



Patient Power

Congress and Cancer Care: How Can CLL Patients Get Involved With Insurance Policy-Making?

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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 5 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.

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