

2016

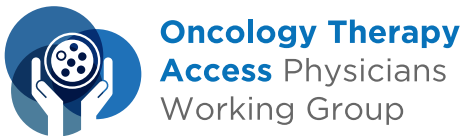
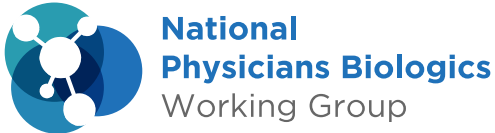
Annual Report

AfPA

Alliance for Patient Access

IfPA

Institute for Patient Access



Dear Members and Supporters:

As we conclude our 10th year of physician advocacy, the Alliance for Patient Access has a single message: **Thank you.**

Humbled by our growth since 2006, and excited about our future endeavors, AfPA strives to remain the foremost voice for physicians on issues of patient access. Your support allows us to continue growing, educating and advocating.

Looking back on the last decade, we see that much has changed. Treatments have become more advanced, more targeted and more effective. Cutting-edge research has resulted in the growth of new biologic and biosimilar therapies, cures for hepatitis C, and the explosion of precision medicine.

But the barriers that stand between patients and these treatments remain—and grow more prevalent. Utilization management techniques delay patients' access to therapies prescribed by their physicians. High deductibles and steep co-pays force patients to put off care or forego treatment altogether. Meanwhile, outside parties such as ICER and the Centers for Medicare and Medicaid Innovation threaten to limit patient access by imposing their own definitions of value.

These challenges stand to undercut patient access and undermine the physician-patient relationship. But AfPA and the Institute for Patient Access continue to amplify the physician voice on crucial patient access issues—from white papers

to white board videos, working group discussions to FDA testimony, earned media to social media, and summits in Washington to workshops in Copenhagen.

Today, with more than 800 members, AfPA's message continues to strengthen and its reach continues to expand.

Under a new presidential administration, the next four years may bring substantive changes to the Affordable Care Act and health care across the United States. AfPA looks forward to bringing the perspective of diverse and committed health care providers to policy discussions in 2017 and beyond.

In the meantime, we invite you to look back with us at the accomplishments of 2016. And to the supporters, health care providers, patients and fellow advocates who helped make the last 10 years possible, we thank you once again.

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 "B Kennedy".

BRIAN KENNEDY
Executive Director

2016 By The Numbers


800+ 
AfPA members


 **14** policy papers

 **48,341**
YouTube video views

 **4,299**
Facebook friends

 **9,099**
Twitter followers

 **47** states represented by AfPA members

41 
members in AfPA's National Council of Physician Legislators

19 
meetings, conferences & summits sponsored

6 
coalitions & alliances managed

50 
congressional champion awards presented

91 
blog postings

7 working groups     

 **3** continents on which AfPA/GAfPA produced programming



2016 ANNUAL REPORT

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**AfPA Physician
Working Groups**

Biologics

The promise of biological medicines continued to unfold this year with the introduction of three new biosimilars. And the Alliance for Patient Access forged ahead with supporting policies that promote pharmacovigilance, informed prescribing and the physician's role in steering patient care.



In April, AfPA's [National Physicians Biologics Working Group](#) teamed up with the Institute for Patient Access and the Biologics Prescribers Collaborative to host the [National Policy & Advocacy Summit on Biologics and Biosimilars](#). The event convened members of Congress and the regulatory community, patients, physicians, industry and fellow advocates. Speakers emphasized the need for naming, labeling and approval processes that give physicians enough information to gauge a biosimilar's suitability for a patient—and to monitor that patient's response.

Throughout 2016, AfPA conveyed the importance of [memorable suffixes](#) to aid physicians and patients in distinguishing one biological medicine from another. Through the work of the Biologics Prescribers Collaborative, AfPA determined that 80 percent of physicians prefer memorable suffixes.



How Patients **LOSE** with the

MEDICARE PART B DEMONSTRATION



When the Center for Medicare and Medicaid Innovation proposed a sweeping demonstration project that would reduce physician reimbursement and patient options for biologics and other medicines, AfPA launched an energized campaign to fight for senior citizens' continued access.

AfPA awarded its Patient Access Award to members of Congress who worked to protect Part B access. The IfPA policy blog followed the demonstration and mounting protest against it. Meanwhile, AfPA [infographics](#) and social media activity informed a growing audience about how the demonstration could impact patient care.

“By reducing payment for complex Part B drugs, which include sophisticated biologic medicines, CMS may cause reimbursement to fall below some clinics’ actual costs to handle and administer the drugs. As a result, fewer practices may be able to offer these therapies. Patient access could thus be affected in two ways: by fewer drug choices being available in the clinic setting and by fewer clinics offering Part B drugs.”

—IFPA POLICY BLOG

Pain

As national attention honed in on fighting the rise in opioid abuse and addiction, AfPA pursued a parallel objective: allowing physicians and patients to personalize pain management by offering more—and safer—options.

One such option is multimodal analgesia, the topic of a [2016 policy brief](#). As [Pain Therapy Access Physicians Working Group](#) member and anesthesiologist Roy Soto, MD, explains in the paper,

“The approach favors the strategic, customized combination of multiple analgesics—both opioid and non-opioid—to provide for safer, more personalized pain treatment.”



AfPA rallied at the state level for bills that afford better access to abuse-deterrent opioid formulations. The medications resists crushing or dissolving opioid medications, curbing recreational misuse.

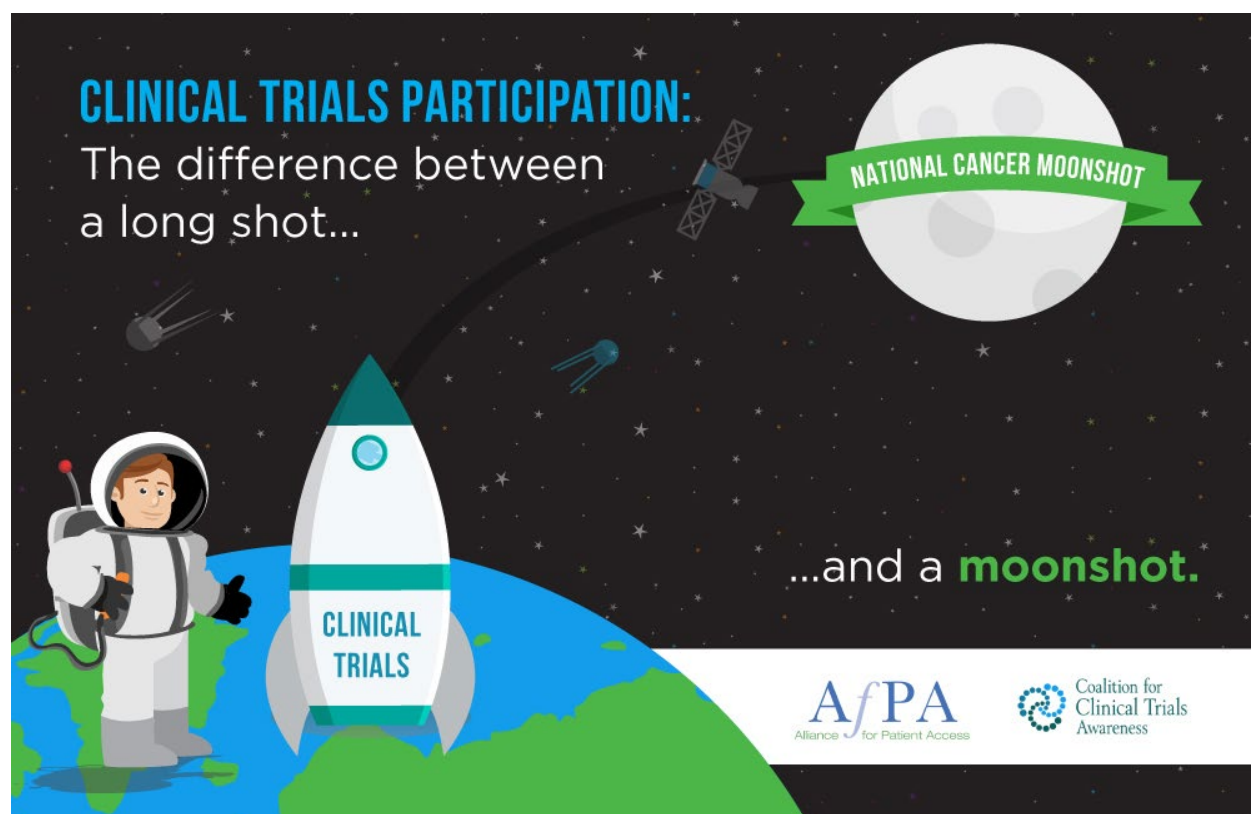
Meanwhile, the working group’s federal advocacy efforts culminated in a new video, “Finding an Opioid Abuse Solution that Works.” The video offers a checklist of key components that patients and physicians can use in weighing abuse solutions such as those proposed by the Centers for Disease Control and Prevention and the National Governors Association.

Restrictive hospital formularies and lack of health plan coverage pose barriers to access, however.



Oncology

This year gave life to the National Cancer Moonshot initiative—and launched hopes for faster, more coordinated and more rewarding efforts toward fighting cancer.



AfPA partnered with the Coalition for Clinical Trials Awareness to address the need for greater clinical trials participation and awareness at its September [health policy roundtable](#).

Meanwhile, AfPA's [Oncology Therapy Access Physicians Working Group](#) highlighted the importance of accessing a hallmark of the moonshot initiative: precision cancer medicine.

Data sharing, collaborative research and breakthrough treatments are laudable, essential goals. But without viable coverage and regulatory structures too, oncologists and cancer patients might just as well be wishing on the moon.”

—IFPA POLICY BLOG

In “[Improving Cancer Patients’ Access to Precision Medicine](#),” oncologist and working group chairman Alan Marks, MD, explores the barriers that impede access to precision diagnostics, which use genomic sequencing to help physicians determine the best course of treatment for patients. The paper laments health plans’ slowness in accommodating access to emerging oncology treatments.

AfPA’s “Access to Immuno-Oncology Therapies” video takes the conversation on health plan cost sharing a step further. By requiring patients to pay 20-25 percent of the cost of new

immuno-oncology therapies, the video explains, health plans are deterring cancer patients from accessing the very therapies that could save their lives.

Heightened national attention to cancer care and the introduction of breakthrough treatments gave new energy to the oncology community. But the Center for Medicare and Medicaid Innovation’s [Part B demonstration](#) threatened to cast a shadow over the year’s progress. AfPA’s oncologist members voiced opposition to the demonstration and its potential impact on their patients’ access to appropriate care.



Hepatitis

Three years after the first direct-acting antiviral cure for hepatitis C became available, many patients across the country spent 2016 still waiting for treatment.



Some states revised heavy-handed prior authorization practices in the face of legal action. Meanwhile, AfPA's [Hepatitis Therapy Access Working Group](#) took an active voice in [urging state Medicaid offices](#) to do right by patients whose livers—and lives—demanded timely treatment.

The working group also [pointed out](#) the access issues faced by state prisoners, those with a higher-than-average rate of hepatitis C infection, but an uncommonly slim chance of accessing a cure.

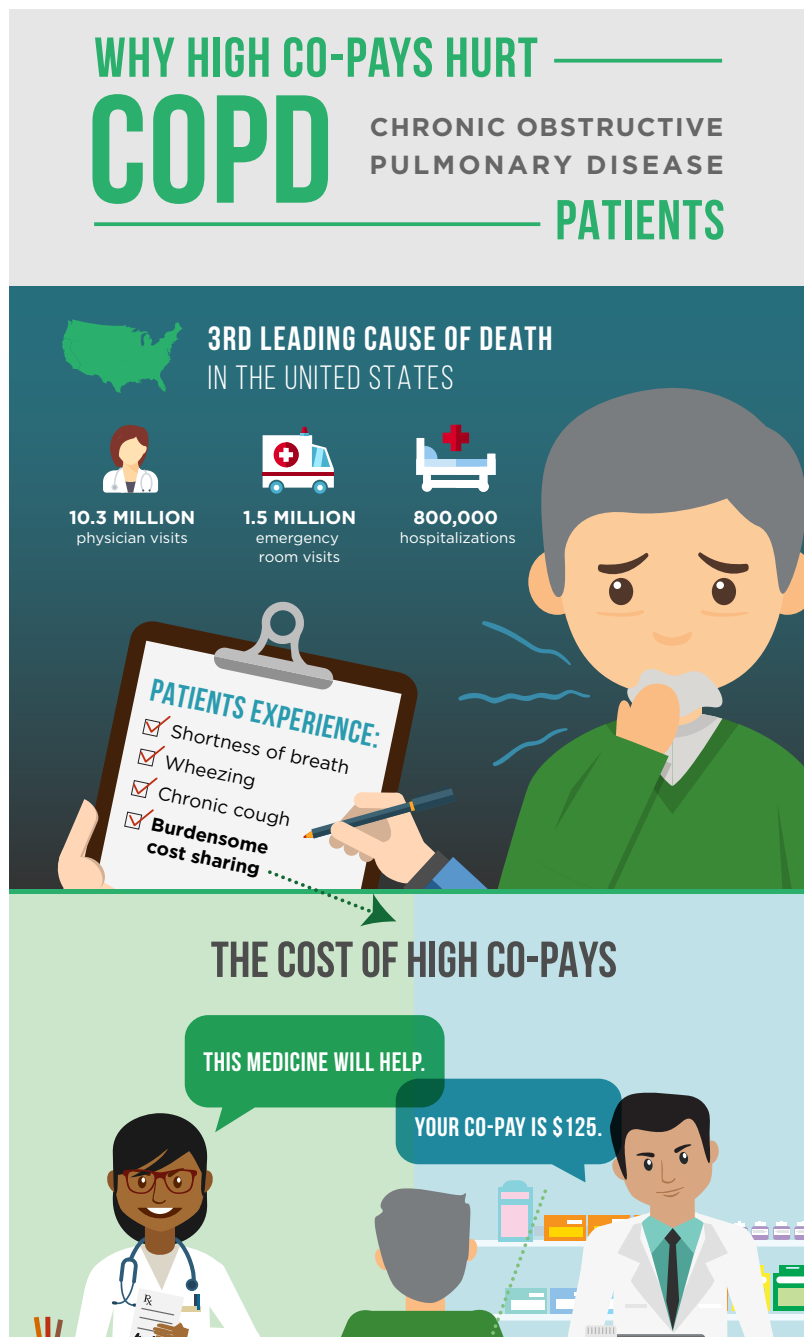
“...States may be breaking the law if they’re unfairly restricting access to hepatitis C treatment.”



—ROBERT GISH, MD, [“ACCESS TO HEPATITIS C CURES FOR MEDICAID PATIENTS”](#)

Respiratory

The allergists, pulmonologists, respiratory therapists and patient advocates who comprise AfPA’s [Respiratory Therapy Access Working Group](#) set a broad agenda this year with the publication of the group’s first white paper, “[Improving Access to Respiratory Care.](#)”



“Patients are often not sick enough to be in critical care but not well enough to manage symptoms without consistent intervention,” the paper explains, identifying high out-of-pocket costs, regulatory challenges and health plan coverage as barriers to the care and medication that patients need.

The group’s [educational materials](#) tackled the challenges of high co-pays, specifically for patients with asthma and COPD.

On the federal level, members supported a telemedicine bill that would provide greater access to respiratory therapists.

AfPA also weighed in on testing for the design of a new patient outcome metric.

Cardiovascular

Cardiovascular disease cuts across ethnicities and demographics as the leading cause of death in the United States. **But access to innovative treatment for cardiovascular disease is something altogether less common.**



To address those access barriers, AfPA launched its **Physicians Cardiovascular Working Group** with an inaugural meeting in August that invited input from physician advocates across the country. Members' concerns about burdensome and unfair prior authorization processes for treatments such as PCSK9 inhibitors took shape in the group's first white paper, **“Improving Access to Cardiovascular Care.”**

Neurodegenerative

The promise of new and forthcoming treatments for Alzheimer's, Parkinson's and Huntington's diseases raises a complex question for members of AfPA's newly formed **Physicians Neurodegenerative Disease Working Group**: **As new therapies for neurodegenerative diseases emerge, will health plans and coverage policies allow patients to access them?**



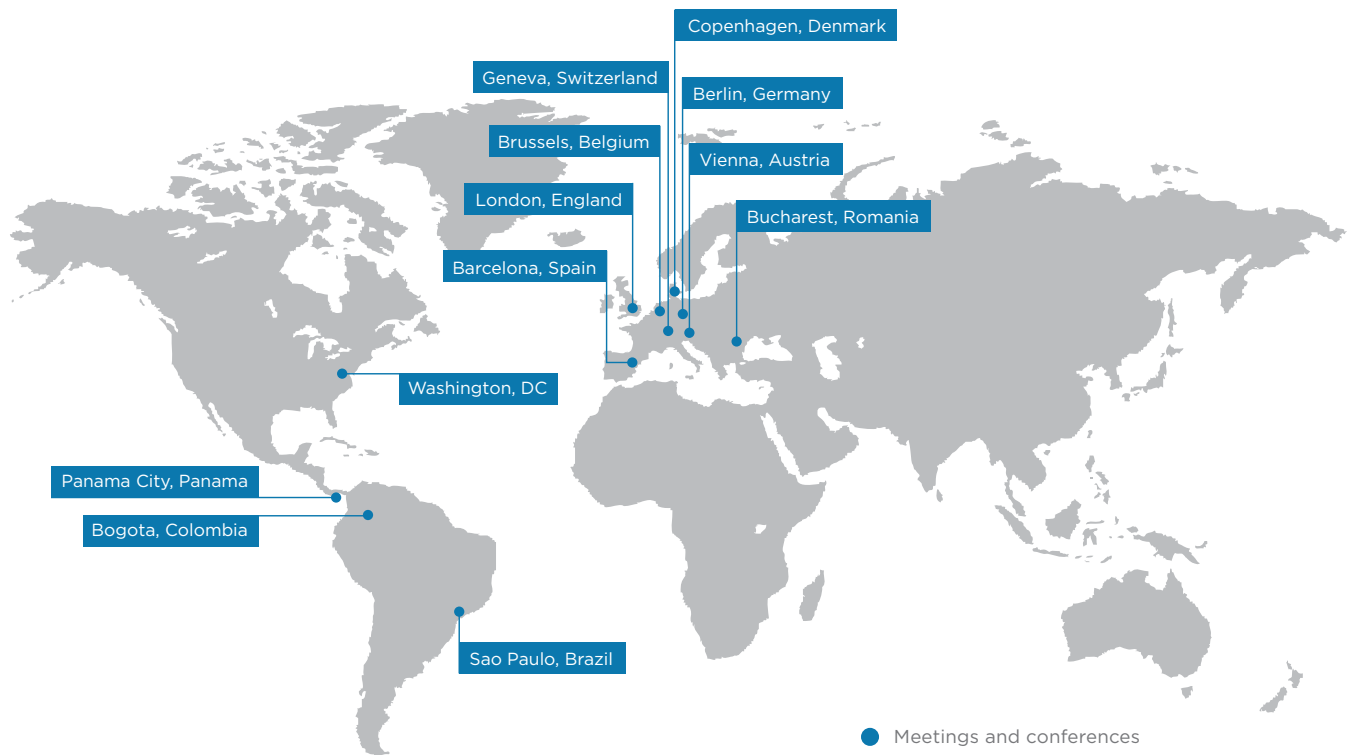
Physician advocates from eight states across the country met in July to discuss this question—and others—at the inaugural working group meeting in Washington, DC. In October, members compiled their insights into the group's first white paper, **“Protecting Patient Access to Treatments for Neurodegenerative Diseases.”**

Ongoing advocacy efforts focus on patient access to emerging therapies and increased funding for research and caregiver services.



Coalitions & Advocacy Initiatives

The Global Alliance for Patient Access



This year the [Global Alliance for Patient Access](#) reached an even bigger, even broader audience with its message of patient access to appropriate medical treatments and health care.

GAfPA partnered with the European Federation of Crohn's & Ulcerative Colitis Associations to host two immensely successful workshops, flying in over 70 international patient advocates to both Barcelona and the European Parliament in Brussels.

GAfPA also made bold strides in developing consensus among its

members and partners. In Bogota, Colombia, more than 20 patient advocacy groups coalesced into a coalition and signed a shared principles document on the importance of patient safety and access to biological treatments.

NOR-SWITCH

What will Norway's infliximab switching study tell us about the safety of switching patients from one biologic medicine to a biosimilar?

GAfPA also helped to bridge geographical divides by providing educational content in multiple languages. Its “NOR-SWITCH” white paper, which explores physicians’ insight on recent biosimilar switching data, was published in English, French, German and Spanish.

For Latin American audiences, GAfPA also provided several Spanish-language [resources](#) on the topic of [biosimilar naming](#).

“As more biosimilars become available globally, clinicians are eager to understand: How does switching between biological medicines affect patients? On June 13, the Global Alliance for Patient Access hosted an international group of physicians, researchers and patient advocates in London to take a closer look at one source of clinical data on switching—the NORSWITCH study.”

—IFPA POLICY BLOG

Medical society abstracts and poster presentations also offered a new venue for GAfPA to reach physicians on issues of patient access. GAfPA presented posters this year at two separate international medical society congresses.

National Coalition for Infant Health



The [National Coalition for Infant Health](#)'s second annual health policy summit saw the culmination of the year's advocacy and education efforts, focused on:

- Ensuring access to an exclusive human milk diet for premature infants
- Raising awareness about Postpartum Depression and Post-Traumatic Stress Disorder
- Encouraging appropriate maternal nutrition and seafood consumption
- Demanding preterm infants' access to prophylaxis for respiratory syncytial virus
- Supporting funding for Zika virus response and protection efforts.

Online and social media efforts made a substantial impact for these issues. The coalition's [infographic](#) on an exclusive human milk diet for preemies garnered thousands of impressions and hundreds of shares and engagements. The graphic's popularity led the coalition to translate it into Spanish, French and Hungarian.

Meanwhile, the challenge of preterm infants without health plan coverage for RSV prophylaxis gave rise to the story of the Gap Baby. The video anchored efforts during October's

#RSVAwarenessMonth, which also attracted thousands of impressions and nearly 9,000 YouTube views for the coalition's video.



Coalition for Clinical Trials Awareness

From support for federal 21st Century Cures legislation to a panel discussion on whether clinical trials conversations should become standard of care, the [Coalition for Clinical Trials Awareness](#) continued its push this year to improve awareness—and, ultimately, enrollment—in clinical trials.



Clinical Trials Awareness Week 2016 gave CCTA the opportunity to present its vision of what a federally sponsored awareness campaign on the benefit of clinical trials might look like.



The organization’s mock public service announcement, “Imagine Clinical Trials,” drew more than 32,000 views on YouTube.

Should Informing Patients About Clinical Trials Become Standard of Care?

A Health Policy Roundtable with Diverse Stakeholders



CCTA also continued exploring topical issues related to clinical trials awareness and enrollment. In September, it hosted a health policy roundtable that asked a diverse group of panelists: Should informing patients about clinical trials become standard of care? The group considered both the advantages and challenges of a health care system in which every patient would hear from his or her doctor about the potential to join a clinical trial.

Alliance for Balanced Pain Management

[The Alliance for Balanced Pain Management](#) made bold strides this year toward its overarching goal: defining the meaning and value of balanced pain management.



With the publication of its first white paper, “A Call for Understanding and Greater Access to Balanced Pain Management,” the group laid out the meaning and importance of comprehensive approaches—multimodal analgesia for acute pain and integrated care for chronic pain. It also highlighted the need for safe use and disposal practices.

A complementary [video](#), “Understanding Balanced Pain Management” offered another tool for the group’s educational efforts.



Finally, AfBPM’s work culminated in the group’s December summit. It brought together diverse stakeholders to explore the value of—and barriers to—balanced pain management. It also gave participants an active role in determining a path forward on making

integrated, personalized approaches more available to patients. Former NFL quarterback Ryan Leaf gave the event’s keynote address, sharing his story of pain treatment and addiction to illustrate the need for more patient options.

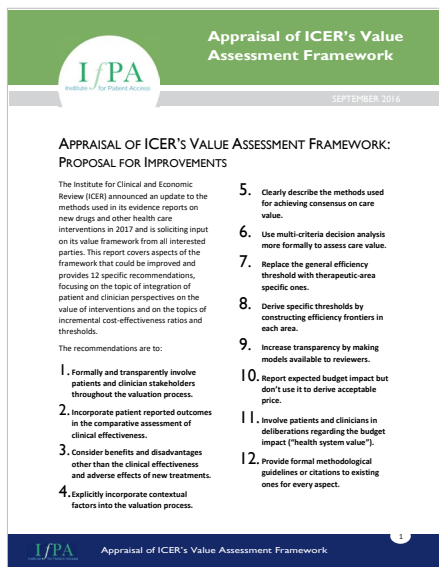
Institute for Patient Access

This year the [Institute for Patient Access](#) expanded its educational resources to include a new focus: economic analysis.

IfPA was vocal in [response](#) to the Institute for Clinical and Economic Review's request for feedback on improving its value framework. It also began responding to ICER's draft reports on the cost effectiveness of advanced treatments.

“Far from an end unto itself, a calculation such as ICER's value-based price benchmark goes on to inform crucial health plan features. These factors often determine whether a patient can access the treatment prescribed by his or her physician, and whether a physician can direct patient care as needed.”

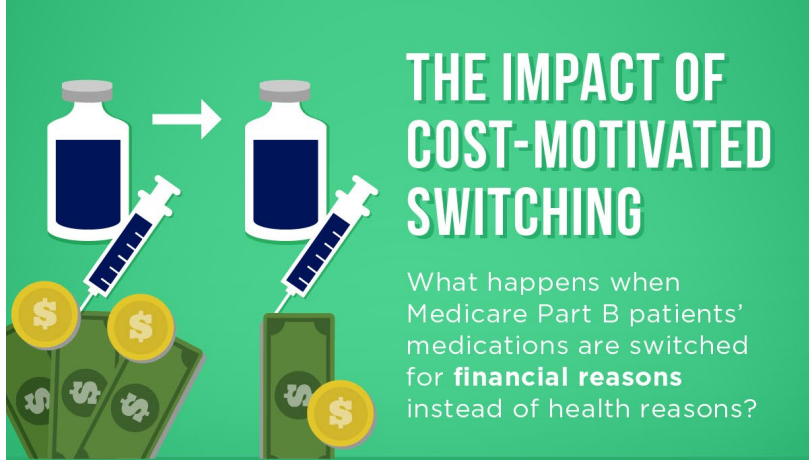
—INSTITUTE FOR PATIENT ACCESS LETTER ON ICER'S VALUE FRAMEWORK, SEPTEMBER 12, 2016



In addition, IfPA forged a new path by generating original data on an issue that has raised concerns across AfPA's working groups—non-medical switching.

AfPA first partnered with Prescription Process to point out how health plans drive patients to the lowest-cost option regardless of health factors, raising awareness via social media using **#DontSwitchMe**.

**PRESCRIPTION
PROCESS**

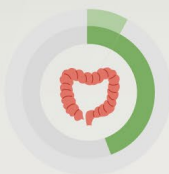


THE IMPACT OF COST-MOTIVATED SWITCHING

What happens when Medicare Part B patients' medications are switched for **financial reasons** instead of health reasons?

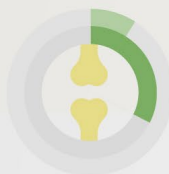
01

SWITCHING BEGETS SWITCHING.



CROHN'S DISEASE

8.1% of patients switched Part B drugs;
44.6% of these patients switched a second time



RHEUMATOID ARTHRITIS

9.9% of patients switched Part B drugs;
32.6% of these patients switched a second time



IMMUNODEFICIENCY

29.4% of patients switched Part B drugs;
46% of these patients switched a second time

02

CUT NOW, PAY LATER.



Rheumatoid arthritis patients who reduced upfront expenses by switching to a cheaper medication saw an increase in annual overall medical expenses of **\$6,254** to as much as **\$14,127**.

03

STABILITY SAVES.

Rheumatoid arthritis patients who were on the same treatment for 271 days or more had a yearly increase in payments of just \$201.

Research through the Institute for Patient Access then brought an analytical lens to the issue of cost-motivated treatment changes. IfPA found that some Medicare Part B patients who switch their medication for cost reasons face several issues later on: additional switches and higher overall annual costs.

IfPA will follow up on this initial data in 2017 with a similar analysis of commercial claims.



**Watch, read, join, friend
and follow us in 2017!**



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