



Patient Power

Take Control of Your CLL

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Julie Lanford:

And greetings from Encinitas, California and the UC San Diego Cancer Clinic. Having an infusion, Andrew Schorr.

Esther Schorr:

Esther Schorr.

Andrew Schorr:

And, welcome to Patient Power...Okay. We are experimenting with some new technology. We have no idea what we're doing. So, here we are.

Esther Schorr:

You're making that really obvious, Andrew.

Andrew Schorr:

Yeah, but basically we're trying to really globalize what we're doing at Patient Power. And today we have a special guest with us, and that is our dear friend, Jeff Folloder. And there's Jeff.

Esther Schorr:

Hey, Jeff.

Andrew Schorr:

Hi, Jeff.

Jeff Folloder:

Hi, guys.

Andrew Schorr:

And Jeff is joining us, and we're going to figure out how we do a split screen. There is some way to do it and I think it's just like that.

Esther Schorr:

Whoa!

Andrew Schorr:

Whoa! Where's Esther?

Esther Schorr:

Here. I'll just rest on your shoulder.

Andrew Schorr:

Jeff's in Houston, and we're trying all kinds of new technology.

Esther Schorr:

And let's get to the meat!

Andrew Schorr:

And, of course, it's on the wrong side of the screen. But anyway, Jeff's in Houston. We're in Encinitas, California and we're running like a TV show here. Jeff, you, like me, have been living with chronic lymphocytic leukemia for how many years now?

Jeff Folloder:

Almost 10 years 10 years now.

Andrew Schorr:

Okay. How you doing?

Jeff Folloder:

Recently relapsed. I enjoyed six-and-a-half years of complete remission after a clinical trial at MD Anderson, was told in July that I've relapsed, so in my brain I know that I've relapsed. My body's not quite paying attention to it. I continue to speed walk every morning and even knocked out a marathon in November.

Esther Schorr:

Wow! Way to go, Jeff!

Andrew Schorr:

Yay, Jeff! Well, Jeff, also, you do volunteer work in Houston with people with all cancers, right?

Jeff Folloder:

Yes, sir.

Andrew Schorr:

And so you've heard it all, and for our discussion today we're going to talk about that. And also, though, you're the sort of leader or administrator of one of the largest groups for CLL patients online. The name of that again is?

Jeff Folloder:

The CLL Support Group on Facebook. I don't know whether it's a good thing or a bad thing, but we're approaching 5,000 members on a Facebook group, which just kind of blows my mind away.

Andrew Schorr:

Right, and I'm part of it. There are some things that come up there that we want to ask you about that probably apply to people living with any cancer today.

Jeff Folloder:

Sure.

Andrew Schorr:

What are some of these recurring themes that you're seeing a lot that people are talking about?

Jeff Folloder:

Well first, I really want to stress that the online community, the social media community has really embraced the idea that CLL treatment is personalized these days. We're not just looking at shotgun approaches with chemotherapy; we're going for personalized approaches with new and novel drugs which make better outcomes, which make less toxicity, less side effects, all the check marks on the list of treatment.

But at the same time, almost daily we have several threads going up on things like, "How can I eat better? How can I exercise better, and will this actually have an impact upon the progression of my CLL?" And there's so much excellent conversation. It's beyond, "I think I should just drink green tea." People are taking a whole-body approach and it's really exciting to see, because some people absolutely can derive positive benefits from an exercise regimen or a better eating regimen. They don't have to be ascetic monks, but they do have to look into making some improvements.

Andrew Schorr:

I think all of us are trying to be more in control. I'm getting my immune globulin injection (Gamunex), or IVIG, now. So this is what I get once a month, so when I'm not in the clinic, which is about once a month, I know I'm trying to bike and I'm happy to say, Andrew got to ride 20 miles this weekend, yay, or we hike. Not everybody can do that. I get it. But whatever you do is to the good and I think all of it is us trying to be more in control. Now people are also—not just exercise – they're looking at diet, you mentioned.

Jeff Folloder:

Yes.

Andrew Schorr:

I am trying a gluten-free diet because our daughter is doing it actually. And I've been losing a little weight and I feel better just having taken the weight off, or however I'm doing that, the exercise. But is that what people are talking about, too, is diet and also even additives? I know there's been some discussion about CBD drops.

Jeff Folloder:

There is all of that going on. It's a whole-body discussion that's taking place in the social media caves and warrens of Facebook. People want to know how they can take an active measure in taking care of themselves, not just going to the doctor and getting an IV like you're doing, but also the exercise. When people say, "I just don't have the energy to exercise," we encourage them to just get up and walk 30 minutes a day, three times a week. It's a great start and most people are not really believing it, but they're willing to give it a try. And once you start moving, things do start to get better.

Now you mentioned the CBD oil. CBD has become quite the hot topic on social media. As more and more states are legalizing CBD, which is a form of cannabis, we're trying to find out will this have an impact upon CLL patients. Will it help lower their white blood cell counts? Will it lower their inflammation? Will it shrink their lymph nodes? And the answer is we don't know yet because we haven't done enough clinical trials to specifically connect the consumption of one CBD product with the reaction of your numbers going down.

Andrew Schorr:

Right. And again, for any—we're talking, you have CLL, I have CLL and also myelofibrosis. It'd be the same.

Esther Schorr:

Well, and also two things, Jeff, I just wanted to comment on: One is because there haven't been these controlled clinical trials as with any other substance that somebody would ingest or infuse or whatever you don't know what the quality of what you're getting if you buy it or you try to consume it yourself is because it's not a controlled thing. And the other thing that I was just going to—somewhere in the conversation, it'd be good to – I'd like to ask you, Jeff, and maybe, Andrew—comment on when loved ones, care partners read about these things that are coming down the pike, you know, sometimes we struggle with should we suggest this to our loved one, to the doctors? I mean, there's so much stuff going on that's coming up like this, we kinda struggle with, you know, what do we do with that information, so...

Jeff Folloder:

...well, I'm glad you mentioned the doctors, because it's become the top of my list, not necessarily as a disclaimer, but I tell people, whether it's on social media whether it's through my clients at CanCare, whether it's through sitting in a lobby at the doctor's office, include your healthcare professional in the decision-making process, because your doctor actually may be right on board with a patient trying CBD oil. He may be able to give you some really good watchouts as to where to get it, how to take it, what to look for, and what issues may come up while you're trying something. But that works with CBD. That works with any dietary supplement.

Esther Schorr:

Vitamins, anything.

Jeff Folloder:

That works with exercise. That works with everything.

Andrew Schorr:

Yeah. You have to talk—somebody watching, Jessie Posso just wrote in, well, could we comment on pain, back pain. So let's talk about that for a minute. Last week, I think it was Friday, I spoke to our friend, a myeloma patient Cherie Rineker, and there's quite a discussion in one of our archived videos that you can see about the opioid crisis, but opioids for cancer patients.

Jeff Folloder:

Right.

Andrew Schorr:

And so it's an active discussion that you need to have with your doctor. Obviously, there are other pain approaches from higher dose of acetaminophen (Tylenol) to physical therapy to...

Esther Schorr:

..acupuncture.

Andrew Schorr:

Acupuncture. And in many of the larger cancer clinics they do have a palliative medicine specialist, or you can ask about that, whose job it is to help you with suffering.

Esther Schorr:

Well, that's sometimes called integrated medicine, too, right, not necessarily palliative. It's...

Andrew Schorr:

So, yeah. Ask about that. But palliative now really is not about end-of-life, but it's really helping you palliate issues you're facing that are affecting how you're living as you're living with cancer. So, you need to speak up about that. There's no—so now Jessie's just written in. Her doctor recommended swimming and core and back exercises, and that's very true. And I have to tell you, I go back to the gym and I do a lot of back and stomach exercises, and I used to have a lot of chronic back pain. I don't anymore. So those are things to think about.

Our producer Theresa put up the link to our discussion with Cherie about opioids. It also has a very interesting discussion about end-of-life planning and the whole death with dignity, which now our friend, Carol Preston, who's in Maryland—and Carol, like you, Jeff works with Patient Power. And there's something going through the Maryland State Legislature to model their law after Oregon and California and Colorado, Washington State, and some others about how you could basically have death with dignity and not suffer when really it is close to end of life.

Esther Schorr:

And that is a separate discussion from what we were just talking about, which is how do you live with...

Andrew Schorr:

...but it's really—it is and it isn't in a way, Esther. It's all about the patient being in control.

Esther Schorr:

Oh, of course. Yeah. I just...

Andrew Schorr:

...and?

Jeff Folloder:

Well, part of that control, though, is also being up front with your care team, and that includes your care partner and that includes your doctor and that includes the PAs and that includes the nurses, everyone. I was told a long time ago in the hospital that you can get anything you want at the hospital as long as you ask for it. And it seems like such simple advice, but we all literally forget that it's okay to ask for things. Yes, there is absolutely an opioid crisis and most doctors are scared to death to write prescriptions for opioids these days. It's a problem.

Andrew Schorr:

Right.

Jeff Folloder:

But if you sit down with your CLL specialist and say, "I'm having back pain."

Andrew Schorr:

Or any cancer specialist.

Jeff Folloder:

Or any cancer specialists and say, "I'm having back pain," or, "I'm having deep bone pain," or, "I can't move my neck," or, "I can't do this, and it's affecting my life," you will come up with a plan to get you to a better place. It may involve opioids; it may be something else.

Esther Schorr:

But if you don't say anything, it won't happen.

Andrew Schorr:

Right.

Esther Schorr:

Sure.

Andrew Schorr:

Well, a couple things about diet you were mentioning. So we do have a series with Julie Lanford, the cancer dietitian, on diet, so we'll be sure to put a link up for that. Take a look at those.

Jeff Folloder:

I caught bits and pieces of that online, and it's excellent information.

Andrew Schorr:

Yeah. Thank you. About 5,000 people have watched that. Also...

Esther Schorr:

...and our recipes.

Andrew Schorr:

We're doing recipes and we invite people to send in their recipes, Patient-Powered Recipes, and we share those. We're also doing programs on meditation and mindfulness.

Esther Schorr:

Yoga.

Andrew Schorr:

Raquel Forsgren does that. Cathy Skinner does a program on exercise—"It's not what you can't do; it's what you can do." And then the whole communication process that Jeff was just talking about sharing all of this with your healthcare team so that it's this 360-degree support for you: exercise, diet, mindfulness, mental health, the right medication, awareness of clinical trials, are there new supplements that could be helpful, or could it be harmful?

Esther Schorr:

I'm going to put in a plug, too, that other than the medication side of things, the treatment side, everything you just mentioned is stuff that care partners and loved ones who are part of that circle of trying to support a patient, all of that—yoga, meditation, counseling, good diet, getting sleep—all of those things I think we need to think about as well to keep ourselves centered and able to be supportive. So we have a Care Partner Center...

Andrew Schorr:

...and a Living Well Center. Tell us about that.

Esther Schorr:

Well, and actually Patient Power is in the midst of a complete redo of our website, which will come in the springtime sometime, early summer. And ahead of that, we've taken all of this content that we were just talking about—diet, exercise, meditation, all the things that apply across all conditions and that also apply to care partners—into a center called Living Well. And so if you're looking for that kind of guidance, a quick way to get to that is to just go to our site and look for Living Well. It's there, and so we've kind of collected all of that in one place.

Andrew Schorr:

Right. And somebody just wrote in about..."reeky." Is that how you say it?

Esther Schorr:

Reiki...Reiki? Sorry.

Andrew Schorr:

Yeah. But anyway, we do have a massage therapist. I think it's Steven Mc—is it Michael McDonald? Stephen McDonald?

Esther Schorr:

Michael McDonald sings.

Andrew Schorr:

Yeah. Well, maybe yeah. He gave...

Jeff Folloder:

...he was part of the Doobie Brothers.

Andrew Schorr:

But we're talking about oncology massage. We've certainly talked about acupuncture, so all of that we're amassing in this Living Well Center, and we welcome your suggestions. Someone just wrote in also about thanking me for kind of defining palliative in a broader way, because that's what it's become in recent years. So hopefully, with the medicines like you and I know about, Jeff and Esther, for CLL or what I've been getting for myelofibrosis, or even people now with stage IV lung cancer living longer and now all of us trying to live better. So these other things come into play. It's not so acute.

Now, on the flip side, we are covering some acute conditions and one of them is acute myeloid leukemia. And we have a webinar coming up, I think on the 22nd, but Theresa will put up the link. If you or a loved one are dealing with acute myeloid leukemia, you know it's, as we describe, a five-alarm fire. But what's so critical now with several new medicines that have come out for different subtypes of that is that you get the right testing so you get the right treatment and it can make all the difference in extending you or loved one's life.

Esther Schorr:

And that's a quicker decision timeline for people, so you really want to be educated fast about it.

Andrew Schorr:

Yeah. The timeline is shorter, but if you can come out the other side, then all of this stuff – diet exercise, everything else we've mentioned—it all comes into play.

Esther Schorr:

Of course.

Andrew Schorr:

Because now maybe you're living and hopefully you've beaten the cancer, but if you haven't beaten it, you've beaten it back and you can go on with your life. Jeff, I want to just thank you for all you do for people generally living with cancer because there you are in Houston as an ongoing volunteer and then online, specifically with the CLL or chronic lymphocytic leukemia, almost 5,000 people and what you do there. Thank you, and when are you going to have treatment again? When does that start?

Jeff Folloder:

It's a big, giant question mark. I am back in that wonderful bucket we call "watch and wait." The first time around, watch and weight scared the bejeeppers out of me. This time, it's not quite that big a deal. My doctors are telling me that yes, I'm relapsed, but no, it's not time. And so I get up in the morning and go knock out 10K. Sometimes I have the bacon...

Esther Schorr:

...keep walking.

Jeff Folloder:

Absolutely. And sometimes I have the bacon cheeseburger, but not as often as I used to.

Andrew Schorr:

And speed walking. Well, just a word is I'm doing well with the IVIG once a month.

Jeff Folloder:

Excellent.

Andrew Schorr:

I think I mentioned last time, Esther and I went to New Zealand. Hello, Kiwi friends and also our Aussie friends. We visit Melbourne, Australia. And no colds no pneumonia, so maybe this stuff works. And then with the myelofibrosis I'm very grateful for now, I think it's seven years I've been taking this medicine, ruxolitinib or Jakafi, and it's been keeping it in check, a genetic inhibitor.

Jeff Folloder:

Andrew, I've got a question from the CLL folks on Facebook. We've been tossing around the term IVIG throughout this video, and you said it a lot.

Andrew Schorr:

Immunoglobulin.

Jeff Folloder:

What is it? What does IVIG do for you?

Esther Schorr:

Great question.

Andrew Schorr:

Thank you. So, what happens is your IGs can become low from the treatment you've had or your blood, and so this is sort of your natural infection-fighting components of your blood. And so there's a blood product that can be made from other people's blood that can be given intravenously to boost some of your IGs. I don't remember whether it's IGA, or there are a few that...

Esther Schorr:

...there's a couple of different IGs, right? Yeah.

Andrew Schorr:

But it boosts it. And at least for me, where we're at risk with leukemia of getting and dying of an infection, this is preventive medicine. So...

Jeff Folloder:

...outstanding.

Esther Schorr:

And in fact, Andrew would not have gone with me to New Zealand on order of his doctor unless he was doing IVIG monthly, because the risk of being in a tin can in the air at 30,000 feet with people sneezing and coughing and doing all that, this is extra preventative. And so I think he thinks it's worth it; I sure do.

Jeff Folloder:

I think you both chose wisely.

Andrew Schorr:

Lots of people are watching. I don't mean to make this too long, but Joey Rhoden, he said do I think that Jakafi is better than peginterferon alfa-2a (Pegasys).

Esther Schorr:

Whoah.

Andrew Schorr:

A couple of brief comments: These medicines are different. Pegasys is an interferon, a pegylated interferon, a longer-active interferon that is used to basically control polycythemia vera in some people. Jakafi – or ruxolitinib is the generic name—is an inhibitor of one of the genes that drives the myelofibrosis and sometimes in some people polycythemia vera, another one of these MPNs, and it can kinda tamp it down, as it has for me. So it's different. And so that's to be discussed with your MPN specialist, Joey.

Esther Schorr:

Absolutely.

Andrew Schorr:

Whether I need an interferon sometime, would that come into play, we'd have to see. But right now I'm on this pill. One last thing before we go, very much this year we're going to be discussing, in the US, drug costs. Okay? It's a big public debate. The medicine that I receive as an oral pill is \$14,000 a month. Medicare pays for the bulk of it, but I have to pay \$708 a month, and in month one of every year like \$2,300, because I work and there are no foundations that come into play. Should we have that cost or should insurance cover more of it. If you have commercial insurance, what about your situation?

Esther Schorr:

And there are some differences between some of the things that are oral and things that are infused and the costs.

Andrew Schorr:

Yeah. This deal costs like \$10,000 a month for the IVIG. Medicare in the US covers all of it. Great, but this is still expensive stuff. Should it all cost that much? And then lastly, for our friends outside the US, access to any of these medicines. Right?

Because the government may say, "Oh, well, we're not gonna do that. We're not going to pay for that," when maybe there's all sorts of medical evidence that could make a huge difference for you.

Esther Schorr:

And there are cost factors in those countries, as well. Is there any existing drug that's worked fine for a long time? They may question why would you move to a more expensive medicine.

Andrew Schorr:

Right.

Esther Schorr:

So there are a lot of issues that people are struggling with, governments as well as individuals and medical professionals.

Andrew Schorr:

In fairness, newer is not always better, okay? The breakthrough medicine is sometimes a breakthrough, and sometimes is just a slight variation on what already exists.

Esther Schorr:

And that's why I stick with you after 30-some years. I'm not looking for a new model.

Andrew Schorr:

Oh, I'm not a breakthrough?

Esther Schorr:

No. Sorry.

Andrew Schorr:

Oh, okay. Jeff's a breakthrough, but he's married. Okay. All right, Jeff. Thank you. We wish you well. Thank you for connecting with us.

Jeff Folloder:

You're welcome.

Andrew Schorr:

I'm going to try just, friends, because I'm a former TV producer, Esther's a producer, to play one little outro video. We'll see if we do it. I don't know all the buttons here. Jeff, I'm going to let you go.

Esther Schorr:

Thanks, Jeff.

Jeff Folloder:

Okay. Thanks again. Thank you.

Andrew Schorr:

Thank you so much. He's the greatest. And we're going to see if we can play this last little clip as we say goodbye. We'll fine-tune our approach. But isn't this cool? And it really doesn't have any real cost to do it, and we hope it's helpful.

Esther Schorr:

And remember, knowledge can be the best medicine of all.

Andrew Schorr:

Andrew and Esther. Right. Bye-bye, everyone.

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