2025

ANNUAL REPORT

Alliance for
Patient Access

DEAR FRIENDS AND SUPPORTERS,

With your help, the Alliance for Patient Access marked another year of ardent advocacy and targeted education. This year brought its fair share of challenges. But with every obstacle—be it abrupt policy shifts, Medicaid cuts or threats to vaccine access—the Alliance for Patient Access rose to the occasion.

- **AfPA remained consistent through every roadblock.** When policy challenges arose, AfPA maintained a clear and consistent voice on Capitol Hill and in statehouses across the country. When the community needed information and advocacy support, AfPA developed trusted resources to reframe the conversation. And when the need for patient and provider voices became more apparent than ever, AfPA held events and provided training that kept the advocacy community engaged and informed. Beyond the headlines, AfPA was on ground — putting the power of advocacy to work for patients and clinicians.
- **Advocacy is only as effective as the community that engages, and AfPA's network is nothing short of remarkable.** This year, patient and clinician voices remained at the center of policy. With every opinion-editorial, media interview, comment letter, social media video, policy roundtable, and testimony on Capitol Hill, in a statehouse, or with a regulator, AfPA advocates brought the power of lived experience to policy discussions.
- **As the organization approaches its 20th anniversary, AfPA reflects on a year defined by meaningful progress.** AfPA advanced patient-centered policies across multiple diseases and geographies, including pharmacy benefit manager reform, limits on utilization management practices, increased access to biomarker testing and greater adoption of personalized medicine. With meaningful wins behind us, AfPA is poised to expand its impact in the years ahead.

Please join us as we reflect on 2025, a successful year of advocacy. Thank you for the support and participation that made this year possible.

With gratitude,

D Charles MD

DAVID CHARLES, MD
Chief Medical Officer

Josie Cooper

JOSIE COOPER
Executive Director

AfPA | 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

Alliance for Gout Awareness

AfPA Policy Collaborative

bpc Biologics Prescribers Collaborative

Coalition for Clinical Trials Awareness

COPD Action Alliance

CFEN Cystic Fibrosis Engagement Network

Generics | Access | Project

Keep My Rx

Movement Disorders Policy Coalition

National Council of Physician Legislators

Patient & Provider Advocates for Telehealth

Vision Health Advocacy Coalition

AFFILIATES

DCAN Derma Care Access Network

The Headache & Migraine Policy Forum

IfPA | Institute for Patient Access

National Coalition for Infant Health

Partnership to advance cardiovascular health

2025 **BY THE NUMBERS**

68.6 MILLION
IMPRESSIONS

2.1 MILLION
YOUTUBE VIEWS

184,927
SOCIAL MEDIA FOLLOWERS

531,751
WEBSITE VIEWS

71
PAPERS

64
BLOGS

25
YOUTUBE VIDEOS

44
EVENTS & WEBINARS

174
COMMENT LETTERS

25
INFOGRAPHICS

2025 ANNUAL REPORT

TABLE OF CONTENTS

POLICY ADVOCACY ISSUES

ADVOCACY BY TOPIC

THE PROVIDER VOICE

POLICY ADVOCACY ISSUES

ACCESS BARRIERS

VIDEOS

- AfPA's 10th Annual National Policy & Advocacy Summit

WHITE PAPERS & POLICY BRIEFS

- AfPA's 10th Annual National Policy & Advocacy Summit
- Focus on Access: How Most Favored Nation Could Fail Patients
- Navigating Insurance Barriers for Biologic Medication
- Focus on Access: Navigating Medicare Part B Negotiation and Its Unintended Consequences Brief
- Access Barriers & Serious Mental Illness: Improving Timely, Consistent Access to Mental Health Treatment
- Navigating Insurance Barriers for Biologic Medication
- Barriers to Genetic Counseling for HCM: Q&A with Bryana Rivers, LGC

INFOGRAPHICS

- Prescription Drug Affordability Boards and Personalized Care
- How PDABs Impede Access
- Reducing Access Barriers for Rare Disease Patients

BLOG POSTS

- The High Stakes of Denied Health Insurance Claims
- Barriers and Solutions to Treating Friedreich's Ataxia

Burdensome utilization management practices continued to threaten patient access in 2025.

- **Prior authorization** and repetitive reauthorization requirements delayed clinician-prescribed treatments.
- **Excessive step therapy protocols** increased the risk of disease progression.
- **Non-medical switching** disrupted treatment stability and undermined quality of life.
- **Expanding lists of formulary exclusions** restricted clinicians' ability to make patient-centered decisions.

These challenges burdened both patients and clinicians, contributing to burnout and placing additional strain on the health care system.

AfPA remained dedicated to sounding the alarm of these barriers and advancing federal, state and health plan-level policies that prioritize patient access and clinical autonomy. A key area of focus this year was pharmacy benefit manager, or PBM reform, with advocacy efforts directed toward reducing PBM influence through legislative solutions that enhance transparency and protect patients' access to prescribed treatments.

The 10th Annual Policy & Advocacy Summit, held in Washington, DC, summarized the year's advocacy efforts. The event brought together patients, clinicians and policy leaders to examine how policy decisions impact access to care, and to underscore the importance of collaboration in achieving patient-centered reform.

COST SHARING

Out-of-pocket costs continued to play a defining role in whether patients could seek care, adhere to treatment and effectively manage their conditions.

In 2025, cost-sharing policies reflected both progress and ongoing challenges. The first-ever cap on out-of-pocket prescription drug costs for Medicare Part D beneficiaries represented an important step toward making medications more affordable. Meanwhile, the Medicare Prescription Payment Plan offered patients the flexibility to spread their prescription costs across the calendar year. To keep patients and clinicians informed about the program's implementation for 2026, AfPA developed and distributed easy-to-understand educational resources.

Other trends, however, introduced new complexities. Copay accumulator and maximizer programs persisted, limiting patients' ability to benefit from manufacturer assistance. Alternative funding programs led to unintended consequences for patients, resulting in treatment delays, reduced quality of care and diverted resources.

These programs have ultimately increased cost-sharing responsibilities for patients, but AfPA continued to advocate for state and federal reforms that alleviate financial burdens on patients. These challenges will remain an area of focus in 2026.

WHITE PAPERS & POLICY BRIEFS

- Focus on Access: Navigating Medicare Part B Negotiation and Its Unintended Consequences Brief
- Fast Facts: The 340B Drug Pricing Program
- Focus on Access: How Most Favored Nation Could Fail Patients
- Medicare Part D Changes: Frequently Asked Questions
- Changes to Medicare Part D: A Patient's Guide

BLOG POSTS

- Medicare Part D Reforms Raise Costs and Concerns for Seniors
- Feds Target 15 More Drugs for Price Negotiations

INNOVATION AND VALUE

WHITE PAPERS & POLICY BRIEFS

- Focus on Access: The Value of Treatment
- FDA User Fee Programs
- Fast Facts: Cell and Gene Therapy
- Biomarker Testing in Neurology
- Fast Facts: What Patients Should Know About Biologics
- Focus on Access: Navigating Medicare Part B Negotiation and Its Unintended Consequences Brief
- Focus on Access: How Most Favored Nation Could Fail Patients

INFOGRAPHICS

- Ensuring Early Testing And Treatment In Alzheimer's Disease
- Encouraging Innovation for Rare Disease Patients

BLOG POSTS

- A Historic Leap in Diagnostic Capacity
- Gene Therapies Promise New Hope and New Barriers
- Gene Therapy Breakthrough for Huntington's Disease
- FDA Clears Path for Wider Use of CAR T Therapies
- Parkinson's Research Brings Promising Developments

This year, **AfPA** continued its work to ensure that patients and clinicians are represented in discussions about value, and that their voices guide how innovation and access are defined.

Throughout the year, AfPA championed innovation through legislative engagement. At the state level, members advocated for policies that expand access to biomarker testing for a range of conditions, including Alzheimer's disease. These efforts aim to ensure that patients can benefit from earlier detection, more personalized care and the full potential of emerging medical advancements.

Clinician members participated in conversations about the unintended consequences of the Inflation Reduction Act. AfPA developed resources and advocacy training for clinicians and partners interested in weighing in on drug price negotiations, while highlighting potential challenges of the program.

AfPA also advocated for broader access to innovative treatments like biologics and biosimilars, emphasizing their role in improving patient outcomes and expanding treatment choices. By working with stakeholders across the health care system, AfPA promoted an environment that fosters innovation for current and future treatment options.

Meanwhile, the growing concern of Prescription Drug Affordability Boards, or PDABs, presented new challenges. While intended to control drug spending, these boards can unintentionally increase patients' out-of-pocket costs. AfPA has been at the forefront of conversations on PDABs, working to increase awareness of their potential impact on patient access and affordability.

At the same time, AfPA has made it clear that care and treatment should be defined by patients and clinicians — those most directly affected by health care decisions. AfPA released three issue briefs that educated policymakers, clinicians and advocates on the current state of national discussions on value and their implications for patients' access to care.

ADVOCACY BY TOPIC

BIOLOGICS

This year, the Biologics Prescribers Collaborative and AfPA's Biologic Therapy Access Working Group led efforts to increase awareness of, and ensure access to, these innovative treatments.

These groups worked in tandem to ensure that policy decisions maintain FDA's authority and encourage continued investment in biologics.

Efforts included:

- **Hosting the 10th Annual National Policy and Advocacy Summit** to discuss how policy decisions influence value, quality and outcomes for patients
- **Convening clinicians and stakeholders for a working group meeting** to discuss access trends in commercial insurance, the biologics and biosimilars landscape, and the Inflation Reduction Act
- **Developing a suite of educational and advocacy materials** to increase patient awareness of biologics and policy barriers that impact access
- **Engaging prescribing societies** to discuss policies impacting biological products
- **Advocating** directly to payers, legislators and regulators on issues related to biologic and biosimilar access
- **Developing a series of policy briefs** on the major issues impacting innovation and patient access

Biologic Therapy Access Working Group

bpc BiologicsPrescribers COLLABORATIVE

VIDEOS

- Understanding Biologics
- AfPA's 10th Annual National Policy & Advocacy Summit

WHITE PAPERS & POLICY BRIEFS

- AfPA's 2025 National Policy & Advocacy Summit Report
- 2025 Meeting Summary
- FDA User Fee Programs
- Biologic Medication and Specialty Pharmacies
- Navigating Insurance Barriers for Biologic Medication
- Fast Facts: The 340B Drug Pricing Program
- Biologics in Respiratory Care: Q&A With James Tracy, DO
- Fast Facts: What Patients Should Know About Biologics
- Focus on Access: How Most Favored Nation Could Fail Patients
- Focus on Access: Navigating Medicare Part B Negotiation and Its Unintended Consequences
- Focus on Access: The Value of Treatment
- Access to Biosimilars: Impact of Insurance Design
- Progress & Potential in the Biosimilar Market

INFOGRAPHICS

- How PDABs Impede Access
- Biologics and Asthma Care
- Prescription Drug Affordability Boards and Personalized Care

CARDIOVASCULAR DISEASE

In 2025, the **Partnership to Advance Cardiovascular Health** and **AfPA's Cardiovascular Disease Working Group** advocated for increased awareness of cardiovascular diseases and the importance of access to treatment options.

Efforts included:

- **Training patients as advocates** through the third annual Cardiometabolic Leadership Academy
- **Mobilizing more than 500 people through a letter desk campaign** for medication access and affordable out-of-pocket costs for Medicare beneficiaries
- **Supporting legislation** that impacts cardiovascular patients
- **Highlighting the impact of related diseases on cardiovascular health** and working cross-functionally with other disease states to raise awareness
- **Through AfPA's HCM Initiative, convening specialists and stakeholders for a working group meeting** to discuss access barriers for cardiovascular patients living with hypertrophic cardiomyopathy
- **Engaging genetic counselors** and hypertrophic cardiomyopathy specialists to develop advocacy resources, raise awareness and engage on policy

Cardiovascular Disease Working Group

PARTNERSHIP TO advance cardiovascular health

VIDEOS

- How Genetically Targeted Technologies Changed Ozzie's Life
- Why Are Heart Patients Paying More Under Price Controls?
- Heart Attack at 28: Tatum's Story
- Step Therapy Puts Patients' Heart Health at Risk
- A MINI Act Could Be Big for Heart Patients
- What is HCM?

WHITE PAPERS & POLICY BRIEFS

- The HEARTS Act
- 5 Things You May Not Know About Women and Hypertension
- Veterans and Hypertension
- FDA User Fee Programs
- 2025 Working Group Meeting Summary
- Fast Facts: The 340B Drug Pricing Program
- Medicare Part D Changes: Frequently Asked Questions
- Changes to Medicare Part D: A Patient's Guide

INFOGRAPHICS

- Measure What Matters
- The Dangers of Step Therapy for Heart Patients
- How PDABs Impede Access
- Delays in Diagnosing and Treating Hypertrophic Cardiomyopathy
- Prescription Drug Affordability Boards and Personalized Care
- Cardiac Myosin Inhibitors As A Treatment For HCM

BLOG POSTS

- Rural and Racial Gaps in Heart Health
- Hypertension: A Growing Concern for Maternal Health
- Making Hypertension History for Veterans Patients

GENERICS ACCESS

This year, the **Generics Access Project** focused on reducing access barriers to complex generics and supporting "skinny labels."

Both align with the coalition's mission to promote generic competition and efficient approval of generic medicines.

Efforts included:

- **Hosting patient listening sessions** with the FDA Office of Generic Drugs to highlight the importance of the patient voice in generic medicine regulatory policies
- **Developing educational materials** to increase awareness of the important role of complex generics in increasing patient access, and on policies such as skinny labeling and Generic Drug User Fee Amendments, or GDUFAs
- **Hosting a webinar teaching advocates** across disease states how to engage on the GDUFA IV reauthorization
- **Engaging with the FDA on GDUFA IV reauthorization,** submitting comment letters and participating in the FDA's public stakeholder meetings

GENERICS | ACCESS | PROJECT

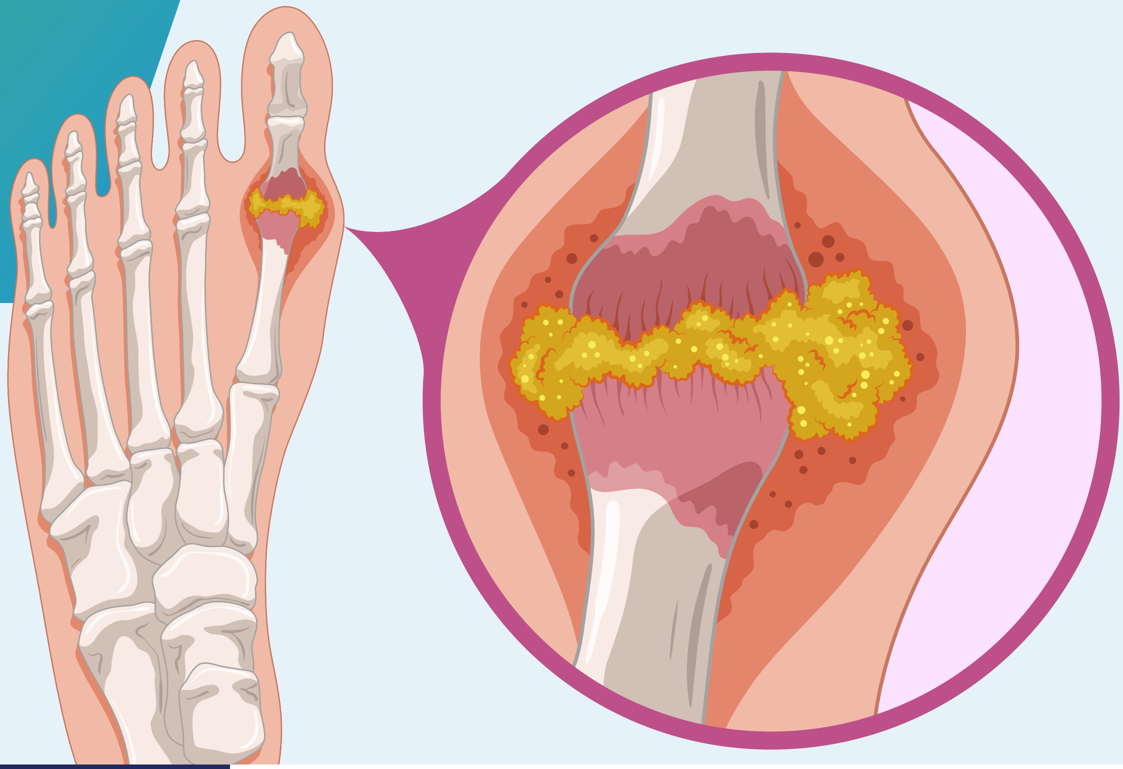
WHITE PAPERS & POLICY BRIEFS

- Complex Generics: Opening the Door to Affordable, Advanced Medicine
- Understanding Skinny Labels A Key to Generic Drug Access
- FDA User Fees

BLOG POSTS

- Federal Report: Pharmacy Middleman Mark Up Crucial Generic Meds Up to 1000%
- A Landmark Law Turns 15
- Uncertainty Grows Around Drug Review Funding

GOUT



VIDEOS

- Gout & Mental Health

WHITE PAPERS & POLICY BRIEFS

- Gout & the Whole Body: Survey Results
- How to Deal with a Medication Denial
- Common Access Barriers in Gout
- Denied Your Treatment for Gout? File a Complaint

TOOLKIT

- Gout Awareness Day Toolkit

INFOGRAPHICS

- Gout & the Whole Body Survey Results Social Graphics

BLOG POSTS

- Gout and Work: Spotlighting Pain Awareness Month

This year, the **Alliance for Gout Awareness** focused on raising awareness of the impact and burden of gout, reducing stigma around the disease, empowering patients in their care, and improving access to gout treatment.

The coalition and its partners collaborated on several initiatives throughout the year.

Efforts included:

- **Conducting a survey of 250 gout patients** to gauge how well patients understand the full-body risks associated with gout
- **Hosting a congressional briefing** on the impact of gout
- **Releasing a video** about the connection between gout and mental health
- **Amplifying patient voices through Gout Awareness Day** activities by joining virtual events and releasing a toolkit with educational resources and sample social media posts
- **Empowering patients at in-person and virtual patient forums** featuring patient and provider speakers
- **Convening advocacy partners** to discuss 2026 priorities at the annual stakeholder meeting in Washington, DC

ALLIANCE FOR
Gout Awareness

HEADACHE & MIGRAINE

In 2025, **The Headache & Migraine Policy Forum** sustained advocacy efforts to increase awareness of debilitating headache disorders and encourage utilization management reform.

The coalition emphasized how practices like prior authorization and step therapy impede access to care that can improve quality of life.

Advocacy efforts included:

- **Co-hosting the ninth annual Capitol Hill Policy Forum, which brings together over 100 attendees** to explore how federal policy can advance optimal migraine management throughout every stage of a woman's life
- **Hosting the "Price of Pain" policy discussion in collaboration with the Alliance for Headache Disorders,** spotlighting migraine as a significant economic and workforce issue
- **Emphasizing how targeted federal policy can drive solutions** through investments in access, research and patient-centered care
- **Collaborating with stakeholders to expand access** to treatments for migraine disease in several states
- **Continuing support for policies** that promote patient access to telehealth
- **Advocating to include migraine screenings** in annual women's wellness visits
- **Collecting data** to determine the connection between the lack of access to treatment and increased costs associated with emergency room visits and exacerbation of comorbid diseases like anxiety and depression

The Headache & Migraine
Policy Forum

VIDEOS

- 2025 Capitol Hill Policy Forum

WHITE PAPERS & POLICY BRIEFS

- The Price of Pain: The Economic Burden of Migraine on the American Economy
- Women's Headache Health Through Life Stages
- Patient Access Success Story: Q&A with Justina Martin

INFOGRAPHICS

- Prioritizing Migraine Screening for Women
- Steps to Headache & Migraine Care
- Migraine Disease Across Life Stages

BLOG POSTS

- Migraine Treatment Devices Can Make a Difference
- Expanding the Treatment Toolbox for Migraine Pain

IMMUNIZATIONS & INFECTIOUS DISEASES

VIDEOS

- Understanding Perspectives on Maternal and Infant Immunizations: Survey Results

WHITE PAPERS & POLICY BRIEFS

- Understanding Perspectives on Maternal and Infant Immunizations: A National Survey Report
- Infant Health Matters: Pneumococcal Disease

INFOGRAPHICS

- Maternal Vaccines: What You Need to Know
- Prescription Drug Affordability Boards and Personalized Care
- How PDABs Impede Access

BLOG POSTS

- A New Federal Strategy to End Hepatitis C
- Will the New Year Bring a New Protection Against RSV?
- Congenital Syphilis: An Increasing Crisis
- Not Too Late to Vaccinate Against Winter Viruses
- Vaccine Panel Shakeup Raises Alarm
- Congress Weighs Proposal to Cure Hep C

This year, the **Hepatitis Therapy Access Working Group, Vaccine Access Initiative** and related coalitions focused on advocating for state and federal reforms.

The groups worked in tandem to support access to care and preventive treatments like vaccines and immunizations.

Efforts included:

- **Engaging clinicians, patients and advocacy groups** to respond to decisions from the CDC's Advisory Committee on Immunization Practices
- **Advocating at the federal level** to increase support for policies that improve access to hepatitis C treatment
- **Advocating at the state level** for increased treatment options for pneumococcal vaccines
- **Engaging on legislation** that supports immunization against hepatitis B for newborns

Hepatitis Therapy Access
Working Group

AfPA's
Vaccine Access
Initiative

INFANT HEALTH

This year, the **National Coalition for Infant Health** raised awareness about a wide range of infant health and safety issues, such as paternal mental health, comprehensive NICU discharge planning and respiratory disease prevention and immunization.

Advocacy efforts included:

- **Publishing a survey** on maternal attitudes toward vaccines and immunizations
- **Co-hosting a roundtable** in Singapore about the burden and impact of thyroid disease on maternal and infant health
- **Leading a partnership campaign** to raise awareness about paternal mental health
- **Raising awareness** about congenital syphilis, pneumococcal disease, pertussis and new preventive RSV measures
- **Producing a clinical proceedings paper** addressing the need for an exclusive human milk diet for premature infants
- **Participating in awareness months** dedicated to RSV, the NICU, prematurity, SIDS and safe sleep, immunizations and breastfeeding
- **Authoring advocacy letters,** including a sign-on letter with other organizations, and mobilizing letter desk campaigns
- **Increasing awareness** about paternal mental health
- **Engaging on legislation** that supports immunization against hepatitis B for newborns

NATIONAL COALITION for Infant Health

VIDEOS

- New Fathers & Postpartum Depression
- Fathers' Mental Health: A Conversation with Lucas
- Congenital Syphilis: A Growing Problem
- Understanding Perspectives on Maternal and Infant Immunizations: Survey Results
- Doretha's RSV Story

WEBINARS

- Addressing the Critical Need for an Exclusive Human Milk Diet for Premature Infants
- Understanding Perspectives on Maternal and Infant Immunizations: Survey Report

WHITE PAPERS & POLICY BRIEFS

- Infant Health Matters: Pertussis
- Addressing the Critical Need for an Exclusive Human Milk Diet for Premature Infants
- Infant Health Matters: Comprehensive NICU Discharge Planning
- Fast Facts: Father's Mental Health
- Infant Health Matters: Lifelong Impacts of Prematurity
- Understanding Perspectives on Maternal and Infant Immunizations: A National Survey Report
- Will the New Year Bring a New Protection Against RSV?
- Infant Health Matters: Pneumococcal Disease

MENTAL HEALTH

VIDEOS

- Access to Mental Health Treatment in Long-Term Care Facilities
- Mental Health is Health: Enforcing Mental Health Parity

WHITE PAPERS & POLICY BRIEFS

- 2025 Meeting Summary
- FDA User Fee Programs
- Access Barriers & Serious Mental Illness: Improving Timely, Consistent Access to Mental Health Treatment

TOOLKITS

- Advocating For Legislation on Serious Mental Illness Toolkit
- Patient Access and the Inflation Reduction Act: Advocacy Toolkit

INFOGRAPHICS

- How PDABs Impede Access
- Prescription Drug Affordability Boards and Personalized Care

BLOG POSTS

- Medicare Beneficiaries Struggle to Find Psychiatric Care
- Pandemic, Precarity Contribute to Mental Health Crisis
- Mental Health Parity at Risk
- Study Finds Maternal Mental Health in Decline

Throughout 2025, the **Alliance for Patient Access' Mental Health Working Group** advocated for policies that would increase and improve access to care for people living with mental health conditions.

The working group also highlighted the mental health challenges faced by people living with chronic illnesses.

Efforts included:

- **Advocating for increased enforcement** of mental health parity laws so patients' mental health benefits from the same level of health plan coverage as their physical health
- **Developing advocacy resources for legislative engagement** on policies that support patients with serious mental illness
- **Hosting a working group meeting** to discuss barriers to proper care for patients with mental health conditions
- **Supporting legislation** that aims to improve treatment access for patients
- **Developing educational materials** that increase awareness of access barriers and resources like the 988 Suicide & Crisis Lifeline
- **Equipping clinicians** to share their perspective with the Centers for Medicare and Medicaid Services on the Medicare Drug Price Negotiation Program

Mental Health
Working Group

NEUROLOGICAL DISEASES

AfPA's Neurological Disease Working Group and the **Movement Disorders Policy Coalition** worked together to promote early testing and diagnosis and patient-centered care for people living with neurological conditions such as Parkinson's, Alzheimer's, Friedreich's ataxia and tardive dyskinesia.

Efforts included:

- **Creating resources and opportunities for clinician advocates** to engage in web-based programming, comment letters and testimonies on Capitol Hill
- **Engaging clinicians** to support policies that cover biomarker testing for early Alzheimer's identification
- **Preparing patients and clinicians** to comment on the Medicare Drug Price Negotiation Program through educational resources and advocacy training
- **Successfully advocating** for coverage policies that allow Parkinson's patients to access innovative medication
- **Convening clinicians and stakeholders** for an annual working group meeting in Washington, DC to discuss policy barriers and reform
- **Working with partners to advocate for state and federal reforms** that will improve access to treatment for patients with neurological conditions like movement disorders

Neurological Disease Working Group

MOVEMENT DISORDERS POLICY COALITION

VIDEOS

- Access to Mental Health Treatment in Long-Term Care Facilities
- Fighting for Access: The Parkinson's Treatment Gap
- Biomarker Testing in Alzheimer's

WHITE PAPERS & POLICY BRIEFS

- Early Screening for Tardive Dyskinesia
- Navigating the Inflation Reduction Act: What It Means for Movement Disorder Patients and Advocates
- 2025 Working Group Summary
- Biomarker Testing in Neurology
- FDA User Fee Programs
- Fast Facts: The 340B Drug Pricing Program
- Friedreich's Ataxia: A Rare Condition Access Challenges

INFOGRAPHICS

- Ensuring Early Testing and Treatment in Alzheimer's Disease
- How PDABs Impede Access
- Prescription Drug Affordability Boards and Personalized Care

BLOG POSTS

- Barriers and Solutions to Treating Friedreich's Ataxia
- New York Moves on Movement Disorders
- Parkinson's Research Brings Promising Developments

OBESITY

WHITE PAPERS & POLICY BRIEFS

- FDA User Fee Programs
- Obesity in Rural America

TOOLKITS

- Patient Access and The Inflation Reduction Act: Advocacy Toolkit

INFOGRAPHICS

- How PDABs Impede Access
- Prescription Drug Affordability Boards and Personalized Care

BLOG POSTS

- Rural Americans Face Higher Risk
- Massachusetts Budget Cuts Threaten Obesity Care

This year, **AfPA's Obesity Initiative** spotlighted the need for comprehensive obesity treatment. The initiative worked to destigmatize obesity, reframe the condition as a chronic disease and convene specialists in other diseases to support a comprehensive view of obesity.

Efforts included:

- **Mobilizing more than 500 people to write to their state policymakers,** urging them to maintain coverage for obesity medications
- **Developing educational resources** that emphasize the value of treating obesity to reduce the risk of related diseases
- **Supporting legislation** at the state and federal level to improve access to obesity care
- **Hosting a panel discussion** with lawmakers to discuss proposed policies that impact access to care for Massachusetts patients living with obesity
- **Developing a digital advocacy campaign** to emphasize the importance of obesity care coverage to state lawmakers
- **Training a diverse set of clinicians** to engage with the Centers for Medicare & Medicaid Services on the Medicare Drug Price Negotiation Program

AfPA's **Obesity** Initiative

ONCOLOGY

AfPA's **Oncology Therapy Access Working Group** supported access to timely care for cancer patients. The working group focused on the importance of personalized medicine in oncology, particularly biomarker testing and gene therapy.

Advocacy efforts supported policies that reduce delays and access barriers that impact care in a time-sensitive disease.

Efforts included:

- **Advocating for increased coverage of diagnostic tools** like biomarker tests to identify disease earlier rather than later
- **Emphasizing the importance of tailored treatment plans** for cancer patients through advocacy resources
- **Supporting legislation** that reforms the role of pharmacy benefit managers in clinical decision making
- **Developing resources** that highlight the importance of curative treatments like cell and gene therapy and the need for innovative payment models to help cover costs

Oncology
Therapy Access
Working Group

VIDEOS

- Understanding Biologics

WHITE PAPERS & POLICY BRIEFS

- 2025 Meeting Summary
- FDA User Fee Programs
- Oncology and Care Pathways
- Fast Facts: The 340B Drug Pricing Program
- Fast Facts: Cell and Gene Therapy
- Focus on Access: How Most Favored Nation Could Fail Patients
- Focus on Access: The Value of Treatment
- Focus on Access: Navigating Medicare Part B Negotiation and Its Unintended Consequences Brief
- Fast Facts: What Patients Should Know About Biologics
- A Patient's Guide to Self-Administered Biologics
- Biologic Medication and Specialty Pharmacies
- Navigating Insurance Barriers for Biologic Medication

INFOGRAPHICS

- How PDABs Impede Access
- Prescription Drug Affordability Boards and Personalized Care

BLOG POSTS

- Women and Young People Face an Increasing Risk of Cancer
- FDA Clears Path for Wider Use of CAR T Therapies
- Privately Insured Patients are More Likely to Survive Cancer
- Gene Therapies Promise New Hope and New Barriers
- Childhood Cancer Receives Funding Boost for AI Research

RARE DISEASES

VIDEOS

- What is IgG4-RD?

WHITE PAPERS & POLICY BRIEFS

- 2025 Amyloidosis Initiative Meeting Summary
- 2025 IgG4-RD Initiative Meeting Summary
- FDA User Fee Programs
- Fast Facts: The 340B Drug Pricing Program
- Fast Facts: Hereditary Transthyretin Amyloidosis with Polyneuropathy
- Friedreich's Ataxia: A Rare Condition Access Challenges
- Comprehensive Treatment for Cardiac Amyloidosis

INFOGRAPHICS

- How PDABs Impede Access
- Prescription Drug Affordability Boards and Personalized Care
- Encouraging Innovation for Rare Disease Patients
- Reducing Access Barriers for Rare Disease Patients

BLOG POSTS

- Cystic Fibrosis Patients Rally for Recognition During Rare Disease Week
- Barriers and Solutions to Treating Friedreich's Ataxia
- Recognizing that "Rare" is Everywhere
- The High Stakes of Denied Health Insurance Claims

This year, AfPA's **Rare Diseases Working Group** and related initiatives, alongside the **Cystic Fibrosis Engagement Network,** supported policies that reduce access barriers for rare disease patients who already have limited treatment options.

The groups worked in tandem to advocate for policies that incentivize innovation for the 95 percent of people who don't have approved treatment options.

Efforts of each group are as follows:

- The **Amyloidosis Initiative** kept clinicians and patients educated and informed on available treatment options. The group advocated for reducing coverage exclusions for patients on commercial health plans. The initiative also saw victory in their advocacy efforts when a step therapy requirement for patients in the Veterans Health Administration system was removed, marking a win for people living with amyloidosis.
- The **IgG4-RD Initiative** convened a diverse group of clinicians to discuss barriers to diagnosis and treatment as well as the vital role of clinicians in rare disease advocacy. The group developed educational resources to raise awareness of IgG4-RD.
- The **Cystic Fibrosis Engagement Network** hosted a Capitol Hill fly-in with a number of its member organizations. As a leading voice in the cystic fibrosis advocacy community, CFEN engaged with a variety of stakeholders from across the country to discuss legislation on utilization management, PBM reform and patient access to supplemental oxygen.
- The working group **partnered with the Friedreich's Ataxia Research Alliance** to develop a policy paper on access challenges faced by FA patients. The paper highlighted common challenges faced by patients, from their arduous diagnosis journey to issues accessing appropriate treatment.

Rare Diseases Working Group

CFEN
Cystic Fibrosis Engagement Network

RESPIRATORY CONDITIONS

In 2025, **AfPA's Respiratory Therapy Access Working Group** and the **COPD Action Alliance** collaborated to increase patient access to respiratory treatments.

Efforts of each group are as follows:

- The **Respiratory Therapy Access Working Group** engaged with pharmacy and therapeutics committees to urge comprehensive coverage of respiratory treatments for patients, including Medicaid beneficiaries.
- The **working group advocated** for pharmacy benefit manager reform and better access to biologic medications. Educational materials enhanced understanding of biologics' role in tailored respiratory care.
- The **COPD Action Alliance** worked to change the face of the respiratory disease by reducing the stigma around COPD and highlighting its impact on veterans, first responders and women.
- The **coalition worked to increase awareness and advocate** for policies that affect people living with COPD through its first in-person meeting, state and federal policy engagement and outreach around COPD Awareness Month. During this successful campaign, the coalition hosted a fly-in featuring CAA members raising awareness, an Axios media event and secured state acknowledgements and media.

Respiratory Therapy Access Working Group

COPD ACTION ALLIANCE

WHITE PAPERS & POLICY BRIEFS

- FDA User Fee Programs
- Fast Facts: The 340B Drug Pricing Program
- Biologics in Respiratory Care: Q&A With James Tracy, DO
- Fast Facts: What Patients Should Know About Biologics
- A Patient's Guide to Self-Administered Biologics
- Biologic Medication and Specialty Pharmacies
- Navigating Insurance Barriers for Biologic Medication
- Veterans & COPD
- COPD in the Line of Duty
- Living with COPD: Patient Experiences & Health Policy Perspectives Survey Report
- COPD & Comorbidities
- Women & COPD

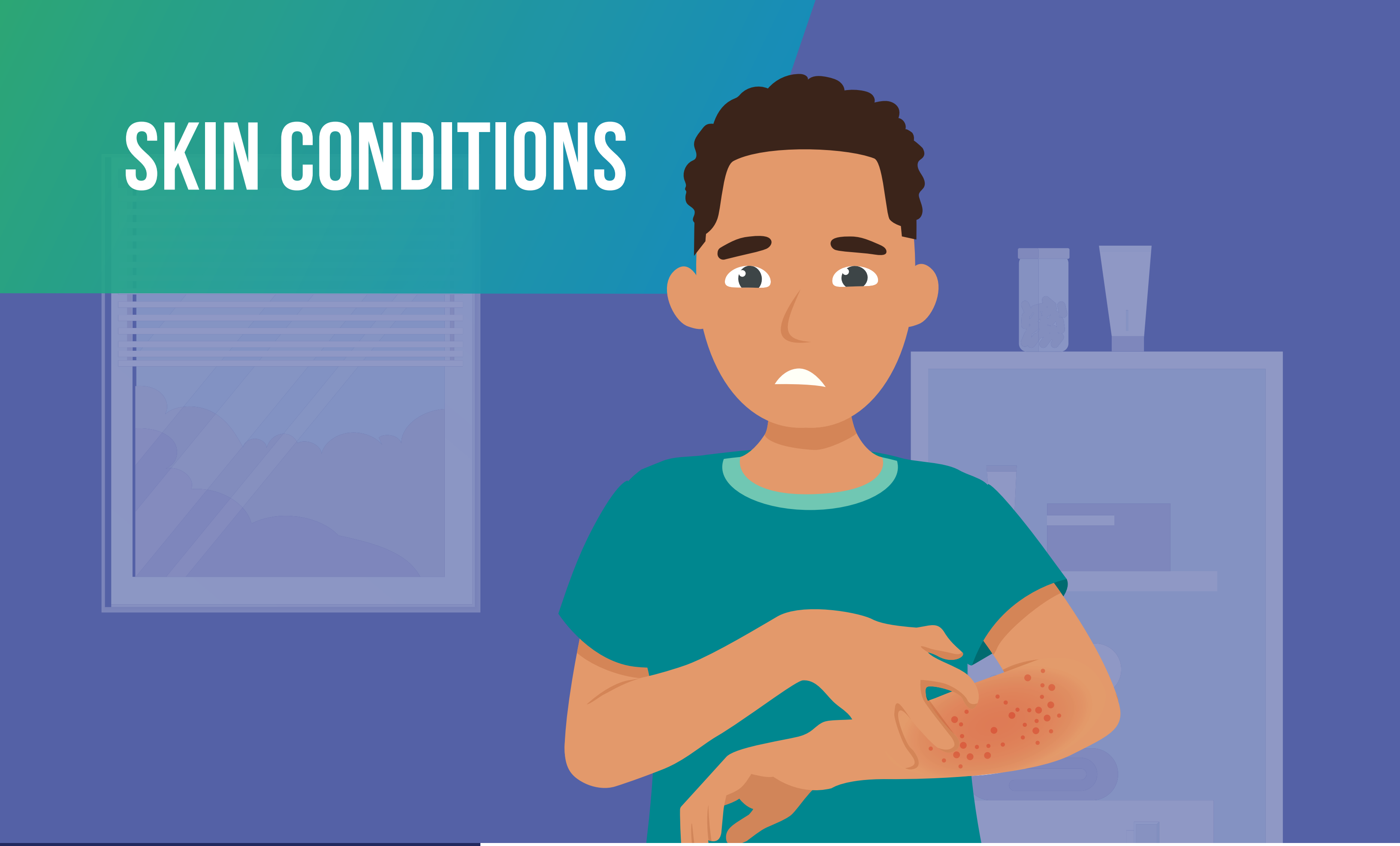
INFOGRAPHICS

- How PDABs Impede Access
- Biologics and Asthma Care
- Prescription Drug Affordability Boards and Personalized Care
- Access to Advanced Asthma Care

BLOG POSTS

- COPD Advocates Go to Capitol Hill
- Cystic Fibrosis Patients Rally for Recognition During Rare Disease Week
- A Crisis in Women's Lung Health
- The Importance of Biologic Medicines

SKIN CONDITIONS



WHITE PAPERS & POLICY BRIEFS

- Alopecia Areata
- Pemphigus & Pemphigoid
- Vitiligo
- Step Up for Skin Health: Briefing Report

BLOG POSTS

- Advocating for Consistent Federal Health Plan Guidelines on Vitiligo
- Beyond Symptom Management: The Critical Value of Remission in Dermatological Care

Throughout 2025, the **Derma Care Access Network** continued advocacy efforts to reduce stigma and support patients. The network also developed new materials to bring awareness to lesser-known skin conditions.

Efforts included:

- **Developing legislation that addresses the misclassification of FDA-approved treatments** for conditions like vitiligo and alopecia areata
- **Collaborating with the Coalition of Skin Diseases** to stand up the first congressional caucus dedicated to skin diseases
- **Supporting policies that minimize utilization management** for patients with skin conditions
- **Mobilizing clinicians** to engage in thought leadership that promotes patient access to optimal dermatologic care

DCAN
Derma Care Access Network

VISION HEALTH

This year, the **Vision Health Advocacy Coalition** advocated to reform barriers to care, like prior authorization and copay accumulator programs. The coalition also worked to empower and support vision patients through educational resources and programming.

Efforts included:

- **Hosting in-person and virtual programs** for patients with thyroid eye disease and their caregivers to learn how to manage the condition, better understand treatment options and ask questions of experts.
- **Convening coalition members** for in-person discussions on barriers to appropriate vision care.
- **Hosting a thyroid eye disease stakeholder meeting** to coalesce around shared advocacy priorities.
- **Increasing policy engagement** at the state and federal levels to improve access to sufficient vision care.

VIDEOS

- Myth Busters: Thyroid Eye Disease

WHITE PAPERS & POLICY BRIEFS

- 2025 Stakeholder Meeting Summary

WEBINARS

- TED Patient & Caregiver Empowerment Forum
- Thyroid Eye Disease: Can I Talk About My Eyes?

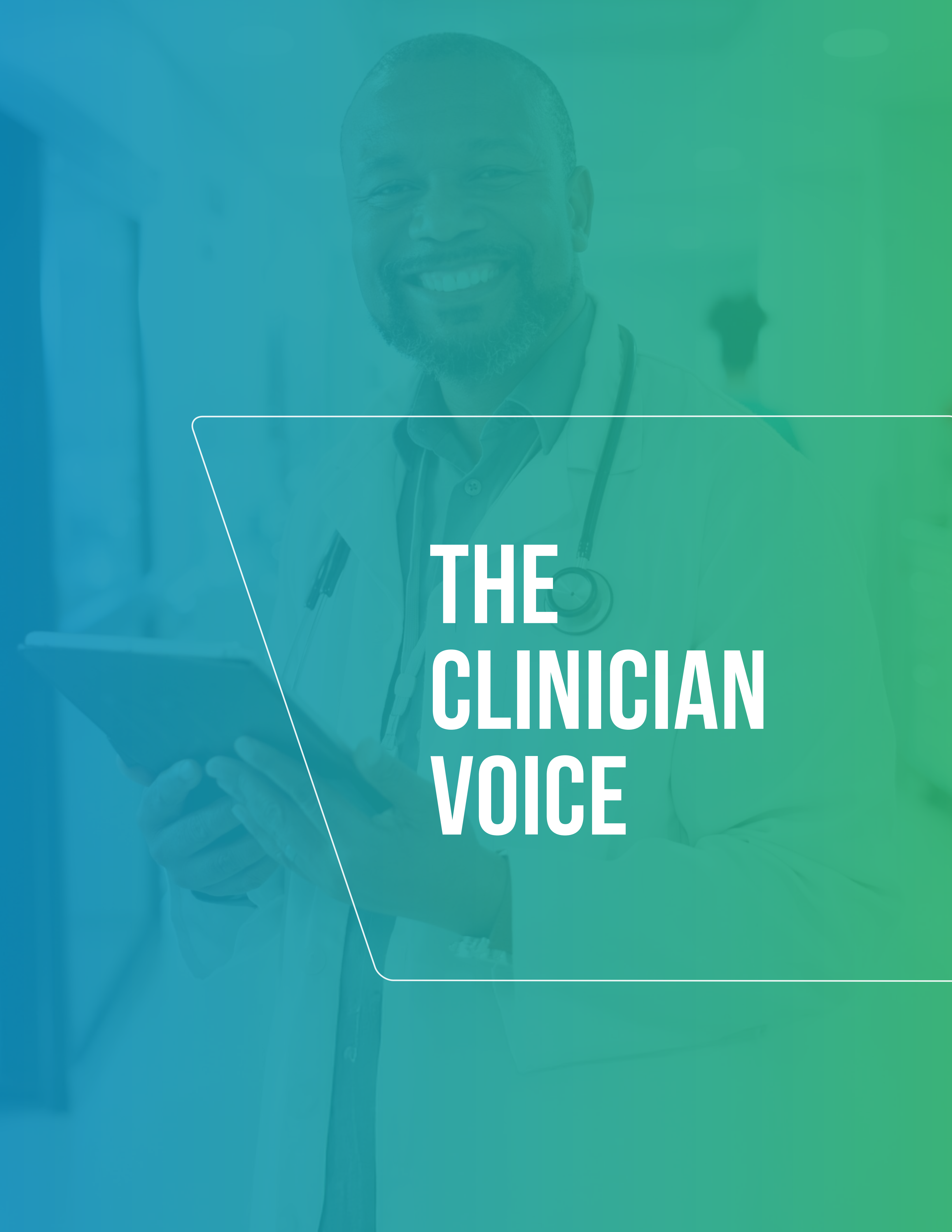
INFOGRAPHICS

- How Clinical Trials Advance Vision Health

BLOG POSTS

- Budget Cuts Leave Vision Health at Risk
- Medicare Part D Reforms Raise Costs and Concerns for Seniors

VISION HEALTH
ADVOCACY COALITION



THE CLINICIAN VOICE

THE CLINICIAN VOICE

Reflecting upon the success of 2025 and the challenges that lie ahead, AfPA clinician advocates describe the importance of using their voice to advance patient-centered care.

“**Clinician advocacy helps patients understand that we are aligned with them as the physician.** We do want the best treatment for them. And we have the power to speak up on behalf of these patients who are unable to speak up for themselves.”

LAUREN GRAWERT, MD

“We as physicians can have a much bigger impact if we'll take our advocacy out of just the one-on-one and do it on a bigger level. **We can extend our help from beyond the clinic to patients we may never see.”**

J. ALLEN MEADOWS, MD

“Other clinicians can become involved as advocates by first recognizing that simply seeing one patient and then another is not going to change the public's health. **We need to work together** to fight back against the degradation in public health and access to care that we've seen across the population.”

KEITH C. FERDINAND, MD

“It has become critical to the future of patients' health that clinicians advocate for legislation at the federal and state level to protect their right to patient-centered care. Health care has become an overwhelming business, and **it is nearly impossible for patients to successfully fight on their own.”**

WESLEY MIZUTANI, MD

“I value the work I do in direct patient care, but **engaging in advocacy allows me to influence health outcomes on a broader scale.** Balancing both roles is important to me as a physician—it lets me contribute meaningfully to individual patients while also shaping policies that impact entire communities.”

WAYNE HO, MD

“**Physician advocacy brings the patient's voice directly into conversations** that determine access, quality and equity. Clinicians understand what helps and what harms. That perspective is irreplaceable in shaping responsible health policy.”

AMITA PATEL, MD

A MILESTONE YEAR AHEAD

As the Alliance for Patient Access approaches its 20th anniversary, the organization stands on the threshold of an exciting new chapter.

Two decades of advocacy and education have shaped AfPA into a trusted voice in health care. The year ahead offers a chance to celebrate that legacy while charting a bold path forward.

With fresh challenges and new opportunities emerging every day, AfPA remains committed to showing up with the same clarity, purpose and determination that have guided its work from the beginning. The coming year will bring expanded partnerships, new avenues for education, and continued efforts to elevate the voices of patients and clinicians.

AfPA's 20th anniversary is not just a milestone. It is a moment to reaffirm the values that define the organization and to strengthen its foundation for the decades ahead. Together with its advocates and supporters, AfPA looks ahead with eagerness, resilience and an unwavering focus on policies that prioritize patients.

AfPA | 20 Years of Advocacy

Alliance for
Patient Access

STAY CONNECTED IN 2026!

AllianceforPatientAccess.org

Alliance for Patient Access

@PatientAccess

AfPApatientaccess

Alliance for Patient Access

InstituteForPatientAccess.org

Health Policy Today