



Can Lung Cancer Patients Be the Engine for Driving Molecular Testing?

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Andrew Schorr:

Hello. I'm Andrew Schorr, cofounder of Patient Power and a partner in the Precision Medicine For Me initiative. And joining me now is a leading patient activist in the lung cancer area, someone who has been living with lung cancer, stage IV, since 2009. Very excited to have with us, Matt Ellefson. Matt, thanks for joining us.

Matt Ellefson:

Thanks for having me, Andrew. It's my pleasure to be here.

Andrew Schorr:

Matt, you are the founder of SURVIVEiT, there where you're from in Sioux Falls, and tell us about why you founded it and really what it's all about in helping patients get the right quality care today.

Matt Ellefson:

Andrew, after I was diagnosed, I learned how difficult it was for me it to search and find the very best in cancer care for my particular type of cancer. And because my cancer was so advanced and a late stage disease, I didn't have a lot of time, and I was very frustrated in my search to find the very best in cancer care. I knew I needed the very best in cancer care to survive, but I didn't know where to look. And so we Googled things, and we tried everything we could, but we just kept hitting one dead end after another.

So through a lot of prayer I was able to locate a clinical trial in Houston, Texas. And through that prayer I also made a promise that if I got through this, I was going to do something about it. There are so many great organizations out there that are providing just fabulous resources for people facing cancer, but nobody was addressing what the patient needs to do in the first 72 hours of being diagnosed.

What questions they need to ask their oncologist. Where should they go for a second opinion? What should I do to—talk to my family members about the disease? What should I do to talk to my employer about the disease? You know, those are things that need to happen rather quickly, and patients are never prepared to do it. So we provide the tools to help people immediately after they're diagnosed—or in some cases survivors when they have a relapse.

Andrew Schorr:

What's your feeling about the Precision Medicine For Me initiative and the importance of precision medicine today for patients to get what may be life extending for them?

Matt Ellefson:

Precision medicine in oncology means knowing exactly what is driving your cancer, and in some cases it might be more than one gene mutation, but you don't know how to attack an enemy until you know what that enemy is.

And so first you need to do some diagnostics, and in the case of cancer you need to have your tissue tested for all known gene mutations, and that isn't happening at every cancer center today. In fact, it's happening at a really small percentage when you look at the big scheme of things.

For example, my tissue was not tested for gene mutations when I was initially diagnosed a little over seven years ago. Then although the clinical trial I was in was effective for me, and I was in remission for about a year. When my cancer came back, my oncologist was looking at another chemotherapy protocol to put me on, and it was at that point that I demanded that I have tissue—that I have surgery, have some of that tissue removed and have it tested for all gene mutations. And that is when I really turned the corner in my treatment process.

I determined that I was positive for ALK rearrangement. I started on a drug that targeted that particular gene mutation, and I felt so good within two weeks I started training for my first ever half-marathon that I ran three months later. And that's just fantastic. And that is really what I want. I want other people to have that same opportunity, but people just don't know. They don't know what to ask. And so that is why it's so important for initiatives like Precision Medicine For Me to educate the public and educate patients, survivors and caregivers about what questions they need to ask, how they can locate the very best in their cancer care, and have those tools to do them very quickly.

Andrew Schorr:

What do you want to say to patients so they get the workup, if you will, and then take action with either the right existing therapies or maybe ones that are in a clinical trial like you've received?

Matt Ellefson:

The first step that they need to do is ask their doctor. Ask their oncologist to have their biopsy tested for all known gene mutations. Then also I think it would be very valuable for them to have the 21 Questions to Ask Your Oncologist, and they can download that free of charge at surviveit.org. It's also available at Precision Medicine For Me. It's a very good document. It has 21 questions that you can ask your oncologist. They're all prepared by long-term survivors like me, specific for each type of cancer.

And that is a very valuable tool, because it sets a stage for your discussion with your oncologist about what the next steps are.

Andrew Schorr:

So why are you so passionate about this?

Matt Ellefson:

I believe that one of the worst sins any human can commit is having the ability to help somebody else and doing nothing about it. And because of what I've gone through and the experiences I've gone through and all the different treatment modalities, the different surgeries, I've learned a lot.

And I'm obligated to share that with people, because that provides purpose in my pains and sufferings, and everything that I've gone through now holds some purpose, and it's very liberating in many, many ways.

I also really believe that, you know, how great it feels when you receive love from somebody else, and you receive that caring spirit from somebody else. There's no greater feeling in the world. But I've also learned that you get that same feeling when you give it to other people as well. And so that's what my purpose is in life is to live a life putting service above self and live a life of helping other people and trying to make our world a better place.

Andrew Schorr:

Amen. I agree with you so much. Matt, let me ask you about the state of medicine today and what your hope is in eliminating this disconnect between leading-edge science, which is starting to happen more in the cancer you have, lung cancer, and the most remote patient getting access to it. What's your hope of how we eliminate that disconnect?

Matt Ellefson:

Right now the industry in America at least with oncology is a closed system. The clinical trials are internal. They're often run by a third-party organization. They're very expensive. They have a lot of requirements, and they're only located in select locations around the country.

So it makes it very, very difficult for patients to participate and enroll in clinical trials that may benefit them. It may require them to travel great distances, and they may not have the resources to be able to do that.

So what I want to see is more of an open system, a system that everybody has access to the very best in cancer care. If there's a clinical trial that early data shows very promising results, then let's open that up to every cancer center that has the ability to run clinical trials. And that will not only increase the enrollment numbers and provide better data, but it also provides life-saving medicine to those who need it most.

If you're fortunate enough to live in a city that has an NCI-designated research cancer center, your odds are much better for you. But unfortunately 85 percent of cancers in America are diagnosed and treated in small community cancer centers, and those people, they need help too. And so you shouldn't be limited by the level of care that you're provided just because of where live or just because of your economic status or just because of the color of your skin or your age. None of that should matter. Everybody should have access to the very best in cancer care.

Andrew Schorr:

So where we are now, with an imperfect system but where people, families are diagnosed with these serious conditions, lung cancer being a notable example? What do you want to say to patients related to what we can do through Precision Medicine For Me, so they take back control to find out what they're dealing with and then locate the resources, unfortunately sometimes at a distance, but locate the resources that can help them with what they have?

Matt Ellefson:

Andrew, what I would like is when a patient is diagnosed for them to be able to know what questions to ask their oncologist, and the first thing they should do is find a second opinion. They should also, though, ask that their tumor tissue be tested for all known mutations. And if they can do those two things, they're going to be far ahead of the game.

Unfortunately, nobody ever expects to receive a cancer diagnosis, so nobody's ever prepared. They don't know what to do when they receive that diagnosis.

That is why it's so important for initiatives like Precision Medicine For Me and organizations like SURVIVEit to help educate the patients to become more engaged in their treatment strategy.

If you use me for an example, I was treated at what is considered the number one cancer center in the world. And I had a relapse. I had not had complete genomic testing. I had learned that I needed to do that through helping other people and talking to other survivors that had had it done. I didn't learn it from my doctors. And so when I had my recurrence, I asked that that tissue be removed through surgery, and we run a complete genomic profiling of that tumor. The doctor there at the number one cancer center in the world wasn't going to do that. I had to ask.

So you can't ever assume that your doctors know everything, even at the very best place this gets missed. So that is really, really important. Never assume that you're receiving the very best in care. Always talk to other survivors, talk to long-term survivors that have demonstrated the ability to face this disease head-on for a number of years and survive it. That is where you're going to get a lot of information.

Now, certainly that doesn't replace an oncologist or doctor. You definitely need your medical team, but it augments it in a very, very big way that can mean the difference between life and death to the patient.

Andrew Schorr:

That's what I was going to ask you. Do you believe that this strategy of the patient and the family really asking questions and speaking up, that that is life extending, maybe even lifesaving?

Matt Ellefson:

Absolutely. Andrew, it absolutely is. There's no question in my mind that it is. Again, you know, we all have friends and loved ones over the years that have received a cancer diagnosis, and they survived. And then another loved one receives the exact same type of cancer, they go through the same chemotherapy treatment, and they don't survive. And the reason it was because they had different gene mutations, but they weren't testing them then. And that chemotherapy agent worked on the one gene mutation, but it didn't on the other cancer patient with the same type of tumor.

We see that happen all the time with people. Some people make it, some people don't, and—and the reason is, nine times out of 10, is because they weren't properly diagnosed. They didn't have the right diagnosis up front. They didn't have their tissue sequenced, and they didn't know what specifically to stop, which gene was driving the cancer.

Andrew Schorr:

So here we are today with medical science moving forward. So there are some approved targeted therapies, some immunotherapies that may help other patients, but there's a lot in research. A lot of people are hesitant about clinical trials or don't even know what it is, so I know we should have more availability of trials. But what would you say to people about finding out is there a clinical trial that might maybe offer them tomorrow's medicine today and that they should consider it?

Matt Ellefson:

A lot of people are afraid of clinical trials just because of the stigma that still lies with them. They feel that they may be a lab rat and that they may receive a placebo and may end up dying because of that, and that couldn't be further from the truth in today's setting.

At the very least, the patient is going to be receiving a standard of care, oftentimes—if you have late disease today, I believe that a clinical trial is the best place you could be, because the researchers and the pharmaceutical companies are at a point right now where they're developing these medicines at such a fast pace. And they're able to take promising medicines and tweak them a little bit to make them also effective for different gene mutations, and it is like night and day difference between having standard of care and having an effective targeted therapy through precision medicine.

So you are actually receiving tomorrow's medicines today. You shouldn't be afraid to enroll in a clinical trial. You should do your research and know what trials are available to you. There are a number of great tools to do that. You can do that at surviveit.org through our partnership with Antidote and search for a clinical trial there as well, and I would highly recommend people to do that.

Andrew Schorr:

Well, we've talked about a lot, and I think in the end it's about the patient and their loved ones who are supporting them really taking back control. None of us wanted to be diagnosed with cancer, it's terrifying, but it seems like you've got to pick yourself off the floor, and, as you said, what are you dealing with and what is the full range of options, existing therapies including what may be in clinical trials. Did I get it right?

Matt Ellefson:

You got it right, Andrew. That's exactly what you need to do.

Andrew Schorr:

Okay. Well, Matt Ellefson from SURVIVEIT, thank you so much for your dedication to patients, your leadership with survivorship and, Matt, we just wish you long-term good health. I'm so delighted you're with us today and hope we can do this again and again and again over many years to help a growing number of patients. Thank you for being with us.

Matt Ellefson:

Well, thank you, Andrew, and thank you for everything you and your team at Patient Power do for those affected by cancer.

Andrew Schorr:

Thank you. Well, Andrew Schorr from Patient Power and as part of the Precision Medicine For Me initiative, we hope this is helpful. Remember, knowledge and you taking back control can be the best medicine of all.

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