Michael J. Fox’s “Testimony to the Senate”

Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education
Hearing on Parkinson’s Research and Treatment ~ September 28, 1999

http://www.michaeljfoxdatabase.com/other-work/testimony-to-the-senate-appropriations-committee/

Specter: We turn now to our second panel: Mr. Michael J. Fox, Mr. James Cordy, Dr. J. William Langston and Ms. Joan Samuelson. If you lady and gentlemen will step forward we will proceed with the testimony.

We welcome you all here. Ms. Samuelson is President of the Parkinson’s Action Network, and very active in promoting funding, and Dr. Langston is the President of the Parkinson’s Institute, and a renowned expert in the field, Mr. James Cordy (where’s your hourglass, Jim?) has been an extraordinarily effective advocate in the field, and as I noted earlier we have with us today Mr. Michael J. Fox, a successful actor for many years, first as Alex P. Keaton on the television series “Family Ties”—you always work with a middle initial, don’t you Mr. Fox?—later in many movies, including Back to the Future, and most recently on television again on the highly acclaimed “Spin City.”

Michael was diagnosed with Parkinson’s in 1991 at the age of 30, and has become very, very active in Parkinson’s advocacy. And one of the facts of life is that when someone like Michael J. Fox steps forward, it very heavily personalizes the problem, focuses a lot of public attention on it, and has the public understanding of the need for doing whatever we can as a country to conquer this disease and many, many others. So we thank you for being here Michael J. Fox, and look forward to your testimony. Again we’ll put the lights on at five minutes on testimony.

Mr. Fox, we’re going to start with you.

Fox: Mr. Chairman, members of the Subcommittee—excuse me, [pauses to pull the microphone down to his level]—the story of my life! The mike is always too high. Mr. Chairman, members of the Subcommittee, thank you for inviting me to testify today about the need for greater federal investment in Parkinson’s research. Some, or perhaps all of you, most of you, are familiar with me from my work in film and television. What I wish to speak to you about today has little or nothing to do with celebrity, save for this brief reference.

When I first spoke publicly about my eight years of experience as a person with Parkinson’s many were surprised, in part because of my age, although 30% of all Parkinson’s patients are under 50, 20% are under 40, and that number is growing.

I had hidden my symptoms and struggles very well, through increasing amounts of medication, through surgery and by employing the hundreds of little tricks and techniques a person with Parkinson’s learns to mask his or her condition for as long as possible. While the changes in my life were profound and progressive, I kept them to myself for a number of reasons: fear, denial for sure, but I also felt that it was important for me to just quietly “soldier on.” When I did share my story the response was overwhelming, humbling and deeply inspiring. I heard from

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thousands of Americans affected by Parkinson’s, writing and calling to offer encouragement and
to tell me of their experience. They spoke of pain, frustration, fear and hope. Always hope.

What I understood very clearly is that the time for “quietly soldiering on” is through. The war
against Parkinson’s is a winnable war and I have resolved to play a role in that victory. What
celebrity has given me is the opportunity to raise the visibility of Parkinson’s disease and focus
attention on the desperate need for more research dollars. While I am able for the time being to
continue doing what I love best, others are not so fortunate. These are doctors, teachers,
policemen, nurses, as you had indicated earlier, legislators, and parents who are no longer able to
work to provide for their families and live out their dreams.

The one million Americans living with Parkinson’s want to beat this disease. So do the millions
more Americans who have family members suffering from Parkinson’s but it won’t happen until
Congress adequately funds Parkinson’s research.

For many people with Parkinson’s, managing their disease is a full-time job; it is a constant
balancing act. Too little medicine causes tremors and stiffness, too much medicine produces
uncontrollable movement and slurring, and far too often Parkinson’s patients wait and wait (as I
am right now) for their medicines to kick in.

New investigational therapies have helped some people like me control symptoms, but in the end
we all face the same reality: the medicine stops working. For people living with Parkinson’s the
status quo is not good enough. As I began to understand what research might promise for the
future I became hopeful that I would not face the terrible suffering so many with Parkinson’s
endure. But I was shocked and frustrated to learn the amount of funding for Parkinson’s research
is so meager. Compared with the amount of federal funding going to other diseases, research
funding for Parkinson’s lags far behind. In a country with a $15 billion investment in medical
research we can and must do better.

At present Parkinson’s is inadequately funded, no matter how one cares to spin it. Meager
funding means a continued lack of effective treatments, slow progress in understanding the cause
of the disease and little chance that a cure will come in time. I applaud the steps we are taking to
fulfill the promise of the Udall Parkinson’s Research Act, but we must be clear we aren’t there
yet.

If, however, an adequate investment is made there is much to be hopeful for. We have a
tremendous opportunity to close the gap for Parkinson’s. We are learning more and more about
this disease. The scientific community believes that with a significant investment in Parkinson’s
research new discoveries and improved treatment strategies are close at hand. Many have called
Parkinson’s the most curable neurological disorder, and the one expected to produce a
breakthrough first. Scientists tell me that a cure is possible, some say even by the end of the next
decade, if the research dollars match the research opportunity.
Mr. Chairman, you and the members of the Subcommittee have done so much to increase the investment in medical research in this country. I thank you for your vision. Most people don’t know just how important this research is until they or someone in their family faces a serious illness. I know I didn’t. The Parkinson’s community strongly supports your efforts to double medical research funding. At the same time, I implore you to do more for people with Parkinson’s. Take up Parkinson’s as if your life depended on it. Increase funding for Parkinson’s research by $75 million over the current levels for the coming fiscal year. Make this a down payment for a fully funded Parkinson’s research agenda that will make Parkinson’s nothing more than a footnote in medical textbooks.

(Turning pages isn’t always easy!) I would like to close on a personal note. Today you will hear from, or have already heard from, more than a few experts, in the fields of science, bookkeeping, other areas. I am an expert in only one: what it is like to be a young man, husband and father, with Parkinson’s disease. With the help of daily medication and selective exertion I can still perform my job, in my case in a very public arena. I can still help out with the daily tasks and rituals involved in home life, but I don’t kid myself; that will change.

Physical and mental exhaustion will become more and more of a factor, as will increased rigidity, tremor and dyskinesia. I can expect in my forties to face challenges most won’t expect until their seventies or eighties, if ever. But with your help, if we all do everything we can to eradicate this disease, in my fifties I’ll be dancing at my children’s weddings. And mine will be one of millions of happy stories. Thank you for your time and attention.

Specter: Thank you very much Mr. Fox for those very profound and moving words.
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1. Identify one example of ethos?

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2. Identify one example of pathos?

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3. Identify one example of logos?

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4. How do you feel about Stem Cell Research? Do you think it’s ethical? Why or why not?

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