



Patient Power

CLL Access to Care: How Patients Can Get Access to the Latest Treatments

Gwen L. Nichols, MD

Executive Vice President, Chief Medical Officer
The Leukemia & Lymphoma Society (LLS)

Larry Saltzman, MD

Executive Research Director
The Leukemia & Lymphoma Society (LLS)

Kathleen Toomy, MD

Medical Director, Steeplechase Cancer Center
Somerset Medical Center

Hildy Dillon, MPH

Vice President, Education and Support Programs
Cancer Support Community

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.

Andrew Schorr:

Hello and welcome to Patient Power, I'm Andrew Schorr. We're on location at the American Society of Hematology meeting in San Diego. So, this is more than 20,000 people, really the leading edge of investigation, research, presentations, new information about testing and treatment for blood-related conditions, and, of course, blood-related cancers.

And I have a wonderful panel with us as we discuss: really, how do you get access to what's changing in this whole hematology field? Because it's one thing if somebody invents it, but if you can't get it, so what? Right? So, we're gonna discuss that, and I'll let them introduce themselves. So, first of all, Dr. Gwen Nichols, your title?

Dr. Nichols:

I'm the Chief Medical Officer at The Leukemia & Lymphoma Society.

Andrew Schorr:

Right, and you've been a hematologist/oncologist for quite a while.

Dr. Nichols:

Yeah, we won't say how long.

Andrew Schorr:

Next to you is Dr. Larry Saltzman, but a good friend who's also a patient, Larry, and with the LLS.

Dr. Saltzman:

Yes, I'm an Executive Research Director with The Leukemia & Lymphoma Society. And I am also a CLL patient going on nine years now. I went through three-and-a-half years of the dreaded "wait and watch" or "wait and worry." and then several treatments, two clinical trials, and I'm now in remission on two oral targeted drugs.

Andrew Schorr:

Really leading edge of medicine.

Dr. Saltzman:

Yes.

Andrew Schorr:

Okay. And then, Hildy Dillon who we've known for many years, and you're with the Cancer Support Community, what's your role there?

Hildy Dillon:

Yes, I'm Vice President of Education and Support Programs for the Cancer Support Community.

Andrew Schorr:

Okay, and each of you—the LLS and the Cancer Support Community—have people who can help you around the country. Okay, that's great. And then, also, let's face it, not everybody goes to a big academic medical center—you used to be at Columbia, and Memorial Sloan Kettering, and I went to MD Anderson—the big university centers, most people do not get treatment at these places, they go to very devoted community oncologists.

And so, joining is Dr. Kathleen Toomy, and you're from Somerville, New Jersey?

Dr. Toomy:

So, I'm the Medical Director of the Steeplechase Cancer Center. and I mostly see breast cancer patients, but I'm a general oncologist, so I see patients with everything.

Andrew Schorr:

As we say, "all comers," and how long have you been in the oncology field?

Dr. Toomy:

So, over 30—over 30 years.

Andrew Schorr:

So, we're talking about seeing thousands and thousands of patients, of course.

Dr. Toomy:

Well, I think I see the forest for the trees now because I have patients that have—I've had for 30 years, so it's wonderful.

Andrew Schorr:

Well, that's good news! So, I wanna start with you, Dr. Toomy, so you're here at this conference, and you continue to hear and learn about the leading edge of medicine, really, and you must be just so thankful that it's changing and improving.

But you also have people back home where it's not always accessible to them, you have concerns about that, tell us about that.

Dr. Toomy:

So, I think almost for the first time—this past week, actually—I had two patients: one who's looking forward to his retirement in three years and telling me that in three years the medicine he's on—he has chronic myelogenous leukemia—that it will cost him \$1,000.00 a month, and he's not sure how he's going to afford it, and he's looking ahead to what he's gonna have to do in three years from now. He has four sons and he says, "My sons can't help me," and I said, "Well, you know, you might have to say them, 'Each of you give me \$250 a month to keep Dad alive,'" the kind of questions and things that people have to think about and go through. I have a second patient—she happens to have lung cancer—but she is a retired nurse.

And there is a newer medication out there—she has something called an EGFR mutation which means there's an oral pill she can take—and she's putting it off until after the first of the year; she is retired, she is on Medicare because of deductibles and the beginning of the year. So, it's—and that was really the first time that I had two patients in the same week talk to me about real concrete plans. In the past, we've tried to help people, and look at foundations, and get our billing department involved, but for a community oncologist we don't have a financial navigator, we don't have an in-house social worker.

I mean, we rely on people like Leukemia Lymphoma Society and then the Cancer Support Community to help our patients navigate, something that I see coming, just looming larger and larger.

Andrew Schorr:

Okay, and you've probably had cases where given the cost of care people have had to get second mortgages on their house, or reverse mortgages on their house, just really be put in a financial strait.

Dr. Toomy:

Well, the thing that I've heard from patients is deciding whether to eat or get their medicine.

Andrew Schorr:

Hmm, right.

Dr. Toomy:

So, it's even—I don't think that oncologists even know—what financial straits our patients are in. We know the ones of the lower socioeconomic groups that might be having problems, and we probably give them more attention than we give to the people in the middle.

Andrew Schorr:

Mm-hmm, mm-hmm.

Dr. Toomy:

That's why I'm starting to worry about the people in the middle!

Andrew Schorr:

Right, right. And Gwen, you've heard like with CML, I know as there were oral therapies developed that were breakthrough...

Dr. Nichols:

Yes.

Andrew Schorr:

...in changing lives. There were people who were cutting their pills.

Dr. Nichols:

We've done a number of studies looking at this, and I think we'll have several that will be published, and one that's at this meeting talking about what people do to be able to continue to take the medicine.

And oftentimes, they are making either personal decisions about giving up other things in order to afford the medicine, or taking the medicine improperly.

Andrew Schorr:

Yeah, changing the dose!

Dr. Nichols:

Changing the dose, skipping the pills, waiting three months—and the efficacy of these medicines—particularly CML is a perfect example—can be dramatically different if it's not taken in the proper dosage, because that's how we know it works. A lot also, rides on us pushing the pharmaceutical companies to do studies of drug holidays and stopping drugs early. And I think that that's—there's some data finally at this conference about: can you stop this medicine at a point of minimal disease?

And I think we're learning finally that isn't in the drug companies' financial interest, right? They want to continue, this is a business.

Andrew Schorr:

But it isn't the...

Dr. Nichols:

But it's in the interest of the patients, and I think they are finally seeing that this is the right thing to do.

Andrew Schorr:

Okay, you mentioned about treatment but, Larry, you know so well too that we're looking at: are treatments working, can you stop? And there's this term that's come up now: testing for "minimal residual disease," or even ahead of that, "what version," like what version of CLL do you have, what version of CLL do I have genomically, right? Or what deletions, et cetera? Are we in a different type of CLL, you than me, et cetera? These tests are expensive.

Dr. Saltzman:

Well, the tests are expensive; frankly, I just had a measurable residual disease test done on my bone marrow. And not to bang on my insurance company, but the \$1,800.00 cost wasn't covered, because the test is approved for ALL, as an example, but not CLL; so this was felt to be an experimental test, and we're still on appeal to see if we can get it covered.

And with regard to the cost of medications—not to speak too personally—but luckily, I made it to Medicare and on the drugs I'm taking, we went through the Medicare Part D analysis of what my co-payments would be, and on an annual basis it would be \$20,000.00 a year to keep the drugs flowing. So, there are significant cost issues, not only with testing but also with the drugs themselves.

Andrew Schorr:

For sure. So, Hildy, the Cancer Support Community has really helped people a lot, not just with the access issues, but also coping just with the stress.

Hildy Dillon:

Right.

Andrew Schorr:

And I think Dr. Toomey was referring to the stress of her patients. You wanna—you've been given this terrifying diagnosis of cancer, there's a promise of modern medicine helping you, and you're trying to say, "Well, how can you cope with this in your life?" The treatments and the affordability, right?

Hildy Dillon:

Right.

Andrew Schorr:

And you all are very devoted to helping people with that.

Hildy Dillon:

Yeah, so the—at the Cancer Support Community through our affiliates and also through our helpline, we do distress screening. And the reason for that is because whether you're just initially diagnosed, or you've been living with your disease for many years, the distress that goes along with this diagnosis—for the patient and the caregiver—does impact your access to therapies, and also adherence, adherence to therapies.

Andrew Schorr:

Sure. Financial toxicity.

Hildy Dillon:

Yeah, yeah. And what we heard here about patients making really some dreadful choices in their lives to be able to afford their therapies, we all hear this all the time. And the most common call that we have—both in our community affiliates and also through our national helpline—is people that need help with financial navigation. When you're diagnosed, I always say that when we wanna buy a car in America, or you wanna buy a home in America, you research, and because you know what you can afford per month.

When you're diagnosed with a devastating disease, or a life-threatening disease, there isn't anybody who can tell you, or who will tell you what this is going to cost you per month in the long run. And it could be the difference between a meal on your table, or a home, shelter; people just—\$20,000.00 a year is a lot of money to people that...

Andrew Schorr:

To anybody!

Dr. Saltzman:

To anybody!

Hildy Dillon:

...or to anyone, and we don't plan for this in our lives. People assume that if they have insurance that they may have to pay something for their care, but they are...until you get sick you don't know what your insurance doesn't cover, so.

Andrew Schorr:

Kathleen, I wanna ask you, we've been hearing about this testing—genomic testing—to know—what subtype of a disease do you have so you get targeted therapy? You mentioned earlier lung cancer; do you have the EGFR gene? Or what is it for me with myelofibrosis, do I have JAK2 V617F? What is driving it and is there medicine for that? And then also, we were talking about minimal residual disease testing, has the therapy you've had worked? But often, there's opposition by insurance companies to paying for tests—like Larry was talking about—as well as paying for treatments. You must have battles at the community level with insurance companies.

Dr. Toomy:

So, I always take the approach that the person on the other end of the line is a human being, and I will be as nice to them as I can because I'm trying to get something for my patient, and that's usually to pay for a test. As I was coming out here, I actually have two calls for something called peer-to-peer looking to get a PET scan for a patient, looking to get a genomic test for a breast cancer patient paid for. And some of the times the physician calls me because it's another physician, and I go, "Blah, blah, blah," and they go, "That's fine, here's your number," and other times they say, "No, the NCCN guidelines do not," and I will tell you, in general, they're reasonable. I think what they're doing is healthcare rationing by inconvenience. We have to set up that call and very interestingly it's only recently that they're now calling us.

Before on my day off—which is always my day to get caught up—I would be, "Okay, I can call them and I can hang on for a half hour, 45 minutes, or I can have a staff member hang on for an hour or whatever it is, and then put me on the phone." So, many people probably drop off from that point of view, "Okay, we won't do this test because your insurance company won't pay for it." I think there's a lot of financial...there's a lot of problems with literacy, financial literacy, I think you hit the nail in the head. I think that we, the physicians, are protected from knowing what financial toxicity our patients have; we don't even know the costs of the tests that we order.

We may know, we may—some of the more common ones we may know, "Oh, okay, they're gonna charge you \$4,000 for that, and it may not get paid." What I've started doing is saying to patients, "Listen, I'm ordering a PET scan on you, your insurance company may or may not agree; I will appeal for you, but in the end, we're going to have to make a decision together about getting that test, or is there another test?"

Andrew Schorr:

Wow, this is—it's a tough time for docs as well as for patients.

Dr. Nichols:

Yeah, and I think there's an education component. In medical school, we were never taught about the cost of any of what we did, because the reason we weren't taught that is that you should do what's right for the patient and not be thinking about how you ration it. And so, it's a real disconnect to now say, "You need to know each different insurance company and whether or not they will cover X, Y or Z," I mean, that just isn't...

Hildy Dillon:

Mm-hmm, any company offers about 10 different plans, yeah.

Dr. Nichols:

...yeah, all different plans. I've been struggling with that because I can't think of what—how we could educate our young physicians about that because it's so complex.

Dr. Saltzman:

Well, I hate to put oil on the fire, but there is another problem which is that—I reside in California, which is deeper into managed care than some other parts of the country, and physicians, young physicians coming into practice mostly are going into settings of groups or managed care.

And frankly, they're reimbursed based on the revenue or not that comes in or does not come in through their clinics, or is expensed, or is expensed out of their clinics. And so, they're starting to learn about cost but in a somewhat negative way, because it impacts their bottom line if you will. This is problematic.

Andrew Schorr:

Do you—you wanna make...?

Hildy Dillon:

Yeah, I would just agree that it's...what both Gwen and Larry are saying is that the—we're at a meeting that is a global meeting, and I always look forward to ASH, because I have an opportunity to see my global advocate peers. And there's an assumption sometimes that here in the United States that all patients have access to these innovative therapies, and it's just not the case.

We see that those of us that are listening to patients and hearing—we generally don't hear from people that are doing well and can manage their expenses, but we are hearing from the people—and there are many of them—that have a problem with this. I think, also, there is—what's happened is that the field is so exciting today, especially in the blood cancer arena. As you were saying, Andy, that the whole paradigm is changing with precision medicine and that is incredibly exciting because we know that there's more hope for patients to be living longer and longer with their disease, and hopefully have a reasonable quality of life along with that.

But quality of life is not just the outcome of your medicines, and it's the impact of that disease on your life, on your family; and that's where our organizations and physicians like Kathleen are so important, because we need to think about the whole person, and not just their disease.

Andrew Schorr:

Mm-hmm, okay. We've talked about the problem; the problem can be acute for some people. Let's start talking about what we can do about it. And I know—so, you on your day off are making appeals calls and you have a lot—in the community oncology—or any physician—you have a lot in trying to first of all keep up with the changes: being a general oncologist, really tough. And then also, really going to bat for your patients so they get what they need and deserve, whether it's treatment, or testing other resources. So, first of all, our hats are off to you, we really...

Dr. Toomy:

So, when I went to the CLL lecture today and heard an international expert in CLL say he's in the 33rd year of his training, it made me feel good.

Because that's what medicine always has been and that's why medicine is exciting: we're always learning, right? Things are always—the edges of medicine are always fuzzy, we're always moving ahead; so that's the great part of it. The bad of it is: I cannot be an expert in anything if I'm an expert in everything, so I have to have a certain level and I have to rely on my academic partnerships, and collaborations, and we all have to work together.

I am on the board of the Cancer Support Community, I've used The Leukemia & Lymphoma Society, I specifically for years have been very interested in getting my patients the things that they need. I will go to any organization to ask for help for my patients, and these are two organizations that have been very helpful to my patients over the years. But what else can I tell my patients, so what other education?

And I'm a medical director of a cancer center, so I'm trying to educate my colleagues on how they can help their patients. So, for example: where do you go to get your medication? What pharmacies charge more, and what pharmacies charge

less? And this is something I learned from NPR: that your mom-and-pop's and Costco—is the only national pharmacy—that will have the lowest prices; the chains? Not at all, okay? So, I may have to tell my patients—and this—in the NPR—episode it was a woman saying that a woman was researching a drug that I give most often called Anastrozole for breast cancer, and at the end—she went to the different pharmacies and found the lowest was at the mom-and-pop. And at the end of this episode, she said, "And that woman was my mother."²

So, we have to make it as personal as possible. So, I will tell my patients—and I have for a long time—"Call around, find out, ask, see what programs are available at the pharmaceutical companies." And we have had—in the past my head biller took it upon herself to help the patients finding the foundations, finding the programs. We now have a bigger billing department, because I am in a bigger group and that's great, The more resources you can get for your patients, that's great. But finding out what is available in the community for your patients, I mean, that's what a doctor does.

Andrew Schorr:

Well, let's talk about it. So, we have the LLS represented here and the Cancer Support Community, you're helping people navigate and also, you're getting calls about the stress people are under, what are some of the resources? Now, sometimes you've had funds that are available for people who need assistance, but sometimes the funds get used up.

Dr. Nichols:

They run out, absolutely. And also, there is a certain financial need level that you have to hit, and unfortunately just as we were hearing, there's a group of people who don't hit that level of—when you look at their numbers—of financial need.

Andrew Schorr:

They don't qualify.

Dr. Nichols:

They don't qualify but they still have a tremendous need. We do have some additional financial support, but more often than not we are trying to help them find company-supported assistance or other ways to navigate this because it is—it's gone way beyond just five times the poverty level. This is hitting everyone, it's not a question that...

Andrew Schorr:

...so, the costs are going up, expensive new treatments and testing, so we're not solving it here but we're gonna try to do as well as we can now.

So, certainly the call if you're dealing with a blood cancer to The Leukemia & Lymphoma Society, a call to the Cancer Support Community, tell us about resources you have, Hildy.

Hildy Dillon:

Well, we will help patients find what resources are available; so we have a pretty extensive database of national, regional, and local resources, including the co-pay foundations that are available. What's interesting is that as we move into precision medicine we've been working closely with the centralized diagnostic companies, and they also are starting to offer patient-assistance...

Dr. Nichols:

...programs.

Hildy Dillon:

And they're coming to us saying, "We're so surprised people are not getting covered."

And so, I think that—what we do is we—but I think more importantly, or equally as important is what we do is we really counsel patients and help them to articulate what their goals are for therapy and for their outcome with their disease so

that we can help them navigate through all of the points that may be causing them distress. So, people may be worried that, "Well, for whatever insurance I have, I may lose it if I can't continue working," or "If my caregiver needs to be with me to have a stem cell transplant, or go through CAR T therapy—and that person is the one who's insured—they might be at risk of losing their job or losing their insurance."

Not all employers are equal in their generosity to people when they have a life-threatening illness that requires an extended hospital stay or extended therapies that may keep you out of work. So, there are things that we can do to help people manage these things.

But as Kathleen was saying before we help them to troubleshoot where the resources are within their support system, we have a program called Open to Options, which is a shared decision tool. And it helps people to raise who is in their support system that could possibly help them; what are their deepest concerns and fears about their illness; and help them to articulate the questions that they really need to ask their doctor. Because it's not every practice that works so personally with each patient to find out what may be causing their inability to adhere to therapy.

So, we really work hard to help people to be able to articulate that and communicate better with their healthcare providers so that the healthcare provider teams can help them as well.

Dr. Nichols:

So that they know, yeah.

Andrew Schorr:

Right, so I wanna about that—right. You mentioned as a physician people don't always level with you, maybe they're even embarrassed to tell you.

Dr. Nichols:

Of course!

Hildy Dillon:

Yeah, there is a shame that goes along with—yeah.

Andrew Schorr:

Right, there's a shame like, "Oh, my god, I'm struggling to pay for this," or...

Dr. Nichols:

...or your doctor won't like to hear it or...

Andrew Schorr:

...yeah, or "They don't have time."

Dr. Nichols:

Yeah, they don't have time, yeah.

Andrew Schorr:

"I don't wanna burden him with that because they're trying to cure my..."

Dr. Toomy:

...so, it's the insurance companies that come to us and say, "Hey, listen, this patient isn't getting their prescriptions filled, did you know that Doctor?" and the answer is, "No." We do ask our patients, "Did you miss any doses this month?" and that

actually helps. When you start to ask about adherence, "Oh, maybe—" and you could tell, "Why did you miss it?" "I missed it because I don't like the side effects," then we can deal with that; or "I missed it because I really can't afford it." I think with the more expensive drugs, we know. We know immediately because either they can or they can't afford it. You have 60 percent of all bankruptcies are medical in this country, the system is broken!

The insurance system is broken, and I don't know how it's gonna be fixed—and it's gonna be fixed at a much higher level than I'm at—but really feeling for these patients and what they have to go through.

Andrew Schorr:

Well, you brought up the word, Hildy, "communication"; Larry, let's talk about that, you and me as patients. So, first of all, people do need to speak up, right?

Dr. Saltzman:

Yes.

Andrew Schorr:

And they do need to get clarity on their own situation and their goals; what would you say to people as far as communication? And you've been a doctor as well as a patient, as far as...

Dr. Saltzman:

...well, I think communication—I think the important thing is that unfortunately, as a primary care doctor who had a schedule to keep, I, unfortunately, had what I call the "seven-minute visit". And so, as a doctor and as a patient, I think it's very important for people to go into a visit with some kind of list, whether it's a written list or a notepad on a mobile phone list, to make sure that you get your questions answered.

I also think it's really important to take another set of ears to a visit. I think that the visits go so fast, and the questions and advice comes so quick, that sometimes the patient themselves are not really in the zone of listening to exactly what's going on. And so, I think it's very important to bring—call it an advocate—but another set of eyes and ears along with the visit.

Andrew Schorr:

Right, let me mention a couple of things I've learned having been a patient for 22 years, so first of all: you do have to get clarity on your goals—and Kathleen—you-all spoke about that—what are your goals for treatment; what are the treatments that can help get you there; what's the testing to know what you need or how well is it working? And certainly, the issues—as Kathleen talked about—will it be paid for and what choices do you need to make on the financial issues?

And then, I think you need to level on what are your resources, either within the family—hopefully, you don't need a GoFundMe campaign—and then, what are external resources? And you could say to whether it's your community physician or your university physician, "What resources do you have to help me figure this out?" Nurse navigators, financial navigators, directions to...

Dr. Saltzman:

...social workers.

Andrew Schorr:

Social—oncology social workers often make them that job. If not, at your center maybe there's one nearby, right?

Dr. Saltzman:

Yes, mm-hmm.

Andrew Schorr:

Okay, so now, the system is broken, right? So, we're trying to put a patch kit on it right now as you have some very exciting things in medicine. And then, we have a kahuna here, and that is Medicare because many of us—Larry, are you on Medicare now?

Dr. Saltzman:

I am now, I made it! My life goal: make it to Medicare.

Andrew Schorr:

I'm on Medicare. So, that's kind of a fluid situation is: what are they gonna cover; we're faced with catastrophic levels usually the beginning of every year; co-pays if we're still working. I'm still working, so I'm in this category where maybe I don't qualify for some of these assistance programs. And then, in some of the areas, some insurance companies—and maybe Medicare—will request what's called "step therapy," where there are certain therapies that you have to fail first...

Dr. Toomy:

..fail first, right.

Andrew Schorr:

In cancer—do you wanna talk that? I mean, some of these policy changes, because I know the LLS is concerned about that.

Dr. Nichols:

We absolutely are and I think important for your listeners to know that we're spending a lot of time in Washington advocating for considering the cost of care and not just the cost of drugs. I think a lot of the conversation has revolved around the cost of drugs, because there are many, many new drugs.

But the truth is: it is a bigger issue than just the cost of your medications. And so, we need to frame this so that our representatives in Washington actually understand that because most of them have excellent healthcare policies, and most of them are not under these kinds of stresses. And I think they're shocked sometimes when they hear—when they get a 28-year-old who had junk coverage—and can't get the bone marrow transplant they need to survive, because they have a pre-existing condition.

There are lots of things that just aren't crossing the minds of our legislators, and these changes in Medicare, and step therapy, the idea that you have to get a less effective therapy first because it's cheaper is really a tough pill to swallow, literally and figuratively.

Dr. Toomy:

So, we're learning here today about in myeloma, for example, it's very important that you get the right therapy first.

Dr. Nichols:

First!

Dr. Toomy:

And if you do step therapy, that's inferior therapy. So, we know that that—so we can't have the insurance saying what is the best medical care.

Dr. Nichols:

And we're learning more and more about the fact that each therapy pushes the disease to a different molecular background, and why wouldn't you want the best thing first?

Andrew Schorr:

Right, so if you got the wrong therapy, first of all, you may be debilitated by it, it didn't work, and...

Dr. Nichols:

Yes!

Andrew Schorr:

...I mean, let's face it, there may be some people who therefore won't survive to get...

Dr. Nichols:

Won't ever be able to get the right therapy.

Andrew Schorr:

...what they should get, there would be more stress.

Dr. Nichols:

Just drop out each time—each line of...

Andrew Schorr:

...so, I wanna make a couple of comments: so you never expected for you or a loved one to be a cancer patient and then you're terrified when it happens. We've all been there.

Then you wanna get the right care. Hopefully, with modern medicine you start to feel better, do better, if you can get access to some of these things and we hope you can. Part of what you're hearing now is there are public policy issues at play, certainly, in 2019 we'll face this. We have launched something called the "ABCs of Patient Empowerment" where we're hoping that all of us can become smarter and then speak out. And let's just talk about that for a minute, they're calling your organizations, they're speaking you as a doctor, but we maybe need to have a louder voice.

Dr. Nichols:

We have thousands and thousands of volunteer advocates, and I would really urge the people who are listening who say, "I wanna do something, this is so frustrating."

Andrew Schorr:

Tell your Congressman!

Dr. Nichols:

To join us, it is very easy! You can do it on your smartphone, you can do it on your computer, or you can come with us to both your state or the federal legislators and talk with them directly.

And we will help make that happen, it is so important! It's great if a doctor goes there, and the Chief Medical Officer of LLS, and blah, blah, blah, blah, blah; but if a patient goes there and says, "I'm your constituent and this is how your policies are affecting me," it is much more meaningful than my very academic discussions with them. And we need you.

Hildy Dillon:

Yeah, yeah. So, ditto! But at the Cancer Support Community, we're doing the same thing, and we are—we coach people to be articulate and go to their state legislators because, really, it's all about votes and constituents. And when people—when

our state legislators understand the struggles that people are having—and this is in oncology and in other illnesses, as well—that's important to them, we hope that that would make a difference.

But we are—there are people that they think, “I can't, I'm too shy, I'm too nervous about going to talk to my state legislator,” we will help you.

Dr. Nichols:

Yeah, and you can do less!

Hildy Dillon:

And we coach people and usually it's people that initially didn't think that they could do it that become the strongest advocates.

Andrew Schorr:

Right, in the media too, if you live in a suburban area there may be smaller newspapers, or there may be groups that you can talk to, go on a radio station, whatever it is but speak up, help other people in your community understand. This isn't a way to make an end run around, but I just wanna talk about clinical trials for a second, because all these medicines, and testing, and everything, everything to get to the goal line with FDA has to go through a clinical trial.

It is worth raising then, isn't it, Kathleen? For instance, even at the community level is there a trial I could be in that you think may be right for me where the cost of the care will be underwritten by the drug company, or whoever?

Dr. Toomy:

So, that's—a very good reason to consider a clinical trial is that if this is a drug that's not yet FDA-approved, you won't be paying for that on the clinical trial. So, the clinical trial is important, because we wanna cure cancers, and we wanna take care of people. You would get the standard of care. but you may get something better, and that something better you won't be paying for you, and you won't have to worry about co-pays, and any extra tests that you have outside of the standard of care will be covered under the clinical trial. So, that's a big motivator for me to offer my patients clinical trials, and especially people who don't have the resources to pay for the regular things.

So, clinical—I feel strongly clinical trials are really important. So, for patients getting the education about the disease considering a clinical trial for treatment, you know that you're going to get standard of care, and you're gonna be watched very closely. I was an IRB chair for 15 years and I have...

Andrew Schorr:

Investigational Review Board.

Dr. Toomy:

...Review Board, and I have a strong background in clinical trials. So for me, it's all about curing cancer, that's what it's about.

Andrew Schorr:

Amen. So, one other thing, Gwen, just so we understand how it works: if somebody's in a clinical trial, and then the FDA says, “Voila! Like what's happened in EML, boom, boom, boom, it's approved,” if you remain on that medicine, in many cases do you continue to get the drug for free?

Dr. Nichols:

The hope is that you do continue to get the drug for free. There are occasionally companies that say, “I'm sorry, that's it, you hit,” but they have to have prespecified that, that if the drug gets approved, or you will only get it for two years.

If they haven't, then the drug should be made available, and we certainly can help you with that if you're on a trial and you're afraid you're going to lose your ability to get the medication and it's approved.

Andrew Schorr:

So, Larry, did we frame this right that you walk the halls here at the convention center, you go in the sessions, that for us patients there's a lot to be hopeful about?

Dr. Saltzman:

Oh, yeah.

Andrew Schorr:

And now we have to really work with our resources and our physicians to try to get what's right for us.

Dr. Saltzman:

Well, exactly. And I will say that I live in a small community, and I have a community oncologist. And from the beginning, I thought, "Well, I'm a physician," so I thought it was important that I plug myself into an academic medical center. Frankly, I think the more people who can do that not necessarily to get treated at the academic center but at least plugged-in with a consultation so when clinical trials come up, you the patient may be on the doctor's radar to say, "Well, here's something that might be applicable for you."

When I needed chemo—which was suggested by the academic center—I didn't go there to have the chemo because the drugs were the same whether I lived in my small community or not, so I was treated locally but managed or suggested academically. And I do think it's important to get plugged-in because—no offense to us who live in the community—but we are not as in-tuned to all the clinical trials that are going on.

Andrew Schorr:

It's a lot to keep up with. Imagine, Kathleen, trying to keep up with what used to be let's say—you could count them on two hands the major cancers, and then she knew about some, and there are all these genomic subtypes.

Dr. Toomy:

So, absolutely. And we in the community are very happy to have our patients be plugged in with an expert anywhere, but we realize that the majority of patients in this country are not treated in academic centers, the majority of patients in this country cannot be treated in academic centers, they don't have the capacity.

So, what I think is really important is for the academic centers to work with the community and bring up everyone so that all boats rise, right? And we're very good in the community with taking care of side effects of treatments, and we're—and listen, traveling to get cancer care is always a problem, you know? And when you're—in the middle of the night on a weekend...

Dr. Nichols:

...and something goes wrong.

Dr. Toomy:

And something goes wrong, you need somebody who knows you and can take care of you locally.

Dr. Nichols:

Yes.

Hildy Dillon:

Exactly.

Andrew Schorr:

I think what it comes down to now is all of us to be as I said: smarter patients, smarter family members, and care partners. So, first have the discussion with your doctor, okay? So, what do we agree is needed in my case? What are we dealing with? What tests are right, are they affordable, hopefully?

Is there another way to do it? How do we know if the treatment's working? Are there support programs? Are there clinical trials? Are there organizations, Cancer Support Community, Leukemia & Lymphoma Society, co-pay assistance groups that line up with my situation? Should I be in a clinical trial? Is that offering me maybe tomorrow's medicine today, new hope? And does it have some economic advantages, as well?

Dr. Nichols:

Can I make a pitch that...

Andrew Schorr:

...yes, ma'am!

Dr. Nichols:

You have a clinical trial navigation service that is free for patients. And that has...where if you wanna learn about clinical trials, we can curate a list for you to bring back to your physician; we can also talk to physicians and help them if they have a patient they need to navigate. I know that it's hard to go through clinicaltrials.gov and look for a trial for a patient.

I would urge people to consider that if they wanna learn about clinical trials or have...

Andrew Schorr:

...amen! I've been in two, and it's been a big thing for me, and I really appreciate it, I would always urge people to look into that. So, we haven't solved the problem here, we've made some suggestions. So, on the one hand, there's very encouraging medical progress here, okay? And really, you didn't wanna have to do this to have to speak out so much, but you and your family do need to get smarter about this so you get what's right for you, and also look for resources so you don't have to break the bank with state-of-the-art cancer care today. And there's support from industry, support from foundations, support form resources, and hopefully, every doctor is like Kathleen Toomey.

Dr. Toomy:

Yeah, well...

Andrew Schorr:

...she is committed to you. I wanna thank you all for being with us. Dr. Kathleen Toomey from New Jersey, thank you...

Dr. Toomy:

You're welcome.

Andrew Schorr:

.for being with us. Hildy Dillon, our old friend from Cancer Support Community, thank you for what you...

Hildy Dillon:

Old—old not in age.

Dr. Nichols:
No, not old.

Hildy Dillon:
Not in age.

Andrew Schorr:
Too many years. My friend, Larry Saltzman. Dr. Larry Saltzman...

Dr. Saltzman:
Thank you.

Andrew Schorr:
..you're living with chronic lymphocytic leukemia, keep going, running, and I'm glad you're doing so well...

Dr. Saltzman:
Thank you.

Andrew Schorr:
...with modern medicine.

Dr. Saltzman:
Thank you.

Andrew Schorr:
And Dr. Gwen Nichols from The Leukemia & Lymphoma Society, thanks for your dedication, Gwen.

Dr. Nichols:
Thank you.

Andrew Schorr:
And we'll all raise our voices together.

Dr. Nichols:
Yes, please, join us!

Andrew Schorr:
A great discussion! Join us, speak up, and we hope that you can get the best medicine for you or a loved one. I'm Andrew Schorr, remember: knowledge—like we've been doing today—can be the best medicine of all.
This is some transcript copy. Use style "Normal" and for the first paragraph in each section, "Normal - First Paragraph"

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.