.org site.

Kudos to Ms. Blazer, Tuchman and Walton, for having the vision, making it happen, and providing a valuable and much needed tool for our community!

*Roberta Rubin has been working in the field of Neurosurgery for 22 years, and specializing in Movement Disorders surgery for the past 13 years.*

## DBS-STN.org is Growing

The DBS-STN.org website is fast becoming a popular Web meeting place for the DBS-STN community. In February 2004 when the site launched, we had some 200 visitors. Now, only nine months later, we have over 2,200 visitors—quite an impressive jump for such a selective audience.

It is vitally important that we continue reaching out and connecting with the DBS-STN community. In this regard, we are proud that our web developer takes an active role in monitoring and improving the search engine visibility of our site. Across all the major search engines, DBS-STN.org currently has a visibility index of 97.5%. That means when someone is using a search engine, he or she has a 97.5% chance of seeing our site listed in the top ten of any search for any DBS-STN-related phrase. In fact, DBS-STN.org is number one for many key phrases.

The most popular area of the DBS-STN.org site is our Forum, which attracts approximately 45% of all page visits during an average month. In addition to postings from patients and caregivers, advisors to our Forum include a neurologist, a neurophysiologist, a neurosurgeon, and a nurse practitioner. Most regulars appear to visit every day or two to see what is new. Some days there can be as many as 200 views to our Forum's pages. About 12% of our visitors go straight to our Forum, either through a bookmark or by finding the Forum through a search engine.

Another popular area of our site is our articles and research pages. Our research team summarizes the most recent medical research on DBS-STN and presents it to our readers in a comprehensive, yet simplified fashion. Our researchers also write articles correlating research with our survey findings. Our surveys are designed to gather information from the patients' point of view and cover a variety of quality of life issues.

DBS-STN.org is committed to helping improve the quality of life of DBS-STN patients and their caregivers, and we are proud of our continued growth. If you have not yet visited the DBS-STN.org website, please join us.

## 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

## Carnegie Center 5K & Fun Run

October 2, 2004

West Windsor, NJ

More than 400 runners, walkers and volunteers gathered on Saturday, October 2 in West Windsor, NJ, for the 5th annual Carnegie Center 5K and Fun Run to raise funds for The Parkinson Alliance. The event raised a magnificent \$35,000!

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, Daniel Feder, with a time of 16:28, and the top women's winner, Katie Kellner, with a time of 21:26 walked away with a trophy and special prizes. For all other race times, visit [www.compucore.com/cs2004/october/carnegi1.htm](http://www.compucore.com/cs2004/october/carnegi1.htm).

Prior to the 5K, 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. Commercial real estate broker and Race Director Jerry Fennelly, his wife Nancy, NAI Fennelly and generous corporate sponsors like Interpool, Tyco, Yardville National Bank, Boston Properties, GE Healthcare, 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.

Photos: (top) Jerry Fennelly addresses the 5K crowd; (left) Daniel Feder with his son, another winner; (right) Katie Kellner.



## "A Step Ahead, A Positive You" Fashion Show & Luncheon

October 24, 2004

West Windsor, NJ



*Fashion Show Finale*

On Sunday, October 24th, nearly 400 people gathered at The Hyatt Regency Princeton to attend "A Step Ahead: A Positive You," a fashion show and luncheon that raised \$40,000.

The crowd began gathering mid-day to enjoy light hors d'oeuvres while viewing and taking chances on over forty gift auction items—such as autographed sports memorabilia, designer clothing, gift certificates, and various gift baskets—and the "Super Raffle" prizes that included a deluxe cruise for two with airfare, a four day spa vacation with airfare, and a handcrafted San Francisco Victorian doll house. In all, over \$25,000 in items were donated from local vendors and businesses. During the luncheon, the lucky winners of

the gift auction were announced and their prizes delivered. After lunch was served, the fashion show delighted the crowd and featured items from Hedy Shepard, Ltd., Forest Jewelers, Step by Step, Suit World, and Foot Solutions. All 59 models who strutted the runway were local volunteers—moms, dads, grandparents, and grandkids—a true community effort. The delightful show concluded with the announcement of the Super Raffle prizewinners. Linda Meisel of Princeton, NJ won the cruise package; Howard Hall of New Hope, Pennsylvania won the spa package; and Anne Merlino of Ewing, NJ won the Victorian dollhouse.

Instrumental in the success of the event were Gail Ruderman and Tracey Destribats who served as co-chairs; Rachel Rabinowitz and Lynn Rabinowitz of Hedy Shepard Ltd. who coordinated the fashions; Metropolis Spa Salon for providing hair and makeup services to the models; Forget Me Not Florist of Hopewell for providing table centerpieces; and Bristol-Myers Squibb, Yardville National Bank, Grand Bank, and Kyowa Pharmaceutical, Inc. for sponsor support.

## Upcoming Events - 2005

### March 6th — Team Parkinson at the Los Angeles Marathon

Support Team Parkinson in its sixth year participating in the L.A. Marathon. Formed in 2000, Team Parkinson is an official charity of the L.A. Marathon and is a non-profit organization staffed by volunteers and dedicated to finding a cure for Parkinson's disease. For more information, visit [www.teamparkinsonla.org](http://www.teamparkinsonla.org).

### April 16th — Parkinson's Unity Walk

Join us, rain or shine, for the 11<sup>th</sup> annual Unity Walk in Central Park, New York City. For more information, visit [www.unitywalk.org](http://www.unitywalk.org).

### May 1st — Team Parkinson at the Lilac Bloomsday Run

Bloomsday is an annual 7.46 mile fun run/walk in Spokane, Washington. Team Parkinson was the first official charity of Bloomsday 2004. For more information, visit [www.teamparkinsonla.org](http://www.teamparkinsonla.org).

### May 18th — Putting for Parkinson's Golf Outing—West

The Tuchman Foundation will again hold its annual golf tournament at the beautiful Chardonnay Country Club's Shakespeare Course in Napa Valley, CA. All proceeds will directly benefit Parkinson's research.

### July 31st — Team Parkinson at the San Francisco Marathon

Team Parkinson is an official charity of the San Francisco Marathon. Join Team Parkinson in its first year of participation in the San Francisco Marathon. For more information, visit [www.teamparkinsonla.org](http://www.teamparkinsonla.org).

### September 26th — Putting for Parkinson's Golf Outing—East

The Parkinson Alliance and The Tuchman Foundation are again combining forces this year providing a great opportunity to raise funds. This golf outing will be held at Forsgate Country Club in Jamesburg, NJ.

### October 1st — Carnegie Center 5K & Fun Run

Our 5K and one-mile fun run, where walkers and families are also welcome, is held annually at the Carnegie Center in Princeton, NJ. Food and refreshments will be served and awards will be given to age-category and group team winners. Relatively flat course. USATF-NJ Certified Course.

#### PARKINSON'S

#### CLINICAL TRIALS

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

[www.PDtrials.org](http://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.

**APT** ADVANCING  
PARKINSON'S  
THERAPIES

[www.PDtrials.org](http://www.PDtrials.org)

### Buy Delicious Pancakes from Pj's & Help Support Parkinson's Research

100% of the net sales proceeds from the online sale of pancake products are donated to The Parkinson Alliance.

**Pj's Pancake House**

<http://www.pancakes.com>

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](http://www.parkinsonalliance.org)  
e-mail:  
[admin@parkinsonalliance.org](mailto: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](http://www.parkinsonalliance.org)