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Testimony of
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on
Pharmacy Benefit Managers: Specialty Drugs
Health Care Availability & Accessibility Committee
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Good morning. I am Carl Schmid, Executive Director of the **HIV+Hepatitis Policy Institute**, which is a leading HIV and hepatitis policy organization promoting quality and affordable healthcare for people living with or at risk of HIV, hepatitis, and other serious and chronic health conditions. I am also a consumer representative to the National Association of Insurance Commissioners. People with HIV rely on medications for their lifelong treatment, those at risk can now take drugs that prevent HIV, while for hepatitis B there is lifelong treatment and for hepatitis C, curative drugs. People with cancer, arthritis, mental health disorders, diabetes and so many other health conditions rely on prescription drugs to remain healthy. While most people would name drug companies and insurers as the entities that determine patient access and affordability to these medications, in reality PBMs control most of those decisions.

I know that this Committee has already heard testimony about the consolidated power of PBMs, their ownership relationships with insurers, their huge profits and reliance on rebates and other hidden fees, and lack of transparency. I would like to highlight the direct impact of PBM actions on patients, specifically on whether they can access the drug that their provider prescribes and the cost they will pay. Much of this is carried out behind the scenes and without regulation. However, that is beginning to change with more states passing bipartisan legislation to regulate PBMs and even the very partisan Congress is working on federal legislation that will hopefully pass this year.

While your provider prescribes the drug that they believe best meets your health needs, that drug may not be on a plan's formulary. Insurers should be following treatment guidelines and their Pharmaceutical and Therapeutic (P&T) Committees, but in reality, the drugs that get on formularies are determined by a negotiation between drug manufacturers and the PBMs. And, as you have heard, that negotiation involves the level of rebates the drug manufacturer is willing to pay the PBM to get coverage and favorable treatment. We are seeing more plans that are not covering recommended treatments or breaking up single-tablet regimens.

Usually, the drugs used to treat HIV, hepatitis, and many other chronic conditions are arbitrarily placed on specialty tiers by the PBMs. On this tier, which was originally for drugs

that needed special handling, patients are required to pay the highest cost-sharing levels, frequently in terms of co-insurance, which can be upwards to 50 percent of the list price of a drug. Fortunately, it has been found to be discriminatory to place all drugs to treat a certain condition on the highest tier, but it is not always enforced.

People who depend on these high-tiered drugs are being saddled with high-cost sharing based on the list price of the drug and are generating revenues for the insurers and PBMs. According to CMS' 2022 National Health Expenditures report, while overall hospital spending is three and a half times higher than what is spent for prescription drugs, the $56.7 billion that patients pay out-of-pocket for drugs is actually higher than the $35.1 billion what we pay for hospitalizations. This is all due to insurance benefit design that the PBMS put together.

Rebates and other price concessions negotiated by the PBMs also play a significant role in determining prior authorization, step-therapy, and other utilization management techniques. These access restrictions present substantial barriers for people trying to access their medications and pose a burden to providers. PBMs also decide whether new and innovative medications are added to formularies and dictate the removal of approved medications from formularies, often done midyear, which force patients to switch from medically stable treatments. PBMs also require patients, especially those taking "specialty drugs" to utilize mail order and the pharmacy that they own, which may not always be convenient to the patient.

While there has been great public attention made to the growing problem of high drug prices, PBMs and the rebates they extract play an increasingly significant role in why we in the United States have high drug prices. It is not uncommon for rebates to total 50 percent or more of the list price of the drug. And this all adds up. Drug Channels estimates that the gross-to-net bubble—the difference between brand name drugs' list prices and net prices after rebates and other reductions—is $334 billion.

PBMs force patients to use more expensive drugs. I remember when the cures for hepatitis C came to the market, there were two early entrants, but then a third was approved with a substantially lower list price. But it never took off because the PBMs did not favor it, they preferred the more costly drugs. These rebates are rarely passed onto consumers. Instead, they incentivize manufacturers to set high list prices in order to account for the expected rebates. They may be used by the plans to lower premiums but is it fair for people who use prescription drugs to be subsidizing health care for everyone?

I know PBMs say they are the ones who are lowering drug prices, but we are not seeing that with generic PrEP, which costs about $20 per month. We know of PBMs that are actually charging hundreds of dollars or even over $1,000 in the private market for generic PrEP. And in the Medicare market, one of Centene's plans in Illinois using Express Scripts is charging $1,212, while Cigna, also using Express Scripts, charges, $800 per month.

Another way in which PBMs enrich themselves is by collecting copay assistance that is meant for the patients and pocketing it themselves instead of applying it to the beneficiary's out-of-

pocket costs. While Illinois has banned copay accumulators for state regulated plans, it is still happening in the large group and self-funded plans.

Much of what PBMs do is happening without any regulation and transparency. But hopefully that is changing. On behalf of patients who are struggling to access and afford their prescription medications, we thank you for undertaking this review and look forward to your next steps.

Should you have any questions or comments, please feel free to contact me at cschmid@hivhep.org or (202) 462-3042.