



SOUTHERN CALIFORNIA RHEUMATOLOGY SOCIETY

October Newsletter

Written by - Dr. Sandy Lee, DO

Coalition of State Rheumatology Organizations (CSRO)

Advocacy Conference

September 20-22, 2024

@ Sheraton Grand Nashville Downtown – Nashville, TN



I had the opportunity to attend CSRO's advocacy conference this year as a representative of SCRS. The conference was highly engaging and involved many panelists debating on issues related to

Medicare spending, drug costs, and, of course, the highly contentious topic of Pharmacy Benefit Managers (PBMs). Here are key issues I took away from the conference that we, as patient advocates, need to be aware of.



- **Prescription drug affordability board (PDAB)** are State appointed boards created to regulate high prescription cost. Maryland is the first state to adopt PDAB in 2019.
- **The issue:** PDABs can set an upper payment limit on drug prices leading to decreased access to innovative medications and increasing operational difficulties (the price cap may not include storage and handling fees)
- **Pharmacy benefit managers (PBM) and their lack of transparency.** PBMs are private, third-party companies that act as the intermediary between health insurers, pharmacies and drug manufacturers. They negotiate drug costs and dictate formulary algorithms in health plans.
- **The issue:** PBMs profit from the rebates provided by the pharmaceutical companies to include the manufacturer's drug on the health plan but these savings are not trickled down to the consumer. PBM are not transparent with the fees included in drug prices.



Some important links to note:

1. <https://csro.info/advocacy/our-issues> – here, you will find all the priority issues CSRO is tackling.

2. <https://csro.info/advocacy/legislative-map-tool> - A useful tool to learn about the existing and pending legislation pertaining to the state and federal level.

3. <https://allcopayscount.org/> - learn about the policies and coalitions fighting to ensure all copays count toward patient's out of pocket costs

- **The use of Alternative funding programs.** These programs are sponsored by third-party companies and charities to provide funding to cover patients' high-cost medications.

- **The issue:** These fundings can be inconsistent, temporary and delay treatment delivery as patients are forced to undergo a time-consuming application process delaying access to treatment. Furthermore, patients of certain tax brackets may not qualify, causing further out of pocket expenses. How is this allowed? There is a loophole in the Affordable Care Act (ACA). The ACA mandates health plans to cover “essential health benefits”, leaving interpretation up to the insurers. Insurers may regard specialty drug coverage as non-essential and thus, will not provide coverage for specialty medications, leaving patients no other choice but to enroll in alternative funding programs to help pay for medications.
- **Maximizers and Accumulator adjustment program (AAP).** Maximizer programs are created by PBMs to manage high-cost specialty medications, by maximizing the cost of the medication and setting a higher out of pocket requirement often up to the maximum amount the manufacturer’s copay assistance will cover. AAP is a strategy employed by PBMs that prevent copay assistance funding from drug manufacturers and charities to count towards patients’ deductibles and out of pocket maximums.
- **The issue:** Both maximizers and AAP exclude copay assistance from contributing to patients’ deductibles. To drive up profit, insurers and PBMs, not only, collect the patient’s copay assistance, but also, continue to charge patients through their deductibles, misleading patients and increasing their out-of-pocket expenses. A court ruling on September 29th, 2023 banned AAP making copay assistance count towards consumers deductibles with caveats. While this is a step in the right direction, this court case can be overturned anytime and does not address maximizers.

CSRO is on a mission to educate legislatures on the state and national level to prioritize these issues afflicting the rheumatology community. Only through advocacy and awareness can we raise these issues to bring about policy change, ensuring our patients’ rights to access the highest quality care in rheumatology.



Some great articles to learn more about the issues above:

1. Great youtube video to understand how AAPs work:

<https://www.youtube.com/watch?v=f8dxz8dB3IY>

2.Clark B., Puthiyath M.S. Can State Prescription Drug Affordability Boards Address High Cost drug prices? Published October 11, 2022. Accessed September 26, 2024. <https://www.commonwealthfund.org/blog/2022/can-state-prescription-drug-affordability-boards-address-high-cost-drug-prices>

3.Kesselheim, A.S., Seeley E. Pharmacy Benefit Managers: Practices, Controversies, and what lies ahead. Published March 26, 2019. Accessed September 26, 2024. <https://www.commonwealthfund.org/publications/issue-briefs/2019/mar/pharmacy-benefit-managers-practices-controversies-what-lies-ahead>

4.Choi D, Zuckerman AD, Gerzenshtein S, et al. A primer on copay accumulators, copay maximizers, and alternative funding programs. *Journal of Managed Care & Specialty Pharmacy*. 2024;30(8):883-896. doi:10.18553/jmcp.2024.30.8.883

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