



CATALYST

Growing Funds for Parkinson's Research

The Parkinson Alliance selected as American Legion Department President Project

Each year the President of the American Legion Auxiliary Department of New York picks an organization to support and promote. Called the "Department President Project," the program lasts for the duration of the President's year term. This year's President, Mary Anne Casadei, of Rome, NY, selected The Parkinson Alliance as her project. For Mary Anne, the cause is close to her heart. Her mother, Alvera Smith, was diagnosed with Parkinson's in 1990.

About six years ago, Mary Anne's mother moved in with Mary Anne and her husband. "I can't tell you the affect it had on our lives and on my siblings' lives. It's been devastating to us. But after talking to Margaret Tuchman and

The Parkinson Alliance organization, they made me feel that we are so close to a cure. They gave me hope."

Mary Anne learned about the Alliance through Nancy McCaffrey while attending The Central New York Parkinson's Support Group, Inc., a group that meets monthly in Ithica, NY. "I read some material on the Alliance and later spoke with Margaret. She explained her deep brain stimulation surgery, the before and after of it, and I was very impressed. She also stressed her belief in the possibility of a cure by 2005."

Mary Anne then learned of The Tuchman Foundation and how its dollar matching program pays all the administrative overhead costs for the

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Parkinson Alliance. This in turn provides the Alliance with the unique ability to spend 100% of all donations directly on research. "I picked The Parkinson Alliance as my organization to promote and support because I thought it would be a wonderful way of increasing the effectiveness of the amount raised from the American Legion Auxiliary. I also like that all donated funds go toward research to find a cure. This is a very difficult time for my mother, and her Parkinson's is quite severe. I feel that if we can find a cure by 2005, what a wonderful thing that would be."

Mary Anne promotes her cause by traveling throughout the state of New York, with the goal of visiting all American Legion chapters in NY's 62 counties. "I personally speak about my experience, my mother's experience with Parkinson's, and about the Alliance and Tuchman Foundation. I want to make sure people know there is hope."

Thus far Mary Anne has raised over \$30,000, but she has a higher goal. "I think that we can raise \$50,000 this



American Legion President Mary Anne Casadei and her mother, Alvera Smith

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DBS/STN and Making A Difference

With every sun-up there is a chance for new discoveries, new drugs, new devices. People are reaching out, helping one another. There is hope for us, individually and collectively.

Before my DBS/STN, I was involved in a variety of self-made projects with an e-mail support group made up of people living with Parkinson's. It was this service to others that gave me a sense of purpose and connectedness. Today my need to be involved and serve continues. In addition to the work I do at the Alliance, I am very proud of my recent work in creating a survey for DBS/STN patients (www.rewiredforlife.org). By analyzing the results of the survey, I want to find answers for the many who are teetering on the verge of surgery and for those who have unanswered questions about their current post-surgical condition. Additionally, with the help of NYU physicians, I am the moderator of the Re-Wired for Life patient forum. The forum offers a place for individuals to share their questions, answers, and concerns regarding DBS/STN.

In February I went through my 12-month post DBS/STN evaluation with the NYU adjustment team. Because the prerequisite for the evaluation is to be off both medications and stimulators for 12 hours, I was very nervous. Yet when I awoke in the morning, I didn't have any of the negative symptoms that I feared. However, as the time approached my 10 a.m. appointment, my tremors increased. During the evaluation I was videotaped and timed tasks were given to me from the Unified Parkinson's Disease Response Scale, Section 3 Motor Examination. The second stage of the annual evaluation is to turn the stimulators back on—an odd, “electrifying” sensation—and do all the tests again. After waiting a short period of time, I took my medications and the evaluation was over. I was pleased to discover this dreaded event did not warrant my initial anxiety. I believe, and my doctor concurred, that I was much improved over my six-month evaluation. I greet this news with cautious optimism. We'll know more after my next annual evaluation. This is what the survey is about—to follow patients for three years and gather data that will assist us all in determining whether this surgery is successful.

My daily life with stimulation continues to show improvement over my pre-surgery state. However, I'm still taking the same amount of medication as I was at my six-month evaluation. When my stimulators were first turned on during this evaluation, I was symptom free. That said, I am continuing with my medication because I want to ensure I am able to continuously function at the level I have grown accustomed to. This is what the forum is about—to ask questions and share our stories.

On a related note, the FDA granted conditional approval of the Medtronic device used for bilateral DBS/STN in early 2002. Medtronic now has to collect sufficient data within three years to be cleared for unconditional approval. This process has several steps. Initially, the government will dictate the guidelines for acceptance to Medicare. Then, each state may or may not accept those guidelines. Finally, individual insurers within the state may or may not choose to pay for the surgery. It is a very discretionary process, and everyone concerned should bring pressure to bear on his or her federal representatives to make the government expedite this process.

This is what reaching out is all about. Collectively we can make a difference.

A handwritten signature in cursive script that reads "Margaret Tuchman".

Margaret Tuchman
President, The Parkinson Alliance

Our Man in Helsinki: An Interview with PD Patient Advocate Jim Maurer

by Kenneth Aidekman

Jim Maurer's agenda at the 14th International Congress on Parkinson's Disease in Helsinki was to soak up as much information as possible and bring it back to his community.

Like an energetic bee intent on cross-pollinating an entire garden, Jim spends his days with doctors, scientists, patients, legislators and reporters exchanging information gleaned from numerous meetings, seminars, and personal conversations. He's an impatient patient advocate with a special gift that allows him to be as comfortable in hospital scrubs observing neurosurgery as he is speaking before a support group.

The following paragraphs summarize the fruits of Jim's trip to Helsinki and include his opinions about the critical issues in PD today. He will tell you he's no healthcare professional, but a lay person with extraordinary curiosity and a commitment to share his knowledge.

Dr. Peter LeWitt of the Clinical Neuroscience Center in Michigan began the Congress with a summary of recent developments in PD genetics. He endorsed the notion that non-primate research in the field is gaining in importance as a tool for investigation. Although the number of cases of familial Parkinson's is actually relatively small the promise of gene-related research is far-reaching. The ability to isolate a PD gene and add or delete it from a research subject helps scientists uncover the complex biochemical chain of events responsible for cell death in dopamine neurons.

Two years ago, Mel Feany, a neuropathologist at Brigham and Women's Hospital in Boston, found that when she injected fruit fly embryos with human DNA containing mutated alpha-synuclein genes

they began to exhibit Parkinsonian motor problems. With this discovery, an exciting new animal model of PD emerged.

What could a simple fruit fly have in common with human brain function? Apparently, when it comes to genes, humans are pretty similar to flies. We share nearly 80% of our genetic fingerprint. Fly dopamine neurons function much like human ones but with no blood brain barrier the effect of a substance introduced into its system of a fly is direct and immediate. This makes them great experimental subjects. With a life

"... PWP's now enjoy at least ten more years of good quality of life than they did in the beginning of the 1990's."

span of only sixty days, scientists can observe the effects of gene manipulation on entire generations of flies in a matter of months. Hopefully, flies will be used to screen thousands of new and old compounds to see whether they can alleviate PD symptoms.

The introduction of the fruit fly and other non-primate genetic models of PD will have a profound effect on the search for a cure. On top of that, they are cheap to keep. Dr. Feany is happy about the savings in cost of meals and board versus primates.

Continuing with the program in Helsinki, Arvid Carlsson of the University of Göteborg in Sweden pro-

vided a summary of the history of PD treatment. It was particularly valuable to hear a presentation by someone intimately involved in many of the great scientific breakthroughs since the 1950s. Carlsson reminded his audience that there was a time not too long ago when progressive neurologists were soundly criticized for administering L-Dopa to their patients.

Dr. Warren Olanow, Chairman of the Department of Neurology at Mount Sinai Medical Center in New York, highlighted recent advances in the treatment. By his estimate, PWP's now enjoy at least ten more years of good quality of life than they did in the beginning of the 1990's. No, a cure is not imminent, but surely we've made progress. Olle Lindvall of the University of Lund in Sweden took the position that continued experimental implantation of fetal dopamine cells in human subjects is still valuable despite setbacks in U.S. NIH-funded studies. In his experience the increased dyskinesia displayed by subjects in the NIH studies is a short-term phenomenon. He also disagreed with findings that there were significant age-related differences in benefits. While the procedure is not for clinical use, Lindvall believes we must not stop research with such great potential. There was considerable discussion at the Congress about the benefits of Deep Brain Stimulation (DBS). Andres Lozano of the University of Toronto said that the most important factor for successful DBS surgery of the Sub-thalamic Nucleus (STN) is the candidate's responsiveness

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Volunteers Raising Money for Parkinson's

I meet many exceptional volunteers from around the country who raise money for Parkinson's research. Each has a unique story, a reason why funding the cure to Parkinson's is close to their heart.

Aaron Moretzsky is one such special individual. Currently Assistant Principal at Pacoima Middle School in Los Angeles, Aaron has an impressive 30 year career in education. But almost three years ago, Aaron was diagnosed with Parkinson's. Rather than doing nothing, Aaron got involved. He began talking to those around him about his disease, listening to the stories of others, and raising money for Team Parkinson. For his 60th birthday Aaron requested donations to Team Parkinson in lieu of presents. He wrote letters to his school staff, students, and members of the community asking for their support. Aaron even obtained a \$5,000 sponsorship from an area foundation. In total, Aaron raised more than \$15,000 for Team Parkinson. Not stopping there, he took his story to the Los Angeles City Council and obtained additional recognition for Team Parkinson for its excellence in awareness of the disease. "When tomorrow comes, this day will be gone forever—in its place is something that you have left behind, and it was something good" says Aaron. Aaron continues his fundraising efforts, and each day he is leaving behind something very good.

San Francisco author Sid Levin survived ten heart attacks, bypass surgery, and ventricular fibrillation—twice. Sid also has Parkinson's Disease. Even at age 75, he fights on. Sid maintains a list of over 300 Parkinson political activists who organize petitions, letters, and postcards to Congress. He went to Washington D.C. as a Parkinson's advocate. Sid also raises money for Parkinson's research by donating royalties from his two latest books, including "Traveling with Uncle Sid." Thus far Sid has donated nearly \$13,000 for research while continuing to directly face the challenges of his disease and live each day to its fullest.

Kate DeGroot of Doylestown, Pennsylvania was only 3 years old when her Dad was diagnosed with PD. For thirty years he worked with doctors, nurses, and his family in battling the disease. Maintaining an upbeat and gracious attitude, Kate's dad often thanks his doctors and nurses for their care and talks about his desire to raise money for research. Two summers ago, Kate, her sister Debbie, and one of their dad's nurses, Vicki, decided to make his fund-raising desire a reality. They planned a dinner/dance fundraiser, complete with a DJ, at St. Joseph's parish. When Kate contacted me, her hope was to raise \$1,000. Kate exceeded her expectations. The event attracted almost 100 attendees, her dad had a grand time, and over \$6,000 was raised for research. A second event is now being planned in April, in honor of Parkinson's Awareness Month.

Aaron, Sid, and Kate are three examples of the many fine individuals who work hard to advocate Parkinson's awareness and raise money to find its cure. The Alliance applauds them.

A handwritten signature in black ink, which appears to read "Carol J. Walton". The signature is fluid and cursive.

Carol J. Walton
Executive Director

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to L-Dopa. There was also consensus on the selection of the STN as the preferred target for DBS.

While Jim brought home quite a bit from Helsinki, he also left his mark there. It was readily apparent to the scientists that Jim had Parkinson's and was there to observe and learn. The professionals were surprised by his wide-ranging knowledge. His presence was a positive influence as doctors and researchers strove to understand his perspective.

Of course, it's not unusual for a patient advocate to know more about life with Parkinson's than the average scientist. Most scientists are deeply immersed in their own field and don't have time to delve into all aspects of PD. Advocates, on the other hand, learn by spending considerable amounts of personal time with PWP's. They don't understand all of the science but their observations and anecdotal reports prove invaluable to researchers.

During one breakfast at the Congress, a group of scientists posited theories about why patients often gain weight after DBS surgery. They discussed various theories about neural signaling of hunger and satiety and which other structures might be affected by DBS. Then, Jim remarked: "Have you ever thought that an improvement in one's ability to get to the refrigerator might be a factor?" Score one for the PWP.

The benefits derived from Jim Maurer's trip to Finland continue as a "work in progress." A patient advocate's interactions help find information that may elude a doctor. Advocates provide this information to professionals and get back new information that they can give to support group members and symposium attendees. The cycle begins all over again creating a "positive feed-

back loop" that is helpful for everyone.

The months following the Congress were busy ones for Jim. From August through December he spoke before twenty-six groups including students at the University of Massachusetts, Boston University, Emerson College and Harvard Medical School. He observed DBS procedures and visited the NIH to discuss vital PD issues with a high-level representative of the Bush administration.

Currently, Jim is spending much of his time on Deep Brain Stimulation. As an important third party resource to many PWP's contemplating the procedure Jim can help by providing information not easily found in the literature or available from surgeons. Another positive result of his Helsinki trip was his meeting Jan Peter Dinkhaus, a PD advocate from Europe. Jim and Jan Peter continue to exchange information on DBS.

Jim believes that two recent developments will ultimately determine when a cure will be found. One is research into the genetic basis of neurodegeneration in Parkinson's and the other is the decision by the NIH to use R-21 grant requests to stimulate increased activity in the field.

Currently, most scientists spend too much time on grant preparation. The paperwork required can be measured in pounds. Once submitted, the NIH staff processes and sends select proposals to members of scientific review boards for final approval. The process can take nearly a year. R-21 submissions are limited to ten pages and are processed within four months. This speeds the course of research allowing scientists more time at work. The goal is to help creative investigators get into the field and stay there.

Another way to attract the best and brightest minds is to expose candidates to the excitement in the PD research arena. Jim plays a role by captivating students. A few years ago, a genetics specialist invited Jim to Harvard Medical School as his "sample patient." Through force of personality and charm Jim took over much of the allotted lecture time with a candid discussion of his Parkinson's symptoms and experiences. After class, appreciative students crowded around to learn more. Jim has been invited back for annual performances.

With a bit of luck, Jim's unique personality and enthusiastic optimism may just tip the scales for a few undecided students to travel the path of Parkinson's research. Maybe one will find the cure. If only there were a dozen Jim Maurers speaking before interested parties around the country. But cloning is not an option, so for now we must make do with one, very special, Jim Maurer. ☺

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year. And with the Tuchman's matching funds program, 100% of the money raised will go directly to research, and that really can make a difference."

Mary Anne's mother has been an Auxiliary member for over 50 years. "I have grown up with the American Legion, and the reason I chose Parkinson's is because of my mother. Our members, over 1,000, saw my mother, heard me talk about her, and they heard

my message. I think that has affected them deeply."

"After one of my talks, a Legioner came to me. He actually had tears in his eyes. He explained that his 24 year-old daughter was diagnosed with Parkinson's. I told him not to give up. There is hope. There are new treatment options, and we are looking at the possibility of a cure by 2005. And if not 2005, then 2006 or 2007. We

are so close. There is hope. And I really believe we are going to make a difference."

The Parkinson Alliance is honored and proud of Mary Anne's efforts and sincerely believes that because of her dedication, and the dedication of others like her, funding to find the cure to Parkinson's will be achieved. ☺

Past Events

Team Parkinson Sets New Fundraising Record at Los Angeles Marathon and Receives Community Recognition

On March 3, 2002, 72 athletes, many with PD, set a new record by raising close to \$85,000 for Team Parkinson when they participated in LA Marathon events. The LA Marathon is the fourth largest in the world. Founded by Mary Yost three years ago, Team Parkinson, an official charity of the LA Marathon, increases Parkinson's disease public awareness and raises funds for research. On February 15th, Team Parkinson was recognized by the LA City Council for its work. Present to receive the recognition were Mary Yost, May May Ali, honorary captain and daughter of Muhammad Ali, Aaron Moretzsky, Dana Schneider, John Ball, and chair of Team Parkinson, Edna Ball.

At the LA Marathon/Honda media luncheon on February 21st, John Ball and May May Ali were honored for their support of Team Parkinson. Additionally, Team Parkinson had a booth at the Quality of Life Expo at the LA Convention Center. On March 2nd, Team Parkinson athletes, sponsors and volunteers attended a carbo-loading dinner at Taix French Restaurant. During dinner, Dr. Marie Francoise Chesselet from UCLA and Dr. Michael Jakowec from USC spoke on research developments in the Parkinson's area. They stressed how vital fundraising for research is and inspired everyone with hope for the future.

On race day, 22 Team Parkinson athletes participated in the 26.2 mile Marathon, 15 in the 20+ mile Acura LA

Bike Tour, and 35 in the 3.1 mile LA Times 5K Run/Walk, including Mrs. Sydelle Mills, who was pushed in a wheelchair by her husband Harold and their son Mitchell. Team Parkinson's loud and enthusiastic cheering section, complete with music and a microphone, encouraged all marathoners, especially its team members. Highlights included John Ball completing his 7th marathon with PD; Moses Remedios, completing his first marathon with PD; May May Ali running for Team Parkinson with Moses and inspiring him to completion; John and Edna Ball's children, David and

Sarah, completing their first marathon; and Mary Yost bravely walking more than half the course. The Acura LA Bike Tour featured Jim Wetherell, Ted Bean and Kelly Stuart, all with PD. The LA Times 5K was completed by PD participants Stacey Downing, Florence Woolery, Susan Lev and David Schneider, who came all the way from Japan. Team Parkinson's grand prize winners for most money raised were Aaron and Harriet Moretzsky, who

thus far have raised almost \$15,000.

Team Parkinson continues to make a difference in the Parkinson's community. For more information on how you can get involved with Team Parkinson, please contact Edna Ball via phone at (562) 692-8504, via e-mail at teamparkinson@hotmail.com, or via the Web at www.teamparkinsonla.org. ☺



Moses Remedios & May May Ali running for Team Parkinson

Dr. Patrick J. Kelly Honored at 2/25 Reception for Receiving the Olivecrona Medal

Margaret and Martin Tuchman were delighted to join Consul General of Sweden Olle Wästberg and Mrs. Inger Claesson Wästberg at a reception in their beautiful Manhattan home on Monday, February 25, 2002, to honor Dr. Patrick J. Kelly for receiving the 2001 Olivecrona Medal, his profession's highest honor.

The Olivecrona Medal is bestowed upon an internationally outstanding neurosurgeon in recognition of excellence and innovation.

The Manhattan reception was co-sponsored by The Brain Tumor Foundation and Re-Wired for Life Foundation, both founded by Dr. Kelly to benefit his patients. Over 100 people attended the reception. Most of the attendees were patients of Dr. Kelly, including Alliance President Margaret Tuchman, and the evening's atmosphere was charged with admiration, gratitude, and love for the honoree. ☺



Dr. Patrick J. Kelly



Consul General of Sweden Olle Wästberg and Mrs. Inger Claesson Wästberg



Martin Tuchman and the Hon. Carolyn B. Maloney, Rep. (D-NY)



Dr. Patrick J. Kelly and Margaret Tuchman

The Parkinson Alliance Carnegie Center 5K & Fun Run A Success

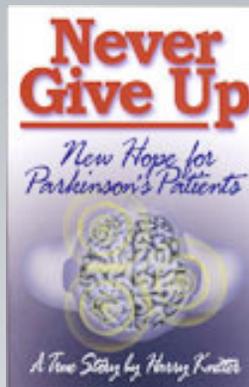


Runners gather in the rain to run for prizes and to raise funds for the Alliance.

The Carnegie Center 5K & Fun Run was held Saturday, October 6, 2002 in West Windsor Twp., NJ to benefit The Parkinson Alliance.

Commercial real estate broker Jerry Fennelly, gave his time and support for a third consecutive year to help make this event—despite the rain—a rousing success. After the Run, walkers,

runners, and their families and friends enjoyed food and refreshments, and several lucky participants were presented with awards. In addition to raising awareness and almost \$40,000 of much-needed funds for Parkinson's research, this year the Alliance donated 25% of net proceeds raised to the Disaster Relief Fund for individuals directly affected by the September 11, 2001 tragedy.



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Never Give Up, New Hope for Parkinson's Patients, is a true story by Harry Knitter. Harry, a Parkinson's patient for ten years, increased his daily medication consumption to over 20 pills. Then he had the opportunity to do something about the disease—he had Deep Brain Stimulation. This is his story. He describes why he made his decision, what surgery was like, and his results. Knitter will donate a portion of the proceeds of this book to The Parkinson Alliance.

Sunday, May 19, 2002 - Tuesday, May 21, 2002

Parkinson's Action Network 8th Annual Public Policy Forum

The Public Policy Forum is a unique educational conference that brings together Parkinson's advocates from across the country in our Nation's Capitol. The Forum encourages advocates to learn more about issues surrounding Parkinson's disease and provides them with the opportunity to meet with their legislators. In addition to the Forum, PAN will host "The 9th Annual Morris K. Udall Awards Dinner" on Tuesday, May 21, 2002. Michael J. Fox will serve as Honorary Chairman, and Sam Donaldson will serve as Master of Ceremonies for the Morris K. Udall Awards Dinner. For more information or to register for the Forum contact:

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web: www.parkinsonsaction.org
e-mail: info@parkinsaction.org

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

Sunday, October 6, 2002—Parkinson Awareness Day

This unprecedented all-day event, which will take place at the NYU Medical Center in Manhattan, will involve other PD organizations and feature the participation of patients, friends, family members, medical professionals, health care providers, the media, and general public. Along with patients and family members, distinguished experts in the fields of neurology, psychology, science, and research will speak. Each forum and discussion will be geared toward providing education, support, and hope to those whose lives are affected by Parkinson's disease. For more information, contact us or visit our Web site at www.parkinsonalliance.net.

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