United States Food and Drug Administration

Patient Focused Panel Discussion, September 22, 2015, Parkinson's Disease

Topic #2 answers presented by panelist Bill Patterson, PWP.

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Patient Panel Discussion Comments

for September 22, 2015

Panelists were asked to answer a few questions on a given topic. Here are the questions (for FDA Topic # 2) and the responses I gave in my oral presentation.

Topic 2: Patients' perspectives on current approaches to treating Parkinson's Disease

Current Treatment

What are you currently doing to help treat your condition or its symptoms? (Examples may include prescription medicines, over-the-counter products, and other therapies including non-drug therapies such as diet modification, exercise.)

Background and Diagnosis:

My name is Bill Patterson. I am a 67 year old retired computer programmer who led a fairly sedentary life and I have Parkinson's disease. From early in 2007 when I experienced micrographia, some balance trouble and foot drop, and through the next three years, I progressively experienced an undiagnosed and frightening reduction of motor function on my right side, despite my visiting a neurologist two or three times a year. I knew I had a serious problem. By 2010 I was limping badly, unable to type or use a computer mouse with my right hand, and unable to use my right foot and leg to drive. My handwriting was small. I was significantly depressed at that point: my sleep schedule was chaotic and I often would lie awake at night and sleep during the day.

On April 22, 2010, to get another opinion I went to what was for me a new medical facility that was 100 miles from my home, at a highly reputed medical school. I saw a neurologist there who gave me the most thorough neurological examination I can remember and gave me a clinical diagnosis of early hemi parkinsonism. This and the neurologist's prognosis scared me into thinking that I could be, worst case scenario, in a nursing home in a few years and possibly dead in five. The fact that I had not been told any of this before was particularly annoying. I decided to learn as much as I could about PD. I scoured the Internet, sought support groups, and began seeing a movement disorder specialist. My research led me to Dr. Jay Alberts' experiments at Cleveland Clinic on the effects of bicycling on PD symptoms.

I also learned about many animal model experiments in which vigorous aerobic exercise seemed to be neuroprotective, i.e. slowed the progress of the disease.

Prescription medication:

My movement disorder specialist started me on a medication schedule that ramped up to 2 tablets of 25/100 carbidopa/levodopa three times a day. A couple of weeks later selegiline (5 mg 2 times per day) was introduced. I found that while I had more control over my movements in general, I was experiencing random writhing movements in my right leg, ankle and foot. I also did not like the nausea and other weird feelings I had. Additional carbidopa was added. It helped.

Over the next five years different strategies were tried, and for two years I was off of carbidopa/levodopa entirely.

Today my anti-parkinsonian prescription medication consists of 1 ½ tablets of 25/100 mg carbidopa/levodopa plus 1 tablet 25 mg carbidopa three times per day and selegiline (5 mg 2 times per day). This is still less than was originally prescribed in the beginning of my treatment.

Dietary supplements:

I take coconut oil because some other patients advised that it helps fine motor coordination in activities such as typing. My typing speed is often good but it varies and I have not isolated anything related to its variance.

Dentist recommendations:

PD can result in reduced saliva. I have used and expect to resume using Biotene mouthwash during the day for dry mouth. I use ACT mouthwash at night. I visit a hygenist every four (4) mouths rather than the usual 6.

Exercise:

I have continued to bike (on a stationary machine) almost daily through the last five and a half years at a cadence generally greater than 90 RPM for 40 minutes. I feel fortunate to be able to do this. I track specific measures of my exercising in a data base.

I practice tai chi and yoga. I have used personal trainers. I use weight machines for strength. I stretch regularly.

Side-effects:

There are side effects from the biking. I feel healthier and have lost weight. But I developed cramps in my feet—I learned to treat them by ingesting more calcium, magnesium, and potassium. I also developed pins and needles feeling in my hands, treated effectively with anti-vibration gloves.

Effectiveness of treatments on symptoms

> How well does your current treatment regimen treat the most significant symptoms of your disease?

I think my current treatment regimen treats the symptoms fairly well; however the number of symptoms, exercises, substances and their interrelationships is overwhelming. At times it is hard to tell which combinations do what.

Beyond mere symptom treatment is the hope that some of these treatments are neuroprotective.

Impact of treatments on daily activities

> How well do these treatments improve your ability to do specific activities that are important to you in your daily life?

These treatments enable me to have a fairly full life, but not as full as I would like. During the first few years of this adventure I was employed full time, now I am retired—that makes things a little easier.

Importantly, I get around very well, type, use a computer mouse, and drive with my right leg and foot. I enjoy my family and friends.

I have noticed some, but comparatively little progression of my symptoms since my starting treatment five and a half years ago, when compared to the progression experienced in the first three years of undiagnosed PD. I find this encouraging and suggestive that my treatments including the aerobic exercise have slowed the disease progression.

Treatment downsides

> What are the most significant downsides to your current treatments, and how do they affect your daily life? (Examples of downsides may include bothersome side effects, need to visit your doctor or take medications frequently, cause sleepiness, etc.)

One downside of my current treatments is that the time required for exercise and related PD activities such as managing prescriptions and attending support groups is significant. Now that I am retired things are better.

Ideal treatment

> Assuming there is no complete cure for your condition, what would you look for in an ideal treatment for your condition or a specific aspect of your condition?

I am grateful for my treatment and the research that supports it. An ideal treatment would eliminate all of these symptoms. Probably the motor symptoms being the worst that I have now would be tackled by an ideal treatment. But if my cognition were impaired as well, cognition would be the symptom I would want tackled first.

As bad as side-effects of certain drugs feel, they are usually not as bad as the condition being treated.

Certainly fear of the future is a real issue.

It is imperative that we learn more about brain functions. Better knowledge AND BETTER DISTRIBUTION OF THAT KNOWLEDGE may enable not only better treatment of PD but better aging overall.

I don't think that I can overemphasize the importance of exercising in my treatments. I feel good most of the time.