



# Years of Advocacy



Alliance for  
Patient Access



Institute for  
Patient Access



**Alliance for Patient Access**



**Institute for Patient Access**

**WORKING GROUPS & INITIATIVES**



**National Physicians Biologics Working Group**



**Hepatitis Therapy Access Physicians Working Group**



**Diabetes Therapy Access Working Group**



**Respiratory Therapy Access Working Group**



**Neurological Disease Working Group**



**Oncology Therapy Access Working Group**



**Pain Management Working Group**



**Headache & Migraine Disease Working Group**



**Rare Diseases Working Group**



**Cardiovascular Disease Working Group**



**Mental Health Working Group**



**AfPA's Urology Initiative**

**STAKEHOLDER COALITIONS**



**Coalition for Clinical Trials Awareness**



**NATIONAL COUNCIL OF PHYSICIAN LEGISLATORS**



**ALLIANCE FOR Balanced Pain Management**



**Patient Access Collaborative**



**ALLIANCE FOR Gout Awareness**



**MOVEMENT DISORDERS POLICY COALITION**



**bpc Biologics Prescribers COLLABORATIVE**



**Partnership to Protect Patient Health**



**Diabetes Policy Collaborative**



**VISION HEALTH ADVOCACY COALITION**



**CFEN Cystic Fibrosis Engagement Network**



**AfPA Survey Hub**

**AFFILIATES**



**NCFIH National Coalition for Infant Health**  
Protecting Access for Premature Infants through Age Two



**DCAN**  
DERMA CARE ACCESS NETWORK



**The Headache & Migraine POLICY FORUM**



**KEEP MY Rx**



**PARTNERSHIP TO ADVANCE Cardiovascular Health**

## DEAR FRIENDS & SUPPORTERS:

Fifteen years ago, the Alliance for Patient Access came together with a bold vision. By shaping health policy, clinicians could improve care not only for their own patients, but for all patients.

First training sessions, and then formal working groups brought together providers from different states and different specialty areas. They shared challenges, offered best practices and, most of all, advocated for better policy for their patients. Over the years, AfPA's work grew to also empower other advocates, including patients, through its stakeholder coalitions.

This year, **we celebrated** what clinician advocacy has become. And we marveled to think how much more it can still accomplish.

The vision of patient-centered care continues to drive advocacy and education, empower AfPA members, and inspire fellow advocates. In this year's annual report, you'll find several examples.

- **A closer look at health disparities** and how they impact patient care, including new educational materials on social determinants of health and disproportionate disease impact.
- **A multifaceted exploration of medical innovation**, from the advent of interchangeable biosimilars to infant-specific medical devices to next-generation diagnostics for rare diseases and cancer.
- **A deep dive on non-medical switching** and cardiovascular disease, with a multimedia collection of video, graphics, national polling and blog posts to illustrate why insurers are mistaken to think the tactic is "No Big Deal."
- **New initiatives spotlighting mental health and obesity**, issues that have posed mounting challenges amid the COVID-19 pandemic.
- A coalition that elevates the voices of **Patient & Provider Advocates for Telehealth** on how policies can sustain access — and how to balance virtual care with in-person visits.

This year, we celebrated what clinician advocacy has become. And we marveled to think how much more it can still accomplish.

COVID-19's challenges have not receded as quickly as we all had hoped. But we are grateful to have enjoyed the collaboration and support of resilient, committed partners this year.

In trying years like this one, we are reminded of just why advocacy is essential. We're thankful to have a role in it — in 2021, in the 15 years that came before and in the many years that lie ahead.

With high hopes for a healthy 2022,



**DAVID CHARLES, MD**  
Founder



**JOSIE COOPER**  
Executive Director

## 2021 BY THE NUMBERS

50



States Represented  
by AfPA

26.8  MILLION

Social Media Impressions

12



Working Groups  
& Initiatives

141,497

Social Media Followers



41

Events & Webinars

15

Years of Advocacy

28 

YouTube Videos

185

Infographics



891,460

YouTube Views



49

Papers

145



Blog Posts

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# BIOLOGICS

“We now enjoy a golden age of medical innovation.”

David Charles, MD



## POLICY SUMMIT

- ▶ National Policy & Advocacy Summit on Biologics

## PAPERS

- ▶ Biosimilars: Expanding Options for Cancer Care
- ▶ Prescribers Perspectives: Policies Impacting Patient Access

## ONE-PAGERS

- ▶ Biologics, Biosimilars & Endocrinology
- ▶ Biologics, Biosimilars & Oncology
- ▶ Biologics, Biosimilars & Rheumatic Disease
- ▶ Biologics, Biosimilars & Gastroenterology

## BLOG POSTS

- ▶ “Most Favored Nation” Doesn’t Favor Patients
- ▶ Embracing Biosimilars
- ▶ Commonsense State Rules Ease Access to Biosimilars

The first interchangeable biosimilars launched a new chapter in the unfolding story of biologic medicine this year.

Their introduction extended ongoing dialogue about the value of innovative medicine, the importance of expanding treatment options and the need for patient-centered care. AfPA’s National Physicians Biologics Working Group, alongside the Biologics Prescribers Collaborative, convened programs and created educational content to keep the voices of health care providers front and center in the conversation. Examples include:

- **A webinar and Biologics Prescribers Collaborative report**, which offered providers’ perspective on how health technology assessments, prescribing incentives and policies such as Most Favored Nation would impact the accessibility of biologics
- **The sixth annual National Policy & Advocacy Summit on Biologics**, which explored biologics’ role in treating rare diseases, health disparities, and how access to diagnostics can empower providers and patients to achieve better health outcomes
- **A series of educational materials** outlining how biologics and biosimilars are shaping oncology, endocrinology, rheumatology and gastroenterology
- **Ongoing advocacy** and education on access, innovation and the policies that will impact these issues moving forward.



# CARDIOVASCULAR & DIABETES



“Non-medical switching is a big deal – especially for heart patients.”

Seth Baum, MD

## POLICY SUMMIT

- ▶ 2021 Cardiovascular Health Policy Summit

## VIDEOS

- ▶ Heart Failure 101
- ▶ Non-Medical Switching: No Big Deal?
- ▶ Pat's Story
- ▶ Social Determinants of Cardiovascular Health

## PAPERS

- ▶ Non-Medical Switching & Cardiovascular Health
- ▶ Improving Secondary Prevention for Cardiovascular Patients
- ▶ The Intersection
- ▶ Cardiovascular Health Policy Priorities for a New Year

## ONE-PAGERS

- ▶ The Dangers of “Bad Drug” Ads
- ▶ Let's Talk About “Bad Drug” Ads
- ▶ 5 Principles of Good Insurance Coverage for Heart Patients

## INFOGRAPHICS

- ▶ 6 Unmet Needs of Cardiovascular Patients
- ▶ Why Employers Should Prioritize Cardiovascular Care
- ▶ What's the Big Deal about Cardiovascular Disease?

This year the Partnership to Advance Cardiovascular Health unveiled a multimedia campaign to highlight the dangers of non-medical switching, while AfPA's Cardiovascular Disease Working Group elevated issues of unmet needs and social determinants of health.

The Diabetes Policy Collaborative and AfPA's Diabetes Therapy Access Working Group came alongside them to explore the interconnected challenges of heart disease, Type 2 diabetes and growing rates of obesity in the United States.

Other efforts included:

- **The fourth annual Cardiovascular Health Policy Summit**, hosted virtually for a broad audience of advocates, patients and other stakeholders
- **Educational outreach** on heart failure and secondary prevention for cardiovascular patients
- **Interviews with health care providers about the dangers that “Bad Drug” ads pose for patients** who take prescription medications for diabetes or heart conditions
- **Educational content** on how health plans and employers can prioritize heart health
- **A webinar series** aimed at empowering patients to take control of their heart health.



# CYSTIC FIBROSIS

“During the pandemic, people with cystic fibrosis weren’t just fighting their disease.”



## INFOGRAPHICS

- ▶ Prior Authorization
- ▶ Co-Pay Accumulator Adjustment Programs
- ▶ Non-Medical Switching
- ▶ Step Therapy

## BLOG POSTS

- ▶ Pandemic Rocked Cystic Fibrosis Patients' Economic Stability
- ▶ Proposed Programs Could Speed Up Drug Approval for Rare Diseases
- ▶ Economic Impact of Rare Diseases Tops \$960 Billion

## As the COVID-19 pandemic dragged on, people living with cystic fibrosis faced mounting challenges.

Alongside heightened medical vulnerabilities, people with cystic fibrosis continued to battle insurance barriers. While some insurers suspended red tape for pandemic measures such as COVID testing and treatment, utilization management stayed steady for other areas of care, including treatments for people living with cystic fibrosis.

In response, the Cystic Fibrosis Engagement Network:

- **Created a new series of educational materials** aimed at raising awareness about insurance barriers frequently experienced by cystic fibrosis patients. Topics included: prior authorization, co-pay accumulator programs, non-medical switching and step therapy
- **Convened cystic fibrosis patient advocacy groups** to share best practices, gather insights and brainstorm how to best support patients living with the disease
- **Used digital media to inform and educate** on the access issues facing people living with cystic fibrosis.

# GOUT



“It could be one of the most important conversations you’ll ever have.”

## VIDEOS

- ▶ How to Talk to Your Health Care Provider about Gout
- ▶ Gary’s Story
- ▶ Gout and Kidney Disease 101

## PATIENT TO PATIENT

- ▶ With Gerald Hayashi
- ▶ With Lori Pasztor

## YOUR GOUT QUESTIONS ANSWERED

- ▶ With Payam Shakouri, MD
- ▶ With Teri Puhalsky, RN, CRNI

## INFOGRAPHICS

- ▶ Step Therapy and Gout
- ▶ Gout Affects the Whole Body

## BLOG POSTS

- ▶ How Men Can Grapple with Gout
- ▶ Gout Awareness Day 2021: More Knowledge, Better Life
- ▶ Gout Patients’ Hidden Heart Risk
- ▶ Movies and TV are Giving People the Wrong Idea about Gout

This year, the Alliance for Gout Awareness continued its commitment to empowering patients and reducing stigma.

- **Educational resources** explored the role that comorbidities have on the lives and medical care of people living with gout, as well as health disparities that persist in the gout community
- **A video tutorial and digital outreach** offered how-to information for patients to seek care and take control of their gout
- **Patient empowerment programs** and virtual forums offered patients a chance to ask questions, share struggles and get actionable information from experts
- **Patient testimonials** allowed those with gout to share their journeys, challenges and success stories, helping to empower other patients
- **Gout Awareness Day** integrated social media outreach and educational content to heighten the disease’s visibility and drive patients to action
- **Education and advocacy efforts** explored the challenges that utilization management tools like step therapy pose to patients living with gout
- **Expanded outreach** allowed the Alliance for Gout Awareness to connect and convene a growing range of advocacy and patient support organizations to sync efforts and maximize the support provided to people living with gout.

# HEADACHE & MIGRAINE

“The urgency is **now.**”

Jon Stewart



## VIDEOS

- ▶ Patient Access to Migraine Devices
- ▶ The Pain of Waiting for Migraine Medication

## PAPERS

- ▶ Chronic Headache Disorders & Toxic Exposure
- ▶ 5 Principles of Good Insurance Coverage

## INFOGRAPHICS

- ▶ Migraine is a Whole-Body Disease
- ▶ Men & Migraine Disease
- ▶ Health Plan Coverage & Migraine Disease
- ▶ Headache Devices for Veterans & Civilians
- ▶ What Does 24 Hours of Pain-Free Life Look Like?
- ▶ Cost Benefits of Effective Migraine Treatment
- ▶ Headache Disorders & Non-Medical Switching
- ▶ Are Insurers Out of Step on Migraine Disease?

## SURVEYS

- ▶ Prior Authorization & Treatment Delays

## BLOG POSTS

- ▶ Insurers Block Pain-Blocking Devices for Migraine
- ▶ Federal Policymakers Signal Openness to Home Oxygen
- ▶ When Health Plan Barriers Trigger Headaches
- ▶ A Second Chance for People with Headache Disorders

This year, The Headache & Migraine Policy Forum and AfPA's Headache & Migraine Disease Working Group worked side by side to increase awareness about the burden of headache disorders and to reduce the barriers faced by those who live with them.

Advocacy, education and programming spanned a range of issues, such as:

- **Onerous utilization management** as a source of delay, disease progression and unnecessary pain for people living with migraine disease and headache disorders
- **Veterans' and 9/11 first responders' experiences** with migraine disease and headache disorders
- **The role of medical devices** in patient-centered migraine care
- **Looking beyond stereotypes**, as through highlighting the experiences of men with migraine and defining migraine as a whole-body disease
- **Medicare policy**, including a national survey report on onerous prior authorization requirements for certain headache treatments and continued calls to cover home oxygen for those living with migraine disease
- **The role of Medicaid Pharmacy & Therapeutics committees** on access to treatment and patient-centered care
- **Cost considerations**, highlighting the cost effectiveness of treating patients proactively as the best use of limited health care resources.



# HEALTH TECHNOLOGY ASSESSMENT



“ICER economists are now suffering from a serious case of mission creep.”

## COMMENT LETTERS

- ▶ Severe Asthma
- ▶ Alzheimer's Disease
- ▶ Hypertrophic Cardiomyopathy

## ONE-PAGERS

- ▶ ICER Mixes Up Priorities in Asthma Drug Review
- ▶ ICER's Evaluation of Alzheimer's Treatment Undervalues Key Groups

## TOOLKITS

- ▶ Asthma
- ▶ Alzheimer's

## INFOGRAPHIC

- ▶ When Health Technology Assessment Discriminates

## BLOG POSTS

- ▶ ICER Crosses the Center Line
- ▶ Cancer and the Long-Term Costs of ICER's Short-Term Thinking
- ▶ Does Patient Input Fall on Deaf Ears?
- ▶ Oklahoma Bans the QALY

As innovation soared this year, limiting definitions of value threatened to impede patient access.

- **The Institute for Clinical and Economic Review exhibited historic overreach**, transforming its analysis of first-in-class Alzheimer's treatment into an opportunity to publicly undermine the Food and Drug Administration. Innovative asthma and cancer treatments also came under fire, courtesy of ICER's persistent use of short-sighted calculations and discriminatory metrics like the QALY.
- **The Alliance for Patient Access and Institute for Patient Access partnered to push back**, empowering clinicians and patients to engage in the ongoing value conversation. From educational content to informational webinars, AfPA and IfPA created opportunities to elevate the patient and provider voice.
- **As ICER's vision of value trickled down into state-level policy**, AfPA's state chapters also undertook an initiative to educate local policymakers about value, access and health technology assessment.



Alliance for Patient Access



Institute for Patient Access



PARTNERSHIP TO ADVANCE  
Cardiovascular  
Health

# HEPATITIS

“The infection can be eradicated with a comprehensive plan.”



## VALUE-BASED PAYMENT METHODS

help state policymakers **stay within budget** while still curing hepatitis C.

### INFOGRAPHICS

- ▶ Expand Testing
- ▶ Explore Innovative Payment Approaches
- ▶ Tailor Strategies to At-Risk Populations
- ▶ Reduce Access Barriers
- ▶ State Medicaid Systems are Failing Patients

### BLOG POSTS

- ▶ A Map to Hepatitis Elimination
- ▶ How Smart Public Policies Can Curb Hepatitis C
- ▶ Some States are Fighting Hepatitis C — and Winning
- ▶ Hepatitis Can't Wait
- ▶ Why Hepatitis B Demands More Attention

This year, AfPA's Hepatitis Therapy Access Physicians Working Group highlighted the growing need for policymakers to find solutions to the country's ongoing hepatitis challenges.

The working group raised awareness about a range of potential approaches, from expanding testing to exploring innovative payment approaches, tailoring outreach strategies to minimizing access barriers.

Efforts included:

- **A series of educational materials** that highlighted potential solutions for policymakers as they develop comprehensive state elimination plans
- **Social media engagement** aimed at putting pressure on states where Medicaid access barriers persist for patients living with hepatitis C
- **A closer look at the growing threat of hepatitis B**, which affects as many as 2.4 million Americans.



**Hepatitis Therapy  
Access** Physicians  
Working Group

# INFANT HEALTH



“RSV is  
incredibly  
hard.”

Vincent Smith, MD

## POLICY SUMMIT

- ▶ 2021 Infant Health Policy Summit

## VIDEOS

- ▶ Safety in the NICU
- ▶ Antibodies & Infant Health
- ▶ Megan's RSV Story
- ▶ The Dangers of RSV

## PAPERS

- ▶ Infant Health Matters: RSV
- ▶ Infant Health Matters: Innovation
- ▶ Infant Health Matters: Antibodies

## INFOGRAPHICS

- ▶ The Signs & Symptoms of RSV
- ▶ How to Prevent RSV
- ▶ RSV: Did You Know?

## BLOG POSTS

- ▶ When Preterm Infants Struggle to Feed
- ▶ COVID-19 Restrictions & the NICU
- ▶ From Mom to Baby: Antibodies & Infant Health
- ▶ False Alarms Signal Urgency of Infant-Specific Devices
- ▶ Stepping up the Fight against Maternal and Infant Mortality

From the rare to the common, health challenges facing infants and their families dominated the National Coalition for Infant Health's education and advocacy this year.

Efforts included:

- **Highlighting the dangers of respiratory syncytial virus,** including a national social media campaign during RSV Awareness Month
- **Exploring how maternal antibodies can lead to rare health complications** for pregnant mothers and their unborn babies
- **Raising awareness about the need for innovation** and how safety in the NICU — and beyond — requires medications and medical devices designed specifically for infants.

The year's programming culminated with the seventh annual Infant Health Policy Summit, held virtually. The event invited health care providers, parents, advocates and policy experts to explore issues such as disparities in the NICU, the impact of COVID-19 separation policies on mothers and newborns, and the value of establishing high standards for human donor milk.

# MENTAL HEALTH

“The next national health emergency is already here.”



## PAPERS

- ▶ Mental Health Care Reform After the Pandemic

## INFOGRAPHICS

- ▶ The Mental Health Treatment Disconnect

## BLOG POSTS

- ▶ What's Happening to Americans' Mental Health?
- ▶ The Widening Mental Health Gap
- ▶ The Looming Mental Health Pandemic
- ▶ Does Telehealth Work for Mental Health?
- ▶ Mental Health Care Deserves a Fair Shake

In its first year, AfPA's Mental Health Working Group delved into a complex challenge: addressing the country's mental health crisis amid the ongoing pandemic.

An inaugural working group meeting led to a comprehensive white paper that highlighted the policy needs of the mental health community. Other educational materials followed, covering topics such as:

- **The emergence of a mental health pandemic**, as the number of people requiring mental health treatment grows during the isolation and loss of the COVID-19 pandemic
- **The problem of provider shortages**, made worse by the growing needs of patients in the United States
- **The importance of mental health parity**, and the need for more widespread implementation
- **The role of telemedicine** in allowing limited providers to reach the patients who need treatment, as well as the need to find a tailored balance of virtual and in-person care for each patient.

AfPA also built and expanded partnerships within the mental health community, joining alongside other advocates to highlight the problems of mental health and non-medical switching, as well as other roadblocks to patient-centered care. Joint advocacy efforts included shared leadership of the new Alliance for Mental Health Care Access.



# NEUROLOGICAL DISEASE

“Tailored treatments are critical.”



## VIDEO

- ▶ Patient-Centered Care for Parkinson's Patients

## PAPERS

- ▶ How to Deal with an Insurance Denial
- ▶ Prior Authorization & Treatment Delays

## INFOGRAPHICS

- ▶ Early Alzheimer's & Dementia Testing
- ▶ Insurance Reauthorization
- ▶ Co-pay Accumulators Harm Movement Disorders Patients
- ▶ Parkinson's Disease & Treatment Access

## BLOG POSTS

- ▶ The Medicare Policy that Disrupts Care for Movement Disorders Patients
- ▶ Who Will Control Access to New Alzheimer's Treatments?
- ▶ Summer Brings Big Wins for Tardive Dyskinesia Patients
- ▶ Imagine the Future of Medicine Without Innovation
- ▶ How Biologics Transformed Care for MS Patients
- ▶ Two Years is Too Long a Wait for Huntington's Patients
- ▶ The Harm in Prioritizing Policy Over Patients
- ▶ Telehealth: A Valuable Asset to Those Living with Movement Disorders
- ▶ Will Alzheimer's Drugs Reach Those Who Need Them?
- ▶ Will Medicare Patients Lose Key Protections?
- ▶ America's Spectrum of Support for Patients
- ▶ Rx Exclusion Lists Shut Patients Out

This year, AfPA's Neurological Diseases Working Group joined alongside the Movement Disorders Policy Coalition to champion access for people living with debilitating conditions that affect mobility, memory or cognition.

Advocacy and education efforts focused on:

- **The burden of utilization management**, which increasingly blocks treatment access even as tailored and innovative treatments make disease management more feasible
- **Medicare Part D issues**, particularly the need for an out-of-pocket cap and for smoothing that makes prescription drug costs more manageable
- **Telemedicine's role** in making care more accessible and continuous, and in making specialists more accessible for patients
- **Awareness about tardive dyskinesia**, a movement disorder whose visibility is poised to grow, as Congress considers a report that could lead to a comprehensive federal strategy for patients.

When the Institute for Clinical and Economic Review incited public controversy about the first disease-modifying medication for Alzheimer's disease, AfPA's Neurological Diseases Working Group worked to keep providers informed and engaged in the valuation process.

Meanwhile, the Movement Disorders Policy Coalition continue to grow and to engage with advocates beyond its own membership by convening a broad range of organizations on challenges facing the movement disorders community.



Neurological Disease  
Working Group



# OBESITY



“Obesity affects more than 42% of American adults.”

## PAPER

- ▶ Root Cause

## INFOGRAPHICS

- ▶ Obesity is Weighing America Down
- ▶ A Fatal Connection

## BLOG POSTS

- ▶ Medication Show Promise in Fight to Curb Obesity
- ▶ New Obesity Drug Wins FDA Approval
- ▶ Getting to the Root of Obesity
- ▶ Obesity Threatens to Roll Back Progress Against Cancer
- ▶ Childhood Obesity Climbs Higher

As the ongoing pandemic drove U.S. obesity rates higher, dialogue about weight, health and effective treatment took on renewed importance.

The Alliance for Patient Access, alongside the Diabetes Policy Collaborative and the Partnership to Advance Cardiovascular Health, undertook an educational campaign to inform the expanding policy discussion. Educational content focused on:

- **The overlap between obesity, Type 2 diabetes and cardiovascular disease**, and the increased risk that patients face as they develop these comorbidities
- **The environmental factors that drive obesity**, and how competing societal messages about weight and body image complicate the issue
- **The need for team-based, patient-centered care** rather than a siloed approach that comes up short
- **The importance of access to the full range of treatment options**, including FDA-approved obesity medications that often lack coverage by Medicare, Medicaid and commercial insurers
- **The value that Part D coverage for obesity medication could bring patients**, and the need to pass legislation that would address the Medicare Part D ban.

# ONCOLOGY

“For cancer patients, time is life.”



## PAPERS

- ▶ Biosimilars: Expanding Options for Cancer Care

## VIDEOS

- ▶ When Cancer Diagnostics are Delayed

## INFOGRAPHICS

- ▶ Innovative Diagnostics Save Cancer Patients' Lives
- ▶ Co-pay Accumulators Are Costing Cancer Patients

## BLOG POSTS

- ▶ Cancer Innovations Worth Celebrating
- ▶ When Prescribing is Personal
- ▶ Cancer and the Long-Term Costs of ICER's Short-Term Thinking
- ▶ What Biosimilars Mean for Cancer Care

Innovation continued to improve patients' chances at more immediate, more targeted and more personalized treatment this year, a trend that AfPA's Oncology Therapy Access Working Group supported through ongoing education and advocacy.

Efforts included:

- **An exploration of biosimilars' role** in expanding clinicians' and patients' options to tackle cancer effectively and cost efficiently
- **Education and awareness raising on the topic of innovative diagnostics**, including biomarker testing, and how timely access to diagnostics is paramount for patient-centered cancer care
- **Highlighting the value and need for continued innovation in oncology**, including commentary on the Institute for Clinical and Economic Review's short-sighted CAR-T therapy assessment
- **The continued need for Medicare Part D reform** to make out-of-pocket costs predictable and manageable for older adults living with cancer.

These issues featured prominently in a panel discussion at the sixth annual National Policy & Advocacy Summit on Biologics, held virtually for a national audience of patients, providers, advocates and policymakers.



# PAIN



“Use that same courage to take care of your health.”

Farron Dozier

## POLICY SUMMIT

- ▶ Summit on Balanced Pain Management

## VIDEOS

- ▶ Reel Talk: Emily's Story
- ▶ Reel Talk: Farron's Story

## BLOG POSTS

- ▶ Improving Patients' Access to Affordable Generic Drugs
- ▶ New Federal Policy Could Limit Non-Opioid Pain Treatments
- ▶ A Better Way to Relieve Pain
- ▶ Giving Patients a Say on Opioid Risks
- ▶ Finding the Right Approach to Pain Management

This year, the Alliance for Balanced Pain Management and AfPA's Pain Management Working Group strove to spotlight the experiences of people living with painful conditions — and to call for improved access to balanced, personalized pain care.

Through a series of new educational materials and advocacy activity, the groups explored:

- **The prevalence of arthritis pain among U.S. veterans** and the need for a balanced approach to treatment
- **The connection between long-term, high-dose NSAID use and gastrointestinal complications,** which can pose dangers to pain patients
- **The importance of access to non-opioid treatment options** and policies that encourage their development
- **The continued need for patient-centered care,** including measures that allow patients to have a say in whether opioids are part of a patient's treatment plan.

These issues shaped discussions at the National Summit on Balanced Pain Management, held virtually for a national audience and featuring insights from patients, providers, advocates and policy experts.



# RARE DISEASES

“Every patient deserves care that meets his or her individual needs.”



## VIDEOS

- ▶ Patient-Centered Care for Amyloidosis

## PAPERS

- ▶ Genetic Testing & Counseling for Rare Hereditary Diseases
- ▶ In Their Own Voices: The Lived Experiences of IgG4-RD Patients

## INFOGRAPHICS

- ▶ Rare Diseases & Cost Sharing
- ▶ What Stands Between Patients & Treatment for Rare Diseases?
- ▶ Accelerated Approval & Rare Disease Patients

## BLOG POSTS

- ▶ Amyloidosis: Rare Disease, Rare Courage
- ▶ Economic Impact of Rare Diseases Tops \$960 Billion
- ▶ Genetic Testing & Counseling Offer Answers for Rare Disease Patients
- ▶ Proposed Programs Could Speed up Drug Approval for Rare Diseases
- ▶ A Rare Disease Captures the World's Attention
- ▶ Focusing on a Rare Threat for Transplant Patients

AfPA's Rare Diseases Working Group continued education and advocacy efforts this year on broad access challenges, while also exploring the barriers faced by patients in several specific disease states.

Advocacy and education activities delved into a range of issues that are important to the rare disease community, including:

- The burden of **high cost-sharing**
- The challenges posed by **utilization management barriers**
- The role of **genetic testing and counseling** in hereditary rare diseases
- The **value of accelerated approval** for rare disease medications.

The working group also took a closer look at several specific rare diseases. Efforts included:

- New educational content and social media outreach to raise awareness about **the burden of amyloidosis** and the need for timely diagnosis and treatment
- **A closer look at IgG4-RD**, including in-depth focus groups with patients to better understand the lived experience of the disease
- **An exploration of PTLD**, a rare cancer that can develop after a transplant.



# RESPIRATORY

“Asthma disproportionately affects the vulnerable.”



## VIDEOS

- ▶ Patient-Centered Asthma Care
- ▶ Value, Access & Asthma

## PAPERS

- ▶ ICER Mixes up Priorities in Asthma Drug Review

## TOOLKIT

- ▶ Asthma

## INFOGRAPHICS

- ▶ When Prior Authorization Delays Respiratory Care
- ▶ When Asthma Patients Get Switched

## BLOG POSTS

- ▶ No Room for Middlemen in the Doctor-Patient Relationship
- ▶ Will Insurers Come Through for Respiratory Patients?
- ▶ Why Patients are Missing Fewer Appointments
- ▶ ICER Crosses the Center Line

The value of new treatment options took center stage this year as AfPA's Respiratory Therapy Access Working Group educated and advocated for patient-centered care.

An all-hands-on-deck response to the Institute for Clinical and Economic Review's assessment of a new biologic treatment for severe asthma included:

- **A webinar to empower clinicians** to engage in the ICER process
- **Educational materials to raise awareness** about the importance of personalized care for asthma
- **A response letter and accompanying materials** to underscore the shortcomings of ICER's evaluation.

Meanwhile, the working group continued to:

- **Raise awareness about the problems** of onerous prior authorization and non-medical switching
- **Highlight the role of pharmacy benefit managers** in driving patients' out-of-pocket costs to unmanageable levels
- **Convey the value of telemedicine** in keeping respiratory patients connected to their providers during the COVID-19 pandemic.



**Respiratory  
Therapy Access**  
Working Group

# SKIN CONDITIONS

“Step therapy can impede our ability to care for patients.”

Avery LaChance, MD



RIGHT  
MEDICATION



RIGHT  
PATIENT



RIGHT  
TIME

## VIDEOS

- ▶ Skin Conditions & Health Insurance Barriers

## BLOG POSTS

- ▶ How Telehealth is Shaping the Future of Dermatological Care
- ▶ Insurers Save Costs at Cost of Skin Patients
- ▶ Rx Exclusion Lists Shut Patients Out
- ▶ How Employers Can Invest in Healthier Employees

## TOOLKIT

- ▶ DCAN Advocacy Toolkit

This year the Derma Care Access Network strove to raise awareness and empower advocates to speak out on the widespread access barriers facing patients with skin conditions.

Efforts included:

- **New educational content** highlighting the impact of burdensome step therapy protocols, which lead to treatment delays and avoidable symptoms for patients
- **An advocacy toolkit and ongoing outreach** on state- and federal-level legislation aimed at curbing step therapy
- **Digital and social media collaboration** with dermatological community partners to maximize awareness days and increase understanding about the importance of patient-centered dermatological care
- **An exploration of telemedicine**, which has encouraged continuous care, helped reduce disparities and laid the path for a more hybrid approach to dermatological care moving forward.



# TELEHEALTH



“Millions of patients and health care providers benefit from access to telehealth.”

## POLICY SUMMITS

- ▶ Getting Telehealth Policy Right

## VIDEOS

- ▶ Voices of Telehealth

## PAPERS

- ▶ Expanding Telehealth after COVID-19

## INTERVIEWS

- ▶ Jenn Heater
- ▶ Matt Connolly
- ▶ Amanda Greene

## INFOGRAPHICS

- ▶ Audio-Only Telemedicine 101
- ▶ Caregivers & Telemedicine

## BLOG POSTS

- ▶ Telehealth Isn't Only for Pandemics
- ▶ How Telehealth Changed My Mom's Life
- ▶ Can Telehealth Make Pregnancy & Birth Safer?
- ▶ Telemedicine Co-Pays Are Back. Now What?
- ▶ I Was a Telehealth Skeptic.
- ▶ Making Telemedicine Work for Underserved Communities
- ▶ Balancing Telehealth and In-Person Care
- ▶ States Gut Telemedicine Policies Amid Delta Variant

As the pandemic waged on, telehealth became a tool and a topic of national importance. Patient & Provider Advocates for Telehealth explored the policy issues that shape telehealth through the voices and experiences of those who know it firsthand.

The coalition's education and outreach considered issues such as:

- Telehealth's impact on **specific disease states and specialty areas**, from respiratory to dermatology to mental health to pregnancy and infant care
- The value of telehealth access for **caregivers**
- The value of **audio-only telehealth** and its use for specific situations
- The challenges posed by the United States' **digital divide**, and how policymakers can improve the matter
- **How telehealth intersects with health disparities** and the benefits and challenges it poses for underserved communities
- The importance of **balancing virtual and in-person care** to provide optimal outcomes for each individual patient.

The year's efforts culminated in a national policy summit, Getting Telehealth Policy Right. Held virtually, the event welcomed experts, advocates, patients and providers from across the country to explore the policies that will shape telehealth access in the years ahead.



# UTILIZATION MANAGEMENT & ACCESS BARRIERS

“These programs can pose real challenges for patients.”



## INTERVIEWS

- ▶ Step Therapy with Kelly Barta
- ▶ Non-Medical Switching with Greg Hansch
- ▶ Prior Authorization with Emma Watson
- ▶ Co-Pay Accumulators with Steven Schultz

## BLOG POSTS

- ▶ Hidden Co-Pay Programs Blindside Patients
- ▶ Will the Biden Administration Tackle Co-Pay Card Reform?
- ▶ How Employers Can Invest in Healthier Employees
- ▶ For Some, Step Therapy is a Matter of Life and Death
- ▶ Californians Call for Patient-Centered Care
- ▶ Will Insurance Coverage Bring “Meaningful Access”

## Red tape, exorbitant cost-sharing and treatment denials loomed large for patients in 2021.

The Patient Access Collaborative strove to empower advocates by developing a new “Advocacy Insights” series to spotlight best practices on utilization management reform from advocates across the community. A series of monthly webinars allowed advocates to collaborate, share updates and brainstorm about how to best tackle the access barriers facing patients.

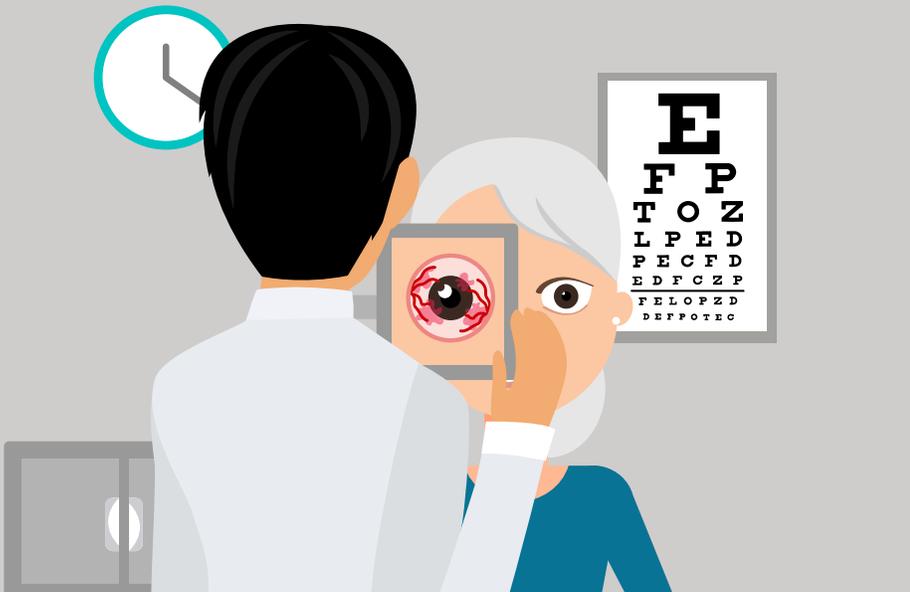
Meanwhile the Keep My Rx campaign monitored and informed state-level legislation on the issue of non-medical switching, while AfPA’s state chapters allowed clinicians and local advocates to partner on driving meaningful policy change.

And the National Council of Physician Legislators continued its work to unite health care providers who also serve in statehouses around the country. Through virtual meetings and ongoing communication, the group explored the diverse challenges facing physician legislators in 2021.



# VISION HEALTH

“Non-medical switching is bad medicine for vision patients.”



## VIDEOS

- ▶ Spotlight on Glaucoma

## ONE-PAGERS

- ▶ Age-Related Macular Degeneration 101
- ▶ Autoimmune & Eye Diseases 101

## TOOLKITS

- ▶ Prior Authorization

## INFOGRAPHICS

- ▶ Prior Authorization Delays Treatment for Vision Patients
- ▶ Non-Medical Switching & Vision Conditions

## BLOG POSTS

- ▶ Insurers Push for Cheaper, Untested Eye Treatment
- ▶ Are Insurers Slighting Sjogren's Patients?
- ▶ Drug Shortage Distress
- ▶ Screen Time, Delayed Care Endanger Eyesight

While 2021 posed challenges for people living with eye conditions, the Vision Health Advocacy Coalition forged ahead with education and outreach.

Efforts included:

- **Continued advocacy and education** on insurance barriers such as non-medical switching and prior authorization
- **A new toolkit** for patients facing prior authorization challenges
- Programming and **advocacy on vision health drug shortages** due to pandemic disruptions
- **A webinar series** to empower and inform people living with thyroid eye disease
- **Ongoing disease-state education**, including new content on glaucoma and macular degeneration
- A closer look at **how autoimmune diseases and eye conditions intersect**
- **Continued social media outreach** to raise awareness about issues such as eye safety, workplace eye wellness and children's eye health.

# MOVING FORWARD

As the Alliance for Patient Access moves into 2022, several new initiatives are taking shape.

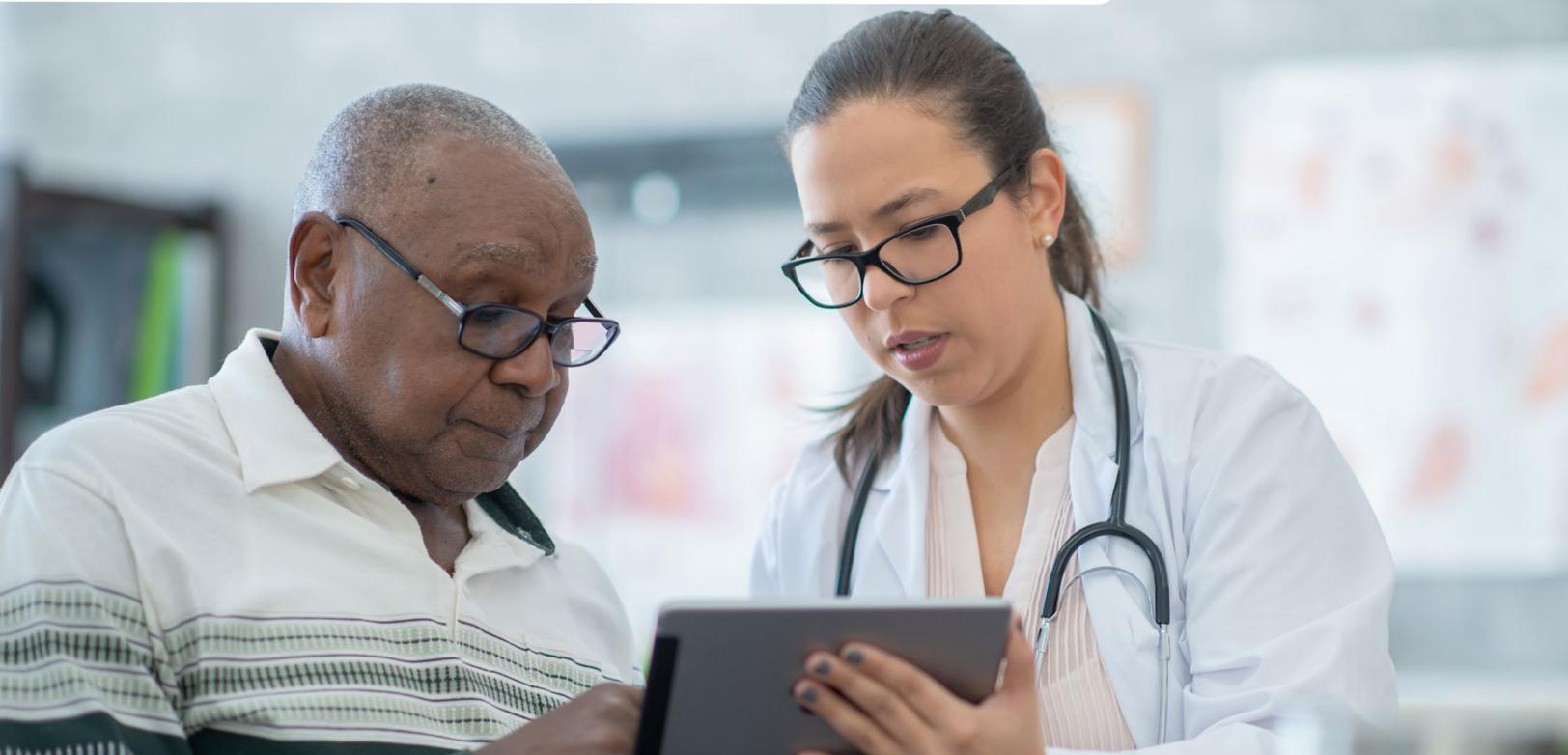
**AfPA's Urology Initiative.**

A new collaboration among health care providers and advocates will spotlight the need for patient-centered care for people living with overactive bladder and other urological conditions. Initiative participants will create educational content and advocate together for policy changes that improve patients' access to care.

**AfPA's Prescription Digital Therapeutics Initiative.**

Technology continues to reshape health care, including through the use of prescription digital therapeutics. Health plan coverage, however, once again lags behind innovation. AfPA's initiative will explore the value of prescription digital therapeutics access in providing patient-centered care for people with substance use disorders, mental health challenges and other medical conditions.

**Utilization Management & Health Disparities Research Initiative.** Next year will also allow the Institute for Patient Access, alongside AfPA and its coalitions, to undertake a first-of-its-kind research initiative exploring how utilization management impacts communities of color and perpetuates health disparities.



15 years of  
**growth.**  
15 years of  
**gratitude.**





# 15

Years of  
Advocacy

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