



2019 ANNUAL REPORT



Alliance for
Patient Access



Institute for
Patient Access



**Alliance for
Patient Access**



**Institute for
Patient Access**

WORKING GROUPS



**National
Physicians Biologics
Working Group**



**Hepatitis Therapy
Access Physicians
Working Group**



**Diabetes
Therapy Access
Working Group**



**Pain Management
Working Group**



**Respiratory
Therapy Access
Working Group**



**Neurological Disease
Working Group**



**Oncology
Therapy Access
Working Group**



**Cardiovascular Disease
Working Group**



**Headache & Migraine
Disease Working Group**

STAKEHOLDER COALITIONS



**Coalition for
Clinical Trials
Awareness**



**NATIONAL COUNCIL OF
PHYSICIAN
LEGISLATORS**



**AfPA
Survey Hub**



**ALLIANCE FOR
Balanced Pain
Management**



Patient Access Collaborative



KEEP MY Rx



**ALLIANCE FOR
Gout Awareness**



**MOVEMENT
DISORDERS
POLICY COALITION**



CFEN
Cystic Fibrosis Engagement Network



**bpc BiologicsPrescribers
COLLABORATIVE**



**Diabetes Policy
Collaborative**

AFPA AFFILIATES



**PARTNERSHIP TO ADVANCE
Cardiovascular
Health**



**The Headache
& Migraine
POLICY FORUM**



DCAN
DERMA CARE ACCESS NETWORK



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

Dear Members & Supporters:

For the Alliance for Patient Access and Institute for Patient Access, 2019 was a year to dig deep and think big.

AfPA started 2019 with a first-of-its-kind national study on how non-medical switching impacts patients' quality of life. Feedback from hundreds of patients painted a devastating picture. Non-medical switching was making patients anxious, unhealthy, unproductive at work and unable to care for loved ones at home.

The results got us thinking. If the impact of insurers' cost-cutting techniques is far reaching, shouldn't the solution be too? The question led us on a journey to broaden AfPA and IfPA's core mission.

We maintain our commitment to patient access to approved therapies and appropriate clinical care. **But we now recognize that patients need something even bigger—a health care system that's centered on their needs.**

That means appropriate diagnostics to guide treatment. Strategies that include caregivers in decision-making. Telehealth, home health and complementary approaches to tailor care to the patient. It means a relationship with a health care provider that isn't constantly undermined by red tape and health plan barriers. And it means patients having a voice in what treatments are worth to them.

In the long term, that gives us better health outcomes, lower administrative costs and fewer hours wasted on one-size-fits-all strategies that exhaust clinicians and make patients sicker.

It gives us a patient-centered health care system.

So, as you review the activities and successes of 2019 on the following pages, please note where the ideals of patient-centered care are coming alive in AfPA and IfPA's work.

Examples include:

- AfPA's new Headache & Migraine Disease Working Group, where clinicians are fighting to personalize treatment by combining preventive migraine therapies
- The Alliance for Balanced Pain Management, which is highlighting the need for patient-centered pain care across a variety of disease states
- AfPA's Neurological Disease Working Group, which is examining how dose reduction requirements impede personalized treatment for patients in long-term care facilities
- The Institute for Patient Access, which is working to keep patients and health care providers, not health economists, in charge of treatment decisions.

Your support has emboldened AfPA and IfPA to pursue an ambitious new vision: a health care system that prioritizes and delivers what each individual patient needs. We look forward to working together, in 2020 and beyond, to make this vision a reality.

Sincerely,



DAVID CHARLES, MD
National Chairman



BRIAN KENNEDY
Executive Director

2019

BY THE NUMBERS



16 COALITIONS
& AFFILIATES



20 YOUTUBE
VIDEOS



244,675
VIDEO VIEWS



2,148
COALITION MEMBERS



127
INFOGRAPHICS



110
BLOG POSTINGS



27
SPONSORED
EVENTS



12,019
TWITTER
FOLLOWERS



44,599
FACEBOOK
REACTIONS, SHARES
& COMMENTS



10
WORKING
GROUPS



10,400
NEWSLETTER
RECIPIENTS



43,115
FACEBOOK
FOLLOWERS



14 PODCASTS



13 WEBINARS



20
POLICY PAPERS



2019 ANNUAL REPORT

TABLE OF CONTENTS



6	Biologics & Biosimilars	16	Neurological
7	Cardiovascular	17	Oncology
8	Clinical Trials	18	Pain
9	Cystic Fibrosis	19	Patient Protections
10	Diabetes	20	Respiratory
11	Gout	21	Skin Conditions
12	Headache & Migraine	22	Utilization Management & Access Barriers
13	Health Technology Assessment	23	Giving Back
14	Hepatitis	24	Moving Forward
15	Infant Health		



BIOLOGICS & BIOSIMILARS

In 2019, the Biologics Prescribers Collaborative worked alongside AfPA's National Physicians Biologics Working Group to highlight how sound policymaking and a robust regulatory structure continue to expand treatment options for patients and clinicians.

Alongside the Institute for Patient Access, AfPA's working group:

- Hosted the fourth annual **National Policy & Advocacy Summit on Biologics and Biosimilars** in Washington, DC
- Weighed in on federal and state policy initiatives regarding access to, naming and billing of biologic medicines
- Published a **"Fast Facts"** summarizing the naming process for biologics and its impact on access and innovation.

Meanwhile, the Biologics Prescribers Collaborative:

- Partnered with the Global Alliance for Patient Access to host a series of physician biosimilar briefings in Latin America and the Middle East
- Produced **infographics** and educational materials about how the regulatory pathway is meeting patients' and providers' needs for safe, effective new treatments
- Convened a **Patient Advisory Council** to explore strategies for greater collaboration between medical societies and patient advocacy organizations.



**National
Physicians Biologics
Working Group**



**BiologicsPrescribers
COLLABORATIVE**

CARDIOVASCULAR



With the help of AfPA's Cardiovascular Disease Working Group and the AfPA-affiliated Partnership to Advance Cardiovascular Health, heart patients' access to innovative medicine has improved in recent years. But the health care system still falls short of meeting each heart patient's unique needs.

This year, the two groups worked together to raise awareness about barriers for at-risk patients. Efforts included:

- Urging elected officials, regulators and health plan officials to address harmful access barriers
- Convening policymakers, health care providers, advocates and patients at the annual **Cardiovascular Health Policy Summit** to explore the importance of treating the whole patient by considering family cardiovascular history and comorbidities
- Creating **educational resources** to accompany the Institute for Patient Access' 2019 **"Health Plan Coverage Report Card,"** which highlighted how barriers to PCSK9 inhibitors remain, even among patients with documented risks
- Producing a **patient testimonial video** capturing the intergenerational impact of cardiovascular health on patients' lives.



Cardiovascular Disease
Working Group



PARTNERSHIP TO ADVANCE
Cardiovascular
Health



CLINICAL TRIALS

In 2019, the Coalition for Clinical Trials Awareness continued to raise public awareness about the societal benefits of clinical trials and rallied for policies that encourage trial participation.

The group's efforts culminated with Clinical Trials Awareness Week—an annual, week-long push from health care providers, policymakers, patient advocates and researchers to draw the public's attention to the importance of clinical trial participation.

As part of the 2019 Clinical Trials Awareness Week, the coalition:

- Hosted a policy panel discussion at the U.S. Capitol about resources for clinical trial participants—and why related expenses shouldn't undermine enrollment and research on advanced treatments and new cures
- Released a **social media toolkit** highlighting the importance of reimbursement to participants for clinical trial-related expenses such as travel, lodging and meals
- Hosted an **interview** on AfPA's Patient Access Podcast about clinical trial costs to patients and the big-picture implications to society
- Summarized the week's policy discussions in a paper titled **"Overcoming Financial Barriers to Clinical Trials Enrollment."**



Coalition for
Clinical Trials
Awareness

CYSTIC FIBROSIS



This year, the Cystic Fibrosis Engagement Network strove to raise awareness and improve access to treatment for patients with cystic fibrosis.

Institute for Patient Access Policy Blog posts highlighted both the day-to-day burden of the disease and **the hope** patients place in innovative, life-changing treatment.

The organization also honed in on the growing threat posed by co-pay accumulator adjustment programs, cost-shifting policies that prevent **co-pay cards** from counting toward patients' annual deductibles.

Efforts included:

- Advocacy raising concerns about co-pay accumulator programs and their impact on patients with cystic fibrosis
- Amplified **patient stories** depicting how co-pay accumulator programs can blindsides cystic fibrosis patients with unmanageable out-of-pocket costs.

Four states ultimately passed legislation on the issue.

The Cystic Fibrosis Engagement Network also geared up to engage in the Institute for Clinical and Economic Review's evaluation of forthcoming triple combination therapy. The organization submitted **comments** on ICER's scoping document and is organizing efforts to respond to ICER's draft evidence report in 2020.



DIABETES

In step with AfPA's focus on patient-centered care, AfPA's Diabetes Therapy Access Working Group and the Diabetes Policy Collaborative worked to highlight the impact of comorbidities and the importance of personalized care.

The two groups:

- Advocated for U.S. health plans to incorporate new Internal Revenue Service guidance on covering preventive care before patients with high-deductible health plans meet their annual deductible
- Urged the Food and Drug Administration and the Department of Health and Human Services to consider the patient access issues related to splitting insulin pen packs in pharmacies. The Food and Drug Administration responded by updating its guidance on distribution
- Engaged alongside the [Institute for Patient Access](#) in responding to the Institute for Clinical and Economic Review's analysis of oral semaglutide for Type 2 diabetes.

The Diabetes Therapy Access Working Group also joined forces with AfPA's Cardiovascular Disease Working Group to conduct the first [Joint Cardiovascular Disease-Diabetes Working Group Meeting](#). The meeting explored cardiovascular disease as a common comorbidity of diabetes and considered how clinical guidelines and treatment practices can promote a patient-centered approach that addresses both conditions concurrently.



**Diabetes
Therapy Access**
Working Group



**Diabetes Policy
Collaborative**

GOUT



In 2019, the Alliance for Gout Awareness continued its two-pronged mission to reduce misconceptions and stigma surrounding gout and to empower patients to seek treatment.

Members collaborated on a comprehensive collection of patient education materials, including:

- An **AfPA Patient Access Podcast** episode chronicling the painful, prevalent and treatable condition that is gout
- **Patient guides** outlining available treatment options
- A series of infographics featuring statistics about gout and common harmful misconceptions
- A national **patient survey** of attitudes toward gout.

The Alliance for Gout Awareness also created a comprehensive patient toolkit in acknowledgement of Gout Awareness Day. Contents included a **video** explaining how gout affects patients, along with social media profiles and **graphics** to spread awareness.

Meanwhile, the group engaged patients directly in a series of patient empowerment forums held around the country. The events allowed patients and clinicians to share their personal journeys with gout and encourage other patients to seek treatment.



HEADACHE & MIGRAINE

This year, AfPA's new Headache & Migraine Disease Working Group welcomed articulate and engaged clinicians to join the fight for patient-centered care. The group's efforts complemented those of The Headache and Migraine Policy Forum, both working to tackle stigma and access barriers.

Advocacy focused on enabling individualized care by addressing policies that restrict clinicians from prescribing patients the medication, or combination of medications, that works best for them. The working group's efforts included:

- A **white paper** identifying headache and migraine treatment challenges
- A new **video on combination therapy**
- Clinician letters to health plans.

The working group also joined forces with The Headache & Migraine Policy Forum to respond to the Institute for Clinical and Economic Review's assessment of migraine therapies.

AfPA-affiliate The Headache & Migraine Policy Forum submitted comments to ICER addressing the need for a patient-centered approach in its acute migraine therapy review and 2020 proposed framework. AfPA's Headache & Migraine Disease Working Group, meanwhile, **mobilized clinicians** through an online "ICER Action" hub complete with **educational materials**.

The groups engaged with the wider migraine community on advocacy and awareness efforts, including the annual advocacy event Headache on the Hill. The working group rounded out the year by releasing new **video testimonials** from clinicians on barriers posed by health plan policies.



**Headache & Migraine
Disease Working Group**



**The Headache
& Migraine
POLICY FORUM**

HEALTH TECHNOLOGY ASSESSMENT

Institute for Clinical and Economic Review



The reports of the Institute for Clinical and Economic Review are often the least understandable to those they most directly affect: patients. This year, the Institute for Patient Access worked to change that by introducing a series of plain-language educational materials on ICER.

The Institute for Patient Access' materials included:

- A **"Fast Facts"** about ICER
- A patient-facing explainer video titled **"What's Wrong with ICER?"**
- A clinician-facing explainer video titled **"Why Health Care Providers Should Care About ICER."**

IfPA also provided direct responses and created advocate-friendly materials on ICER reports involving:

- **Type 2 diabetes**
- **Rheumatoid arthritis**
- **Acute migraine therapies.**

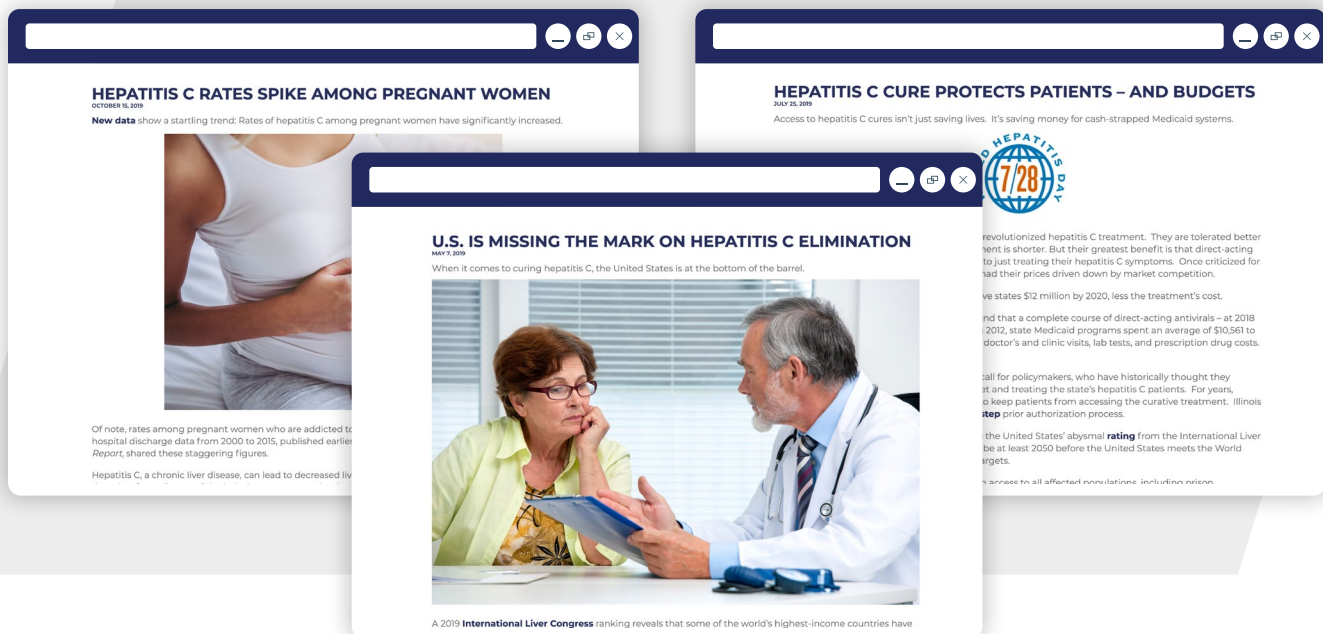
Meanwhile, the Institute for Patient Access Policy Blog continued to chronicle ICER's activities and their impact on patients through posts such as:

- **ICER vs. Infants**
- **ICER and the Real World**
- **ICER's Rare Disease Problem.**



Institute for
Patient Access

HEPATITIS



From **state elimination** plans to Netflix-style medication subscriptions, policymakers explored a variety of approaches to treating hepatitis C. AfPA's Hepatitis Therapy Access Physicians Working Group continued to push, at both the state and federal level, for increased access to curative treatments.

State-level efforts included:

- Advocacy in Texas, the largest state yet to address serious barriers to curative treatment in the Medicaid system
- Activity in California, where issues involving supplemental payments pose a barrier to treatment for many patients
- Research on the implementation of **subscription pricing** initiatives in Washington and Louisiana to help guide other states interested in expanding access.

The working group also submitted a federal comment letter encouraging the U.S. Preventive Services Task Force to expand hepatitis C testing guidelines beyond the current “baby boomer” recommendation.

Meanwhile, the Institute for Patient Access Policy Blog continued to chronicle efforts across the United States to improve treatment for patients from all walks of life and, in some states, to eliminate hepatitis C altogether.



**Hepatitis Therapy
Access** Physicians
Working Group



INFANT HEALTH

In 2019, the AfPA-affiliated National Coalition for Infant Health applied its core values of safety, access, nutrition and equality by advocating on several key issues.

The coalition:

- Highlighted the importance of **preventive care** for **respiratory syncytial virus**
- Called for **safe and accurate** medical devices that meet the unique needs of NICU patients and raised awareness about the importance of **tubing safety**
- Addressed **feeding challenges** that affect **preterm infants** and underscored the value of **human milk**
- Advocated for clear, science-based nutrition advice for pregnant and breastfeeding mothers, highlighting new guidelines supporting seafood consumption
- Created educational **infographics** to raise awareness of the importance of early intervention for preterm infants
- Raised awareness about the prevalence and impact of **postpartum depression**.

The coalition's efforts culminated in the fifth annual **Infant Health Policy Summit**. The day-long event was attended by over 100 health care providers, parents, advocates and congressional staff in Washington, DC, who gathered to consider how policy can address the challenges facing infants and their families.

NEUROLOGICAL



This year, AfPA's Neurological Disease Working Group and the Movement Disorders Policy Coalition focused on addressing barriers that threaten treatment access and quality.

The two groups weighed in on topics such as:

- How **non-medical switching**, prior authorization and step therapy undermine the clinician-patient relationship and disrupt patient-centered care
- How inappropriate cost sharing impedes patients' access to treatment
- United States Pharmacopeia drug classifications.

The Movement Disorders Policy Collaborative also undertook efforts to increase awareness about the link between movement disorders and mental health.

Efforts included:

- Using an original Movement Disorders Policy Coalition video and new **infographics** to raise public awareness during Tardive Dyskinesia Awareness Week
- Hosting a panel at the Mental Health America conference.

Meanwhile, AfPA's neurological disease working group continued to push for patient-centered care in long-term care facilities. The group issued a new **video** highlighting the potential harm that gradual dose reduction could have on patients taking psychotropic medications and advocated to the Centers for Medicare and Medicaid Services on access to appropriate treatment for these patients.



Neurological Disease
Working Group



Out-of-Pocket Caps



Next-generation cancer therapies increase the necessity of a patient-centered health care system—one where clinicians and patients can access the diagnostics, procedures and treatments that are right for them. In 2019, AfPA’s Oncology Therapy Access Working Group recognized this reality by advocating for protected drug classes, CAR-T coverage and policies to make Medicare out-of-pocket expenses more affordable.

The working group:

- Partnered with other advocacy groups to urge Congress to maintain **protected drug classes**, which ensure that patients and clinicians have a choice among treatments. The Centers for Medicare and Medicaid Services ultimately scrapped their proposal to weaken the protections
- **Articulated** its support of Centers for Medicare and Medicaid services’ intention to **reimburse for CAR-T** therapies

- Advocated for an out-of-pocket cap for Medicare Part D
- Advocated for a **smoothing mechanism** to make out-of-pocket payments more predictable and manageable for seniors.

The working group also created a new **video** on out-of-pocket caps to accompany the Institute for Patient Access’ “**Fast Facts**” on the same topic. And working group members capped off the year with the release of their most recent white paper, “**Innovative Approaches in Patient-Centered Cancer Care.**”



**Oncology
Therapy Access**
Working Group



PAIN

The Alliance for Balanced Pain Management, with insight from AfPA's Pain Management Working Group, spent 2019 advocating for a comprehensive, patient-centered approach to pain care.

Advocacy efforts included:

- An Alliance for Balanced Pain Management **"Fast Facts"** and **video** explainer on **arthritis treatment**
- A series of **infographics** that highlight why balanced pain management is necessary across a variety of disease states
- Input to the Health and Human Services Pain Management Best Practices Inter-Agency Task Force. The Alliance for Balanced Pain Management's letter highlighted the **need for innovative**

treatment and delivery modes, while the Institute for Patient Access Policy Blog **chronicled** the task force's efforts.

The Alliance for Balanced Pain Management and AfPA's Pain Management Working Group concluded the year by hosting the sixth annual **Summit on Balanced Pain Management** in Washington, DC. The summit profiled experiences of pain across disease states and examined policy initiatives that would reinforce a patient-centered approach to treatment.



Pain Management
Working Group



ALLIANCE FOR
Balanced Pain
Management

PATIENT PROTECTIONS



“Bad drug” lawsuit advertisements have become pervasive on TV sets across America—endangering frightened viewers who abandon their prescription medication without first talking with their physician. In 2019, the Partnership to Protect Patient Health raised awareness about how misleading ads can hurt patients and sabotage the physician-patient relationship.

Building upon 2018 efforts, the group produced several new educational materials, such as:

- A physician testimonial video explaining **“Why ‘Bad Drug’ Ads are Bad for Patients”**
- An **infographic** drawing awareness to the harmful consequences of “bad drug” ads on patient health and the physician-patient relationship
- A **one-pager** summarizing what “bad drug” ads are and how they impact patients.

As these resources and targeted advocacy contributed to a growing groundswell, the Partnership to Protect Patient Health celebrated:

- New laws in Texas and Tennessee that increase regulation of “bad drug” ads
- The American Medical Association’s **resolution** encouraging regulations on attorney drug advertisements
- The Federal Trade Commission’s **attention** to the issue of “bad drug” ads.

RESPIRATORY

ASTHMA PATIENTS' CORTICOSTEROID CONUNDRUM

AUGUST 29, 2019

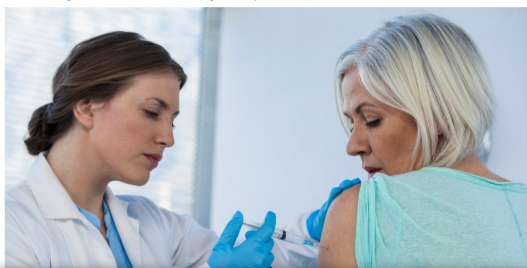
For someone with a flare-up of asthma symptoms, a short course of **oral corticosteroids** like prednisone can be a welcome relief. But when these potent medications become a regular remedy, asthma patients may have a problem.



THE ASTHMA OPTIONS PARADOX

JUNE 26, 2019

The introduction of a new treatment is a boon for any disease state. But what happens when health plans use the availability of new treatments to actually reduce patients' choices?



INFANTS AREN'T THE ONLY ONES HURT BY RSV

JUNE 13, 2019

A seasonal respiratory virus that threatens the lives of infants also can have a ripple effect on caregivers, families and workplaces, a new **data analysis** demonstrates.



AfPA's Respiratory Therapy Access Working Group jumpstarted the year in January with its annual meeting, where clinicians and advocates redoubled their commitment to pursuing patients' access to the most effective, most appropriate treatment for them.

Their commitment led to targeted efforts to preserve options for the treatment of uncontrolled asthma. The advent of new therapies, while good news for patients, opened the door for health plans to drive patients to the lowest-cost option rather than maintaining access to the treatment best suited to the individual patients. The issue featured in an Institute for Patient Access Policy Blog [post](#) and also prompted a letter to policymakers highlighting the importance of maintaining asthma patients' options among treatments.

The working group also highlighted concerns about overreliance on **oral corticosteroids** for the treatment of asthma. When short-term solutions become a go-to treatment for chronic conditions, patients' health can suffer—as respiratory clinicians well know. Working group members continue their work into 2020 to raise awareness about access to proper asthma treatment.



**Respiratory
Therapy Access**
Working Group

SKIN CONDITIONS



This year, the AfPA-affiliated Derma Care Access Network took its message to a critical new audience: employers.

In partnership with HR.com and the Aimed Alliance, the Derma Care Access Network offered a series of webinars to highlight health coverage best practices for human resources professionals—and to explain why access to treatment is critical to maintaining a healthy, productive work force.

The Derma Care Access Network also offered advocacy training sessions for patients, where the organization provided tips and tools for patients to become their own advocates.

Meanwhile, the group worked diligently to expand its advocacy network and champion efforts to improve access to care for patients with skin conditions.

That included:

- Highlighting the **long wait times** facing patients who need to see a dermatologist
- Raising awareness about specific skin conditions, such as **hyperhidrosis**
- Conveying the harmful effects of step therapy to a variety of stakeholders.

The group also lent its voice to the Institute for Patient Access' year-long blog series, **"By All Accounts."**

UTILIZATION MANAGEMENT & ACCESS BARRIERS



Across AfPA working groups and coalitions, advocates focused this year on ensuring patient-centered care by eliminating access barriers and reducing burdensome utilization management. Meanwhile, the Keep My Rx campaign maintained its emphasis on implementing patient protections, as the Patient Access Collaborative served as a vibrant hub for advocates to share best practices and materials.

Non-Medical Switching

AfPA started the year by releasing results of a first-of-its-kind **national study** on the qualitative impact of non-medical switching. The study's **findings** conveyed the widespread negative consequences of this cost-cutting technique and bolstered the Keep My Rx campaign's work on state-level initiatives to maintain stable patients' access to their medication. The campaign engaged with stakeholders in Texas, Florida and Iowa, among other states.

Utilization Management

Meanwhile, the Patient Access Collaborative served as a hub for advocacy organizations from across disease communities who recognize that step therapy, non-medical switching and prior authorization impede patient-centered care. The group shared best practices and educational materials to raise awareness about the harm caused by restrictive utilization management practices. It also held a series of webinars featuring guest hosts from organizations like Arthritis Foundation, Medicare Access for Patients Rx and the Biologics Prescribers Collaborative.



GIVING BACK



This year, AfPA took time to give back to the community it has called home for 13 years.

Staff spent a day this summer at the DC Central Kitchen, which provides meals, jobs and training to help combat poverty and hunger throughout Washington, DC. The AfPA team tried their hands at slicing apples, chopping lettuce, organizing spice cabinets and bagging trash—all while wearing signature hairnets.

In October, AfPA hosted a diaper drive during its fifth annual Infant Health Policy Summit.

Summit organizers and attendees overwhelmed AfPA with donations of diapers, wet wipes and Pull-Ups for infants and toddlers. AfPA was pleased to deliver more than 2,000 diapers to the Greater DC Diaper Bank, which empowers families throughout the region by providing for basic baby needs.



And in November, Executive Director Brian Kennedy represented AfPA and IfPA at San Diego's annual Padres Pedal the Cause, a community-wide cancer research fundraiser.

Brian completed the Olympic Challenge, a 55-mile bike ride, and raised more than \$3,000 for the cause.



Alliance for
Patient Access

MOVING FORWARD

AfPA enters 2020 ready to build upon existing advocacy efforts—and to launch two new initiatives dedicated to building a patient-centered health care system.



First, the new year will also bring a new stakeholder coalition. The Vision Health Advocacy Coalition works to raise awareness and improve treatment access for the millions of Americans living with macular degeneration, thyroid eye disease, dry eye syndrome and other vision conditions.



Second, AfPA will embark upon its 10th clinician working group, this one dedicated to patient-centered care for rare diseases. AfPA's Rare Diseases Working Group will hold its first meeting in February 2020.

Look for details, new materials and initiatives from these groups at AllianceforPatientAccess.org.



**WATCH, READ, LISTEN, JOIN,
FRIEND AND FOLLOW US IN 2020!**



AllianceforPatientAccess.org



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[AfPA Patient Access Podcast](#)