



# Patient Power

## What Can CLL Patients Do About Expensive Co-Pays?

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Patient Advocate

This is the guest's affiliation. Use style "Guest List – Affiliation"

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**Andrew Schorr:**

Let's also talk about copays because the copays 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 to 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—a 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 copay 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.

**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 copay, 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 copayment 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 copay 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.

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