



# ACCELERATING THE CURE

The newsletter for friends and supporters of  
 The Michael J. Fox Foundation for Parkinson's Research

SPRING 2009

## Patient Power

Recent MJFF partnerships and initiatives aim to amplify the voices and experiences of people with Parkinson's in the research process to help speed better treatments and a cure for PD

The Michael J. Fox Foundation has recently entered into several projects that draw on one of the deepest reservoirs of expertise in the Parkinson's disease community — that of people with Parkinson's (PWP).

"Only people with PD can truly know what Parkinson's is and how it manifests. Yet today there are too few ways for researchers to gather information directly from large numbers of patients, so that their disease experiences can directly inform ongoing research efforts," said Katie Hood, chief executive officer of MJFF.

"Our Foundation sees opportunities emerging to establish next-generation tools and resources that will enable this interchange, ensuring that data can be collected in a rigorous and useful fashion that might accelerate meaningful discoveries and observations."

### Web-based Clinical Assessments Initiative

In September MJFF awarded \$1 million total to four research teams under the *Developing and Validating Web-Based Clinical Assessments for Parkinson's Disease* program. The initiative seeks to drive the creation and testing of Web-based tools that would allow patients to participate in clinical research from the comfort of their own homes, decreasing hurdles to participation in critically needed clinical studies.

Awardee Paolo Bonato, PhD, of Harvard University will develop novel wearable sensor technology to record patient data based on standard clinical evaluations (using the Unified Parkinson's Disease Rating Scale, or UPDRS) that can then be accessed via Web-based systems. He and his colleagues already have such technology under development; MJFF funding will be used to optimize the hardware and software in the context of a study in PD patients.

Jay Alberts, PhD, of The Cleveland Clinic will develop two versions of cognitive and motor tests: one to be completed electronically during a routine clinical examination, the other to be administered via the Internet. For the initial validation study, data will be collected from 100 mild to moderate PWPs as they complete the cognitive and motor tests during an in-person clinical examination, as well as remotely using the internet. Cognitive and motor data gathered from in-person clinical and remote methods of data collection will be compared with standard UPDRS clinical measures of motor function.

"The capability to accurately assess patients' cognitive and motor function simultaneously and remotely offers us an opportunity to objectively track the progression of the disease," said Dr. Alberts. "What's more, the effectiveness of adjustments in medication or experimental interventions used in clinical trials can be expanded through more-frequent assessments of cognitive and motor function, without requiring the patient to necessarily return to the site of the clinical trial."


### The 23andMe PD Research Community

In a related project, MJFF joined the effort in March to recruit at least 10,000 PWPs to a new research community conceived and led by personal genetics company 23andMe of Mountain View, California. The community represents an unprecedented effort to leverage DNA technology, the Internet, and patient participation to contribute patients' personal experiences with PD to a new database that will eventually attempt to overlay lifestyle and environmental factors with individuals' genetic profiles on a large scale. The ultimate goal is to shed entirely new light on human understanding of Parkinson's disease, thus accelerating the development of breakthrough treatments.

Since May 2008 the Foundation has been funding 23andMe and The Parkinson's Institute and Clinical Center of Sunnyvale, California, to partner on creating Web-based tools and surveys that can gather scientifically valid information from a community of PWPs. Formal work is now beginning to build the community whose members will serve as subjects for these tools and surveys.

Ms. Hood said MJFF fully understands that the decision to become involved with a community such as this is a personal choice, one which each patient must make for her- or himself. "There are many high-profile issues associated with this project — genetic testing, involvement of a commercial interest in science, validity of the Web to do research," she remarked. "We view it as an experiment in how we can do research faster and better — one that we hope will leverage patients' contributions for quicker discovery and development of new treatments."

More information about all four awards funded under *Web-based Clinical Assessments*, as well as MJFF's partnership with 23andMe, is available at [www.michaeljfox.org](http://www.michaeljfox.org).



ELENA OLIVO

## NEWS FROM THE CEO

With another Parkinson's Awareness Month upon us, we thought it fitting to publish this special edition of *Accelerating the Cure* and highlight the amazing Parkinson's community that inspires all of us at The Michael J. Fox Foundation every day.

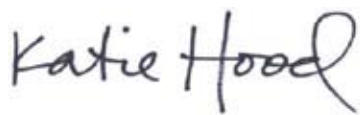
It is you, the individuals whose lives are touched by Parkinson's disease — whether because you are a person with PD, a caregiver or friend to someone with the disease, or a researcher working toward therapeutic breakthroughs — who spur us on in our mission to speed progress toward better treatments and a cure.

We've packed this newsletter with information about Web-based technologies that aim to increase participation in clinical research and amplify PWPs' voices in the research process; updates on a few of the current and future projects we're most excited about; and the stories of PWPs themselves, who share their secrets for living with courage, optimism and grace in the face of the daily challenges posed by PD. We know you will recognize parts of your own story in their words.

Please know how grateful we are for your ongoing commitment to our mission. It is with you in mind that we set our priorities, forge new partnerships and celebrate tangible progress.

For everything you do to keep us moving forward, thank you.

Warm regards,



Katie Hood, CEO

INSIDE

PASSION AND PURPOSE:  
 PWPs IN THEIR OWN WORDS (PP. 2–4)

PLANNED GIVING ADVICE:  
 GIFT ANNUITIES (P. 4)

MJFF HOSTS WORKSHOP ON  
 PLACEBO RESPONSE IN PD (P. 5)

MARK SELIGER

# “Passion and Purpose”: PWP’s in Their Own Words

Michael J. Fox may be one of the best-known people with Parkinson’s facing the disease with courage, grace and optimism every day. But he is far from the only one who does so. In honor of Parkinson’s Awareness Month, **The Michael J. Fox Foundation salutes PWP’s everywhere who are living their lives with spirit, joy and hope, in spite of the challenges posed by their disease.** Here are a few of their stories.

If you would like to share your story for possible publication in an upcoming edition of *Accelerating the Cure*; *FoxFlash*, our e-newsletter; or on the MJFF Web site, please e-mail 350 to 400 words to [mystory@michaeljfox.org](mailto:mystory@michaeljfox.org).

## EVAN HENRY: I’VE ALREADY GOT PLENTY OF #%^&\* CHARACTER

When I’d just been diagnosed with Parkinson’s, a friend looking for the silver lining offered, “Maybe it’s one of those character-building experiences.”

“I’ve already got plenty of #%^&\* character,” I replied.

My personal conviction is that having Parkinson’s disease doesn’t happen for any particular reason. But as humans, we have a wonderful capacity to ascribe meaning to the events that shape our lives — and, perhaps more importantly, to make lemonade out of lemons.

In the six years since my diagnosis, though I’ve been lucky that my PD progression seems to be on a slow trajectory, barely a moment has gone by that my body hasn’t reminded me I have the disease. My coping strategies have run the gamut. I wrote a Parkinson’s-themed novel and helped to start the California Parkinson’s Group Foundation, a nonprofit that supports those with young-onset PD. I also serve on the University of California, Irvine, Stem Cell Research Center’s Patient Advocacy Committee. These efforts have been challenging, rewarding and affirming, and they’ve returned incredible friendship and support.

In the day-to-day, I remind myself that what’s important now isn’t really any different from what it was before Parkinson’s. I’m a husband, father, breadwinner, neighbor, runner, would-be chef, handyman, TV channel-changer, ice-cream-from-the-carton-eater and Scrabble player. Life goes on. I’ve just figured out that if you live with Parkinson’s, it’s a pretty good idea to keep a pitcher of lemonade in the fridge.

*Evan Henry lives in Orange County, California, with his wife and two teenage daughters. He is a lifelong environmental professional and author of the thriller Shaker Guy.*

## ROBERT B. ETTLEMAN: FINDING A DIFFERENT ROAD TO CONTINUE IN A BELOVED PROFESSION

I was diagnosed with Parkinson’s disease six years ago, after a tremor in my fingers progressed to my entire hand. Many people can continue working with a tremor, but I knew I would have to give up dentistry, the profession I loved. I was fortunate that I quickly found a buyer for my practice (and that he let me come into the office and schmooze with my former patients). Still, there was an emptiness.



*Evan Henry with (l-r) wife, Dillon, and daughters Amy and Lauren*



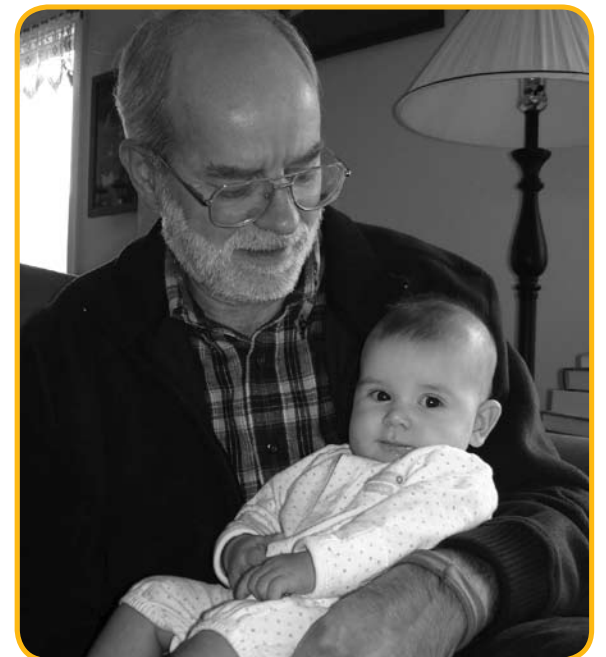
*Robert B. Ettleman and volunteer doctor Sol G. Brotman*

Yet I began to feel inspired by Michael J. Fox. If he was able to go from actor to advocate, I too could alter my path.

Soon my wife, Janet, and I founded Gulf Coast Dental Outreach — a community dental project that creates access to dental treatment for adult patients in need. We are a coalition of volunteer dentists and hygienists from the private sector, educational institutions, social services, country health officials and commercial supply and dental labs. In just 14 months we have provided \$280,000 in care through 800 dental patient visits to low-income adults. Janet is CFO and I am Executive Director. It is a big job considering the size and growth of the organization, but the smiles on our patients faces make it worthwhile. I also find time to speak to dental students about access to healthcare and social responsibility in healthcare, and I’m training dental assistant students in business management.

I guess you could say I’m still practicing dentistry. I’ve just taken a different road.

*Robert B. Ettleman, DDS, MAGD, was the recipient of the Florida Dental Health Foundation’s 2008 Humanitarian Award for his work with Gulf Coast Dental Outreach.*



*Mike McConnell holds granddaughter Vera*

## MIKE MCCONNELL: IT COULD HAVE BEEN A WHOLE LOT WORSE...

I was diagnosed with Parkinson’s disease in 2004, at age 53. I’ve had to give up a few things I used to enjoy, like woodworking — shaky guys and 10-inch table saw blades don’t work well together. But there are positives as well. I eat more slowly (helps in losing weight), drive more slowly (shouldn’t we all?), and find that I have to organize my thoughts and think about what I’m going to say before I open my mouth to speak. What a concept!

Like everyone else, I do worry about things. Will our savings last long enough? How will my mental faculties be affected? Will I be able to hold my grandbabies? I worry that someday all I’ll be able to do is sit and watch the History Channel in between massages and sponge baths from Inga,

the blond healthcare worker I keep dreaming about (there's that positive attitude again).

I'm not letting PD define my existence, but I've gotten involved in advocacy, and I fight back by raising money for a cure and participating in clinical trials — 14 since 2005. All have been learning experiences, and I've been buoyed by meeting all the caring docs and nurses, and smart scientists, who are working to cure PD.

We're all going to come down with health problems eventually. At least now I know what I've got. And it could have been a whole lot worse. I'm a pharmacist, and I used to work in a hospital full of people who would have gladly traded their health problems for mine.

*Mike McConnell lives in an Indianapolis suburb with Cindy, his wife of 35 years. If he were to publish his life story, he, too, would title it Lucky Man.*



Mary Anne Ostrenga

### MARY ANNE OSTRENGA: A PASSION AND A PURPOSE

The surprising thing about having Parkinson's disease and asking for help is that almost everyone says yes. I am eternally grateful for the compassion, generosity and donations of money and time I have received from unexpected acquaintances, family, old friends and former neighbors. Two friends travel to Naperville from Colorado every year to volunteer at the Garden Walk. The mayor attends and is our best cheerleader. I am constantly amazed by the support of my community.

I was diagnosed in 2001. Learning to cope with Parkinson's has made me more courageous, sympathetic and compassionate. I became an advocate, telling my story publicly to bring awareness to the need for continued research toward a cure. I met other advocates, including former Attorney General Janet Reno and Michael J. Fox. Hearing Michael speak at the World Parkinson Congress in 2006 made a big impression on me. I realized that when you tell your story and make it personal, people step up to help you. That was when I decided to join Team Fox and began planning the first Garden Walk.

I have so many wonderful new friends whom I would never have met if not for PD. I now have a passion, gardening, and a purpose, fundraising for PD research; together they give new meaning to my life.

*Team Fox member Mary Anne Ostrenga has raised over \$70,000 for MJFF by hosting garden walks in her hometown of Naperville, Illinois. This May she will be honored as Woman of the Year by the Naperville branch of the American Association of University Women for her work with Team Fox and MJFF.*



Katie Heteji and Dave Dorsey



Sheryl Jedlinski

### SHERYL JEDLINSKI: ALL WE WANT IS TO GIVE BACK

Seeing myself through the eyes of others has given me confidence in my ability to beat Parkinson's.

I was diagnosed with Parkinson's 11 years ago, at age 44. I joined an online patient advocacy group to regain a sense of control over my life; there I made a new friend, Jean Burns, with whom I co-founded pdplan4life.com. It's a Web site where people with PD can come to get helpful information, tips and support. Our goal is to empower others to live well with Parkinson's by sharing our daily challenges and triumphs, fears and coping strategies. (I find humor in everything from the King Kong-size hickeys left on my back by massage cupping to the drowning of my cell phone in a pedicure bath.)

When I was first diagnosed, I could never have imagined how many lives I would touch as a result of PD. To date, people from all 50 states and more than 50 countries have visited pdplan4life. Every time we speak, people line up to hug us, shake our hands, and thank us for making them laugh and giving them hope. My disease has progressed, and I have days when my initial anger and sadness return. But I am doing far better than I would have expected. This year, Jean and I are crisscrossing the country to speak at five major conferences. All we want is to give back.

*Sheryl Jedlinski and Jean Burns will speak at the Annual Kenton Kilmer Parkinson Disease Symposium, June 12, in Waukesha, Wisconsin, and at the Southeastern Parkinson Disease Conference, October 8-10, in Rome, Georgia.*

### DAVE DORSEY: WITH COURAGE, PERSEVERANCE AND FORTITUDE YOU WILL OVERCOME ANY CHALLENGE

I was diagnosed with young-onset Parkinson's at age 39. Two years later, I was prescribed the gold standard treatment for Parkinson's — levodopa. It was the only drug that could combat the now-relentless tremor controlling the left side of my body, but it presented horrifying side effects. My neurologist suggested deep brain stimulation, an elective surgery that could suppress my tremor without the side effects of levodopa. In July 2008 I underwent the eight-hour surgery, and I've seen great improvement.

Sharing my story is therapeutic; I only hope others might benefit from my experience. Parkinson's is debilitating, but for me, it also has inspired solid friendships and even acts of heroism. Soon after my diagnosis my cousin, Katie, announced that she would run the ING NYC Marathon — her first — for Team Fox. Her run raised over \$6,000 for Parkinson's research. I was honored to run the last three miles with her, and as she crossed the finish line she forever changed my outlook on life. She taught me that with courage, perseverance and fortitude you will overcome any challenge.

*Dave Dorsey is director of audiovisual services at The Inn at Penn in Philadelphia, Pennsylvania, where MJFF will hold a Research Roundtable on June 26.*

### RICK SCHWARTZ: MY LIFE IS BLESSED

No one I know wants to have Parkinson's, including me. But sooner or later, life will put real challenges in front of all of us. When I think about the nine years since my diagnosis, I find that they've been some of the best of my life. Because of PD, I've been willing to open doors to a different kind of reality — not just walk by them.

While I always worked hard before Parkinson's, most things came easily to me. With PD, "easily" is not an option. That humbled me and made me think. I came to the conclusion that Parkinson's is not the end, but the beginning: of testing my own mettle, of recognizing that there are many things far crueler than PD in this world, of realizing that I didn't have time to feel sorry for myself.

I reached out to help where I could; I'm in the trenches helping other PWDs get information or obtain a walker or join a support group in the Rocky Mountain region. So many people I never would have met otherwise have become

continued on page 4



## Planned Giving Advice: Gift Annuities

By Martin M. Shenkman, CPA, MBA, PFS, JD

Every contributor to The Michael J. Fox Foundation wants to provide ongoing support for the Foundation's mission to cure Parkinson's disease. In times of recession, though, charitable giving can feel out of reach. If the economy has hammered your retirement savings, gift annuities are a creative option that could help you keep giving. A gift annuity will provide you with cash flow while helping further MJFF's efforts to drive high-impact PD research.

A gift annuity is a contract between you and MJFF. You give the MJFF a one-time payment. You then receive a fixed monthly payment; this is the "annuity." On your death (or the death of a spouse or other loved one, since you can name up to two beneficiaries), MJFF will receive all the funds that remain.

The amount of the annuity is determined when you set up the gift; you will know exactly what you'll be getting before you pay. While monthly payments from gift annuities can beat CD rates, because of the way these tools are structured they're unlikely to make sense for anyone under age 55. For those aged 55 to 60 they might make sense. At age 60 to 65 they look better. From age 65 and up they can be tremendous.

Note that if you name anyone other than a spouse to receive the annuity you might face a gift tax. And it's important to be cautious about the amount you commit, since once the gift is made, you cannot access the principal in the event of an emergency.

### Gift Annuities Are Safe

When you buy an MJFF gift annuity, MJFF will obligate itself to pay you a monthly or quarterly check for the rest of your life. The payment can substantially exceed the pittance you'll get at the local bank. (No toaster. Sorry!) That can be a great deal — you'll get a fixed amount regardless of what the markets do.

Gift annuities are highly regulated by the states where they are offered to ensure that MJFF will be able to meet its contractual obligations to pay you. States require an initial registration, regular monitoring, and annual filings by the charity. You'll be able to sleep at night.

### Income Tax Bennies

When you buy a gift annuity, you may qualify for an income tax deduction of part of the value of what you give to MJFF for the annuity. Since you'll be receiving a lifetime annuity, only part of what you give MJFF is deductible. Your deduction will depend on the estimated amount MJFF will retain upon your death. The greater your age when you buy the gift annuity, the bigger the tax deduction.

If you give appreciated assets, you won't have to recognize capital gains immediately, as you would if you sold the property and purchased a commercial annuity. Instead, the taxable gain will be recognized over the period the annuity is expected to be paid (your actuarial life expectancy). If you have them, cherry-pick appreciated stocks to pay for the gift annuity.

Possible income tax savings on your annuity payments are another benefit. Unlike interest you receive from a CD, all of which is taxable, a portion of every annuity payment you receive will be tax-free. The IRS will treat it as a return of part of your payment for the annuity. The tax rules are complicated, so you should consult your accountant. And you'll need to read and understand the materials MJFF provides you on its gift annuity program.

### If You or Your Spouse or Partner Has PD

If you or your spouse or partner has PD, knowing that you'll receive a fixed amount every month can simplify budgeting and other worries. A gift annuity also eliminates the need for you to continue to manage the assets: Your investment and cash flow are on auto pilot. If you're struggling with the demands and stresses of PD, having a portion of your portfolio converted to a tax-advantaged annuity could be financially and personally beneficial.

There are a myriad of creative ways to rethink and restructure your support to MJFF so that economic turmoil doesn't have to prevent your continued support. Gift annuities are just one of many options.

*Martin M. Shenkman is an attorney and certified public accountant with specialized expertise in planned giving. This is the second in a series of articles he is contributing to Accelerating the Cure. To read the first article, please visit [www.michaeljfox.org](http://www.michaeljfox.org). Note: This article is provided for informational purposes only. As with any financial instrument, consult your accountant and financial planner before proceeding.*

## "Passion and Purpose" continued from page 3

friends. I'm truly inspired by the twinkle in their eyes, their capacity to see humor in both good and bad times, their resolve to keep living life to the fullest. And I have the stability and comfort and love of a wonderful family and a partner who could have walked out but elected to stay.

Parkinson's is a battle. But it's a battle that energizes me and gives me new purpose. Don't get me wrong: I have my fair share of not-so-good days. I've had setbacks to rebound from. But I've also gained insights that I hope made me a better man. My life is blessed.

*Rick Schwartz is Board President of the Parkinson Association of the Rockies. He had a 26-year career in television news, including serving as News Director for Fox Sports Net Rocky Mountain. Prior to that he was a teacher and played baseball for the Cleveland Indians. He lives in Denver, Colorado, with his wife, Linda.*



Rick Schwartz with nieces Lauren (l) and Katie

### JIM MURRAY: EVERY DAY IS A GIFT

When I was 40, I learned that I was a perfect bone marrow match for a 26-year-old man dying of leukemia. We met in person after the harvesting and donation of my marrow, and he told me how incredible it was to him that I would help someone I didn't even know. But from my perspective, I'm so grateful to have had the incredible opportunity to give like that.

Ten years later I noticed a twitch in my left hand. Learning it was PD was a shock. Like everyone, when I was younger, I felt invincible. My grandparents all lived long, healthy lives, two of them into their late 90s. I had always assumed I would as well.

Since my diagnosis, the biggest change for me has been to let go of my assumptions. I look around and realize that others, too, are coping with life's curve balls. But I also see that my experiences before my diagnosis were already preparing me for this realization. PD is a struggle, but I haven't been at death's door in a cancer center, waiting for bone marrow to save my life.

I know I'm not alone in fighting this disease. I have so much hope that a cure is just around the corner. The dedication I see in the efforts of



Jim Murray with his wife, Beth

Michael J. Fox, the Foundation's researchers and my family and friends really keeps me going.

I've always been aware of how precious life is, but there is no question that my PD diagnosis heightened that awareness. Every day is a gift. Every morning is another day in Paradise.

*Jim Murray and his wife, Beth, live in Fort Collins, Colorado. They are Team Fox members and longtime supporters of MJFF.*

# NEWSBRIEFS

THE MICHAEL J. FOX FOUNDATION ROUTINELY POSTS UPDATED INFORMATION ABOUT FUNDED PROJECTS ON ITS WEB SITE. FOR MORE INFORMATION ABOUT THE PROJECTS LISTED BELOW, PLEASE VISIT [WWW.MICHAELJFOX.ORG/RESEARCH.CFM](http://WWW.MICHAELJFOX.ORG/RESEARCH.CFM).

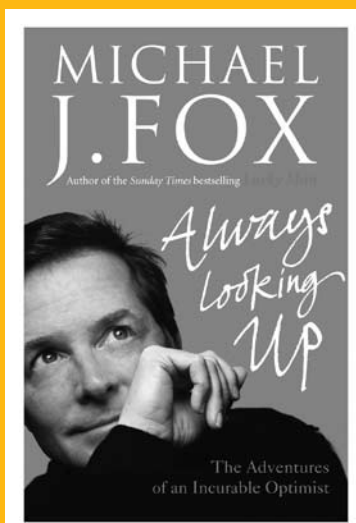
## FOUNDATION HOSTS WORKSHOP ON PLACEBO RESPONSE IN PARKINSON'S

Placebo response — a positive medical response to an intervention lacking active components as if it were an efficacious treatment — has occurred in several Parkinson's disease clinical trials, confounding the interpretation of results. Most recently, this occurred in Ceregene, Inc.'s failed trial of CERE-120. On March 30 The Michael J. Fox Foundation hosted a workshop bringing together top experts to review current understanding of placebo response in PD and discuss ways to control for it in future clinical trials. "Placebo-controlled study design is the current gold standard methodology for testing the efficacy of experimental PD therapeutics," said Todd Sherer, PhD, vice president of research programs. "But the placebo response is poorly understood and raises significant barriers for the design and interpretation of placebo-controlled trials — it also complicates design of open-label Phase 1 studies." Workshop participants also brainstormed ways to leverage the placebo response to improve existing PD therapies. MJFF is currently assessing the workshop participants' recommendations to determine next steps.

## SUPPLEMENTAL FUNDING GRANTED TO TWO DOPAMINE-NON-RESPONSIVE SYMPTOMS OF PARKINSON'S DISEASE AWARDEES

Dopamine-non-responsive symptoms of PD, such as problems with posture and gait and gastrointestinal dysfunction including constipation, are often reported by PWDs to be among the most disruptive to overall quality of life. MJFF's 2006 *Dopamine-non-responsive Symptoms of Parkinson's Disease* program funded research into these symptoms. Now two awardees have received grant supplements for further exploration. Chantal François, PhD, of Hôpital de la Salpêtrière in Paris, France, developed a pre-clinical model to increase understanding of gait and posture disturbances as well as speed drug development for new treatments. The investigators successfully induced symptoms by injecting a toxin into a certain part of the brain; the team also showed that these symptoms were not alleviated by changes to the dopamine system. The team will now refine the model to create posture and gait disturbances as close to those seen in human Parkinson's disease as possible. Jim Greene, PhD, of Emory University characterized gastrointestinal (GI) dysfunction in four pre-clinical models. He will now work to determine the effects of aging on GI symptoms in an alpha-synuclein transgenic model of PD, and the effects of dopamine replacement on colon motility in normal and dopamine-depleted models.

### MICHAEL J. FOX: ALWAYS LOOKING UP



**Attention bookworms:** Michael J. Fox's latest book is available now on bookstore shelves! *Always Looking Up: The Adventures of an Incurable Optimist* documents the legendarily positive perspective that has made Michael a role model to millions. In his uniquely engaging and witty voice, Michael describes how he developed a personal policy of engagement and discovery and became a happier, more satisfied person by recognizing the gifts of everyday life. And tune in to ABC-TV on Thursday, May 7, at 10 p.m. for Michael's inspiring and entertaining hour-long special on the power of hope and optimism.



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Announcing Fox Shop, MJFF's official online store, launching April 2009. Find Team Fox gear and other wearables that announce your support of MJFF and the millions living with PD. All purchases help fund our efforts toward better treatments, and ultimately a cure, for Parkinson's disease. Great gift ideas, too!

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## SPRING 2009 NEWSLETTER

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THE MICHAEL J. FOX FOUNDATION IS DEDICATED TO FINDING A CURE FOR PARKINSON'S DISEASE WITHIN THE COMING DECADE THROUGH AN AGGRESSIVELY FUNDED RESEARCH AGENDA AND TO ENSURING THE DEVELOPMENT OF THERAPIES FOR THOSE LIVING WITH PARKINSON'S TODAY.