

PERSPECTIVES

## A little education goes a long way for advocacy

**Publish date:** March 16, 2023

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IN COLLABORATION WITH  **CSRO**  
COALITION OF STATE RHEUMATOLOGY ORGANIZATIONS

If you are reading this, you probably know what a PBM is or at least know what the acronym stands for (pharmacy benefit manager). But don't be surprised if many people, even physicians, still have never heard the term or don't know (or really care) what it stands for. This past weekend, I saw how important even a little bit of education on this seemingly boring topic can create passionate advocates in less than an hour.

On March 10, the Coalition of State Rheumatology Organizations had its [Fellows Conference](#) on real-life topics such as evaluating a contract, malpractice troubleshooting, getting out of debt and creating wealth, and learning about the latest coding issues, among others. We had a record-breaking number of fellows in attendance this year. I gave a presentation on formulary construction (list of drugs that insurance will cover), what tools are used to keep the formulary profitable, and what are the potential consequences for patients with the use of these tools, such as step therapy and nonmedical switching. Remember that if you have a condition requiring an expensive drug that is not covered on the formulary, you will not have access to it unless it is given to you for free by some type of assistance program, or you happen to be very wealthy.

It was the first time I gave this talk at our Fellows Conference, and I realized fairly quickly that a decent proportion of the audience did not know what PBM stood for, much less the power that PBMs have in setting up the list of expensive drugs that they will pay for. I wasn't so surprised by how little they knew about the particulars of this topic – for example, that lower-priced medications are often shunned by PBMs because they are not as profitable for the PBM as higher-priced drugs. However, I was very pleasantly surprised at the number of fellows who came to me after my talk with almost as much passion as I have for this topic. Many asked how they could get involved and what they could do right now to support advocacy for their patients. It all seemed to fall in place for them as they began telling me stories of the problems they had in getting medications for their patients – adults and kids alike.

The “meme” on the street is that drug pricing, patient access, and the drug supply channel is “much too complex” for the non-economist to understand. That was not the case at the Fellows Conference. It started off with me moving back and forth across the stage explaining how the system is run by entities whose fiduciary responsibility is to their shareholders, not our patients. I explained the fierce competition, the bidding process, the “rebate equation,” and many stories of egregious policies and behaviors by an oligopoly of health insurers and their powerful PBMs. I repeated over and over that “If you make an expensive drug that is not on the formulary, no one will take to your drug, unless you give it away for free.”

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It became clear to the room that the competition among expensive drug makers to get preferred status on the formulary is fierce. I explained how to win that coveted spot on the formulary by legally kicking back the most money, in the form of rebates and fees, to the PBM. Unfortunately, these rebates and fees are generally a percentage of the list price, so often it is the highest-priced drug that wins the coveted spot. I explained that patients get no benefit from the money kicked back to the PBM, and in fact, because their coinsurance is often based on the list price of the drug, patients’ cost share will go up when PBMs pick the drug with the highest price. I gave the example of a major PBM placing a \$10,000 brand-name drug on the formulary and excluding the \$400 generic version of the same drug. I told them that PBMs call these the “lowest cost” drugs – for them. This made them angry. I also explained to the fellows that these kickbacks are legal because PBMs have “safe harbor” from the antikickback statute. And yes, that made them even angrier. The more I spoke about the harm done to patients both physically and monetarily by utilization management tools such as step therapy and nonmedical switching, the angrier and more passionate they became.

What started as a room full of fellows wondering whether they really were interested in a talk about PBMs and formulary construction turned, in less than an hour, into a room filled with passion and fury: Rheumatology fellows ready to go and fight for their patients. It’s not as complicated as everyone wants you to believe. In that short time, fellows who had walked into that conference hall, not knowing what to expect from me, walked out with a new attitude and passion, hungry for the next step they could take to advocate for their patients. My slogan on Twitter has always been that I will continue to educate and advocate as long as my passion stays ahead of my cynicism. My passion certainly got a boost as I watched the fellows in the conference hall turn into “Rheums for Action” before my eyes.

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