Advances in Primary Brain Tumor Research
Webcast
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Marc Chamberlain, M.D.
Lisa Dempsey

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Lisa’s Story

Andrew Schorr:
What are the latest advances in treating primary brain cancer? We're joined by a leading specialist in the field and a researcher as he discusses ongoing studies and new developments, and we'll meet a patient who has benefitted from participating in a clinical trial. It's all next on Patient Power.

Hello and welcome to Patient Power. I'm Andrew Schorr. This program, like so many others, is sponsored by the Seattle Cancer Care Alliance.

We're going to talk about brain cancer, and in this discussion we're going to talk about brain cancer when that's a primary brain cancer. Now, it's not common, and there are many different forms, and everybody's situation can be different, and that's a reminder all along the way, but we're not talking about brain cancer that has spread from another part of the body—it was breast cancer or lung cancer, another type. We're going to talk about when brain cancer starts right there, and where are we now with what we can do for these very serious diseases.

And to help us first understand, let's start with someone who received a diagnosis of primary brain cancer, and that's Lisa Dempsey. Lisa joins us from Edmonds, Washington, just up from Seattle. She's 48 years old. She has a master's degree now, after kids were going off to college, in special education, and that's what she does. She helpings autistic children, kids with different disabilities, and that's in the Lake Stevens school system just north of Seattle.

Lisa, you were getting migraines for years, right?

Lisa:
Yes, Andrew.

Andrew Schorr:
And so you learned that if you didn't drink red wine, that could help alleviate them, and certain kinds of foods, and additives, MSG, everybody finds out different triggers. So you were used to headaches, but going back about a year and-a-half now, you were getting really bad headaches, weren't you?

Lisa:
Yes, they increased in frequency and in intensity.

Andrew Schorr:
And not just that, you were getting dizzy spells as well?

Lisa:
Yes.

Andrew Schorr:
So you were driving to work one day and [experienced] dizziness, nausea, what was it like?

Lisa:
I arrived at work and got out of my car, walked into my classroom, and my classroom has a special full-spectrum lighting for students with autism. I walked in, but my vision had changed. I had little floaty things, and I almost had a cone-like vision. I sat down at my desk, and I was really frightened by that, but I thought maybe if I just ate a granola bar I’d feel better. So I had a granola bar and the vision changes were better, but after that, my dizziness went away, but for the next several weeks I increased on a pattern of dizzy spells.

Andrew Schorr:
Oh, my.

Lisa:
And horrible headaches.

Andrew Schorr:
So you went to a general practitioner. I know the regular doctor wasn't there. You saw another one, and he said, “Well, you've got low blood pressure,” and he said, “Eat more salty foods.”

Lisa:
Yes. He did some blood work and I had to call, I didn't hear from the doctor, but these spells continued, and when I finally called they said that my blood work was normal, so they thought it was just low blood pressure, so maybe if I ate more salty foods I would feel better.

Andrew Schorr:
Now, we should mention that, again, primary brain cancer is rare, and you're already guessing that’s what this turned out to be, so it's not unreasonable for a doctor to think it would be something more common, something like that. But, anyway, eventually you're bulling through your work, and you come home one day and your husband and your daughter look at you, and what do they see?

Lisa:
My daughter said, “Mom, something is wrong.” And my husband came around the corner to look, and he said, “Lisa, we need to take you to the hospital. You're
going to the hospital now,” and I said, “I don't want to go to ER on a Friday night. I'll go tomorrow.” And I was stubborn about that, so the next day we went to the ER.

**Andrew Schorr:**
And you went, and they did an MRI, right, of your brain?

**Lisa:**
Yes.

**Andrew Schorr:**
And the neurologist came down and said?

**Lisa:**
Well, he pulled up the MRI on his computer screen--first of all, my husband wasn't in the room. He was out getting a sandwich. And he didn't want to give me the results without my husband in the room, so I thought, well, there must be something not so hot here. So they finally tracked down my husband, and they said, well, this is probably not the news you wanted to hear, but you have a brain tumor.

**Andrew Schorr:**
Oh, my. And I'm sure some of our listeners, they've received that message, too. Now, you have to be in shock. I would imagine they pick you up off the floor when you hear that.

**Lisa:**
Yes, it was a surreal moment because I could see this blob on the screen in the middle of my brain and it kind of does have a monstrous look to it. And my husband almost fainted, but at least for me there was some sort of relief. Okay, I have a brain tumor. At least I know why I've been in so much pain. We can get things going here, get this thing out, and I'll be okay. But that's just more my personality.

**Andrew Schorr:**
Right, let's deal with it.

**Lisa:**
Uh-huh.

**Andrew Schorr:**
Now, you did have surgery, and the neurosurgeons did cut out all they could, right?

**Lisa:**
Yes.

**Andrew Schorr:**
But you were told that you need more.
Lisa:
Well, when they tell you you have a brain tumor you don't really think, “Oh, my brain tumor is going to be cancer.” I mean, you think, “Okay, I have a brain tumor, that's not good.” And my thinking was, you know, I'm going to be positive about this, it's just a brain tumor, we'll get it out and I'll be okay. So you go through a whole another step in the hospital where the doctors come in again, and they even look a lot more worried, then at that point they have to tell you that the brain tumor was malignant. And so that part was even more difficult.

**Considering a Clinical Trial**

Andrew Schorr:
Let's fast forward. Your doctors told you that there was a chance that the type, the actual biology of your tumor might qualify you for a clinical trial where they were trying a new approach where maybe they could do better, right?

Lisa:
Yes.

Andrew Schorr:
And that connected you with Dr. Marc Chamberlain, who we're going to meet in a minute, who is the director of the neuro-oncology program at the Seattle Cancer Care Alliance. Now, you probably had no familiarity with the idea of a clinical trial, but you met with Dr. Chamberlain. That must have given you hope that maybe you could do better?

Lisa:
I was really hopeful immediately when they said that. Not only did I think, “Well, this gives me hope” but I thought, “Well, this is a horrible thing to happen but I could give back to other people knowing that in a clinical trial it's hopeful—it's helpful data for others and, you know, you're doing a better thing for medicine in general.

Andrew Schorr:
Right. Well, you have been. And we should mention now we're many, many months later, and since the fall—we're in the spring now of 2012 as we record this, just about in the spring, but in the fall at the beginning of the school year you went back to work, right?

Lisa:
I did. That really motivated me to get better. I love my job, and I love working with students with autism, so I was very motivated to recover as quickly as possible.

Andrew Schorr:
And how do you feel?
Lisa:  
I feel wonderful. I was told all the time that I would really suffer from low energy and since I'm a high-energy person that that might be difficult for me, but I've been able to get through it okay.

Andrew Schorr:  
Wow. Well, let's meet your doctor, who is also a leading researcher. Again, Dr. Marc Chamberlain, director of the neuro-oncology program at the Seattle Cancer Care Alliance. He's also a professor of neurology and neurologic surgery at the University of Washington.

Dr. Chamberlain, you and I have talked before about how difficult it is in treating primary brain cancer, and I know Lisa, if I've got it right, has a diagnosis of glioblastoma, and that's a tough diagnosis, but it sounds like here maybe at a clinical trial there's the prospect of doing better. So help us understand.

Dr. Chamberlain  
Well, I think, as Lisa indicated, having a diagnosis of cancer can be overwhelming, and decisions are made fairly quickly. And it's not always easy for patients to make decisions in a more collected environment where they're able to kind of reflect on what may be in their best interest. And I think to Lisa's physicians who cared for her outside of the Seattle Cancer Care Alliance, they recognized that Lisa might benefit from being included in a clinical trial. And I think the majority of patients with cancer often don't have that opportunity, and clinical trials offer patients potential for new therapies that hopefully improve upon our standard therapy.

And Lisa did in fact not only show enthusiasm for participating in the clinical trial but importantly was eligible for a clinical trial that he had to offer. And I think that's one of the aspects of clinical trials that's hard for many patients to understand is that there are many kinds of cancers and we don't necessarily have clinical trials for all kinds of cancer at all stages of that cancer. But Lisa certainly was willing to participate and proved to be eligible for a clinical trial, so it was a very good fit.

Primary Brain Tumor Clinical Trials at Seattle Cancer Care Alliance

Andrew Schorr:  
Let's talk about that for a minute. So there were some advanced lab tests that were done on the tissue that had been removed from Lisa's brain, her glioblastoma. Not all glioblastomas are alike, so what were they looking for to see whether she could enroll in the trial that you were one of the investigators for? What were they looking for?

Dr. Chamberlain  
Specifically, they were going to measure a repair enzyme that fixes or corrects the injury caused by the common chemotherapy that we use to treat such tumors, that chemotherapy being Temodar. And it appears that a significant marker for effectiveness of that drug is the tumor content of that repair enzyme. And if the
tumor contains a large quantity of that enzyme, which 60 to 70 percent of all glioblastomas do, Temodar is far less effective in that patient group because those tumors are capable of quickly converting an injurious lesion to a noninjurious lesion.

Andrew Schorr:
Wait, I just want to make sure I understand. So the Temodar, has been widely used as a drug for these tumors, it's trying to kill the cancer cells, and what you're saying is some people have a lot of this enzyme, and it repairs the cancer cells and lets them keep living.

Dr. Chamberlain
Correct.

Andrew Schorr:
So the trial was trying other drugs after that to see if it could knock that back so that Temodar could do its job?

Dr. Chamberlain
So in this larger group of patients, commonly and even still today, we would treat those patients much as we would treat patients who as well have very low tumor content of this DNA repair enzyme. Those patients sustain a significant benefit to the inclusion of Temodar in their treatment regimen, whereas it's far less compelling in the larger group of patients that overproduce this enzyme. And so our need particularly is for this large group of patients for alternative therapies to Temodar, and so this trial is designed in the post-radiation phase to provide patients with alternative drug therapies that work through a different mechanism of action and are not dependent upon or responsive to this injury-repair system that's in place in their tumors.

Andrew Schorr:
What were these drugs that you've added in the trial? What are they called?

Dr. Chamberlain
So one is called Avastin or bevacizumub, and this is of fairly widespread use in cancer today as it's the first drug to be commercialized for inhibiting new tumor vascular growth, what's called angiogenesis. And so this is an angiogenic inhibitor that's preventing cancer from growing new blood vessels to support itself and to grow still further. So it blocks that pathway.

The second drug that is used with Lisa, which is an oral drug--Avastin is an intravenous drug--is a drug called Tarceva or erlotinib, a drug well known to patients with non-small cell lung cancer, but as is common for most cancers, so-called epithelial cancers, which make up the majority of patients with solid cancers like lung cancer, brain cancer, these patients have a disturbance in this particular pathway which is a growth factor pathway, and this oral drug is meant to inhibit that signal that allows the growth factor then to turn a cancer cell on to allow it to grow and survive and prevent death.
Andrew Schorr:
Wow. So I always think of with these multidrug approaches, if you will, one is sort of trying to knock the cancer cell down, hit it in the stomach, another one is like a punch to the jaw, but taken together to try to knock that cancer cell down and out with this sort of multipathway approach. Is that the idea?

Dr. Chamberlain
That's exactly the idea, Andrew.

Andrew Schorr:
Okay. Let's take it further. So this trial that we've just used as an example is for a group of patients in this case with glioblastoma, right, who are newly diagnosed? They haven't had any treatment.

Dr. Chamberlain
Correct. Surgery only.

Andrew Schorr:
Now, you have other trials where someone has had a recurrence, so tell us about one you might care to talk about there.

Dr. Chamberlain
Well, unfortunately, glioblastoma frequently recurs, and then patients are in the position to have to decide what would be next treatment. And with respect to drug treatments, one that we've recently participated in and completed is using another intravenous drug, Medimmune 575. Since it's not commercialized, it does not have a common lay name. And this drug like Avastin is a large protein. It's a monoclonal antibody, and that antibody binds to a specific target. So this is--rather than term these chemotherapies we more properly term these targeted therapies. And Medimmune 575 targets a protein that is found on the surface of both the tumors cell and the blood vessels that support the tumor cell and again by binding to this site prevents the signal that allows the cancer cell to grow and support itself.

Andrew Schorr:
So in a sense the first trial we talked about was like first-line therapy in a way, I mean after surgery and radiation. And then here is somebody if somebody had a recurrence there's this trial. I know this one has been completed but I imagine there will be others, as a second line. So when somebody gets this diagnosis and they have a discussion with you, either about approved therapies or trials in this area, can they feel that there can be an approach and hopefully that will work for a long time and then there still may be another that can give them more time, if you will?

Dr. Chamberlain
Yes. I think our desire right now is that we recognize that with glioblastoma we don't have curative therapies, and so we're attempting to change the trajectory, the course of this cancer where rather than having it behave as a relatively acute
illness with short survival to prolong survival and maintain good quality of life with therapies punctuated throughout the course of the cancer in order to provide that improved survival and improved quality of life.

**Andrew Schorr:**
Dr. Chamberlain, we've been talking about one type of cancer. Now is glioblastoma the most common primary brain cancer?

**Dr. Chamberlain**
Actually, it's not. The most common primary brain cancer would be a meningioma. That constitutes 25 to 35 percent of all primary brain tumors. Glioblastoma, amongst the gliomas would be the most common and the second most common brain cancer.

**Andrew Schorr:**
Now, in the meningiomas, how are we doing there as far as research and trials that you have?

**Dr. Chamberlain**
Our group is interested in clinical trials for meningiomas, and interestingly this same signaling pathway inhibitor, Avastin, appears to be a common mechanism as well with meningiomas, and we presently have a clinical trial open and enrolling patients with recurrent meningioma who don't otherwise have further surgical or radiation treatment options with which we can use this drug as well.

**Andrew Schorr:**
I know there are many different types of brain cancer, and we've talked about a couple, and we've also talked about recurrence. So when somebody comes to see you it sounds like it needs to be a very individualized discussion. What is their brain cancer situation, their biology related to their tumor, their health status, and then how does that match up with either standard therapies or what may be in research? Am I right? It's a very personal discussion.

**Dr. Chamberlain**
Yes, and I think it's always been that way, but I think increasingly this concept of personalized cancer care is moving still forward, and Lisa I think exemplifies that very well because we've now taken glioblastoma and rather than treating all comers the same begin to subdivide glioblastomas into various biologic subtypes and attempt to have therapies that are specific for that subtype and thereby personalize care still further.

**Andrew Schorr:**
All right. Given that changing landscape, I know you wished it would change a lot faster and we go further and we could use the word cure along the way, it would seem that if someone, wherever they may be listening to this, is diagnosed with a primary brain cancer a consultation, at least, with a neuro-oncologist such as yourself and a discussion about trials included in that would be important, wouldn't it?
Dr. Chamberlain
I believe so, but I think we have to recognize that clinical trials aren't necessarily for all patients, that there are at times logistic issues that come up. We see a fair number of patients, for example, who might reside in Alaska or Montana, and it's very difficult to enroll such patients on clinical trials because of the long distances involved and the need for close follow-up. But I think patients living in the Puget Sound area by all means hopefully they would have the opportunity to at least discuss potential clinical trials for which they may be candidates.

Lisa’s Advice to Other Patients

Andrew Schorr:
Lisa, what do you say about it? From the patient's perspective, given this scary diagnosis, what advice would you give people in at least how to proceed to get information and understand what's right for them?

Lisa:
Well, I feel very fortunate in that Dr. Kline connected me with Dr. Chamberlain right away.

Andrew Schorr:
That was your neurosurgeon?

Lisa:
Yes. And so things were handled, my tumor was removed and sent to the correct laboratory, but I think people that live in other places--and I actually know of a case, someone I know that it didn't occur that way, and once the tumor is removed and it isn't sent to the proper laboratory and a different kind of treatment has started then you can--then you can't participate in the clinical trial. But because everything happens really quickly and it is such a surreal experience--I mean, you don't expect to go in and get an MRI and then have them say, “You have a brain tumor,” [or] have this happen to a spouse or a child.

And I think in today's technology the first thing that people do is to go online, and they just start Googling things, and I've discouraged people from just doing random, you know, checks like that because you get really--there's so much information out there you get really frightened really quickly.

Andrew Schorr:
Right.

Lisa:
And there is no way of checking how factual it really is. But the SCCA website helped me a lot. And so when people have called me since I tell them really to limit their searching on the internet and just stick to the SCCA website.
Right. And they'll hear this program.

Lisa:
The there are plenty of links to other resources there.

Andrew Schorr:
So, Lisa, this program is going to be on the SCCA website. What do you want to say right now to somebody who is listening or reading the transcript, has this diagnosis? You were not, quite frankly, given long to live, whether it was accurate or not by the early doctors you saw, and here you are. You've been doing your job full-time and feeling good for many months. What would you say? It doesn't always work out that way, but what would you say to them? Because they're terrified.

Lisa:
Well, I have to say, I mean, I didn't expect any of this to happen, but I love quotes and I looked through for quotes all the time. I found this quote that said, "Truly happy people enjoy the scenery even while they're on a detour." And I thought, "Oh, that kind of makes sense. My cancer is a detour." But I have been enjoying the scenery, and at SCCA it's easy to enjoy the scenery. You have a beautiful view of Lake Union, and it's like going on a gallery walk every time you have to go for treatment.

Andrew Schorr:
Oh, my.

Lisa:
And so it's not ideal, but I have some good friends to take me for my treatments, and my husband usually comes along once a month, but it's like a girl's day out, and we go to SCCA, and we enjoy the view, and we get to see all this changing artwork.

Andrew Schorr:
Wow.

Lisa:
So I've watched the seasons go by. And I really do feel empowered as a patient. I mean, Dr. Chamberlain has been amazing and his nurse Sandra. Whenever I have a question or if I have had problems that have arisen because of some sort of a medication change and a certain side effect, they get back to me right away and we're able to resolve the problem.

Andrew Schorr:
Wow.

Lisa:
So it's been a learning experience for me.
Andrew Schorr:
Well, I’m glad you’re doing so well. Dr. Chamberlain, I’ve asked you this before, you know, someone who has devoted their life as you have professionally to this field, you’re sort of our barometer for how it’s going, and we gave a couple of examples, and Lisa is an example for sure. I know it’s very variable patient to patient, cancer type to cancer type, even within brain cancer, but what’s your sense of how it’s going now?

Dr. Chamberlain
I think we continue to make significant improvements. We have a much better understanding of the biology of glioblastoma today, and, as I mentioned earlier, are increasingly personalizing cancer care for patients with this disease. And I think every several years we have an incremental movement in a positive direction that provides increasing hope for the treatment of this disease, and I think this is an exciting time. The numbers of targeted therapies based on understanding basic biology of cancer has exponentially increased and provided us with so many new tools, and those are being applied increasingly in patients, as Lisa indicated, in whom we’re often able to specifically look at a patient’s tumor and try to customize therapy based on a molecular analysis of their particular cancer.

Andrew Schorr:
Right. And one other point I think we should underscore, too, and it was sort of implied here, Lisa, you had surgery and you had radiation as well as you’ve had these various drug approaches, right?

Lisa:
Yes.

The Team Approach at Seattle Cancer Care Alliance

Andrew Schorr:
So, Dr. Chamberlain, maybe we should just underscore for people there’s a lot of team work that goes in here. Neurosurgeons, pathologists of course, radiation oncologists, radiology as well, and then you in neuro-oncology all working together.

Dr. Chamberlain
Yes. This is an enormous team at the University of Washington and the Seattle Cancer Care Alliance. We have three neurosurgeons that spend a predominant amount of their time dealing with brain and spine cancer, two radiation oncologists, a dedicated neuroradiologist, three research nurses, four clinic nurses, two nurse practitioners, myself and my partner as medical oncologists, administrative staff. So it’s an enormous team effort that requires a remarkable degree of cooperativity and collegiality in order to achieve results like with Lisa.

Andrew Schorr:
Lisa, so this is kind of a public forum here. Is there any word of thanks you want to say publicly right here to Dr. Chamberlain and that big team that works with him?
Lisa:
Oh, I just—I have my life, and I am so thankful. I would also like to thank Dr. Kim, my radiation oncologist and his staff. And Dr. Chamberlain probably remembers when I first came to Dr. Chamberlain I was really impressed with Dr. Chamberlain. He is also a teacher, and my biggest concern was radiation, and I could handle the surgery, I could handle the chemotherapy, but radiation was really hard for me. When I think of radiation I think of nuclear power plants and yellow caution tape, HazMat suits. It's not someplace I want my brain.

And Dr. Chamberlain was able to draw me a picture and explain everything in detail from a scientific standpoint in a way that I could understand. And for me the knowledge empowered me, and I was still are really, really frightened by the whole radiation part, and I had to go to radiation all day every summer before I began the clinical trial, but Dr. Kim and his staff, they were just amazing and they helped me get through that. And on my last day of radiation I was actually sad to say good-bye because they became like family.

Andrew Schorr:
Wow. Well, Dr. Chamberlain, hearing Lisa tell these stories and her view of it I'm sure helps you—propel you and what you do, and I know we all want to thank you for what you do. Dr. Chamberlain, we'll continue to do interviews, and I hope each time we do it you tell us about some progress. Whether it's incremental or a big, giant step we hope, we just look forward to further results and we're encouraged. And, Lisa, you're an example of that, right?

Lisa:
Thank you, Andrew.

Dr. Chamberlain
Thank you, Andrew.

Andrew Schorr:
Yeah. Dr. Marc Chamberlain is with us, Lisa's doctor, director of neuro-oncologist at the Seattle Cancer Care Alliance, and also Lisa Dempsey. Lisa, thanks for your courage in what you're doing, your dedication to other patients and then day in, day out your dedication to children with special needs. Thanks for all you do.

This is what we do on Patient Power. I meet such wonderful people, and it's really inspiring. Thank you for joining us. I'm Andrew Schorr. Remember, knowledge can be the best medicine of all.

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