



Issue Briefing and Advocacy Training on Policy Priorities for Patient Advocates

A policy discussion for advocates

Presenters



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*Vice President of Public
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Who is CCPA?

A network of state and regional health care advocacy organizations advancing public policy that improves the lives of those living with chronic conditions and diseases.



Core Principles



Prevention



Affordability



Access to Care



Quality Health Care

Resources Provided to Groups



- Advocacy Trainings
- State of Chronic Disease
- Federal Policy Background
- Education

Recent Engagement

- Copay Accumulator Regulation
 - Copay accumulators raise costs for vulnerable patients by excluding copay assistance from counting toward deductibles and annual out-of-pocket maximums
- Protecting innovation
 - Legislation that ties drug pricing to foreign countries (most recently, H.R. 3) threatens to significantly reduce the number of medicines available to treat and cure new disease

Recent Engagement

- Protecting comprehensive prescription drug coverage in Medicare
 - CCPA is supportive of the non-interference clause in Medicare Part D.
 - Repealing this clause would likely result in the formation of restrictive formularies, which would limit the availability of treatments on which some patients rely for their health and wellbeing

NI Letter: Protect Protect Comprehensive Prescription Drug Coverage in Medicare





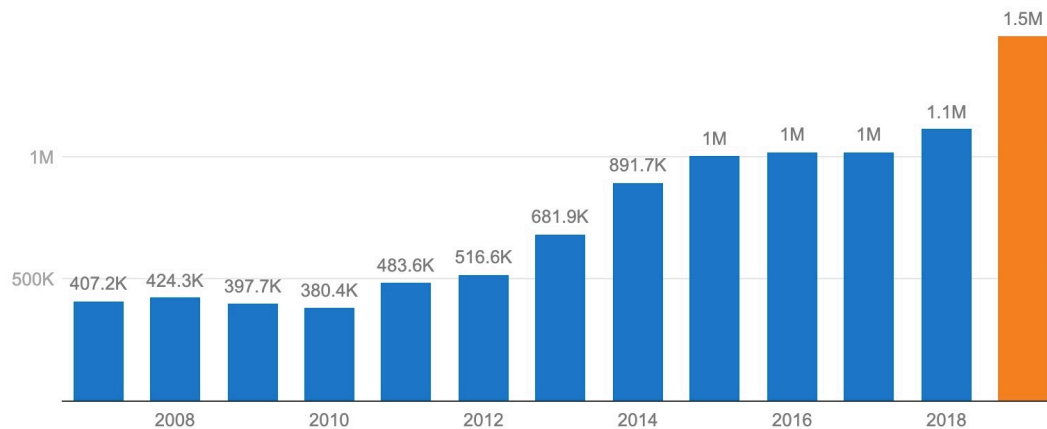
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Barriers.



The Patient Landscape (Medicare)

The Number of Medicare Part D Enrollees With Out-of-Pocket Spending above the Catastrophic Threshold in a Given Year Has Increased Since 2010 and Has Been At or Above 1 Million Enrollees Since 2015



NOTE: Analysis excludes beneficiaries receiving full low-income subsidies (LIS), who have no cost sharing above the catastrophic threshold, and those receiving partial LIS, who pay nominal copayments above the threshold.

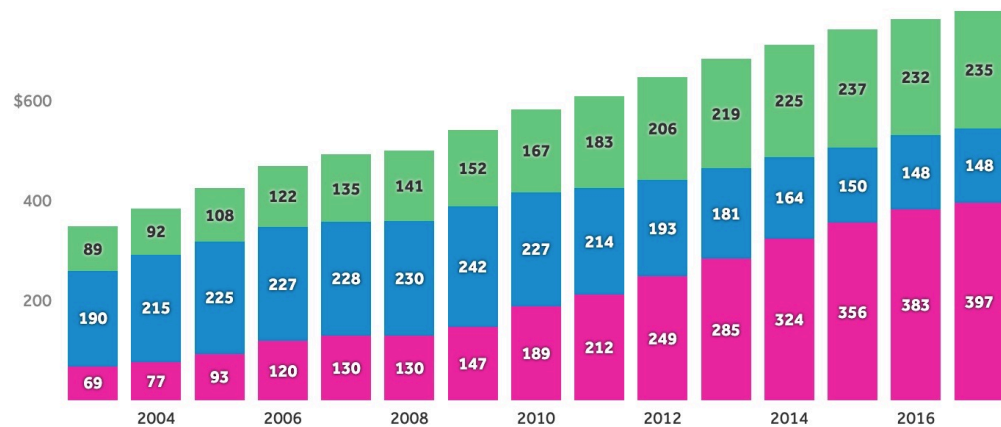
SOURCE: KFF analysis of 2007-2019 prescription drug claims from the CMS Chronic Conditions Data Warehouse. • [PNG](#)

The Patient Landscape (Private)

On average, people with large employer coverage now spend almost \$800 per year out-of-pocket

Average out-of-pocket spending for people with large employer coverage

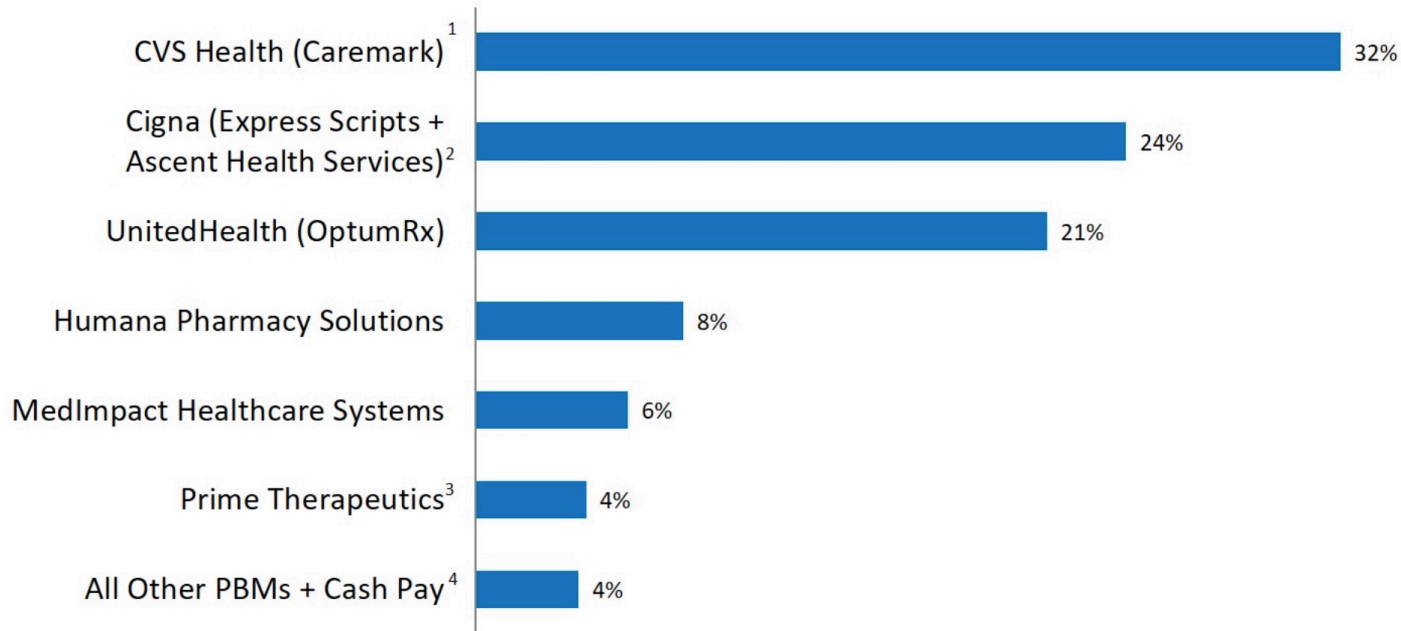
■ Deductible
 ■ Copay
 ■ Coinsurance



Source: KFF analysis of IBM MarketScan Commercial Claims and Encounters Database
[• Get the data • PNG](#)

Peterson-KFF
Health System Tracker

PBM Market Share, by Total Equivalent Prescription Claims Managed, 2020



1. Excludes Drug Channels Institute estimates of double-counted network claims for mail choice claims filled at CVS retail pharmacies.

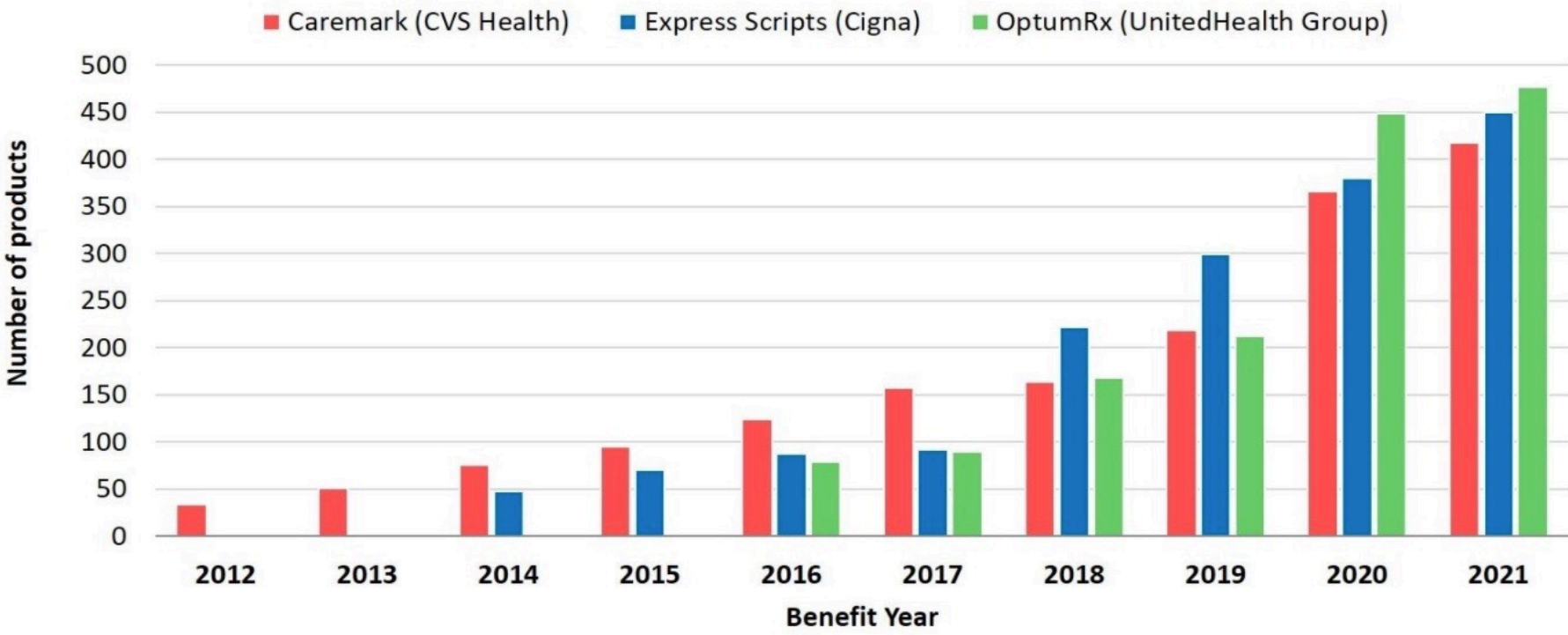
2. Includes Cigna claims, which fully transitioned to Express Scripts by the end of 2020. Includes Ascent Health Services, which includes Kroger Prescription Plans and a partial year of Prime Therapeutics.

3. Excludes Drug Channels Institute estimates of 2020 claims for which Ascent Health Services handled rebate negotiations and pharmacy network contracting.

4. Figure includes some cash pay prescriptions that use a discount card processed by one of the 6 PBMs shown on the chart.

Source: [The 2021 Economic Report on U.S. Pharmacies and Pharmacy Benefit Managers](#), Drug Channels Institute, Exhibit 92. Total equivalent prescription claims includes claims at a PBM's network pharmacies plus prescriptions filled by a PBM's mail and specialty pharmacies. Includes discount card claims. Note that figures may not be comparable with those of previous reports due to changes in publicly reported figures of equivalent prescription claims. Total may not sum due to rounding.

Number of Products on PBM Formulary Exclusion Lists, by PBM, 2012 to 2021



Source: Drug Channels Institute analysis of company reports; Xcenda. Note that some data have been restated due to midyear additions to exclusion lists. Express Scripts did not publish exclusion lists before 2014. OptumRx did not publish exclusion lists before to 2016. Note that PBMs may exclude many of the same medications., so certain products may appear on multiple lists.

Published on *Drug Channels* (www.DrugChannels.net) on January 12, 2021.

U.S. Health Insurers' Profits Boom Amid Pandemic

Net income of selected U.S. health insurance providers



* Owns insurance provider Aetna as well as other non-insurance brands.

Source: Respective companies



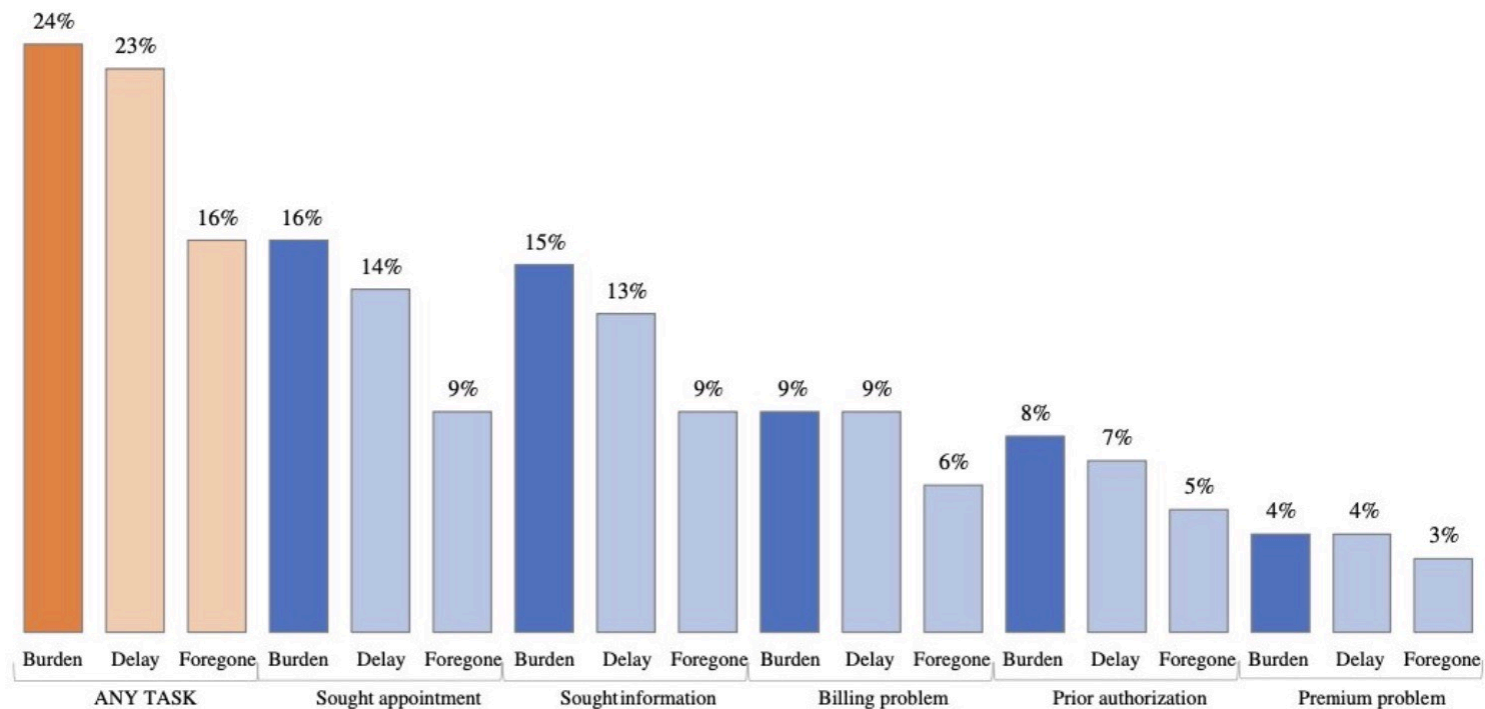
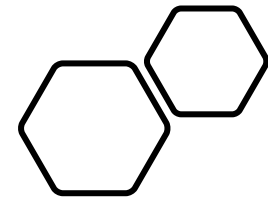
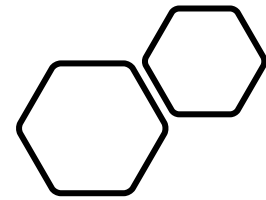


FIGURE 2 Percent of total respondents who reported any burden, any delayed care, or any foregone care, by administrative task type. Authors' analysis of Q1 2019 Health Reform Monitoring Survey. Percentages are survey-weighted, unadjusted descriptive statistics. Denominator for all categories is the total sample ($n = 4155$) [Color figure can be viewed at wileyonlinelibrary.com]

Kyle, MA, Frakt, AB. Patient administrative burden in the US health care system. *Health Serv Res.* 2021; 1-11. <https://doi.org/10.1111/1475-6773.13861>

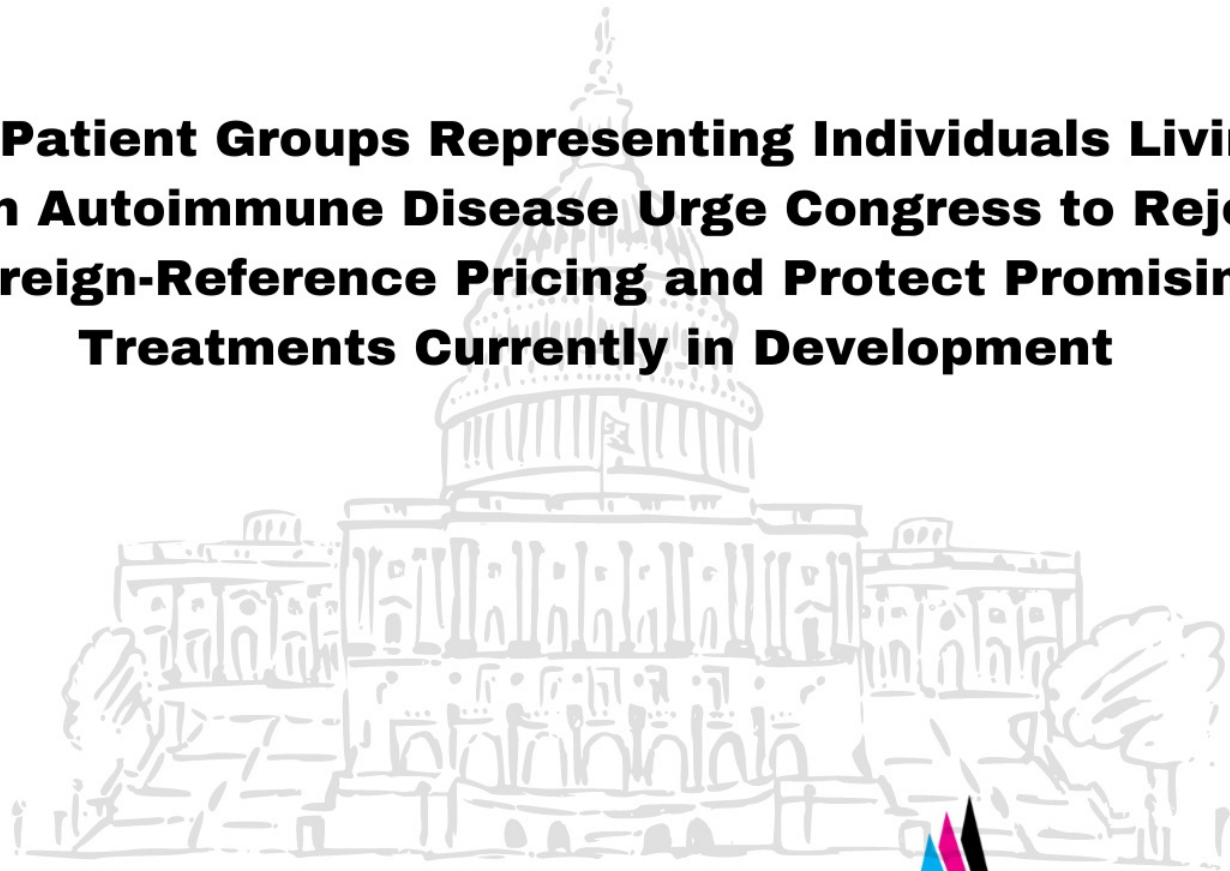


Patients are increasingly an afterthought in the system.



The Federal Landscape

**55 Patient Groups Representing Individuals Living
With Autoimmune Disease Urge Congress to Reject
Foreign-Reference Pricing and Protect Promising
Treatments Currently in Development**



**American
Autoimmune**

Related Diseases Association, Inc.



The Road Ahead



Alex Khan
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Legislative Advocacy in the Covid Era

Tips, tricks, and pitfalls

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Scheduling a Meeting

- **Plan ahead**—meetings can take weeks or months to set.
- Be patient... but not too patient. Two weeks is a reasonable time to wait before following up.
- You should be prepared to offer flexible date/time options and to accommodate various meeting formats (conference call, Zoom, in-person?)
- Send sufficient information to allow the scheduler to feel comfortable advancing the request: Do you have a relevant fact sheet, position letter, press release or other background materials?
- **What's your hook?** Are you a constituent? Do you or your organization have a relationship with the elected official? Why should the member or staff take time out of their busy schedule to meet with you?

Preparing for the Meeting

- **“The worst time to ask an elected official for something is the first time they meet you.”** Lay the groundwork for a successful working relationship.
- Staff meetings vs. member meetings
- **Do your homework:** know your issue, know the process, know why it matters to the members you’re meeting with.
- Learn as much about the member as you can: career, legislative background, interests, district issues, etc.
- Make sure you have materials to leave the member or staff with.

Running a Successful Meeting

- Be on time! Stay on time!
- Clearly state the reason for the meeting up front.
- Provide the level of background or detail that is appropriate for the audience.
“Are you familiar with this issue?”
- Why is this issue important to the elected official? District nexus? In line with priorities?
- Have a dialogue, not a lecture.
- Leave time for questions.
- Make sure your “ask” is clearly communicated.

Post-Meeting Follow-Up

- If you committed to providing follow-up information, make sure you do.
- Send a thank you. Better yet, post one on social media.
- Track your meetings. Save your notes.
- Send reminders to the office ahead of key hearings/votes.

Pitfalls to Avoid

- Win, lose, or draw, always be respectful.
- Keep your commitments.
- If you don't have an answer, be honest and follow-up. Never make up an answer.
- Know the law! Are you lobbying? Do you need to register?
- Make staff's job easy or they will make yours difficult.

Q&A

Thank You!

For additional questions or inquiries, please contact Liz Helms at lizhelms@chroniccareca.org and Brett McReynolds at bmc Reynolds@aarda.org