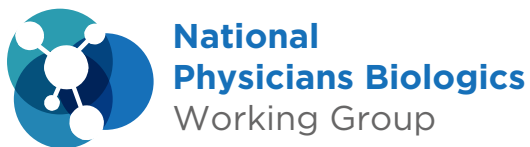




2017 ANNUAL REPORT

AfPA
Alliance for Patient Access

IfPA
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



**Physicians
Neurological Disease**
Working Group



**Diabetes
Therapy Access**
Working Group



Coalition for
Clinical Trials
Awareness



NATIONAL COUNCIL OF
**PHYSICIAN
LEGISLATORS**



The Headache
& Migraine
POLICY FORUM



ALLIANCE FOR
**Balanced Pain
Management**

NCfIH

National Coalition
for Infant Health

Protecting Access for Premature Infants through Age Two



AfPA
SurveyHub



MOVEMENT
DISORDERS
POLICY COALITION



PARTNERSHIP TO ADVANCE
**Cardiovascular
Health**

bpc

BiologicsPrescribers
COLLABORATIVE

**PRESCRIPTION
PROCESS**



DCAN

DERMA CARE ACCESS NETWORK



CFEN

Cystic Fibrosis Engagement Network



Diabetes Policy
Collaborative

Dear Members & Supporters:

With your help, we have had an outstanding year of unprecedented growth.

The Alliance for Patient Access forged ahead in 2017, adding another physician working group and six new coalitions. Yet our vision remains unchanged: a health care system where the physician-patient relationship remains paramount, where patients' voices matter, where the value of treatment is more than a dollar amount on a ledger, and where access keeps health care decisions in the hands of doctors and patients.

We've worked to keep these values alive as the policy challenges around us have grown ever more complex.

We hear our members describe the rapid expansion of health plan barriers. Once reserved for the most specialized and high-priced therapies, utilization management tactics such as prior authorization and fail first have become commonplace. The growing influence of pharmacy benefit managers has resulted in non-medical switching tactics that confuse or outright drive patients to the least-costly treatment option, despite their individual needs and physician's recommendation. Meanwhile, health analytics from third-party groups such as the Institute for Clinical and Economic Review stand to draw a line in the sand about whether patients can access innovative medicine.

The Alliance for Patient Access is fighting back – through direct advocacy, digital campaigns, trainings, and collaborations throughout the patient advocacy community. Meanwhile, the Institute for Patient Access continues to provide a steady stream of educational materials, summits, and health economic analyses.

We trust that this growing arsenal of capabilities has prepared us for 2018.

But first, we invite you to look back with us on the accomplishments of 2017. Thank you for your time, your input, your resources, and your faith in our ability to amplify the voice of health care providers and patient advocates.

We are grateful. And we stand ready for the challenges that lie ahead.

Sincerely,



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

DAVID CHARLES, MD
National Chairman



A handwritten signature in black ink that reads "Brian Kennedy".

BRIAN KENNEDY
Executive Director

2017 BY THE NUMBERS

800+

AfPA
Members



399

Coalition
Members



11

Coalitions &
Alliances



States Represented
by AfPA Members

26

Sponsored
Events



1,117

Attendees
at Events

9

Policy
Papers



26

Sponsored
Events



1,117

Attendees
at Events

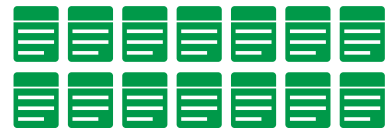
9

Policy
Papers



14

Access
Report Cards



15 YouTube
Videos



63,478 Video
Views



9,688

Facebook Reactions,
Shares & Comments



8,711

Twitter
Followers



6,933

Newsletter
Recipients



8

Working
Groups



44

Infographics

91



Blog
Postings



4,951

Signatures on Petitions
to Policymakers

2017 ANNUAL REPORT

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Biologics

This year brought new questions about how regulators should distinguish one biological therapy from another, what justifies switching patients' course of treatment, and how pharmacovigilance tools can help with tracing adverse events.



AfPA's National Physicians Biologics Working Group created new educational materials, which explored:

- The importance of [pharmacovigilance](#)
- The need for distinct [billing codes](#) for biological medicines
- The importance of high standards for biosimilar [interchangeability](#).

The group's advocacy included:

- A Capitol Hill fly-in day in Washington, DC
- Two meetings of working group members
- Official comments to the Food and Drug Administration on naming guidance and interchangeability draft guidance
- Comments to the Centers for Medicare and Medicaid Services on billing code policy
- Input in several states regarding biosimilar substitution laws.

In April, these issues came alive at AfPA and the Institute for Patient Access' **National Policy & Advocacy Summit on Biologics and Biosimilars**. The event featured members of Congress and the regulatory community, as well as patients, physicians, industry representatives, and fellow advocates.

AfPA also continued its work with the Biologics Prescribers Collaborative, which developed new educational materials and interacted with the FDA and the Centers for Medicare and Medicaid Services to ensure that prescribers' perspectives inform policy on biologics and biosimilars.



**National
Physicians Biologics**
Working Group



BiologicsPrescribers
COLLABORATIVE

Cardiovascular

This year, AfPA's Cardiovascular Disease Working Group collaborated with the Partnership to Advance Cardiovascular Health to raise awareness about a growing problem: patients' inability to access innovative treatment.



Education and advocacy efforts included:

- A series of [access report cards](#) from the Institute for Patient Access revealing staggering rates of health plan denials for PCSK9 inhibitors
- A series of [infographics](#) from the Partnership to Advance Cardiovascular Health amplifying the findings of the Institute for Patient Access report cards
- An educational video from the Partnership to Advance Cardiovascular Health entitled, "Access Barriers Affect Real People"
- A series of town hall meetings in multiple states that mobilized patients

and health care providers to engage with policymakers about reducing access barriers

- New AfPA [educational materials](#) on the impact of [prior authorization](#).



Cardiovascular Disease
Working Group



PARTNERSHIP TO ADVANCE
**Cardiovascular
Health**

Diabetes

This year, AfPA launched both a Diabetes Therapy Access Working Group and the Diabetes Policy Collaborative, each aimed at addressing high co-pays, non-medical switching, and other barriers that impede patient care.

Both groups are committed to the idea that health plan designs should facilitate, not undermine, diabetes patients' ability to make personalized health care decisions.

Advocacy and education efforts included:

- A Diabetes Policy Collaborative explainer [video](#) entitled, "Diabetes and Non-Medical Switching"
- Social media [graphics](#) to encourage online dialogue about the impact of switching on diabetes patients.

The Diabetes Therapy Access Working Group, which consists of policy-minded endocrinologists, internal medicine, and other health care providers, holds its first meeting in 2018.



**Diabetes
Therapy Access**
Working Group



**Diabetes Policy
Collaborative**





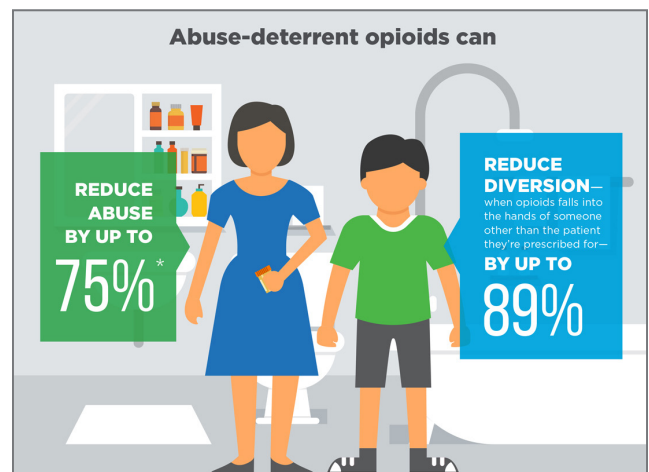
Pain

In 2017, America's opioid abuse epidemic became a priority at nearly all levels of policymaking. AfPA advocated for improved access to more treatment options for pain – including abuse-deterrent forms of opioids as well as other pharmacologic and non-pharmacologic options.

Alongside the Alliance for Balanced Pain Management, AfPA advocated for:

- More inclusive hospital formularies
- More comprehensive health plan coverage
- Patient access to physical and occupational therapies, cognitive therapies, chiropractic care, and other modalities of pain treatment.

In November, the third annual **National Summit on Balanced Pain Management** featured U.S. Representative Tim Ryan (D-Ohio) as well as members of the regulatory community, nonprofits, industry, and patient groups. The day-long event explored the value of a [multi-prong approach](#) to pain treatment.



Neurological

The efforts of AfPA's Neurological Disease Working Group were amplified this year by the formation of the Movement Disorders Policy Coalition – a platform for patients, health care providers, and other stakeholders to weigh in on health policy issues.

The groups' advocacy and education included:

- A Movement Disorders Policy Coalition [white paper](#) that tackles access issues as well as questions of stigma, mental illness, and caregiver burden
- [Feedback](#) on an Institute for Clinical and Economic Review report regarding the cost effectiveness of treatments for tardive dyskinesia
- Social media engagement on access barriers such as step therapy, prior authorization, and cost sharing

- [Educational materials](#) on access for patients with multiple sclerosis
- Collaboration with The Headache and Migraine Policy Forum on [migraine treatment](#).



**Physicians
Neurological Disease
Working Group**



Movement Disorders: Impact and Access to Treatment



Impact of Movement Disorders

COST
The financial cost of movement disorders is **staggering**. Parkinson's creates a U.S. economic burden of about \$25 billion a year, including missed work or job loss for patients and their caregivers, Social Security payments, and the cost of treatment.¹⁰ Nursing home services make up 57 percent of additional medical costs for Parkinson's patients.¹¹

Meanwhile, people diagnosed with tardive dyskinesia can rack up total health care costs of more than \$55,000 a year.¹² And a study ending in 2009 found that some Huntington's patients had annual health care costs of almost \$40,000.¹³

The personal costs are also profound. Movement disorders may hinder patients' ability to work, travel, exercise, engage in leisure activities, and interact with friends and family. Older patients in particular may find their independence fading as they increasingly rely upon caregivers for day-to-day support.

Movement disorders may hinder patients' ability to work, travel, exercise, engage in leisure activities, and interact with friends and family.

MOVEMENT DISORDERS POLICY COALITION • OCT 2017 3



Headache

In 2017, The Headache and Migraine Policy Forum worked to raise awareness and offer broad education about the experience and impact of headache.

Efforts included:

- A Capitol Hill policy forum, which welcomed Kenneth Thorpe, PhD, to present his findings on "[Prevalence, Health Care Spending and Comorbidities Associated with Chronic Migraine Patients](#)" to headache patients, advocates, and congressional staff
- The 10th Annual Headache on the Hill advocacy day
- A [video](#) and [infographic series](#) exploring the question, "Who are Headache Disorders and Migraine Hurting?"

Educational materials explained that these conditions not only debilitate patients but also affect society by impacting community involvement, family life,

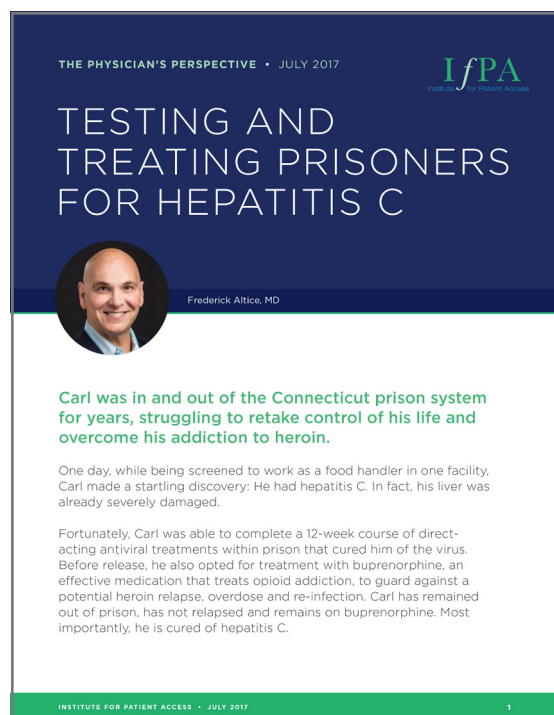
workplace productivity, and by generating expenses for both employers and the health care system.

Wrapping up the year, The Headache and Migraine Policy Forum supported [a panel discussion](#) at the **2017 Summit on Balanced Pain Management** to explore the issues of stigma and stereotype for migraine and headache disorders. Featuring input from a migraine patient, a physician, and a patient advocate, the panel revealed the challenges of fighting an invisible disease.



Hepatitis

This year, AfPA's Hepatitis Therapy Access Physicians Working Group used new educational materials to spotlight patient populations where access issues were most pronounced – and most dangerous.

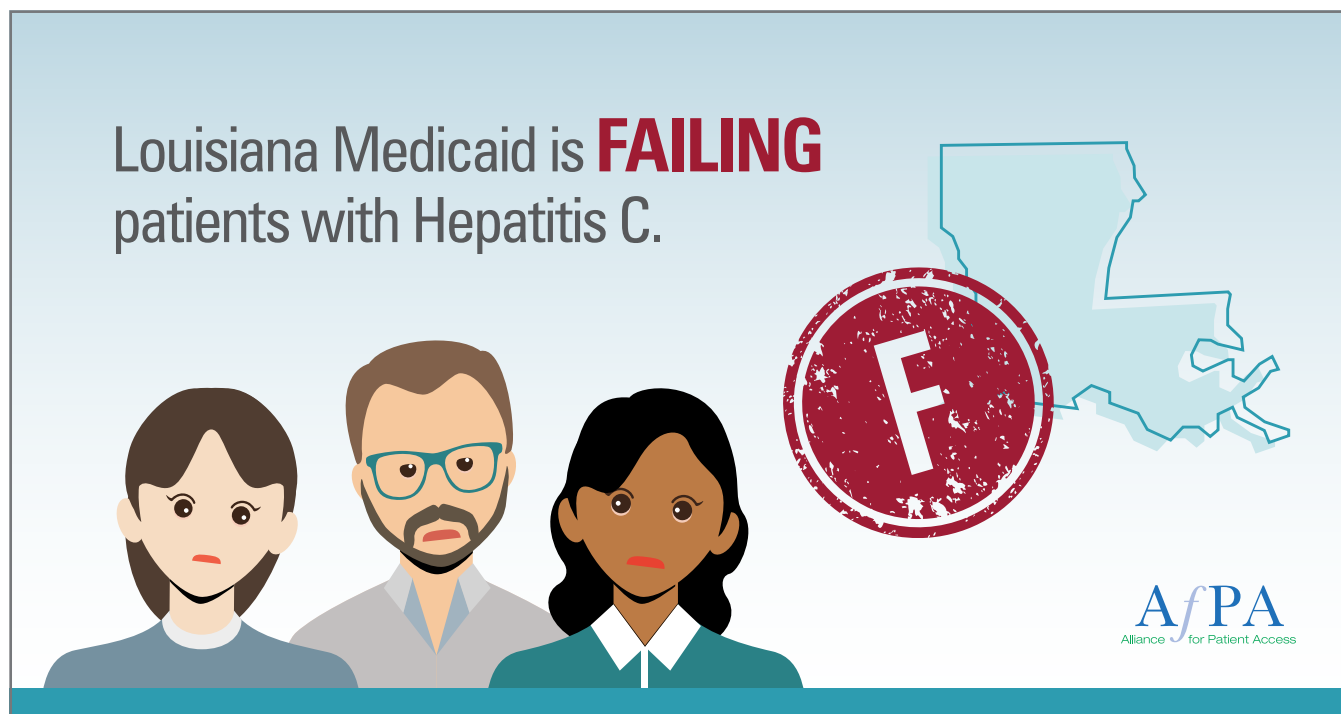


Education and advocacy included:

- An AfPA [policy brief](#) on access to hepatitis C cures for men and women in the U.S. prison system
- An [infographic series](#) and Institute for Patient Access policy [blog post](#) raising awareness about continued access barriers in state Medicaid systems
- A [video](#) produced in partnership with the National Coalition for Infant Health to educate patients and policymakers on the danger that untreated hepatitis C poses to women of childbearing age.



**Hepatitis Therapy
Access** Physicians
Working Group



Oncology

As concepts of value grew to dominate public dialogue and public policy on oncology this year, AfPA's Oncology Therapy Access Physicians Working Group created new materials to educate stakeholders.

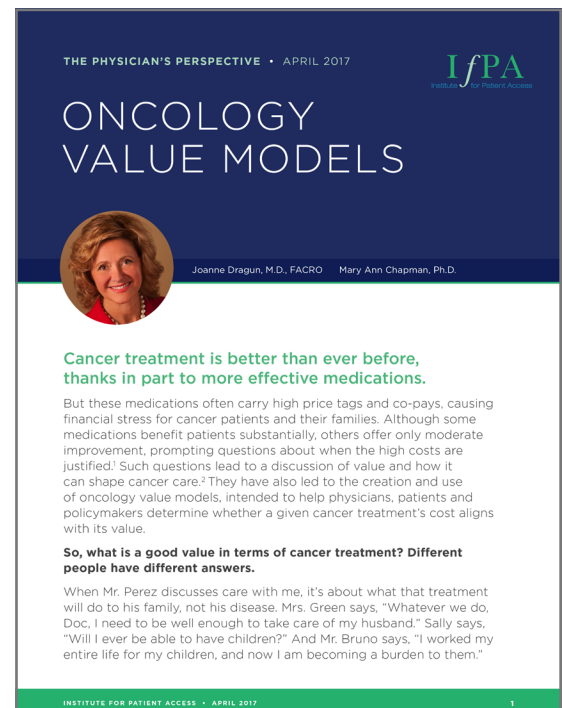


Efforts included:

- A physician-authored [policy paper](#) on oncology value models. The document explains that models should support, not supplant, physician judgment
- An explainer [video](#) about value-based contracting – how it works and what barriers prevent it from being used more broadly
- Input to the Food and Drug Administration's Oncologic Drugs Advisory Committee.



**Oncology Therapy
Access Physicians
Working Group**



Infant Health

The National Coalition for Infant Health's third annual health policy summit saw the culmination of the group's 2017 advocacy and education efforts, focused on:

- Ensuring access to an exclusive human milk diet for premature infants
- Protecting premature infants through the use of [safe hospital tubing](#)
- Raising awareness about [postpartum depression](#) and post-traumatic stress disorder
- Encouraging appropriate maternal nutrition and [seafood consumption](#)
- Advocating for preterm infants' access to prophylaxis for respiratory syncytial virus
- Ensuring [access to treatment](#) for hepatitis C for women of childbearing age.

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



Respiratory

This year, the allergists, pulmonologists, respiratory therapists, and patient advocates who comprise AfPA's Respiratory Therapy Access Working Group honed in on several access barriers that plague their patients: prior authorization, high co-pays, and non-medical switching.

Education and advocacy included:

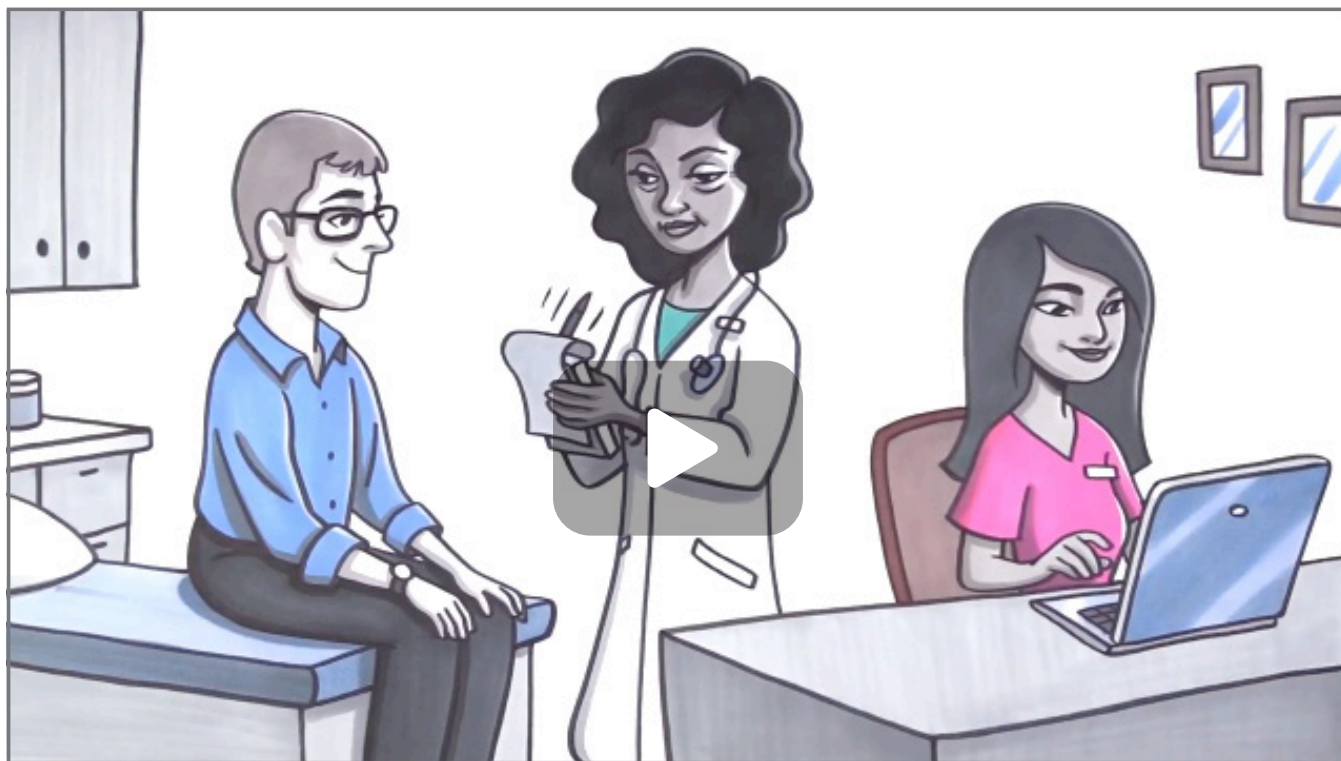
- A new [explainer video](#) on prior authorization. While the process ensues, the video explains, patients must wait – even those with chronic conditions that require ongoing treatment
- A Fast Facts [policy paper](#) from the Institute for Patient Access that explores the issue of co-pay coupons, which "make it more affordable

for patients to faithfully follow the medication regimen recommended by their physician"

- [Research](#) and [infographics](#) from the Institute for Patient Access about how non-medical switching affects patients with COPD and asthma.



**Respiratory
Therapy Access**
Working Group



Clinical Trials Awareness

The Coalition for Clinical Trials Awareness continued its push this year to improve awareness – and, ultimately, enrollment – in clinical trials.



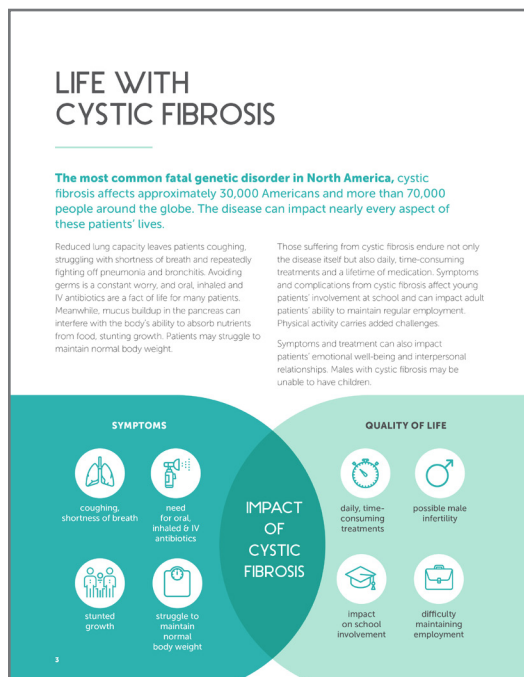
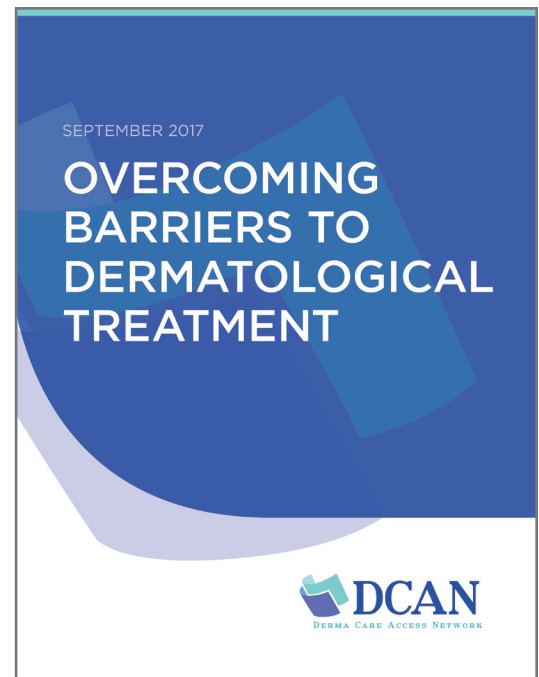
Advocacy and education included:

- Clinical Trials Awareness Week 2017, which gave rise to a social media campaign about participation challenges
- Online infographics highlighting statistics related to clinical trials enrollment
- A Twitter chat entitled, "Can Digital Media Save Clinical Trials?," which explored the role of technology in improving clinical trials awareness and participation
- A May 3 event at the U.S. Capitol that featured remarks by U.S. Representative Diana DeGette and a [roundtable discussion](#) inviting perspective from the health care, regulatory, and patient advocacy communities to consider ideas for improving clinical trials awareness.

Skin Conditions

This year, the Derma Care Access Network formed to bring together likeminded stakeholders to educate and advocate on behalf of patients with skin disorders.

The group laid the foundation for its advocacy with an inaugural white paper, “[Overcoming Barriers to Dermatological Treatment](#).” The group encourages policy at all levels that reinforces shared decision making between the patient and physician and makes treatment more available for patients with skin conditions.



Cystic Fibrosis

In response to the access challenges faced by the estimated 30,000 Americans with cystic fibrosis, AfPA launched the Cystic Fibrosis Engagement Network this year. It serves as a central voice of patients advocating for better access to approved therapies for the disease.

The group introduced a [white paper](#) in May describing both the impact of cystic fibrosis and the need for improved treatment access. Members continue to weigh in on federal, state, and regulatory policies that impact patients' ability to get the treatments they need.



Non-Medical Switching

In 2017, patient advocates saw non-medical switching emerge as a central access barrier across multiple disease states. The Alliance for Patient Access and the Institute for Patient Access worked to increase awareness and drive policy solutions.

Through [an analysis](#) of commercial health plan claims, the Institute for Patient Access discovered that certain patients who switch to a less expensive prescription drug actually experience higher non-drug health care costs later on. Continuity of care, however, keeps costs lower. Patients who did not switch medications experienced the lowest increase in non-drug health

care spending. The findings garnered both earned media and social media attention.

Non-medical switching also became the focus 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.

SWITCHING COSTS

Switches to **lower-cost drugs** yielded **higher average non-drug expenses** later on.

Patients who underwent multiple switches also saw higher average non-drug costs.



CONTINUITY OF CARE SAVES

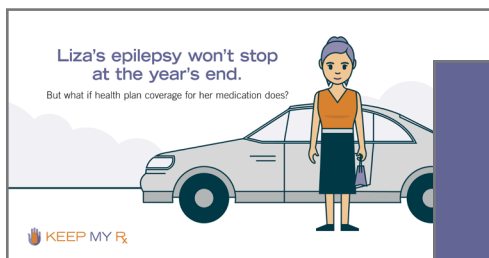
Patients who **did not switch** medications had the lowest per-member, per-month spending.





KEEP MY Rx

Through the Keep My Rx campaign, AfPA raised public awareness about non-medical switching in statehouses and advocacy communities. The campaign educates on the benefits of medical stability and the impact of non-medical switching through a steady stream of video and social media tools.



PRESCRIPTION
PROCESS

Meanwhile, Prescription Process launched an updated website that offers still more resources to educate and mobilize patient advocates on non-medical switching, as well as other access barriers such as step therapy and specialty tiers.

Cost Effectiveness & Health Technology Assessment

Gauging the cost effectiveness of innovative medicine has become a popular exercise, with one price analysis organization growing to prominence: the Institute for Clinical and Economic Review. This year, the Institute for Patient Access voiced concerns about flawed analyses and their impact on patient access, responding to ICER cost-effectiveness reports on arthritis, atopic dermatitis, abuse-deterrent opioids, and tardive dyskinesia.

In addition to submitting comments directly to ICER, the Institute for Patient Access also raised the issue:

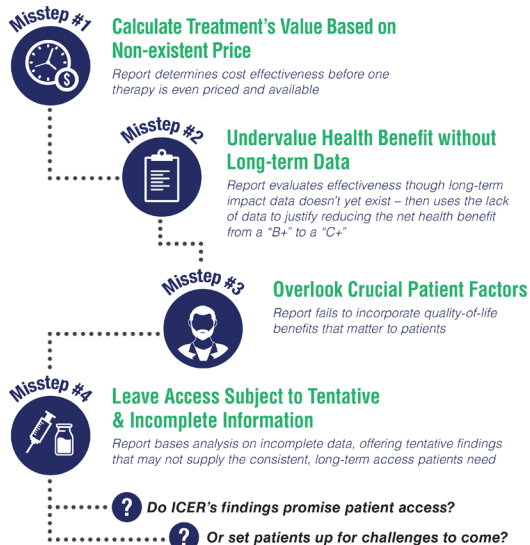
- On social media
- Through blog posts
- Via Twitter and Facebook activity

- By creating advocate-friendly one-pagers outlining IfPA's concerns.

The Institute for Patient Access will continue providing input during these analyses, premised on an important fact – the value of innovative medicine depends largely upon who's defining “value.”

How ICER's Missteps Leave Access in Doubt For Atopic Dermatitis Patients

The Institute for Clinical and Economic Review finds new treatments for atopic dermatitis to be cost effective – justifying health plan coverage for the medications. But methodological missteps invite questions about how secure patients' access to the treatments will be.

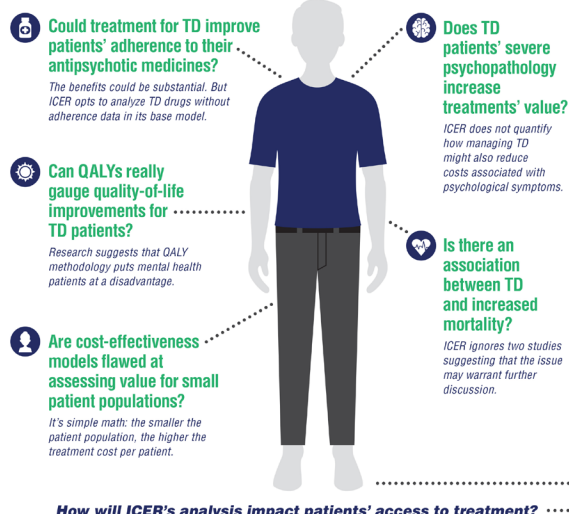


IfPA
Institute for Patient Access

What ICER's Analysis of Tardive Dyskinesia Treatments Doesn't Explain

The Institute for Clinical and Economic Review recently evaluated treatments for tardive dyskinesia, a movement disorder related to the long-term use of antipsychotic medications to treat serious mental illness. Men and women with TD experience uncontrollable movements of their face, limbs or torso – along with intense social stigma.

ICER's report says the treatments are not cost effective. But it leaves several key questions unanswered.



IfPA
Institute for Patient Access

allianceforpatientaccess.org/institute-for-patient-access

Watch, Read, Join, Friend & Follow Us in 2018!



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