



CATALYST

Growing Funds for Parkinson's Research

Public and Private Funds Working Together to Support Stem Cell Research

The Parkinson Alliance pioneered the private support awarded to Dr. Ron McKay at the National Institutes of Health in 1999. The \$180,000 of private funds were leveraged into a multi-million dollar study for stem cell research. Stem cells, which are self-renewing elements that can generate many cell types in the body, may one day be harnessed for tissue repair in degenerative disorders such as Parkinson's, heart disease, and diabetes. In a letter to Martin Tuchman (Chairman of the Board of The Parkinson Alliance) dated May 11, 2001, Dr. McKay states, "Stem cell biology is one of the most exciting areas of bio-medical research." As a result of this research, two major advances in the concept of using embryonic stem cells to regenerate human tissues were

recently reported in major newspapers and scientific journals. In one report, biologists at the NIH used mouse embryonic stem cells to generate insulin-producing organs resembling the islets of the pancreas, an accomplishment that holds potential for treating Type 1 diabetes. In a second report, biologists proved therapeutic cloning works in mice by cutting off a small portion of the tails of mice and converting the tails' skin cells into embryonic stem cells. From those stem cells, the NIH's colleagues at the Memorial Sloan-Kettering Cancer Center then changed them into dopamine-producing cells of the brain that are lost in Parkinson's disease.

"In animal studies, the transplantation of cells into the diseased or injured brain shows that both cellular

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repair and behavioral recovery are possible," states McKay. While animal studies and the limited use of cell transplant technology in human trials has revealed the potential for behavioral repair, there is a greater "need for a much more detailed understanding before stem cell therapy can be a viable therapeutic option for Parkinson's patients."

He continues, "For example, what controls cell differentiation pre- and post-transplantation? What factors allow cells to survive and integrate into host tissue? What controls synapse formation and dopamine release? To answer these questions, we need a routine source of dopamine neurons. In the last year, we have demonstrated that embryonic stem (ES) cells can generate unlimited numbers of dopamine neurons. We have also used ES cells to generate functional pancreatic islets. In another study we have regenerated heart muscle in a model of a heart attack. These experiments unequivocally demonstrate that stem cell technology has clinical potential across many areas of medicine."

"Although stem cell technology is often seen as the basis for cell transplants,

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Dr. Ron McKay at the National Institutes of Health

Deep Brain Stimulation of the Subthalamic Nucleus (DBS/STN)



I reserve this space to rant and rave, or have opinions about any subject that has particularly increased my level of adrenaline. For this, the premier issue of our newsletter, *The Catalyst*, what is most appropriate is talking about new beginnings for me and the sisters and brothers who share my surgical experience of bilateral deep brain stimulation of the subthalamic nucleus.

Q: What is DBS/STN?

A: Dr. Benabid in Grenoble, France discovered that

it wasn't necessary to cause a lesion in parts of the brain that controlled movement to improve the clinical motor symptoms of People With Parkinson (PWP). Depending on the symptoms that need to be alleviated, location of the surgically placed electrodes vary. The generators with replaceable batteries (3-5 years usage) are implanted in the chest cavity under the collarbone. Chronic high frequency electrical stimulation by electrodes placed in the sub-thalamic nucleus improves tremor, rigidity, bradykinesia (slow or no movement) and gait disturbances (freezing, stutter stepping).

"The technique of deep brain stimulation for the treatment of Parkinson's disease is evolving very rapidly. The subthalamic nucleus has become the preferred target in the past few years since it has been demonstrated that high frequency stimulation in this nucleus improves all cardinal features of Parkinson's disease (PD), including resting tremor. This benefit in the parkinsonian symptoms allows a drastic reduction in daily levodopa requirements. Dyskinesias become drastically reduced, thus avoiding the problems associated with standard levodopa replacement therapy." *Neurology* 2000, (12 Supp):S40-4 Benabid, et al.

The Federal Drug Administration has approved unilateral DBS in the thalamus only for tremor which is often not the most disabling of PD symptoms. The National Institute of Neurological Disorder and Stroke (NINDS) released a statement on 9/27/99 "... that DBS is one of the most dramatic advances in decades for treatment of neurological disorders." FDA approvals for additional forms of DBS are promised in

the near future.

Q: What is the reason for the increased level of interest in DBS/STN?

A: Whereas medical therapy has been the mainstay of treatment for PD, after several years of drug therapy a large portion of patients experience worsening of their parkinsonism and develop incapacitating motor fluctuations and dyskinesias. Continuing the mixing of the drug cocktails to get through another day becomes frustrating and too limiting.

DBS/STN has the advantages of being: (1) reversible; (2) the stimulators' parameters can be adjusted to physiologically change the area of inactivation; and (3) to implant both sides without the high incidence

of complications associated with bilateral pallidotomy.

NINDS has done much in recent years to promote research in neuro-degenerative disorders. They have advanced the interest in deep brain stimulation and by organizing a DBS Con-

sortium of neurologists, neuro-surgeons, researchers, and patients have opened the door to the beginnings of a long list of suggested topics for future investigation as well as encouraging original thinking.

Possibly the most important aspect of all the DBS studies is the tantalizing evidence that chronic stimulation may be not only long lasting but also possess neuro-protective elements, thus slowing the progression of Parkinson's disease.

Q: What is Re-Wired for Life (RWfL)?

A: A 501(c)(3) non-profit organization made up of a diverse membership of movement disorder patients, their family members, caregivers, and healthcare professionals. RWfL is proposed to be set up as volunteer chapters in the U.S.A. and abroad. These chapters will be clearing houses for information for DBS patient care. The New York Chapter is in the process of setting up the national headquarters complete with a governing body. RWfL promotes the understanding of DBS including appropriate follow-up care for implanted patients. RWfL is providing clear, easy to access, up to date, unbiased information. The website will house the interactive aspects of RWfL.

"Most people in the world thrive on certainty and an absence of puzzlement, which brings to them mental comfort and security. Scientists, on the other hand, thrive on doubt and the existence of natural puzzles, which brings to them energy and an urge to find answers. Doubt and a joy in solving puzzles are the main engines in the practice of science."

Julian Tobias Biologist, Neurophysiologist, (1911-1964)

Q: How do we promote large scale interdisciplinary research into what happens during DBS. Why does it work? What can we do to take advantage of the favorable convergence of available federal funding, private matching funding, and scientific interest to: (a) in the short term to ameliorate symptoms; and (2) to ultimately find cure(s) for Parkinson's disease.

A: Continue already started communication and cooperative efforts among the NIH, FDA, Medtronic, DBS/STN centers, and organizational activities of Re-Wired for Life.

Prior to my surgery, when I began the search for all relevant information about DBS/STN, I could not find any statistical information on the number of procedures performed, the successes and failures, or the problems getting prime care post-surgically. Seemingly, each center doing the procedure has their own "press kit". Very few of them are candid about the results of all their surgeries. A patient doesn't know what questions to ask and has no criteria to measure against. I quickly realized the need for the following:

1. **A patient registry.** A patient survey has already been formulated to collect information on the ongoing progression and impact of DBS in PD patients. The survey will be distributed through the Internet via bulletin boards and existing e-mail groups. For those not on the Internet, a paper and pencil version will be available through DBS centers. According to information that NIH released, approximately 2,000 people worldwide had DBS to control their PD symptoms. The updatable database will be made available to all participants with patients' identity protected.

2. **A physician database exchange.** There has been significant interest in neurological/neurosurgical circles to look at the whole process and

standardize the surgical as well as the follow-up procedures.

3. **Advocacy** for continued and increased federal funding to promote more research into the role that DBS/STN can serve in the treatment and possibly the cure for Parkinson's disease.

4. **The active participation of patients in NINDS DBS Consortium.** The International Scientific Board of Advisors has been created by Re-Wired for Life so that information can be gathered, shared, and exchanged among existing centers for DSB/STN and movement disorder practices not performing DBS/STN.

My successful bilateral DBS/STN surgery on December 28, 2000 qualified me for membership in Re-Wired for Life (RWfL), the "real live" group of the fortunate patients who had their surgery done by the surgical team of Drs. Kelly, Beric and Sterio at New York University Hospital.

The more one reads questions, comments, and problems we experience the more the need for patient friendly resources becomes obvious. Responses from the neurologists, surgeon, or the FDA, or the insurance companies, and the manufacturer of the implanted devices are often incomplete, not timely, or not forthcoming. Although there is an underground network of caring post surgery persons who are willing to help the persons seeking information, the vast majority of the estimated 2,000 DBS/STN recipients worldwide have no communication or support of any kind. A database of patients' information together with up-to-date factual information and a bulletin board for Q & A will make the RWfL website invaluable and a lively place to visit.

Q: And, what am I most interested in?

A: It is to have a cadre of brilliant and interested researchers and enough money from NIH and private invest-

ment to pursue an interdisciplinary, fast track, research program exploring the nature and limitations (if any) of DBS/STN.

I cling to information such as what R.J. Andrew cited in Ann NY Acad Sci 2001 Jun:939:114-25 "Neuroprotection for the new millennium" writes "deep brain stimulation of the subthalamic nucleus (DBS/STN) for Parkinson's disease has offered significant improvement in quality of life for many who had exhausted cocktail drug treatment for their disease. DBS/STN offers a novel treatment for Parkinson's disease where a technological advance may actually be an intervention with effects that are normally expected from pharmacologic agents."

Dr. Andrews continues with the most important piece of information, "Rather than merely "jamming" the nervous system circuits involved in PD, DBS/STN appears to improve the neurotransmitter imbalance that lies at the heart of PD. It may also slow the progression of the disease."

Basic requirements need to be met, such as:

- FDA approval for bi-lateral DBS/STN
- adequate insurance coverage for all
- board certified DBS neuro surgical teams adhering to standards
- improved technology to replace the current electrode design, connectors, generators and batteries
- more comfortable stereotactic head gear, redesign the operating table.

For information on DBS, or any information relating to the Patient Registry Survey or to the role of The Parkinson Alliance, please contact me at 1-800-579-8440 or via e-mail at: admin@parkinsonalliance.net. ☺



Margaret Tuchman
President, The Parkinson Alliance



Welcome to our first issue of The Parkinson Alliance Catalyst

This newsletter is part of our continuing effort to communicate with our donors on our events, research updates, and where your research dollars are being invested. For The Alliance, the first half of 2001 has been excellent. We had some very successful events—Derby Eve in Louisville, KY; Team Parkinson at The Los Angeles Marathon; Parkinsong including Jon Stewart from Comedy Central; Bachelor Auction; Parkinson Alliance Golf Classic, along with smaller dinners, bowling tournaments, and various other ways to creatively collect money for research. We are especially proud to be part of a public/private partnership involving a new type of grant program for Parkinson's research.

This grant program is an unprecedented collaboration with the National Institute of Neurological Disorders and Stroke, other NIH Institutes and private Parkinson's organizations to jointly fund a program of up to \$8 million in Parkinson's disease research grants. The R21 Fast Track Grants for Parkinson's disease research aim to stimulate novel, innovative, or high impact approaches relevant to the cure, cause, prevention or improved treatment of Parkinson's disease. The new grant process includes: (1) An emphasis on innovative projects—no preliminary data required; (2) An abbreviated application form—maximum ten-page project narratives; (3) An accelerated review and award process; and (4) A proven, multidisciplinary review committee.

The Parkinson Alliance, along with the following NIH Institutes and private foundations, is included in the public/private partnership:

1. National Institute of Neurological Disorders and Stroke
2. National Institute on Deafness and Other Communication Disorders
3. National Institute of Mental Health
4. National Institute of Environmental Health Sciences
5. Michael J. Fox Foundation for Parkinson's Research
6. Parkinson's Disease Foundation/National Parkinson's Foundation
7. The Parkinson Alliance/Parkinson's Unity Walk

We are very proud to be working with NINDS on this extraordinary collaborative project and believe it gets us one step closer to finding the cure to Parkinson's by 2005.

There is an important message when you look at the above listed organizations. The Parkinson's community is truly working together when it comes to research. In addition, to the \$1.5 million from NINDS, look at the institutes within NIH that are also helping us in this goal to find a cure: NIMH, who is asking for researchers to study depression in Parkinson's; NIDCD, who is studying study speech and swallowing issues; and NIEHS, who is studying the environmental issues. These institutes joined this partnership and together came up with an additional \$1.3 million.

Margaret and I were at NINDS earlier in August, and one of our meetings was to better understand the R21 program. The program has had an incredible response from researchers—over 200! In late September, we will be provided with a list of all applications, as well as the first round of scores and write-ups from the reviews of the grants. And, after the first year, we are invited to a meeting with the principal investigators who will report on their research. This is excellent accountability, and we will be sharing the information with all of you. As always, for more information, please visit our Web site at www.parkinsonalliance.net. ☺

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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information derived from stem cells will be critical for any new therapy. For example, the potential use of gene therapy to control the survival of dopamine neurons will be greatly enhanced by a detailed understanding of the action of these gene products on dopamine neurons. So stem cell technology and gene delivery technology are not in opposition, but are complementary strategies. Recent work in gene and cell therapy

provides a strong foundation for further advances in understanding and treating Parkinson's disease."

Funds provided by The Tuchman Foundation (the backbone of The Parkinson Alliance) supports scientists and clinicians working on several applications of stem cells. McKay concludes, "Access to private support is an important mechanism, giving flexibility that complements the more restricted uses permitted for government funds. This

combination of federal and private support has generated a research program that is recognized as world leading in Parkinson's disease, diabetes, and heart disease."

For more information on how The Tuchman Foundation is the backbone of The Parkinson Alliance, visit <http://www.parkinsonalliance.net>. For more information on the National Institute of Neurological Disorders and Stroke, visit <http://www.ninds.gov>. ☺

Stem Cell Advocacy

While many of us can appreciate the President's dilemma and his desire to compromise, our needs have not changed and the facts regarding stem cells have not changed. The fact is that Embryonic Stem Cell Research (ESCR) has such great potential to help Parkinson's patients that it must be aggressively explored. We need to encourage scientists to explore all possible alternatives without delays and without excessive bureaucracy.

There are many opposed to ESCR who are mounting campaigns to further restrict the research.

If our goal is to evaluate the possible contribution of ESCR to curing Parkinson's disease, we need to ask the scientists what they need, including how many lines of stem cells and how soon they can do it based upon different funding levels. To take 10 years to do something that could be done in 3 is not acceptable.

If we want something, we need to let those who can help us know what we need.

If we are quiet, then everyone will assume that the President's proposal is sufficient for us and we are content. If you are not content to see the delays, funding limitations, and restrictions on stem cell usage, let those who have the power to change it know what you want. **We need to make our voices heard.**

We Need to Take Action!

Let the President know what you think. Encourage him to be open to new information as it becomes available on the need for more funding, the need for more research flexibility, and the need for more stem cell lines. E-mail the President at president@whitehouse.gov or call the switchboard at (202) 456-1414, or fax him your thoughts at (202) 456-2461.

We need to encourage our elected officials to work to reduce or eliminate the President's limitations on ESCR. Let them know your thoughts. If they are supporting ESCR, thank them.

To find your congressional representative's e-mail address, visit <http://www.house.gov/writerep>.

To find your senator's e-mail address, visit <http://www.senate.gov/contacting/index.cfm>.

Register your opinion whenever possible. Many polls are attached to major news publications and are only active for a short period of time. When you see

a poll being taken, respond to it and let others know about it.

We need to encourage the major national organizations to be our collective voice and champion ESCR.

While many of us can appreciate the President's dilemma and his desire to compromise ... we need to make our voices heard.

Let them and any other group who can help know your thoughts. Visit their Web sites, contact them, and encourage them to take action on your behalf:

Coalition for the Advancement of Medical Research (CAMR):

<http://www.stemcellfunding.org>

Parkinson's Action Network (PAN)

<http://www.parkinsonsaction.org>

Juvenile Diabetes Research Foundation (JDRF)

<http://www.kdrf/prg>

If you have not already done so, sign the petition by members of the Massachusetts General Hospital Neurological Web Forum and other concerned citizens in support of broad funding for fetal and embryonic stem cell research by visiting <http://www.petitiononline.com/stmcll>.

Take Action. Be heard. Be visible. Now is the time to let your voice be heard. ☺

Team Parkinson Sets New Record at Los Angeles Marathon

Team Parkinson 2001, an official charity of the Los Angeles Marathon, had a tremendously successful event to raise funds for research to find a cure for Parkinson's disease. With guidance from The Parkinson Alliance and the Parkinson's Unity Walk, and with the generosity of The Tuchman

Foundation, Team Parkinson was able to raise \$60,000.

Festivities included a booth at the Quality of Life Expo, which plays host to over 80,000 people, a carbo-loading dinner where athletes and key contributors were honored, and race day itself with Team Parkinson athletes participating in the 26.2 mile marathon, the 20+ mile Acura Bike Tour, and a 5K walk/run.

Highlights of the event were the guest appearance at the dinner of May May Ali, daughter of Muhammad Ali, the incredible fundraising efforts of Jean and Daniel Marcus, who raised more than \$10,000, the completion of his sixth LA Marathon by John Ball, who has had Parkinson's disease for over 20 years, and the participation of 14 students from Pacoima Middle School in honor of their vice-principal, Aaron Moretzsky, who has PD.

"The Parkinson's community came together for the LA Marathon to make a tremendously successful fundraising event on behalf of Parkinson's disease research," said Edna Ball, Chair of Team Parkinson 2001.



From left to right: Edna Ball, May May Ali, daughter of boxing great Muhammad Ali, and Carol Walton

Team Parkinson also thanks its many volunteers, Steve Gryczman and Presbyterian Intercommunity Hospital, Whittier for their in-kind donations, and Taix and La Parrilla restaurants for their exemplary service during our event.

Team Parkinson acknowledges and congratulates the Silver Medal level Sponsorships of \$1,500 or more:

The Hotckin Family
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In Memory of Chana Bialek
California Neuroscience Institute, Oxnard
NPF Orange County Chapter

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UCLA Dept. of Physics & Astronomy
SRLA-Pacoima Middle School

Pedal for Parkinson's—Oberlin, Ohio



From left to right: Leah Kos, Donna Kos, Mrs. Edward Kos, Terry and Brenda Kos, Hannah Kos, and Carrie Ann Kos

On May 19, 2001, Mrs. Edward Kos (center) participated in the Pedal for Parkinson's Bike-A-Thon, a fundraiser for The Parkinson Alliance, along with some of her children and grandchildren.

Spare a Strike for Parkinson's Disease Waco, Texas



On July 15, 2001, Kees Paap, who has had Parkinson's disease for 11 years, bowled from noon till 6 p.m. against teams and individuals to raise money for research. For extra donations Kees bowled in "special" ways, including bowling in wooden shoes and between his legs.



Golf Tournament & Family Fun Day Chillicothe, Illinois

Joan Snyder's Golf Tournament and Family Funday, held May 4, 2001, gathered people who live with Parkinson's from all over the United States, and one even from Canada! There was something for everyone —golf, a magician, storyteller, games, animals, and silent auction. Joan is pictured with Congressman Lane Evans (seated) and Gina Morss (standing) of News 25.

Second Annual Parkinson Alliance Golf Classic Princeton, New Jersey



The Borden Perlman Insurance Agency was the winning foursome at the Second Annual Parkinson Alliance Golf Classic held at the Cherry Valley Country Club on July 17, 2001. The event brought familiar faces and some new faces to raise funds for Parkinson's disease research.

2nd Annual Derby Eve At The Olmsted Louisville, Kentucky



Sen. Mitch McConnell from Kentucky and his wife, Elaine Chao, Secretary of Labor under President Bush, attended our 2nd Annual Derby Eve at the Olmsted. The event was held May 4, 2001 on the grounds of the Masonic Home in Louisville, Kentucky.

Carnegie Center 5K & Fun Run for The Parkinson Alliance—October 6, 2001

Join us, rain or shine, on Saturday, October 6, 2001, for the Carnegie Center 5K & Fun Run at 101 Carnegie Center Parking Lot in West Windsor Township, New Jersey to benefit Parkinson's research. In light of the tragic events of 9/11/2001, we will donate 25% of all net proceeds raised to the Disaster Relief Fund for individuals directly affected by the tragedy.

For more information on the race, or to volunteer or be a sponsor, please contact the race hotline at (609) 631-9211. All walkers and families are welcome. Food and refreshments will be served, and awards to age-category and corporate team winners will be presented.

The Parkinson Alliance extends our deepest sympathy to the families and friends of those who lost their lives in the attack on America. We offer our sincere gratitude to the thousands of volunteers who have tirelessly served in the rescue operations, and we salute the indestructible spirit of America.

2001 Parkinson's Unity Walk—Cancelled

Ordinarily, the annual Unity Walk is a celebration of people with Parkinson's and their families. Individuals from around the world gather in Central Park, New York for a gentle walk and a day of festivities. The purpose is to raise funds for research. Due to recent horrifying acts of terrorism, and out of respect for those whose lives are forever changed, the September 23, 2001 Unity Walk was cancelled.

We cannot, however, cancel the progress of Parkinson's disease. We must continue to financially support research. Your donations are crucial.

The Unity Walk urges that, if you registered as an individual or as part of a team, you make your promised donation. For your convenience, online donations are accepted at their secure Web site at www.parkinsonwalk.org. You can also mail donations directly to the Parkinson's Unity Walk at 30 West 90th Street, Suite 9B, New York, New York 10024. Information on the 2002 Walk will be available on its Web site as it becomes available or call (212) 580-6505.

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