



# 2023 ANNUAL IMPACT REPORT



# Letter

## FROM THE BOARD OF DIRECTORS

Dear Friends and Supporters:

In 2023, Aamed Alliance continued to advocate for upholding, enforcing, and expanding health care consumer protections, including those under the Patient Protection and Affordable Care Act, and promoting professional discretion in treatment planning. Throughout the year, Aamed Alliance engaged in original research and analysis on our policy priorities, such as expanding access to treatments; upholding disability rights, anti-discrimination laws, and consumer protections; ensuring the reliability of health insurance coverage; and balancing reasonable and transparent drug pricing with the need to fund health care innovation and research.

We created sound, patient-centered policy recommendations that we disseminated through reports, fact sheets, brochures, legislative maps, letters, and comments. Representatives from Aamed Alliance also engaged other organizations to convey these messages, including by presenting to diverse stakeholders, communicating with the media, and collaborating with like-minded organizations whose missions align with our educational, policy, advocacy, and outreach activities.

In 2024, we will continue building upon our past achievements and developing new projects that will advance the interests of healthcare consumers and providers nationwide. As we work on the policy areas we have historically prioritized, we will also engage in new advocacy surrounding access to genetic testing, vaccines, and other tools that help with early identification and treatment of conditions, diseases, and disorders. We look forward to working with you to protect and enhance the rights of healthcare consumers and providers.

Sincerely,

**- Eifer Goldberg**

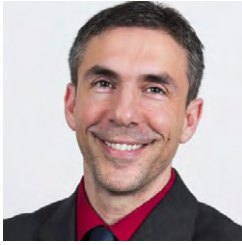
Director

**- Shari A. Hicks, CPhT**

Director



# KEY STAFF



## **DR. SHANNON GINNAN, MD**

As Director of Medical Affairs for Aimed Alliance, Shannon Ginnan, M.D., provides the organization and its collaborators with valuable insight from a practitioner's perspective and serves as a liaison to the medical and healthcare technology communities.



## **ASHIRA VANTREES, ESQ.**

Ashira Vantrees is Counsel at Aimed Alliance. Ms. Vantrees brings with her extensive experience in researching a wide variety of issues, including public health, health education, health law, human rights, women's rights, and disability rights. She provides unique strategic planning and legal insights through research and analysis of laws, regulations, legislation, and advocacy initiatives.



## **MICHAEL BARNES, ESQ.**

Michael C. Barnes, Esq. is Counsel to Aimed Alliance. He is also Managing Attorney at Sequel Health Law, where he practices health and drug law and policy. Mr. Barnes's research and analysis have been published in more than 15 legal, policy, and medical journals. He is a member of the advisory board for the Rx and Illicit Drug Summit, the board of directors for the Legislative Analysis and Public Policy Association, the National Sheriffs' Association's Drug Enforcement Committee, and the editorial board for the Journal of Opioid Management. He is a recipient of the Federation of State Medical Boards' Ray L. Casterline, M.D., Award for Excellence in Writing.



## **OLIVIA BACKHAUS, ESQ.**

Olivia Backhaus provides legal counsel to Aimed Alliance and is an Associate at Sequel Health Law. Prior to joining the Aimed Alliance team, Ms. Backhaus was a law fellow at the Environmental Working Group, where she gained practical experience in policy advocacy and legislative research and strategy. She earned her J.D. from Georgetown University Law Center. She received a bachelor's degree in biology from Sewanee: The University of the South.



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## BELIEFS

We believe that Americans should value their health care and prioritize it as consumers.

We believe that health care industry stakeholders should place the health and safety of patients above all other considerations.

We believe that the costs of health care services should be reasonable and transparent.

## MISSION

Aimed Alliance is a 501(c)(3) not-for-profit health policy organization. The mission of Aimed Alliance is to protect and enhance the rights of health care consumers and providers.

## VISION

The vision of Aimed Alliance is a society in which consumers, in consultation with their health care providers and loved ones, can make informed and individually appropriate decisions about their health care, and those decisions are not overridden by third parties.



# 2023 BY THE NUMBERS

28 

New Online Resources

9 

Fact Sheets

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114 

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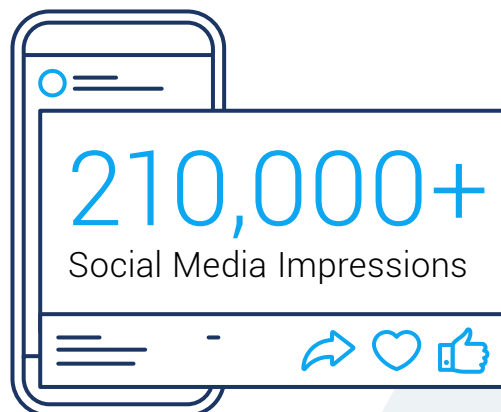
Know Your Rights Consumers

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In the Media





# Advocacy

## AIMED ALLIANCE WORKED ON THE FOLLOWING ISSUES DURING 2023:



Encouraged federal action to address non-essential health benefit (non-EHB) and alternative funding programs (AFPs).



Assisted 11 patients in navigating health insurance appeals and insurance questions.



Successfully advocated for a new state law to improve access to consumer information surrounding step-therapy denials.



Educated patient and provider groups about copay accumulators, non-EHBs and AFPs.



Educated state legislators and consumers on cannabinoids.



Confirmed scope of New York step therapy law as it applies to medical necessity policies, expanding the applicability of New York step therapy protections.



Facilitated and hosted two meeting with patient advocacy organizations and the Federal Trade Commission (FTC) regarding the harms of AFPs.



Participated as a member of the planning committee for the 2023 National Vaccine Law Conference.



Facilitated and hosted meeting with Tennessee Insurance Department and Center for Consumer Information and Insurance Oversight (CCIIO), an organization within the Centers for Medicare & Medicaid Services (CMS) in the U.S. Department of Health and Human Services (HHS), regarding state plan compliance with Patient Protection and Affordable Care Act (ACA) exceptions process. Resulted in CCIIO launching investigation into potential illegal conduct.



Received confirmation from U.S. Food and Drug Administration (FDA) of Aired Alliance analysis of AFP conduct and inconsistency with FDA importation policy.



Filed amicus briefs to ensure District Courts' understood how litigation could impact consumers ability to access and afford their medications.



# Advocacy HIGHLIGHTS

Aimed Alliance supports laws, regulations, and policies that encourage or require public and private payers to offer quality access to individualized, culturally appropriate, efficient, and transparent health care. Aimed Alliance also supports curtailing the use of discriminatory practices in the delivery of health care and the administration of health insurance and employee benefits. To accomplish these goals, Aimed Alliance educates patients, providers, employers, policymakers, and other stakeholders.



## LEGISLATIVE SUCCESSES

### Increasing Patient Protections for New York Patients

#### The Issue:

Step therapy policies, also known as “fail first,” are used by insurers and pharmacy benefit managers (PBMs) to require consumers to try and fail on alternative treatments, before the insurer or PBM will cover the originally prescribed treatment. As a result, treatments that may be most effective at treating a condition may be inaccessible to consumers until alternative treatments are proven ineffective. Without proper guardrails, step therapy policies may also require patients to try and fail on off-label treatments, multiple different treatments, and treatments consumers have previously failed on under a different health plan. Policies can also require consumers to try and fail a treatment for more than 30 days, forcing consumers to continue to experience symptoms without relief. In 2016, New York passed a step therapy law, but it had limited protections for consumers.

#### Our Work:

Over the past several years, Aimed Alliance has led the New York Step Therapy Alliance, which works with a group of nonprofit patient advocacy organizations, professional associations, regulators, and legislative officials to determine how the current New York step therapy law could be improved to better protect



patients' access to their necessary medications, and to ensure that bad actors that violate the step therapy law are held accountable. In 2023, Aimed Alliance supported Senator Neil Breslin and Assembly Member John T. McDonald's introduction of four bills to fill the gaps in the New York step therapy law: (1) [Protected classes](#); (2) [Reporting requirements](#); (3) [Transparency](#); and (4) [Additional rules and protections](#). Our fact sheet on the legislation is available [here](#).

### **Outcome:**

In 2023, following Senator Neil Breslin and Assembly Member McDonald's leadership, the New York Senate and Assembly passed new [transparency requirements](#) for health plans starting in 2024. The bill was signed by Governor Hochul in December 2023.

As a result of this legislation, all New York health plans will be required to include in an adverse determination letter: (1) instructions on how to initiate standard and expedited appeals; (2) notice of the availability, upon request of the enrollee, or the enrollee's designee, of the clinical review criteria relied upon to make such determination; (3) what, if any, additional necessary information must be provided to, or obtained by, the utilization review agent in order to render a decision on the appeal; and (4) for an adverse determination related to a step therapy protocol override request, information that includes the clinical review criteria relied upon to make such determination and any applicable alternative prescription drugs subject to the step therapy protocol of the health care plan.

During the 2023 session, the "additional rules and protections" bill passed the Senate, but was not ultimately passed by the Assembly. Therefore, Aimed Alliance will continue to build upon the 2023 legislative success in 2024 to further expand New York patient protections.

## **ADVOCACY, COMMENTS, & LETTERS**












Aimed Alliance met twice with the FTC regarding non-EHBs and AFPs. Aimed Alliance also met twice with the Tennessee Department of Insurance and the CCIIO to discuss state compliance with the ACA exceptions and appeals processes. Aimed Alliance also participated in the All Copays Count Coalition's Capitol Hill Day.
















Other 2023 federal and state advocacy efforts included the following:

## FEDERAL

-  [Comment](#) to CMS on EHB request for information
-  [Comment](#) to HHS on 2024 Notice of Benefit and Payment Parameters
-  [Letter to FTC](#) on AFPs
-  [Letter to FDA](#) on international importation by AFPs
-  Letter to FDA on janus kinase (JAK) inhibitors
-  [Comment](#) on updated Medicaid Best Price Rule
-  [Comment](#) to CMS on 340B Drug Pricing Program
-  [Input to Congress](#) on CBD legislation
-  [Aimed Alliance comment](#) on IRA listening sessions
-  [Aimed Alliance comment](#) on GOP Health Care Taskforce
-  Aimed Alliance [letter to CMS](#) regarding the use of double-step fail first policies in Medicare Advantage

## STATE

-  [Letter to North Dakota](#) Legislative Assembly supporting copay accumulator reform
-  [Letter to Connecticut Insurance Commissioner](#) on non-EHB programs in state employee union plan
-  [Letter to New York Governor](#) urging signage of step therapy
-  Letter to New York legislators on New York bill on step therapy reform
-  [Letter to New York Governor](#) on biomarker legislation
-  [Comment to Pennsylvania Insurance Commissioner](#) on EHB requirements in benchmark plans
-  [Letter to New York State Department of Health](#) regarding use of step therapy in Medicaid
-  [Aimed Alliance comment](#) to Ohio House of Representatives on HB 177 copay accumulator reform
-  [Aimed Alliance comment](#) on Massachusetts QALY ban
-  30 meetings with New York legislators' offices and Governor Hochul's office supporting step therapy reforms
-  Communicated with New York Department of Financial Services regarding the scope of the current step therapy law



In addition to the federal advocacy activities listed above, Aimerd Alliance signed on to letters supporting the Equitable Community Access to Pharmacist Services Act; requesting a prohibition on the use of QALYs under Section 504 of the Americans with Disabilities Act; encouraging passage of amendments to the Mental Health Parity and Addiction Equity Act of 2008; advocating for expansion of CPT codes for movement disorders; and supporting the National Community Pharmacists Association's efforts to

enhance access to COVID-19 antiviral treatments. We also signed on to comments on the Physician Fee Schedule, telehealth access, and the Inflation Reduction Act.

In addition to the state advocacy activities listed above, Aimerd Alliance signed on to letters supporting health care consumer protections in Missouri, Florida, and Ohio.

Lastly, Aimerd Alliance directly engaged with payers several times in 2023 to ensure payers complied with state and federal patient protection laws. In 2023, Aimerd Alliance sent letters to [WellCare](#), [Payer Matrix](#), [Aetna](#), and [United Health Care](#) regarding their problematic coverage policies.

## LITIGATION

Aimerd Alliance drafted and, along with 28 co-signing organizations, submitted an [Amicus Brief](#) in the *HIV + Hepatitis Policy Institute, Diabetes Patient Advocacy Coalition & Diabetes Leadership Council v. Department of Health and Human Services* federal lawsuit to educate the court on the case's likely impacts on patients, caregivers, and providers.

Aimerd Alliance drafted and, along with 23 co-signing organizations representing health care consumers and providers, filed an [Amicus Brief](#) in a federal lawsuit challenging the practices of a company operating an alternative funding program on behalf of employer-sponsored health plans. The civil matter, *AbbVie Inc., v. Payer Matrix LLC*, is before the U.S. District Court for the Northern District of Illinois, Eastern Division.



# RESEARCH & ANALYSIS

In 2023, Aimerd Alliance conducted research and provided analysis on its policy priorities, much of which was embodied in the comments and letters described above. Aimerd Alliance also presented its research and analysis in reports, fact sheets, brochures, and legislative maps. Our research and analysis activities in 2023 included the following:



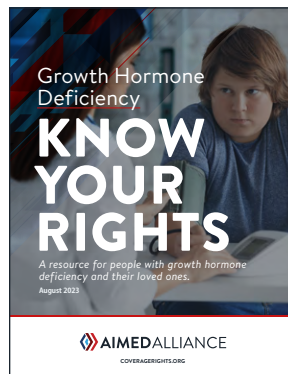
## KNOW YOUR RIGHTS



### Movement Disorders:

In partnership with the Movement Disorders Policy Coalition, Aimerd Alliance developed a Know Your Rights resource to help patients with movement disorders navigate the health plan appeals processes.

[English](#) | [Espanol](#) | [Easy Read](#)



### Growth Hormone Deficiency:

Aimerd Alliance developed a Know Your Rights brochure to help patients with growth hormone deficiency and their caregivers. The brochure discusses treatment options and describes the health plan benefit appeals process.

[English](#) | [Espanol](#)



### Rare Endocrine Disorders:

Aimerd Alliance developed a Know Your Rights brochure to help individuals living with rare endocrine disorders navigate the appeals process and challenge the often-used insurer tactic of deeming health care products and services "experimental."

[English](#) | [Espanol](#)

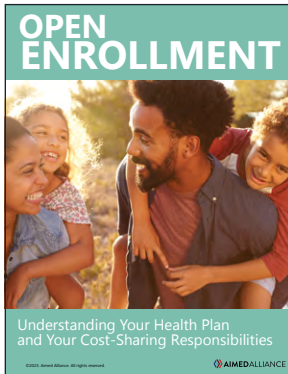






# OPEN ENROLLMENT

Aimed Alliance published the following resources in 2023 to help consumers find and enroll in an appropriate health insurance plan.



**Open Enrollment:**  
Understanding Your Health Plan and Your Cost-Sharing Responsibilities



**2024 Medicare Open Enrollment:**  
Understanding Your Medicare Plan and Your Cost-Sharing Responsibilities



**Open Enrollment:**  
Selecting Benefits for Your Employees to Protect Their Health

## LET'S TALK: Questions & Conversations You Should Have with Your Health Care Provider

For many individuals, it can feel overwhelming to be diagnosed with a rare or chronic condition. This can be especially true for individuals who otherwise have had a limited interaction with the health care system. Therefore, to help ensure consumers have the necessary tools to be active participants in their health care decision making, Aimed Alliance created a new resource titled "[Let's Talk: Questions and Conversations You Should Have with Your Health Care Provider.](#)"

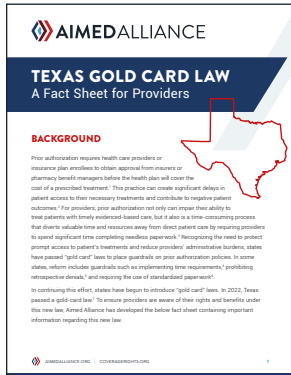
This new tool provides consumers with questions they should consider asking their health care provider before, during, and after an appointment. Additionally, this tool provides short explanations as to why consumers should consider asking these questions. Aimed Alliance has also created a short worksheet form at the end of the document that can be printed and used by consumers to help them track their health care concerns before, during, and after their visit.



Questions & Explanations  
[English](#) | [Espanol](#)  
 Questions, Explanations & Worksheet  
[English](#) | [Espanol](#)  
 Worksheet Only  
[English](#) | [Espanol](#)

# REPORTS & FACT SHEETS

Aimed Alliance regularly develops focused reports and fact sheets to help educate consumers, providers, caregivers, and policymakers on a variety of complex issues. Below are some of our reports, fact sheets, and additional resources from 2023:



**Fact Sheet:**  
[Texas Gold Card Law](#)



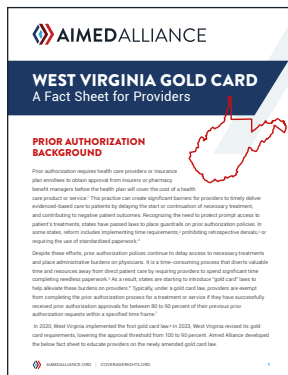
**Fact Sheet:**  
[Texas Step Therapy Law](#)



**Fact Sheet:**  
[New York Step Therapy Legislation](#)



**Fact Sheet:**  
[West Virginia Step Therapy Law](#)



**Fact Sheet:**  
[West Virginia Prior Authorization Law](#)



**Report:**  
[Gold Card Law Analysis 2019-2023](#)



**Fact Sheet:**  
[Essential Labeling Requirements for Consumer Products Containing Cannabis-Derived Ingredients and Intended for Human Ingestion](#)



**Fact Sheet:**  
[Essential Elements of a Regulatory Framework for Consumer Products Containing Cannabis-Derived Ingredients and Intended for Human Ingestion](#)

## STATE MAPS: Bills & Laws

Aimed Alliance regularly tracks and monitors state-based legislation that would improve consumers access to their medically necessary treatments and alleviate administrative burdens on providers. This legislative tracking includes the following maps:



- ▶ **Step Therapy**  
[Active](#) & [Enacted](#)
- ▶ **Copay Accumulators**  
[Active](#) & [Enacted](#)
- ▶ **Non-medical Switching**  
[Active](#) & [Enacted](#)
- ▶ **Prior Authorization**  
[Active](#) & [Enacted](#)
- ▶ **Biomarkers Maps**  
[Active](#) & [Enacted](#)
- ▶ **Oral Parity Maps**  
[Active](#) & [Enacted](#)

## LAWSUIT TRACKERS

Various stakeholders often file lawsuits to create a change within the health care system. These stakeholders can include pharmaceutical companies, PBMs, health insurers, payers, and even non-profits. To help advocates track and monitor the potential impact of these lawsuits, Aimed Alliance provides lawsuit summaries of relevant litigation, including:

- ▶ [Medicare Drug Price Negotiation Litigation](#)  
[\*National Infusion Center Association et al., v. Becerra\*](#)
- ▶ [Alternative Funding Programs](#)  
[\*AbbVie v. Payer Matrix LLC\*](#)
- ▶ [ACA's Preventative Care Coverage and Religious Freedom](#)  
[\*Braidwood Management v. Becerra\*](#)
- ▶ [HHS 2021 NBPP Rule and Copay Accumulators](#)  
[\*HIV + Hepatitis Policy Institute, Diabetes Patient Advocacy Coalition, and the Diabetes Leadership Council v. HHS\*](#)



**Fact Sheet:**  
[Understanding the  
Extent of the 2021  
NBPP Decision](#)



# Thought LEADERSHIP

Using its research and analysis, Aimerd Alliance develops sound, patient-centered policy recommendations. Representatives for the organization disseminate messages by interacting with the news media and presenting to audiences of patients, advocates, practitioners, human resource professionals, policymakers, and the public. In 2023, our thought leadership included:



## SPOTLIGHT PRESENTATIONS:

### Copay Accumulators/Non-EHBs/AFPs

To inform consumers, employers, providers, and caregivers about the impacts of copay accumulators, non-EHB programs, and AFPs on patients, Aimerd Alliance hosted a series of webinars on these issues. These webinars provided patient and health care professional perspectives, legal and regulatory analysis, and employer insights on the impacts of these programs.

- ▶ Aimerd Alliance, Panel Participant: "[Expert Panel: Pharmacy Fiasco – Key Topics & Opportunities for Employers](#)" at the Midwest Business Group on Health
- ▶ Aimerd Alliance, Panel Participant: "[Policymaker Engagement: Tackling Barriers to Access](#)" at the National Policy & Advocacy Summit on Biologics
- ▶ Aimerd Alliance & Alliance for Patient Access, Hosts: "[Emerging Trends: What Employers Need to Know About Alternative Funding Programs & Drug Carveouts](#)" Webinar

### Health Equity

Aimerd Alliance is committed to protecting against discrimination within the health care system and in the workplace. These efforts include preventing discrimination against individuals on the basis of health condition, disability, race, gender, as well as reducing health disparities.

- ▶ Aimerd Alliance, Panel Participant: "[Addressing Barriers to Patient Accessibility to Necessary Therapies](#)" at the 2023 National Minority Quality Forum Summit on Health Disparities and Spring Health Braintrust
- ▶ Aimerd Alliance, Presenter: "IBD Patients Know Your Rights: Americans with Disabilities Act & Family Medical Leave Act", at the April 2023 Collaborating for Care Meeting.
- ▶ Aimerd Alliance, Panel Participant: "[Managing the High Cost of Chronic Disease](#)" at the 2023 Chronic Disease Month Symposium





## CBD:

To inform consumers, employers, and policymakers, Aimed Alliance hosted a webinar on cannabinoid-related issues, such as health insurance coverage, employee assistance programs, workplace safety, and recovery support. The speakers shared insights on cannabinoid-related developments that could affect employer and consumer behaviors.

- ▶ Aimed Alliance, Guest: "[From Farm Bill to FDA](#)" on CareTalk Podcast
- ▶ Aimed Alliance, Presenter: "[Cannabinoid Clarity: The Need for Federal Legislation to Protect Consumers, States, and Industry](#)" at the National Foundation for Women Legislators (NFWL) Annual Conference
  - Presentation resulted in NFWL members passing a resolution urging the U.S. Congress to provide the FDA with the authority and resources to regulate consumer products such as CBD oils, and recognizing the need for a new federal regulatory framework and enforcement mechanisms to mitigate product risks and protect consumers from harm. Read the NFWL resolution [here](#).

- ▶ Aimed Alliance, Panel Participant: "Updating and Encouraging Participation in Federal and State Policy" at the American Society for Pain Management Nursing Annual Conference

## Step Therapy:

Step therapy polices, also known as "fail first," are a practice used by insurers and pharmacy benefit managers (PBMs) to require consumers to try and fail on alternative treatments, before the insurer or PBM will cover the originally prescribed treatment. As part of Aimed Alliance's work leading the New York Step Therapy Alliance, Aimed Alliance participated in thought leadership to raise awareness about proposed legislation.

- ▶ Aimed Alliance, Panel Moderator: "[General Policy Session](#)" at New York BIO Annual Meeting

## In 2023, Aimed Alliance also participated in:

- ▶ [ENDO 2023](#)
- ▶ [National Vaccine Law Conference](#)
- ▶ [Rx and Illicit Drug Summit](#)



## In the Media

Aimed Alliance was published, quoted or recognized by the following media outlets in 2023:

### USA TODAY

We must protect NY patients from health insurers' coverage limitations

### DIGITAL JOURNAL

ADAP Advocacy Association Joins Amicus Brief to Protect Patients

### yahoo!finance

New York Legislature Passes Legislation Expanding Patient Protections

### CONQUER

What You Need to Know about Cannabinoid Law and Science

### HealthCentral

Your Guide to Drug Discounts



Employers Expand Use of Alternative Funding Programs—But Sustainability in Doubt as Loopholes Close

### yahoo!finance

New Resources Support Individuals with Rare Endocrine Disorders

### HealthCentral

Best Money-Saving Tips When You're Chronic

### Democrat & Chronicle (Special to USA TODAY Network)

Patient advocates claim partial victory in New York—but there's more work to do

### yahoo!finance

New Resources Support Individuals with Growth Hormone Deficiency

### EVERYDAYHEALTH

Who Should Be on Your EPI Treatment Team?

### CareTalkHealth

Why Congress and the FDA Must Regulate CBD Consumer Products Now

### yahoo!finance

Groups File Amicus Brief to Shed Light on Harmful Drug Sourcing Tactics



Employers Expand Use of Alternative Funding Programs—But Sustainability in Doubt as Loopholes Close

### yahoo!finance

Aimed Alliance Submits Amicus Brief in HIV + Hep Lawsuit



# Organizational COLLABORATION

Aimed Alliance partners with like-minded organizations whose missions align with our efforts by participating in coalitions and sharing our research and analysis at meetings and conferences. In 2023, our organizational collaboration activities included:

## COALITIONS

### Leader

- ▶ New York Step Therapy Alliance

### Member

- ▶ State All Copays Count Coalition
- ▶ Federal All Copays Count Coalition
- ▶ Safe Step Act Coalition
- ▶ Collaborative for Cannabinoid Science & Safety
- ▶ Ohio All Copays Count Coalition
- ▶ Ohio Biomarker Coalition
- ▶ Pennsylvania All Copays Count Coalition,
- ▶ Utah All Copays Count Coalition
- ▶ Alternative Funding Program Task Force
- ▶ New York Biomarker Coalition
- ▶ Patient Advocacy Leaders and Drug Development Industry Network (PALADIN)

# Looking **AHEAD**

In 2024, Aimed Alliance will build upon past achievements with new projects that advance the interests of health care consumers and providers nationwide. We will continue our outreach to employers regarding employee health benefits; tracking of active legislation, enacted laws, and health care reform lawsuits; and projects focused on access to care, copay accumulator programs, mental health, cannabinoid regulation, health equity, value-based initiatives, and stopping discrimination against providers or in the workplace.



To stay up to date on our health policy activities, sign up for our monthly newsletter at [aimedalliance.org/newsletters](https://aimedalliance.org/newsletters), and follow us on social media:



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