



CATALYST

Growing Funds for Parkinson's Research

The Parkinson's Community Must Stop Apologizing for the "State of the Parkinson's Community," by Martin Tuchman

The big problem some are having with our group of major Foundations—all supporting this year's Parkinson's Unity Walk—is that there are too many organizations representing our constituents. Yet should this be perceived as a problem? Must we apologize for it?

In November of 1997 President Clinton signed the Udall Bill—a bill authorizing the annual expenditure of \$100 million dollars for Parkinson's disease research. However, the Parkinson's community learned the hard way the difference between "authorization" and "appropriation." In Senate hearings in 2000, Dr. Gerald D. Fischbach, the then Director of National Institute of Neurological Disorders and Stroke, stated that we could cure PD in 5 to 10 years with appropriate funding. The Parkinson's 5-year research agenda was developed, and the funding amounted to almost one billion dollars. Dr. Fischbach was our community's "PD Champion," and our goal was to get very close to the cure by 2005.

In January 2001 Dr. Fischbach left his position. There is no successor yet in his place. His departure left the entire Parkinson's community with no advocate at the National Institutes of Health (NIH) to fight for additional Udall centers and the additional research needed to cure this dreadful disease. Someone must be appointed to this

position—an individual dedicated and passionate about finding a cure for Parkinson's disease. While the NIH is a governmental entity, politics must take a back seat. It is simply incomprehensible and inexcusable that in our vast nation such an individual has not yet been found and appointed. What can possibly be the hold up?

That brings us to the "state of the Parkinson's community"—the various organizations involved in seeing the end of Parkinson's come to fruition. Some believe the number of major organizations result in negative competition and split representation of our constituents. I do not agree.

As a member of the Board of Directors of most major Parkinson organizations, I am in a unique position to see the clear-cut differences, strengths, and clarity of purpose of each. Understanding their differences leads me to the conclusion that it is not detrimental that these groups operate independently from each other.

The American Parkinson Disease Association (APDA) is patient oriented. While they do support research with their own well-respected Scientific Advisory Board, their emphasis is on patient services. Their services are second to none in the area of providing information, follow-up services, and a sense that regardless of your financial status you will be treated with respect.

The National Parkinson Foundation (NPF) has given millions to research over the years, and their model, while differing from the other organizations, has resulted in some breakthrough studies. For example, the NPF was responsible for providing funding to Dr. Ron McKay at NIH. McKay's exciting studies demonstrating dopamine regeneration were reported extensively—not only in the scientific journals, but the New York Times and Wall Street Journal as well.

The Parkinson's Institute (TPI) conducts patient care, clinical and basic research. The Institute's founder, Dr. J. William Langston, is also on the Scientific Advisory Board of the Michael J. Fox Foundation for Parkinson's Research. Dr. Kenneth Olden, Director of National Institute for Environmental Health Sciences (NIEHS) recently announced a new \$20 million dollar national research initiative to find the cause(s) and cure for Parkinson's disease. The Institute was chosen as the Coordinating Center for this effort. The award also included Emory University in Atlanta and UCLA in Los Angeles.

The Parkinson's Disease Foundation (PDF), while being perhaps the gold standard when it comes to research, has concentrated its efforts with The Columbia Presbyterian Hospital where state of the art labs are currently under

construction. And while two-thirds of research was done at Columbia in previous years, PDF has begun a very aggressive grant program with accountability requirements involving the funding of other research facilities outside the traditional New York City area. These high watermark standards have carried over to other groups, who now are also demanding accountability.

As the above demonstrates, competition created by multi-organizational structure has been very helpful. One can only imagine the quagmire research would find itself in if there was but one organization (like the U.S. Government).

The Parkinson's Action Network (PAN) is the unified advocacy voice of the Parkinson's community. The efforts of this group were mainly responsible for the passage of the Udall Bill, which was signed into law calling for the expenditure of \$300 million for research. Their continuous effort is one of the main reasons for whatever funds are flowing.

The Michael J. Fox Foundation for Parkinson's Research, a newer group based upon the popularity of one man, continues to have a wonderful effect on raising the consciousness of the American people and U.S. government officials. There is no question of Mr. Fox's help to the community.

Finally, there are The Parkinson Alliance and the Parkinson's Unity Walk that do not have Scientific Advisory Boards. They raise funds and turn the money over to the major organizations for disbursement to the researchers selected by the various Scientific Boards.

The leaders at the head of each of these organizations are passionate, dedicated, and intelligent. They are generous of their time and in many cases of their own funds. You simply would not get this spectrum of personnel at one large organization.

The Parkinson's community is unified in finding the cure for Parkinson's disease. An excellent example of our unity is the "R21 Fast Track Grant Program for Parkinson's Disease Research." This program, the largest initiative in the history of NIH's Parkinson's disease research, is an unprecedented collaboration among the NIH and private Parkinson's organizations jointly committed to funding \$11 million dollars in research over the next two years. Another example is the fact that almost ten years ago NIH was funding Parkinson's research at \$25 per patient per year. As a result of our community being *invisible no more*, we are now over \$200 per patient per year.

In the final analysis it is the Foundations' Scientific Boards—many of whose members are shared among the organizations—together with NIH's Institutes' own scientists who determine the direction of Parkinson's disease research.

Again, the Parkinson's community must stop apologizing for the "state of the Parkinson's community." The state of our community is strong and diverse. It is helping patients. It is funding research. It is telling the government to fund money for research. Most importantly, the state of our community is united in the common goal of curing Parkinson's disease.

In working towards our goal, I'd like to take this opportunity to personally invite each of you to the 9th annual Parkinson's Unity Walk to be held in Central Park, New York City, on Saturday, April 26, 2003. For more information, visit www.unitywalk.org or contact the Unity Walk offices toll free at 1-866-PUW WALK (1-866-789-9255).

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the Parkinson's Unity Walk

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