



CATALYST

Growing Funds for Parkinson's Research

A Consensus Meeting to Discuss Deep Brain Stimulation for Parkinson's Disease New York City: 4/01/09 through 4/03/09

Deep Brain Stimulation (DBS) therapy is one of the state of the art treatments for individuals with Parkinson's Disease (PD). It has proven to be effective in treating some of the cardinal signs of PD and motor complications of levodopa therapy. However, DBS has also been found to have limited impact, no impact, or at times worsening effects on other important symptoms that impair the quality of life of individuals with PD (e.g.,

constructively discuss the role of DBS in the treatment for PD. The task assigned to these experts was not to craft a typical consensus statement for themselves [the clinicians], but to come up with a document aimed squarely at their true customers—the patients.

The topics of the Consensus Meeting were many and included patient selection, gait and speech DBS outcomes, non-motor DBS outcomes (mood and cognition) and long-term DBS outcomes, to name a few. The dialogue among



Dr. Jeff Bronstein, Director of Movement Disorders, UCLA School of Medicine

poor balance, speech disturbance and psychiatric conditions). Therefore, there is a necessity to critically review all of the related components of DBS therapy, its effectiveness, benefits, and risks.

On April 1st-3rd The Parkinson Alliance (with shared sponsorship provided by the Davis Phinney Foundation, the LSVT Foundation, and the National Parkinson Foundation) convened a panel of the world's experts on DBS for PD to

the clinicians was riveting and informative, and progress was made in discussing where we currently stand, some steps to further improve the efficacy of DBS and the treatment of PD, and what questions still remain and warrant further research/ investigation. The ultimate focus was on improving the effectiveness of the intervention and the quality of life of those individuals who have undergone or those who will choose to undergo DBS. A written

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report of this Consensus Meeting is currently being generated and will be summarized and posted on our websites —www.dbs-stn.org and www.parkinsonalliance.org. At the conclusion of the Consensus Meeting, a group of PD patients with and without DBS was invited to an open forum where several clinicians shared their experiences working with this population, and they answered participants' questions. There were many pertinent questions that are commonly asked in the PD community; for example, questions related to patient selection for DBS, timing of the DBS surgery in the context of the course of PD, issues related to surgical intervention, programming, the effects of DBS on symptoms of PD (cardinal signs of PD, speech, emotional well-being, etc.), the status of alternative types of treatment for PD, and many other questions addressing a variety of topics. A detailed summary of this open forum can be accessed via our website, as noted in the aforementioned paragraph. If you would like to discuss the write-up with any of our staff, you can contact us at 1-800-579-8440.



The 15th Parkinson's Unity Walk: A Step in the Right Direction for the Parkinson's Community

On Saturday, April 25th, family and friends came out in full force on this unusually warm and sunny spring day to join more than 10,000 people in New York's Central Park for the Parkinson's Unity Walk.

This was the 15th Walk, and it remains the largest grassroots fundraiser in the U.S. for Parkinson's disease (PD). This year the Parkinson's community truly stepped it up to make the 15th Anniversary one to remember, with the largest crowd yet. The day was filled with courage, hope, optimism and a feeling of being part of a special community.

Even in this difficult economic period, we raised over \$1.5 million, thanks to the time, dedication and support of the PD community. People worked hard to raise funds, in honor or memory of a loved one, to find a cause and cure for this devastating disease.

As pledged since the inception of the Walk, every penny raised continues to go directly to Parkinson's research. This is made possible through the Unity Walk's Premier Sponsor and Proud Partner for the 9th year, Boehringer Ingelheim Pharmaceuticals, Inc.; our Diamond Sponsors, Solvay Pharmaceuticals Inc., Teva Neuroscience and Valeant Pharmaceuticals International; as well as our Platinum and other Sponsors; and the seven national Parkinson's disease organizations.

The excitement in the air is always so addicting at the Walk, and this year was no exception. There was a lot of interaction at the "Ask the Doctor" booth, the pink Boehringer Ingelheim booth and the other sponsor and organization booths. Yorkie the Clown was welcomed back with smiling faces, and teams got together for a photo with a beautiful New York City background. Solvay Pharmaceuticals, Inc. introduced the "Message of Hope" Wall. Participants wrote their own messages of inspiration. In commemoration of the 15th Walk, Solvay donated \$15 per message, and raised a total of \$15,000, all of which went directly to research.

This year's event also included an international presence, with Susanna Lindvall, Vice President of the European Parkinson's Disease Association, addressing the audience about the importance of worldwide partnerships in the fight against Parkinson's. The past, present and future of Parkinson's disease was also the focus of several other powerful speeches, including those from Former Attorney General Janet Reno, and Dr. Jean Hubble, of Boehringer Ingelheim Pharmaceuticals, Inc.

It was an unforgettable day and everyone that came left with more knowledge about PD and an incredible sense of belonging. ☺



Solvay Pharmaceuticals, Inc. "Message of Hope" Wall



Speakers – seated l to r: Joel Gerstel, Janet Reno, Susanna Lindvall; Standing l to r – Cliff Maloney, Carolyn Maloney, Martin Tuchman



Pine Tree State Parkies Team

Start Your Fundraising Now!
The 16th Parkinson's Unity Walk
Community & Education Day — April 2010

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

Team Parkinson at the Los Angeles Marathon 2009

Team Parkinson at the Los Angeles Marathon 2009 was dedicated in loving memory to Kevin Adams, who last year ran the marathon despite Parkinson's disease and a cancer diagnosis. We lost Kevin just six weeks later, but he impressed us all with his spirit and determination. That spirit was more than evident in every way during this year's event.

The weekend started at the Expo and in our booth we got to see old friends and meet new ones as TP athletes came by to pick up their t-shirts. A special thanks to Celeste Bocian, who was on hand representing Solvay Pharmaceuticals, our premier event sponsor. Invaluable help, as always, was provided by Kippi Stolz, both in setting up and staffing the booth. And Doug and Mimi Macglashan once again took the final shift and closed things down, as we all headed to our carbo load dinner at Taix French Restaurant.

The carbo dinner served as a pre-race pep rally and the evening was wonderful, with about 80 people in attendance. Justine Lassoff, TP dinner coordinator did another excellent job in making the evening flawless. And thanks to Norm Reeves Honda Superstore, our dinner was fully sponsored. Mary Kay and Jerry Woudenberg staffed the registration table. Carol Walton, of The Parkinson Alliance, spoke a little about the Unity Walk in NY and the recently held DBS Consensus Meeting. John Ball served as emcee for the evening. Lisa Adams talked bravely and so beautifully about Kevin and what Team Parkinson and last year's marathon meant to him. Dr. Michael Jakowec of USC spoke about PD research he's conducting and explained how your donated dollars work. May May Ali read a delightful poem she composed about John, winner of this year's Alan Bonander Award at the Unity Walk. Edna Ball thanked some key people who made the weekend so successful. One of those was Matthew Chezum, TP's volunteer photographer, who was presented with a lovely award. Lastly, we announced a tie for top fundraising honors for Team Ackerberg (consisting of team leader Lisette Ackerberg) and The Dynamic Duo (Debbie Jew and Jessica Chadbourn). It really was a terrific evening and everyone left excited and ready for race day!

Because of the date change by the marathon, we were a bit worried about participation and the weather. But it turned out to be a terrific



Team Ackerberg



Get Involved!

www.team-parkinson.org



Dynamic Duo Tandem Bike Team

weekend for Team Parkinson! The weather was especially kind, staying cool, cloudy and breezy for the entire morning of race day. We had about 85 athletes total. Three of the 22 marathoners, John Ball, Gary Miller and Willard Krick, have Parkinson's disease and completed the entire 26.2-mile course! And six of our 60 5K participants ran or walked with Parkinson's as well...Lisette Ackerberg, Dan Kiefer, Al Rosenheck, Eddie Schindler, Sandy Webb and Jerry Woudenberg. In the bike tour, Debbie Jew of The Dynamic Duo tandem team has PD and was out there for the 5am start in the dark! Congratulations to all for having the courage and determination to get moving despite the PD. You are all a shining example of what's possible.

A total of \$114,000 was raised! Thanks to everyone for all the hard work training, fundraising and cheering as we get closer to a cure. ☺

Upcoming Events to Support Parkinson's Research

Carnegie Center 5K & One Mile Fun Run for The Parkinson Alliance

Saturday, September 26, 2009

Princeton, NJ

Team Parkinson at the Pasadena Marathon

Sunday, February 21, 2010

Pasadena, CA

Team Parkinson at the Los Angeles Marathon

Sunday, March 21, 2010

Los Angeles, CA

Parkinson's Unity Walk

April 2010

Central Park, NYC

Team Parkinson at the San Francisco Marathon

Saturday, July 25, 2010

San Francisco, CA

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Your Support Counts!



Aaron Moretzsky has been a tireless friend and supporter of Team Parkinson for several years. In that time, he has been one of our top fundraisers, bringing in \$130,000 in hopes of finding a cure!

The Central Coast Parkinson Support Group in Arroyo Grande, CA has entertained audiences with their Central Coast Follies for the past six years. The cast of over eighty performers dance and sing to help fund a cure for Parkinson's disease. The cast is supported by other volunteers, including a back stage crew, a production crew led by Bernie Kautz, Producer, and their super-multi-talented Director, Choreographer Jason Sumabat. **They have raised over \$140,000.00 for PD research.** ☺



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The Parkinson Alliance.

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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