

## Deep Brain Stimulation for Parkinson's

Webcast

**January 21, 2009**

Kim Burchiel, M.D.,

Bruce Geis

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### **Introduction**

#### **Andrew Schorr:**

We're live on "Ask the Experts." I'm Andrew Schorr. Tonight we're going to talk about Parkinson's, which is the second most common degenerative neurologic disorder in America, and we're going to hear about deep brain stimulation and what it can mean for Parkinson's patients where medicines are not as effective as we wish they were to give people their lives back. We're going to have an expert from Oregon Health and Science University where they have years of experience in deep brain stimulation. It's all coming up next on our "Ask the Experts" program.

Thank you for joining us once again for our "Ask the Experts" program. I'm Andrew Schorr broadcasting from Seattle. We do this every two weeks in partnership with Oregon Health and Science University to discuss very significant medical issues, connect you with leading experts at OHSU, and inspiring patients and caregivers and family members.

We're going to do that tonight related to Parkinson's. Now Parkinson's of course is a very serious movement disorder, and it can definitely affect your quality of life, and there are medications that can help control Parkinson's and various strategies, but some people need more, and that more, one approach, is something called deep brain stimulation. What you might not know if you've heard about so called DBS is that OHSU has many, many years of experience and has been a pioneer in the research of deep brain stimulation, and in just a minute we will be connecting you with one of the true experts in the country who is at OHSU and is actually Chair of Neurosurgery there.

### **Bruce's Story**

#### **Andrew Schorr:**

I always like to begin with a discussion with someone who's been affected by the illness we're discussing and benefited by approaches to it. So I want to introduce you to Bruce Geis. Bruce is retired now. He for many years was a welder and a truck driver in Portland where he continues to live, and then he started developing tremors in his hands and other uncontrolled movements. Well, he took medication of course, and then finally in 2003 he had this deep brain stimulation that we're discussing tonight.

I also want to introduce you to a really cool partner in Bruce's life, and that is Diane Michaels. They've been together three years now, but they actually met many years ago as they were in high school together, and then they reconnected at their 40<sup>th</sup> high school reunion. So Diane has observed the change in Bruce as he's benefited with deep brain stimulation, and they're able to do lots of activities.

Bruce and Diane, welcome to the program. Bruce, let me start with you. Bruce, how bad were the tremors there at work as you were developing Parkinson's? What was it like?

**Bruce:**

It was unpleasant because other people really notice the tremors in my hand and in my neck, and I was limping. I had trouble walking backwards. I'd lose my balance.

**Andrew Schorr:**

Was it getting progressively worse?

**Bruce:**

Yes, it was.

**Andrew Schorr:**

Now obviously you get diagnosed with Parkinson's, and then they say, 'Well let's try these medications.' How well did the medications control the tremors?

**Bruce:**

Reasonably well at first and then in time it didn't make any difference at all.

**Andrew Schorr:**

Okay, so you went a number of years, then you had the deep brain stimulation at OHSU as I said where they really helped pioneer it in America, and so how were you after the surgery? How are you today?

**Bruce:**

I'm reasonably well. There is no tremor and no limp, and my balance still a little off, but there's no comparison.

**Andrew Schorr:**

Now, you do gardening and yard work I understand. Of course you're retired, and you have an 80-pound Doberman, Rose. So you're able to do the activities with the dog and in the yard even though you have Parkinson's?

**Bruce:**

Yes I am.

**Andrew Schorr:**

Let's get someone else's perspective. Diane Michaels, you have a wonderful love story, if you will, of connecting at your high school reunion. So Diane, tell us from your perspective what a difference this approach, the deep brain stimulation, has made for Bruce.

**Diane:**

Well, it's been a tremendous difference. I actually reconnected with him after the surgery, but he had a tape of how he had been beforehand, which I could see, and then listening to his friends, and then he actually lost like 30 pounds I believe just from the tremors. He would fall down quite a bit, and now he has no tremors at all, and he moves a little slower than his other friends our age, and he stumbles a bit but nothing compared to the way it was before.

**Andrew Schorr:**

Now we recognize of course that it's a chronic condition. It can be a progressive condition, so we're not talking about a cure, but we're trying to help give somebody back a fuller quality of life.

What sort of activities do you and Bruce do now given that the deep brain stimulation and medications that he's taking too help control the Parkinson's?

**Diane:**

I guess mainly the gardening because that's just kind of an ongoing thing. We drive down the beach. He can drive his truck, and we can go for short walks on the beach. He does tire easily, but we can still get out and do things, and there's actually down on the Tillamook River a handicap dock, and he can throw a fish line in. So there's still, I mean, the normal go for a walk and go to the store; the normal things us retired people do.

**Andrew Schorr:**

Okay, and with that love story I described I hope you get to hold hands too.

**Bruce and Diane:**

Oh yes.

**News in Surgical Management of Parkinson's**

**Andrew Schorr:**

There you go. All right, well that's what life's about. Let's meet one of your doctors, the Chair of Neurosurgery at Oregon Health and Science University in Portland, and that's Dr. Kim Burchiel. Dr. Burchiel has really been on the ground floor of deep brain stimulation surgery for Parkinson's and as a matter of fact has been very much involved in all sorts of published research. Dr. Burchiel, welcome to our program.

I know some new research has just been published, so tell us about that and what it means for people with Parkinson's.

**Dr. Burchiel:**

Good evening, it's a pleasure to be here. We've been involved in this work for a long time, but many surgical procedures are done for reasons related more to history and what surgeon's think might work well. One of the differences with Parkinson's disease and sort of the era that we're in right now is that we're really trying to prove that things work rather than just be convinced that they work based on our experience.

Over the past decade or so there's been a number of studies that have been done. Actually one of the first studies that was done on deep brain stimulation for Parkinson's was done here at OHSU, but we have a limited number of patients that we take care of in this region, and around ten years ago we began to think about putting together a bigger national study, one that would really put the issue to rest and really convince us all whether or not this surgery worked.

So after a lot of planning and working initially with the Veteran's Administration and then later on with the National Institutes of Health, which is the big research enterprise in Washington, we put together a protocol to study whether this type of surgery, deep brain stimulation, was better than the best medical management in patients with advanced Parkinson's disease, and that study went on for five or six years after that, and it's only now that we're beginning to get the results of that study, and having completed the evaluation of the patients that have gone through this very rigorous trial.

That work just was published in the "Journal of the American Medical Association" about two weeks ago now that showed that clearly deep brain stimulation was superior to medical management in a patient with more advanced Parkinson's disease. So that's really I think a breakthrough for surgical management of Parkinson's.

There are a few other questions that will be addressed in that same study over time, and we'll see several papers come out over the next few years that will look specifically at issues related to where the implants are done and other symptoms more specific for the targets for the implants. So it's been an exciting thing to be involved with.

**Andrew Schorr:**

Wow, yes, and you've been involved in it in your department for many years. We're going to have lots of questions that come up is to help us understand what it is exactly, what you're doing as a neurosurgeon, how it works to help limit the effects of Parkinson's and then also who is it right for with Parkinson's and when, what does it do to the progression of the disease. Lot's of questions. We'll be right back with more of our "Ask the Experts" program.

Andrew Schorr from Patient Power back with you live on our webcast tonight. You're welcome to ask a question as we continue our discussion with the Chair of Neurosurgery at OHSU, Dr. Kim Burchiel, and also one of his patients who has

benefited greatly from deep brain stimulation for more advanced Parkinson's, Bruce Geis and his partner in life now Diane Michaels, and we'll talk with them more as we go along. Remember that there are national Parkinson's foundation's Centers of Excellence around the country, and one of them, certainly the main one right there in Oregon, is OHSU. Then of course at these centers there are medical and clinical trials, and there are about fifteen or twenty going on at OHSU, and we'll talk more about research as we go on, but let's understand the basics.

## **Deep Brain Stimulation**

### **Andrew Schorr:**

Dr. Burchiel, when we talk about deep brain stimulation I've got this idea of like wires connected somewhere in your head and like little zappers going off, so what is deep brain stimulation and when you do this surgery on someone where are you connecting it; what is it physically; what does it mean?

### **Dr. Burchiel:**

I guess the simplest way to think about it is a brain pacemaker. There are wires that actually go down into the brain very precisely targeted to areas that we wish to control. In many cases it's sort of paradoxical that stimulation of an area of the brain actually inhibits it, that it slows it down. It inhibits the output of that center that we're stimulating, but the stimulator requires an electrode to be precisely placed in the brain, and then that's connected to a small device that looks very much like a heart pacemaker. It's implanted under the skin usually just below the collarbone on one side or the other, and that stimulator can be controlled from a handheld device that the patient has and also the doctors have more complicated devices they can use to program these pacemakers. So effectively it's a brain pacemaker.

### **Andrew Schorr:**

Now I know there are some brain surgeries where the patient is sort of sedated and any pain is taken care of, but they're actually awake so you can talk to them and do things. Is that the case with this surgery that you need to kind of talk to them to see if the movement or tremors have been controlled? Tell us about actually what happens in the operating room.

### **Dr. Burchiel:**

Most of these procedures are done with the patient awake. The pain is controlled by local anesthetics and usually very minimal sedation. It's not an uncomfortable operation. We need to have the patient awake for most of these operations because we will do some very sophisticated recording from the brain to verify the target, that is that we are placing our electrode where we want it to be and also because we can examine the patient for tremor for example during the operation or stiffness or slowness of movement. These things we can measure during the procedure, and it's very helpful to know that we've actually inhibited the tremor for example with the electrode stimulation. So we're really proving that the therapy is working right there on the operating table.

**Andrew Schorr:**

Wow, it sounds like a lot of, you know, it's like an electrician looking at the circuits and all that kind of thing. Now we mentioned you said that it's for more advanced Parkinson's. What does that mean because obviously if you can take a pill and that controls your Parkinson's and your tremors that's a way to go certainly rather than having brain surgery, so tell us when it sort of crosses over.

**Dr. Burchiel:**

Largely what that means is that the initial medical therapy has been successful but that over time and with progression of the Parkinson's disease the medications become less and less effective just as Bruce described earlier. His initial medication worked well to control his tremors but gradually he had to take more and more and it became less and less effective, and he developed other symptoms of Parkinson's such as stiffness or slowness of movement, balance problems, walking problems. Often what happens then is the medication dose is increased, other medications are added, and then ultimately the medication is given so frequently that it becomes almost impossible to really keep up with the disorder.

In addition, again it's odd that some of the medications, particular levodopa, which is in many ways a miracle drug, can begin to cause other problems. Over time people with advanced Parkinson's disease develop extra movements, that is uncontrolled movements related to the drug so they end up living in a bit of a nightmare, which is to say if they don't take the drug they're rigid, immobilized, tremulous, but when they take the drug then they have these wild uncontrolled movements called dyskinesias, so they really don't have any quality time. So that's the type of patient that we describe as "advanced" or what we might call medically intractable meaning we're not able to manage them with medication any more because they're taking the medication too frequently, they're having side effects from the medication such as the dyskinesias, the medications are no longer effective, and in addition patients that are taking drugs every few hours can experience rapid fluctuations between being immobilized and then being in a more mobile and higher quality time. These what we call "on/off" fluctuations can come and go very rapidly and become a problem in and of themselves. So every patient with Parkinson's disease has a litany of problems and in a way when someone reaches that point of medical intractability, patients look a bit different, but they're all at a point where medicines simply aren't doing it.

**Andrew Schorr:**

So the idea with the deep brain stimulation is to try to reset things back to a better time and give them a lot more "on" time I guess you'd say.

**Dr. Burchiel:**

That's right. Yes, it gives them a better quality of life, and one of the things that this most recent study showed is we're improving that "on" time a good five hours per day, which is pretty substantial for someone who really doesn't have any quality time.

**Andrew Schorr:**

Okay, now let's understand Parkinson's just in general. What's going on when someone is diagnosed with Parkinson's? What's happening in the brain? Is it a chemical problem? What's going on?

**Dr. Burchiel:**

There's a chemical in the brain called dopamine, which is a very important neurotransmitter. That's a chemical that connects or signals between neurons, nerve cells, brain cells, and this chemical is found throughout the brain and the nervous system and very important for many different functions of the brain probably the most obvious being movement. There's a center in the brain which produces this neurotransmitter, and in Parkinson's disease this part of the brain seems to degenerate prematurely, that is you in effect run out of the cells that are producing dopamine. You cannot live normally without this neurotransmitter, so it is a process of aging to a degree, but it's accelerated in patients that have what we call idiopathic Parkinson's disease.

**Andrew Schorr:**

Now of course there are some famous people with Parkinson's, the actor Michael J. Fox, and I was watching the inauguration yesterday as we do this program in January, and of course Mohammed Ali, and we know how they've been affected. We can't cure it can we? It's still the progression may well continue. I know it varies by people but so is the idea that this can just help give people back some time and quality?

**Dr. Burchiel:**

That's basically the idea. We have always been intrigued with the possibility that this might slow down the progression of Parkinson's disease, but right now we don't have any evidence that that actually occurs. It is a symptomatic treatment or what we might call a palliative treatment. It improves the quality of life, but ultimately it is not changing the degeneration that is causing Parkinson's disease.

**Andrew Schorr:**

Dr. Burchiel, we mentioned that OHSU has a long history of this, and you personally. Tell us how long ago you got involved with this and helping continue the research that started in Europe, here.

**Dr. Burchiel:**

I was fortunate to meet a French neurosurgeon, actually the gentleman that really developed much of this technology. In 1989 I went to Grenoble in France and visited with him and learned some of the things that he was doing at that time mostly for tremor in Parkinson's disease, and much of the work that came along after that, again pioneered by Dr. Benabid who was the neurosurgeon in Grenoble, hadn't even started yet. So I learned some of the techniques related to tremor control, and around that time he began to do some of the other work related to

controlling other symptoms of Parkinson's, and we kept up with that, but we were the first center outside of France to really introduce this surgery in around 1990, and at that point it was of course experimental.

We went to the usual agencies to be able to do this work through FDA and through NIH, and we were able to get it started pretty early in the 1990s at OHSU, and after a few years and after other neurosurgeons and neurologists began to see what we were doing, other people have picked up the technology to the point now that there are probably over a hundred centers in the United States that do this work from time to time.

**Andrew Schorr:**

You must be very gratified though with this latest "JAMA" study and sort of the evidence-based medicine because I'm sure there were skeptics along the way in your field.

**Dr. Burchiel:**

I think the skepticism was rapidly replaced by kind of amazement. I must say one of the most gratifying things that I've experienced in my career was the reaction and response of my colleagues to seeing what we could do with this technology. I mean it was very impressive for folks who had never seen this before to witness how dramatic deep brain stimulation could affect somebody's quality of life.

As with most things, as we've gone along now, it's become almost the expected norm to see these dramatic changes such as Bruce experienced, but early on it was I would say the average response was nothing short of amazement.

**Andrew Schorr:**

Wow. Now Bruce, let me just ask you a question. So Dr. Burchiel was your surgeon, but you continue your care with neurologists and the rest of the team at OHSU, so how often do you consult with them? How often do you go over to OHSU as they check on how you're doing?

**Bruce:**

Yes, I have an appointment about every three months now that the study is completed.

**Andrew Schorr:**

Okay. Now I know sometimes there's a battery change just like there would be with a pacemaker, but sometimes do they make little adjustments to the stimulator?

**Bruce:**

Yes, they have up until now.

**Andrew Schorr:**

And with this idea of stimulation, do you feel anything if it's firing, if you will? I know my dad had a pacemaker and then other people have other heart devices, and sometimes they can feel something. Do you feel anything?

**Bruce:**

If I have it turned down and turn it up in the morning I'll get a strange buzzing feeling in my head.

**Andrew Schorr:**

But no pain?

**Bruce:**

No pain.

**Andrew Schorr:**

Okay. Dr. Burchiel, help us understand that because I know one part of it is the placement of the electrodes as you said and maybe that's becoming more standard, but I know there's a whole art to adjusting the devices and not just on day one but over time as a patient's situation changes. So tell us about the kind of fine art of adjusting the stimulator.

**Dr. Burchiel:**

We do have several different targets we use in the brain for different symptoms, so each one of these has its own personality and in a way natural history of how adjustments are made. We have learned a lot. I think this, what you've really put your finger on now is sort of the state-of-the-art today is how, you know, we've accomplished this extraordinary feat of implanting the stimulators, there's no doubt that it works, but I think one thing to communicate is that once these electrodes are implanted and the pacemaker is implant, as difficult and as extraordinary as that is, that's just the beginning of this therapy.

It is truly the fine tuning, the maintenance, the attention to this that makes the therapy work, and it requires a tremendous dedication on the part of clinical groups, neurologists, nurses, to begin to work with the patient to see what their needs are. In some cases it requires increasing the voltage. In other cases it requires changing the combination of stimulation and changing the location of stimulation. The electrodes that we place are not simply one contact. They have multiple sites for stimulation along the electrode, and so we can actually move the point of stimulation in effect up and down the electrode to achieve different clinical effects.

So we're just, as I say, despite the fact that we're a good fifteen years into this therapy we're still learning about how to do that. I would say in this case, like surgery, experience in programming is everything. An experienced center and individual is absolutely critical and that the relationship that the patient has to the programmer is critical and the ability to frequently update the program.

**Andrew Schorr:**

Yes, I think that's important for anybody with a chronic illness. Parkinson's for sure is. Now if you have this therapy, the approach, and then you need a team that supports you and of course we're saying this is a condition that unfortunately we can't cure now, so that may be a moving target, it's progressive, so how do you need these adjustments along the way, and so certainly you need a leading center like OHSU and a dedicated team that can help you.

We have a lot more to ask Dr. Burchiel about and Bruce and Diane living with it either as a caregiver or a patient. We'll be right back with much more of our "Ask the Experts" program live when we come back. Stay with us.

We appreciate you listening in to this program whether you're joining us live in January 2009 or listening or reading our transcript weeks or months later, but we hope if you're touched by Parkinson's this discussion of deep brain stimulation can help you and our expert with us. Our expert physician is Dr. Kim Burchiel who is Chair of Neurosurgery at Oregon Health and Science University in Portland. We have with us his patient, Bruce Geis, who had the surgery in 2003 and is doing really well, and then Diane Michaels his partner who enjoys life with Bruce.

**Age, Expectations, and Medications**

**Andrew Schorr:**

Dr. Burchiel, a bunch of questions. One is we wonder well, is there an age cutoff for the surgery, I mean after all it's brain surgery. That's daunting for anyone. So we talked about how advanced it might be but what about an age? Does that matter or even somebody's other health issues?

**Dr. Burchiel:**

It does matter. In our study we did exclude individuals who were over eighty years old, and in general I think that's still probably true that after a certain age we're probably not going to recommend the surgery for a variety of reasons related to medical problems, problems with memory, and other issues that do crop up at that age. So we have a relative cutoff at the upper end. One of the things that we did with this study though is we looked at patients that were over seventy and under seventy, and at least in the groups that we looked at, and again we excluded the very elderly patients, we really couldn't see any great difference in the outcome between the older and the younger patients, which was a bit surprising to me, but that was one of our findings. So I think with under probably age eighty/eighty-five it doesn't seem to be a disadvantage to have this in your seventies, and there doesn't seem to be any great advantage to do it earlier.

So I believe age is a relative contraindication, but certainly we're talking about patients who are still over seventy and getting benefit.

**Andrew Schorr:**

Now let's talk about reasonable expectations. So somebody may be listening to this and say, you know, 'Medications aren't working so well anymore. Boy if I could just have this surgery, maybe go to OHSU where you've had so many years of experience with it. It's going to give me my life back, and I'm going to be fine forever.'

First of all, let's talk about how things vary in Parkinson's for people whether it's medication or DBS and having a realistic view of what the outcome will be.

**Dr. Burchiel:**

I think with Parkinson's disease it's extremely important in effect to have some realistic goals. As we said before, this isn't going to stop the progression of the disease. It will help symptoms. The things that we seem to do best at with deep brain stimulation relate to these dyskinesias that I described earlier, that is this drug side effect of levodopa that produces these wild and uncontrolled movements. Those are very well treated by deep brain stimulation.

Another aspect that is treated very well is what we've referred to as "on" time, that is that quality time that someone experiences during the day. Often patients at the advanced level that we're treating have almost no quality time. With deep brain stimulation they have a much smoother period of function that they're able to move, they're not rigid, they're not immobilized, and they're able to enjoy life and to carry on with their normal activities. So the increasing "on" time is an important benefit and one of the biggest benefits of deep brain stimulation.

Other than that, the other symptoms of Parkinson's disease such as the stiffness that we call rigidity or the slowness of movement we call bradykinesia as well as tremor are all improved by deep brain stimulation.

So all of these add up to that quality time I discussed. We can reasonably expect improvement or maybe complete relief from dyskinesias, better "on" time, improved slowness of movement, improved stiffness, improved tremor, and these are the things that we try to communicate to patients. The degree to which that will occur in an individual patient is to a large extent based on the severity of their symptoms.

If they're very far advanced they may have a modest improvement. If they only have mild symptoms they may be effectively normal when they're using deep brain stimulation. So it really is a very individualized thing, but I believe that the patients have to recognize and the families need to recognize this is something that we're doing to improve symptoms but not again completely reverse them or stop the progression of the Parkinson's disease.

**Andrew Schorr:**

Bruce, here's another question for you now. Now you still take some medication, right? It's not like you don't swallow any pills. You do take medication right?

**Bruce:**

Yes I do.

**Andrew Schorr:**

Okay, and you still take some levodopa, right?

**Bruce:**

Right.

**Andrew Schorr:**

Okay, so let's ask your doctor about that. So it's not like you get away with not taking any medication Dr. Burchiel. Is it the idea to, and that's part of the puzzle I imagine is who gets the DBS, how do you adjust it, how does that affect the use of medication so it can have positive effects and not negative. It's like a big puzzle it would seem to me.

**Dr. Burchiel:**

One of the things that we found here initially at OHSU and later at this larger study that we've been talking about is that the site of implant, that is the target that we place these electrodes, really has a lot to do with what happens with the medications. In Bruce's case he was implanted in a target where effectively the medication use may stay about the same, and the use of the levodopa-type medication may actually even go up a bit. It's just that now the patient has been relieved of the side effects of the drug and so they can get the benefit without the side effect. That target is distinct from another target in which often the medication use drifts down, and the patients may be able to substantially cut their drug. Rarely do we see a patient that doesn't require any drug whatsoever, but these two targets do have quite different effects on the drug usage.

**Andrew Schorr:**

Now we've been getting some e-mail questions. Here's a question from John. He's been listening, and he wants to know, 'Does essential tremor relate to Parkinson's? Can that be cured?' Because he has it in both his hands and mostly in his right hand and maybe as part of that answer Dr. Burchiel, we'd wonder well if he has essential tremor if there's any connection can DBS work there?

**Dr. Burchiel:**

It's a great question, and I'm glad that came up because for all the recognition of Parkinson's disease very few people know what essential tremor is, and this is a condition that's probably about ten times more common than Parkinson's disease. It is one of these disorders though that it's under-recognized by the public and I think actually in the medical community.

The answer to his question is yes. We do surgery all the time including deep brain stimulation surgery. I did one today for a woman with bilateral essential tremor, very severe tremor. It is very successful, and we don't, I hate to use the word "cure" because we're still not curing this disorder, but a patient with essential

tremor doesn't have a progressive, degenerative disease like someone with Parkinson's does, so if we can stop the tremor we have effectively "cured" the patient as long as the tremor is gone, and we can do that in most cases very effectively.

**Andrew Schorr:**

Diane, so you're listening to this and here you have a loved one living with it, so you know it's a continuing condition. What's your take on this technology and what a difference it's made for Bruce?

**Diane:**

Well, it's pretty remarkable considering how he was before and how he is now, so he's really come out well. It's giving him back a normal life.

**Andrew Schorr:**

And gives you Bruce, the full Bruce.

**Diane:**

Yes, right.

**Andrew Schorr:**

So Bruce, I know that you talk to other people with Parkinson's, and they may be a little daunted is the word I use about having an implant, yet when you think of heart pacemakers nobody would think twice maybe about having a heart pacemaker. Was it a big deal for you to have this surgery, and is it a big deal to have this device by your collarbone?

**Bruce:**

No. I was in such bad shape that I just felt it was worth taking any chances or taking any possibilities I could find to help cure it. I was just, the medications weren't working any longer, so to me it was a godsend. It really was.

**Andrew Schorr:**

It sounds like you've got a great team that has worked with you throughout this at OHSU.

**Bruce:**

Oh I can't speak highly enough of Dr. Burchiel as the surgery he did on me was incredible. I think at that time he had done over a hundred surgeries, and the followup I got through Dr. Penelope Hogarth and the staff was just incredible.

**Looking Ahead In Research**

**Andrew Schorr:**

Neat, well Dr. Hogarth I know is one of the neurologists we've been speaking about who really helps you long term.

Dr. Burchiel, OHSU is known for research, and this is an area in neurology and neurosurgery that your center's been very dedicated to for a long time. Where are we headed for people with movement disorders and Parkinson's? We'd like to hear the "cure" word along the way, but where are we headed?

**Dr. Burchiel:**

I think we can safely say over the next few years that deep brain stimulation is still going to be the dominant therapy. It's been so successful. I don't see a major change in the therapy over the next couple of years. I don't want to dwell on failure, but much of what research explores are areas of the unknown, and success is not a common outcome of research.

At our institution we've looked at many, many different types of therapies that will attempt to either restore the center of the brain that's degenerating in Parkinson's disease. We've been involved in a number of studies looking at what are called neurotrophic factors. These are proteins that enhance the health of these degenerating neurons. One in particular is a substance called glial derived neurotrophic factor, which is a mouthful, or GDNF, and we've tried to apply GDNF in many different ways in patients with Parkinson's disease, and so far that hasn't worked out. We have not found a way to administer this in such a fashion as to either slow down the progression of Parkinson's disease or reverse the progression. So that has been a bit of a blind alley.

We have explored and other centers have explored the use of stem cells. That's a bit of a buzzword in I think even in the lay press and media. As we sit here today there's not been a successful study on stem cells. Every stem cell trial that has been attempted in Parkinson's disease has not shown benefit. I do believe we're going to see much more along those lines, but there's nothing promising at the moment in that regard.

There are a couple of studies going on now looking at gene therapy, that is trying to replace defective genes in these cells in order to have them not degenerate and to produce normal levels of dopamine. The jury is still out on the gene therapy story, and there's a series of studies right now, and we may hear more on those within the next couple of years, but I can't tell you whether those are going to be positive or not.

Ultimately, and I hope I see this during my career, what we're going to see, and this may take another ten years, will be the ability to transplant or implant genetically modified neurons, maybe from the patient themselves, to take them out of the patient to modify them and reintroduce them with genes now embedded in these cells to be able to become stem-cell-like centers for the regeneration of these brain centers that are degenerating. We're already working on that here in other disorders, other nerve degenerative disorders, and I don't think we're more than ten years out from being able to engineer cells to replace these dying neurons within the brain of patients with Parkinson's disease. So I think that's on the far horizon.

Really for the next, I would presume five years or so, deep brain stimulation is still going to be the dominant therapy.

**Andrew Schorr:**

Okay. Thank you for this look into your crystal ball. We're going to take another brief break. When we come back we're going to help get some guidance from Dr. Burchiel on what kind of conversation someone affected by Parkinson's should have with maybe their neurologist to then have a discussion about whether it's time to talk about deep brain stimulation, have some guidance on when that might be helpful in the course of their dealing with this illness, and we'll get some final inspiring comments from Bruce and from Diane. It's all coming up next as we continue our "Ask the Experts" program.

We're going to put it all in perspective for you now when we talk about deep brain stimulation and deep brain stimulation surgery for people with more advanced Parkinson's.

**Potential Complications and Side Effects of DBS**

**Andrew Schorr:**

Dr. Burchiel it sounds like for some people it can make a big difference in giving them more quality of life, but obviously in any situation there can be people that it's not right for, and there can always be the risk of some complications or side effects from the treatment. So let's talk about that for a minute and put it in perspective, who you feel it's right for. People need to go in with their eyes open what can also come from the approach that maybe is not desirable.

**Dr. Burchiel:**

Right. One of the requirements we have for this type of surgery in patients with Parkinson's disease is a history of a good response to medication. The typical drug that's used for Parkinson's disease, at least initially, is a compound that contains levodopa. It is actually called Sinemet, and it's a combination of levodopa plus another drug to help sort of combat some of the side effects of levodopa if taken by itself. If a patient doesn't have a track record or a history of response to levodopa, they're probably not going to be a candidate for deep brain stimulation for Parkinson's disease. So that's an essential part.

One of the things that I think has inflated our expectations about this surgery has been largely due to the, maybe it's a product of medical marketing to a degree. Patients who have, to achieve a good response from a levodopa, in effect have established a ceiling; that is they have what you see at their best is what you're going to see in general at their best with deep brain stimulation. We don't raise the ceiling so to speak. What we do is we spend more time at that high level. In the past decade or so, and there have been many programs, TV shows, and other things that have shown individuals that look remarkably good with deep brain stimulation and look just terrible before surgery, and of course that makes for good

drama and good TV, but what you don't see is the variability of someone with Parkinson's disease and how good they respond to medication. So I think that unintentionally we have inflated expectations by these types of presentations.

What I'm saying is that if a patient is not getting much benefit, may have had benefit in the past but not getting much benefit from levodopa now, they're not likely to get great benefit from deep brain stimulation. So that's just something to in effect explore with your doctor, with your neurologist, and ask what could I expect to get out of this?

As you said, Andrew, this is brain surgery. There are complications that can arise from this surgery. Fortunately they're not common, but we can see hemorrhages from placing the electrodes. That happens probably between one per one hundred times or one in two hundred times. We can see infections that crop up probably on the order of about one percent of the time. We can see problems with memory, problems with thinking that occur particularly in someone who's already got those problems that occur from placement of the electrode. In many cases we're dealing with very fragile people, and it doesn't take much to tip the balance towards a poorer memory in some cases.

Then of course the therapy requires replacement of the hardware at some point, that is the generator, the pacemaker as we discussed, probably needs to be replaced every couple of years, and there's a small risk associated with that, generally a risk of infection and not much else.

So I think that patients and families that go into this therapy we call deep brain stimulation have to really think about two things. First, the risks and benefits relative to their disorder at the moment of surgery and going into the surgery, and then the second thing is the commitment that it requires in terms of maintenance because as I said before it's the maintenance of this therapy and the repeated visits and the fine tuning and the adjustments that really make the therapy work. It's not a "set it and forget it" surgery. It is an implant followed by extensive maintenance.

So those are the things that need to be discussed prior to going into this very big commitment.

**Andrew Schorr:**

I think you've had a tremendous commitment yourself over many years now in helping explore it, understand it, and help people with it, and I know I speak for many people, Dr. Kim Burchiel, when we thank you for that and your whole team but also this very realistic discussion tonight.

So Diane, what's your hope for you and Bruce going forward here? You've got the dog. You've got the two places to live. You've got a lot of gardening and yard work, and yet Bruce has got a chronic condition.

**Diane:**

Right, but we'll just keep working with it, and if his medications need adjustment we'll work with that. He had one battery replaced, and I'm sure there will be another one, but we'll just keep going forward and hope that we have many more years.

**Andrew Schorr:**

Right, well right now it sure beats the alternative of the way he was before as you saw in that old "before" film, right?

**Diane:**

Exactly. Much, much better.

**Andrew Schorr:**

Bruce, I want to give you the last word sir. So what's your hope for the future? You had the time back in the 1990s when things started shaking; that's got to be pretty scary; and now you have a lot of "on" time as Dr. Burchiel was saying. What's your hope as you recognize you still have Parkinson's but the therapy seems to be working?

**Bruce:**

The reason I got this surgery in the first place was to buy some time hopefully until a cure can be found. That was my original reason, that and to if the surgery was successful, which it was, was to experience some things that I hadn't taken the time to do yet. So Diane and I have gone on train rides and done some of the things I'd always thought about doing but never got around to actually taking the time to doing it. So my original hope is to gain time hoping for a cure but accepting the fact that anything would be better than what I was, and I'm certainly again thankful for Dr. Burchiel's excellent job on the surgery.

**Andrew Schorr:**

Dr. Burchiel, I know that must make you feel really good to hear that from Bruce.

**Dr. Burchiel:**

It makes my day.

**Andrew Schorr:**

Okay, all right. Well, I want to wish Diane and Bruce a long, high-quality time together and maybe get on a cruise some time and hold hands on the beach, and you've got your Doberman Rose with you, and I love this sort of love story aspect of you meeting at your 40<sup>th</sup> high school reunion. All the best to you Bruce and Diane. Thank you for being with us on our "Ask the Experts" program.

Dr. Burchiel, keep on keeping on. You're helping a lot of people. Thank you for being with us.



**Dr. Burchiel:**

My pleasure.

**Andrew Schorr:**

All right. This is what we do. I'm very appreciative of OHSU helping support these programs and their dedication to research and to patient care, and I urge somebody affected by Parkinson's to look into a leading center like OHSU to help you get the best chance of controlling this chronic illness.

I'm Andrew Schorr. We'll be back in a couple of weeks with another program with OHSU experts. Remember, knowledge can be the best medicine of all. Good night.

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