



Patient Power

Access to Better Care: Overcoming Financial and Insurance Barriers

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Andrew Schorr:

And, hello from somewhat gray and gloomy Southern California today. I'm Andrew Schorr. We are just back from the big American Society of Hematology meeting, which was down the road in San Diego, and hopefully, you saw some of the programs there. I'm going to talk about more that's coming—a lot to talk about—and that, of course, relates to treatment. It doesn't mean anything unless you have access to it and it's affordable.

So, we are talking now in our series we call "The ABCs of Patient Empowerment," all about that. I wanna thank our financials for this—Janssen, as well as Pharmacyclics. They have no editorial control. We invite your questions. Send them to cll@patientpower.info. We have some great guests. And, of course, if you have to go early, you can't stay with us a whole hour, there'll always be a replay of this program, as there is for all of our programs.

I wanna introduce our guests as we get into these access issues, barriers to getting what you need issues, and also some public policy issues that affect us all. First, let's go to Bullhead City, Arizona, where we're joined by a CLL friend of mine, Eliot Finkelstein. Eliot, welcome to our program.

Eliot Finkelstein:

Hello!

Andrew Schorr:

Hi. Just start your video there, Eliot.

Eliot Finkelstein:

I did.

Andrew Schorr:

Okay, so you'll pop up. There he is! There's Eliot. And, Eliot, we'll go into your story in just a minute. I wanna introduce our other guest, and that is the counsel to something called the Aimed Alliance, and she is a healthcare attorney—you may have seen programs we've done with her before—joining us from Washington, D.C., Stacey Worthy. Stacey, welcome back to Patient Power. Hi, Stacey.

Stacey Worthy:

Hi. Thank you for having me.

Andrew Schorr:

Okay. So, Stacey is a healthcare attorney, very adept at all these issues—insurance issues, et cetera. Now, you can send in questions to cll@patientpower.info, but don't send in a question like Stacey is your lawyer. "Stacey, this is my situation. What should I do?" Pose issues you may be facing could affect many of us, and Stacey will give you more general answers. Is that fair, Stacey?

Stacey Worthy:

Yes, absolutely.

Andrew Schorr:

You can't practice law over the internet. Eliot, let's go back over your situation a little bit. So, I was diagnosed in 1996 and treated in the FCR trial in 2000 and 2001. I've only had infused therapies, and I went 17 years through remission, and then I got obinituzumab (Gazyva), which I know you're gonna tell us you received along the way as well, but I've never had an oral therapy for CLL. I do take an oral therapy for another condition, ruxolitinib, and I'm on Medicare, Medicare Part D, and I have substantial co-pays, and I still work, so it's not cheap. Eliot, what's your CLL situation? When were you diagnosed?

Eliot Finkelstein:

I was diagnosed in May of 2013. I had no treatment until January of 2016, and at that time, I did have CR for six months.

Andrew Schorr:

Okay, didn't last for you. And, I know you developed some pretty significant skin issues, right?

Eliot Finkelstein:

Correct.

Andrew Schorr:

And then, what other treatment have you had?

Eliot Finkelstein:

Well, it was about six months after I finished my FCR. They put me on ibrutinib, (Imbruvica), and it worked really quickly, really well. But, three weeks after I started, I started having skin issues, and they thought it was related to the ibrutinib, so they stopped the ibrutinib, put me on prednisone (Deltasone), and that started my journey for my skin issues—my autoimmune skin issues—and that took until August of 2017 to diagnose. Going every other week down to Mayo, which is a five-hour drive.

Andrew Schorr:

In Scottsdale, Arizona. Well, lots of doctor visits now. What treatment have you had since then for the CLL?

Eliot Finkelstein:

We only really started the CLL treatment because the dermatologist said my skin issues are from my CLL, and so, we started, and my doctor put me on venetoclax (Venclexta) and obinituzumab, so I did the six months of obinituzumab.

Andrew Schorr:

Obinituzumab, or Gazyva.

Eliot Finkelstein:

Right, "Gazyva" is easier to pronounce.

Andrew Schorr:

So, you had the obinituzumab, and now you continue with the venetoclax, trade name Venclexta—you're continuing with that. How are you doing?

Eliot Finkelstein:

Right. I'm doing great. I haven't really had any side effects whatsoever. I was on 400 for about 15 months, and we dropped me down to 300, and still haven't had any issues whatsoever.

Andrew Schorr:

Okay. Let's talk about the financial side of it. You've had some hassles related to all these different doctor visits, procedures, and things like that, right?

Eliot Finkelstein:

Correct. The biggest things are—part of it was billing from the insurance companies, part of it was they claimed I did not get pre-approval, and the easiest one to say is when I went in for surgery, I got my doctor's approval, they got the insurance approval, come to find out the anesthesiologist was not approved under the insurance, and they expected me to pay that, and I said, "No, I'm not paying that."

I did what I was supposed to, and I filed for appeal, and one of the times, they said, "Well, we're not going to approve it." I go, "Fine, give me all my documents, and I'll take it to the state appeal," because my Blue Cross/Blue Shield was out of the state of California under the CalPERS, and the next appeal goes up to the state, and once they heard that, they decided to pay it. So, it's just like you have to keep fighting it.

Andrew Schorr:

We're gonna talk about that. And, related to your co-pays for your venetoclax or even ibrutinib, have you had difficulties with that?

Eliot Finkelstein:

Not really. My doctor seemed to be approved. I'm seeing Dr. José Lis, if that's okay to say.

Andrew Schorr:

Right, but not the doctor visits – the co-pays for the medicine.

Eliot Finkelstein:

Right, right. He got it approved, and he made the phone calls to the insurance companies, and also the approval, so in that respect, my leukemia medications generally have not been a problem.

Andrew Schorr:

All right. Stacey, first of all—so, some of us need medical procedures. We have doctor visits, get second opinions, so first of all—then, they say – or, even when he was asleep in a surgery procedure, there was an anesthesiologist I kind of sensed was out of network...

Eliot Finkelstein:

Correct.

Andrew Schorr:

...no control over that.

Stacey Worthy:

Right.

Andrew Schorr:

So, tell us about this appeal process a little. Is it just—he just had to really speak up for himself and take it up a couple of levels. What would you say about that?

Stacey Worthy:

Yeah, absolutely. You always have to be your own advocate and make sure you fight. Appealing is the best way to get coverage. It is common to have these surprise bills when you're getting treatment at a hospital because, as was the case here, one of the providers in the hospital—even though the hospital may have been in-network, the provider was out-of-network. There are states that are starting to enact laws to prevent those surprise bills, but not every state has enacted those.

So, do exactly what you did, Eliot, and that is appeal. So, typically, the appeals process starts with an informal conversation with your insurer. Then, typically, you may have to file a formal appeal with your insurer.

At that point, if they deny you, you have the ability to request an independent review by a reviewer who's not affiliated with your insurance company, and at that point, if that is denied, then you can always file a complaint with your insurance commissioner or state attorney general.

And sometimes, all it takes is a threat. So, you call them up, you say, "I'm gonna appeal, I'm gonna file a complaint with my insurance commissioner," and they switch it like that. Another way to get them to approve the claim pretty quickly is to go to the media. If you have a pretty egregious case and you talk to a reporter, or even through social media, and you let people know what's going on, they don't want that bad publicity, so they're gonna change that decision pretty quickly.

Andrew Schorr:

I'm just gonna give an example that's not really a medical one, but my kid was a student at the University of Oregon and transferred, and somehow, not the dorm, but one of these off-campus apartment buildings that are pretty expensive had on record that he had signed something at 19 years old that he was gonna be a tenant again, and then we started getting bills.

He'd left the school months before, and I had guaranteed it for his first year, but I hadn't guaranteed it for the second. In the state of Oregon, it's not required that the co-signer be made aware that there's this renewed financial commitment by a minor, basically—or, if he was—and I raised hell, and I said, "The parents of the university would be really upset if they knew this. This is not right, and we're gonna go to the state legislature and the governor if we have to to change it." So, guess what? They dropped all the charges.

So, all I'm saying is speak up. I don't think you have to be a media celebrity, you're saying, but you have to threaten it—that you have something like this whole thing—the anesthesiologist being out of network—you never met the anesthesiologist, perhaps.

Eliot Finkelstein:

Exactly.

Andrew Schorr:

So, okay. But, let's also talk about co-pays because the co-pays can be very expensive for me, not on a CLL medicine, but for another condition—I have myelofibrosis—it's \$680 a month, and if you still call it, Stacey, the "donut hole"—every January, I have to reach this catastrophic level. And, I work. You guys tell me if I work hard enough, but I work, and so I'm not qualifying for some of the assistance programs.

I'm on Medicare, so I'm prohibited from getting any co-pay assistance from a drug company, which—I think all this is crazy. So, I'm kind of betwixt and between, and it's really expensive—\$10,000-12,000 a year. I recognize that drugs are expensive.

So, first of all, Stacey, help us understand for the Medicare patients—is there anything we can do? What can you do?

Stacey Worthy:

If you're in a tricky situation, especially when you're in the donut hole, and there is an impending donut hole Part D cliff coming up, so that catastrophic threshold could potentially rise to \$6,300— little bit over that. Yeah, it's pretty bad.

Basically, we're trying to call on Congress to place a cap on that threshold so it doesn't rise that high because it's just gonna get harder for Medicare beneficiaries, and it's not fair.

But, in the meantime, it is very hard. It's possible you could look in to private plans. There are some patient assistance programs that might be able to help, whereas you can't get assistance from a drug manufacturer with co-pay cards, which somebody could use if they're on a private plan. Some of these nonprofit patient assistance programs like the Patient Advocate Foundation are permitted to help people, even if they are Medicare beneficiaries.

Andrew Schorr:

Oh, really? Let's go over that again. Hold it. So, Patient Advocate Foundation, and there's another one, NeedyMeds, Good Days—there are a few of them, and we'll make sure they're listed on our website, but there are thresholds. Now, what if somebody is retired? They're not impoverished—I don't wanna say "impoverished"—they still have a decent lifestyle, but all of their income is passive. In other words, maybe they take some money from their savings to support themselves, but they have a decent amount of savings. My understanding is they can apply for these programs because they don't have a regular income. Is that right?

Stacey Worthy:

I'm not entirely sure. So, you're saying somebody who's retired but does not have insurance?

Andrew Schorr:

Well, they have insurance, but they're not—so, they don't have a job. I have a job, so I get a regular paycheck, if you will, from Patient Power.

But, let's say they don't have that, but they're not—they can pay their rent, or they maybe own a home. Do they have to give up all that before they can qualify for one of these assistance programs for somebody on Medicare?

Stacey Worthy:

No, I don't think so. I guess it depends on the situation. It also depends on the patient assistance program. Usually, it is for somebody who has some financial difficulties, so if you're able to pay and you can afford your medication, you probably are not going to be able to qualify, but if you are in financial hardship, then you may be more likely to qualify for one of these nonprofit patient assistance programs.

Andrew Schorr:

Okay. Well, we're gonna talk more about that because it's kind of the middle class, because now, the cost of these medicines is so high that you're middle class, and you've never asked for any assistance before. It's uncomfortable to do that—getting a second mortgage on your house, reverse mortgage, whatever you wanna talk about – it just doesn't seem right.

But, let's go back to this cliff here you were talking about, Stacey.

So, what's pending related to Medicare rules? When would this kick in? Maybe we need to go the "Mad About That."

Stacey Worthy:

Yeah. So, under the Affordable Care Act, there was a provision that had sort of caps—or, not really caps, but they had limits on what you would be paying, the threshold, that catastrophic phase of the Part D plan. Typically, the way it works is you're in the deductible phase, you pay 100 percent of the medication until you meet the deductible. Then, you go on to the initial coverage, where you're paying 25 percent co-insurance until you get into that donut hole. And then, in 2019, I think you get into the donut hole when you reach about \$3,800.

Then, you're in the donut hole where you have really high co-insurance until you meet that threshold for catastrophic coverage which, in 2019, is gonna be about \$5,100. In 2020, that's when the ACA provision is scheduled to sunset, so that catastrophic coverage threshold rises to \$6,300, which is a big chunk of change. So, that's why we want to encourage people to write to Congress and ask them to fix this by enacting a path on out-of-pocket costs for Part D plans.

Andrew Schorr:

All right, let's see—I understand. So, just for the Medicare folks – and, let's face it, a lot of people—Eliot, you're younger. How old are you?

Eliot Finkelstein:

I'm 60.

Andrew Schorr:

Okay. So, you've got another five years before—maybe they'll change that. Who knows?

Eliot Finkelstein:

Hopefully.

Andrew Schorr:

Yeah. But, right now, I'm 68, so for my friends who are 65 or older and on Medicare, we then are paying—reach the catastrophic level pretty quick. In 2018, was it \$3,800.00?

Stacey Worthy:

That's the initial coverage period.

Andrew Schorr:

Okay. But, you're saying in 2019, it's gonna be yet higher?

Stacey Worthy:

Yeah, so, for the catastrophic coverage, it's \$5,100.00.

Andrew Schorr:

And then, the plan is for 2020, over \$6,000.00?

Stacey Worthy:

Yes.

Andrew Schorr:

Whoa. So, we pay that?

Stacey Worthy:

Mm-hmm.

Andrew Schorr:

And then, I think, it drops to – we have a co-pay of five percent, right?

Stacey Worthy:

Yes, exactly.

Andrew Schorr:

Then, I have a question—5 percent of what?

So, there's been a question whether we—the Medicare consumer—I just wanna stick with Medicare for a second—we, the Medicare consumer, are paying basically five percent of the retail cost, if you will, even though whoever was providing us the medicine may be getting rebates and pocketing the money. Am I right?

Stacey Worthy:

Yeah.

Andrew Schorr:

What do we do about that?

Stacey Worthy:

That requires additional reform. So, we need reform of the PBM system, and making sure that PBMs are not pocketing those rebates that they're passing...

Andrew Schorr:

...quite frankly, there was an affair in the Rose Garden at the White House, and however you feel about Trump or Republican or Democrat, that was the discussion. Are there these middlemen pocketing money and us poor cancer patients or other people with expensive medicines getting hammered with higher co-pays when those guys are making money in the middle?

Stacey Worthy:

Exactly. So, basically, what's happening is they're reclassifying rebates that should be passed on to the insurers, and then ultimately to patients—plan enrollees—as administrative fees, and then they get to keep that money instead of passing that savings on.

Andrew Schorr:

All right, Stacey. So, while we're talking about this, we can be converted to not just self advocates, but patient advocates. What can we do? Write our new congressman or our old congressman? What do we do?

Stacey Worthy:

Yeah, so, you wanna talk to both your state legislators and federal legislators—policymakers—and encourage them to enact PBM reform that doesn't permit them to pocket those rebates, that forces them to pass them on to the consumers.

Andrew Schorr:

Okay. So, that's that one about pocketing the money—the rebates they get—rather than passing on the savings to us.

Stacey Worthy:

Yeah.

Andrew Schorr:

You're used to that. You go to Costco, you know they negotiate lower prices so that you can buy it cheaper, but here, we're stuck with the higher co-pay. Okay, but what about these cliffs you're talking about at the catastrophic level? That's nationally, federally, with [inaudible] for Medicare and Medicaid. What do we do about that one?

Stacey Worthy:

So, that one is you're gonna wanna talk to Congress and try to get them to put a cap on what you're gonna pay out of pocket, and it's much lower than that cliff amount. So, most health plan—or, many of the health plans do have out-of-pocket caps. At least with the ACA plans, the cap is \$7,000 for individuals and \$14,000 for families, which is also very high, but at least there is a cap on what you would be paying. So, when you take into consideration you're paying 25 percent of a drug at one point and five percent of a drug at another point, it could get really expensive, as you mentioned.

But, if there's a cap on what you pay out of pocket, then once you reach that amount, you won't be paying any more.

Andrew Schorr:

Okay. Now, Eliot, you're on what we call a commercial plan—Blue Cross, Blue Shield, one of those.

Eliot Finkelstein:

Blue Cross/Blue Shield of California through Los Angeles Unified.

Andrew Schorr:

So, you're still in a group plan from the Los Angeles Unified School System. Were you a teacher or your wife was a teacher?

Eliot Finkelstein:

My wife was an office worker at an elementary school, so I'm living off of her insurance.

Andrew Schorr:

Okay. So, let's talk about that, Stacey. Are there things that any of us can do that may be better—first of all, Medicare, where we wanna be—maybe we have a spouse with a better plan, and we wanna do that. And then, we could have this appeals process that we go through, like Eliot described.

Stacey Worthy: Yeah, absolutely. I would highly recommend that when you're looking into health insurance, you be a—you do comparative shopping. So, look to see what other plans are out there and whether they offer better coverage. If there's a private plan, just because you're a certain age doesn't mean you can't enter into it. You can look to see what plans are available even through the insurance marketplaces—so, those individual plans. That's also another option.

The one thing I would say you wanna steer away from is those short-term plans—these are the plans that used to be for 30 to 90 days, or when there's a coverage gap when you've lost health insurance, but now they last up to 364 days. I wouldn't recommend looking into those plans because they're allowed to discriminate based on pre-existing conditions, so if you have cancer, they can disqualify you. They don't have to offer [inaudible], things like that. But otherwise, I would absolutely recommend looking into private plans as well.

Eliot Finkelstein:

Can I jump in?

Andrew Schorr:

Yes, please.

Eliot Finkelstein:

Every year, of course, even we—under the commercial or private plan—we have open enrollment. So, we're always checking, but unfortunately, because ours is from Los Angeles or California and we're out of state, we have to stick with the one plan, and we have to accept what they change. But, we're always checking each year to see what we could do to improve what we've got.

Andrew Schorr:

Now, something just happened with Blue Shield of California, which my wife has, and I don't know how universal this is. They're not gonna pay for basically non-emergent or non-emergent follow-up care out of state. So, our daughter Ruthie is in Florida, so if she's on my wife's Blue Shield plan, they're not gonna pay for that unless it's emergency.

So, she's gonna go through the health exchange on healthcare.gov, and she's gonna find a plan for her, and she'll be covered on that in Florida. But, that was a real surprise, because it used to feel like if something came up and you were in another state but covered from California or whatever it was, it would be covered, and now they're saying no if it's not an emergency or a follow-up to an emergency. So, Stacey, these policies change. These plans change. Eliot, you were talking about checking every year. Right now, as we do this on December 5th, we're still in this period where we can make changes—open enrollment, right? But, just for a few days.

Eliot Finkelstein:

And, for me, because my wife is officially retired, then nothing's really gonna change unless LAUSD decides to change something, and then we find out about it.

For the most part, I guess we're grandfathered in and stuck, but it's a relatively good plan.

Andrew Schorr:

Okay. Now, you also have some insurance through the military because you're a veteran, TRICARE. Has that helped you?

Eliot Finkelstein:

Well, I just got on TRICARE in August. So, because I met my deductible in May, I don't have to worry about it until January, and my deductible out-of-pocket for the year is \$7,500. So, I'm making sure everybody has my TRICARE, and mine is

TRICARE Select because I'm not near a military base. When I turn 65, it'll be TRICARE For Life. And, the way I understand, it'll pick up all my deductible of the \$7,500 minus \$150.

Andrew Schorr:

So complicated. Let's just back up a little bit.

...in the U.S. or...so, commercial insurance like Blue Cross or other policies—right, Stacey? And then you need to check to see if something's changing each year that would affect you living with a chronic illness like CLL, and if you were switching from infused therapy, which might be paid with the hospital or directly, and you're going on an oral therapy, how does that affect you financially? Based on your financial situation, if you're now gonna be on Imbruvica, venetoclax or something else that comes along, is there an assistance program—either co-pay assistance from the drug company or some other foundation? Did I get it right, Stacey?

Stacey Worthy:

Yeah, absolutely. You definitely wanna look into all of those things. Sometimes, it's really hard to make sense of the health plan. The language can be really tricky, so I would absolutely recommend calling the insurer to have them clarify if you can't find the information that you're looking for.

Andrew Schorr:

Yeah, and tell them specifically what you're on.

Eliot Finkelstein:

Let me jump in. I've called my ombudsman many times, and she knows me personally by name because I keep calling her to ask her questions about the details of the plan, what's covered, and everything else. So, that's important, and you're absolutely right about going from infused therapy to pills. It changes everything, and it changes—the infused therapy typically is covered under regular medical coverage. These pills are covered under a prescription plan, which is way different.

Andrew Schorr:

Right. So, let's explain that. So, if you're getting rituximab, or inotuzumab, or ofatumumab, or maybe some other "mab" that'll come along, typically, that's administered at the clinic or the hospital, and that's covered under—is it Medicare Part A?

Stacey Worthy:

Part B.

Andrew Schorr:

Part B, sorry—the nursing costs, the doctor costs related to that. But, if you then go on one of these oral therapies, that would either be—if you're on Medicare—Medicare Part D, or are you covered through a commercial plan, like we described?

Stacey Worthy:

Yeah.

Andrew Schorr:

So, here's something I heard about the other day, and I have to check into it myself, and you might check into it with a broker. So, Eliot is covered under his wife's plan through retirement, and then he has the military veteran one kicking in, too.

My wife also has a family plan. Esther has a few years to go before she gets to Medicare. And, what I'm gonna look into—and, I heard about this from another patient—could I get my drug benefit as a member of that family plan? Would it be cheaper than me being covered under Medicare Part D? So, it adds cost to the family plan, but it's less than what the gap is under Medicare Part D.

So, I'm gonna call our insurance broker today—I just heard about this the other day.

So, this navigation that we have to do in trying to get the medicine that we want—now, Eliot, I'm gonna skip back to your doctor. Your doctor was also making calls for you to help in your journey with CLL, right?

Eliot Finkelstein:

Correct. He was calling the insurance company, I presume directly. Also, my skin doctor was calling the insurance company directly, and so, relatively speaking, on the drug part and the infusions, I really didn't have any trouble.

I will say—and, this may be too rare for most people, but I'm getting IVIG permanently for the rest of my life—infusions. And, one doctor—one of my cancer doctors—submitted my request for IVIG under my cancer. Well, it didn't work; they denied it, because it's different requirements under cancer or CLL than it is for my skin disorder. And so, it was accepted under my skin disorder, but not under my cancer, so I almost had to yell at them to explain, and I had to tell them four times and several doctors' offices to make sure it's submitted under my skin disorder.

Stacey Worthy:

That's a really good point. I would like to piggyback on that.

A lot of times, when you're denied access to a treatment, it could be as simple as the practitioner just using the wrong billing or coding information when submitting the claim. So, even before you do any appeals process, it's always helpful to talk to your doctor and make sure that they are using that correct billing and coding information.

Andrew Schorr:

All right. Let's talk about IVIG—immunoglobulin—which some of us in CLL need long-term to boost our immune system because our immune system isn't as strong as it should be. For me, I travel a lot for work, and sometimes for fun, and my doctor here in San Diego, Tom Kipps, routinely has many of his patients out. I said, "When can I stop IVIG?" Tom says, "When you stop traveling." So, you're saying—and, please, wipe down things when you fly on the plane...

Eliot Finkelstein:

...and in your hotel room.

Andrew Schorr:

Yeah, and in your hotel room, right. And so, when I get IVIG now, I get it at the clinic as an infusion, and I think the cost is probably \$10,000. It's a lot. Fortunately, right now, Medicare and my Medicare supplement are getting it. Some of you—I was talking to Dr. Rick Furman, who's a CLL specialist in New York, maybe you're his patient—some people have been saying, "Well, I get IVIG at home," which can be administered.

I asked my doctor's clinic about it, and they had a company call me, and apparently, under Medicare, CLL—and, maybe I'm wrong, I'm checking into this, navigating this—it's not one of the conditions where they typically authorize IVIG at home even though it's cheaper for them. Go figure, right?

Eliot Finkelstein:

Yeah, really.

Andrew Schorr:

So, you have to be an advocate. Like Eliot, you probably have to make a lot of calls. Stacey, this is so unnerving for us who are dealing with cancer.

Stacey Worthy:

Absolutely.

Eliot Finkelstein:

Can I add?

Andrew Schorr:

Yeah, go ahead. We're gonna have to fight Medicare, call our congressman, make sure our doctor has the right code...

Eliot Finkelstein:

...let me add a couple things. One is we don't pay a bill now until we see both the doctor bill as well as the explanation of benefits, and then we make sure everything is correct on it. That's one. The other one is that—I just lost my train of thought. We cover ourselves, and we make sure everything matches up in what it should be.

Andrew Schorr:

So then, it brings us to the question—Stacey, you're a healthcare attorney. When do people need to get an attorney involved? You talked about the appeal process, which can have a couple levels, or Eliot calls an ombudsman, which is great if somebody at his insurance company can go to that.

Social media you mentioned, and our daughter Ruthie actually used that with Blue Shield of California. She rattled cages on social media. Suddenly, somebody higher up saw it and got involved. I did some peer-to-peer review that got something covered that they were saying they wouldn't. But, when do we need to look for an attorney to write a lawyer letter or do something more?

Stacey Worthy:

I would say if you wanna file a lawsuit, that's a last-case scenario. If you need help with the entire process, you don't necessarily need an attorney. You may be able to find a patient navigator. I know other groups—American Cancer Society offers assistance with patient navigators, who can walk you through the whole process and help you with the appeals process, and oftentimes, they provide those benefits for free. So, you don't necessarily need an attorney unless you want to file a lawsuit.

Andrew Schorr:

What about just a so-called "lawyer letter" on your stationery?

Stacey Worthy:

You can definitely send a strong message with that.

Eliot Finkelstein:

Well, the other part is—I'm a member of Legal Shield. I imagine I could go ask Legal Shield and say, "Hey, could you write a letter on my behalf?" It's a local attorney.

Stacey Worthy:

Yeah.

Andrew Schorr:

It's kind of a pain, because here, you or your spouse, your loved one, is dealing with this, and it takes a lot of energy. I will tell you that just the other day, we recorded a program that'll be posted in about a week, and it's with the Chief Medical Officer for The Leukemia & Lymphoma Society and the Vice President for Education for another organization, Cancer Support Group. Some of you may remember it as the Wellness Community or even Gilda's Club in some cities.

And so, you can call them, and they will often have resources to help you, as you were just saying, Stacey, with the American Cancer Society. You don't have to go it alone and you don't necessarily have to call an attorney. You can be guided on some of these processes.

But, you can start by calling your insurance company—or, for me, with this issue about Medicare, is there a workaround I could have with my wife's insurance? We did not have an insurance broker, but I arranged one just the other day. She was very knowledgeable. I'm gonna see if she can go to bat for us and help us figure out a better way to do this, where one person is on Medicare, one person isn't, has a family plan. Can I get a greater benefit that way?

And then, There's the whole public advocacy part of it, and that's why we call it the ABCs of Patient Empowerment, because you know these debates are gonna be going on in Congress, and then you have Medicare changing its policies independent of Congress unless Congress weighs in. How does it work? You're back there in Washington, Stacey. How much can Medicare do on its own, and how much can Congress change it?

Stacey Worthy:

So, there's a law in place, and it gives CMS, the Centers for Medicare and Medicaid Services, authority to issue rules interpreting that law. Medicare is allowed to change the program as long as they're interpreting the laws in place to allow them to do so. If the law is pretty—unambiguous on its face, at that point, Congress would be in charge of making the change.

Andrew Schorr:

Okay. And, what about—so, Eliot has insurance in California, my wife does too. Is that regulated by the state? How much of it is regulated federally?

Stacey Worthy:

Private health insurance? It depends on—typically, private health insurance is run through the state, and then, if you have an employer-sponsored plan, then it's a little trickier, because I think the Department of Labor has some jurisdiction over those types of plans, so that's federal. But, if it's through the insurance marketplace exchange, then that's through the state. However, in some states, even the exchanges are run federally, so it really depends on the state and the type of plan.

Eliot Finkelstein:

Confusing.

Stacey Worthy:

Very confusing.

Andrew Schorr:

Okay, now, let me ask about this. So, if you work for a corporation—you talked about an ombudsman.

If you're having these issues, do you go to HR? Is that who goes to bat for you? Hopefully, you work for a large corporation, and they have some clout.

Stacey Worthy:

Yeah, absolutely. You can definitely talk to your HR professional, get some clarification on your healthcare policy. I don't know that they would go and file the appeal for you. I think your best bet is to go and work with your doctor directly, because oftentimes, when you're appealing a decision, they're gonna want proof of medical necessity. And only your doctor can provide that, but I think it's definitely worth talking to HR professionals as well.

Andrew Schorr:

Okay. So, now, if you have questions folks, I want you to send them in to – you can do it either way—c11@patientpower.info or questions@patientpower.info, and send us questions, but not too specific. Eliot, what advice do you have to people? You've had this journey, you've had to double-check with a magnifying glass your doctor bills, your hospital bills, and you have a couple different insurance policies now.

Eliot Finkelstein:

My biggest thing is you need to stand up, you need to speak up in a very nice way. Also, whenever you're prescribed a drug, call the drug company, go online to the drug company, see if you can get it cheaper. I'm doing eyedrops because I've got dry eyes, and I went online to the company, and they have a discount that you can print out, and I didn't have to contact anybody. So, it went from my maximum of \$30 a month, down to \$5 to \$10 a month. So, you can call the drug company. You can take care of whoever it is and see what they've got, and you can ask. Don't be shy about calling. The other thing is to speak up when you get a bill.

Some of my bills, because I'm out of state—mine is Blue Cross/Blue Shield of California—how crazy it is is the lab sent a bill to Blue Cross of Nevada, and it was supposed to be sent to Blue Cross of Arizona, where I live, but if it's sent to Blue Cross

of California, it's considered out of network. And so, it's a billing error, but we keep getting those, because someone in the billing department of whatever company sent it to the wrong place.

So, you have to keep eyes out for that, and you have to be really strong in talking to the people, and if you don't get the answer you want on the phone, you say, "Let me speak to someone who can give me that answer," and you keep pushing it up the ladder. They'll try and tell you, "Well, the supervisor is not here." "Well, you're not the head of the company. Give me someone else. Give me their supervisor." Keep pushing and take names, dates of when you talked to them, and the gist of the conversation, and just write it down. Those are the biggest things. And, you're allowed to tell a doctor no.

Andrew Schorr:

Well, first of all, I think that is a—Stacey, I think we've talked about this on other programs—when I needed CLL re-treatment, it was a discussion that Dr. Kipps and I had about what would be effective therapy at the time, and would it be oral therapy, where I was already taking expensive oral drugs for another condition, or would it be infused therapy? At that time, last year, we agreed on infused therapy, because we were concerned about additional co-pay costs for an additional Tier 5 oral medicine. So far, so good. My CLL is in check. So, I think in this age of oral therapy, infused therapy, what drug when, unfortunately, there may be a financial question based on the vagaries of insurance.

Is it covered by in-hospital and in-clinic care, where it's covered more completely than oral care? Have that discussion, because often, your doctor is gonna say—some doctors will be knowledgeable; some may not be. Hopefully, there's a financial navigator at the clinic or in the hospital group, or you can turn to The Leukemia Society or the Cancer Society—one of these groups—to help navigate this, because these are not trivial decisions with expensive medicine.

Obviously, you want the right care, but could you go left or right? In the words of your doctor, would they be equivalent at this time? But obviously, you need to make calls.

Stacey, let's go through the process because some of our folks have been asking—the appeal process. So, you are denied coverage, or it's gonna be really high co-pay, or whatever.

...scan or maybe some...take us through the process. Just walk us through.

Stacey Worthy:

Sorry, you froze. Could you repeat the last thing that you said?

Andrew Schorr:

Could you take us...

Eliot Finkelstein:

...take us through the appeal process.

Stacey Worthy: Oh, okay. So, you're gonna get a—if you're denied care, you're going to get a letter in the mail that explains that your care was denied. At that point, you're gonna wanna read it, review it, figure out what was the reason that they denied the care, let your doctor know, and then you're gonna call the insurance company. And, as Eliot said, you wanna take a lot of notes here as to who you're talking to, what they told you, and everything that happens.

Make sure you put the date down, time, everything, the name of the person, and find out what the appeals process looks like, try to get more information about why it was denied, what the next steps are. Then, you're gonna work with your doctor to file an appeal. So, it might be a formal appeal where the doctor needs to submit some type of form or documentation proving that the treatment was medically necessary or whatever was going on, whatever reason it was denied.

At that point, they'll likely give you another letter, and they have time limits on when they're required to respond. The time limits might be different per state, but typically, it's no longer than 15 days, and in some instances, they're required to allow you to remain on your treatment while you're appealing, so it really is state by state. Unfortunately, it differs by state.

Eliot Finkelstein:

And company by company.

Stacey Worthy:

Exactly. That's absolutely true. So, at that point, they're gonna give you another letter. Either it'll tell you that they granted the appeal, whether fully or partially, or that you were denied. If you were denied again, that's when they should give you a letter that gives you a list of independent reviewers. So, this is the private entity—or, it's an entity that's not affiliated with your insurer, and you can appeal to this independent body at this point, and you can ask them to review.

They're gonna do another medical review and determine whether the insurer was justified in denying your claim or not. If they deny, then that's when you're going to want to go to either your insurance commissioner or attorney general, and they're gonna be looking at it from more of a consumer protection perspective to see if they did something that was in violation of a consumer protection law or unfair or deceptive, and then hopefully get you coverage that way.

But, as I said—as we both said, you can always try and threaten ahead of time. When you do that very first informal conversation, you can threaten to skip right to that complaint process, and maybe they'll approve the treatment sooner than later.

Eliot Finkelstein:

On mine, Andrew, it's very specific. You have to do the written appeal first, and then if you get denied, my second appeal goes directly to the state board. Some people do other things.

Stacey Worthy:

Yeah, absolutely. That's a very good point. So, you're gonna wanna find out what the process is from your insurer, and then make sure you follow that to a T because if you don't follow the process, they can find any reason to deny you.

Andrew Schorr:

Okay. And, if you're a Medicare patient and it seems like they've got these big books—is there any appeal process within Medicare?

Stacey Worthy:

I'm not entirely sure about that, so unfortunately, I can't give you more information there.

Andrew Schorr:

And then, what about—you mentioned going to the media or even—a lot of us here are on the Internet a lot. What do we do about going to social media? In other words, if we're having a beef with Blue Cross of whomever or whatever the policy, should we do @bluecross or look it up somehow and just say, "I'm having a big fight, I'm living with a cancer—a leukemia—and they're giving me a hard time about the coverage that my doctor thinks I need"?

Stacey Worthy:

Yeah, absolutely. I would recommend tagging your insurer, and then tagging all the big patient advocacy groups as well, and Patient Power. Tag everybody, because they can amplify your voice, retweet you, and get you a lot of coverage, so I think it can be a very powerful tool.

Eliot Finkelstein:

Just don't curse.

Andrew Schorr:

Yeah, don't curse. Be respectful. But, I'll just say—also, the drug company that makes the medicine that you need wants you to get it, right? And, they may have assistance programs. They often do, even in some cases for non-Medicare patients. I know a woman who needed certain breast cancer drugs and couldn't get them in any way, and they had free drug programs. So, I want you to call them and name...

Eliot Finkelstein:

I'm not—my connection is bad.

Andrew Schorr:

...go ahead.

Eliot Finkelstein:

Okay. I found out—and, I'm getting my venetoclax through Mayo, and they said, "Oh, we have a special going on from the manufacturer, so you get it at 75 percent off," and I hadn't even asked for it—75 percent off my co-pay, so it was really nice.

But, like you said, you definitely wanna ask. Some of the discounts are only for commercial or private insurance. Some don't help with the Medicare; some don't help with that, so you've gotta keep asking, gotta keep pushing—again, call the manufacturer, get ahold of them, email them, talk to them.

Stacey Worthy:

I would like to add one thing about co-pay assistance. The new latest and greatest thing that insurers are doing—they're implementing policies called co-pay accumulator programs. I don't know if you guys have heard about this, but traditionally, when you get co-payment assistance from the drug manufacturer—those coupon cards—their assistance counts toward your deductible, so it's helping you spend down that deductible throughout the plan year, and it helps you even sooner, and then, once you meet the deductible, either you have a really, really small co-payment or it could be free for the rest of the plan year.

Well, with these co-pay accumulator programs, they're not allowing you to apply those coupon cards towards your deductible, which means it takes twice as long to meet it, and as a result, sometimes people—when they run out of co-pay assistance, it may come to a shock to them that they still owe for that entire deductible.

Eliot Finkelstein:

With that, Stacey, I found out from one of the smaller companies—it depends on how the biller bills it to the insurance company. Are they disclosing the co-pay assistance or not? And so, my people said, "We never disclose co-pay assistance," so my deductible per drug goes down and my overall co-pay—I'm sorry, my co-pay goes down, and my deductible stays where it's at, and ends up finishing faster.

Stacey Worthy:

I have heard of a couple plans that have tried to curb that as well, so they've implemented a provision in their plan basically saying if you don't disclose that you're getting assistance from a manufacturer, then they can essentially drop you from coverage.

Eliot Finkelstein:

Ouch.

Stacey Worthy:

I'm not even sure that's entirely legal, but they're trying. They're really trying to get around this.

Andrew Schorr:

Well, I listen to this, and I just think here we are, living with a potentially fatal condition, trying to take advantage of progress in medicine, and we're just getting hammered. That's a bigger debate, and I think that is the kind of thing that you can tell the media, tell your congressman, things like that because the costs are going up. I heard the other day that the oral medicine I take for this other blood cancer – myelofibrosis—when it came out was \$86,000 a year. Now, it's \$156,000 a year. Of course, co-pay goes up with all that. And, we could have another discussion about why do drugs cost what they do, and that's a big discussion.

But also, though, how do you, the cancer patient, cope? Now, one of the questions we got in is just to tick off some of these organizations that can help with co-pay assistance. So, we talked about co-pay cards and co-pay programs if you're on commercial insurance, but if you're Medicare age, then they won't let you do that, but there are these foundations, and Stacey referred to it earlier.

So, one is the Patient Advocate Foundation, another is NeedyMeds, another is Good Days, and what we'll do is we'll get our producers to post links in if they send you a follow-up email after this webinar. We'll get the links in there so that you can talk to them, and they may have people who can help you. Now, one of the issues has been do these funds run out of money sometimes during the year? That was a concern earlier in the year, and one of the foundations—The Leukemia & Lymphoma Society has assistance as well.

So, you wanna ask them, but hopefully, there are ample funds to help you, and you—no matter what your financial situation is, you should talk to them and say, “Can I qualify? Can I get some assistance?” as well as we go to the mat, if you will, on these policies with Medicare, et cetera on what is our share that we have to pay. Other questions, folks—send it in anytime. cll@patientpower.info.

Eliot Finkelstein:

Also, you're talking about how they run out, but a lot of them will get more during the year, so what they told me, actually, at The Leukemia & Lymphoma Society is keep reapplying. Check every day, check once a week, check once a month, because all of a sudden, there might be money there that next day and you can apply for it. So, all of these you can keep applying for. It's not just because you're turned down one time for the year. You can keep applying during the year and keep checking back in.

Andrew Schorr:

Apply with more than one foundation.

Eliot Finkelstein:

Yes, apply for all of them.

Andrew Schorr:

It's just like applying for more than one college. So, Stacey, as you look forward to this, tell us more about the activities at Aired Alliance and how we can help, because you're way down in Washington, D.C., which is sort of action central for a lot of these policies.

Stacey Worthy:

We're an organization that works to protect and enhance the lives of healthcare consumers and practitioners. So, we're looking to see what laws there are available to protect you as a patient and as a healthcare consumer, both at the state and federal level, and we're trying to educate people on what those laws are, and so, I would say come to our website, go to www.aimedalliance.org, take a look at our materials.

We have a brochure on open enrollment that tells you exactly what to look for when you're selecting your health plan, things to consider, whether your health plan's gonna cover your doctor, whether your health plan's gonna require a referral, what you're gonna have to pay for your medication, things like that. And then, we also—where we do identify deficiencies in the law, we do look to make recommendations on how those can be strengthened. We don't typically do direct lobbying per se, but we do work to educate policymakers, so we would definitely love help amplifying those messages.

Andrew Schorr:

Okay. So, Patient Power is very conscious of this. You may be aware—if you go to the Patient Power website—and, we'll send you the link again—we've established a Patient Power ambassador program. Eliot, I don't know if you've signed up, but if you haven't, I hope you will. It's where you can say, “Here, I am, I live in Bullhead City, Arizona, and I've been living with CLL for so long.”

And, what we're gonna increasingly do is do programs like this so that you are smart – not just about the treatment and side effect management issues or watching weight for CLL—we do all that too, but also where we may educate you on more of these policy issues or obstacle issues, and where you can speak out in your own community or in your own state. Then, we can work with the Aired Alliance to say, “Here are people in California, here are people in New Jersey who wanna speak up,” and that'll help you, right, Stacey?

Stacey Worthy:

Yes.

Andrew Schorr:

If you have grassroots patients who are dealing with these issues and we can go to the media or to legislators, that's a powerful story.

Stacey Worthy:

Absolutely.

Andrew Schorr:

All right. None of us want to be diagnosed with a cancer—or a loved one—and that's a heavy burden to deal with, and Eliot's been dealing with it for a while, and he's had his windy road, doing well now.

I've had mine for 22 years, and then with a second condition for the last seven years, so it's enough to deal with it just ourselves, and now we're saying deal with these insurance issues, now you're getting older, dealing with Medicare instead of these insurance issues. Should you be on some mix of the two?

And then, we're saying speak out because the insurance companies are trying to pocket more money or spend less money, and we talked about those pharmacy benefit managers, and Medicare is trying to control costs, and the Affordable Care Act is going under review, and some things are sunseting—some provisions that Stacey talked about. So, unless we speak up, we're caught in the middle. Eliot, would you agree?

Eliot Finkelstein:

I would agree. You've gotta do everything you can to watch yourself and pay attention.

Andrew Schorr:

Right. And, I will say just a couple of other things. The doctor, who often is so busy practicing medicine and managing the complexity of leukemia care now with all new choices, testing, et cetera—it's a lot for them to do. But, trying to help with the financial issues – and, I'll just take a little story because you'll hear it in this program coming up that we recorded the other day at the ASH meeting.

So, we had a community doctor from Somerville, New Jersey, Kathleen Toomey, and she talked about—she's been practicing over 30 years—how, on her days off, she calls the insurance companies for her patients in fighting these battles. She's an exemplary doctor.

Eliot Finkelstein:

Wow.

Andrew Schorr:

Not everybody does that. It is a "wow." But, this is the battle we have—your doctor, nurse navigator, financial navigator may be able to help. Ask if they're available.

Social workers can help as well. If there's an oncology social worker at the clinic you go to—certainly, I went to MD Anderson, and they have them. If you go to a big hospital, they may have oncology social workers who may be very familiar with these foundations or these ombudsman programs. It's a lot. Stacey, any final thoughts or advice for our viewers on how they can get access to what they need and deserve, and is it just to speak up? What would you say?

Stacey Worthy:

Yeah, absolutely. I think just reiterating the message that we've provided for healthcare—you're your own advocate, so you've gotta advocate for yourself, and definitely, speak up.

Andrew Schorr:

Okay. How about you, Eliot? Final comments from you?

Eliot Finkelstein:

Like Stacey said, you've gotta speak up. You can't be shy. And, bring someone else with you to all your doctor's appointments. Even if they just sit there, they'll keep an eye on you, make sure you ask the questions.

Andrew Schorr:

Look at those bills.

Eliot Finkelstein:

Look at those bills, and don't pay your bills until you get all the bills for that particular situation, and you might end up—surgery, you typically get at least three bills, so you wanna see all of them and see what's going on with everything.

Andrew Schorr:

Right. One last thing is just a little bit about clinical trials. On an earlier program that we did with the Patient Empowerment Network, we did a program with a woman named Dana Dornsife with the Lazarex Foundation, and they provide support for people being in clinical trials, because often, in clinical trials, there are some things that are not covered, that are not free. Or, you may have logistical issues in participating in a trial.

We want you to consider being in the trial; that's how we get new medicines, right? But, you may say, "I can't get a babysitter, I can't get off work, I don't have transportation, and I can't pay—my insurance company wants me to pay for that extra CT scan or whatever, and I can't afford it."

There are foundations like the Lazarex Foundation that fill in there so that your oncology social worker—or, we'll remind you on Patient Power of this to deal with the cost. Hopefully, we can navigate this. Thank God people like Eliot and me are doing well with CLL, and there's a lot of news coming out that we'll be sending you from the American Society of Hematology meeting that just happened. So, all the best to you. Eliot, all the best to you. I wanna thank you for being with us, and Stacey, thank you for being with us once again.

Stacey Worthy:

Thank you for having me.

Andrew Schorr:

Okay. Andrew Schorr, reminding you that we think about these issues for you and we're gonna have programs, certainly, on treatment, research—all those kind of things coming your way, but also, work with us so we can speak up so you get access to the care you need and deserve, and the policies are right and fair for us. Remember, knowledge can be the best medicine of all.

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