The Latest Advances in Parkinson's Disease
Webcast
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Monique Giroux, M.D.

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Alice's Story

Andrew Schorr:
Hello, this is Andrew Schorr. Thank you for joining us for Patient Power as we talk about an area that is emerging, changing, and hopefully giving more hope for many people who are affected by movement disorders, and that includes Parkinson's disease, but we're going to talk about more than that, and I'm delighted that we're going to focus today with experts from the Booth Gardner Parkinson's Care Center at Evergreen Hospital Medical Center in Kirkland, Washington, where they have a whole team of people that specialize in this, but first let's talk about Parkinson's as it affects an individual, and I want you to meet Alice Cleeton. Alice lives near Seattle and not too far from where Evergreen Hospital Medical Center is, but back in Pittsburgh nine years ago on your birthday, Alice, what happened?

Alice:
Yes, I was diagnosed with Parkinson's on my 40th birthday.

Andrew Schorr:
That's kind of a sucko birthday present.

Alice:
It was, but the alternative was to wait six weeks for another appointment, so I took it then.

Andrew Schorr:
What were you, now you were just 40 years old, what were you experiencing? You go to a neurologist, and the neurologist probably wasn't expecting someone of your age to walk in with Parkinson's. What were the symptoms that you had?

Alice:
I had tremor in my right little finger that was being a really big bother to me because I was on the computer with my job constantly, and it kept twitching and hitting the different keys when I wasn't asking it to move at all, so I knew something was wrong, and I had other little tidbits of things like lightheadedness. I felt like I was falling every once in awhile, and went to the doctor, the family doctor. He referred me to the neurologist in the town that I lived, which was outside of Pittsburgh. It was a very
small town. There was only one neurologist, and then he referred me down to Allegheny General to Susan Baser.

Andrew Schorr:
And that was a specialist in movement disorders who you saw there.

Alice:
Correct.

Andrew Schorr:
And she says, 'you may be 40, but this is Parkinson's in a younger patient.'

Alice:
Exactly. That's exactly what she said.

Andrew Schorr:
But then your husband gets a new job and you move clear across the country to near Seattle in Kirkland, Washington, and I guess you're really fortunate that there was a Parkinson's center at Evergreen right there.

Alice:
I was very fortunate, and the care and everything they give to their patients here is unbelievable. I definitely don't want to leave.

Andrew Schorr:
Well, and let's just find out a little bit about the treatment you've had. Now, it's not just about medicine or surgical approaches, and we're going to discuss that as we go along and meet the director of the center in just a minute, but you have had a variety of medicines, and those increased over time, and ultimately you had one of the newer approaches, deep brain stimulation, right?

Alice:
Correct. December 17th of last year I had a DBS unit put in, and I'm doing very well. I'm really happy to report that I've decreased some of my meds, and that's going to continue, and it has been programmed by Sierra, and it's up to its optimum level right now.

Andrew Schorr:
And we'll mention about Sierra is a member of the team at the Parkinson's Center at Evergreen, and about how this equipment is adjusted makes a big difference.

Diagnosing Parkinson's Disease

Andrew Schorr:
Well, let's put this in medical perspective. Let's meet Dr. Monique Giroux. She's the Director of the Booth Gardner Parkinson's Care Center at Evergreen Hospital Medical
Center, and of course a neurologist who specializes in movement disorders. Dr. Giroux, thanks for being with us.

**Dr. Giroux:**
You're welcome. I'm glad to be here.

**Andrew Schorr:**
So first of all, it sounds like Alice was able to get a diagnosis from an experienced physician pretty quickly, but these symptoms can often be something else too, so I would that getting an accurate diagnosis from someone who specializes in movement disorders is really important.

**Dr. Giroux:**
Getting an accurate diagnosis really is important, and some of the symptoms, at least in the beginning, can be rather vague because people with Parkinson's may have like Alice some tremor and movement of their hand or their fingers, but also generalized muscle rigidity, slowness of movement, and maybe some change in walking, and you can see that these can be some common symptoms or problems with people in general, and oftentimes it takes a specialist to put this together to piece it together to come up with a diagnosis, and the diagnosis, as you can imagine, is especially difficult sometimes in someone like Alice who is younger because we're not necessarily expecting to look for or find Parkinson's in a younger person. Parkinson's is something we typically think of the average age for somebody is perhaps in their late 50's, so it does take I think some experience to diagnose Parkinson's, especially at a younger age.

**Andrew Schorr:**
Let's back up for a second. When someone has Parkinson's, what's going on in their brain that is causing this increasing disability?

**Dr. Giroux:**
Parkinson's is what we call a neurodegenerative disorder, and that means there are certain nerve cells or areas in the brain in which these nerve cells degenerate or die off over time, and it just so happens that the area of the brain called the basal ganglia controls movement. That's why a lot of the symptoms that we talk about and that Alice was experiencing is related to movement and movement motor control, and these nerve cells just happen to produce a chemical or a neurotransmitter called dopamine, so that allows us a way that we can then go ahead and treat the symptoms to give back or replace some of that chemical in the medicines that we use.

**Andrew Schorr:**
Okay, now that will deal with the symptoms, but you don't have a cure at this time.

**Dr. Giroux:**
Unfortunately we don't have a cure at this time. Parkinson's does change. It does get worse, although for most people it changes slowly, so the treatment now is really
based on treating the symptoms, treating the movement problems or maybe some other issues that could go along with Parkinson's disease, but the good news is that research is exploding in Parkinson's disease, and a big focus of research is what can we do, can we find ways to put the brakes on the Parkinson's so can we actually change how it changes over time and slow it down.

**Treatment Modalities**

**Andrew Schorr:**
That would be great. Now, we'll mention some different modalities, and Alice has kind of experienced them. Alice, you had first one medicine, I think Sinemet is one of the ones that's used, and then you had other medicines layered on top of that, and I imagine these medicines and dosages needed to be monitored over time because things change. The disease changes and you change, right? How many medicines were you taking let's say prior to that deep brain stimulation, how many medicines were you taking?

**Alice:**
I was taking I believe it was four.

**Andrew Schorr:**
Four medicines every day.

**Alice:**
It was every four hours.

**Andrew Schorr:**
Wow, okay.

**Alice:**
And it wasn't, they were starting to wear off. They weren't working all the time.

**Andrew Schorr:**
But they had been working for awhile but the disease was progressing.

**Alice:**
Yes initially, yes.

**Andrew Schorr:**
So Dr. Giroux, help us understand. I mentioned this newer approach, deep brain stimulation. Where does that come in and what experience do we have with that now because I know Alice, you're doing really well now, right?

**Alice:**
Right. Very well.
**Dr. Giroux:**
Well, deep brain stimulation, or sometimes we use the term "brain pacemaker" is a surgical technique. So the neurosurgeon actually has to go in and implant tiny little electrodes into the deep areas of the brain that are affected by Parkinson's, and what we know is by electrically stimulating these areas we can basically approximate or try to normalize the neurologic activity, the electrical activity in the brain, so normalize some of those brain circuits or brain circuitry, and the person who does well with deep brain stimulation is someone who has Parkinson's disease and their movement symptoms were well controlled with medicine, but unfortunately over time as the Parkinson's worsens, just as Alice said, their medicines start to wear off. So maybe they were taking medicines every five hours and then they have to change to every four hours or maybe they notice that the medicine only lasts two hours, so they fluctuate where their symptoms are better and then they're symptoms are worse, a phenomena that we call on/off fluctuations, and what the surgery does, or the DBS does, is helps smooth that out so there's more better time. There's an increase in the amount of time that the medicine is working and then also the surgery can attack and improve certain symptoms as well.

It's very good for treating tremor and then another condition which is actually to some degree a side effect of the medicine that we just to treat the various symptoms of Parkinson's, and that other condition, we call it dyskinesia; it's too much movement, and that's a situation where we use medicine to try to help movement and enhance movement for someone but then as we increase the dose or add more medicines, the pendulum swings, and we can actually cause too much uncontrolled involuntary movement. So the surgery can help the tremor, those uncontrolled movements caused by our very medicines and really smooth out the effect that one feels from the medicine throughout the day.

**Andrew Schorr:**
So Alice, let me ask you now. So you've had the deep brain stimulation, you had the medications earlier, and you have two boys in their 20's, and I know there are things you love to do. You've told me on the phone you like quilting and watercolor painting, and you're active in your church. How active can you be now, and what's your outlook on life even with Parkinson's?

**Alice:**
Even with Parkinson's? I somehow thing I'm very blessed that I have it as opposed to anybody else in my family, and in that aspect I'm okay with it. I'm hoping to be dancing at my sons' weddings someday.

**Andrew Schorr:**
There you go.

**Alice:**
I don't feel that I cannot do something. If somebody calls and says, 'Let's go do this.' I got do it.
Andrew Schorr:
Good for you.

Alice:
If somebody else calls and says, 'Let's go do that.' I'll go do it. If somebody else says, 'Let's go up to the clinic and talk on the phone to somebody,' I'll go do that.

A Team Approach to Care

Andrew Schorr:
Good for you. Well, Dr. Giroux, what's your outlook on this. Now I know you have a whole team at Evergreen. It's not just the neurologists and the movement disorder MD specialists, you have a whole team. Where does that come into play in helping support people like Alice and their families and maybe outline who are some of the members of that team? What roles do they fill?

Dr. Giroux:
Well, you know, the Booth Gardner was started for people just like Alice. Alice exemplifies what our vision is and why we're here, and that is we don't treat Parkinson's disease, we treat people that just happen to have illness such as Parkinson's disease, and I think that's an important differentiation because if you think about it along those lines, not only is the physician important, but in some ways the physician is probably not the most important person on the team, and other support members of the team become even more important over time as we partner with the patient to help them do well and then live their best with Parkinson's, and I think that really is the focus of what our treatment is. We're not just treating symptoms. We are trying to give people the tools and be the guides to help people live well, enhance their quality of life, and like Alice says, 'The things I can do, I'm gonna do, and I'm going to focus on what's important to me and maintain a sense of wellness and health, or wellbeing for myself with Parkinson's despite Parkinson's so Parkinson's doesn't define me.

So having said that, there are many different people on our team, and other patients may have different members on their team, but of course a physical therapist is an important member of the team because they deal with a lot of the movement function, the flexibility, the coordination, the walking and the balance, for instance. An occupational therapist is also an important member of the team, and occupational therapists deal with more than work and occupation, they really deal with everyday activities. What are the ways that we can help you do better, do your task better, your hobbies better, your work better, and just everyday activities such as eating, hygiene, and taking care of yourself. Parkinson’s diseases can be associated with speech and for some people even swallowing problems, so we have a speech and swallowing specialist on our team.
In addition to the physicians who are trained in movement disorders of which Parkinson's is a movement disorder, there are multiple other team members. We have a physician assistant who works with Parkinson's diseases but more importantly, especially in Alice's case, she's a specialist in deep brain stimulation management and programming, so the long-term management of treatments like deep brain stimulation. We have a nurse and a social worker, again very important to support the emotional and the social aspect of an individual and to round out the team we have neuropsychologists, and these are psychologists who are especially trained in neurologic conditions, and they care for and assess not only some of the behavioral problems that can occur, for instance, like depression and anxiety but also thinking problems, cognitive functions.

**Andrew Schorr:**
Okay and we mentioned, of course we're focused on Parkinson's as part of this discussion, that's part of the name of your center, but there are other movement disorders that this team is devoted to as well, right?

**Dr. Giroux:**
Yes there are. The most common movement disorder is actually tremor or central tremor is a very common disorder that we take care of, but that's not the only movement disorder. Conditions called dystonia, ataxia, or balance problems, Huntington's diseases, Tourette's disorder, myoclonus and many other involuntary movements, spasticity, which is a condition of muscle spasm or muscle contraction after injury such as stroke or head trauma or spinal cord trauma, so there are many movement disorders or movement related problems that we take care of.

**Andrew Schorr:**
Alice, tell me about this whole team approach, this sort of holistic approach. How has that helped you?

**Alice:**
The whole team approach is really, it was really important when I got here to the clinic I kind of went through and they did, I went and saw everyone and got a baseline for everything so that when things came up later on, I thought well okay we can look back here and see where I was then. Am I worse now or am I at the same level, and what can we do with it? It really been very helpful. They psychologists, I had them speak to my family just to touch base to see how they were feeling about things.

**Andrew Schorr:**
I was going to ask about that. I would think that when there's a center like this with a whole team and mom or from the point of view of a husband, your spouse is going, that you feel that you can kind of take a little sigh of relief in that, first of all as you said, they can help support you, the family member, but they also know that you're well-cared for as the patient. I think that's really important, and Dr. Giroux, it's a family diagnosis really, isn't it?
Dr. Giroux:
It is. The family has Parkinson's because the family is living with the Parkinson's' on a
day-to-day basis, and that can be a good and a bad thing, and Alice could perhaps
speak to this. The family does have to adjust to some of the changes that someone
experiences with Parkinson's. On the flip side, I have also seen families that have
grown closer together because of it.

Andrew Schorr:
Alice, tell us a little bit about how your family has adapted. It's been nine years now.

Alice:
It has been nine years, and they have shown their support and they, oh how do I
want to say this; the two boys are out of the house now. David's on his own, and he
has his own place, and Mike's in his last year of college, and that leaves Larry at home
with me, and over the years as it did seem to progress and the Parkinson's had gotten
worse, it was more real subtle little, oh, 'Are you okay making dinner tonight? Don't
worry about it, I'll do it, or I'll bring dinner home tonight, or do you need a ride to
your appointment or can you get yourself there?' Because I would never know from
day to day when I got up in the morning if I was going to be able to get myself
dressed and drive to the clinic for my appointment. So, they were just very caring,
and we're very close, and I think this has brought us closer together overall.

Andrew Schorr:
I'm a leukemia survivor, and I've found that too. Also, I see things differently too. I
celebrate every day, and I'm sure you do, and you have your own test is, 'How well am
I moving today? How well am I talking today? How well am I walking today? Do I
feel like I can go to that appointment that my friend has invited me to?' So you have
your own kind of meter, but it sounds like generally you're doing really well as you
said.

Now I understand before you had the deep brain stimulation you kind of have to go
off your meds. How disabled were you when you were kind of "naked" as far as
medicine goes prior to the deep brain stimulation?

Alice:
Well, when I had to go off of the meds I had been on the medication for eight to nine
years. That was a long time, and I had no clue, and actually I was looking forward to
it to find out the degree of the Parkinson's and how bad it was, and then I found out,
and it was really bad. I'm sure Dr. Giroux could attest to that. I was in a wheelchair. I
couldn't walk, couldn't talk. I pretty much couldn't do anything.

Andrew Schorr:
Hmm, so that's really a tribute to the power of the medicines that we've had that have
been available to you now, and then now have you had less medicine as the deep
brain stimulation has taken over as part of your control of your condition?
Alice:
Yes, I had it tweaked yesterday. I call it "tweaked" but it was tuned up. I have it set as high as it's going to be set, and they will over the next six to nine months I guess it will be basically playing around with the medications to get them down as low as they can go, and I'm steady and everything is on course. You could look at me now, and I don't really look like I have Parkinson's.

Andrew Schorr:
And you're certainly talking pretty fluently, that's for sure, and you came over to the clinic for this interview.

Dr. Giroux, help us understand that. So I am impressed all the time these days with the art of medicine. So first of all we talked about diagnosis earlier. There's not like a blood test or just a simple test for Parkinson's, so I understand the art of medicine for you as a subspecialist and your peers to make an accurate diagnosis. Then we have these treatments that come into play, both the medicines and maybe combination therapy, and then you add a surgical approach like deep brain stimulation, so it sounds like you really need a team that's not just there on day one but then over time to make adjustments as the patient changes and their condition changes or one modality may start having more effectiveness.

Dr. Giroux:
You know, that's absolutely correct. We have to change with the patient and what we focus on will change over time as someone like Alice or any patient really has different priorities. One moment it might be trying to titrate or change the medicines to give someone the best movement throughout the day. The next moment it might be to try to improving walking, balance, or endurance, or perhaps over time it's dealing with other issues that could be related to Parkinson's such as depression or coping or adjustment, so it really is about listening to the patient and observing the patient.

Treating Parkinson's is an amazing blend of art and science, and the longer that I take care of people with Parkinson's disease as a physician, the more I respect the art of medicine despite the fact that we have such fantastic and high tech procedures and treatments even like deep brain stimulation based on the most complex brain circuitry, we always still come back to the art of medicine, and that is working with someone, partnering with someone, so they can continue to well with this lifelong disease, and it's possible, although you know at times the definition of wellness and how someone does and how they define it needs to be changed over time, but by working with that, setting those priorities, and having, you know, a positive, can-do, active attitude, for instance like Alice, it certainly is possible.

Andrew Schorr:
Dr. Giroux, so given that this expertise and a team like yours is not on every corner and in every town, how far and wide do people come from to the Booth Gardner Parkinson's Care Center?
Dr. Giroux:
The majority of our patients come from Western Washington, although many come throughout the whole Northwest and even the nation. We even have approximately I think eight countries represented outside of the United States, and in general when people come to the Booth Gardner Parkinson’s Care Center, they’re coming because they’re searching something else. They have Parkinson’s, they know they have Parkinson’s, and many times they’re also getting very accurate and appropriate medical treatment for their Parkinson’s, but what they’re seeking is that other piece, and that’s where the team comes in. So how do I care for myself with Parkinson’s? How do I do well? What's in store for me, and how do I make the best lifestyle changes to do the best over time? How so I support my family? How does my wife or may care partner get support? Those kinds of questions are the common questions that bring someone to the center, and oftentimes they travel because of that unique approach.

Andrew Schorr:
I heard one story where someone came from Canada. They had had deep brain stimulation and had the device put in, but I understand it’s often about the art of the adjustment of it, and I don't know whether it was Sierra Farris, or specialists in that who helped, but I know people come far and wide not just to see the M.D., but to see other members of your team for the tweaking I think that Alice was saying of in that case the deep brain stimulation device.

Dr. Giroux:
Yes, that is correct, and one of the areas of expertise that we bring to the community is the long-term management of a person who has deep brain stimulation, and with deep brain stimulation, there are multiple people involved in the process; that is the neurologist is typically involved so that you select the right person that's going to benefit from the surgery, of course the surgeon has to do a good job and get the lead placed in the right area of the brain for the surgery to be effective, but then after that it's the long-term management, the adjustment of the stimulation, understanding what deep brain stimulation can and can't do for someone, understanding the interplay and interaction between the deep brain stimulation and the medicines and so how that can be adjusted and manipulated over time, and if it’s not done correctly you can cause just as many problems as you could potentially help with DBS.

So the long-term management is especially critical, and again, I think this is where at the Booth Gardner Parkinson’s Center we shine. We have one of the nation's most experienced deep brain stimulation programmers, and then we don't stop there. So the patient's not just defined by their deep brain stimulation. We have the whole team again that when needed can kick in and help take care of the patient and guide the patient through the process living with DBS in the long-term.
Research and Clinical Trials

Andrew Schorr:
Right, I know, I can understand that, and of course we're learning. I mean this is a progressive condition with rates varying among people.

So Alice has had medication, deep brain stimulation, and hopefully more medications can be moved to their lowest dose, but who knows what lies ahead, so then you start thinking about research.

Alice, it may be that someday your team there will say, 'Well, there's a clinical trial that might be helpful to make your life better' Would you be open to that?

Alice:
I'm always open to that kind of thing. If you would have asked me five years ago about DBS, I wouldn't have thought that I would go for it, but when you get to that point where your grasping for anything to improve your situation, you can't tell what your answers going to be.

Andrew Schorr:
Right, right. So, Dr. Giroux, you mentioned about research, and it sounds like you are encouraged as you're devoted to this field with your team that there are exciting things that may be popping over the next few years, and your center's involved in the research. So it would mean then if someone's in a relationship with you if it's appropriate, then that becomes part of the discussion?

Dr. Giroux:
That's correct. So we have what are called clinical trials, and those are research programs that are looking at new medicines that could potentially be helpful for Parkinson's where we're studying the safety and the potential benefits of these medicines for Parkinson's, and research is really focusing on along a couple of lines, and one line of research is the majority of our treatments today focus on the biochemical, the neurotransmitter dopamine, and that's been the source of the majority of our medicines; they help enhance the effect of dopamine in the brain. Well, there are areas of research now that are looking at new chemicals, new drugs that attack not just dopamine but other systems, so it opens the doors to many more possibilities as different neurotransmitters and chemicals may be effective for the symptoms of Parkinson's diseases, but that research looks at the symptoms, improving the symptoms.

My hope for Alice and other individuals with Parkinson's disease is that we will have medications or treatments that are what we call neuroprotective, and that's a big area of research. What we mean by neuroprotective is there are certain brain cells that degenerate and die off over time with Parkinson's. What if we had a treatment that we could protect those neurons so that they would not degenerate and die off? So, again, put the brake on the disease, and that is a focus of research.
Then research is even going beyond that is what about neurorestoration? And that is we know there are certain nerve cells that are vulnerable and vulnerable to cell death. If we had a way that we can actually give back more of those nerve cells, and there are techniques like gene therapies that are being studied where perhaps we can promote nerve growth and give back the nerve cells that are degenerating.

And then of course, we are all waiting for and so much research is looking at what is the cause? What causes Parkinson's so that we can nip it in the bud before it's a problem. Is it genetic? Is it environmental influences? And there's so much research looking at that potential interaction as well. So as far as research is going, it is one of the more exciting areas in brain science. There's a lot we know. There's a lot we don't know, but it is probably the most advanced as far as medication options and then other more innovative treatments.

Andrew Schorr:
Well, I want to just congratulate you on what you have there at the Booth Gardner Parkinson's Care Center for Parkinson's and also for all movement disorders, your devotion to it, and also your excitement about the future.

So Alice, what would you say to other people who get this diagnosis, hopefully not on their birthday, but no day is a good day to get this diagnosis, about connecting with the right team and then working with them over many, many years to really have the highest quality of life?

Alice:
I think it's very important that you connect. I think you have to have the relationship with your doctor and the team as a whole that you're comfortable with them because you have to talk to them about everything, and I think it's very important that you find that connection and you move forward. If you come to the Booth Gardner Clinic, it's just unbelievable up here. Everybody's extremely caring and helpful, and I'm hoping that there's going to be a light at the end of the tunnel.

Andrew Schorr:
Well, it sounds like that's not more than a hope from what Dr. Giroux is saying. Dr. Giroux, I want to wish you all the best with your team and again congratulate you on the work that's done there. It's really thrilling for me as a patient advocate to hear about this work in this area. I'm not personally touched by it, but certainly Alice is, and I talk to people like that, and I know what a difference you make. Alice, she makes a big difference for you, doesn't she?

Alice:
Huge, huge difference.
Andrew Schorr:
Well, I'm so delighted we could do this program, and I would certainly commend the Booth Gardner Parkinson's Care Center to people, and I know, I have a personal point of view that it really makes sense for people to consult with specialists in the condition you've been diagnosed with because if in fact we all believe, want to believe, and I think it's true, that medical progress is being made, then who's going to know the most about it, and that is the people who deal with it every day. That's what's happening at the epicenter there at Evergreen Hospital Medical Center.

Dr. Giroux, thanks for being with us.

Dr. Giroux:
Thank you Andrew, and thank you for your kind words as well.

Andrew Schorr:
Oh sure, and Alice Cleeton, all the best to you. You're going to dance at those boys' weddings.

Alice:
I will. Thank you Andrew, I appreciate it.

Andrew Schorr:
Okay, well, as always we've learned that knowledge can be the best medicine of all. I'm Andrew Schorr wishing you all the best.

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