



# CATALYST

Growing Funds for Parkinson's Research

## What a Year for Team Parkinson

As he finished the LA Marathon with five of his teammates, John Ball, co-chair of Team Parkinson thought to himself, "What a year this has been for Team Parkinson! Who would have believed when Mary Yost started this organization in 2000 that we could reach \$170,000 in fund-raising this year?" When contacted later at her home in Oregon, Mary said she was "stunned to see how far the organization had come in these four short years." Current Co-chairs for the event, John and Edna Ball, are the driving force behind Team Parkinson. John was diagnosed with Parkinson's in 1983, and Edna's mother lived with PD for 37 years. "I guess you could say it runs in the family," Ball said. At the team's celebration dinner the night before the marathon, John continued, "Team Parkinson is dedicated to finding a cure for this disease, and my wife and I will not rest until our children no longer have to worry about Parkinson's disease in their future."

On the March 3rd race day, 30 Team Parkinson athletes participated in the 26.2 mile Marathon, 2 in the 20+ mile Acura LA Bike Tour, and 45 in the 3.1 mile LA Marathon 5K Run/Walk. Every one of the Team Parkinson entrants finished his or her event, including three marathon participants with the disease. They were: John Ball who finished his 8th L.A. Marathon in 5:13:55, Steve Evans, who undoubtedly made history by being the first post-DBS surgery patient to complete a marathon, and David Schneider, who traveled from Japan to participate for Team Parkinson.

Team Parkinson dedicated this year's event to the memory of Daniel Marcus, whose courage and commitment inspired everyone who met him. In spite of his blindness and suffering from Parkinson's disease, Daniel participated in the LA Marathon in 2000 and 2001 in his wheel chair. He was the top fund-raiser for the event in 2001. Unfortunately, Daniel was too ill to compete the

following year and passed away in July 2002. His family carried on this year in his honor, as his widow Jean Marcus and daughter Joanie Colvin, along with ten of his caregivers, ran the last 10 miles of the 2003 marathon with a large banner bearing Daniel's picture. Daniel's son-in-law John Colvin also ran in his honor, completing the 26.2 mile course in 4:39:40. In the 5K walk/run, Team Parkinson had several first-time finishers, including three with Parkinson's. Jim Wilber, Bruce Wisnicki and

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Dr. Marty Polonsky each completed the first-time attempt. For Polonsky, it was a major step forward after several years of back and leg problems due to Parkinson's. Polonsky's neurologist, Dr. Giselle Petzinger said, "Just two years ago, Marty was in a wheelchair from injury and in constant pain. Last year we got him up on crutches, and this year I encouraged him to train for the 5k. I know he's worked hard to get himself ready." Marty didn't make it without some help, as it turned out. Nearing the end of the three miles, Marty slipped on some trash by the side of the road and fell to the ground. Medical personnel from the event immediately assisted him, but the best help came from Dr. Petzinger, who was walking the event with her husband and their three small children. She gathered up Marty's water bottle, answered his ringing cell phone, and assisted him to his feet. Then, arm-in-arm, they walked the last tenth of a mile to the finish.

It was also a first time effort for Bruce Wisnicki and his family. Bruce and his wife Kathy were this year's top fund-raisers for Team Parkinson. It was a year of growth for Team Parkinson in 2003 as the team began branching out to other marathons and other kinds of fund-raising events, including a Comedy night in Hollywood hosted by May May Ali, daughter of "the Greatest" and a dog walk called "Poop on Parkinson's".



Members of Team Parkinson

*continues on page 4*

## Message from the President



As you most likely noticed, this issue has less pages than usual.

Why? We are in the process of creating a new *Catalyst* section devoted to DBS/STN topics with an emphasis on patient advocacy. Our decision came from our growing interest and involvement with the patient population who either are considering surgery or have undergone DBS/STN. We decided that, while we are developing our DBS/STN section, we would publish this 4-page newsletter to keep you updated on important Alliance news.

Our next issue will return to 8 pages. In addition to Alliance news, we will feature the latest DBS/STN news that either support or not the current beliefs and thinking in the medical and patient community. We may include a mini-survey based on a single issue patient concern. We are planning guest articles.

The Alliance's primary goal is raising funds for Parkinson's disease research. Additionally, I am personally driven as a DBS/STN patient advocate. As part of that advocacy, I have published the results of the first DBS/STN Patient Survey on the Rewired for Life web site ([www.rewiredforlife.org](http://www.rewiredforlife.org)). In continuing that advocacy, I will provide you with as much helpful information as possible in the Parkinson's DBS/STN arena.



**Margaret Tuchman**  
President, The Parkinson Alliance

## Message from the Executive Director



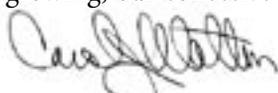
In the last issue of *The Catalyst*, I wrote about the importance of unity and collaboration in Parkinson's community. I am excited to share new collaborative ventures among the PD community.

Earlier this year, our friends at the Parkinson's Action Network (PAN) started a bi-weekly conference call among the major PD organizations. A variety of topics were discussed—updates on advocacy issues, the status of issues on Capital Hill affecting the PD community and how each organization can assist in advocacy, news on research projects, information on events that each organization is sponsoring, and other major issues for the PD community such as clinical trials. PAN also held a Summit in New York City where representatives from all the major PD organizations met in person.

Our friends at NINDS started the "Parkinson's Information Exchange," a major communications vehicle for the PD community. Meetings and opportunities for collaborations in the public and private sector, and updates on research, are being discussed every two to three months among the major PD organizations and NINDS staff. One result of the Parkinson's Information Exchange—a first for NINDS—is a system for active recruiting for the neuroprotection trial. Other results will happen.

The largest PD initiative ever undertaken by the NIH was the R21 Fast Track Grant Program. This was a joint commitment of \$11 million over 2 years among the major PD organizations and institutes within the NIH. The Parkinson Alliance and the Unity Walk are now proud to be part of the Michael J. Fox Foundation's Community Fast Track 2003 program. As Deborah Brooks, Executive Director of MJFF stated, "Over time, we hope that Community Fast Track serves as a springboard to greater collaboration within the Parkinson's community as we all strive toward the goal of curing PD."

With the PD community unified, and collaboration growing, our collective objective of finding the cause and cure to Parkinson's will be found.



**Carol J. Walton**  
Executive Director

## **The 9th Parkinson's Unity Walk — What a Sight To See!** **April 26, 2003** **New York City, NY**

It may have rained, but the inclement weather did not dampen the spirits of over 4,000 people that began arriving in Central Park as early as 9 a.m. for the annual Parkinson's Unity Walk. Participants came from all over the United States and raised more than \$500,000. 100% of all donations raised from the Walk will go directly to Parkinson's research—a tradition that continues since the first Walk in 1994.

The day was full of festivities. Music was provided by the Persuasions. Top doctors in the field of Neurology provided educational information. Major companies, such as Pfizer, Medtronic, Novartis, and Titan Pharmaceuticals, Inc. offered important research information. Seven major Parkinson's foundations provided literature for patients and caregivers. Additionally, Dr. Joao Siffert of Pfizer Neurology Group presented the second annual Mirapex® Victory Research Award. The \$10,000 grant, designed to encourage scientists who are committed to neurological research in the field of Parkinson's disease, was presented to Clifford Shults, MD, of the University of San Diego, for his groundbreaking work with co-enzyme Q10.

We invite you to join us for the 10th Parkinson's Unity Walk in April 2004. For more information on the Parkinson's Unity Walk, please call 1-866-PUW-Walk (1-866-789-9255) or visit the web site at [www.unitywalk.org](http://www.unitywalk.org). ☺



*The ribbon is about to be cut to begin the 2003 Unity Walk.*



*Some of the 4,000 Unity Walk participants.*

## **"A Step Ahead: A Positive You"** **Fashion Show and Luncheon** **March 23, 2003** **Princeton, NJ**

The Parkinson Alliance held its very first fashion show and luncheon at The Westin Princeton at Forrestal Village in Princeton, NJ. The event proved to be a great success with over 400 people attending. Participating stores included Hedy Shepard, Ltd., Hamilton Jewelers, Ici Fashion for Children, and Nick Hilton Studio. A sumptuous lunch was served as fabulous door prizes were awarded. The fun continued with two super raffles—one for a cruise for two, and the other for dinner for eight prepared and served in the winner's home by Marc Fertoukh of Paris Desserts & Catering. The raffles were won by two very happy people. Thanks to our Premier Sponsors—Bristol Myers-Squibb, Pharmacia/Boehringer Ingelheim, Yardville National Bank—the net proceeds of this event will go directly to Parkinson's disease research.

## **The 2nd Annual Shake, Rattle, & Roll** **June 29, 2003** **Peoria, IL**

It was a picture perfect Sunday as nearly 200 people with Parkinson's, their families and friends gathered to walk along the scenic Peoria riverfront for the Second Annual Shake, Rattle and Roll for Parkinson's Disease. For more information on the walk and the People Living with Parkinson's Symposium visit our web site at [www.parkinsonalliance.net](http://www.parkinsonalliance.net).



*Pat Sullivan and Holly Angus*

## Upcoming Events

### Team Parkinson events:

October 19, 2003

The US Half Marathon, San Francisco, CA

November 2, 2003

2nd annual "Poop on Parkinson's" Dog Walk, Los Angeles, CA

February 29, 2004

Sheraton Hyannis Marathon, MA

March 7, 2004

Team Parkinson at the LA Marathon, Los Angeles, CA

### Parkinson's Unity Walk, New York City, NY

April 24th or 25th, 2004 (see [www.unitywalk.org](http://www.unitywalk.org) for finalized date)

### Team Parkinson — *continued from Page 1*

Under the guidance of The Parkinson Alliance and the Parkinson's Unity Walk, Team Parkinson guarantees that 100% of all net proceeds go directly to research.

"On a more personal note," John said, "Edna and I are thrilled with this year's success. We can't imagine right now what it will take to make next year even better. I guess we'll just have to figure out a way." One certain way the team plans to grow is to expand to other marathon events around the country. Edna is working closely with new team members around the San Francisco Bay to coordinate the first Team Parkinson fund-raiser at the US Half-marathon in San Francisco on October 19, 2003. "We think this will be a terrific opportunity," Edna said. "We have several new runners around the Bay Area who are already launching their own personalized web pages in our team web site. And our on-site coordinator, Jennifer Bugnatto, is doing a terrific job."

For more information visit: [www.teamparkinsonla.org](http://www.teamparkinsonla.org), or contact Team Parkinson at (866) 822-CURE.

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.net](http://www.parkinsonalliance.net)

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