



# 2018 ANNUAL REPORT



**Alliance for  
Patient Access**



**Institute for  
Patient Access**



**National  
Physicians Biologics**  
Working Group



**Hepatitis Therapy  
Access** Physicians  
Working Group



**Pain Therapy  
Access** Physicians  
Working Group



**Respiratory  
Therapy Access**  
Working Group



**Oncology Therapy  
Access** Physicians  
Working Group



**Cardiovascular Disease**  
Working Group



**Neurological Disease**  
Working Group



**Diabetes  
Therapy Access**  
Working Group



Coalition for  
Clinical Trials  
Awareness



NATIONAL COUNCIL OF  
**PHYSICIAN  
LEGISLATORS**



**The Headache  
& Migraine**  
POLICY FORUM



AfPA  
**SurveyHub**

**NCfIH**

National Coalition  
for Infant Health

Protecting Access for Premature Infants through Age Two



**KEEP MY Rx**



ALLIANCE FOR  
**Balanced Pain  
Management**



**MOVEMENT  
DISORDERS**  
POLICY COALITION



PARTNERSHIP TO ADVANCE  
**Cardiovascular  
Health**



**DCAN**  
DERMA CARE ACCESS NETWORK



ALLIANCE FOR  
**Gout Awareness**



Patient Access Collaborative

**bpc**

BiologicsPrescribers  
COLLABORATIVE



**CFEN**  
Cystic Fibrosis Engagement Network



**Diabetes Policy  
Collaborative**

Dear Members & Supporters:

In a year of unprecedented policy challenges and polarizing politics, the Alliance for Patient Access and Institute for Patient Access forged ahead with their hallmark advocacy, education and leadership. **With your support and participation, we didn't just build upon existing initiatives; we made 2018 a year of exciting firsts.** For instance:

The Institute for Patient Access assumed an online presence all its own when [InstituteforPatientAccess.org](https://InstituteforPatientAccess.org) launched in August. The website showcases original educational materials generated through IfPA. It also houses the organization's independent analysis and responses to health technology assessments such as those issued by ICER.

We embarked upon polling, conducting national surveys to ask questions such as: Does the 340B program benefit patients? Are lengthy prior authorizations for life-saving drugs justifiable? Are parents equipped to protect their young children from preventable disease? The surveys were conducted across IfPA and AfPA coalitions, with results catalogued on AfPA's [SurveyHub](#).

We welcomed the Alliance for Gout Awareness to AfPA's cadre of coalitions. From patient empowerment forums to educational videos, the group aims to elevate public dialogue about a disease that many people have—but few talk about.

AfPA launched its [Patient Access Podcast](#) series. Interviews capture expertise from physicians, patients and experts throughout AfPA's working groups, coalitions and partner organizations. Initial episodes explore insulin affordability, rare disease awareness, utilization management policies and more.

Finally, AfPA and IfPA hosted their first-ever health policy leadership retreat. Entitled "Worth It?," the two-day event explored value and valuation in today's health care system. It also afforded AfPA the chance to dive deep, asking: What drives us? What differentiates us? What directs us toward the future? The answer led us to crystalize our mission into three core pillars: the physician-patient relationship, value and access.

Meanwhile, we continued strengthening core competencies. AfPA bolstered relationships with members of Congress, holding one-on-one meetings during Capitol Hill days, and hosting panel discussions for congressional staff and advocates. We presented 47 Champion of Medicare Access awards to U.S. senators and representatives.

We also boosted our supply of educational materials on policy issues that impact patient access, releasing more original videos and IfPA Policy Blog posts than in any year past.

And we continued to grow our membership, welcoming still more ardent, committed physician advocates to the fight for patient access—and opening our coalitions to even more dynamic member organizations.

Please take a moment to look back with us on an exciting year. These achievements would not have been possible without your time, resources and encouragement. We are grateful for your support, and we look forward to the year ahead.

Sincerely,



A handwritten signature in black ink, reading "D Charles MD".

DAVID CHARLES, MD  
National Chairman




A handwritten signature in black ink, reading "B Kennedy".

BRIAN KENNEDY  
Executive Director

# 2018

## BY THE NUMBERS

**75**   
INFOGRAPHICS

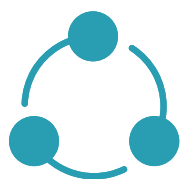
 **14** ACCESS  
REPORT CARDS

 **19**  
PAPERS

**14**  
COALITIONS

 **109**  
BLOG POSTS

**2,023**   
SURVEY  
PARTICIPANTS



**556**  
COALITION  
MEMBERS

**29** SPONSORED  
EVENTS



**8** WORKING  
GROUPS 




**800+**   
AFPA MEMBERS

 **6** PODCASTS

**24**   
VIDEOS

**10,129**  
TWITTER  
FOLLOWERS



 **36,646**  
FACEBOOK  
REACTIONS,  
SHARES &  
COMMENTS

# 2018 ANNUAL REPORT

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# BIOLOGICS



Marked by a rapid succession of proposals, policy plans and regulatory developments, 2018 may well have been the year of biosimilars policy. AfPA's National Physicians Biologics Working Group kept pace, weighing in and advocating for patient access.

Efforts included:

- Official comment and testimony on Food and Drug Administration regulatory issues, including interchangeability, innovation and marketplace competition
- Letters in 10 states on the issue of biosimilar interchangeability
- Presence at major society meetings and trade shows
- A working group meeting and Capitol Hill fly-in for working group members.

The group also produced several new educational materials, including a video on "[Understanding Pharmacovigilance](#)" and a

"[Fast Facts](#)" policy paper summarizing the year's regulatory and policy developments. These topics also materialized at the Institute for Patient Access and Alliance for Patient Access' third annual [National Policy & Advocacy Summit on Biologics and Biosimilars](#).

The working group's efforts were reinforced by the work of the [Biologics Prescribers Collaborative](#), a project of AfPA whose membership includes six medical societies. The collaborative offers educational resources on prescribing and approval of biologics and biosimilars.

# CARDIOVASCULAR



Cardiovascular health has captured headlines this year, from new clinical guidelines to dramatic price reductions in innovative therapies. All the while, the Partnership to Advance Cardiovascular Health and AfPA's Cardiovascular Disease Working Group have pushed forward—raising awareness and fighting for better access to treatment.

The two groups advocated through:

- A national cardiovascular health policy [summit](#) held in Washington, DC featuring policymakers, health care providers, advocates and patients
- A series of [testimonial videos](#) outlining the detrimental effect of prior authorization for patients at risk for heart attack or stroke
- An [educational video](#) highlighting the link between cardiovascular disease and diabetes
- State-specific, physician-led efforts to improve access to innovative PCSK9 inhibitors, complete with opinion-editorials, state newspaper coverage, a petition, a radio media tour and a letter to a state insurance commissioner signed by 12 health care providers
- A national [online survey](#) confirming that Americans consider access barriers for cardiovascular patients “unreasonable” and “dangerous.”



**Cardiovascular Disease**  
Working Group



PARTNERSHIP TO ADVANCE  
**Cardiovascular  
Health**

# DIABETES



From advocacy training to educational content, the Diabetes Policy Collaborative and AfPA's Diabetes Therapy Access Working Group strove this year to address a growing problem: people with diabetes' inability to access appropriate medicine and supplies.

Advocacy and education efforts included:

- A physician-authored white paper from the Institute for Patient Access entitled, "[Protecting Access to Diabetes Care](#)"
- "[The Middleman](#)," an educational video from the Diabetes Policy Collaborative narrating the role of the pharmacy benefit manager in insulin unaffordability
- A [testimonial video](#) from the Diabetes Policy Collaborative detailing Type 1 patients' struggles with non-medical switching
- An AfPA Patient Access Podcast physician [interview](#) entitled, "Why Isn't Insulin Affordable?"
- Training sessions at prominent Type 1 diabetes conferences to equip patients to advocate for improved access.



**Diabetes  
Therapy Access**  
Working Group



**Diabetes Policy  
Collaborative**

# HEPATITIS

Some state Medicaid systems are **FAILING** patients with **Hepatitis C**



Health plan barriers block patients from being cured of the progressive disease.

This year, AfPA's Hepatitis Therapy Access Physicians Working Group continued its work toward eliminating barriers that keep hepatitis C patients from curative treatment.

Members honed in particularly on Medicaid populations—and with encouraging success. [Illinois](#), which had previously required a 17-step prior authorization process, opened access to all infected patients—regardless of their liver fibrosis severity. Other states, such as [Oregon](#) and Ohio, also shifted course.

To drive its pro-access agenda, the working group met with state Medicaid officials for briefings on patient access. A series of [report cards](#) helped to raise the issue's

visibility online, while state-by-state successes were chronicled in the Institute for Patient Access [Policy Blog](#).

Meanwhile, members forged vital relationships with legislators to ensure that legislation addressing the opioid crisis also encompassed the needs of hepatitis C-infected patients. Members will continue pushing for improved access in 2019, both for Medicaid populations and incarcerated patients with hepatitis C.



**Hepatitis Therapy  
Access** Physicians  
Working Group

# NEUROLOGICAL

AfPA's Neurological Disease Working Group made strides this year in its effort to protect access to appropriate therapies for patients. Members' education and advocacy focused on issues such as:

- Access to treatment for pseudobulbar affect, which can impact patients with neurological conditions such as Alzheimer's and multiple sclerosis
- Non-medical switching of [botulinum neurotoxins](#), used to treat migraine and spasticity
- Additional diagnosis codes for Parkinson's-related conditions such as dyskinesia and [off periods](#)
- Impact of step therapy on patients with [epilepsy](#)
- Accessibility of headache and migraine therapies for patients who are [veterans](#) of the U.S. Armed Forces.

The working group's efforts were amplified by the work of the Movement Disorders Policy Coalition. Through a series of infographics and Institute for Patient Access Policy Blog posts, the coalition highlighted the link between [mental health](#) and movement disorders. It also raised awareness about the [problem](#) of [stigma](#).



# ONCOLOGY

AfPA's Oncology Therapy Access Physicians Working Group encountered a range of advocacy challenges in 2018—none more pressing than a series of federal proposals and policy decisions about Medicare.

When the Trump administration suggested shifting Medicare Part B drugs to Part D, AfPA responded with:

- A letter outlining concerns about how such a policy would impact patient care
- An [infographic](#) depicting potential access challenges that could result
- An Institute for Patient Access Policy [Blog post](#) explaining how the move could hurt cancer patients.

When the administration suggested a Medicare experiment that would import foreign prices for Part B medicines and change the way these medicines are delivered in the United States, AfPA likewise responded with:

- A letter explaining why the proposed experiment could be disruptive for cancer care
- An Institute for Patient Access Policy [Blog post](#) highlighting concerns about the experiment
- An advertising campaign designed to raise public awareness on the issue.

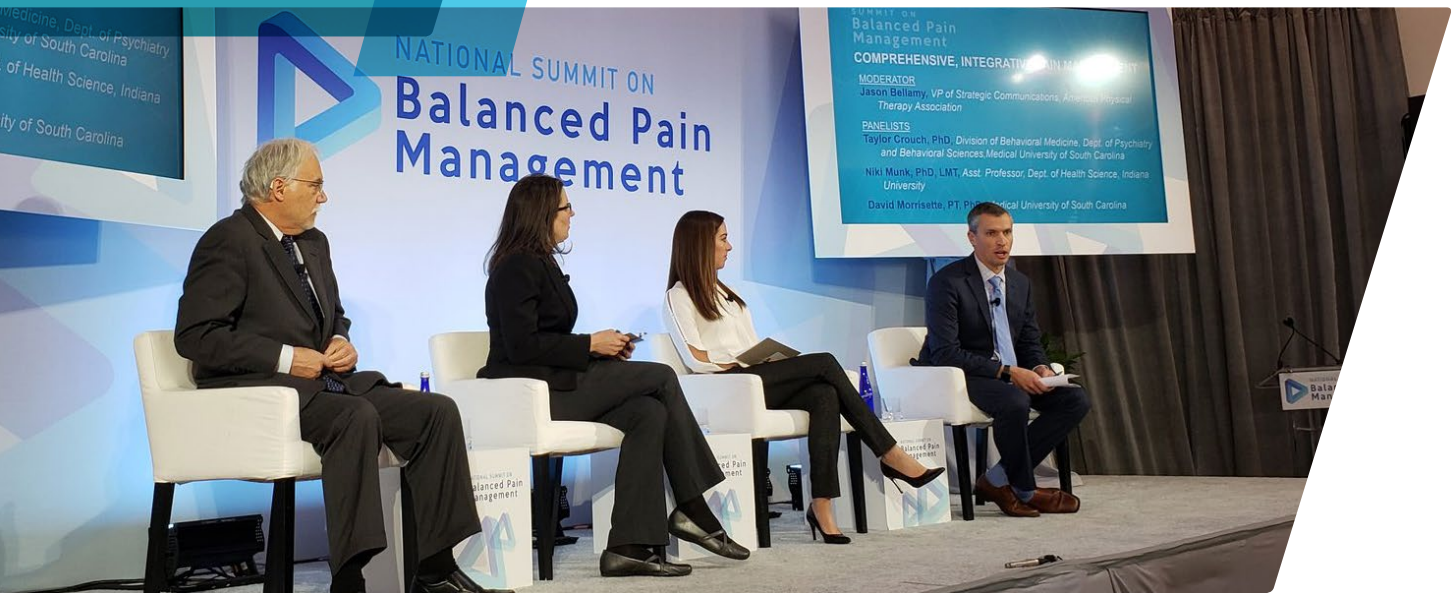
The working group also continued education efforts on longstanding access challenges, releasing a [video](#) describing specialty tiers and why high out-of-pocket costs hurt patient access.



**Oncology Therapy  
Access** Physicians  
Working Group



# PAIN



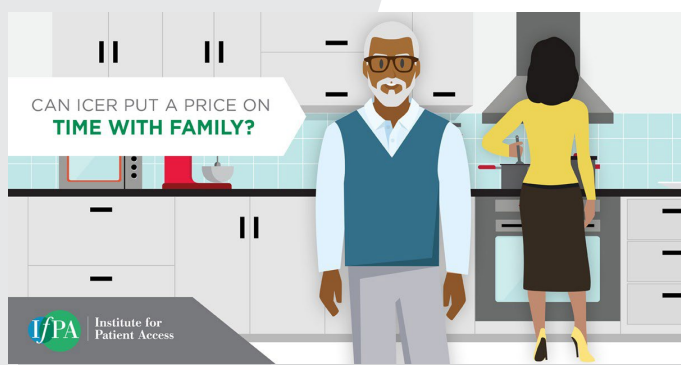
In 2018, the Alliance for Balanced Pain Management and AfPA's Pain Therapy Access Physicians Working Group advocated for health plans and formularies that allow better access to physical and occupational therapy, cognitive therapies, technology-based pain treatments, chiropractic care and other modalities of care.

Efforts included:

- A [white paper](#) identifying policy strategies for addressing pain amid the national opioid crisis
- A [national survey](#) gauging public attitudes toward balanced pain management
- A [testimonial video](#) depicting how comprehensive, integrative pain care helped a U.S. veteran overcome opioid addiction.

The groups' efforts culminated in the fifth annual [National Summit on Balanced Pain Management](#), held November 27 in Washington, DC. The event featured members of the regulatory community, nonprofits, industry and patient groups. The day-long event examined how patient engagement, technological advancements and policies that allow for more integrative care can move the nation towards a safer, more personalized approach to treating pain.

# RESPIRATORY



In 2018, AfPA's Respiratory Therapy Access Working Group stood by a core message: Respiratory care is not a one-size-fits-all endeavor.

To relay this message into meaningful policy, two working group members authored an Institute for Patient Access policy brief, "[Asthma & Non-Medical Switching](#)."

The working group also engaged with ICER, or the Institute for Clinical and Economic Review, in its analysis of innovative therapies for uncontrolled asthma. Participation yielded:

- An official [response](#) to both ICER's scoping document and its draft evidence report on the therapies
- An advocate-friendly [one-pager](#) outlining the flaws of ICER's report
- A series of [graphics](#) to raise awareness through social media about the report and its potential impact
- An Institute for Patient Access Policy Blog [post](#) summarizing concerns about ICER's report and its potential impact on patient access
- [Earned media](#) conveying IfPA's concerns about the final evidence report.



**Respiratory  
Therapy Access**  
Working Group

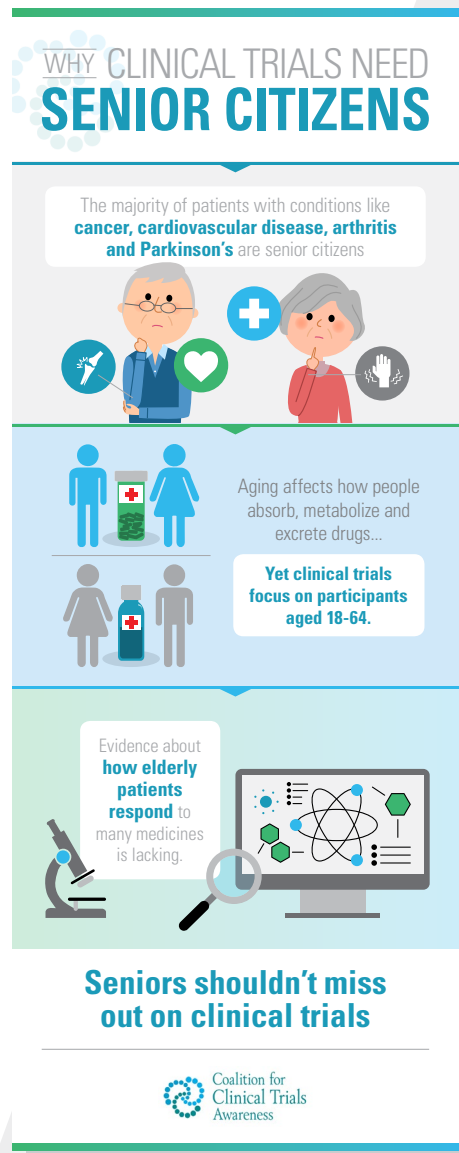
# CLINICAL TRIALS

This year, the Coalition for Clinical Trials Awareness pushed to improve awareness about clinical trials participation for two historically underrepresented groups: infants and senior citizens.

The issue dominated the 2018 [Clinical Trials Awareness Week](#), which included:

- A [Twitter](#) town hall event where patients, families of clinical trials participants, and patient advocacy organizations discussed the importance of clinical trials participation
- A [panel discussion](#) at the United State Capitol featuring physicians and advocates on the topic of infant participation
- A series of graphics designed to raise awareness about the need for [seniors](#) and [infants](#) to participate in clinical trials.

The event led to earned [media coverage](#), a presentation before the [National Institutes of Health](#) and continued support by the Coalition for Clinical Trials Awareness and the National Coalition for Infant Health for the Promoting Life Saving New Therapies for Neonates Act, H.R. 2641.



**WHY CLINICAL TRIALS NEED SENIOR CITIZENS**

The majority of patients with conditions like **cancer, cardiovascular disease, arthritis and Parkinson's** are senior citizens

Aging affects how people absorb, metabolize and excrete drugs...

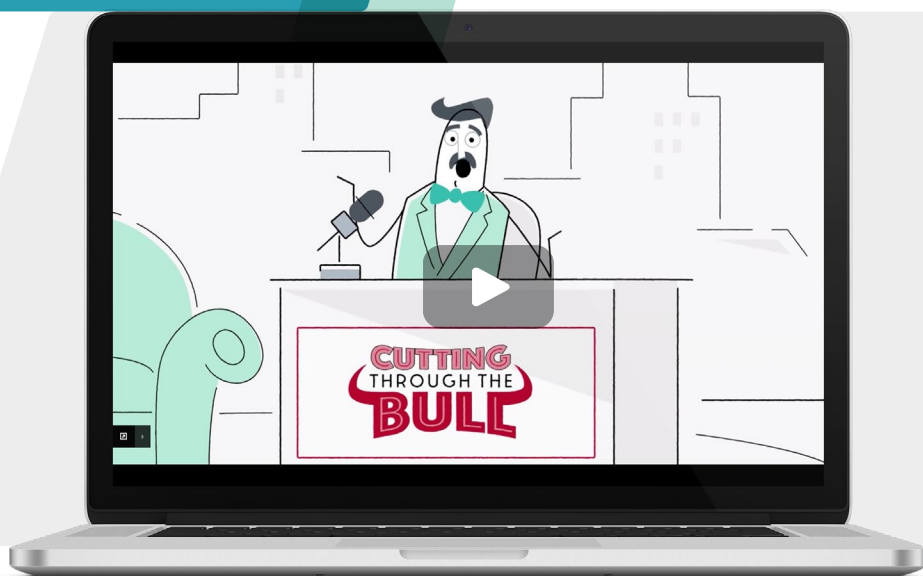
**Yet clinical trials focus on participants aged 18-64.**

Evidence about **how elderly patients respond** to many medicines is lacking.

**Seniors shouldn't miss out on clinical trials**

Coalition for Clinical Trials Awareness

# CYSTIC FIBROSIS



This year, the Cystic Fibrosis Engagement Network tackled policies that undermine access to treatment for patients with cystic fibrosis.

The organization addressed proposals for Medicaid work requirements head on, submitting a letter to the Centers for Medicare and Medicaid Services and issuing an [infographic](#) to raise awareness about what such policies could mean for people with cystic fibrosis.

CFEN also took a hard look at the issue of prior authorization, providing a sardonic synopsis in its “[Cutting Through the Bull on Prior Authorization](#)” video. Access issues again took center stage in an AfPA [Patient Access Podcast](#) episode, “Every Day is a Battle Against Cystic Fibrosis.”

What *does* work for these patients and their families? The Food and Drug Administration’s fast track process, also the topic of a 2018 CFEN [educational video](#).

And, in the interest of other policies that support access, CFEN developed its “[Health Care Bill of Rights](#).” The document offers a framework for regulators and legislators weighing decisions that could impact patients with cystic fibrosis.

# GOUT



The Alliance for Gout Awareness launched this year with a core message: Gout is debilitating and stigmatized—but also treatable.

The group aims to educate the public about the disease and its impact—and to empower patients to persevere, find community and get the treatment they need. In pursuit of these goals, the Alliance for Gout Awareness:

- Held two Patient Empowerment Forums, one in Austin, TX and one in Honolulu, HI. The events advised patients on how to live with and manage the disease
- Issued a “[Fast Facts](#)” document outlining the basics of the disease and its treatment
- Released two motion graphics videos, “[Gout Hurts All of Us](#)” and “[Dealing with Uncontrolled Gout](#).”
- Created a series of [graphics](#) highlighting key statistics on gout’s societal impact as well as the facts about uncontrolled gout
- Conducted a national survey about the experience, stigma and treatment associated with gout
- Used national awareness events such as Pain Awareness Month and Gout Awareness Day to highlight educational materials on gout
- Released an AfPA Patient Access [Podcast](#) episode with Kenneth Thorpe, PhD, on the societal burden of gout.

# HEADACHE



The voice of patients and health care providers rang loud and clear this year through the work of The Headache & Migraine Policy Forum.

The group continued its education on the impact of migraine and headache disorders by:

- Releasing a powerful patient [testimonial video](#)
- Participating in the annual Headache on the Hill event, contributing to a record number of meetings with members of Congress
- Hosting a Capitol Hill [policy panel](#) event on headache's impact on veterans of the U.S. Armed Forces.

But perhaps The Headache & Migraine Policy Forum's biggest feat came with its engagement, along with that of other headache and migraine stakeholders, with the

Institute for Clinical and Economic Review's report on innovative CGRP inhibitors. The group made tremendous strides, including:

- Producing a series of [infographics](#) to generate awareness and dialogue about ICER's impact
- Creating a toolkit to equip physicians and patients to engage in the process
- Contributing to a record-breaking number of patients comments and input in the process.

Finally, HMPF conducted an [online survey](#) of women's perspectives on migraine and related policy.

# INFANT HEALTH



## The National Coalition for Infant Health's 2018 advocacy and education focused on:

- Access to [optimal nutrition for both](#) infants and expectant mothers
- Safe tubing [technology](#) in NICU facilities
- Respiratory syncytial virus [awareness](#) and prevention
- The unique needs of late-preterm infants and awareness of the [full spectrum](#) of prematurity
- Clinical trials [participation](#) and the development of therapies for neonates.

Efforts culminated in the fourth annual [infant health policy summit](#), which brought together health care providers, parents, advocates and congressional staff in Washington, DC, to consider how policy can address the challenges facing infants and their families.

# SKIN CONDITIONS



From the Royal Embassy of Denmark to the halls of the United States Capitol, the Derma Care Access Network used 2018 to trumpet its message of access to treatment for patients with skin conditions.

The organization—made up of patients, advocates, physicians and scientists—made step therapy a particular focus. The issue arose at DCAN's 2018 [annual meeting](#), held in May, and was the sole topic of discussion at the group's Capitol Hill [policy panel](#) event in November.

DCAN also weighed in on step therapy legislation, providing input at the federal level and also submitting letters to six states with step therapy legislation. Meanwhile, the organization continued education efforts through:

- An AfPA Patient Access [Podcast](#) episode featuring DCAN Medical Director Adam Friedman, MD
- Educational [infographics](#)
- Social media [engagement](#).

# NON-MEDICAL SWITCHING

Non-medical switching occurs when health plans drive stable patients to change from their current medication to a less expensive alternative—regardless of medical factors. And in 2018, the issue shaped the work of the Keep My Rx initiative, as well as efforts across the Alliance for Patient Access and the Institute for Patient Access.

Through a robust [online](#) and on-the-ground presence, Keep My Rx reached a broad swath of patients impacted by non-medical switching. Their effort included:

- Inviting patients to share their stories via an online portal
- Coordinating letter-desks to allow patients to contact their state legislators
- Conducting a [patient survey](#) in Texas to quantify patients' desire for policy solutions.

The effort was met with several successes. Both [Illinois](#) and [Maine](#) passed bills aimed at protecting patients facing non-medical switching.

The issue of non-medical switching also continued to inform a steady stream of educational materials, including:

- Infographics on non-medical switching for people with [mental illness](#), [chronic disease](#) and conditions treated by [neurotoxins](#)
- Physician-authored policy briefs on non-medical switching for patients with [asthma](#) and for patients treated with [botulinum neurotoxins](#)
- A [video](#) from the Diabetes Policy Collaborative featuring the testimonials of people with Type 1 diabetes.

# UTILIZATION MANAGEMENT



Prescription Process continued as a powerful source for educational resources on utilization management barriers, while the Patient Access Collaborative launched to unite advocates in raising awareness about these barriers and the importance of patient access.

Prescription Process' [online library](#) continued to grow in 2018, providing videos, graphics, papers and other educational resources on issues such as non-medical switching, step therapy, prior authorization, high co-pays and specialty tiers.

Meanwhile, the [Patient Access Collaborative](#) offered advocates from across disease communities the opportunity to join forces against burdensome utilization management techniques. The collaborative aims to share and disseminate resources on these issues—and coordinate efforts to protect patient access.



# HEALTH TECHNOLOGY ASSESSMENT

As the funding level—and the influence—of the Institute for Clinical and Economic Review grew, the Institute for Patient Access redoubled its efforts to bring the patient and clinician voice to the controversial valuation process.

IfPA continued its analysis of ICER reports, providing:

- [Official comment](#)
- Advocate-friendly [one-pagers](#)
- Social media [graphics](#) to raise awareness online
- IfPA Policy Blog analysis on valuations for [asthma](#), [endometriosis](#), [cystic fibrosis](#) and [migraine](#) therapies.

IfPA also expanded the scope of its response effort, [weighing in](#) earlier in the ICER review process and maintaining its message throughout.

Finally, IfPA teamed up with The Headache & Migraine Policy Forum to provide a record-breaking level of patient engagement in response to ICER's valuation of CGRP inhibitors. The effort included IfPA's first patient and physician toolkit, designed to equip and embolden advocates to participate in the effort.



# CO-PAY ACCUMULATORS



The “Co-Pay Surprise” frustrated patients and physicians alike this year.

In a sly cost-shifting move, health insurers introduced co-pay accumulator adjustment programs to discourage the use of manufacturer-provided co-pay cards for high-cost medicines. The results could mean unmanageable and unexpected expenses—even medication abandonment—for patients.

AfPA and IfPA tackled the issue head on, striving across working groups and coalitions to help providers and patients understand the phenomenon. The effort included:

- A quick-draw explainer [video](#) detailing how accumulator programs work
- A physician-authored [policy brief](#)
- [Infographics](#) to raise online awareness
- A [fact sheet](#) on potential policy solutions
- A series of IfPA Policy Blog [posts](#) on the issue.

Co-pay accumulators also served as the topic of a policy [e-brief](#) distributed by the National Council of Physician Legislators. The group consists of physicians who also serve as legislators in statehouses throughout the country.

# MOVING FORWARD

**AfPA and IfPA move into 2019 with a renewed sense of purpose.**

The organizations' joint 2018 health policy leadership retreat provided a chance to explore and distill core values. Thus, 2019 advocacy and leadership will stem from three fundamental ideals, which serve as the ideological pillars of the organization:

**Pillar 1: The Physician-Patient Relationship**

- Trust yields better health outcomes
- The physician-patient relationship encourages patient-centered care
- Policies should reinforce the physician-patient relationship.

**Pillar 2: Value**

- All stakeholders deserve a voice
- Valuation is not a one-size-fits-all endeavor
- Valuation should not dictate coverage.

Learn more online about these [principles](#) and the [health policy leadership retreat](#) that sparked them.

**Pillar 3: Access**

- Pricing should prioritize access
- Society shares both benefits and risks
- Utilization management should not undermine patient access.





Alliance for  
Patient Access



Institute for  
Patient Access

## WATCH, READ, JOIN, FRIEND AND FOLLOW US IN 2019!



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AfPA Patient Access Podcast