



CATALYST

Growing Funds for Parkinson's Research

Udall Centers Getting it Together

by Ken Aidekman

In the process of funding research there exists a natural give and take between the pursuit of pure science and the effort to accomplish treatment-oriented goals. Fundamental curiosity and the desire to contribute to a growing body of knowledge motivate scientists. A large part of their time is spent fashioning studies that have sufficient scientific merit to be funded and then, once funded, carrying out the experiments that will prove or disprove their hypothesis. With a lot of hard work and a bit of luck the results of their labors will be published in journals and add to our understanding of neuroscience. To judge each published report on the basis of how much closer it has brought us to a cure would be counter-productive because no one can anticipate the exact pathway that will ultimately lead to a cure.

By passing the Morris K. Udall Act, Congress clearly instructed the National Institutes of Health to make

curing Parkinson's would require a level of organization imposed upon scientists from outside the scientific community. It may seem like common sense that cooperation and sharing among scientists will speed us toward a cure, but it is by no means proven and it still requires a certain amount of creative thinking to successfully implement.

The Morris K. Udall Act stipulates that "The Secretary (of the NIH) shall provide for the establishment of 10 Parkinson's Research Centers. (In fact, there are 11 centers.) Such centers shall ... coordinate research with other such Centers and related public and private research institutions." The National Institute of Neurological Disorders and Strokes (NINDS) staff has been given the job of facilitating research by promoting interaction between independent Udall researchers. Unfortunately, they do not have the time, neither the resources nor the expertise to solve the many complex issues they face within

"By passing the Morris K. Udall Act, Congress clearly instructed the National Institutes of Health to make their best effort to cure Parkinson's disease."

their best effort to cure Parkinson's disease. Not only were they told what to do, but also they were given guidelines for how they should do it. Part of the plan involved the establishment of Morris K. Udall Centers for Parkinson's Research, including an outline of how they should interact. For better or worse, those who drafted the original Udall Bill made the assumption that

a reasonable period of time. On the plus side, they are taking steps to foster coordination. One of these steps is to reach out to members of the private community who have a strong interest in curing PD.

With this directive from Congress in mind, NINDS convened its Fourth Annual Meeting of the Udall Centers

INSIDE

- Message from the President..... 2
- Message from the Executive Director 4
- Team Parkinson Going National .. 5
- Barry Green Takes on Medicare and Makes a Difference 5
- American Legion Raises \$51,000 for the Alliance 5
- Alliance donates to The Todd M. Beamer Foundation 5
- Past Events 6-7
- Upcoming Events 8

of Excellence for Parkinson's Disease Research. 2002 was the first year in which NINDS invited laypersons from the Parkinson's community to observe the proceedings and provide input. While including us at the meeting may seem a bit unorthodox, there are advantages.

So what good does it do to have a group of non-scientists around struggling to keep up with the latest developments in research? One thing we can do is pass on information about the extraordinary science that is being conducted. At the morning "data blitz" session, Udall Center directors gave fifteen-minute summary presentations about the latest work done at their institution. In the afternoon researchers covered specific issues of shared concern in breakout sessions, including the discussion of biomarkers, genetics, animal and cell models and clinical and neuropathological correlates. During the breakouts participants often raised questions that lent themselves to input from an audience with a diversity of backgrounds and experience outside the scientific and academic community.

continues on page 3



Medicare's Powerful Role in Setting Surgical & Clinical Standards in Patient Care

In December 2000, after suffering with Parkinson's disease for 23 years, I had deep brain stimulation of the subthalamic nucleus at New York University Hospital. Through my contact with PWP's, and my involvement with Re-Wired for Life (www.rewiredforlife.org), I learned that the most frequently asked questions PWP's and their family members ask are: (1) how do I find the best surgical team; (2) how dangerous is this surgery; (3) what improvements can I expect after surgery; and (4) does insurance cover the cost of the procedure and after care?

These questions and my curiosity prompted me to research various issues, including the existing protocols of surgery and after-care; which regulatory agencies are involved with setting standards of performance; insurance coverage for DBS, especially as it relates to the subthalamic nucleus; and what performance standards are currently in place to insure patient safety while navigating the within the health care system.

I learned that there are no standards that are evident for existing protocols of surgery and after-care. Surgeons use their own criteria for patient selection, pre-operative screening, preferred site of implantation, choice of unilateral or bi-

lateral, and surgeons practice anywhere from single-staged to four-staged procedures. Variations in procedures were initially necessary due to the FDA's limited approval of unilateral thalamic surgery for tremor, and the insurance companies were not willing to extend their coverage to experimental procedures. In January 2001, the FDA gave provisional approval to the use of Medtronic hardware for bilateral deep brain stimulation of the subthalamic nucleus and globus pallidus thus opening the door for single staged, bilateral procedures. But many surgical practices continue to operate with the unilateral, multi-staged system. Some believe that their patients encounter less negative side effects with one protocol; others firmly believe the opposite.

On September 25, 2002, Carol Walton and I attended the second public meeting in Baltimore that was convened to hear, discuss, and act upon the recommendations made to the Center for Medicare and Medicaid Services (CMS) by the Medicare Coverage Advisory Committee's Medical and Surgical Panel members. This is the entry point where patient advocates—either as individuals or representing a group—can enter the system and ask for a change in current practices.

Medicare controls the national agenda for defining the type and amount of coverage approved for diagnosing and treating each disease. State carriers handle the national mandates for Medicare. Therefore, it is of utmost importance that the rules and regulations mirror the best treatment options presently available and future advances are carefully considered.

The Medical and Surgical Panel met for the second time (first hearing was in June 12, 2002) and unanimously voted in favor of accepting the pro-

posed language on the status of bilateral subthalamic nucleus deep brain stimulation as being “substantially more effective and improving health outcomes by a substantial margin for a well-defined set of Medicare patients with Parkinson's disease.” The same wording was also approved for bilateral stimulation of the internal globus pallidus. The impetus for the panel to consider Medicare's coverage of the procedure was the result of one person with Parkinson's disease requesting that the CMS issue a national coverage decision for the bilateral use of the Medtronic device in the subthalamic nucleus.

In presenting data pertinent to the panel discussion, expert medical witnesses testified representing the FDA, the Medtronic Company, and neurologists and neuro-surgeons promoting the bilateral placement of electrodes in both the subthalamic and globus pallidus regions of the brain rather than the earlier approved unilateral thalamic stimulation.

As the number of middle to late stage Parkinson's patients increase, the demand for deep brain stimulation will multiply. More and more patients will be willing to “take a chance” having brain surgery at even a younger age.

Now is the time to implore the medical profession to grapple with the heavy issues of setting up professional criteria that holds patient safety as paramount.

Medicare Coverage Policy:
<http://www.cms.gov/coverage>.
Medicare Cov. Advisory Committee
<http://www.cms.hhs.gov/coverage/8b1.asp>.

A handwritten signature in black ink that reads "Margaret Tuchman".

Margaret Tuchman
President, The Parkinson Alliance

Take, animal models, for instance. In recent years the number of different animal models in PD research has multiplied significantly. Scientists have developed transgenic mice which can synthesize greater than normal amounts of proteins that are of interest in PD. They can also develop “knock-out” models in which the animal is unable to make certain proteins. These models can be used to add or delete molecules that are intimately involved in the process of cell death in Parkinson’s such as Parkin, Alpha Synuclein and Ubiquitin. With so many new animal models researchers can plan a wider array of experiments that add to our knowledge base and also test the efficacy of replacement compounds that may slow dopamine cell degeneration.

Udall Center scientists who have developed a new animal model are enthusiastic about their contribution and its potential. They are deservedly proud and eager to share their models with other researchers in the field. They are certainly inclined to act in accordance with the Udall directive to coordinate their efforts. But, between generously offering to share resources, like animal models, and getting resources to other deserving scientists who request them, there is a gap in efficient processing. Even the most successful Udall researchers are not organized in a business model that is well suited to efficient distribution. They do not have systems to bring products to “market” nor are they set up to process orders and ship “product” to customers all over the world. They have neither the funds nor the expertise to dedicate to this function.

While, ostensibly, the NINDS might be called upon to facilitate beneficial transactions between Udall Centers, there is a cost. If a Udall Center suggests that the NINDS provide a staff person to help share resources, someone has to pay the bill. These budgetary items come out of

the total PD research pie. In a normal state of affairs scientists would prefer that total funding available for research grants should not be cut back for the sake of administrative needs. But, apparently, the attractiveness of gaining greater access to innovative resources is sufficient for many scientists to accept a slightly smaller pool of available grant dollars.

Discussion about the sharing of resources brought about lively debate among Udall researchers in Boston. Most agree that they can do more and better research if they can share resources like animal models, brain tissue and specific reagents. They agree that a cost benefit analysis will show spending money in this area

“Discussion about the sharing of resources brought about lively debate among Udall researchers in Boston. Most agree that they can do more and better research if they can share resources ...”

will be advantageous. Along with NINDS personnel they cite examples of working programs put together by other groups, especially the AIDS and Alzheimer’s communities. Unfortunately, frustration with the status quo has not yet reached the critical mass needed for all parties involved to take action.

At one point in the discussion of resource management, Mahlon DeLong, M.D., Center Director of the Emory University in Atlanta, GA suggested that this might be a question for the private “volunteer” community to take up. We volunteers and members of our advocacy groups have expertise de-

rived from working backgrounds in many diverse fields. We also have the time, perspective and, hopefully, the motivation to attack obstacles on the road to a cure. What may start out as a frustrating problem from one perspective can be an excellent opportunity for others to help. However, it will take a bit more visibility about these issues in the Parkinson’s community to get adequate action. Part of the solution is as simple as making a concerted effort to study how other groups deal with the problem successfully. The answers are out there.

Too often the limitations of a two-day conference force critical discussion to be tabled just as progress is being made. The NINDS staff proposed forming “work groups” among Udall scientists to address issues that were raised at the meeting. The action was met with enthusiasm — a step in the right direction.

We all want scientists to come up with solutions for our health problems and we pay for them to come up with results. Congress has heard the American people and doubled NIH spending in the last five years, an action that seemed pure wishful thinking at a time when cutbacks

in discretionary spending across the board were the norm. We’ve come a long way and the level of cooperation between the NIH, Parkinson’s scientists and the Parkinson’s community is at an all time high. Still, there are untapped resources that we possess. We need to continue to increase the flow of our charitable dollars for research but we can also find creative ways to help researchers surmount some of the more mundane obstacles that lay in the path of a cure. ☞

Ken Aidekman,
Parkinson Alliance Board Member and
co-Founder and former Chairman of
Parkinson’s Unity Walk



Collaboration *kəl-ab'er-ā-shən – adj*
to work together, especially in a joint intellectual effort.

I am witnessing the Parkinson's community embrace the power of collaboration to make enormous strides in its effort to find a cure.

Since January of 2002 I have attended five Parkinson's meetings: The NIH 5-year Parkinson's Research Agenda meeting in Rockville, MD; Michael J. Fox research update in New York City; The Parkinson's Action Network Forum in Washington DC; Deep Brain Stimulation Consortium Meeting sponsored by NINDS in Rockville, MD; and the 4th Annual Meeting of Udall Centers of Excellence for Parkinson's Research in Boston.

The common thread running through all of these meetings was collaboration.

Whether it's researchers at the Udall Centers, the Department of Defense at the PAN Forum, or the R21 Public/Private partnership with NIH, I am excited to report that many in the Parkinson's community are working cross party lines, collaborating, to find a cure for this disease.

For many years the Parkinson's community was nearly invisible. If anyone heard Parkinson's mentioned in the news it was huge for us. Now, many articles that talk about medical research mention Parkinson's first. This "top billing" status is a direct result of collaboration among the Parkinson's community.

The 4th Annual Meeting of Udall Centers held in Boston in August is another example of collaboration. For the first time, individuals other than Udall Center Directors were invited. Many of the Parkinson's organizations were represented, and tremendous suggestions were made

as to how private PD organizations could work more closely with the Centers. Ideas such as issues around brain banks, collecting DNA, and clinical trials were discussed.

Additionally, we now have the merger of The Parkinson's Disease Foundation and The National Parkinson Foundation and the \$20 million dollar grant from the National Institute of Environmental Health Services (NIEHS) to three major centers: The Parkinson's Institute in Sunnyvale, California; Emory in Atlanta, Georgia; and UCLA in southern California. These three centers are collaborating and sharing data on the environmental issues concerned with Parkinson's. Bill Langston, M.D., Founder and CEO of the Parkinson's Institute located in Sunnyvale, California, summed it perfectly, "I believe this could be the last Chapter in the cause of Parkinson's disease."

I recently received a letter from Joan Samuelson, President and Founder of The Parkinson's Action Network, recounting several of the above events. She said, "These recent events together suggest that we may be on the cusp of an historic turning point in our 10-year fight to end Parkinson's suffering. Of course we can't predict future events, much remains to be done, and we must remain engaged in our necessary role. But one thing is clear, we've come a long way."

When I started my advocacy work in California in the early 1990s and met Joan, NIH was spending \$25 per patient per year on Parkinson's research. Today, that amount is almost \$200 per patient per year.

Through collaboration, we have come a long way. By continuing to collaborate, we will cure Parkinson's.

Carol J. Walton
Executive Director

Team Parkinson Going National

by John & Edna Ball, co-Chairs Team Parkinson

Team Parkinson, an all volunteer fundraising effort that started as one of several official charities of the Los Angeles Marathon in 2000, is rapidly growing and going national. In 2001, Team Parkinson raised \$50,000 for Parkinson's disease research and has increased its total each year, raising over \$90,000 in 2002. The goal for 2003 at the Los Angeles Marathon is \$125,000.

Also, in June 2002, thanks to the remarkable efforts of Gabriel Zamora of Houston, Texas, whose father has PD, Team Parkinson was represented in the San Diego Rock 'n' Roll Marathon, and Gabriel and his family and friends raised \$10,000!

There is now interest in Team Parkinson participating in races in Boston, Utah, and Dallas as well. These are definitely exciting times as Team Parkinson grows!

For more information on how you can bring Team Parkinson to a marathon in your city, please contact Edna or John Ball, co-chairs, at teamparkinson@hotmail.com or toll-free at 866-822-CURE (2873).

Barry Green Takes on Medicare and Makes a Difference

Barry Green, Ph.D and publisher/editor of the Parkinsonian Publications, from Tyler, Texas, is a premier example of how one frail but determined individual can declare war on the system and move it along. Barry is 70+ years old, has had PD for 20 years, and reached a point of progression of his PD when medications were no longer effective. Since age is a consideration when selecting a "good" candidate for deep brain stimulation of the subthalamic (DBS/STN), Barry had no time to waste once he decided to go the surgery route.

The problem arose because Texas was not one of the early States that approved STN for coverage. There are currently 25 states where there is some type of coverage for DBS, but there is still no national policy which takes precedent over local determination. Barry's formal request to Centers for Medicare and Medicaid Services (CMS) on October 19, 2001 initiated all the actions that have taken place since then. As a result of Barry's efforts, Texas Medicare finally approved the coverage of the procedure in Barry Green's case.

American Legion Department President Project Raises \$51,000 for The Parkinson Alliance

As featured in the Winter/Spring *Catalyst*, Mary Anne Casadei, President of the American Legion Auxiliary Department of New York, selected The Parkinson Alliance as her charity to support and promote for her one-year term. She traveled throughout the state of New York, visiting all American Legion chapters, and personally spoke about Parkinson's and the need to find a cure. In July, Mary Anne presented Margaret Tuchman and Carol Walton with a check for \$51,000.00—an amount surpassing her original goal of \$50,000. The Parkinson Alliance greatly appreciates Mary Anne's hard work and devotion, and we thank her.

Buy Delicious Pancakes from Pj's & Help Support Parkinson's Research

100% of the net sales proceeds from the online sale of pancake products are donated to The Parkinson Alliance.



<http://www.pancakes.com>

The Parkinson Alliance donates to The Todd M. Beamer Foundation

The October 6, 2001 Carnegie Center 5K & Fun Run was held in West Windsor Township, New Jersey to benefit the Alliance. In addition to raising funds for Parkinson's research, the Alliance promised to donate 25% of the net proceeds to the September 11, 2001 Disaster Relief Fund. After much research and careful consideration, the Alliance presented this money, \$8,500, to the Todd M. Beamer Foundation at the 2002 Carnegie Center 5K & Fun Run held October 5, 2002.

The Todd M. Beamer Foundation is a nonprofit organization established on September 24, 2001. In honor of Todd Beamer, and the other heroes of United Flight 93, Todd's family and friends established The Foundation to carry on his legacy of character, faith, and courage to a new generation of young people. We encourage you to visit this web site at www.beamerfoundation.org.

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The 2002 Parkinson's Unity Walk Raises More than \$1,000,000!

Eight years ago, the Parkinson's Unity Walk began with a collection of 200 friends, family members, and fellow Parkinson's disease patients who supported founder Margot Zobel's vision of finding a cure for this debilitating disease. On Sunday, April 14, 2002, close to 6,000 walkers gathered in sunny Central Park to participate in a two-mile walk to carry on Margot's vision. On June 18th, at the Thank You Reception held at City Hall in New York City, Chairman Martin Tuchman announced that the 2001/2002 Walk raised over one million dollars from participants and sponsors—the most money ever raised at a Unity Walk!

The opening ceremonies at the 2001/2002 Walk featured noted broadcaster Dr. Frank Field; Rep. Carolyn Maloney (D-NY); Margot Zobel; Martin Tuchman, Chairman; Evan Stern, President; Robin Elliott, Executive Director of The Parkinson's Foundation; Michael J. Fox;



Thousands walk in Central Park, NYC at the 2001/2002 Unity Walk.



Chairman, Martin Tuchman, reads Proclamation from NYC Mayor Bloomberg

and Joan I. Samuelson, President of The Parkinson's Action Network. Additionally, title sponsors Pharmacia Corporation and Boehringer Ingelheim, makers of MIRAPEX® (pramipexole dihydrochloride tablets) presented the first ever MIRAPEX® Victories Research Award. Designed to encourage scientists who are committed to neurological research in the field of Parkinson's disease, the \$10,000 grant was presented to M. Flint Beal, M.D., Neurologist-in-Chief at New York Presbyterian Hospital, and Professor and Chairman of Neurology at Cornell University Medical College.

Festivities prior to and after the walk included live music by The Dom Minasi Septet, activities for children—such as face painting, balloons, and sign making—the latest information on Parkinson's from major U.S. foundations and corporate sponsors, and an "Ask the Doctor" area with Parkinson's medical experts answering questions.

Distributions were made at the Thank You Reception to seven major Parkinson's disease foundations—The American Parkinson's Disease Association, The National Parkinson's Foundation, The Parkinson's Action Network, The Parkinson's Disease Foundation, The Parkinson Alliance, The Parkinson's Institute, The Michael J. Fox Foundation for Parkinson's Research—to be spent on research. Included in the distributions were funds raised from Team Parkinson at the Los Angeles Marathon.

For more information on the Parkinson's Unity Walk, please call 1-866-PUW-WALK (1-866-789-9255) or visit its Web site at www.unitywalk.org.

The 4th Annual Putting for Parkinson's Golf Outing Monday, September 17, 2002

The Parkinson Alliance and The Tuchman Foundation combined tournaments this year to jointly raise close to \$100,000 for Parkinson's research. The golf outing was held during a perfect sunny day at Forsgate Country Club in Jamesburg, NJ. After a sumptuous buffet dinner, raffle prizes were awarded. Prizes included tickets to Carnegie Hall, a variety of gift baskets, a weekend in NYC. The event concluded with the raffle of several Grand Prizes—including a combined TV and DVD, a complete wine cooler set with several vintage wines, a 61" HDTV, a diamond tennis bracelet, a set of Taylor 360 irons, a vacuum cleaner, and a Las Vegas vacation.

In addition to the winning teams pictured below, Tim Michel won the Longest Drive, and Marty McDonald won Closest to Pin.



Margaret Tuchman, Jane Lowe-Rodriguez, and Carol Walton



Low Net foursomes winning team—
Jim Diaz, Marc Barenberg, Curt Bourne, and Rick McCoy.



The Low Gross foursomes winning team—
Tony Armenti, Neil Bencivengo, Pat Ryan, and Jay Destribats.

Robert Fiori Memorial Golf Tournament Saturday, August 3, 2002



The Second Annual Robert Fiori Memorial Golf Tournament was held on Saturday, August 3, 2002 at the Westvale Golf Club in Syracuse, NY. The tournament, founded by Cara and John Fiori, raised over \$1,500.00 for Parkinson's disease research.



top photo (left to right):
John Fiori, Co-Chair, Matt & Jennifer Tarolli, Amanda Fiori, John Potamianos, & Cara Fiori-Potamianos, Co-Chair.
bottom photo (left to right):
James Ferrante, Lud Ferrante, Ann Herron, & Pat Herron.

ParkinSong April 13, 2002

The 2nd Annual ParkinSong, originated in honor of Selma Litowitz of Lawrenceville, NJ, was held April 13, 2002 at the Council Rock High School in Newtown, PA. The concert featured musical artists Catie Curtis, Grey Eye Glances, and Ana Egge. The concert raised close to \$30,000 for Parkinson's disease research.



Guest Host, Pierre Robert, DJ, WMMR FM, with Selma Litowitz



Musical recording artist Catie Curtis

**“Laughing the Night Away” Comedy Show & Live Auction
Sunday, November 10, 2002**

Team Parkinson is presenting a comedy show and live auction at the world famous Comedy Store at 8433 Sunset Boulevard, Los Angeles, California, 6-9 p.m. Join the fun as the Honorary Captain of Team Parkinson, May May Ali, hosts the best comics in Los Angeles and auctions Lakers tickets and autographed Muhammad Ali memorabilia. Due to limited seating, we suggest you buy your tickets in advance. Deadline for advanced tickets is Monday, November 4th.

Please call toll free 1-866-822-CURE (2873) to order tickets. Major credit cards are accepted. Prices are \$30 (\$35 at door) for 1st level seating and \$20 for (\$25 at door) for 2nd level seating. Parking at the Comedy Store is \$10, and there is a 2-drink minimum.

To order tickets by mail, please send a check made payable to Team Parkinson and send to 6412 Broadway, Whittier, CA 90606.

**“A Step Ahead: A Positive You” Fashion Show/ Luncheon
Sunday, March 23, 2003**

Join us at The Westin Princeton at Forrestal Village (formerly the Princeton Marriot), 201 Village Boulevard, Princeton, New Jersey, 1-5 p.m., where music will fill the air while clothing and jewelry are modeled. Headlining stores include Hedy Shepard, Ltd., Ici Fashion for Children, Nick Hilton Studio, and Hamilton Jewelers.

Lunch will be served as fabulous door prizes are awarded. The fun will continue with a super raffle that includes two prizes—a deluxe cruise for two including airfare, and dinner for eight prepared and served in your home by Marc Fertoukh of Paris Desserts & Catering.

Tickets are \$50 per person and include the fashion show, lunch, and great door prizes. To reserve a seat, please call us toll-free at 1-800-579-8440 or fax us at 609-688-0875. American Express, Visa, and Master Card are welcomed.

Checks made payable to The Parkinson Alliance may be sent to us at 633 Prospect Avenue, Princeton, New Jersey 08540, Attention: Fashion Show. Please include your phone number.

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

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