



2024 Annual Report



Alliance for
Patient Access

Dear Friends & Supporters:

The Alliance for Patient Access is grateful for a year marked by exciting advances in policy advocacy.

- ▼ **Landmark AfPA research on utilization management and physician burnout** was featured in the American Journal of Managed Care this year. The findings quantified what AfPA clinician members have shared for years — that excessive red tape undermines patient care, contributes to burnout and worsens physician shortages.
- ▼ **A wide-scale Medicare Part D education campaign** from AfPA provided actionable information on changes to out-of-pocket costs coming in 2025. The resources were among the most viewed and downloaded of AfPA's educational materials this year.
- ▼ **A new AfPA stakeholder coalition, the COPD Action Alliance**, took shape to address the need for awareness and treatment access for COPD. Launched in October 2024, the coalition has already made strides in capturing policymakers' attention.
- ▼ **Unfolding conversations on value and access** provided steady opportunities for AfPA's clinicians and coalition members to convene and educate. The voices of patients and clinicians informed policy discussions on the unintended consequences of the Inflation Reduction Act, the impact of pharmacy benefit managers, the role of state prescription drug affordability boards and more.

Please join us in looking back on a successful year of advocacy. And thank you for the support and partnership that made this year possible.

With best wishes,



DAVID CHARLES, MD
Chief Medical Officer



JOSIE COOPER
Executive Director



Alliance for Patient Access

WORKING GROUPS & INITIATIVES



Biologic Therapy Access
Working Group



Cardiovascular Disease
Working Group



Diabetes Therapy Access
Working Group



Hepatitis Therapy Access
Working Group



Mental Health
Working Group



Neurological Disease
Working Group



AfPA's
Obesity
Initiative



Oncology Therapy Access
Working Group



Rare Diseases
Working Group



Respiratory Therapy Access
Working Group



AfPA's
Vaccine Access
Initiative

STAKEHOLDER COALITIONS



AfPA Policy
Collaborative



KEEP MY Rx



PATIENT & PROVIDER
Advocates
for Telehealth



AFFILIATES



The Headache & Migraine
Policy Forum



Institute for
Patient Access



2024 By the Numbers

50



STATES REPRESENTED
BY AFPA



100

PAPERS

45



EVENTS & WEBINARS

99



BLOG POSTS



257

COMMENT LETTERS



44

INFOGRAPHICS



29

YOUTUBE VIDEOS

182,664

SOCIAL MEDIA FOLLOWERS



88.5

MILLION

SOCIAL MEDIA IMPRESSIONS



1,535,114

YOUTUBE VIEWS

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Policy Issues

This year AfPA advocated for **patient-centered care** in the face of persistent access barriers.

Access Barriers

Onerous prior authorization and redundant reauthorization requirements slowed patients' treatment paths. Overuse of step therapy put patients at risk for disease progression, while non-medical switching undermined their quality of life. Growing lists of formulary exclusions tied clinicians' hands.

These barriers impacted clinicians and patients alike. As national research from the Alliance for Patient Access demonstrated, utilization management fuels physician burnout. Often linked to physician shortages, burnout can reduce the quality and availability of care for patients.

AfPA worked throughout the year to raise awareness about the impact of these barriers and to advocate for policy solutions — at the health plan, state, regulatory and federal level. By connecting ardent advocates with timely opportunities to shape policy, AfPA furthered the cause of patient-centered care. One victory came in the form of non-medical switching reform in Iowa — legislation that AfPA has championed. This legislation passed in 2024, protecting stable patients from being switched from their medication.

The ninth annual Policy & Advocacy Summit, held in Washington, DC, capped a successful year of advocacy. Patients, health care providers, advocates and policy experts shed light on the decisions and decisionmakers who impact patient care and underscored the power of collaboration to improve patient access.

EVENTS/SUMMITS

- » Ninth Annual Policy & Advocacy Summit Report
- » Ninth Annual Policy & Advocacy Summit Video

VIDEOS

- » When Insurance Barriers Lead to Physician Burnout

PUBLICATIONS

- » Utilization Management and Physician Burnout

PAPERS

- » Physician Burnout & Utilization Management

INFOGRAPHICS

- » Prior Authorization & Asthma
- » Access the Right Treatment for IgG4-RD
- » Barriers to Curing Hepatitis C

BLOG POSTS

- » Insurers' Delay Tactics are Burning Physicians Out
- » Medicaid & Medicare Reform Prior Authorization
- » California Clinicians Champion Pro-Patient Health Reforms at First Fly-In
- » New Bill Could Help Seniors Avoid Insurance Delays
- » Survey Shows Prior Authorizations "Wreak Havoc on Patient Care"
- » Biden-Harris Administration Invests \$206 Million to Improve Care for Seniors
- » New Law Protects Iowans from Non-Medical Switching of Medicines



Questions of access are, for patients, often a matter of **affordability**.

Cost Sharing

Out-of-pocket costs can determine whether patients seek care, adhere to treatment and manage their conditions to protect their health.

In 2024, cost-sharing policy trends posed both opportunities and challenges for patients. The Centers for Medicare and Medicaid Services' \$2,000 cap on out-of-pocket costs for Part D prescription drugs, effective in 2025, as well as its new Medicare Prescription Payment Plan, stand to make treatment more manageable for patients. When awareness about the policy changes lagged, AfPA developed and actively disseminated a suite of easy-to-understand educational materials for patients.

In other policy areas, cost sharing became more complex.

Copay accumulators and maximizers continue to limit access to care. And, the rise of alternative funding programs presented a new challenge for patients on employer-sponsored health plans. AfPA joined with other national advocates in urging federal policymakers to rein in these programs and developed educational materials to raise awareness about the impact of alternative funding programs. Additionally, AfPA educated employers and HR professionals on the impact of AFPs on employers through a continuing education program.

VIDEOS

- » Understanding Part D Changes
- » Copay Compliance: Understanding Cost-Sharing and Fiduciary Obligations for Employers

PAPERS

- » Changes to Medicare Part D: A Patient's Guide
- » Medicare Part D Changes: FAQs

ONE-PAGERS

- » How Alternative Funding Programs Harm Rare Disease Patients
- » How Alternative Funding Programs Harm Cancer Patients

INFOGRAPHICS

- » How Alternative Funding Programs Impact Vision Patients

BLOG POSTS

- » Insurers Drop Coverage for More than 600 Drugs



Patient-centered care is rooted in a **trusted relationship** between clinician and patient.

Decision Makers

As AfPA made clear in 2024, outside decision makers can have an outsized influence on the choices clinicians can make and the ability their patients have to follow the recommended treatment path. While some of these decision makers are well known, others are less in the forefront, making education and activation efforts all the more important. AfPA continued in 2024 to provide advocacy training to clinicians members and partners on who these decision makers are and how advocates can weigh in.

Pharmacy benefit managers (PBM) in particular wield a powerful influence on patient care. At clinician working group meetings throughout the year, as well as during the National Policy & Advocacy Summit, AfPA provided a platform for clinicians, patients and advocacy partners to speak out on how formulary exclusions, specialty tiers, non-medical switching and other PBM tactics delay and disrupt patient care. AfPA advocated for reform that would put commonsense limits on PBM practices.

AfPA also flagged the growing influence of Medicare administrative contractors. A Medicare Administrative Contractor (MAC) is a private health care insurer that has been awarded a geographic jurisdiction to process Medicare Part A and Part B (A/B) medical claims or Durable Medical Equipment (DME) claims for Medicare Fee-For-Service (FFS) beneficiaries. AfPA educated on the role that Medicare administrative contractors play and the need for access policy that supports Medicare patients.

Other work included education and advocacy related to Medicaid P&T Committees, along with the Institute for Clinical and Economic Review.

PAPERS

- » The Right Care for Rare: A Policy Roadmap to Support Rare Disease Patients

ONE-PAGERS

- » How Medicare Administrative Contractors Impact Patient Access

BLOG POSTS

- » Patients and Medicare Both Forced to Pay More
- » Health Economists Weigh in on Schizophrenia Rx
- » ICER Doubles Down on Flawed Metrics
- » Insurers Drop Coverage for More than 600 Drugs
- » California Clinicians Champion Pro-Patient Health Reforms at First Fly-In
- » Federal Report Condemns PBMs for Obstructing Drug Access



Conversations about **value** in health care are ongoing.

Innovation & Value

AfPA continues work to ensure that both patients and health care providers are heard — and that their perspectives are included in any decision on value.

This year, organizations such as state prescription drug affordability boards and the Institute for Clinical and Economic Review furthered a limited view of treatment value, exacerbating patients’ access and cost-sharing challenges.

AfPA worked to expand the value conversation, urging advocates to speak out and calling for policy solutions. Extensive state-level efforts raised awareness about prescription drug affordability boards and the need for policies that better balance affordability and access. At the federal level, AfPA engaged clinicians in policy dialogue and advocacy on the Inflation Reduction Act and the unintended consequences of drug price negotiation.

All the while, AfPA continued to raise awareness about the unintended impact of health technology assessments such as those developed by the Institute for Clinical and Economic Review.

EVENTS/SUMMITS

- » Ninth Annual Policy & Advocacy Summit Report
- » Ninth Annual Policy & Advocacy Summit Video

VIDEOS

- » Prescription Drug Affordability Boards & Patient Access

PAPERS

- » Fast Facts: Prescription Drug Affordability Boards
- » Fast Facts: Genetically Targeted Technologies

INFOGRAPHICS

- » Prescription Drug Affordability Boards: What Patients Need from Policymakers
- » Prescription Drug Affordability Boards’ Narrow View of Value
- » How Prescription Drug Affordability Boards Impact Patients

BLOG POSTS

- » State Panels Decide Whose Drugs Are “Affordable”
- » Health Economists Weigh in on Schizophrenia Rx
- » ICER Doubles Down on Flawed Metrics
- » A “MINI” Act Could Be Big for Patients



Advocacy by Topic



Biologics, biosimilars and interchangeable offer patients a **wide range of options.**

Biologics

This year, the Biologics Prescribers Collaborative and AfPA's Biologics Working Group strove to raise awareness about the value that biologics and biosimilar treatment options offer patients and to further policies that improve patient education and access.

Work included:

- ▶ **Hosting a national policy summit** to discuss the impact of innovation on biologics
- ▶ **Conducting research** on trends in biosimilar uptake to identify the impact of further competition on the marketplace
- ▶ **Raising awareness** on policy barriers that impact patients' ability to access biologic medications
- ▶ **Developing educational materials** to better inform patients on biologics that are self-administered

PUBLICATIONS

- » Nurturing the Potential of the Biosimilar Market

FAST FACTS

- » Fast Facts: Prescription Drug Affordability Boards

ONE-PAGERS

- » A Patient's Guide to Self-Administered Biologics

INFOGRAPHICS

- » How Medicare Administrative Contractors Impact Patient Access

BLOG POSTS

- » A Breath of Fresh Care
- » How Biosimilars Could Lower Health Care Costs
- » Breakthrough Biologic Improves Lung Function in COPD Patients
- » Patients and Medicare Both Forced to Pay More



Cardiovascular Disease

In 2024, the Partnership to Advance Cardiovascular Health and AfPA's Cardiovascular Disease Working Group advocated for greater awareness and access for medications, devices and treatments for cardiovascular conditions.

Efforts included:

- ▶ **Spearheading a multi-stakeholder effort** to raise awareness about cardiovascular health during National Hispanic Heritage Month, including a [social media toolkit](#) and targeted earned media
- ▶ **Producing a second iteration of the Cardiometabolic Leadership Academy**, an advocate training program for cardiovascular patients with instruction on health policy issues and media engagement
- ▶ **Convening the seventh annual Cardiovascular Health Policy Summit**, which convenes patients, advocates and clinicians to discuss some of the most pressing policy issues in cardiovascular care

AfPA's Cardiovascular Disease Working Group convened medical experts from across the country through its Hypertrophic Cardiomyopathy Initiative, newly launched in 2024. The initiative developed educational resources highlighting the impact of HCM and the need for access to breakthrough treatment options, along with direct clinician advocacy to policymakers.

VIDEOS

- ▶ Giving Hypertension Patients New Treatment Options
- ▶ Understanding Specialty Pharmacies
- ▶ A MINI Act Could Be Big for Heart Patients
- ▶ Fail First Is Failing Heart Disease Patients
- ▶ Alternative Funding Programs
- ▶ Caring for Patients with Hypertrophic Cardiomyopathy

WEBINARS

- ▶ Genetically Targeted Technologies and the MINI Act

PAPERS

- ▶ Fast Facts: Prescription Drug Affordability Boards
- ▶ Optimizing Care for Hypertrophic Cardiomyopathy

TOOLKITS

- ▶ Make Hypertension History
- ▶ Deje La Hipertensión En La Historia

ONE-PAGERS

- ▶ Hypertrophic Cardiomyopathy: What New Management Guidelines Mean for HCM Patients
- ▶ Genetically Targeted Technologies & the MINI Act
- ▶ New Hypertension Treatments Give Patients Options
- ▶ Nuevos Tratamientos Contra La Hipertensión Brindan Opciones A Los Pacientes
- ▶ Alternative Funding Programs Harm Patients
- ▶ Medicare Expanding Extra Help Program in 2024
- ▶ 2024 Working Group Meeting Summary

INFOGRAPHICS

- ▶ Genetically Targeted Technologies A Big Win for Heart Patients
- ▶ Tecnología médica y control de la hipertensión
- ▶ La pesada carga de la hipertensión
- ▶ Obesity & Cardiovascular Care
- ▶ Cardiovascular Patients & Mental Health Care
- ▶ Deadly Disparities in Heart Health

BLOG POSTS

- ▶ National Organizations Back New Drug Class for Care of Hypertrophic Cardiomyopathy Patients
- ▶ A "MINI" Act Could Be Big for Patients
- ▶ The Cardiologist Crisis of Rural America
- ▶ Communities of Color Face Unequal Access to Obesity Treatments
- ▶ MINI Act Could Shield Patients from Unintended Consequences
- ▶ Research into Top Killer of Women Often Excludes Them
- ▶ Preventing Migraine Can Improve Comorbid Conditions, Too
- ▶ Using Patient-Reported Outcomes in Heart Disease Clinical Practice
- ▶ Medicare Part D Extends Coverage of Obesity Treatments for New Indication
- ▶ Patients Deserve Modern Approaches to Heart Valve Disease





For 40 years, generic drugs have **increased treatment access** for patients.

Generics Access

This year, the Generics Access Project focused on raising awareness about drug shortages that can keep patients from accessing the care that they need — and encouraging policy solutions.

Efforts included:

- ▶ **Encouraging Congress to address the systemic issues** that contribute to drug shortages, leading sign-on efforts with **more than 40 patient advocacy partners**
- ▶ **Hosting webinars** for advocates on the need for action
- ▶ **Releasing an infographic series and video** on drug shortages

The Generics Access Project also continued its work in other areas, celebrating 40 years of the Hatch-Waxman Act, engaging on a range of generics policy issues through direct advocacy and hosting its third listening session with FDA's Office of Generic Drugs.



VIDEOS

- » Generic Drug Shortages & Their Impact on Patients

ONE-PAGERS

- » Big Questions: How Can Drug Shortages Be Addressed?
- » Big Questions: Why Do Drug Shortages Happen?
- » Big Questions: What is a Drug Shortage?

INFOGRAPHICS

- » Celebrating 40 Years of the Hatch-Waxman Act

BLOG POSTS

- » Celebrating Hatch-Waxman's Transformation of Prescription Access
- » Generic Drug Shortages Leave Patients in Limbo

LETTER

- » Letter To HELP Committee and House Energy and Commerce Committee on Drug Shortages



A lack of awareness, stigma and access barriers can keep gout patients from managing their condition successfully.

Gout

This year, the Alliance for Gout Awareness focused on improving gout care and highlighting the disease's mental toll. The coalition also worked with partners to produce educational resources and programming to showcase the full-body impact of gout.

Efforts included:

- ▼ **Creating a roadmap to better care** to highlight how policymakers can support optimal treatment for patients
- ▼ **Releasing a patient guide** on the physical and mental impact of gout — and resources to help manage the disease
- ▼ **Developing educational materials** that outline how gout affects the entire body
- ▼ **Supporting patients** through in-person and virtual patient empowerment forums, including an event focused on the gout and cardiovascular disease connection
- ▼ **Leading Gout Awareness Day activities** that included state proclamations, a toolkit and a social media campaign to raise awareness
- ▼ **Hosting a stakeholder meeting** to convene advocacy partners on shared priorities

VIDEOS

- » Gout is a Full Body Disease
- » A Roadmap to Better Gout Care

TOOLKITS

- » Gout Awareness Day Toolkit

INFOGRAPHICS

- » A Roadmap to Better Care For Gout

ONE PAGERS

- » Navigating Open Enrollment
- » Gout & Heart Disease
- » Gout Treatment & Utilization Management

PAPERS

- » Navigating the Physical and Mental Health Impact of Gout

Headache & Migraine

This year, The Headache & Migraine Policy Forum continued advocating for improved access to migraine treatment. The coalition focused its efforts on raising awareness about how step therapy can delay care and keep patients from the treatment they need.

Efforts included:

- ▶ **Co-hosting the eighth annual Capitol Hill Policy Forum** with more than 200 patients in attendance to discuss the dangers of step therapy and migraine treatment
- ▶ **Working with stakeholders** to improve access to treatments for migraine disease in several states
- ▶ **Releasing a toolkit** to help patients navigate insurance barriers
- ▶ **Empowering patients** to share their stories with lawmakers and know their rights when insurance companies deny treatment
- ▶ **Focusing on the full-body impact of migraine disease**
- ▶ **Supporting policies** that will promote patients' continued access to telehealth

PAPERS

- » Advocacy in Action: How Advocates are Improving Access to Migraine Treatment
- » Changes Coming to Medicare Part D
- » New First-Line Treatment for Migraine Prevention: How Updated American Headache Society Guidance Impacts Patients
- » Step Therapy Fails Patients: A Policy Panel Discussion
- » Advocating for Migraine Treatment: A Focus on Insurance Barriers
- » Survey Summary: Insurance's Impact on Patient Access to Migraine Treatment
- » When Step Therapy and Rx Denials Lead to the Emergency Department
- » Advocacy Toolkit

INFOGRAPHICS

- » The Clock of Care for Migraine
- » Migraine & Heart Disease
- » Migraine & Comorbidities
- » Taking Action on Insurance Denials
- » Sharing Your Migraine Story with Lawmakers
- » Know Your Coverage
- » Diversity In Clinical Trials for Migraine
- » Poorly Managed Migraine is Expensive for Everyone
- » Migraine Is Not a "One Treatment" Disease
- » "Fail First" Should Not Be a Treatment Option
- » Migraine Doesn't Wait — It Chronifies

BLOG POSTS

- » "Time is Money" Takes on Telephonic Red Tape
- » "BioBonds" Could Revolutionize Funding for Medical Research
- » Preventing Migraine Can Improve Comorbid Conditions, Too
- » Headache Patients Go to Washington
- » Can AI Diagnose Your Migraine?
- » Congress Questions AI's Role in Medicare Advantage Denials

Headache and migraine disease can be debilitating. But **innovative treatment options** offer hope to patients.





Hepatitis remains a **serious** public health crisis.

Hepatitis & Infectious Diseases

Throughout 2024, the Alliance for Patient Access' Hepatitis Therapy Access Working Group tackled a number of advocacy issues and fought for patients' access.

The working group's efforts included:

- ▶ **Developing educational materials** to spotlight the value of immunizations
- ▶ **Highlighting the need for point-of-care testing**
- ▶ **Engaging on social media** to raise awareness about hepatitis
- ▶ **Meeting with policymakers** to highlight the need for expanded testing

PAPERS

- » Fast Facts: Prescription Drug Affordability Boards

INFOGRAPHICS

- » Barriers to Curing Hepatitis C
- » Expanding Hepatitis C Testing for Patients of Color

BLOG POSTS

- » Curing Hepatitis C Could Save the Nation \$7 Billion
- » Can the Country Catch Up Amid the Global Push to End Hepatitis C?
- » Treating Hepatitis C Patients Where They Are





Immunization remained a **central** awareness and access issue for AfPA in 2024.

Immunizations

In the face of low vaccination rates and lingering misinformation, AfPA convened experts for a 2024 roundtable discussion. Key takeaways featured in an event report shared across AfPA platforms and informed advocacy work on immunization issues throughout the year.

AfPA also launched a dedicated AfPA Vaccine Access Initiative, which serves as a network for policy-minded clinicians and advocacy partners who recognize adult immunization's role in healthy aging and community health. Advocacy victories included the expansion of the Advisory Committee on Immunization Practices' recommendations on pneumococcal vaccines, which paves the way for broader access.

At the state level, AfPA's chapter of local advocates in Massachusetts urged state lawmakers to safeguard patient choice where multiple vaccine options exist to prevent the same disease.

VIDEOS

- » The Umbrella of Immunizations

PAPERS

- » Increasing Vaccination Against COVID-19: Highlights from an Expert Roundtable Discussion

TOOLKITS

- » Vaccine Access for All Ages: Toolkit for Advocacy Partners

ONE-PAGERS

- » Vaccines for Every Age

BLOG POSTS

- » Vaccines: A Vital Tool for Healthy Aging
- » Reducing Health Inequities Through Vaccination
- » Committee Votes to Lower Recommended Age of Vaccination



Infant Health

This year, the National Coalition for Infant Health raised awareness of several infant safety issues, from sun protection to safe sleep. The coalition also emphasized the importance of nutrition, both for pregnant women and babies in the NICU.

Advocacy efforts included:

- ▶ **Raising awareness** about new RSV preventive measures
- ▶ **Encouraging families to engage with health care providers** regarding the nutrition their babies receive in the NICU
- ▶ **Participating in RSV, SIDS & Safe Sleep and Prematurity Awareness Months**
- ▶ **Hosting a webinar** to discuss guidance on new RSV prevention vaccines
- ▶ **Conducting a survey** on parental attitudes toward vaccines
- ▶ **Developing a new logo and website** to raise the organization's profile and better feature advocacy materials and information

PAPERS

- » Infant Health Matters: NICU Impact on Siblings
- » Statement On Nutritional Practices In The NICU For Extremely Low Birth Weight Infants
- » Infant Health Matters: Prenatal Nutrition
- » RSV Prevention Options for Infants

INFOGRAPHICS

- » Why Infants Need the Vitamin K Shot

BLOG POSTS

- » Meeting the Nutritional Needs of Neonates
- » Reducing Infants' Hospitalization from RSV
- » House and Senate Agree: New Mothers Need More Support
- » Medicaid Rule Changes Poised to Improve Postpartum Care for New Moms
- » Healthy Start Programs Receive \$105 Million to Reduce Maternal Mortality
- » House Bill Boosts Nutrition for NICU Babies
- » Congress Boosts "Hope" for Infants with Rare Diseases
- » Congress Moves to Reduce Stillbirths

Innovation and awareness are **critical** for improving outcomes for infants.

Mental Health

Throughout 2024, the Alliance for Patient Access' Mental Health Working Group prioritized patients with serious mental illness, recognizing the need for greater legislative reform to better support their unique needs.

Efforts included:

- ▶ **Engaging state policymakers** to raise awareness on serious mental illness and increase access to treatment through legislative reforms
- ▶ **Advocating with legislators** for mental health access reform and parity
- ▶ **Creating educational resources** that demonstrate the value of adherence for patients with mental health conditions
- ▶ **Engaging with decisions makers** like the Institute for Clinical and Economic Review to advocate for appropriate coverage value determinations

AfPA also worked to highlight the value of whole-person treatment, advocating for policies that allow patients with chronic diseases to also manage their related mental health challenges.

Serious mental health conditions must be taken **seriously.**

VIDEOS

- ▶ Serious Mental Illness & the Value of Adherence
- ▶ The Obesity & Mental Health Connection
- ▶ Taking Serious Mental Illness Seriously

PAPERS

- ▶ Fast Facts: Postpartum Depression
- ▶ Fast Facts: Prescription Drug Affordability Boards

ONE-PAGERS

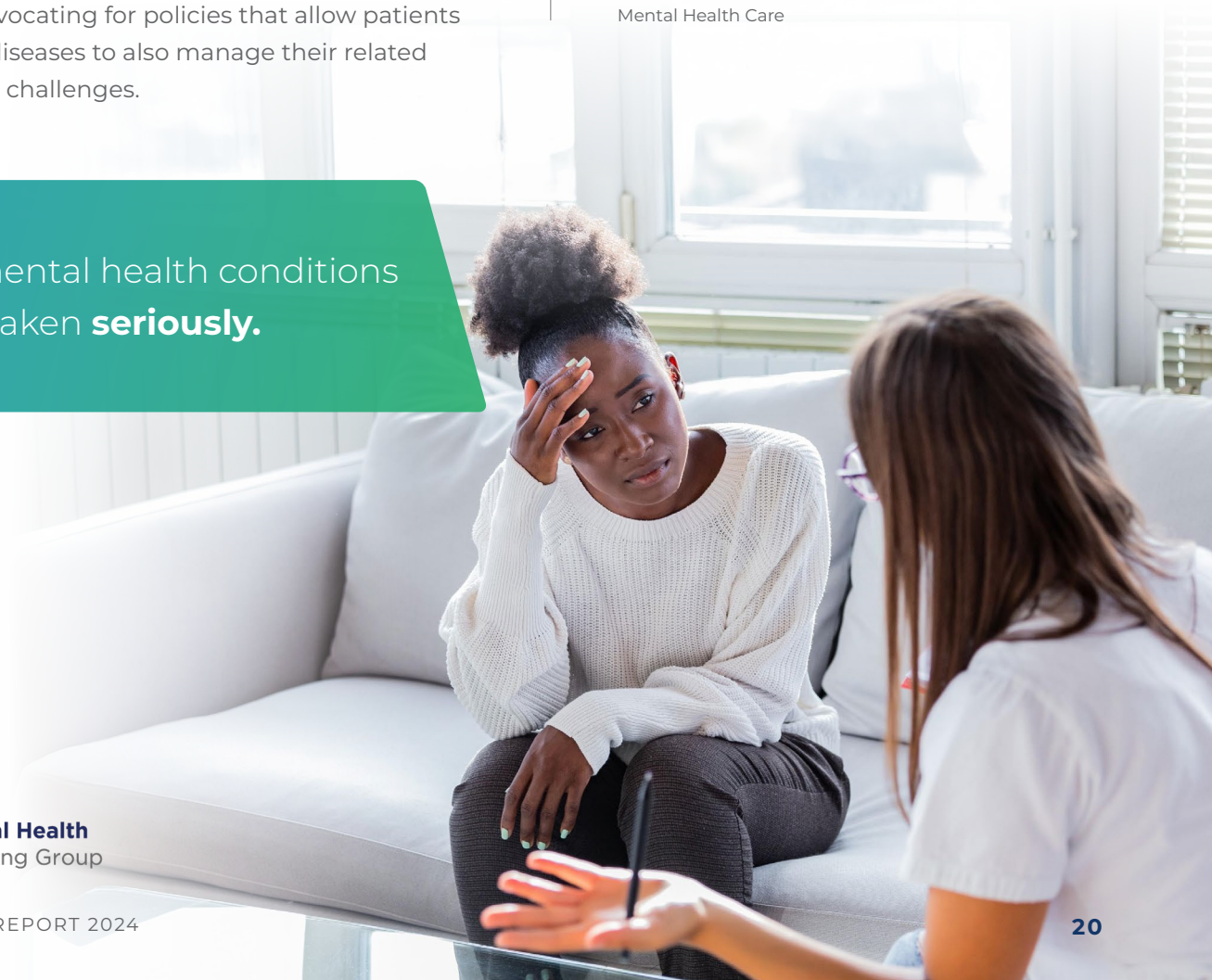
- ▶ 2024 Mental Health Working Group Meeting Summary
- ▶ Obesity & Mental Health: Q&A with Charles Nguyen, MD

INFOGRAPHICS

- ▶ Headache, Migraine & Mental Health Care
- ▶ Cardiovascular Patients & Mental Health Care
- ▶ The Long-Term Benefits of Long-Acting Injectables
- ▶ Rare Disease Patients & Mental Health Care

BLOG POSTS

- ▶ House and Senate Agree: New Mothers Need More Support
- ▶ 988: The Lifeline Millions in Need Don't Know About
- ▶ Promoting Access for Postpartum Depression Care in the State House
- ▶ Preventing Migraine Can Improve Comorbid Conditions, Too
- ▶ Just 1% of Adults Believe Nation Handles Mental Health Well
- ▶ First Awareness Day Gives Hope to IgG4-RD Patients
- ▶ Amyloidosis Awareness Marches Forward
- ▶ Future Treatments Excite Rare Disease Patients & Providers
- ▶ Congress Moves to Reduce Stillbirths





Patient-centered care is critical for people living with neurological conditions.

Neurological Diseases

In 2024, AfPA's Neurological Disease Working Group, alongside the Movement Disorders Policy Coalition, worked to raise awareness and improve health policies for people living with neurological diseases like Alzheimer's, dementia and movement disorders.

Efforts included:

- ▶ **Highlighting the challenges posed by onerous utilization management tactics** and advocating for state and federal reforms.
- ▶ **Raising awareness** about the unique challenges facing patients with neurodegenerative conditions like Alzheimer's and dementia, including access to disease-modifying therapies and treatment access in long-term care facilities
- ▶ **Advocating for reforms** that support Parkinson's patients' ability to access innovative treatments
- ▶ **Educating about the impact of cost sharing**, including the harm posed by alternative funding programs and the opportunity for more manageable out-of-pocket costs under policy changes to Medicare Part D

VIDEOS

- ▶ Medicare Administrative Contractors

PAPERS

- ▶ Parkinson's Disease: Improving Treatment While Working Toward a Cure
- ▶ Fast Facts: Prescription Drug Affordability Boards

ONE-PAGERS

- ▶ 2024 Neurological Disease Working Group Meeting Summary
- ▶ A Patient's Guide to Self-Administered Biologics
- ▶ Navigating Open Enrollment: A Guide for People Living with a Movement Disorder

INFOGRAPHICS

- ▶ How Medicare Administrative Contractors Impact Patient Access
- ▶ Obesity & Neurological Care
- ▶ Headache, Migraine & Mental Health Care

BLOG POSTS

- ▶ ICER Doubles Down on Flawed Metrics
- ▶ Who's At Risk for Tardive Dyskinesia?
- ▶ MINI Act Could Shield Patients from Unintended Consequences
- ▶ Headache Patients Go to Washington
- ▶ A "MINI" Act Could Be Big for Patients
- ▶ Can AI Diagnose Your Migraine?



Neurological Disease
Working Group



MOVEMENT
DISORDERS
POLICY COALITION



Obesity is a **serious** disease. But insurers don't always see it that way.

Obesity

This year, AfPA's Obesity Initiative continued its work to advance policy that will improve patient access to treatment. The initiative also worked to raise awareness of the comorbidities often associated with obesity.

Efforts included:

- ▶ **Advocating for the passage of the Treat and Reduce Obesity Act**, including holding a Capitol Hill fly-in and hosting a congressional roundtable
- ▶ **Working collectively with health care providers** from a broad range of specialties from across the U.S.
- ▶ **Hosted educational programming** and supported advocate engagement on a recently proposed rule to expand coverage for obesity treatment
- ▶ **Releasing series of educational materials** on obesity's impact on other chronic conditions
- ▶ **Meeting with legislators in California** — and supporting clinician testimony — to discuss legislation that would improve access to treatment
- ▶ **Highlighting the importance of obesity advocacy** at a national policy summit

VIDEOS

- ▶ The Obesity & Mental Health Connection
- ▶ Mental Health & Obesity: Patient-Centered Care

WEBINARS

- ▶ Overview of Proposed Rule to Cover Obesity Management Medications

PAPERS

- ▶ Obesity & Mental Health: Q&A with Charles Nguyen, MD

INFOGRAPHICS

- ▶ Obesity & Arthritis Care
- ▶ Obesity & Cardiovascular Care
- ▶ Obesity & Neurological Care

BLOG POSTS

- ▶ Bipartisan Bill to Allow Ongoing Use of Obesity Treatment Advances
- ▶ Communities of Color Face Unequal Access to Obesity Treatments
- ▶ California Clinicians Champion Pro-Patient Health Reforms at First Fly-In
- ▶ Medicare Part D Extends Coverage of Obesity Treatments for New Indication
- ▶ Why Employers Should Invest in Obesity Treatment
- ▶ State Leaders Tackle Obesity
- ▶ Biden Administration Acts to Expand Coverage for Obesity Medication





As innovative options are developed for cancer, patients must be able to **access** these treatments.

Oncology

Cancer patients need access to targeted treatments based on their unique condition. While many options are available, health plan barriers can complicate and even delay treatment. Removing barriers has been a key priority of the Alliance for Patient Access.

AfPA's Oncology Therapy Access Working Group educated patients and providers and advocated for policies to protect cancer patients.

Working group efforts included:

- ▶ **Advocating for legislation** to improve access to biomarker testing
- ▶ **Developing educational materials** to support the working group's engagement with patients, providers and legislators
- ▶ **Supporting provider members** in weighing in on issues like lung cancer screening barriers
- ▶ **Advocating for policies** that simplify access to precision medicine
- ▶ **Informing employers** about the dangers of alternative funding programs specifically to cancer patients

PAPERS

- » Fast Facts: Understanding Precision Medicine
- » Fast Facts: Prescription Drug Affordability Boards

ONE-PAGERS

- » How Alternative Funding Programs Harm Cancer Patients
- » A Patient's Guide to Self-Administered Biologics
- » 2024 Working Group Meeting Summary

BLOG POSTS

- » Celebrating Florida's Expanded Access to Biomarker Testing
- » More Young People Are Getting Cancer
- » Lung Cancer Screening: Why It's Crucial and Addressing Barriers to Access



Rare Diseases

This year, AfPA's Rare Diseases Working Group and related initiatives, along with the Cystic Fibrosis Engagement Network, made strides in furthering policies that make diagnosis and treatment more accessible for rare disease patients.

Efforts included:

- ▶ The **Amyloidosis Initiative of AfPA's Rare Diseases Working Group**, which convened clinicians to explore treatment challenges, including access to treatment within the Veterans Affairs, along with access to infused treatment at home. AfPA also developed educational resources to support timely, appropriate treatment of cardiac amyloidosis.
- ▶ The **IgG4-RD Initiative of AfPA's Rare Diseases Working Group**, which continued its work to ensure policies keep up with innovation in IgG4-RD. The group published its first clinician-authored policy paper and developed advocacy resources that encourage timely access to care. The group also provided advocacy training on insurance barriers through partnerships with allied patient advocacy groups.
- ▶ The **Cystic Fibrosis Engagement Network**, which drove consensus among member organizations on issues related to treatment and access policy.

VIDEOS

- ▶ The Diagnostic Odyssey

PAPERS

- ▶ The Right Care for Rare: A Policy Roadmap to Support Rare Disease Patients
- ▶ Fast Facts: Prescription Drug Affordability Boards
- ▶ Fast Facts: Cardiac Amyloidosis
- ▶ Addressing Access Barriers for IgG4-RD Patients

ONE-PAGERS

- ▶ How Alternative Funding Programs Harm Rare Disease Patients
- ▶ Improving Colorectal Cancer Care for Cystic Fibrosis Patients: A Consensus Statement
- ▶ Guidelines to Ensure Prescription Affordability Boards Protect Rare Disease Patients
- ▶ A Patient's Guide to Self-Administered Biologics
- ▶ Supplemental Oxygen & the SOAR Act

INFOGRAPHICS

- ▶ Recognize The Value of Treatments for IgG4-RD
- ▶ Accessing The Right Treatment for IgG4-RD
- ▶ Rare Disease Patients & Mental Health Care
- ▶ How "Alternative" Rx Funding Programs Fail Cystic Fibrosis Patients

BLOG POSTS

- ▶ New Rare Disease Innovation Hub Stands to Benefits Researchers and Patients
- ▶ Survey Shows Prior Authorizations "Wreak Havoc on Patient Care"
- ▶ MINI Act Could Shield Patients from Unintended Consequences
- ▶ Just 1% of Adults Believe Nation Handles Mental Health Well
- ▶ New Roadmap Identifies Support Opportunities for Rare Patients
- ▶ A "MINI" Act Could Be Big for Patients
- ▶ First Awareness Day Gives Hope to IgG4-RD Patients
- ▶ Congress Boosts "Hope" for Infants with Rare Diseases
- ▶ Future Treatments Excite Rare Disease Patients & Providers
- ▶ First Gene-Editing Treatment Approved

Living with a rare disease presents a unique range of challenges and demands **policy** that supports patient-centered care.



Rare Diseases
Working Group



CFEN
Cystic Fibrosis Engagement Network

Respiratory Conditions

Innovative respiratory treatments continue to offer patients unique options, allowing them to manage their condition and breathe easier.

Throughout 2024, AfPA's Respiratory Therapy Access Working Group was a consistent advocacy voice for policies that protect respiratory patients from insurer overreach.

Efforts included:

- ▼ **Direct advocacy** to Medicaid plans and commercial insurers on the importance of access to asthma biologics
- ▼ **Developing new educational materials** on innovation in asthma care — and opportunities for policymakers to support treatment access
- ▼ **Raising awareness** about potential care barriers that patients may experience.

COPD Action Alliance

This year, the Alliance for Patient Access launched the COPD Action Alliance, uniting stakeholders to advance patient-centered COPD policies at the state and federal levels through advocacy, awareness, and grassroots support.

The coalition has already achieved significant milestones, including a successful Capitol Hill briefing that secured bipartisan support from the U.S. House of Representatives, underscored by a floor speech. Its efforts have also resulted in the adoption of impactful resolutions at both county and state levels, showcasing its growing momentum and influence in shaping COPD policy nationwide.



VIDEOS

- » Introduction to the COPD Action Alliance

TOOLKITS

- » COPD Awareness Month Toolkit

PAPERS

- » Breath of Fresh Care: Improving Asthma Patients' Access to Innovative Treatments
- » Fast Facts: Prescription Drug Affordability Boards

ONE-PAGERS

- » A Patient's Guide to Self-Administered Biologics
- » 2024 Working Group Meeting Summary
- » COPD Fact Sheet

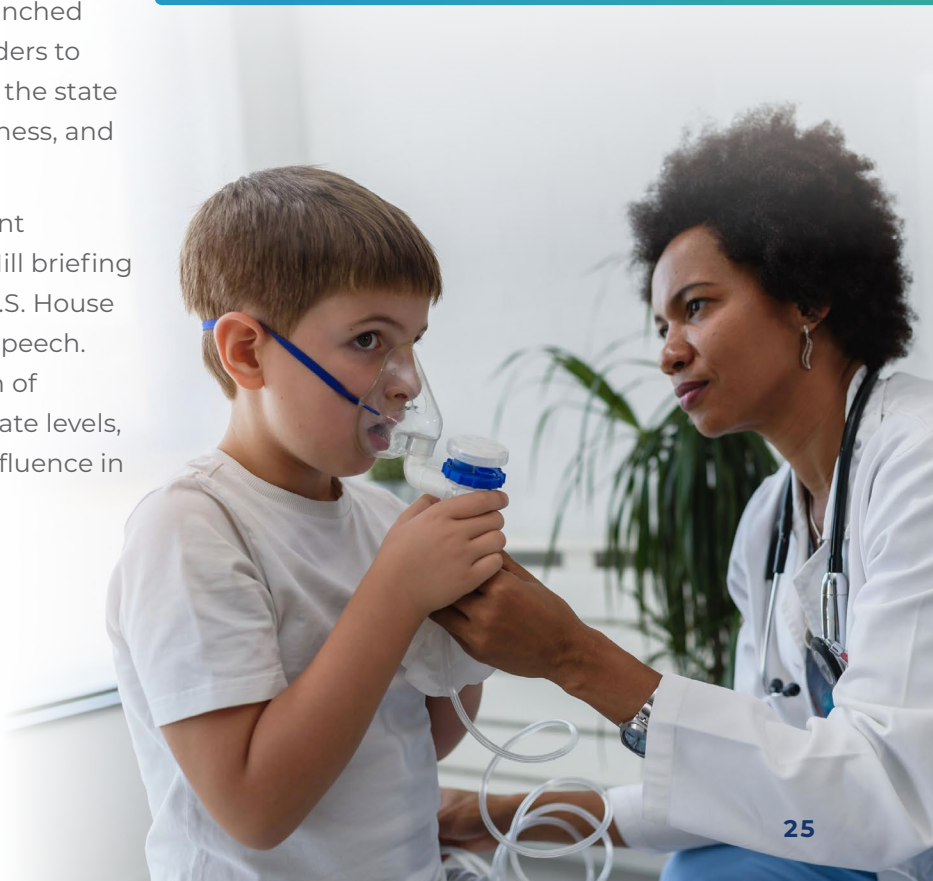
INFOGRAPHICS

- » How Medicare Administrative Contractors Impact Patient Access
- » Health Disparities in Asthma

BLOG POSTS

- » A New Action Alliance Against COPD
- » Breakthrough Biologic Improves Lung Function in COPD Patients
- » Despite Being Preventable and Treatable, COPD Remains Deadly
- » New Law Protects Iowans from Non-Medical Switching of Medicines
- » A Breath of Fresh Care

Breathing well impacts **every second** of a patient's life.





Caring for skin conditions is a **critical** part of caring for the whole patient.

Skin Conditions

In 2024, the Derma Care Access Network furthered its efforts to support patients with skin conditions. The network developed educational materials about a wide variety of skin conditions to inform patients and reduce stigma.

Efforts included:

- ▼ **Supporting advocacy efforts** to minimize utilization management for patients with skin conditions
- ▼ **Developing educational materials** on skin conditions like vitiligo to raise awareness among patients and providers
- ▼ **Advocating for the further innovation of biologics and biosimilars** to expand competition and increase treatment options

ONE-PAGERS

- » Hidradenitis Suppurativa
- » Navigating Open Enrollment
- » Skin Care Provider Shortages
- » Medicare Part D: Updates for 2025

INFOGRAPHICS

- » Talking About HS
- » Talking About Vitiligo

BLOG POSTS

- » Vying for Vitiligo Treatment





Innovative treatments offer options to patients with a vision condition. But access can present challenges.

Vision Health

This year, the Vision Health Advocacy Coalition continued to raise awareness of vision conditions and advocate for reforms to the policy barriers that keep patients from treatment. The coalition hosted events, released new advocacy resources and developed programming in multiple languages to expand its reach and empower patients to seek treatment.

Efforts included:

- ▶ **Releasing a patient and provider video series** on the thyroid eye disease experience
- ▶ **Empowering patients** through virtual and in-person patient empowerment forums
- ▶ **Producing educational materials** that highlight the challenges that rare vision disease patients face
- ▶ **Advocating at the state and federal level** for reforms that improve access to vision care
- ▶ **Partnering with coalition members** on congressional briefings aimed at educating policymakers on the importance of access to vision care

VIDEOS

- » The Thyroid Eye Disease Experience: Signs and Symptoms
- » The Thyroid Eye Disease Experience: Mental Health
- » The Thyroid Eye Disease Experience

WEBINARS

- » Patient Empowerment Forum (Russian)
- » Patient & Caregiver Empowerment Forum

ONE-PAGERS

- » Navigating Open Enrollment

INFOGRAPHICS

- » Rare Vision Conditions & Health Plan Barriers
- » Barriers To Genetic Testing And Counseling
- » How Alternative Funding Programs Impact Vision Patients
- » How Telehealth Can Reduce Health Inequities
- » Navigating Open Enrollment

BLOG POSTS

- » ICER Doubles Down on Flawed Metrics



Clinician Advocacy in 2025

With a new year of policy challenges and advocacy opportunities ahead, AfPA members reflect on why it's important for clinicians to inform the policies that shape patient care.

“Red tape and regulations make my job increasingly difficult,

often without improving patient care. With AfPA, I have seen that lawmakers are willing to listen and collaborate, and that we can make a positive impact for patients.”

FATIMA HUSSEIN, MD

“Advocacy is all about relationships.

Throughout my years with AfPA, my advocacy successes have come with elected officials that I have cultivated relationships with for decades. And those successes benefit my patients, who also have an established and trusted relationship with me.”



J. ALLEN MEADOWS, MD

“There is so much misinformation and stigma out there.

Policy is basically empty if the people developing it don't know the ins and outs of clinical care. AfPA recognizes that clinicians must be at the forefront when decisions impacting the people we treat are being made by others.”



RIMAL BERA, MD

“The ever-changing landscape of health care in the U.S. has led to unprecedented barriers for patients to access care.

That is why physicians need to advocate for patients — both on an individual level and a legislative level. AfPA recognizes that this is the only way that patients will have access to needed medical care.”



WESLEY MIZUTANI, MD



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