



# CATALYST

Growing Funds for Parkinson's Research

## The Parkinson Alliance Participates in Ground-breaking Conference on Neural Interfaces

On June 21, 2010, The Parkinson Alliance presented at the Neural Interfaces Conference in Long Beach, California. This critical conference brings together leading researchers, scientists, and clinicians to learn about new Deep Brain Stimulation (DBS) technologies and therapies. The best applications of these therapies for patients with motor symptoms—including patients with Parkinson's disease (PD)—are presented at this international forum.

We have come a long way in understanding DBS and its impact on motor symptoms of PD and the "patient's well-being," but there is much more to learn and improve, including, for example, understanding the mechanisms that make DBS effective, non-motor symptoms of PD, and how to optimize the benefit of and further enhance this innovative intervention.

Generous contributions enable The

Parkinson Alliance to remain at the forefront of knowledge about promising research for the treatment—and one day cure—of Parkinson's disease including participating in key research forums. Much advancement in neural prosthetics, such as DBS, has been realized, and we need to work collaboratively in the research and clinical communities to improve our understanding and effectiveness of DBS therapy.

Here are a few highlights from the conference:

### DBS for PD: What is the Target?

Bill Marks, MD presented the results of a study endeavoring to differentiate the stimulation effectiveness of the two most common targets of DBS for PD (the subthalamic nucleus (STN) and the globus pallidus interna (GPi)). The study, known as the VA/NINDS Cooperative Study, found that DBS of the STN and the GPi are as effective in treating some motor symptoms of PD and have favorable outcomes for many PD patients who are good candidates for DBS therapy. The benefits of DBS that were seen after the first few months remained stable over a two-year period.

DBS was found to be more effective than the best medical therapy (medications) alone on some of the outcome measures, such as quality of life and UPDRS III motor scores in the "off" state. There was no difference between DBS and the best medical therapy on the UPDRS III motor "on" state and measures of cognition (thinking skills) and emotional well-being. There was a greater medication reduction for some of the participants in the STN group than in the GPi group. Thus, the

## INSIDE

- A Thank You from The Parkinson Alliance* ..... 2
- Thousands Walk in Support of the Parkinson's Community at the 2010 Parkinson's Unity Walk* ..... 3
- Team Parkinson Sets New Fundraising Record* ..... 3
- Upcoming Events* ..... 4
- Princeton Dined Out for Parkinson's Research* ..... 4
- A Voice for the Patients' Perspective: Completing The Parkinson Alliance Survey* ..... 4

need or desire for medication reduction may influence choice of target.

### Pedunculopontine Nucleus Deep Brain Stimulation:

Clement Hamani, MD facilitated a lecture regarding research outcomes for DBS of the pedunculopontine nucleus (PPN). The PPN is a "brainstem locomotive center" that also processes sensory and behavioral information. A few studies have shown improvements in freezing, the frequency of falls, and to a lesser extent gait and posture. Although there are controversial perspectives of PPN DBS for PD motor symptoms, there is evidence that PPN stimulation improves sleep and cognition. Further studies are needed to determine the effectiveness and benefit of stimulating this brain structure.

### Computational Models for Deep Brain Stimulation:

Cameron McIntyre, Ph.D. is a biomechanical engineer who facilitated a talk about using computational models (computer models) to help improve the effectiveness of DBS. There are sophisticated software tools capable of



Dr. Jeffrey Wertheimer, Ph.D.  
Research Consultant  
The Parkinson Alliance

## A Thank You from The Parkinson Alliance



Margaret Tuchman

Dear Generous Friend,

Your support of The Parkinson Alliance means so much—words don't seem adequate to express my gratitude. Still, I want to use the two words that, however inadequate, come closest to conveying how we feel:

Thank you.

I'm so proud of what we've been able to accomplish together for millions of people with Parkinson's Disease who are desperately waiting for signs of hope. I trust you'll enjoy reading about our latest efforts in this issue of the Catalyst.

The research findings discussed at the Neural Interfaces Conference gives hope to many seeking relief for their symptoms; and I know you will feel satisfaction seeing how your contributions have translated into some very exciting upcoming grants.

Every time we receive a gift from a person like you, I'm proud to be able to match it with contributions from the Tuchman Foundation so that 100% of your gift goes to vital research.

We won't give up until we find a cure for Parkinson's Disease. And, with you by our side, I know that day will come.

Gratefully yours,

*Margaret Tuchman*

The Parkinson Alliance, Founding Member & President

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predicting theoretically optimal stimulation parameter settings on a patient-specific basis. This software program could help identify the distribution of the voltage (electric energy), the volume of tissue activated by DBS, the optimal settings, and a clearer picture of the effectiveness of DBS. By reducing the area that is stimulated (due to better targeting), greater controlled benefit and reduced unwanted side effects will likely ensue. Automated algorithms (step-by-step problem-solving procedures) help to minimize clinical guess work, reduce the time necessary to effectively implement DBS, and improve clinical outcomes. This tool also helps to maximize power efficiency, which will potentially extend battery life.

### **Closed Loop Control:**

Jerrold Vitek, M.D., Ph.D. provided some comments about closed loop control for DBS in patients with PD. Closed loop control in deep brain stimulation is an engineering design where feedback signals (between the body and the device) will be interpreted by the DBS device and will then modify stimulation parameters, stimulation locations, and other factors that can have an effect on the overall system performance.

Dr. Vitek stated that there is promise for closed loop control in a variety of diseases that utilize DBS or some form of stimulation to the brain. As it relates to PD, however, he indicated that too many questions remain before closed loop control (for DBS) in such a complex disease can be implemented.

### **Balance Confidence in Patients with PD: The Patient's Perspective:**

Jeffrey Wertheimer, Ph.D., a research consultant for The Parkinson Alliance, presented our most recent research, assessing balance confidence in patients with PD with and without DBS. The paper can be found on our website: [DBS-STN.org](http://DBS-STN.org).

### **Concluding Remarks:**

Many advancements in neural prosthetics, such as DBS, have been realized, and we need to work collaboratively in the research and clinical communities to improve our understanding and effectiveness of DBS therapy.

To read more about the information presented at this conference visit [DBS-STN.org](http://DBS-STN.org). ☺

## Your Research Dollars at Work

The Parkinson Alliance is funding a clinical trial at UCLA using repetitive transcranial stimulation (rTMS). Please visit our website at [www.parkinsonalliance.org](http://www.parkinsonalliance.org) to read how this trial might help Parkinson's patients.

# Thousands Walk in Support of the Parkinson's Community at the 2010 Parkinson's Unity Walk

## *Largest grassroots fundraiser in the U.S. for Parkinson's disease research*

With spring in the air and spring in their step, more than 10,000 people joined forces to help raise funds for Parkinson's disease research on Saturday, April 24, at the 16th Parkinson's Unity Walk in New York's Central Park. This year's participants included teams from across the country and comprised the largest grassroots initiative in the U.S. for Parkinson's disease research. This year's Walk raised \$1.5 million for research.

The 2010 Parkinson's Unity Walk was dedicated in memory of Margot Zobel, who passed away earlier this year. Zobel, who had Parkinson's disease herself, began the walk in 1994 with 200 participants and helped to grow the walk over the following 15 years.

"The Unity Walk continues to be such an inspiring experience, seeing so many people come together in support of our efforts to educate the community and find a cure for Parkinson's disease," said Carol Walton, Executive Director of the Parkinson's Unity Walk and CEO of The Parkinson Alliance. "We deeply missed Margot this year, but the inspiration she brought to this walk continues and I know she would be proud of the great work we've accomplished in her honor."

The Unity Walk is made possible through the support of its many sponsors, including this year's premier sponsor, Solvay Pharmaceuticals, now Abbott. For the second year, Solvay Pharmaceuticals featured its Messages of Hope™ Wall at the Unity Walk, collecting photos and inspirational messages from Walk participants and donating \$15 for each message, up to \$15,000. Additional Unity Walk sponsors included Boehringer Ingelheim, LSVT Global, Medtronic, Novartis and Teva Neuroscience.

For more information on the Parkinson's Unity Walk, visit [www.unitywalk.org](http://www.unitywalk.org). ↻



*Parkinson's Unity Walk Finish Line*

## Team Parkinson sets new fundraising record!

### *In one word... WOW!*

This year the LA Marathon raised \$120,000, the SF Marathon over \$80,000 (a new record!), and events all over the country made a contribution as well. We are so grateful for your continued participation and support and excellent fundraising effort. This extraordinary outpouring brings us that much closer to a cure as we continue to fund Parkinson's disease research with 100% of all net proceeds.

## Q&A with Team Parkinson co-chairs, John and Edna Ball

**Q: This is your 11th year participating in the LA Marathon. How is this year different from other years?**

Edna: Each year is different and better because we meet more and more people who motivate us to keep doing what we're doing.

**Q: What else are you trying to do for the growth of Team Parkinson?**

John: We want to raise awareness, to give people a sense of what it means to have Parkinson's. How it affects your family and how it affects your society around you. We want to raise money to provide the research capability to find a cure for this disease. The third thing is to empower people who have Parkinson's to set goals for themselves, to set targets to train for a specific event and to care for their lives therefore.

**Q: What do you think you've learned about how strenuous exercise and having Parkinson's affects you?**

John: What I found for myself at least is that, if I go out and go to the gym and do hours worth of exercise and do that repeatedly, I'm going to be able to maintain a certain level of fitness and capability, but if I want to regain what Parkinson's is trying to take away for me, I actually have to go push myself beyond what I'm comfortable with, beyond what I think I'm capable of and by pushing myself over and over and over again, I've found that I actually regain things that I thought I lost and I've actually been able to maintain the level of performance that's normal. I'm still running after 30 years of having Parkinson's, and I'm still surviving and living life to the fullest.

For more information about Team Parkinson visit [www.team-parkinson.org](http://www.team-parkinson.org).



*Team Parkinson at San Francisco Marathon*

## Upcoming Events to Support Parkinson's Research

### Team Parkinson at the Los Angeles Marathon

Sunday, March 20, 2011

Los Angeles, CA

### Parkinson's Unity Walk

April 2011 (exact date TBA)

Central Park, NYC

### Team Parkinson at the San Francisco Marathon

Saturday, July 31, 2011

San Francisco, CA

## Princeton Dined Out for Parkinson's Disease Research

April is Parkinson's Awareness Month and The Parkinson Alliance raised awareness of Parkinson's disease in the Princeton area during the month of April.

On April 29th eight area restaurants participated by donating a percentage of their proceeds from that evening's dinner sales to The Parkinson Alliance. Participating restaurants included Blue Point Grill, elements, Eno Terra, Gennaro's, Mediterra, Teresa's Caffe, Witherspoon Grill and the Yankee Doodle Tap Room.

In addition, all three McCaffrey's Supermarkets gave customers the option of donating \$1 or \$5 to The Parkinson Alliance each time

they checked out of the store. Colorful cardboard circles were hung all around the stores, representing those donations and the generosity of our community.

Thank you to all who made donations, enjoyed dinner out on April 29th at one of the participating restaurants and to the merchants for making this possible. All donations will go directly to research and will be matched by The Tuchman Foundation. ☺



*Donation circles brighten the Princeton, NJ McCaffrey's*

## A Voice for the Patients' Perspective: Completing The Parkinson Alliance Survey

One facet of our many goals is to contribute to the improvement of quality of life through conducting survey-based research to obtain the "patient perspective" about the experience of PD for those with and without Deep Brain Stimulation (DBS). You are invited to participate

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in our survey at [www.dbs-stn.org](http://www.dbs-stn.org). In addition, if you would like to participate by completing a survey using paper and pencil, please call us at 1-800-579-8440, and we will be happy to assist you. ☺

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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  
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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