

*Editor's note: In the March issue of HAPS HAPPENINGS, I encouraged our readers to make a difference in the future of Parkinson's disease, to step forward and take an active role. Priscilla Sarver took my plea to heart and went to Washington. Unfortunately, we had to cancel our plans to attend due to my husband's health. Thank you, Priscilla, from all of us. Her report follows...*

## **PARKINSON'S ACTION NETWORK PUBLIC POLICY FORUM 2002**

**Priscilla Sarver**

As a caretaker for my husband who was diagnosed with Parkinson's disease three years ago, I would like to share some exciting news about the potential for a breakthrough for this devastating disease.

On May 19th thru May 21st, I joined with hundreds of Parkinson's advocates from across the nation who participated in the Parkinson's Action Network 2002 Public Policy Forum in Washington, D. C., to lobby Congress for an increased federal commitment for Parkinson's research.

There is no cure for Parkinson's disease at present. However, scientists believe Parkinson's disease is the neurodegenerative disorder most likely to produce a breakthrough, and that a cure is possible by the end of the decade if the research dollars match the research opportunity.

The Parkinson's Action Network (PAN) is committed to pursuing a rigorous public information agenda that will increase the level of support and improve the coordination and focus of federally funded Parkinson's research. PAN is committed to advocating for a public policy agenda that supports identifying the cause and cure for Parkinson's disease through efforts such as lobbying to allow Somatic Cell Nuclear Transfer (also referred to as Therapeutic Cloning) research to continue. The multi-pronged PAN agenda for FY 2003 follows.

- Double Funding for the National Institutes of Health (NIH) in Five Years with a budget increase of \$3.7 million, to ensure sufficient resources to fully fund the NIH Parkinson's Research Agenda, and to increase funding for other biomedical research
- Fully Fund the NIH's Five Year Parkinson's Research Agenda with an increase of \$197.4 million over the baseline year for year three of the Agenda, including funding for translational and clinical research.
- Increase Funding for the Department of Defense (DoD) Parkinson's Research Plan, with a budget increase of \$52.5 million for the continuation and expansion of the Department of Defense's Neurotoxin Exposure Treatment Research Program.
- Support the Department of Veterans Affairs Parkinson's Program continuation and expansion.
- Increase National Institute of Environmental Health Sciences budget by \$30 million for Parkinson's focused research.

PAN has recently developed a Grassroots Advocacy Program to broaden the number of interested advocates for Parkinson's disease Research. Accordingly, the initial meetings of

the Public Policy Forum were an introduction to PAN and a discussion of items related to the Grassroots Advocacy Program.

The last and most interesting discussion of the day was a panel discussion on the National Institute of Neurological Disorders and Stroke (NINDS) Neuroprotection Initiatives. Members of the panel included Dr. John Marler and Dr. Bernard Ravina (NINDS), Dr. Karl Keiburtz (University of Rochester Medical Center), and Dr. Ross Stein (Brigham and Women's Hospital).

The NINDS representatives reported that neurological degeneration clinical trials have been largely ignored by scientists in the past, partially because of the expense of such trials. NIH will now fund studies with clinical trials that will include 3,000 patients, and are currently soliciting proposals for those studies. NINDS will consult over a hundred experts to get the names of drugs, select the most promising agents (thru pilot studies), and find agents that get into the brain. They will also explore promising drugs that are "safe" and do not require the normal trial process, to expedite the studies. PAN will help get a broad sample of patients to participate in the studies.

During lunch on the first day, Morton Kondrake spoke to the Forum attendees about his experiences as the caregiver for his wife, who has been diagnosed with Parkinson's disease, and the politics of Parkinson's disease research. These experiences are documented in his recently published book, Saving Milly, and may soon be made into a movie. Later in the afternoon he autographed paperback copies of the book, which were provided to the attendees of the Forum.

The first agenda item on the second day of the Forum was a panel discussion on Federal Program Funding of Parkinson's Research. Participants included Terrel Halaska

(Deputy Chief of Staff, Office of Secretary Thompson, HHS), Dr. Diane Murphy (Program Director, NINDS), Dr. Cindy Lawler (National Institute for Environmental Health Sciences), and LTC Karl Friedl (Neurotoxin Exposure Treatment Research Program).

Dr. Murphy advised that most of the NIH funds are used for research, and 90% of the research funds go to outside participants. These studies are divided among genetics, animal studies, and clinical trials. The 3,000 person neurological degeneration clinical trial is the largest trial ever done, and will be conducted at 45 sites in the United States and worldwide. The Department of Veterans Administration will be conducting a study on DBS at six of their Parkinson's Centers of Excellence during FY 2003. Dr. Lawler reported that the recently completed Twins Study, in California, had shown a much lower than expected genetic relationship in Parkinson's Disease, and a much higher environmental influence is now recognized in late-onset Parkinson's disease. As a result, the Collaborative Centers for Parkinson's Disease Environmental Research will emphasize genetic and environmental interactions in Parkinson's disease research. LTC Friedl explained that the Neurotoxin Exposure Treatment Research Program focuses on the importance of possible environmental causes and risk factors. The research is vital for civilian and military populations alike. It will give us the tools to detect, prevent and treat environmental toxicity. It will also enable the military to protect our service men and women from exposure to harmful chemical, industrial, or agricultural agents that may act as triggers in the onset of cell death and Parkinson's and Parkinson's-like symptoms.

The next session was a panel discussion of the latest drug therapies for Parkinson's, and consisted of two parts. Representatives from pharmaceutical corporations GlaxoSmithKline (Linda Sigmund-Requip), Schwarz Bio Sciences (Dr. Joseph Bianchine, M. D., Ph. D.- Dopamine agonist patch), and Teva Neuroscience (Dr. Phyllis Salzman, PhD.- Etilevodopa, Rasagiline) were on the first panel. The second panel was made up of Amersham Health (Dr. David Brooks, M. D. - What Brain Imaging Can Offer Parkinson's Disease) and Titan Pharmaceuticals (Dr. Roy Bakay-Spheramine Therapy).

In the first session, Dr. Bianchine's discussion of the Rotigotine patch was very interesting. This transdermal patch must be replaced once daily, can be used during surgery, eliminates early morning stiffness, and eliminates on-and-off fluctuation. They are entering the Phase III trial soon, and are looking for patients to participate in the clinical trial. In the second session, Dr. Brooks stated that 10% of the patients diagnosed with Parkinson's disease were found not to have Parkinson's disease when examined with the appropriate imaging technology. The Spheramine study, discussed by Dr. Bakay, was done by Dr. Watts and others at Emory University in Atlanta, and was especially interesting. After the surgery, on-time was increased, off-time was diminished, motor function showed an average improvement of 51%, and the QOL showed a 40% average improvement. After the discussion by Dr. Bakay, it was my privilege to discuss the study with one of the six patients who participated in the study. She was very pleased about the improvement she has experienced, which she reported was the most significant improvement of any of the other participants in the study.

The rest of the day was spent in preparation for the visit to the Hill scheduled the next day. During this period, attendees were assembled by State to discuss strategies for the meetings they would be attending. There were ten representatives from Florida at the Forum, and this was a good opportunity for them to become better acquainted.

The last day of the Forum started off with an extremely interesting Scientific Briefing in the Hart Senate Office Building. The panel was chaired by Senator Paul Wellstone, who was introduced by the PAN President, Joan Samuelson. Members of the panel were Dr. Deborah Cory-Slechta, M. D., Ph. D.

(University of Rochester), Dr. Jeff Kordower, PhD (Rush Presbyterian Medical Center), and Dr. John Gearhart, M. D. (John Hopkins Hospital).

Dr. Cory-Slechta said that in the past the three most accepted theories for the onset of Parkinson's disease have been genes, aging, and the environment. Of these three, genes were considered the most likely factor. Now, as a result of the "Twin Study," genes have become less of a factor in Parkinson's research. Instead, combinations of aging and the environment, aging and genes, and the environment and genes, are now being studied. In addition, scientists are also studying the neuroprotective attributes of tobacco, coffee and smoke, among others, for which we need a better understanding. Dr. Kordower discussed fetal cell transplants, stem cells, and the Atrophic factor Gila cell line-derived neurotrophic factor (GDNF). (In animal studies, scientists have shown that direct infusions of GDNF into the section of the brain affected by Parkinson's disease can actually restore function to brain cells that are damaged or dying.) He explained that the Amgen GDNF study had been stopped because it had caused uncontrollable dyskinesia during clinical trials. However, GDNF research is now being continued using another factor. Presently there are no negative effects with this research, and an "off-switch" is being developed to avoid run-away results. It will be

six to eight months before clinical trials will be initiated with this new technology. Dr. Gearhart discussed stem cell strains, their pluripotency, and the self renewal of the stem cells. These stem cells are legally acceptable for research, and the research can be federally funded. He also discussed the advantages of Somatic Cell Nuclear Transfer research, which is to develop stem cells that will not be rejected by the patient's immune system.

Following the Scientific Briefing, members of the Forum disbursed to the Hill to lobby our Congressmen and Senators. Specifically, we asked our Members of Congress to fully fund the NIH Parkinson's Disease Research Agenda, which calls for an increase of nearly \$1 billion over five years for Parkinson's research. To date the Agenda has been severely under-funded by NIH.

I am pleased to report that the staffers I visited in Congressman C. W. Bill Young's Office (10th District, FL) and Congressman Michael Bilirakis' Office (9th District, FL) were very receptive and promised to work to achieve the requested level of Funding. However, it will take a sustained, national movement calling on Congress to fund this Research Agenda to make our dream of a cure for Parkinson's disease a reality.

The 9th Annual Morris K. Udall Awards banquet was held at the Washington Hilton Hotel on the last day of the Forum. It was an elegant affair. This year the Udall Awards went to Senator Tom Harkin, Chairman, Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies; Representative Jerry Lewis, Chairman, House Defense Appropriations Subcommittee; and Millicent Kondracke, wife of Morton Kondracke. Both Senator Harkin and Representative Lewis have been strong supporters of Parkinson's disease research, and Millicent Kondracke was given the award for her outstanding Parkinson's advocacy. A special award has now been created which will be awarded annually to an advocate who demonstrates the incredible strength of spirit and commitment to advocacy that Milly demonstrates every day. This year's Millicent Kondracke Award for Outstanding Advocacy, was awarded to Greg Wasson, California, by Michael J. Fox. Mr. Wasson was honored for extraordinary advocacy which started soon after he was diagnosed in 1995, and since then his vision and creativity have yielded tremendous results in the fight for an increased federal investment for Parkinson's research. Last year Greg authored and promoted an online Stem Cell Petition to President Bush, which gained over 20,000 signatures. He has also worked closely with PAN to develop an e-based Grassroots Advocacy Network to expand our army of patient advocates and currently serves as the Grassroots Coordinator for Northern California. All attendees at the banquet were presented a courtesy copy of Michael J. Fox's new book, Lucky Man.

On May 22, many of the Forum participants stayed on in Washington to attend a hearing on Parkinson's Disease Research before the Senate Appropriations Subcommittee on Labor, Health and Human Services and Education, Chaired by Senator Harkin. Witnesses included Mohammad Ali, whose wife Lonnie testified on his behalf; Michael J. Fox; PAN President Joan Samuelson; the Director of NINDS; a Parkinson's patient from Senator Harkin's home state; and expert medical researchers who testified on their research, including SCNT, and the need for increased funding for Parkinson's disease research. Special guests at the hearing included Morton and Millicent Kondracke, and eight former Senators who have been diagnosed with Parkinson's disease. Although the video provided a better view of the witnesses, who had their backs to the audience, it was a thrill to be there.

Overall, attending the PAN Public Policy Forum, the 9th Annual Morris K. Udall Awards Banquet, and the Senate Appropriations Subcommittee Hearing, was exciting and exhilarating and rekindled my hope that we will indeed have a cure for Parkinson's disease within the next five years!

Priscilla Sarver