

Managing Your *Life in Motion* Webinar Transcript New Therapies in Parkinson's Disease Management

Date: October 4, 2006

Time: 8:00 pm EDT

Moderator: Ms. Judy Blazer

Moderator: Ms. Joy Leffler

Presenter: DR. MARK STACY

[EDITOR'S ADDITIONS ARE SHOWN IN BRACKETS]

JUDY BLAZER: Welcome everyone to this WE MOVE webinar. I wanted to introduce you to Dr. Mark Stacy. He is going to be our presenter or our teacher for tonight and is going to talk to us about Parkinson's disease and new therapies. Dr. Mark Stacy is the Medical Director of the Duke University Parkinson's disease and Movements Disorder Center in Durham, North Carolina. Dr. Stacy is also a Board member at WE MOVE and I am very pleased to say that he is the Chairman of WE MOVE Education Committee. Welcome Dr. Stacy.

MARK STACY: Thank you.

JUDY BLAZER: WE MOVE, as I said, is the sponsor of this webinar. I am assuming that all of you have visited our website at www.WE.MOVE.org but you may not know much about the organization. We are a not-for-profit organization and our mission is to raise awareness of movement disorders including Parkinson's disease. So that means we teach healthcare professionals, physicians, nurses, physical therapists etc. about movement disorders and we also sponsor events like these for people living with movement disorders and their caregivers. Again, we invite you after this webinar to visit our website at www.WE.MOVE.org. Our website directed to healthcare professionals is www.mdvu.org, that stands for Movement Disorder Virtual University and we also have a third website that is dedicated to our Life in Motion Awareness Campaign and you [the] URL for that site is <http://www.life-in-motion.org/>. Funding for tonight's event has come from Valeant

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Pharmaceuticals International and WE MOVE gratefully acknowledges their unrestricted educational grant.

I wanted to go through the road rules for tonight's webinar. I am sure you have read most of them in the e-mail that was sent to you before the webinar. Again, Dr. Stacy will be our presenter. I am Judith Blazer, the Executive Director of WE MOVE. You have been hearing from Joy Leffler, who is WE MOVE's Director of Education and we will serve as moderator [and facilitator] for tonight's call. The webinar itself is actually divided into three parts, and the first part will be Dr. Stacy. He will present to us via a series of slides information about Parkinson's disease and new therapies. The second part of the event will feature a Q&A. Many of you registered questions before the webinar via the website. We got hundreds and hundreds of questions and we obviously can't answer them all during this call. We will answer selected questions during the second part of the webinar. During the third part of the event, Dr. Stacy will be answering questions from the audience. So, that's who is participating in the webinar.

If you are typing in questions, we have WE MOVE staff members who are scanning the chat log and looking for questions from the audience. So, during the third part of the event, we will be taking those questions and Dr. Stacy will be answering them.

As Joy Leffler mentioned, there will be a complete copy of the text portion of this webinar available on our website at www.WE MOVE.org, where you will be able to read it and also print it. Dr. Stacy will try to answer as many questions tonight from the audience as possible. As we said we have had hundreds of questions posted in advance and I am sure all of you have many questions to ask tonight. If we don't get to your question, we invite you to visit the website, www.WE MOVE.org and post your questions to the Discussion Forum on Parkinson's disease. You may want to start conversations with others who are living with the daily challenges of PD and also be sure to visit the WE MOVE website, where you can read more information about Parkinson's disease.

I would now like to introduce Dr. Stacy and begin part one of our webinar event. The presentation is "New Therapies for Parkinson's Management." Welcome Dr. Stacy.

MARK STACY:

Thank you Judy. I will try to move through this first part fairly rapidly, so we'll have some more time for questions.

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As most of you know, Parkinson's disease is a neurologic movement disorder. What that basically means is, neurology is a study of the brain and nervous system and a specific area that I am interested in is classified as movement disorders. Parkinson's disease is a hypokinetic movement disorders, which means a slow movement disorder, as opposed to a hyper[kinetic] which are fast movement disorders. We have demonstrated over the course of the last 50 years that Parkinson's disease symptoms come from a loss of specific brain cells in the area of the brain called the substantia nigra. When these cells begin to drop out, the brain gets a decrease in a chemical called dopamine. So you have a nigrostriatal pathway that when it is not working well. It doesn't produce enough dopamine.

So our therapy for many years has been based on trying to replace that dopamine with a compound called levodopa or to mimic that dopamine with drugs called dopamine agonists. So, while not all symptoms of Parkinson's can be treated, the motor symptoms can be treated with a lot of different therapies. So we will try to through those in a little bit of detail in the next few minutes.

The goal of any Parkinson patient and any Parkinson physician is to maintain quality of life and motor function. I think that the best thing to...to predict how well patients are going to do in the long-term treatment of Parkinson's disease is [to look at] how well they communicate with their doctors. I would urge you to think of your doctor as someone who is the source of your information, but I would like to be thought of as a vendor at its most basic. I think of myself as a car mechanic. A friend of mine once told me that he took his car to get looked at...at a car shop and they told him all these things that were wrong with it. He responded to them saying, "I do not care what's wrong with it, when I drive my car out of here, I want it fixed."

So I think that if you become more dogmatic and more assertive during your office visits and come in with a list of questions and a list of expectations saying, "I want these fixed." In my office, I am very comfortable saying, "Well, I can work with this, but I can't do this one. I can work with this one and I can't do that one." So, if you give me a list of 10 things to work on and you hand it to me, I can pick out seven that I think I can work on, or four or even nine. We can begin to move forward to try to improve your motor ability.

My goal in Parkinson's disease is also to maintain your lifestyle. There are very few times when I decide that a patient needs to think about disability. My definition for disability is you spend 12 hours of your life trying to get eight hours

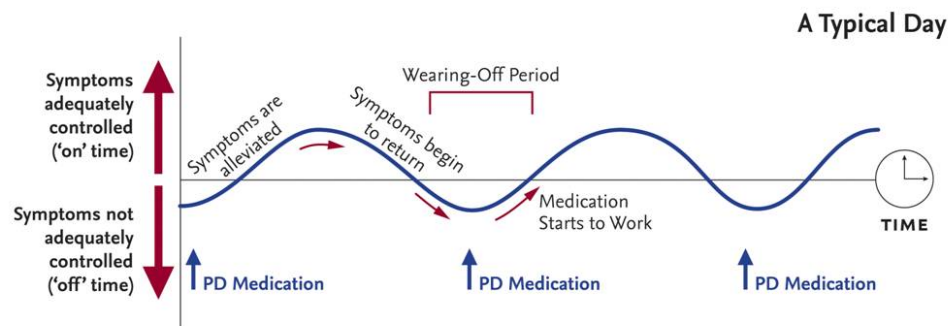
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of work done. In that instance, I believe that it is most important for me as your physician to say, "I would like for you to have a life and I think you need to look at disability." It has nothing to do with memory; it has nothing to do with mobility or being in a wheel chair or anything like that. It is basically you are spending 12 hours of your life, trying to do eight hours work and when I went through and looked at a population of 600 plus Parkinson's patients and more than 2,500 office visits in my practice that I had in Phoenix, I found that the average time for patients to get to that point, where I would recommend they consider going on disability or stopping work was 12 years. So any of you who are newly diagnosed with Parkinson's disease and you are waiting for this axe to fall, I hope that you will become more optimistic as we go through.

Finally, the point of good quality management of Parkinson's disease medication early is to evade later side effects, so we will talk a little bit about those. This is a little diagram that I made. I had some help from colleagues. We drew a diagram that suggested what wearing off looks like.

Typical Pattern of Wearing-Off During the Day



So if I start you on a drug called levodopa and combine that with carbidopa, that drug is called Sinemet or carbidopa/levodopa in the generic. Typically a patient can be put on Sinemet or carbidopa/levodopa and they do extremely well for a year or two. After a while you begin to notice that perhaps your Parkinson's symptoms are back after you wake up in the morning and you are slow to "kick in." So, if you look at the line...that is the straight line in the middle, is connected to the time graph, that ...that line is a graphic representation of no Parkinson's symptoms. If you are above the line, you have no symptoms. If you are below the line, you have symptoms.

So, you wake up in the morning and you take your first dose of medication and after 20 or 30 minutes, after Sinemet, you are moving better. That will peak in about an hour and a half to three hours, depending on how long you've had Parkinson's disease. Then you may notice by the time you hit your noon dose, you are having symptoms of Parkinson's that have returned. So you take another dose of medication and you kick in again and then three to four hours later, you wear off and you take your third dose of medication. When you talk to your Parkinson's physician, it is very useful for you to have these concepts understood to say my tremor comes back four hours after I take my medication and it then it takes me an hour for my tremor to go away, after I take my medicine.

All of your Parkinson's doctors will understand that concept and you need to know that you may develop problems with involuntary movements. The more Sinemet you take, the more likely you are going to have wiggly movements. I think that if you want to get an example of off-time, Muhammad Ali does not like to take medicines very often. He does end up in these off periods because he is able to overcome them; he is the heavyweight champion of the world and he is used to overcoming things. Michael J. Fox on the other hand will take medicine a little more often and he will have these dyskinesias particularly in his left arm two to three hours after he takes his medicines. Both represent different management challenges.

The strategies for managing off time [management] are I can give you more Parkinson's medicine.



What is "off time"?

- Strategies for management
 - Increase dose or dosing frequency of existing medications
 - Add a new medication
 - Consider additional approaches

So instead of one tablet of Sinemet, I can give you one and a half or I can increase the dosing frequency between the medicines. So while you initially took medicines at 8am, noon and 4pm OR 7am, noon and 5pm, with time you notice that you need to take it more often. Sometimes you can take that as often as every three hours. For those of you who are taking in more frequently than every three hours, I do think that you need to look at other medication strategies. I think that taking medicine, taking Sinemet more often, then that is not good for you in the long run. If I can hit that three-hour time limit where I can't keep you mobile for three hours or I am giving you dyskinesias by increasing the dose of Sinemet, I will always consider adding a new medication. Initially, those new medications will be probably a dopamine agonist or some other medicines that have been available for quite a while. We also have some new medicines that represent new alternatives in terms of treating these symptoms of wearing off.

The new therapies that we have are the drugs that have different delivery methods.



What exactly are "new therapies"?

- New drug OR new delivery method
- New approved use of old drug
- In the past two years:
 - Zydys selegiline (Zelapar ODT)
 - Rasagiline (Azilect)
 - Apomorphine (Apokyn)
- Additional non-drug approaches



The ones that have different delivery methods are Zydys selegiline or Zelapar. That's a drug that dissolves rapidly in your mouth. There is a drug called apomorphine or Apokyn. That's a drug that you inject just under your skin with an injection kit; it's like a migraine injection kit. Rasagiline is the other drug that's listed there. That is a traditional pill form of medication.

So, in terms of now talking about wearing off with these new agents, the Zydys selegiline or rasagiline are drugs that are designed to prolong on-periods. You

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take those drugs once a day and they have been demonstrated to keep on-periods—make on-periods last longer. Apomorphine is a more of a rescue approach. Apomorphine is a drug that you can inject when you have a sudden wearing off. So while Sinemet takes an hour for some of you to kick in, apomorphine would take 20 to 30 minutes.

If you have been tried on a number of medicines and you are tried on levodopa and you are on a dopamine agonist, which could be either Mirapex or Requip, or some of you may be on Permax, and you are still having off-time, I think you ought to consider adding other agents. What I would suggest is to tell that physician, "Don't you wish you had one more hour a day. Think of what you could get done." When someone tells me that they work 8 to 12 hours a day, and if I can have one more hour a day, I think, "Boy, I could really accomplish something then. There is no way I can give myself another hour a day, but in your case you may be able to have that hour with some medication adjustments." I do believe it's very important and that's the best way I know of to get my attention.

The goal of these new therapies is to really increase the time you are mobile; conversely that would decrease the time you are not mobile.



*What are the benefits of new therapies?
Can they really help ME?*

- Increase in "on time"
- Decrease in "off time"
- Possible rapid return to "on time"
- Benefits sustained for a period of time

Find out if these new approaches can help you
to improve your quality of life and attain
improved relief of symptoms



Those agents to do that [increase the time you are mobile] are Zelapar and Azilect. A rapid return on on-time would be done with Apokyn or using apomorphine. Sustaining the benefits for a long period of time would not

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happen with apomorphine; it lasts for about 30 minutes to even 60. All these other agents can last all day long.

In terms of taking care of Parkinson's disease, there are lots of people in your life that are important.



*A Coordinated Team Approach to
PD Management*

- While PD presents in certain ways, no one experiences the disorder in the same way.
- To manage PD, an individualized treatment plan needs to be developed that addresses the specific needs of each individual.
- The management of Parkinson's disease is not the responsibility of one individual, rather the responsibility of the intra-disciplinary team.
- All members are accountable.



Parkinson's disease is different in everybody. We call that managing Parkinson's disease individualization of treatment and it's important for you to be the CEO of your Parkinson's disease. You may have a lot of people who are providing you transportation or coming in to help in the house and you have a caregiver who is providing help. All those people have specific roles, but it's very important to me in managing people with Parkinson's disease to make sure that the Parkinson's disease patient is still in-charge.

If I have a patient who comes in and the spouse talks to me about difficulties that she wants taken care off or he wants taken care off in the patient, if that patient doesn't really feel those are a need or a problem, I will be less likely to address them. I think that as a Parkinson's disease patient, you must remember that your caregivers are here to help you. You are very grateful to them for that, but you have to provide the direction for the help.

Here are the people that we have imagined who could be involved in a Parkinson's disease care module.

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*A Coordinated Team Approach to
PD Management*

- Primary Care Physician
- Movement disorder specialist
- Neurologist
- Neurology Nurse
- Psychiatrist
- Physical therapist
- Occupational therapist
- Speech language therapist
- Ophthalmologist
- Nurse Practitioners
- Others



Clearly, a primary care physician is very important in managing other medical problems than Parkinson's disease. As a Parkinson's disease specialist, I come into conflict with that primary care physician in really one area. Parkinson's disease and Parkinson's disease medications lower blood pressure. If you have Parkinson's disease or if you had blood pressure problems for 30 years and you develop Parkinson's disease, it is very well that the medicines and the Parkinson's condition will cure that problem [high blood pressure]. If you don't recognize that, you will begin having symptoms of low blood pressure. So after you would eat or after you take your medicine, you may notice that you are tired, sleepy and you don't have as much energy or cognitive ability as you did an hour before. When those things happen or when you feel dizzy or you feel lightheaded, please check your blood pressures sitting and standing. Now, I would suspect that your blood pressure is dropping 20 or 30 points when you stand up.

As I tell my fellows it doesn't matter how well a movement disorder manages Parkinson's medicines; if blood pressure drops to 60 over 0, you are not letting your patients walk. So, I would ask all of you to never let your primary care physician's office take your blood pressure just sitting. Always make them take it sitting and standing because while they are trying to keep your sitting blood pressure low, I am trying to keep your standing blood pressure high.

I do think that in terms of a neurologist and movement disorder specialist, there are some differences. If you had a headache or a stroke or peripheral neuropathy or ALS, you certainly would prefer to see a neurologist as opposed to

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me because I spend most of my time taking care of people with Parkinson's disease. So, in certain situations, I am a luxury and in certain situations, movement disorder specialists are somebody that I think I can really make a difference in your care. We're used to dealing with a host of issues regarding Parkinson's disease, motor and non-motor symptoms. An annual evaluation may be something that would help you to keep a direction in moving forward.

Neurology nurses are very important in terms of getting phone calls returned. I also think they are very important in teaching you common sense aspects of your health and to teach you how to properly give apomorphine injections and the like.

Physiatrists are very important in terms of looking at different ways to work with stiffness, different ways to work with mobility. We sometimes work with a physiatrist if a patient comes in and has real immobility problems; we are able to with some medicine changes to make mobility much better or with deep brain stimulation make mobility much better. We would want a physiatrist to start a physical therapy program to get that patient back into playing shape. That's a very useful thing to do in an intense inpatient setting or in an outpatient setting.

I saw—I think Cheryl was talking about my friend Becky—Becky Farley at University of Arizona who is a physical therapist doing research in Parkinson's disease. I think that she is very enlightened in terms of how she approaches a Parkinson's disease patient. People who live in Tucson area are very lucky to have her. That can't happen everywhere, but I think a physical therapist should really pay attention to your mobility and should make great effort into finding ways to maximize that mobility.

I would say that outpatient physical therapy, instead of home physical therapy, is better. Many times Parkinson's disease patients will become a bit shut-in and I like for patients to have something to do during the day to give them a chance to wake up, to interact with other people. It would help their sleep in the evening. I am a strong proponent of exercise and I think exercise with physical therapy is very important. Occupational therapy is really directed at letting you use your hand better—handwriting, mobility in the hands, strengthening the hands. They are also quite good at cognitive tricks. They teach you memory tricks and they teach you a number of things that will help your mobility and your quality of life.

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Speech therapy—you may have heard Becky's friend Cynthia Fox talk about being loud. I think speech therapy can teach a Parkinson's patient to be how to practice to be better heard, which is a very important part of communication.

Ophthalmology is important to improve your vision to make sure you are less likely to fall.

Nurse practitioners are going to do very much the same thing as physicians and neurology nurses and then anybody else you can name.

Let's talk about new therapies for Parkinson's disease management. I have already mentioned the orally disintegrating tablet Zydys selegiline.



Zelapar (ODT): Zydys Selegiline

- A new orally disintegrating tablet (ODT) formulation of selegiline
- Approved by FDA as adjunct to levodopa
- Reduces off time and increases dyskinesia-free "on time" when used with levodopa
- Dissolves in the mouth, no need for swallowing or taking with water



Selegiline is a medicine that has been around [since] the late 1980s—early 1990s. That drug was approved for early Parkinson's disease. Zydys Selegiline differs in its indication. It's a medicine that has been demonstrated to be an adjunct therapy to levodopa. It has been demonstrated to reduce off time and increase on time. Most importantly, it's on time that is dyskinesia free. I think the Zydys selegiline is a drug that will be a very interesting part of our armamentarium. It is a matter of learning the appropriate patient and the appropriate way to use it. It dissolves in the mouth. They have provided physicians with free samples of that tablet and it does disintegrate rapidly in the mouth. Some of you may have tried Parcopa. The Parcopa tablet does not give you that same where-did-it-go type feeling and so I do think that this formulation does what it says [rapidly disintegrating].



Zelapar (ODT): Zydys Selegiline

- When compared with the swallowed selegiline tablet, relatively faster delivery to bloodstream with higher levels of selegiline and lower levels of by-products
- At therapeutic dose (2.5 mg daily), no dietary restrictions with tyramine-containing foods
- Benefit seen as early as one week



By getting rapid absorption you have a more rapid kick in. It bypasses a lot of metabolism in the liver. One of the problems with selegiline [swallowed tablet] being metabolized in the liver is that there are some amphetamine metabolites. You don't have as much problem with that [amphetamine metabolites] with Zelapar. The therapeutic dose is 2.5 mg daily and there are no dietary restrictions with tyramine-containing foods [at that dose]. With this drug, you don't have to worry about eating cheese, drinking red wine and eating foods high in tyramine. The benefit can be seen quite rapidly and in the clinical trial that is most sighted, benefit was seen as early as one week.

The other medicine that I want to talk about is rasagiline or Azilect. This is a new oral medication. It's a MAO-B inhibitor like selegiline. It received approval very recently for treatment of early Parkinson's disease and is an adjunct to levodopa. The approval was based on three [clinical] trials, one with monotherapy and two as adjunctive therapy.

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Azilect (rasagiline)

- A new oral medication (an MAO-B)
- Received FDA approval in early 2006 “for the treatment of signs and symptoms of Parkinson’s disease as initial monotherapy and as adjunct therapy to levodopa.”
- Approval was based on three clinical trials, one employing rasagiline as monotherapy and two as adjunctive therapy.



Rasagiline was also shown to improve on time [with less] off time, which conversely improves on time. It showed an improvement in quality of life by rating scales. The approval letter in the package insert from the FDA says to avoid tyramine-rich foods. It is a warning, and not a contraindication. In the clinical trials that I participated in, we did not see any interaction with tyramine. Nonetheless, I think the FDA is a very responsible and I would always try to listen to them when they provide these warnings.



Azilect (rasagiline)

- Improvement in “off time”
- Improvement in quality of life (as measured by rating scales)
- Warning to avoid tyramine-rich foods, beverages and dietary supplements and amines (refer to syllabus for lists)



Azilect is a drug that you take once a day and it has shown similar benefits with the melt-in-your-mouth type of Zydys selegiline.

Apokyn is an injectable drug. It's a very rapid-acting drug and can be used up to 10 times a day for patients who suddenly develop off symptoms. It is ideal for someone who, without warning, can have a symptom in which they rapidly go from moving reasonably well to not moving at all.



Apokyn (apomorphine)

- Apomorphine: injectable new drug
- Fast acting
- "Rescue therapy" for sudden "off time"
- Can be used up to 10 times per day
- May delay need for surgery



In those patients, an injection with this drug from this Penject system will allow them to be moving sometimes [in] as rapidly as 10 minutes. If you are a patient that has three of these episodes a day, three injections with apomorphine may delay your need for surgery, which I think is always worth doing. This is a drug that I think will be used in a different place when compared to the other two agents I talked about. Zelapar and Azilect [are] drugs that will be used fairly early in Parkinson's disease while Apokyn will be used in the more advancing population.

Let's talk about additional approaches. My friend Dr. Bill Koller had a very funny joke—at least I thought it was funny. When people asked him about exercise he said, "I feel so strongly about exercise, I am going to do it myself someday."

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Additional Approaches

- Exercise: very important for general health
 - Cardiovascular, muscle tone, balance, mental health
 - Low-impact: walking, swimming, gardening, etc.
- Voice training: think loud
 - Proven techniques for improving vocal volume (Lee Silverman and others)



I think that that is the hurdle. So, whatever you do, you need to exercise and you need to do something that you can stand to do. So, I would urge all of you to make a resolution that you are going to try to get exercise at least three times a week for 20 minutes a day. Exercise will improve your posture, will improve your health, [and] will improve your sleep because you will be more tired. All of [these] things will make your Parkinson's symptoms much better.

I already talked about the think-loud technique—that's the Lee Silverman Voice Technique. You can search that on the web on "LSVT." I am sure that the WE MOVE [Movement Disorder] Virtual University [www.mdvu.org] has some information about that and certainly the Parkinson's disease web sites do. You can go to www.Parkinson.org and find those. However, in Parkinson's disease there is a feedback in which a patient perceives himself to be speaking much louder than he really is. This training program allows you to kind of reset that feedback.

So, I would urge all of you to begin to get back into a physical therapy program. [During] the next visit you have with your physician, it would be useful for you to have a physical therapy and occupational consultation just to see if from physical therapy there are exercises or transfer techniques that would improve your safety and mobility. [An] occupational therapist can often come into your home and do a home assessment that would decrease your likelihood of falling and allow you to know whether you could [use] other assistive devices, like things in the shower and things for the toilet.

Proper nutrition is important. I am not a big fan of a number of a number of vitamins and mega vitamins. I think a daily multiple vitamin is quite reasonable.

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The comment about protein budgeting—sometimes, if you have a high protein meal, that protein will breakdown into amino acids. Amino acids are pieces of protein and levodopa, [which is] the active ingredient in Sinemet and also an amino acid. If you have a lot of protein and a lot of amino acids that you consume with your levodopa, that will prevent you from absorbing all of the levodopa in the pill. For some people who notice that they do not move as well after a big protein meal, [they] will try to spread their protein out through the day. If you don't need or if you don't notice that the protein is a problem then I wouldn't worry about it.

So, when is the right time to talk to my doctor?



When is the right time to talk to my doctor about new therapies for PD Management?

- Whenever you have a question
- When you want to know your doctor's opinion if a new medication could help you!
- At the time of diagnosis
- During regular office visits and follow up
- When medications start to lose their effectiveness



I think whenever you have a question. What I would like for you to do, since I am talking too much time and I want you to have sometime for questions, is to come in with a list of their questions, a list of [your] concerns and I go through the list and so I may say pass to a few. I can't do anything about your mother-in-law, but I can do something about your symptoms of low blood pressure. I can do something about your sleepiness. I can do something about your depression. I can do something about your waking up six times a night to relieve your bladder. I can do a lot of those things and so you just need to take a list of everything that bothers you and try to make a very organized list for your physician when you visit.

I do very much appreciate when patients are prepared for their office visit. I like their written questions.

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*When is the right time to talk to my doctor
about new therapies for PD Management?*

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I like for you to take your notes and really your caregiver record the notes during the visit. When I used to take my child to the pediatrician, even though I was good friends with that pediatrician in my working life, I always had trouble remembering what he told me. I do believe there is a doctor-patient communication difficulty, even when that doctor is your friend. It's important for you to take as much information out of that visit as possible. I will also tell you that it is your responsibility to make sure the doctor understands that you want a successful office visit. If I am coming and running late and trying to run in and out of your office, you need to just slow me down and say, "I have got a number of things to talk about. I know you are behind and then you move on. I will let you take as little time as possible."

So, in your Parkinson's disease, you have to understand how your Parkinson's affects or bothers you.

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*Talking to Your Doctor
about New Therapies*

- Most doctors appreciate it when people are prepared for their office visit
- Bring written questions
- Take notes or record the visit
- Bring a friend to take notes and listen



When I come into ask you how you are doing, I don't really think you should say fine. How are you? I think you should in fact even consider if I don't ever notice or your doctor does not ever notice that you have real Parkinson's symptoms, do not take your medicine. Believe me, I am much more motivated to help somebody who I see has trouble getting out of a chair than somebody who walks in normally and has no apparent problems. Given that you know how to manage your medicines, you know how to look your best for your doctors so you can get some information from me and communicate with me. It's not always the most adaptive way to get the most out of your office visit.

I urge all of you to maintain your ability to be informed [about] Parkinson's disease. Please go to responsible web sites. I vote [for] WE MOVE as a responsible web site at all times. The other Parkinson's disease organizations have very good information. You need to take your medicine as we prescribe it. You need to take it during the [right] time of the day and you need to pay attention at when that medicine does not work. If you can tell me, "Okay. I will take my medicine at the same time just about everyday and the medicine does not work at 2 o'clock in the afternoon", I can concentrate on 2 o'clock in the afternoon and make responsible changes to improve that.

You want to keep all of your physicians' recommendations into a daily routine.

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It's about Accountability

- Understand how PD affects **you**. You know your body. Listen to what it is telling you.
- Be frank and open with your healthcare professionals. Ask them to repeat back to you what they heard you say.
- Stay Connected...Stay Informed
- Take medication as prescribed
 - Correct dosage
 - Correct frequency
 - Correct time of day
 - Other instructions (e.g., take with food or other medications, etc.)



Besides exercise and diet, I urge all of my patients to drink an 8-12 ounce glass of water—water at breakfast and lunch, no ice, just water. [Drink] it down like a medicine and when you finish that glass of water you can get up from the table. Seek out support and be proactive in the management of your disorder.



It's about Accountability

- Incorporate your physician's non-drug recommendations into your daily routine (e.g., exercise, diet, etc.)
- Report unusual feelings and sensations to your physician. A symptom and medication journal can be helpful here.
- Bring a family member or caregivers to your physician visits – two sets of ears are better than one
- Seek out support
- Be proactive in the management of your disorder



Now, another note to your caregivers; caregiving is stressful. You can't lose track of your own person taking care of somebody. You have to know your limits and I will tell you that, in advancing Parkinson's disease, if the caregiver breaks, the whole system breaks. There is a cynical saying that I like and it is "if

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LIFE IN
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mamma don't sleep, daddy goes to the nursing home." So you have to make sure that you don't fall apart because you are needed. If you don't take care of yourself, you can't be taking care of others. I would say that a support group for caregivers is something very important for helpful suggestions. For example, "Oh...I have had that issue and this is what it is. These are the strategies we use to work on that."



Am I doing enough now or can I do more?

- Compliance with medications: taking them on time at the dose prescribed
- Persistence: continuing to take medications that the doctor prescribes
- Call the doctor when there is a problem
 - Ask questions...get answers
- Don't *be* your disease
 - The goal of treatment is to maintain your quality of life, not to absorb you in the details of your treatment



I don't know if anybody can ever say where you are doing enough to take care of your Parkinson's. I think there are always little things you can do better. Just like in my life, if I exercise a little bit more I would feel better. If I drank a little more water during the day, I would feel better. I think that one of the cruelties of Parkinson's disease, as Michael J. Fox says, "It's the gift that keeps giving." As you develop new symptoms it is very important for me as a doctor to know about them and it's very important for me to make sure you understand that I don't consider [that] your symptoms [are] you and you should not either.

I got through the first part. Hopefully everybody can be a little more interested now [because] we are going to talk about questions that we felt were pertinent to this [event]. [These questions] were sent to us by the audience prior to this lecture. So why don't we go ahead?



***Part Two of Webinar Event:
Answers to Questions
Submitted by Participants
During Registration***



JUDY BLAZER:

Thank you Dr. Stacy. The questions that we are going to answer during this part of the webinar were submitted to WE MOVE by the people who came to the web site. Some of the questions relate to new therapies, but I think Dr. Stacy covered the topic very well; other questions do not [relate to new therapies]. As we mentioned, there were an overwhelming number of questions, over 100; so obviously we are not going to get to all of them tonight. If you have questions after the webinar, we again refer you to your syllabus, which was sent to you via e-mail, for additional information. We also invite you to visit the WE MOVE Discussion Forums and watch for the transcript of this webinar and the Q&A to appear on the web site.

Dr. Stacy, one of the questions we received was what medicine is preferable to levodopa?

DR. MARK STACY:

It depends on the patient. Levodopa is the most effective medicine we have for Parkinson's disease motor symptoms. With that said, it's also is a medicine that is associated with wearing off and a medicine that is associated with dyskinesias. So, I see a patient who is young, which I define differently every year, but let's say a patient who is 60-years-old. This patient will likely have Parkinson's disease for 20 to 30 years. So levodopa was associated with motor fluctuations, I would probably start that patient on a dopamine agonist. Now if I see a patient with diagnosis of Parkinson's disease in their 70s, I am not as concerned about the wearing off from levodopa because the time frame is not as long and

Managing Your
LIFE IN
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levodopa is a drug that is, I think simpler to use in many respects than dopamine agonists.

JUDY BLAZER: Thanks Dr. Stacy. Our next question is, other than stress and protein, what other elements can make levodopa temporarily ineffective?

DR. MARK STACY: I think the most hidden problem with Parkinson's disease that people don't notice is low blood pressure. So, I harp on it all the time. I would urge you all to. If you notice that, if you play golf and you are tanking on from hole 14 to 18, your blood pressure is probably low and you need to drink more fluids. I would check your blood pressure at home with a wrist blood pressure cuff or a finger blood pressure cuff. If that's not the case, then I would look at other things.

Some people who eat large meals will have a delayed GI transit time. The food does not move to their gut as rapidly as it should and it will sometimes "smother" levodopa tablets. You don't absorb the medications and so taking smaller meals more often will improve that GI transit time. It will improve the benefit from your medicine. The other things listed there I think are all quite good.

JUDY BLAZER: Thank you Dr. STACY. The third question, are there any other drugs available to manage wearing off?

DR. MARK STACY: Yes and so I think that when you notice these symptoms of wearing off that is from levodopa, you need to know there are other options and so, many doctors have different ways of approaching this, but I think that it's a symptom that is manageable. You shouldn't give up on it and there are a host of medicines to try. I will list them and I will tell you that I use them in different circumstances> If you are on a dopamine agonist and levodopa and have wearing off, then I want to improve those symptoms of wearing off. I can do that with the medicines we have talked about, which are the selegiline, including Zydys selegiline or rasagiline.

I can do that with COMT inhibitors. There are two COMT inhibitors that we have. The first one approved was tolcapone, the second was entacapone. Tolcapone or Tasmar, several years ago, was found to be associated with metabolic problems and liver failure. We needed to figure out whether that risk was really a significant risk to our patients. The more we looked at the drug, the more that we have felt that it was not a significant risk to patients. Many of you may already be on Comtan. If you are not doing well on Comtan or Stalevo,

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which is Sinemet plus Comtan, I think it is quite reasonable for you to consider restarting Tasmar. It lasts a little bit longer and many Parkinsonologists [physicians who specialize in the treatment of Parkinson's disease] would say that Tasmar, tolcapone, was more effective than entacapone when we were using it before.

JUDY BLAZER: Dr. Stacy, where can people go when they have a movement disorder to find the coordinated care that you mentioned earlier in the webinar?

DR. MARK STACY: As a member of the Education Committee at WE MOVE, I would say that the way to best approach that is just to go to the WE MOVE web site and look for a physician in your area. I think it's very useful to look at the medical schools in your area and most medical schools will have a movement disorder specialist. More and more movement disorder specialists are being trained and going into private practice. I think getting involved in a support group locally, if for no other reason, they can tell you what physicians are the physicians to go see. While a movement disorder specialist is great, [as a physician] you have to have a heart for Parkinson's disease and there are some neurologists who have that heart and others who do not. You need to find the people who do.

JUDY BLAZER: Thank you. Here is another question that we received. Does dopamine get depleted by physical activity and what does this mean for dosing? I know you are a big fan of exercise and some people are concerned that exercise might actually deplete dopamine. Is that true?

DR. MARK STACY: There is no evidence that increasing muscle activity would decrease, or would make a change, in your brain's dopamine activity. What I think really happens...and you may have heard me say this before...as your exercise decreases, your blood pressure changes and you are not putting blood in your head, you are not thinking well. You are not moving well, and you are tired.

JUDY BLAZER: Okay, so we should all continue to exercise and I know that we have heard a lot about that lately. Another question. How do you know if you are taking enough medication to treat your Parkinson's, or if you are actually under medicating or not taking enough medication?

DR. MARK STACY: There is a [clinical] trial that was recently completed called the ELLDOPA trial. It was a 40-week trial in which we put patients on 150 mg daily of levodopa, 300 mg a day, 600 mg a day of placebo. We found that people who were put on a 150 mg a day of levodopa, by the time 40 weeks came around, their symptoms

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LIFE IN
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Patient Webinar Series presented by WE MOVE

improved when they started the medicine but [they] had returned to the baseline.

I believe that Parkinson's therapy needs to be adjusted about every six months and perhaps increased every six months. If you have gone a year without having a Parkinson evaluation and your medicine change, I think that your symptoms have progressed so gradually you have not noticed. You may have return of your motor problems and need to be retreated.

JUDY BLAZER: It's important for everyone and their caregivers to notice their symptoms at home during the day and also to talk to their physician about increasing off-time, or the time when their medication seems to not be working. Next question. How does a patient with limited ability to walk get enough exercise, and at what point is it more trouble than it's worth?

DR. MARK STACY: Exercise is never more trouble than it's worth. One of the things that I worry about in patients who are no longer able to walk is that they will begin to have kind of a decrease in their chest wall volume. They can't take as deeper breaths and that really affects their ability to talk. Even sitting in a chair, you are able to exercise and one of the most important exercises that has been featured on the NPF website is to take kind of a plastic strap and put that behind your back and grab it in both hands and push your hands forward. That improves your posture and improves your strength and breathing. I think it is a very important thing to do to maintain your pulmonary health and that's even at the most advanced Parkinson's disease.

I think a stationary bicycle is a great way to exercise if you have a spot you would like to do it. Swimming, I think is probably the best of all exercises. I certainly can get more tired more rapidly while swimming than anything else. If you are lucky enough to have a heated pool where you can exercise, that gives you some place to go and they get you out and enjoying some company with other people. I think that before you start an exercise program or significant change, it's always useful to see a physical therapist or occupational therapist. Some states will allow me to write a prescription and that can be given to your insurance or even written off your state income tax.

JUDY BLAZER: Excellent. Next question. Are Parkinson's symptoms the same for everyone? How do they relate to age, race, diet and even genetics?

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DR. MARK STACY: I think one of the reasons I like taking care of people with Parkinson's disease is everybody is different. Every person represents a new challenge. Certainly, we don't understand differences in medication response between races, but we recognize that people of different races have different responses to medicines. Age of onset is very important in terms of the progression and type of progression of Parkinson's disease. People with young onset Parkinson's disease are more likely to develop dyskinesias than people with who develop Parkinson's disease in later life. We are learning [more and more] about genetics. The more we learn about genetics the less we really *know*. The more we understand...we don't understand them. But we will find that there are genes that are associated directly with the development of Parkinson's; then we will find candidate genes that, in combination with other genes, are more likely to cause Parkinson's but we are far from understanding that.

JUDY BLAZER: Thank you. The field of genetics is really complicated and one of the things that WE MOVE tries to do is to retell the results of genetic clinical trials or research in language that everyone can understand. We do that via our WE MOVE Newsletter service. If anyone on the call has not yet subscribed, you can do that via our web site and it is free. [www.wemove.org]

Another question is...frequent exercise seems to increase my rigidity and it leads to pain and injury. Should I increase the medication?

DR. MARK STACY: Probably, but I think that if you notice an increase in rigidity, you take your medicine at noon, go to work out at 2 o'clock, and at 3 o'clock you notice an increase in your rigidity, it may be just that your medicine is wearing off. If you are having increasing pain and that pain does not seem to be related to your medicine or you are injuring yourself, I think you should have an evaluation by your neurologist who considers issues other than Parkinson's disease.

JUDY BLAZER: You mentioned it's important to possibly consult a physical therapist when you are embarking on an exercise routine and your neurologist so you are not hurting yourself.

Here is the next question now. Is there a difference between Parkinson's disease and parkinsonism or the disorders like progressive supranuclear palsy? How are these different from Parkinson's?

DR. MARK STACY: I think the bluntest and most basic answer is that people with Parkinson's disease respond fairly well to antiparkinson medications. People with

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parkinsonism or Parkinson's plus syndromes do not respond as well to those medicines. If you are a patient in a support group and you hear people talking about getting dyskinesias from medicines or their tremor going away from medicines or you don't have those dyskinesias and really don't have a lot of tremor and more problems with falling than other patients, it is quite likely that you don't have Parkinson's disease.

These are difficult questions for me to broach in my office in a very intimate personal setting, and even more difficult to broach with a large audience because there are a lot of things that go into these discussions. I think that if you are starting to have problems with falling quite early in your Parkinson's symptoms, or if you have problems with memory or problems with mood, it's important to talk with your doctors to say, "Okay, I know there is a difference between Parkinson's disease and parkinsonism. Do I have Parkinson's disease and what are you going to do to help me? Do I not have Parkinson's disease and what are you going to do to help me." The options are a bit different, but I think it's quite important for you and your family to know what your doctor is thinking.

JUDY BLAZER: Thank you, next question please. You already mentioned that taking a multiple vitamin is a good idea. What's your opinion of vitamin therapy for Parkinson's disease?

DR. MARK STACY: When I lived in Phoenix I called all of these supplements cactus hair. I am not a big believer in all of these things. I think they are very expensive. Vitamin E was not shown to help in Parkinson's disease in a controlled clinical trial called DATATOP.

More recently Coenzyme Q10 was tested in doses of 1200 mg daily, 900 mg, 600 mg and 300 mg of placebo. The 1200 mg daily dose showed a slight benefit compared to placebo. Now, the way they did those statistics, they were able to say that was a 44% difference; but over the course of 16 weeks, progression in Parkinson's disease is very small. So you can have a 44% difference in very small group, which is not very much and 1200 mg daily of co-enzyme Q10 is a lot of money, so I think if you are going to spend \$2 a day, if you only have \$4 a day for your Parkinson's medicines, don't spend \$2 dollars a day on co-enzyme Q10.

JUDY BLAZER: And I think you would agree that basic fitness is important to general health and not just to Parkinson's disease.

DR. MARK STACY: That's right.



*Part Three of Webinar Event:
Answers to Questions
Submitted by Participants
During Webinar*

JUDY BLAZER: This is the last part of tonight's webinar [part three] and we still have five minutes left. If you have a question, we ask you to please type it in to the chat box and direct it to the host. We also may have additional questions from the pre-registration that we are waiting to answer, so Dr. Stacy will be with us for another few minutes.

MARK STACY: We started late; I will stay a little longer.

JUDY BLAZER: Okay.

JOY LEFFLER: I would also just suggest that rather than direct questions right at Dr. Stacy, if you could direct them to all the participants so that we can all see those questions as well. I think the first question we have Dr. Stacy is this. Can you just tell us please, what is off-time and what is on-time?

MARK STACY: I am sorry that I did not explain that fully. We call on time when you are moving well; so that is when your medicine is working. Off-time is when your Parkinson's symptoms are back. If you have tremor-type Parkinson's symptoms, your off-time would be as your tremor predictably reemerges after medicines or early in the morning when you first wake up. You may be less mobile than you

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are an hour after you have been awake and your medicines have not started to work. The less mobile time is an off time and when your medicines start to work, it is an on-time. Some people don't experience that and early in Parkinson disease, you may not. If you have had Parkinson's disease for over five years and you don't really experience that on and off time, I think you should talk to your physician about whether you have parkinsonism or Parkinson's disease as I was talking earlier.

JOY LEFFLER: Thank you Dr. Stacy. Any other speakers have questions they'd like to present to Dr. Stacy at this time?

JUDY BLAZER: We have an interesting question. You talked about taking levodopa more frequently in pill form. Someone has asked what about using liquid Sinemet.

MARK STACY: [Next question from Webinar audience] Rosemary, I see your question. I did not mention liquid Sinemet, but that was a game that we tried earlier and it works very well on some people. Dr. Matt Kurth was a person that kind of perfected the recipe. What he would suggest is you take 10 Sinemet 25/100 tablets and put them in 10 ounces of water with two tablespoons of Tang or Vitamin C. Tang is easier and you can make a liquid solution of that. Then one ounce of water would be equivalent to one tablet of Sinemet. Some people who take one tablet of Sinemet notice a lot of dyskinesia, but if you take half an ounce or a third of an ounce or you know 10th of an ounce, you can regulate your Parkinson's mobility by sipping that on an hourly basis. It is very busy, but it is a way to work.

[Next question from Webinar audience] Let me go through Sue's question about blood pressure that is actually considered low. If I have your blood pressure sitting at 150/90, I am content with that. If your blood pressure standing drops that top number...drops below 100, I am very concerned that you are not getting enough fluid and your mobility will suffer and then your vision. There is a vision problem question. Parkinson's disease is usually associated with maybe double vision, so people can see the TV, but they have trouble reading and that is from eye movement problems. Your ophthalmologist can give you a prism in your glasses to kind of help that in some occasions.

Other vision problems can occur in Parkinson's disease that are quite rare, have to do with glaucoma. Sinemet has been rarely associated with glaucoma and so you might have to have your intraocular pressure measured by your ophthalmologist

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[Next question from Webinar audience] Now Dr. Richard Fuller asked about Prozac causing Parkinson's disease like symptoms. Sometimes severe depression can produce symptoms of parkinsonism. I would say that Prozac does not cause the parkinsonism. It could be that the depression associated with why you would take Prozac would do that.

[Next question from Webinar audience] Burning feet and hands, you guys are fast...so burning feet and hands can be associated with wearing off symptoms of Parkinson's, so if you notice those symptoms two to four hours after you take your Sinemet and it goes away right after you take your Sinemet, I think that that is a problem of wearing off and you would use the strategies that I discussed earlier to try to limit that. Other times you can have burning hands and feet. I suppose that if...if you were hyperventilating, you can get a tingling in your hands and feet and if you have a peripheral neuropathy, you could have that and so nerve conduction velocity and EMG will help.

[Next question from Webinar audience] [Are there] new treatments for PD and cervical dystonia. I think I will let that one go. There is going to be...I am sure...some webinars about cervical dystonia in the future.

[Next question from Webinar audience] [Is there] any connection between RLS and PD? Yes there is. Restless legs syndrome seems to be a condition, a sensory syndrome associated with low dopamine states. Parkinson's disease is a motor condition associated low dopamine. Some people who have had Parkinson's disease and been on Sinemet for a while will notice that as their medicine begins to decline, and they would get a tingling, a "heebie-jeebie" feeling in their legs, usually on their more parkinsonian side. Redosing of medication should relieve those symptoms. I think I caught up [with the questions].

JOY LEFFLER:

Dr. Stacy, a question. A participant said that his wife had a massive stroke and recently diagnosed with Parkinson's disease. Now the stroke has affected her left side and she has "left side neglect." Will the fact that she has had a stroke accelerate her Parkinson's disease?

MARK STACY:

It should not, but the neglect is going to be a bit of problem because she may not always recognize her symptoms of Parkinson's. I think as her caregiver, it is even more important for you to give her feedback to that side. If she is able to move her right side, it is important for her to know where that right side is and

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cueing for that. An occupational or physical therapy would be helpful in teaching you how to better prompt her and how to move. I think that it is. The only way a stroke could really worsen Parkinson's symptoms, if it was in the basal ganglia where Parkinson's disease "lives" or if your wife was having problems with digestion and she was put on Reglan or a medicine for nausea like Compazine or if she was agitated and put on medicines to control agitations, major tranquilizers. I would look at her medicines and make sure that nothing has snuck in to worsen her Parkinson's symptoms.

JOY LEFFLER: Thank you. Are there any other questions at this point from our online audience? Okay Judy.

MARK STACY: I think she is on mute.

JUDY BLAZER: I am back.

JOY LEFFLER: Okay.

JUDY BLAZER: Thank you everyone. I don't see any additional questions, again please visit our Discussion Forum on the WE MOVE web site. We will be watching for your questions and also again, please subscribe to WE MOVE News that you can stay up with the latest in Parkinson's disease research. Please watch the web site for additional webinars. We thank all of you for joining us tonight. We especially thank Dr. Stacy and we look forward to talking with all of you in the future. Thank you.

JOY LEFFLER: Thank you all very much.

MARK STACY: Thanks. Good night.

JOY LEFFLER: Good evening.

END