



Annual Report



Alliance for
Patient Access





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

STAKEHOLDER COALITIONS



AFFILIATES



Dear Friends & Supporters,

This year we've witnessed a surge in health care innovation.

Diseases that have plagued patients and health care providers for generations — from postpartum depression to Alzheimer's disease, hypertension to cancer and RSV — are now confronted by powerful new preventive and acute treatments. Meanwhile, a steady increase in biologics, biosimilars and complex generic drugs has increased clinicians' and patients' options for treating chronic and debilitating conditions.

But this year has also seen a continued rise in barriers that put bureaucrats squarely between patients and their health care providers.

- ▼ **At the employer level**, third-party vendors institute new alternative funding programs that cut medication coverage at the expense of patient assistance programs.
- ▼ **At the health plan level**, pharmacy benefit managers exert expanding influence as drug exclusion lists grow, specialty tiers increase, copay accumulator and maximizer programs proliferate, and utilization management becomes even more burdensome.
- ▼ **At the state level**, prescription drug affordability boards and drug utilization review boards pose a growing threat to patient access.
- ▼ **And at the federal level**, the looming impact of the Inflation Reduction Act has patients and advocates alike wondering how government price negotiations could impact short-term treatment options — and long-term innovation.

The Alliance for Patient Access continues working alongside its affiliates and related coalitions to mobilize members and raise awareness about these and other threats to patient access. Our dedicated advocates — health care providers, patients and patient advocacy organizations — have worked tirelessly this year to:

- ▼ **Educate policymakers, patients, advocates and the media** about the importance of patient-centered care.
- ▼ **Capture and share patients' and providers' experiences** and expertise wherever policy takes shape.
- ▼ **Advocate to reduce barriers** that prevent patients from getting the optimal, tailored care they deserve.

Thank you for supporting us, working alongside us and taking the time to celebrate our shared progress in this year's annual report.

With best wishes,



A handwritten signature in dark ink, reading "David Charles, MD".

DAVID CHARLES, MD
Chief Medical Officer



A handwritten signature in dark ink, reading "Josie Cooper".

JOSIE COOPER
Executive Director

2023 By the Numbers

50



STATES REPRESENTED
BY AFPA



81

PAPERS

46



EVENTS & WEBINARS

100



BLOG POSTS



178

COMMENT LETTERS



31

INFOGRAPHICS



18

YOUTUBE VIDEOS

169,681

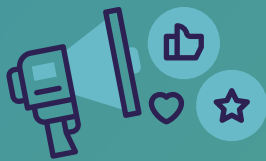
SOCIAL MEDIA FOLLOWERS



47.1

MILLION

SOCIAL MEDIA IMPRESSIONS



785,165

YOUTUBE VIEWS

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AfPA ANNUAL REPORT 2023

Policy Advocacy Issues



Access Barriers

The right treatment can have a powerful impact — if patients can access it.



Utilization management tactics like prior authorization, step therapy and non-medical switching often prevent patients from accessing their prescribed treatment. Pharmacy benefit managers are also increasingly becoming a barrier of serious concern, cutting drugs from formularies and frustrating patients and providers alike.

Throughout 2023, AfPA mobilized clinician members and activated coalitions to advocate for patient-centered care at the health plan, state, federal and regulatory levels. Seventeen states passed access reforms.

▶ The **Patient Access Collaborative** launched a series of educational materials calling attention to decisionmakers who influence and limit patient access. It also hosted recurring webinars that highlighted opportunities for utilization management reform at the state and federal level.

▶ The **Keep My Rx campaign** focused advocacy efforts on non-medical switching, highlighting through social engagement and educational materials the burden this tactic places on patients.

▶ The **National Council of Physician Legislators** worked to support health care providers who also serve in their statehouses. The organization provided policy insights and offered educational materials to help members navigate today's complex health policy topics.

▶ The **Partnership to Protect Patient Health** engaged with policymakers and advocated against potentially harmful “bad drug” ads. Significant legislative progress was made in several states.



VIDEOS

- » Spotlight on Patient Access
- » “Bad Drug” Ads Have Real-Life Consequence

PAPERS

- » At What Price? Medication Value, Patient Care & the Inflation Reduction Act
- » Pharmacy Benefit Managers' Impact on Patient Access
- » The High Costs of Alternative Funding

ONE-PAGERS

- » Who Decides? Pharmacy Benefit Managers & Medication Access
- » Who Decides? How Prescription Drug Affordability Review Boards Impact Patient Access
- » Who Decides? How Pharmacy and Therapeutics Committees Impact Patient Access
- » “Bad Drug” Ads are Bad News

INFOGRAPHICS

- » How “Alternative” Rx Funding Programs Fail Patients

BLOG POSTS

- » Patient Access Reform in the States: Previewing 2023
- » Protecting Patients from Misleading “Bad Drug” Ads
- » Access to Care Shouldn't be Rare
- » New Bill Would Protect Patients by Banning QALYs
- » Improving Transparency and Speed of Prior Authorizations
- » Legislating Access to Serious Mental Illness Treatments
- » Pharmacy Benefit Managers in the Spotlight
- » Coverage Barriers Block Patients from Revolutionary Alzheimer's Treatment
- » The Hidden Impact of Pharmacy Benefit Managers

Cost Sharing

Copay accumulators, copay maximizers and alternative funding programs present a serious threat to patients.



Out-of-pocket costs remain a key factor in whether or not patients can access their prescribed treatment. But third parties continue to shift costs in an effort to maximize profits — often at patients' expense.

In 2023, the Alliance for Patient Access called attention to these tactics and how harmful they can be for patients.

- ▼ AfPA engaged with policymakers on the topic of **copay accumulator programs**, which can disrupt patients' treatment regimens and force difficult financial decisions. A federal court ruled earlier this year that the programs were unlawful, but health plans, pharmacy benefit managers and third-party vendors are already looking for other ways to shift costs back onto patients.
- ▼ The Alliance for Patient Access led advocacy efforts to combat **alternative funding programs** through the creation of educational materials that explain how these programs work. Efforts included a highly attended educational webinar for health care providers and an HR.com webinar for employers on the topic of alternative funding programs.
- ▼ Advocates also highlighted the harm of **copay maximizers** on patients and their financial well-being.

AfPA working groups and coalitions continue to advocate for reform and transparency so that patients can afford and access the treatment they need.

VIDEOS

- » [Alternative Funding Programs](#)

PAPERS

- » [Pharmacy Benefit Managers' Impact on Patient Access](#)

INFOGRAPHICS

- » [How "Alternative" Rx Funding Programs Fail Patients](#)

BLOG POSTS

- » [An Easier Way for Seniors to Cover Rx Expenses](#)
- » [Patient Access Reform in the States: Previewing 2023](#)
- » [Policymakers Trying to Refocus PBMs on Patients](#)
- » [What "Alternative" Rx Funding Programs Mean for Patients](#)
- » [Pharmacy Benefit Managers in the Spotlight](#)
- » ["Alternative" Funding Programs Put Patient Health at Risk](#)

Innovation & Value

Limited definitions of value can undermine medical innovation's potential for patients.



The Inflation Reduction Act has forced the health care community to ask an uncomfortable question: What happens when government agencies and providers disagree on the value of a treatment? Meanwhile, the proliferation of prescription drug affordability boards across the country underscores the critical need for clinicians and patients to play a role in value discussions.

Members of the Alliance for Patient Access remained vocal advocates, amplifying patient and clinicians' perspectives into evolving conversations about value, policy and access.

This year, the Alliance for Patient Access:

- ▶ **Engaged with the Institute for Clinical and Economic Review** and empowered clinicians and patients to weigh in on several medication value assessments, including those for schizophrenia and Alzheimer's disease.
- ▶ **Highlighted the harm of the quality-adjusted life year**, a metric used by ICER that often fails to recognize true value for many patients, through educational materials and coalition education.
- ▶ **Advocated on issues of drug pricing**, ensuring that new policies recognize the patient perspective, patient access and the need for continued innovation.
- ▶ **Highlighted through educational materials** how new treatments can improve the patient experience and patient outcomes.
- ▶ **Engaged with local advocates** and state-level policymakers during the development of prescription drug affordability boards.

PAPERS

- » How Overlooking Societal Impact Undermines ICER's Cost-Effectiveness Assessments
- » At What Price? Medication Value, Patient Care & the Inflation Reduction Act

TOOLKITS

- » Amplifying the Voices of Alzheimer's: ICER Toolkit
- » Elevating the Experiences of Schizophrenia Patients & Providers: ICER Toolkit

INFOGRAPHICS

- » Defining Medication Value: Government vs Physicians
- » When Government & Health Care Providers Disagree on Medication Value
- » How the Inflation Reduction Act Could Impact Patient Care

BLOG POSTS

- » ICER's Hasty Analysis of New Schizophrenia Treatment
- » What Innovative Drugs are Worth to Society
- » Alzheimer's Drug Faces Hurdles in Reaching Patients
- » ICER Causes Alzheimer's Community to Hold Their Breath, Again
- » NASH Patients Suffer Liver Symptoms and Bureaucratic Dysfunction
- » New Bill Would Protect Patients by Banning QALYs
- » Government and Physicians May Disagree on Rx Value



Alliance for
Patient Access



Institute for
Patient Access

Telehealth

While the COVID-19 pandemic has subsided, access to telehealth remains a policy priority.



This year, Patient & Provider Advocates for Telehealth spotlighted the importance of a balanced approach to telehealth and advocated for continuity of care.

Priorities included:

- ▶ **Hosting a virtual program** educating stakeholders on state legislative opportunities.
- ▶ **Developing educational resources** that highlight the value of telehealth access and the importance of ensuring telehealth coverage during open enrollment.
- ▶ **Convening more than 80 patient advocacy and physician groups** through a sign-on opportunity in support of a balanced approach to telehealth through the Medicare Physician Fee Schedule.
- ▶ **Analyzing federal and state legislation** and urging policymakers to support appropriate access to telehealth services.
- ▶ **Publishing a policy paper** on the future of telehealth policy and opportunities for policymakers to support patient access.



PAPERS

- » Navigating the Future of Telehealth Access

ONE-PAGERS

- » Navigating Open Enrollment
- » My Telehealth: Q&A with Lindsay

INFOGRAPHICS

- » Cultivating Innovation in Telehealth: At-Home Testing

BLOG POSTS

- » What's the Future of Telehealth Access?
- » State Wins Help Preserve Telehealth Benefits
- » Will Telehealth Flexibilities Become Permanent?



AFPA ANNUAL REPORT 2023

Advocacy by Topic

Biologics

Biologics and biosimilars offer patients innovative and targeted treatment options.



As the biologics marketplace underwent significant changes in 2023, the Biologics Prescribers Collaborative and AfPA's Biologic Therapy Access Working Group remained active advocates for patient-centered care.

Efforts included:

- ▶ **Conducting national polling** to understand the patient perspective on biosimilars as a new competitor in the biologics marketplace and to identify opportunities for patient education.
- ▶ **Hosting the National Policy and Advocacy Summit on Biologics**, which explored a number of topics including the biologics landscape, data and advocacy, and policies impacting patient access.
- ▶ **Educating patients and providers on the harmful practices of pharmacy benefit managers** and their impact on patients through formulary decisions.
- ▶ **Developing educational materials** to distill complex health policy topics and help patients and providers better understand the value of biologics to various disease states.



POLICY SUMMIT

- » 8th Annual National Policy & Advocacy Summit on Biologics

PAPERS

- » Pharmacy Benefit Managers' Impact on Patient Access
- » The High Costs of Alternative Funding

ONE-PAGERS

- » Biologics, Biosimilars & Cancer Care
- » Biologics, Biosimilars & Dermatology
- » Biosimilars vs. Generics
- » Understanding Medicare Administrative Contractors

SURVEYS

- » Patient Choice: National Survey on Innovator Biologics and Biosimilars

INFOGRAPHICS

- » Overcoming Hurdles to Cancer Care

BLOG POSTS

- » A Biosimilar Boom Could Be a Financial Boon For Patients
- » Do Patients Choose Biosimilars?
- » National Biologics Policy & Advocacy Summit in Five Quotes

Cardiovascular

Cardiovascular disease remains the leading cause of death in the United States.



This year, the Partnership to Advance Cardiovascular Health advocated for patient access to critical medications, devices and treatments for a range of cardiovascular conditions. Special focus in 2023 was on hypertension, AFib, peripheral artery disease, high cholesterol and hypertrophic cardiomyopathy — all of which can lead to serious health complications for patients.

Efforts included:

- ▶ **Launching the Cardiometabolic Leadership Academy**, an advocate training program for cardiovascular patients with instruction on health policy issues and media engagement.
- ▶ **Holding the sixth annual Cardiovascular Health Policy Summit**, which convenes patients, advocates and clinicians to discuss some of the most pressing policy issues in cardiovascular care.
- ▶ **Providing a briefing at the U.S. Capitol** to highlight how pharmacy benefit managers can undermine high-quality, timely care for patients.
- ▶ **Developing educational content** on disease prevention, harmful utilization management practices and the need for innovative treatment options.



POLICY SUMMIT

- » 2023 Cardiovascular Health Policy Summit Report

VIDEOS

- » Let's Make Hypertension History
- » Disparities in Hypertension
- » Former U.S. Surgeon General Jerome Adams on Hypertension
- » Latrice's Journey with High Cholesterol
- » Hypertension Patient Perspectives

PAPERS

- » Pressure's Mounting: The Urgent Need for Innovation in Hypertension Care
- » A Country in Cardiovascular Crisis: Access to Innovative Treatment

ONE-PAGERS

- » Recap: Capitol Hill Briefing on Pharmacy Benefit Managers
- » Atrial Fibrillation
- » Hypertension
- » High Cholesterol
- » Hypertrophic Cardiomyopathy
- » Heart Failure
- » Heart Transplant
- » Understanding High-Deductible Health Plans

INFOGRAPHICS

- » Formulary Exclusions: When Patients Lose Access to Prescribed Medication
- » Medical Technology & Hypertension Management
- » The Heavy Burden of Hypertension

BLOG POSTS

- » Racial Disparities Still Haunt Progress Against CVD
- » Heart Health Barriers in 6 Quotes
- » Calling Out a "Silent Killer"
- » Heart Health & the Summer Heat
- » Pressures Mounting for America's Hypertension Crisis
- » When Insurers Push Heart Patients Off Their Medication

Generics Access

Generic drugs play a major role in increasing patient access to medications.



In its second year, the Generics Access Project continued to advocate for policies that promote generic competition and efficient approval of generic medications.

In 2023, the organization focused on:

- ▶ **Conducting a national survey** on patients' trust and familiarity with generics to be used in educating policymakers.
- ▶ **Improving timely patient access** to lifesaving drugs by engaging patients and policymakers around the drug shortage crisis through educational materials, advocacy letters and listening sessions.
- ▶ **Promoting the timely and efficient approval** of generic medications by developing educational materials.
- ▶ **Encouraging the FDA's processes to prioritize unmet patient needs** and elevating patient voices in FDA's Office of Generic Drugs by participating in FDA listening sessions.
- ▶ **Educating policymakers** on the value of generic drugs by submitting comments and letters to congressional leadership.



VIDEOS

- » The Generic Drug Approval Process

PAPERS

- » Fast Facts: User Fees and Drug Development
- » Fast Facts: Drug Shortages

ONE-PAGERS

- » Meeting Summary: FDA Listening Session
- » Big Questions: What Is a Generic?
- » Big Questions: How are Generic Drugs Approved?
- » Big Questions: How are Generic Drugs Manufactured?

SURVEYS

- » Blind Trust: Generic Drugs & Patient Knowledge

BLOG POSTS

- » Do Patients Understand Generic Drugs?
- » Drug Shortages Leave Patients Vulnerable
- » Shortage of Cancer Drugs Demands Action

Gout

Gout is the most common form of inflammatory arthritis — yet patients often suffer in silence.



This year, the Alliance for Gout Awareness continued heightening public awareness and addressing common misconceptions to empower patients to seek the treatment they need.

Education and programming included:

- ▶ **A new website** that makes it easier for patients, caregivers and health care providers to learn, in both English and Spanish, about gout, treatments and overcoming stigma.
- ▶ **Educational materials** that highlight the importance of proactively managing gout and related mental health challenges.
- ▶ **A consensus paper** identifying actionable opportunities to improve gout care through public policy, education, and increased emphasis on proactive screening, diagnosis and treatment.
- ▶ **A robust Gout Awareness Day**, including 19 state proclamations, a social media toolkit and other easy-to-use resources.
- ▶ **Patient empowerment forums around the country** that brought together patients and providers to discuss gout management.
- ▶ **Increased outreach to communities disproportionately impacted by gout**, including a campaign around Minority Health Month and translation of educational resources into Spanish and Hmong.
- ▶ **Convening member organizations** to collaboratively address access challenges.

PAPERS

- » A Roadmap to Better Care for Gout
- » Improving Gout Management & Reducing Stigma: A Consensus Statement
- » Fast Facts: Gout (Hmong Translation)

ONE-PAGERS

- » How Gout Affects the Whole Body
- » A Gout Patient's Guide to Biologics
- » When Gout Goes Untreated
- » Gout & Mental Health

TOOLKITS

- » Gout Awareness Day Toolkit

BLOG POSTS

- » Fighting Gout Includes Addressing Racial, Cultural Disparities
- » Gout's Excruciating, but it Doesn't Get the Attention it Deserves
- » The Chronic Pain that Nobody Talks About
- » Gout Affects Young People Too
- » Women Speak Out on Health, Stigma and Fighting for Treatment
- » The Contractors Who Determine Medicare Access

Headache and Migraine

Headache and migraine can hinder a patient's ability to participate in everyday life. But with the right treatment, patients can thrive.



This year, advocacy efforts by The Headache & Migraine Policy Forum included:

- ▶ **Co-hosting a Capitol Hill policy summit** to shed light on long COVID and headache disorders.
- ▶ **Calling attention to utilization management** practices as causes of potential disease progression.
- ▶ **Amplifying survey research** on step therapy's impact on people living with headache and migraine.
- ▶ **Creating a guide** for patients who want to challenge their health insurer's coverage denial.
- ▶ **Advocating for access** to attack-based treatment plans, so that patients can better manage their disease.
- ▶ **Highlighting the role of medical devices** in patient-centered migraine care.



VIDEOS

- » Making Migraine Treatment Accessible

WEBINARS

- » Look Ahead: Federal Policies Impacting Patient Care
- » Step Therapy for Migraine Survey Results
- » Migraine Therapies: Insurance Delays, Denials & Switching Survey Results

PAPERS

- » Challenging Your Health Insurer's Decision: A Step-by-Step Guide
- » Long COVID & Headache Disorders: A Policy Panel Discussion
- » Recap: Multi-disease Coalition Capitol Hill Briefing on Pharmacy Benefit Managers

SURVEYS

- » Step Therapy for Migraine and Other Headache Disorders

INFOGRAPHICS

- » Headache & Long COVID
- » Access to Migraine Treatment Devices
- » Step Therapy & Migraine

BLOG POSTS

- » COVID-19 Continues to Challenge People Living with Headache
- » When Migraine & Menstruation Collide
- » Why So Many Migraine Patients Get Treated in the ER

PUBLICATIONS

- » Claims Rejections and Emergency Department Use for People with Migraine

Hepatitis and Infectious Diseases

Hepatitis presents a deadly and persistent public health challenge.



This year, AfPA's Hepatitis Therapy Access Working Group highlighted the importance of strategic, coordinated efforts toward eliminating hepatitis C. The working group raised awareness about national strategies and advocated for policy reforms at the state level that could facilitate screening and encourage treatment adherence for patients.

The working group highlighted the value of immunization, which can help prevent some forms of hepatitis as well as many other infectious diseases. Members also advocated for better access to curative treatments for hepatitis C.

Efforts included:

- ▶ **Educational materials** on policy considerations related to hepatitis C elimination.
- ▶ **Advocacy materials** explaining the benefits of vaccination for preventing infectious diseases.
- ▶ **Social media engagement** aimed at raising awareness about hepatitis.
- ▶ **Direct engagement with policymakers** advocating for increased access to hepatitis C testing for infants and children.



VIDEOS

- » The Umbrella of Immunizations

ONE-PAGERS

- » Next Steps to Hepatitis C Elimination

INFOGRAPHICS

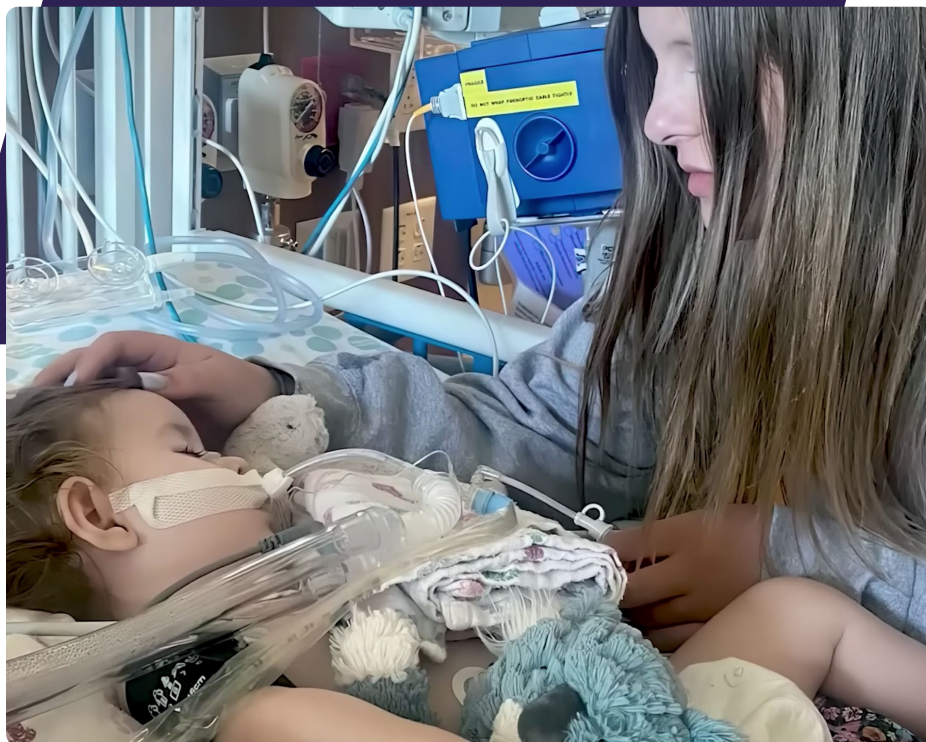
- » It's Time to Tackle Infectious Disease Disparities
- » Understanding Hepatitis

BLOG POSTS

- » Patient Access Reform in the States: Previewing 2023
- » Will Hepatitis C Testing for High-Risk Infants be Expanded?
- » Biden's Budget Proposed \$11B to Eliminate Hep C

Infant Health

Medical innovation continues to open doors for infants and their families.



In 2023, the National Coalition for Infant Health advocated on behalf of infants and their families to improve awareness of and access to targeted treatments. The coalition saw major strides in RSV care this year, such as the inclusion of preventive monoclonal antibodies in the U.S. Vaccines for Children Program and the approval of a maternal vaccine to protect infants.

Advocacy efforts included:

- ▶ **Raising awareness** of perinatal mood and anxiety disorders.
- ▶ **Sharing information about RSV preventive interventions** and other vaccines for pregnant women and infants.
- ▶ **Advocating directly with state lawmakers** for access to an exclusive human milk diet for infants, especially those born preterm.
- ▶ **Creating educational materials on infant health safety**, especially in hospital settings like the NICU and PICU.
- ▶ **Conducting a first-of-its-kind national survey** on the burden of RSV, the leading cause of hospitalization for U.S. infants.

NCfIH National Coalition
for Infant Health

VIDEOS

- » Emily's RSV Story
- » Managing RSV's Indirect Impact
- » The Burden of RSV
- » Closing the Gap: Disparities & RSV
- » The Umbrella of Immunizations

WEBINARS

- » Under the Immunization Umbrella: Options to Reduce the Burden of RSV
- » Protecting Infants from RSV: Understanding Guidance on New Prevention Tools

ONE-PAGERS

- » Infant Health Matters: Perinatal Mood & Anxiety Disorders
- » Infant Health Safety: Call to Action

SURVEYS

- » The Indirect Impact of RSV: RSV Parent & Provider Survey Results

INFOGRAPHICS

- » Prioritizing New Parents' Mental Health

BLOG POSTS

- » Will Hepatitis C Testing for High-Risk Infants be Expanded?
- » FDA Grants Priority Review to Drug for Depressive Disorders
- » Latest Data Show Maternal Mortality Continues to Spike
- » CDC Committee Tackles Childhood Immunizations
- » How Better Data Could Reduce Stillbirths
- » The Health Wonders of Human Milk
- » Will Newly Proposed FDA Guidance Discourage Pediatric Drug Development?
- » Officials Recommend New RSV Immunization for Children
- » Breast is Best, But Mothers Have Feeding Options for Their Babies
- » 1 in 3 Counties Lacks Care for Pregnant Women
- » New Hope for Postpartum Depression Treatment
- » Why Infant Deaths are Rising in 2023

Mental Health

Access to mental health care remained a pressing priority for patients, health care providers and policymakers this year.



AfPA's Mental Health Working Group advocated across a wide range of mental health and access issues in 2023, highlighting patient needs at the health plan level and emphasizing the need for greater clinician support.

Efforts included:

- ▶ **Supporting policies on serious mental illness** across the country, which will reduce barriers and improve access, through webinars and educational content.
- ▶ **Creating a white paper** that shares clinician perspectives on how mental health providers can meet patients where they are.
- ▶ **Raising awareness about the national 988** mental health hotline.
- ▶ **Spotlighting postpartum depression** and how policies can best support new mothers.
- ▶ **Advocating for mental health reform and parity** through letters and speaking at hearings.
- ▶ **Engaging with the patient advocacy community and ICER** in discussions of value and schizophrenia treatments.



Mental Health
Working Group

PAPERS

- » Meeting Patients Where They Are

ONE-PAGERS

- » Comprehensive Treatment for Tardive Dyskinesia
- » Supporting Patients with Serious Mental Illness

TOOLKITS

- » Elevating the Experiences of Schizophrenia Patients and Providers: ICER Toolkit

INFOGRAPHICS

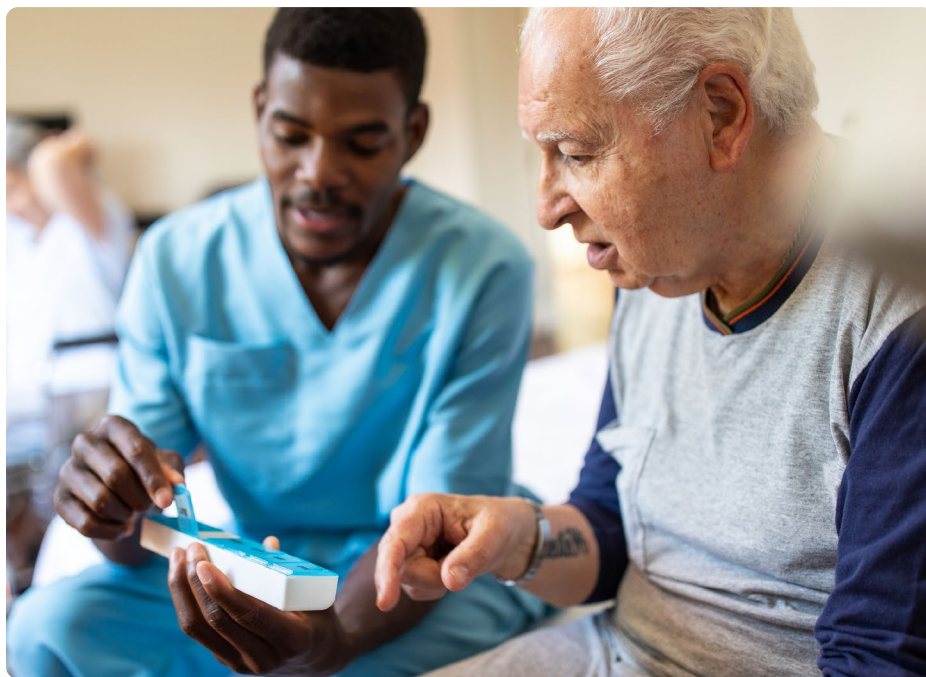
- » Helping Women Overcome Postpartum Depression
- » Cancer Patients & Mental Health Care
- » Obesity Care & Mental Health Care

BLOG POSTS

- » Patient Access Reform in the States: Previewing 2023
- » FDA Grants Priority Review to Drug for Depressive Disorders
- » New Paper Identifies Key Challenges for Providers Treating Mental Health
- » Legislating Access to Serious Mental Illness Treatments
- » Making Good on Mental Health Parity
- » Simplified Suicide Hotline Improves Access to Mental Health Support, But Challenges Remain
- » Mental Health Demands Better Screening
- » New Hope for Postpartum Depression Treatment
- » What's the Future of Telehealth Access?
- » ICER's Hasty Analysis of new Schizophrenia Treatment

Neurological Diseases

Movement disorders and other neurological diseases continue to impact families across the country.



This year, AfPA's Neurological Diseases Working Group worked alongside the Movement Disorders Policy Coalition to bring attention to policies affecting people living with neurological diseases like movement disorders.

Efforts focused on:

- ▶ **Advocating for patient access to innovative treatments and diagnostic testing**, including direct engagement with the Centers for Medicare and Medicaid Services, for a range of conditions affecting cognition and mobility.
- ▶ **Increasing awareness about movement disorders**, including tardive dyskinesia, dystonia, Huntington's and Parkinson's, and access barriers to treatment that patients may face.
- ▶ **Leading coalition sign-on efforts** on critical state and federal access issues.
- ▶ **Supporting TD Awareness Week** through educational materials, social media engagement and an online toolkit.
- ▶ **Leading advocacy efforts for patient access** to Alzheimer's treatments and testing, including appropriate coverage of amyloid beta PET scans.



Neurological Disease
Working Group



MOVEMENT
DISORDERS
POLICY COALITION

PAPERS

- » Know Your Rights
- » Overburdened by Alzheimer's: The Need for Care, Innovation and Access

ONE-PAGERS

- » Comprehensive Treatment for Tardive Dyskinesia
- » Dystonia: The Need for Treatment Access
- » Huntington's Disease: The Need for a Cure

TOOLKITS

- » Amplifying the Voices of Alzheimer's: ICER Toolkit

INFOGRAPHICS

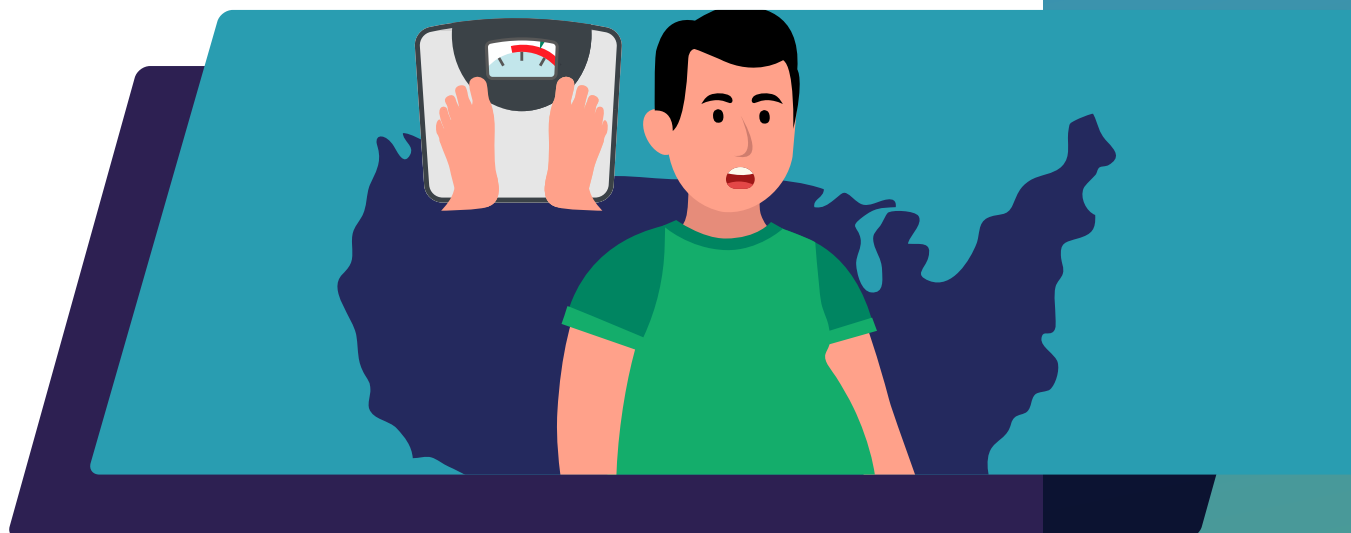
- » Agitation in Alzheimer's

BLOG POSTS

- » Fight Continues to Expand Federal Benefits for Huntington's Disease
- » Parkinson's Cases Have Been Underestimated by 50%
- » First Alzheimer's Agitation Drug Could Help Patients, Caregivers
- » Why We Don't Understand Parkinson's in Black Americans
- » Congress Has a Plan to End Parkinson's
- » FDA Grants Priority Review to Drug for Depressive Disorders
- » Medicare Lifts Cap on PET Scans for Alzheimer's Patients
- » Coverage Barriers Block Patients from Revolutionary Alzheimer's Treatment
- » Alzheimer's Drug Faces Hurdles in Reaching Patients
- » Medicare Doubles Down on Restricting New Alzheimer's Meds
- » ICER Causes Alzheimer's Community to Hold Their Breath, Again
- » Alzheimer's Burden Demands Policy Solution

Obesity

Obesity is a serious, chronic disease that impacts more than 40% of Americans.



Innovative treatment options are making it possible for more patients to imagine a life that's not defined by their disease. But as new treatments become available, policies must ensure that they are also accessible.

This year, AfPA's Obesity Initiative highlighted policies that would increase access to obesity treatment.

Efforts included:

- ▶ **Advocating for the Treat and Reduce Obesity Act through several advocacy initiatives**, including letters to legislators, a series of webinars and an extensive online campaign that resulted in hundreds of letters to lawmakers.
- ▶ **Hosting a Capitol Hill briefing** on the Treat and Reduce Obesity Act for federal policymakers.
- ▶ **Educating state lawmakers about the seriousness of obesity among their constituents** through tailored one-pagers and webinars.
- ▶ **Creating educational materials that highlight disparities in obesity treatment** and the comorbidities associated with the disease.
- ▶ **Working with clinicians across the country** to support increased coverage of obesity treatments.
- ▶ **Co-hosting a webinar** on obesity and chronic diseases for patient and policymakers highlighting upcoming federal policies.

VIDEO

- » Medicare and Obesity Treatment

ONE-PAGERS

- » Obesity: A Serious & Widespread Disease
- » Obesity in California
- » Obesity in Massachusetts
- » Obesity in Texas

INFOGRAPHICS

- » Obesity Care & Mental Health Care
- » Disparities Weigh Heavier on Communities of Color

BLOG POSTS

- » NASH Patients Suffer Liver Symptoms and Bureaucratic Dysfunction
- » It's Time for Congress to Finally Treat Obesity Like the Epidemic It Is



Oncology

Cancer care continues to improve every year, yet patients may still face a host of barriers.



Timely, targeted treatment can vastly improve the lives of cancer patients, families and caregivers. But patients need access to a full range of treatments. That's why advocacy efforts have prioritized policies that remove barriers and make it easier for cancer patients to access the care they need.

AfPA's Oncology Therapy Access Working Group advocated for policies that put cancer patients first.

Working group efforts included:

- ▶ **Educational materials to demonstrate the value of biomarker testing** as a tool to provide targeted cancer care.
- ▶ **Partnerships with advocates** to implement policy reform at the state level to improve access to innovative testing and treatments.
- ▶ **Advocacy to reduce utilization management**, which impedes patients' treatment plans.
- ▶ **Raising awareness of precision medicine** and educating patients on how to advocate for access to personalized care.



ONE-PAGERS

- » Biologics, Biosimilars & Cancer Care: Expert Perspectives

INFOGRAPHICS

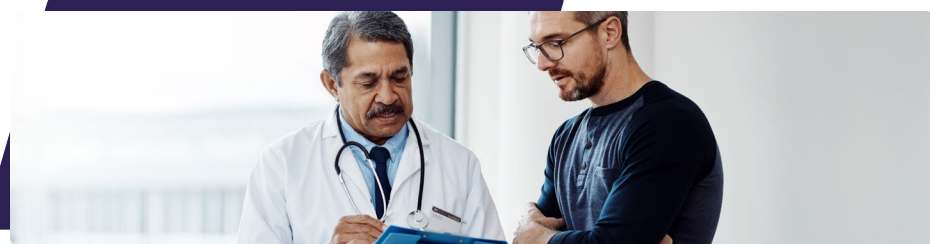
- » Overcoming Hurdles to Cancer Care
- » Cancer Patients & Mental Health Care

BLOG POSTS

- » Patient Access Reform in the States: Previewing 2023
- » With New Cancer Treatments Come Bigger Insurance Hurdles
- » Shortage of Cancer Drugs Demand Action
- » Pediatric Chemotherapy Drugs are in Short Supply
- » With New Cancer Treatments Come Bigger Insurance Hurdles
- » Health Plan Delays Put Cancer Patients at Risk

Rare Diseases

One in 10 Americans has a rare disease.



But despite the prevalence of rare diseases, patients commonly face obstacles to care. Many struggle to find a diagnosis, let alone receive the right treatment.

AfPA's Rare Diseases Working Group continued to raise awareness of rare diseases and the needs of patients and providers who manage these conditions. Meanwhile, the Cystic Fibrosis Engagement Network supported advocates' work to expand patient access.

Efforts included:

- ▶ **Developing educational materials on the harm of utilization management** and the excessive burdens that rare disease patients face as they seek diagnosis and treatment.
- ▶ **Advocating for the creation of rare disease advisory councils** across the country to give rare disease patients and providers a greater voice in policy discussions.
- ▶ **Spotlighting the value of innovation** as new treatments become available and the importance of access for patients with rare diseases.
- ▶ **Engaging directly with state policymakers and local advocates** on the creation of prescription drug affordability boards.

AfPA's Rare Diseases Working Group focused its efforts on several disease states, supporting educational and advocacy efforts.

Efforts included:

- ▶ **Raising awareness of IgG4-RD** and new treatments on the horizon through educational materials.
- ▶ **Convening providers familiar with IgG4-RD** for the inaugural working group meeting.
- ▶ **Testifying before federal policymakers at the FDA** on the value of new treatment options for amyloidosis patients.
- ▶ **Creating educational materials on amyloidosis** to highlight the need for access to innovative treatments.
- ▶ **Supporting advocacy efforts** to reduce access barriers and ensure veterans with amyloidosis can access timely, effective treatment.

The Cystic Fibrosis Engagement Network also supported advocacy efforts at the state and federal level to raise awareness of the health plan challenges many rare disease patients face, including high cost sharing and alternative funding programs.



Rare Diseases
Working Group



Cystic Fibrosis Engagement Network

VIDEOS

- » Patient Centered Care Shouldn't be Rare

PAPERS

- » Understanding IgG4-RD

INFOGRAPHICS

- » How "Alternative" Rx Funding Programs Fail Cystic Fibrosis Patients
- » Diagnosing IgG4-RD Patients
- » IgG4-RD and Mental Health

BLOG POSTS

- » Rare Disease Patients and Clinicians Gain Traction
- » Access to Care Shouldn't be Rare
- » Fight Continues to Expand Federal Benefits for Huntington's Disease
- » Updated: Putting Genetic Science to Work for Patients
- » Overcoming Barriers for Patients with Rare Vision Conditions
- » Veterans with hATTR Amyloidosis Need Access to Critical Meds

Respiratory

Respiratory conditions can turn patients' lives upside down. But with the right treatment, patients can breathe easier as they manage their condition.



As more innovative respiratory treatments become available, policies must ensure patients can access them. But insurers' overreach can block timely care.

In 2023, AfPA's Respiratory Therapy Access Working Group remained a steadfast advocate for policies that prioritize patient safety and access.

Efforts included:

- ▶ **Creating educational materials about Medicare administrative contractors** and the role they play in patient access.
- ▶ **Raising awareness about pharmacy benefit managers** and policies that could limit practices that harm patients.
- ▶ **Highlighting the value of immunizations** across disease states and conditions through educational materials and national polling.
- ▶ **Educating patients on improvements in asthma care**, including potential access barriers and how patients and providers can combat them.



**Respiratory
Therapy Access
Working Group**

VIDEOS

- » The Umbrella of Immunizations

PAPERS

- » Pharmacy Benefit Managers' Impact on Patient Access

ONE-PAGERS

- » Understanding Medicare Administrative Contractors

SURVEYS

- » The Indirect Impact of RSV: RSV Parent & Provider Survey Results

BLOG POSTS

- » Amidst Tripledemic, the Burden of RSV Makes Itself Known
- » Calls for Medicare Coverage of Digital Therapeutics
- » A New RSV Vaccine Could Save Seniors' Lives

Skin Conditions

One in four Americans is impacted by a skin disease.



Patients can experience discomfort, pain, embarrassment, loss of sleep and reduced quality of life. Emotional struggles and financial obstacles can further harm patients' health outcomes and well-being. Getting on the right treatment path swiftly can have a profound impact .

That's why the Derma Care Access Network took action this year to provide educational and advocacy resources for patients and clinicians.

Efforts included:

- ▶ **Supporting patients** as they advocate for optimal care.
- ▶ **Increasing awareness** of the burdens that pharmacy benefit managers, step therapy and prior authorization can place on patients and health care providers.
- ▶ **Calling attention** to the debilitating effects of skin conditions.
- ▶ **Launching efforts to advocate at the federal level** to support patient access.



PAPERS

- » Recap: Multi-Disease Coalition Capitol Hill Briefing on Pharmacy Benefit Managers

TOOLKITS

- » Advocacy Toolkit

INFOGRAPHICS

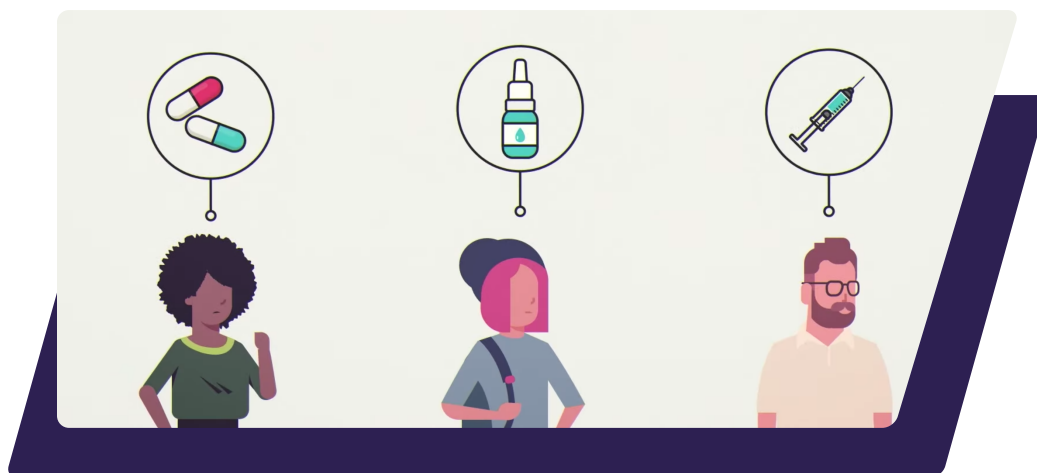
- » The Effects of Non-Medical Switching are More Than Skin Deep

BLOG POSTS

- » Comfort in One's Own Skin: The Case for Regular Skin Cancer Screening
- » Derm Patients With This Skin Condition Suffer In The Dark
- » Skin Patients Struggle with Non-Medical Switching

Vision Health

Innovative technologies, testing and treatment can provide vision patients with much-needed support.



But for patients with vision conditions, access to the right treatments and services can be an uphill battle.

This year, the Vision Health Advocacy Coalition led direct advocacy efforts to address patients' unmet needs. The coalition also developed programming and educational materials to equip patients with the tools to advocate for timely treatment.

Efforts included:

- ▶ **Raising awareness of rare vision conditions** through a policy paper on addressing unmet needs and a new series of educational one-pagers highlighting rare vision conditions.
- ▶ **Supporting patients with rare vision conditions** through virtual and in-person patient empowerment events.
- ▶ **Continuing to educate vision patients, providers and policymakers** on harmful utilization management tactics like prior authorization and step therapy.
- ▶ **Hosting educational patient and caregiver events** in both English and Spanish.
- ▶ **Urging federal and state legislatures** to protect patients' access to physician-prescribed treatments through sign-on letters that supported policies limiting utilization management tactics.
- ▶ **Convening the coalition's stakeholders** for the first in-person event to identify patients' unmet needs and advocacy priorities.



VIDEOS

- » Spotlight on Patient Access
- » Thyroid Eye Disease Patient & Caregiver Event
- » Living Well With Thyroid Eye Disease
- » Thyroid Eye Disease Patient & Caregiver Event: Presented in Spanish

PAPERS

- » Addressing Unmet Needs for Patients with Rare Vision Conditions

ONE-PAGERS

- » Gene Therapy 101
- » An Eye on Rare Vision: Thyroid Eye Disease
- » An Eye on Rare Vision: Retinitis Pigmentosa
- » Biologics & Vision Health
- » An Eye on Rare Vision: Keratoconus

BLOG POSTS

- » This April, Women's Eyes Have It
- » Closing the Gap in Vision Health
- » Overcoming Barriers for Patients with Rare Vision Conditions
- » How Aging Impacts Eyesight

AfPA ANNUAL REPORT 2023

Next Steps





Moving Forward

Following a year of successful advocacy for patient access, AfPA looks forward to 2024.

In the new year, AfPA will prioritize policies at the health plan, state and federal level that put patients first.



Navigating policy discussions of treatment value.

As new policies begin to impact patient care, the Alliance for Patient Access will work to ensure that access and affordability for all patients remains a priority.



Reducing harmful cost-sharing tactics.

The Alliance for Patient Access will continue advocacy efforts directed toward reducing the harm of cost-shifting approaches like alternative funding programs.



Advocating for patient-centered mental health care.

Many patients experience mental health challenges as a symptom or comorbidity of other diseases. Raising awareness among patients and providers about the overlap between physical and mental health is a priority for the coming year. And as serious mental illness policies become a greater focus in statehouses, the Alliance for Patient Access will continue raising awareness and advocating for patient access.



Educating on the evolving biologics landscape.

As more biosimilars and interchangeable biosimilars become available, AfPA will continue advocating for patient access to these tailored treatments.



Identifying key policy reforms to ensure affordability.

As statehouses continue to create prescription drug affordability boards, the Alliance for Patient Access will promote a patient-centered approach to exploring drug value.

Stay connected in 2024!



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