



How and Why to Fight the Insurance Companies to Get Access to the Medicines You Need

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Andrew Schorr:

Hello and welcome to Patient Power. I'm Andrew Schorr. All of us who are cancer patients or if we have a loved one who is a cancer patient, we know it's not just about new and better medicines being developed or being in trials. It's also having access to them, and unfortunately there are often obstacles related to cost and access, related to that.

Joining us now is a leading healthcare attorney from Washington, D.C. That's Stacey Worthy. Stacey is the Executive Director of something called the Aimed Alliance. Stacey, thank you so much for joining us.

Stacey Worthy:

Thank you for having me.

Andrew Schorr:

Stacey, first of all, what is the Aimed Alliance? What does it stand for, and why is it needed?

Stacey Worthy:

So the Aimed Alliance is the Alliance for Access to Innovations and Medicines, and we're a nonprofit organization that focuses on expanding access to treatment. So we make sure that patients and providers make healthcare decisions without inference from an insurer or from their pharmacy benefit manager, which is that middleman that makes that—that creates discounts and negotiations between your health plan and you. And we do all that with a legal lens, so we do it through changing the laws, through educating the patients on what their legal rights are.

Andrew Schorr:

Okay. We're going to get much more into that as we continue our interview here, Stacey. I'm just going to talk about my own situation and see if that's germane, if you will.

So I take an expensive genetic inhibitor for a condition called myelofibrosis, and I'm finding that my co-pay initially in one month, with a pharmacy benefit manager, somebody who is calling me and shipping the medicine to my house, was \$2,000. Then some kind of catastrophic limit with Medicare Part D, and now it's gone down to like \$300 for a medicine I take in the

morning, and another some 300-some-odd dollars, and I'll have that for the rest of the year, I think about \$10,000 out of pocket, and then it resets itself the next year.

And I don't know from pharmacy benefit managers, I don't know if I have to keep with the one I have. Can I get a lower price somewhere? And also they're telling me that my cost is based on 5 percent of the cost of the drug. But I understand this is not very transparent. In other words, it's hard for me to really know what's going on behind the scenes.

Talk about that for a minute. I have one insurance company, but I know there are many. So what's the problem now in the consumer, me, trying to know what am I paying for, what's it going to cost me, and what's it based on?

Stacey Worthy:

So that is a really big problem right now, is there's a huge lack of transparency. So your insurer and your pharmacy benefit manager working together, the pharmacy benefit manager negotiates with the drug manufacturer to get discounts and to decrease what your insurer ultimately is going to pay. Although the pharmacy benefit manager can then keep part of that discount for himself and deem it an administration fee, so it's holding on to some of that discount.

Then it passes on additional discounts to the insurer, but then, you know, insurers want to make a profit too, so they may decide also to hold on to some of those discounts. And basically there's no guarantee that you, the patient, is going to receive any of those discounts, and that's just a lack of transparency.

We saw that recently with a lawsuit against Express Scripts in a lawsuit between Anthem and Express Scripts, and we saw that Express Scripts is actually keeping \$5 billion in what was seen as profits, so a windfall of profits just in these discounts not passed on. And once this lawsuit went in place or brought these facts into light, only then did patients and plan enrollees learn how much of this discount was not being passed on to them.

Andrew Schorr:

Stacey, there's been a lot in the news and political campaigns and ongoing about the high cost of medicines, and I think the assumption is that the drug companies are gouging the public. And there have been a few examples, and even people have gone to jail for that. But, generally, I know that it's expensive to develop new medicines and increasingly for subsets of patients sometimes with very rare conditions, and that's expensive. We'll have to revisit that, of course, how can we control the costs from the drug companies.

But it sounds like what you're saying is there are other players, insurance companies and these pharmacy benefit managers where we, the patients, haven't been so aware of the billions of dollars they're making on our backs. Is that right?

Stacey Worthy:

Absolutely. I can give you another example, is a lot of times pharmacy benefit managers will have in their contract with the pharmacy what they call a gag clause. So that means in fact they might be charging you more out of pocket for what a medication will cost than if you didn't go through your insurance whatsoever.

So you have these generic drugs that they might be \$5 out of pocket. But if you go through your plan because your PBM, your pharmacy benefit manager, kept all this discount for itself, you're now paying \$20 out of pocket instead of that \$5 co-pay. And your pharmacist is not allowed to share that information with you, because that contract has bound him or her from disclosing that information.

Andrew Schorr:

Oh, my goodness. So lack of transparency. So how can the Aimed Alliance, how can we work with you so that we, the consumer, somebody facing maybe a very serious life-threatening cancer, we can get what's right for us and fight back.

Stacey Worthy:

Yes. So what we're trying to do is raise awareness of some of these issues, especially of some of the barriers to access. So a patient may say step therapy, for example, where an insurer or a PBM will require the patient to try and fail on a cheaper medication before they can access the one that was prescribed for them. But for a patient with cancer that can mean that

if you're stable or in remission, you could come out of remission and relapse, or your disease could progress while you're waiting for access to that medication most appropriate for you.

So we don't want patients to have that sort of delay. We want to educate them. And so if you ever are faced with a policy like this we want to make sure that you know about it, know what's happening to you and then speak up for yourself so you can work with your doctor to file an appeal and get access to the proper medication.

Andrew Schorr:

Okay. So do you through the Aimerd Alliance have any tools, so we can file appeals, whether we go to the insurance commissioner in our state or appeal with the insurance company? In other words, do you have like a tool kit somehow?

Stacey Worthy:

We do. So we have what we call our Know Your Rights campaign, and that's available at www.coveragerights.org. And what it is is it provides an overview of some of these policies that insurers and PBMs impose, such as step therapy, and then it provides state-by-state specific information on how you can file an appeal. So it walks you through the process of working with your doctor, contacting your insurer, filing the correct paperwork.

And if for some reason your insurer still denies you after that appeal, then how you can file a complaint with either your insurance commissioner your attorney general? Because the more complaints that are filed the more willing they are to be able to identify bad actors in the industry and take action to prevent them from doing that to any other patients.

Andrew Schorr:

Oh, my. So we're asking people who are sick, or their loved one is sick, to go through all this paperwork, if you will. How do we change the system, Stacey? You're in Washington. There are lots of healthcare legislation debates going on. Should we be lobbying our congressmen, or what can we do, so there's transparency so that sick people basically don't have to suffer more through all of this trouble with access to the medicines they need?

Stacey Worthy:

So there are several states that have taken the initiative to introduce legislation that would create transparency among PBMs and insurers and that would also limit some of these policies such as step therapy or that would place a cap on the co-pays of how much you would have to pay out of pocket per month.

So we want to support those efforts and would absolutely encourage individuals to reach out to their local congress members and encourage them to pass these laws themselves. Or if they haven't been even introduced, then to consider introducing them, get that ball rolling and get that conversation started. And oftentimes we can search for a local patient advocacy group that deals with your particular condition and maybe advocating or lobbying on this issue.

Andrew Schorr:

Yeah, I think that's where we are now. We at Patient Power have done a lot of coverage of new medicines that exist or are in development, but this whole question of access and the ability to get it at an affordable price where you don't have to go bankrupt if you're diagnosed with a serious illness. That's where we are now.

Well, Stacey, thank you at the Aimerd Alliance for all you are doing, and we have a smart attorney leading the way. And could you repeat that website again where—for Know Your Rights?

Stacey Worthy:

Absolutely. So it's www.coveragerights.org.

Andrew Schorr:

Okay. All right. I'm going to go there, and it's good to know that you, Stacey, are going to bat for us, too. Thank you for being with us today and the work you do at the Aimerd Alliance.

Stacey Worthy:

Thank you for having me.

Andrew Schorr:

I'm Andrew Schorr. Very important issues about access to the treatment you need and deserve. Remember, knowledge and power can be the best medicine of all.

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