



2022 ANNUAL REPORT





Alliance for Patient Access

WORKING GROUPS & INITIATIVES



Biologic Therapy Access Working Group



Cardiovascular Disease Working Group



Diabetes Therapy Access Working Group



Headache & Migraine Disease Working Group



Hepatitis Therapy Access Physicians 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 Urology Initiative

STAKEHOLDER COALITIONS



AFFILIATES



DEAR FRIENDS & SUPPORTERS:

Many of us had envisioned a return to normal this year. Instead, 2022 ushered in what can only be described as a new normal.

More resilient and more grateful, we faced the reality that some level of uncertainty is a constant in our world. We recognized COVID-19, with its ever-changing variants, as a long-term challenge. We faced economic turbulence, political polarization and international unrest.

Most importantly, we embraced the challenges before us, and at the Alliance for Patient Access we strengthened our commitment to the education and advocacy causes that we have long championed. AfPA found new avenues for advocacy — and a renewed resolve to tackle the barriers that impede patient-centered care.

In this year's annual report, you'll see evidence of our continued commitment to raising clinician and patient voices to guide policy and improve access.

For example:

- ▼ **Policy events and resources emboldened patients to expect more.** From optimal respiratory care to personalized urology treatment to more meaningful engagement in health value conversations, AfPA urged advocates to aim higher and ask more of health plans and policymakers.
- ▼ **AfPA's state presence grew, with a new state chapter established in Massachusetts.** Expanded capabilities at the state level offered the national organization more opportunities to spur policy change.
- ▼ **The Institute for Patient Access policy blog rebranded as Health Policy Today.** The new platform offers the education organization a fresh chance to reach a broader audience.
- ▼ **New data exposed lingering challenges.** IfPA explored national claims data to pinpoint how utilization management disproportionately impacts minorities. Meanwhile, the Partnership to Advance Cardiovascular Health took a closer look at states where medication access reveals dangerous patterns of discrimination.

There's no going back to pre-pandemic norms. And based on the bold transformations we've seen in 2022, perhaps that's good news. As we enter 2023, AfPA stands alongside its committed partners, emboldened and excited to meet the year ahead.

With best wishes,



A handwritten signature in black ink that reads "D Charles MD".

DAVID CHARLES, MD
Chief Medical Officer



A handwritten signature in black ink that reads "Josie Cooper".

JOSIE COOPER
Executive Director

2022 BY THE NUMBERS

50 STATES REPRESENTED BY AFPA



77 PAPERS



43 EVENTS & WEBINARS



102 BLOG POSTS



205 COMMENT LETTERS



167 INFOGRAPHICS



120,644 SOCIAL MEDIA FOLLOWERS



26 YOUTUBE VIDEOS



376,195 YOUTUBE VIEWS



15.4 million SOCIAL MEDIA IMPRESSIONS



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ACCESS BARRIERS

Patients, alongside their health care providers, should decide which treatment is right for them.

Step therapy, non-medical switching and co-pay accumulator programs, among other utilization management practices, continued to deter patients in 2022. The Alliance for Patient Access advocated at the federal, state, regulatory and plan levels to limit these barriers and expand patients' access to prescribed medications, contributing to reforms in nine states this year.

- ▼ The **Patient Access Collaborative** continued its series of quarterly webinars to inform advocates about policy developments at the state and federal level. The group also launched a series of educational materials about the entities that define health care value and access.
- ▼ The **Keep My Rx campaign** monitored and informed state-level legislation on the issue of non-medical switching, while AfPA's state chapters allowed clinicians and local advocates to partner on driving meaningful policy change.
- ▼ And the **National Council of Physician Legislators** continued its work to unite health care providers who also serve in statehouses around the country. The group shared insights and explored new ideas, policies and issues that shape the practice of medicine.

VIDEOS

- » [Sacrificing Quality for the QALY](#)

ONE-PAGERS

- » [Who Decides: Defining the Value of Medical Treatment](#)

TOOLKIT

- » [Prior Authorization & Vision Health](#)

INFOGRAPHICS

- » [Step Therapy Stifles Asthma Patients](#)
- » [Movement Disorders Patients' Journey Through Step Therapy](#)
- » [The Danger of Prior Authorization for Rare Cancer Patients](#)
- » [Co-pay Accumulators Don't Add Up for Patients](#)

BLOG POSTS

- » [Urgent Action Paused by Prior Authorization](#)
- » [Exclusion Lists Leave Rx's Off, Patients Behind](#)
- » [Feds Poised to Take a Hard Look at Pharmacy Benefit Managers](#)
- » [More States Adopt Step Therapy Limitations While Federal Protections Remain Elusive](#)
- » [Non-Medical Switching Pushes Patients to the Brink](#)
- » [Patients Pay the Price When Insurers Switch Mental Health Medications](#)
- » [When Patients Get Edged Out by Profits](#)
- » [CVS Caremark "Switch" Puts Heart Patients at Risk](#)





BIOLOGICS

Biologics continue to offer patients more options for targeted, accessible treatment.

In 2022, AfPA's Biologic Therapy Access Working Group and the Biologics Prescribers Collaborative worked to educate patients on the value, safety and diversity of biologics and biosimilars — including interchangeable biosimilars.

Efforts included:

- ▼ **Disease-state educational materials** highlighting biologics developments in the fields of rheumatology, geriatrics, respiratory, neurology and oncology
- ▼ **Educational content** tailored for older Americans whose treatment includes biologics
- ▼ **Advocacy and education** on the role of pharmacy benefit managers in biologics access
- ▼ **Continued engagement with clinicians and advocates** to educate patients and policymakers about the landscape for biologics
- ▼ **The National Policy and Advocacy Summit on Biologics**, which convened clinicians and patient advocates to discuss the biologics landscape, treatment access issues and advocacy successes

POLICY SUMMIT

- » National Policy and Advocacy Summit

VIDEOS

- » Innovator Biologics vs. Biosimilars vs. Interchangeables

PAPERS

- » Fast Facts: Policies to Support Older Americans
- » Biologics & Biosimilars in Rheumatology
- » National Policy and Advocacy Summit Report

ONE-PAGERS

- » Biologics & Asthma
- » Biologics, Biosimilars & Interchangeables
- » Biologics, Biosimilars & Neurological Disorders

INFOGRAPHICS

- » Biologics in Cancer Care

BLOG POSTS

- » National Policy & Advocacy Summit on Biologics





CARDIOVASCULAR DISEASE

Cardiovascular disease remains a major public health concern, but advocates are working to usher in patient-centered policies.

This year, AfPA's Cardiovascular Disease Working Group and the Partnership to Advance Cardiovascular Health heightened awareness about disease prevention, highlighted barriers limiting patients' access to critical treatments and took a closer look at treatment access.

Efforts included:

- ▶ **Successfully advocating** to a national pharmacy benefit manager to restore coverage for a cardiovascular medication
- ▶ **Undertaking a national claims data project** to identify trends in cardiovascular health care disparities
- ▶ **Raising awareness** about the need for screening and early treatment of peripheral artery disease, a serious cardiovascular disease affecting 12 million Americans
- ▶ **Producing educational content** to raise awareness about cardiovascular disease prevention, harmful utilization management practices and the need for treatment options
- ▶ **Hosting the fifth annual Cardiovascular Health Policy Summit**, which brought together patients, advocates and clinicians to examine policy needs and advocacy opportunities



POLICY SUMMIT

- » Cardiovascular Health Policy Summit

VIDEOS

- » LP(a) 101
- » Peripheral Artery Disease 101
- » Ann's Story: A Journey Through Peripheral Artery Disease
- » Rejected: Patients Denied Access to Life-Saving Heart Medicine

PAPERS

- » Addressing Unmet Needs in Peripheral Artery Disease
- » Rejected: How Life-Saving Heart Medication Eludes Women, Southerners & People of Color
- » Cardiovascular Health Policy Summit Report

ONE-PAGERS

- » Navigating Open Enrollment

INFOGRAPHICS

- » Addressing Unmet Needs in Peripheral Artery Disease
- » Rejected: How Life-Saving Heart Medication Eludes Women, Southerners & People of Color
- » Preventing Secondary Heart Attacks
- » Summertime and Cardiovascular Health
- » Don't Leave Atrial Fibrillation Unaddressed
- » Staying Heart Healthy During the Holidays

BLOG POSTS

- » The Cardiovascular Health Policy Summit in Five Quotes



DISPARITIES IN HEALTH CARE

Health disparities can worsen outcomes for underserved populations.

As societal awareness of health disparities continued to grow, AfPA and IfPA prioritized discussions of access for underserved communities.

Efforts included:

- ▼ **Taking an in-depth look at national claims data** to explore treatment and coverage disparities for specific disease states — and their downstream health effects on communities of color
- ▼ **Exploring disparities in treatment access** among heart patients of color and those living in the American South
- ▼ **Highlighting disparate levels of maternal care** and the maternal mortality rate
- ▼ **Examining how diseases such as gout impact certain communities more severely** — and what providers and policymakers can do to ensure proper care
- ▼ **Prioritizing action** to address health disparities through policy reform

VIDEOS

- » Rejected: Patients Denied Access to Life-Saving Heart Medicine

PAPERS

- » Health Disparities & Medication Access
- » Rejected: How Life-Saving Heart Medication Eludes Women, Southerners & People of Color

ONE-PAGERS

- » Disparities in Gout Risk & Treatment

BLOG POSTS

- » Addressing Unmet Needs in Peripheral Artery Disease
- » Narrowing the Gout Information Gap
- » Employer-Sponsored Health Insurance Leaves Some Wanting
- » Enhanced Pregnancy-Related Death Data Elucidates Opportunities for Intervention





GENERICS ACCESS

Generic medications offer patients effective, affordable treatment options.

This year, AfPA launched the Generics Access Project, which advocates for policies that promote generic competition and efficient approval of generic medications.

The project's inaugural year was dedicated to:

- ▶ **Educating patients** on how to engage with the FDA
- ▶ **Encouraging the FDA** to prioritize its review of applications for the first and second generic of a given medication
- ▶ **Convening stakeholder groups** across disease states to advocate for generics access
- ▶ **Highlighting the value of timely FDA review**, including reviews for complex generic drugs
- ▶ **Successfully advocating for the reauthorization of the Generic Drug User Fee Act and the Prescription Drug User Fee Act**, both of which the FDA revisits every five years

LETTERS

- » Welcoming Acting Director of the FDA Office of Generic Drugs
- » Commending Senate and House Leadership on FDA User Fee Agreement and Passage
- » Commenting on Evaluation of Therapeutic Equivalence; Draft Guidance
- » Prioritizing the Timely Passage of FDA User Fee Amendments

INFOGRAPHICS

- » Expanding Access to Generic Drugs

BLOG POSTS

- » Congress Ensures New Drug Review Program Remains Funded
- » New Coalition Aims To Increase Access To Generic Drugs



GOUT

Gout is painful and debilitating — but also treatable.

This year, the Alliance for Gout Awareness continued its work to eliminate stigma, raise awareness, and equip patients to find the community and treatment they need.

Education and programming included:

- ▼ **A national survey** that explored the physical and emotional challenges that patients face
- ▼ **Educational materials** that highlight comorbidities associated with gout as well as their impact on disease management
- ▼ **A closer look at disease disparities**, particularly those experienced by Black and Asian Pacific Islander patients
- ▼ **Patient interviews**, which allowed people living with gout to relay their experiences with the condition, empowering others in the process
- ▼ **Gout Awareness Day**, a national awareness effort that leveraged social media to heighten disease awareness and drive patients to take action
- ▼ **A compilation of community resources** to help gout patients manage their disease

VIDEOS

- » Gout & Uric Acid

PAPERS

- » In their Own Voices: Lived Experiences of Gout Patients
- » The Journey Toward Disease Management: A National Survey of Gout Patients
- » Fast Facts: Gout

ONE-PAGERS

- » Patient to Patient: Marty Dickinson
- » Patient to Patient: Dave Arntsen
- » Gout and Hispanic Communities
- » Treating Gout: A Podiatrist's Perspective

MEMBER RESOURCES

- » Resources for Gout Patients

INFOGRAPHICS

- » Step Therapy and Gout

BLOG POSTS

- » Rising Gout & Kidney Disease Rates Underscore Treatment Issues
- » What Men Should Know About Gout



HEADACHE & MIGRAINE

For patients experiencing migraine attacks, it is important to find the right treatment regimen.

This year, The Headache & Migraine Policy Forum and AfPA's Headache & Migraine Disease Working Group worked together to heighten awareness about headache disorders in underserved communities and to reduce patients' barriers to treatment.

Efforts included:

- ▶ **Highlighting utilization management** practices as sources of treatment delay and potential disease progression
- ▶ **Advocating for access** to attack-based treatment plans, so that patients can better manage their disease
- ▶ **Urging the Women's Preventive Services Initiative** to add headache to the list of diseases that are screened for during routine OB/GYN visits
- ▶ **Highlighting the role of medical devices** in patient-centered migraine care
- ▶ **Co-hosting a Capitol Hill policy summit** to bring attention to headache and migraine disparities in American Indian and Alaskan Native populations
- ▶ **Highlighting the barriers to therapeutics** and health disparities that impede patient care in the headache and migraine community

VIDEOS

- » Infused Migraine Medication 101
- » Attack-Based Care

PAPERS

- » Ensuring Equitable Access to Migraine Treatment
- » Fast Facts: Infused Medication

ONE-PAGERS

- » Attack-Based Treatment

INFOGRAPHICS

- » How Inadequate Treatment Leads to Chronic Migraine
- » Combination Therapy Works for Migraine Patients
- » The Burden of Migraine Disease

SURVEYS

- » Survey Report: Migraine in the ER & Urgent Care
- » Survey Report: Combination Therapy for Migraine

BLOG POSTS

- » Telehealth Can't Replace In-Person Care for Migraine Disease
- » Infused Medication Offers Migraine Patients a New Option
- » An Opportunity to Expand Veterans' Access to Migraine Medication
- » Veterans Exposed to Toxic Burn Pits Now Eligible for Benefits
- » Advocates Call for Adding Migraine Screening to Well-Woman Visit
- » Open Enrollment Features Limited Options for Migraine Patients





HEPATITIS & INFECTIOUS DISEASES

With the right combination of resources and resolve, America can eliminate hepatitis C as a serious public health threat.

This year, AfPA's Hepatitis Therapy Access Physicians Working Group highlighted the need for improved hepatitis screening and state-level efforts to reduce hepatitis C infections.

The working group raised awareness about policy reforms at the state level that could facilitate screenings and treatments for hepatitis.

Efforts included:

- ▼ **Educational resources** outlining how state hepatitis elimination plans can reduce disease prevalence and benefit public health
- ▼ **Social media engagement** aimed at raising awareness about hepatitis and the importance of proactive screening
- ▼ A closer look into **disparities in hepatitis prevalence and treatment**, particularly among incarcerated populations



**Hepatitis Therapy
Access Physicians
Working Group**

PAPERS

- » Fast Facts: Eliminating Hepatitis C in America

INFOGRAPHICS

- » The ABCs of Hepatitis

BLOG POSTS

- » Hepatitis C Elimination Within Reach, If Not for Senseless Barriers
- » Making Hepatitis C History
- » Committing to Address Hepatitis C Among the Incarcerated



INFANT HEALTH

As one of the most vulnerable populations, infants can face serious health challenges.

In 2022, the National Coalition for Infant Health advocated on behalf of infants and their families to improve awareness, remove access barriers and empower families to advocate for optimal care.

Advocacy and education efforts included:

- ▶ **Raising awareness** about the burden that respiratory syncytial virus, or RSV, poses for infants and young children by launching a national, multi-prong awareness campaign
- ▶ **Advocating for the inclusion of monoclonal antibodies** to treat RSV in the Vaccines for Children program
- ▶ **Highlighting the dangers of rare blood disorders** that some expectant mothers and their infants may face
- ▶ **Exploring the need for high standards** and improved regulation of donor human milk

The coalition's advocacy efforts culminated in the eighth annual Infant Health Policy Summit, which brought health care providers, parents, advocates and policymakers together in person and virtually. Summit participants discussed the Black maternal health crisis, health disparities, the burden of RSV, and the need for safe and accessible donor human milk.

VIDEOS

- » Human Donor Milk Safety
- » The Troublemaker
- » What is RSV?
- » Melanie's RSV Story

PAPERS

- » Monoclonal Antibodies: Inclusion in the Vaccines for Children Program
- » The Burden of RSV: Impacting All Families

INFOGRAPHICS

- » Fetal & Neonatal Alloimmune Thrombocytopenia
- » Hemolytic Disease of the Fetus & Newborn
- » DeEtta's RSV Story

BLOG POSTS

- » Knocking Down Pneumococcal Disease
- » Alleviating the Burden of RSV for Infants and Children
- » When a Small Cry is Worth It
- » Statement on the Formula Shortage Crisis
- » It Was Worse Than Open-Heart Surgery
- » Respiratory Syncytial Virus Takes a Toll on Families
- » Enhanced Pregnancy-Related Death Data Elucidates Opportunities for Intervention
- » We Should Protect Every Baby from RSV
- » Early Beginnings, Big Challenges: Breastfeeding in the NICU



INNOVATION & VALUE

Scientific breakthroughs and emerging technologies offer hope to millions of patients. But access is often complicated by value assessments.

In 2022, the Alliance for Patient Access celebrated treatment breakthroughs while also equipping patients and providers to raise their voices in policy conversations about value and access.

- From educational resources to informational webinars, the Alliance for Patient Access and Institute for Patient Access partnered to **empower clinicians and patients to share their perspectives during value assessments** by the Institute for Clinical and Economic Review.
- As ICER's vision of value trickled down to state-level policy, **AfPA's state chapters educated local patient advocates and policymakers** about ICER's quality-adjusted life year metric and best practices for engaging with state utilization review boards.
- IfPA hosted a national policy forum in Washington, DC**, to explore treatment breakthroughs, innovations in public health and ongoing federal policy initiatives.
- New educational resources explored treatment technologies** such as prescription digital therapeutics—software-based applications that fuel better outcomes for patients—and headache devices that offer a complement or alternative to pharmacologic treatments.

VIDEOS

- » What to Expect From Asthma Care
- » Innovation: A Mother's Story

PAPERS

- » Treatment Options & Access for EBV+ PTLD
- » Fast Facts: Prescription Digital Therapeutics
- » Fast Facts: Accelerated Approval

ONE-PAGERS

- » Who Decides? Defining the Value of Medication

BLOG POSTS

- » Volume, Not Competition, Drives Down Drug Prices
- » Open to New Options for Treating Depression
- » Federal Approvals Open Doors to New Treatments
- » Game-Changing Medication Brightens Outlook for Vision Patients
- » Infused Medication Offers Migraine Patients a New Option
- » Innovation Puts Patients Back in Charge
- » Prescription Digital Therapeutics Blend Technology with Patient-Centered Care
- » Landmark Discovery Could Help Patients Cut Excess Weight
- » Innovation Brings Rare Disease Patients Tears of Joy
- » Preventing Alzheimer's Disease by 2025



MENTAL HEALTH

As the mental health crisis in America continued to grow, AfPA's Mental Health Working Group strove this year to identify ways that clinicians and support networks can meet patients where they are.

Efforts included:

- ▶ **Spotlighting the dangers and complications** that non-medical switching can cause mental health patients
- ▶ **Exploring the value of telemedicine** and a balanced approach to care for mental health patients
- ▶ **Successfully advocating** to a state Medicaid plan for step therapy reform
- ▶ **Pursuing policy reform** at the state level to improve access to hard-to-reach medications
- ▶ **Convening the working group for the first time in person**, welcoming a broad range of providers, from psychiatrists and child psychologists to emergency room and primary care physicians
- ▶ **Engaging policymakers** at the state level to ensure an effective 988 national suicide hotline

PAPERS

- » The Dangers of Non-Medical Switching for Mental Health Patients
- » Mental Health Care & Non-Medical Switching

INFOGRAPHICS

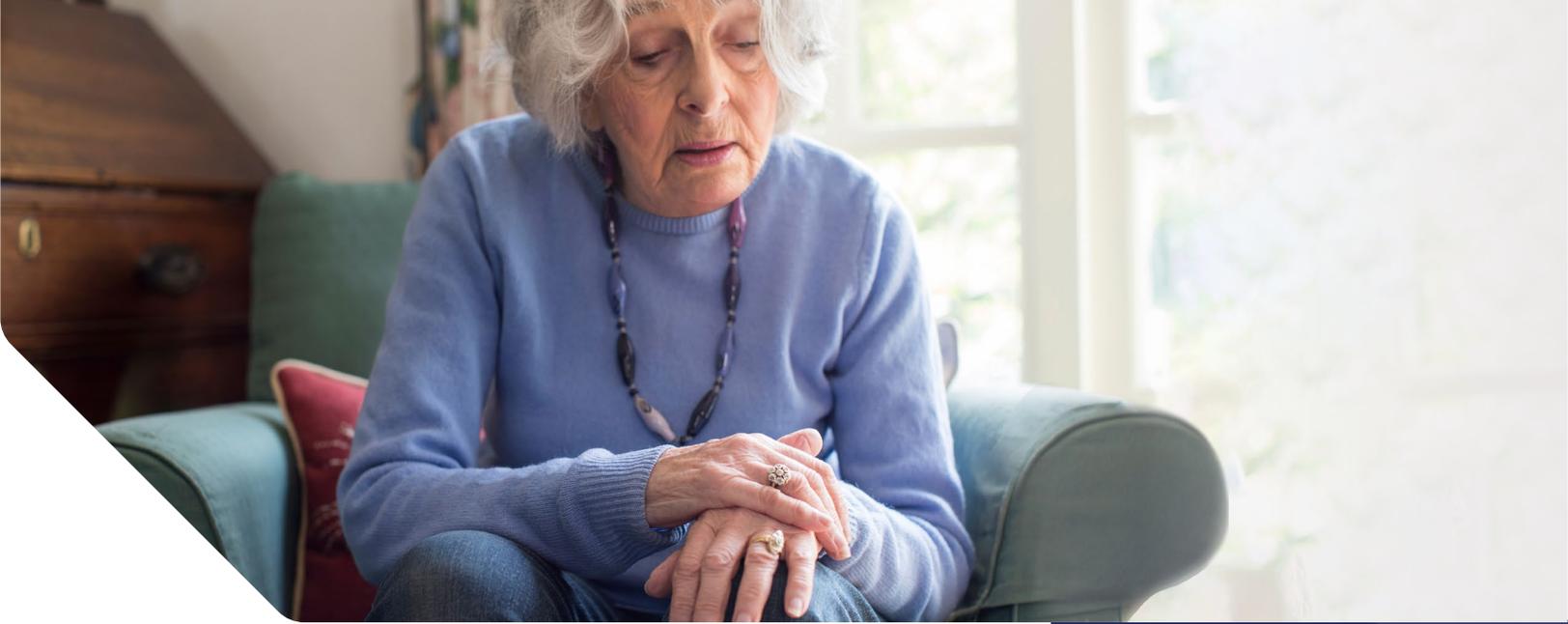
- » How Telemedicine Can Help Mental Health Patients
- » Barriers to Mental Health Care
- » Mental Health Parity

BLOG POSTS

- » A Multi-Pronged Approach to Tackling Mental Illness
- » The Most Pernicious Obstacle to Care: Stigma
- » Open to New Options for Treating Depression
- » House Acts to Extend Eased Telehealth Rules
- » Non-Medical Switching Pushes Patients to the Brink
- » Patients Pay the Price When Insurers Switch Mental Health Medications



Mental Health
Working Group



NEUROLOGICAL DISEASES

As research and medical innovations continue, more can and should be done to improve diagnosis, treatment access and care.

In 2022, AfPA's Neurological Diseases Working Group strove alongside the Movement Disorders Policy Coalition to improve policies for people living with neurological conditions, including Alzheimer's, dementia and movement disorders.

Advocacy and education efforts prioritized:

- ▼ **Patient access to innovative treatments** for a range of conditions including movement disorders and neurodegenerative conditions
- ▼ **Care for patients with Alzheimer's and dementia**, including addressing caregiver burden, behavioral treatments and access in long-term care facilities
- ▼ **Coverage for innovative Alzheimer's-modifying medications**, as well as diagnostic tests, such as PET scans
- ▼ **Increased awareness** about movement disorders like tardive dyskinesia

As the Institute for Clinical and Economic Review undertakes a formal value assessment of Alzheimer's medications, AfPA's Neurological Diseases Working Group continues to educate and equip patient advocates to participate in the review process.



Neurological Disease
Working Group



MOVEMENT
DISORDERS
POLICY COALITION

VIDEOS

- » Impact of Alzheimer's

PAPERS

- » Fast Facts: FDA's Accelerated Approval Pathway

ONE-PAGERS

- » Comprehensive Treatment for Essential Tremor
- » Treatment for Patients with Parkinson's Disease
- » Navigating Open Enrollment

TOOLKITS

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

INFOGRAPHICS

- » Non-Medical Switching and Movement Disorders
- » Patient-Centered Care for Parkinson's Disease
- » Movement Disorders Patients' Journey Through Step Therapy

BLOG POSTS

- » Veterans Battling Amyloidosis Deserve Better
- » Accelerated Approval Prioritizes Patients' Access to Promising Treatments
- » Medicare Revisits PET Scan Restrictions for Alzheimer's Patients
- » Innovation Puts Patients Back in Charge
- » Will Congress Commit to Investing in Brain Disease?



OBESITY

Patients need access to the full range of treatment options.

A known driver of both cardiovascular disease and Type 2 diabetes, obesity remains a serious disease and public health concern. Medication coverage, however, remains elusive.

This year, the Alliance for Patient Access's Obesity Initiative worked alongside the Partnership to Advance Cardiovascular Health to advocate for policy reforms that would improve access to obesity treatment.

Efforts included:

- ▼ **Urging Congress to pass the Treat and Reduce Obesity Act of 2021**, which would enhance care for Americans living with obesity
- ▼ **Encouraging employers and HR professionals** to pursue health plan options and wellness programs to empower and incentivize employees battling with obesity
- ▼ **Creating educational materials to highlight the prevalence of obesity**, the value of accessible treatment options and the need for a team-based care model
- ▼ **Unifying more than 400 clinicians** in support of federal treatment access

VIDEOS

- » Dismantling Access Barriers to Obesity Treatments

ONE-PAGERS

- » Selecting Insurance Plans for Your Organization

INFOGRAPHICS

- » Lightening America's Obesity Burden
- » Prioritizing Employees' Health

BLOG POSTS

- » ICER Makes It More Difficult to Obtain Obesity Management Drugs
- » Why Don't Insurers Take Obesity Seriously?
- » Doctors to Congress: Help Obesity Patients





ONCOLOGY

When every second counts, cancer patients deserve the very best.

This year, innovative technologies and treatments continued improving cancer patients' prospects for a longer life. AfPA's Oncology Therapy Access Working Group provided ongoing education and advocacy to elevate the importance of a personalized approach to cancer treatment.

Education and advocacy included:

- ▼ **Partnering with providers to highlight the role of biomarker testing** in providing targeted, patient-centered cancer care
- ▼ **Educating patients, providers and policymakers** on the value of a personalized treatment plan
- ▼ **Working at the state level** to improve cancer patients' access to testing and treatment
- ▼ **Advocating for reforms** that limit out-of-pocket costs and non-medical switching
- ▼ **Partnering with advocates** to pass an out-of-pocket cap and smoothing measure for Medicare Part D patients



VIDEOS

- » Biomarker Testing Helps Cancer Patients

PAPERS

- » Biomarker Testing: Allowing Individualized Treatment for Cancer Patients

INFOGRAPHICS

- » Utilization Management in Oncology
- » Biologics in Cancer Care

BLOG POSTS

- » Study: Cancer Patients' Out-of-Pocket Costs Climb Toward Crisis
- » Accelerated Approval Prioritizes Patients' Access to Promising Treatments
- » Cancer Patients Want More Information on Rx Switches

RARE DISEASE

A patient's disease may be rare, but that doesn't mean treatment access must be.

This year, AfPA's Rare Diseases Working Group expanded its advocacy and education efforts to encompass still more rare diseases – and the needs of patients who live with them. Meanwhile, the Cystic Fibrosis Engagement Network continued its work to bring advocates together as a unified force for patient empowerment and treatment access.

Activities and outreach included:

- ▶ **Advocating to establish rare disease advisory councils** across the country so that patients and providers have a voice in policymaking
- ▶ **Highlighting the value of new and forthcoming treatments**, as well as informing policymakers about the need to eliminate access barriers for such treatments
- ▶ **Creating educational resources** on the harm patients experience because of prior authorization, reauthorization and other utilization management tactics
- ▶ **Protecting the FDA's accelerated approval pathway**, which expedites medication access for patients with serious diseases and limited treatment options

AfPA's Rare Diseases Working Group focused on the needs of patients across several disease states, which included:

- ▶ **Supporting amyloidosis patients** and ensuring veterans with amyloidosis have access to treatment
- ▶ **Examining innovative treatment options for EBV+ PTLD**, in addition to the access barriers and challenges that many patients face
- ▶ **Exploring the patient experience for people with IgG4-RD** and highlighting unmet needs and the importance of new treatments
- ▶ **Identifying the unmet needs of patients with PHI** and crafting policies to improve conditions for patients

The Cystic Fibrosis Engagement Network also worked to raise awareness of how state-level drug utilization review boards can impact patients' access to life-saving treatment.



VIDEOS

- ▶ Innovation: A Mother's Story
- ▶ Rare Disease Advisory Councils Give Patients A Voice

PAPERS

- ▶ Treatment Options & Access for EBV+ PTLD
- ▶ Addressing Unmet Needs in the PHI Patient Population
- ▶ In Their Own Voices: The Lived Experiences of IgG4-RD Patients [Report Update]
- ▶ Fast Facts: Accelerated Approval

INFOGRAPHICS

- ▶ Accessing Treatment for Amyloidosis
- ▶ The Danger of Prior Authorization for Rare Cancer Patients
- ▶ When Drug Utilization Review Boards Hurt Cystic Fibrosis Patients

BLOG POSTS

- ▶ Raising the Profile of Rare Diseases
- ▶ Innovation Brings Rare Disease Patients Tears of Joy
- ▶ Cystic Fibrosis Patients' Annual Fight for Access to Treatment
- ▶ Rare but Not Alone: 1 in 10 Live with a Rare Disease
- ▶ Unlocking Codes for Rare Disease Patients
- ▶ Veterans Battling Amyloidosis Deserve Better





RESPIRATORY

Innovative treatment options create new opportunities for tailored care.

Ensuring patients can understand and access their treatment remains a priority for AfPA's Respiratory Therapy Access Working Group.

This year, the working group advocated for patient-centered care amid policies and utilization management tactics that undermine treatment access.

Efforts included:

- ▼ **A successful advocacy campaign** that protected treatment access for asthma patients by reversing a problematic Medicare Administrative Contractor decision
- ▼ **New educational materials encouraging patients** to expect more from asthma care and highlighting innovative treatment options for patients with severe respiratory conditions
- ▼ **Awareness efforts** on why early diagnosis for young children with asthma is critical to reduce the lifelong burden of the condition
- ▼ **Collaboration with the National Coalition for Infant Health** on a range of educational materials highlighting the burden of respiratory syncytial virus, or RSV



**Respiratory
Therapy Access**
Working Group

VIDEOS

- » The Troublemaker
- » What to Expect from Asthma Care

PAPERS

- » Advocacy Win for Asthma Patients: Protecting Access to Clinician-Administered Biologics

INFOGRAPHICS

- » Step Therapy Stifles Asthma Patients

BLOG POSTS

- » An Unhappy New Year for Asthma Patients
- » Respiratory Syncytial Virus Takes a Toll on Families
- » Asthma Patients Could be Forced into Unsafe Situation
- » Advocates Earn Asthma Patients Safe Access to Injectable Medication



SKIN CONDITIONS

Skin diseases affect as many as one in three Americans at any given time.

This year the Derma Care Access Network strove to educate patients, providers and advocates about barriers to care – and to support their voices in pushing for reform.

Education and advocacy efforts included:

- ▶ **Launching The Resource Hub**, a program to help patients and providers better understand individual disease states and to help patients access prescription assistance
- ▶ **Participating in state and federal legislative efforts** to reform pharmacy benefit manager practices that create barriers to patient access
- ▶ **Creating new education materials** to empower patients to navigate open enrollment or file complaints with their state insurance commissioner after prescription denial
- ▶ **Supporting telehealth legislation** as a balanced approach to dermatological care and emphasizing the importance of policies that protect the physician-patient relationship

ONE-PAGERS

- » Guide to Filing An Insurance Complaint for Skin Condition Patients & Providers
- » Navigating Open Enrollment

BLOG POSTS

- » Protecting Patients' Skin and Skin Patients This Winter
- » A Vicious Circle Connects Eczema And Mental Illness



TELEHEALTH

Even as society emerges from the pandemic, continued access to telehealth remains a priority for many patients, providers and advocates.

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

Efforts included:

- ▼ **Monitoring legislative efforts** to protect patients' access to telehealth services and highlighting those decisions for patients and advocates
- ▼ **Interviewing patients** across a variety of disease states and geographical locations and sharing their telehealth experiences through educational resources
- ▼ **Developing educational resources** that highlight the value of telehealth for Americans regardless of where they live, the type of regular medical care they need or their socio-economic status
- ▼ **Convening stakeholder members** around telehealth provisions within the Medicare Physician Fee Schedule



VIDEOS

- » Telehealth: The Balanced Approach

ONE-PAGERS

- » How to Use Telehealth: A Patient's Guide
- » My Telehealth: Q&A with Shannon Dingle
- » My Telehealth: Q&A with Donna Matlach
- » My Telehealth: Q&A with Emily Kramer-Golinkoff

INFOGRAPHICS

- » Telemedicine & Rural America
- » How Telehealth Can Help Mental Health Patients
- » The Value of Telemedicine in Overcoming Economic Barriers
- » The Many Uses of Telemedicine

BLOG POSTS

- » House Acts to Extend Eased Telehealth Rules
- » Telehealth Can't Replace In-Person Care for Migraine Disease
- » Breathing a Virtual Sign of Relief
- » Congressional Momentum Builds for Telehealth Expansion



UROLOGY

Certain policy challenges stand in the way of personalizing urological care.

In its first year, the Alliance for Patient Access's Urology Initiative brought together clinicians to advance patient-centered care for people living with a variety of urological conditions.

Inaugural education and advocacy activities included:

- ▼ **Convening urology clinicians** to explore current challenges as well as promising innovations in the field
- ▼ **Developing a clinician-authored policy paper** that examines the growing toll of overactive bladder and the challenges posed by one-size-fits-all treatment approaches
- ▼ **Raising awareness about the growing shortage of health care providers** in the field of urology and the dangers this trend poses to patients
- ▼ **Creating educational materials** to highlight the impact that utilization management practices have on patient care

VIDEOS

- » Overactive Bladder & Patient-Centered Care

PAPERS

- » The Need for Patient-Centered Care in American Urology

INFOGRAPHICS

- » The U.S. Faces a Shortage of Urology Care Workers
- » Step Therapy & Overactive Bladder

BLOG POSTS

- » How Coverage Barriers & Bureaucracy Hurt Urology Patients
- » Overcoming Overactive Bladder Safely



AfPA's
Urology
Initiative



VISION HEALTH

To treat a condition effectively, providers and patients must know what they're up against.

This year, the Vision Health Advocacy Coalition provided patients and providers educational resources and tools that empowered them to advocate for access to optimal treatment.

Efforts included:

- ▼ **Developing a comprehensive toolkit** to support patients and providers as they face arduous prior authorization processes
- ▼ **Highlighting the role of genetic testing** in delivering individualized vision care
- ▼ **Supporting patients with rare vision conditions** through education and patient empowerment resources
- ▼ **Taking a closer look** at the connection between autoimmune diseases and vision conditions
- ▼ **Offering a series of events** and education opportunities to deepen patients' understanding of sight conditions, vision loss and patient access



VISION HEALTH
ADVOCACY COALITION

ONE-PAGERS

- » How to Navigate the Prior Authorization Process
- » The Harm of Prior Authorization
- » How Prior Authorization Can Impact Vision Health
- » Genetic Testing and Retinal Conditions 101

TOOLKITS

- » Prior Authorization & Vision Health

INFOGRAPHICS

- » Vision Health for Autoimmune Patients

BLOG POSTS

- » Game-Changing Medication Brightens Outlook for Vision Patients
- » More States Adopt Step Therapy Limitations While Federal Protections Remain Elusive



MOVING FORWARD

A new year presents new opportunities for the Alliance for Patient Access to pursue several core objectives:



Using data advocacy to spur policy change.

From insurance claims to opinion polls, data gives credence to patient and provider experiences — and helps drive policy solutions.



Navigating the shifting biologics landscape.

With a growing number of biosimilars, including interchangeable biosimilars, the evolving biologics marketplace stands to significantly change patients' and providers' treatment experiences.



Reducing health disparities.

Inequality permeates the health care system. Reducing those inequalities begins with identifying trends, defining outcomes and pinpointing affected populations.



Exploring how price and cost influence patients' access to treatment.

The policies and practices that shape drug pricing and coverage influence patients' treatment, finances and health outcomes now more than ever.



Expanding opportunities for continuing education.

Now recognized by the Accreditation Council for Continuing Medical Education, IfPA is poised to foster ongoing learning in 2023.



STAY CONNECTED IN 2023!



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