2020
Annual Report

AfPA | Alliance for Patient Access
IfPA | Institute for Patient Access
Dear Friends & Supporters:

In a year when everything from high-school graduation ceremonies to Thanksgiving dinner was canceled, health policy advocacy held its own.

In fact, the COVID-19 pandemic drew a new level of national attention to health care issues. And at the Alliance for Patient Access and the Institute for Patient Access, the voice of health care providers rose to inform those policy conversations. As you review the pages of this year’s annual report, you’ll see examples such as:

• A series of clinician interviews highlighting how the pandemic impacts patients facing rare diseases, cancer, migraine disease, high cholesterol, asthma or osteoarthritis.
• A sweeping white paper titled “Fear Factor,” which spotlights the dangerous gaps in care occurring during the pandemic.
• Advocacy to limit out-of-pocket expenses for patients amid financial uncertainty—through Medicare Part D smoothing and limits on co-pay accumulator adjustment programs.
• Education and advocacy across AfPA working groups, coalitions and affiliates on the need for comprehensive, continued telemedicine access.

AfPA and IfPA’s online presence soared, evidenced by an unprecedented **15.5 million impressions on social media.**

But 2020 advocacy wasn’t limited to COVID-19. Heightened attention to health policy also allowed advocates to raise long-standing policy issues in a new light. For example:

• A national survey of people with thyroid eye disease examined the value of Medicare home infusion for more treatment options.
• A national claims data analysis underscored the ongoing access barriers facing premature infants who need preventive treatment from another deadly virus, RSV.
• And a renewed focus on utilization management took shape. As health plans waived utilization management for COVID-19 patients, advocates posed the question: If these barriers are bad for coronavirus patients, aren’t they bad for all of us?

Meanwhile, a new virtual platform for advocacy summits, webinars and working group meetings broadened the message of patient-centered care far beyond Washington, DC, welcoming new advocates into the fold. AfPA and IfPA’s online presence soared, evidenced by an unprecedented 15.5 million impressions on social media.

Together, we have made the most out of a deeply challenging year. We owe sincere gratitude to our clinician members, who continue to live out the principles of patient-centered care in dangerous circumstances, and to our supporters, who continue to make our work possible.

As we enter the new year, we are thoughtful about the challenges and the opportunities that lie ahead. We look forward to working hand in hand in 2021 to champion access, highlight the voices of patients and health care providers, and turn national attention on health policy into a heightened appreciation for patient-centered care.

With gratitude & hope for a healthy new year,

DAVID CHARLES, MD
Founder

JOSIE COOPER
Executive Director
2020 By the Numbers

STATES REPRESENTED BY AFPA MEMBERS: 50
WORKING GROUPS: 10
EVENT ATTENDEES: 2,439

YOUTUBE VIDEOS: 32
VIDEO VIEWS: 338,939
VIDEO IMPRESSIONS: 15.5 million

TWITTER FOLLOWERS: 13,725
FACEBOOK FOLLOWERS: 89,271

INFOGRAPHICS: 154
BLOG POSTS: 121
SURVEY PARTICIPANTS: 1,534
WEBINARS: 33
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In 2020, AfPA’s National Physicians Biologics Working Group and the Biologics Prescribers Collaborative dedicated their efforts to programming and educational content that increases awareness of biologics and biosimilars. Efforts included:

• The fifth annual National Policy & Advocacy Summit on Biologics, presented virtually for a diverse audience of stakeholders
• Webinars on barriers to biologic therapies and the impact of COVID-19 on chronic disease patients
• A look at the impact of precision medicine on biologics and patient-centered care
• An online survey highlighting where patients’ understanding of biologics still lags
• Continued policy discussion and education on biosimilar uptake and how the regulatory pathway is delivering on its promise to patients.

Ten years after Congress adopted a regulatory pathway for biosimilars, the promise of biologic medicine continues to expand for patients across a vast range of disease states.
Cardiovascular Disease & Diabetes

And given the growing link between diabetes and cardiovascular disease, the Diabetes Policy Collaborative and AfPA’s Diabetes Therapy Access Working Group joined alongside them. Efforts included:

- Hosting a webinar to empower health care providers to weigh in on the Institute for Clinical and Economic Review’s analysis of therapies for high cholesterol
- Rallying the community around the importance of access to cardiovascular and diabetes care during the pandemic
- Spotting the importance of telemedicine for ensuring continuity of care
- Highlighting heart failure, along with the diabetes-heart disease connection.

The year’s advocacy efforts culminated in the third annual Cardiovascular Health Policy Summit, held virtually. The event, which drew a record number of attendees, explored a range of issues. Topics included COVID-19, statins and patient-centered care, value assessments, telemedicine, and the interrelated challenges of heart disease and diabetes.

This year AfPA’s Cardiovascular Disease Working Group and the Partnership to Advance Cardiovascular Health combined efforts to reduce access barriers for heart patients and bridge the gap in racial health disparities.
COVID-19

Through the Institute for Patient Access Policy Blog and a months-long series of “In Conversation” interviews, AfPA explored the pandemic’s impact across patient communities and disease states. Sustained social media outreach and a steady flow of social media graphics underscored key challenges and critical access messages for patients and providers. The effort culminated in a white paper titled “Fear Factor,” a sweeping look at how COVID-19 concerns had led to dangerous gaps in care.

Meanwhile, the Coalition for Clinical Trials Awareness dedicated its annual Clinical Trials Awareness Week to highlight the pandemic’s impact on critical research. The week also considered the pandemic’s long-term impact, exploring whether the urgent push for a COVID-19 vaccine might increase overall public awareness of the importance of clinical trials participation.

As the COVID-19 pandemic pushed the health care system to the brink, the Alliance for Patient Access worked to bring the provider perspective to the forefront.
This year, an Institute for Clinical and Economic Review assessment of triple-combination therapy for cystic fibrosis set off a heated public debate about cost, value and access.

To rally the collective voice of patients and caregivers, the Cystic Fibrosis Engagement Network launched a social media campaign united by the hashtag #NumbersThatMatter. The effort contrasted the numbers prioritized by ICER economists against the numbers that represent quality-of-life improvements for patients.

Meanwhile, the group continued to spotlight access barriers facing people with cystic fibrosis, such as prior authorization, step therapy and co-pay accumulator adjustment programs.
Members, patients, providers and advocates worked together to raise public awareness and empower patients facing the debilitating disease. The result was an array of educational programming and new resources:

- **A new series of “Patient to Patient” interviews** allowed people living with gout to speak candidly about their experiences in the hope of encouraging other patients.

- **A new Q&A series, “Your Gout Questions Answered,”** highlighted health care providers’ perspectives on symptoms, treatment options, and proper disease management for people living with gout.

- **Patient empowerment forums** continued to raise awareness about the impact of gout and educate patients across the country on managing their disease through proper treatment. Historically held in person, most forums occurred online this year. The virtual platform attracted an even broader audience, offering patients the chance to learn from others’ experiences and get answers to their questions about this disease.

- **Gout Awareness Day** presented an opportunity to spotlight the lived experiences of patients through the Alliance for Gout Awareness’ Voices of Gout initiative. The effort interwove social media activity, infographics and a motion graphics video to honor the experiences of those living with gout.

In 2020, the Alliance for Gout Awareness focused on empowering patients beyond the stigma and misconceptions that surround gout.
Headache and Migraine

In 2020, AfPA’s Headache & Migraine Disease Working Group collaborated with The Headache & Migraine Policy Forum to improve treatment access and reduce stigma for people living with migraine disease and headache disorders.

Initiatives included:

- **Advocating at the state level** to reduce health plan access barriers such as closed formularies, step therapy and non-medical switching
- **Ensuring continuity of care during COVID-19** by advocating for comprehensive telemedicine coverage
- **Addressing burdensome prior authorization requirements** for botulinum toxin treatment under the Centers for Medicare and Medicaid Services
- **Exploring the impact of COVID-19** on people living with migraine disease through a national online survey and report
- **Examining the impact of racial disparities** on migraine care
- **Addressing the shortage of migraine specialists** in the 2020 Headache on the Hill policy roundtable.

The group also celebrated a first-of-its-kind congressional resolution acknowledging the disproportionate impact of migraine disease and headache disorders on women.

RESOURCES

**REPORTS**
- Access to Migraine Treatment During COVID-19
- The National Headache Doctor Shortage

**PODCASTS**
- How Insurers Hold Headache Patients Back

**GRAPHICS**
- Cluster Headache 101
- Telemedicine & Migraine
- How Businesses & Employees Benefit from Migraine Management Programs
- Life Hacks: Changes to Health Care Plans
- Life Hacks: Telemedicine for Continuity of Care
- Life Hacks: Emotional Support During a Pandemic
Controversial and high-profile assessments from the Institute for Clinical and Economic Review drew media attention, as did the group’s assessment of COVID-19 treatment remdesivir. But the media coverage too often served to reinforce ICER’s own narrative—that the organization is impartial, altruistic and unequivocally scientific.

In a continued effort to curb ICER’s impact on access, the Institute for Patient Access countered with a patient-centered narrative that elevates real-life experiences and patients’ values. From migraine disease to high cholesterol to cystic fibrosis, IFPA joined alongside AfPA working groups, coalitions and affiliates to keep the voices of patients and providers alive in the ever-critical value conversation.

In a year where health care issues dominated public attention, questions of value and access became paramount.
Hepatitis

The Alliance for Patient Access’ Hepatitis Therapy Access Physicians Working Group strove to highlight the growing prevalence of the disease as well as the urgent need for innovation and comprehensive policy strategies to eliminate hepatitis C.

Through outreach to state-level health officials and the creation of new educational materials, the working group emphasized the importance of:

- Expanding testing for hepatitis C
- Allowing more health care providers, not just specialists, to prescribe hepatitis C cures
- Removing treatment barriers, such as extensive prior authorization
- Exploring outside-the-box payment strategies, such as “subscription” pricing plans
- Tailoring treatment approaches for at-risk populations, such as veterans and prisoners.

Though it was COVID-19 infections that dominated headlines, rates of hepatitis C also skyrocketed in 2020.
In 2020, the National Coalition for Infant Health advocated for safe, accessible treatment and nutrition for all infants while also highlighting the impact of racial disparities and the challenges facing infants and their families during the COVID-19 pandemic.

Efforts included:

- Raising awareness about the nutritional benefits of seafood for expectant and nursing moms and their babies
- Debunking vaccines myths
- Educating expectant mothers, parents and advocates about staying safe and healthy during COVID-19
- Exploring the impact of racial disparities on NICU care
- Heightening public awareness about the dangers of respiratory syncytial virus and the access barriers facing parents whose preterm infants need preventive treatment.

The coalition’s advocacy and education initiatives culminated in the sixth annual Infant Health Policy Summit, held virtually this year. The event featured diverse panel discussions among health care providers, parents, advocates and policy experts and, due to its digital platform, welcomed a larger-than-ever audience.
Neurological Disease

AfPA’s Neurological Disease Working Group, alongside the Movement Disorders Policy Coalition, used this year to raise awareness about the barriers that undermine patient-centered care—and the policy solutions that patients need.

The groups’ advocacy and education highlighted:

- The growing challenge of utilization management on neurological care
- The need for policies such as Part D out-of-pocket caps and smoothing to make treatment affordable and accessible for patients with movement disorders
- The role of telemedicine in maintaining care during COVID-19
- How an aggressive prior authorization policy is undermining care for Medicare and Medicaid patients with movement disorders who rely upon botulinum toxin therapies
- The importance of mental health, including support for a national suicide hotline and continued awareness efforts around tardive dyskinesia.

RESOURCES

- PAPERS
  - Why Medicare Matters for Movement Disorders

- BLOG POSTS
  - Time to Make Telemedicine Policy Permanent
  - Medicare Rule Could Delay Movement Disorder Treatment

- GRAPHICS
  - How Telemedicine Helps Movement Disorders Patients
  - Non-Medical Switching & Neurological Care
  - Insurance Reauthorization & Neurological Care
  - Step Therapy & Neurological Care
  - Prior Authorization & Neurological Care
  - How Excessive Prior Authorization Hurts Patients
Oncology

As cancer care felt the impact of COVID-19, AfPA’s Oncology Therapy Access Working Group advocated for policies to keep care accessible for patients.

Efforts included:
- **Weighing in on Medicare Part D smoothing and a cap on out-of-pocket spending for Medicare patients.** Both measures aimed to make out-of-pocket costs more manageable.
- **Exploring the impact of COVID-19 on patient access,** including access to clinical trials for patients with cancer.
- **Raising awareness about dangerous delays in accessing cancer diagnostics under Medicare.**
- **Highlighting the role of precision medicine** in facilitating patient-centered cancer care.
- **Examining how the Center for Medicare and Medicaid Innovation’s demonstrations** can impact cancer care.
- **Raising awareness about the potential impact of reference pricing** on patient access.

RESOURCES

- **VIDEOS**
  - Medicare Part D & Out-of-Pocket Smoothing

- **PAPERS**
  - Fast Facts: Reference Pricing
  - Fast Facts: Center for Medicare & Medicaid Innovation

- **BLOG POSTS**
  - Congress Aims to Expand Access to Clinical Trials
  - Reimbursement Policy Leaves Cancer Patients in a Lurch
  - Access Issues Linger for Cancer Patients

- **GRAPHICS**
  - Medicare Barriers to Cancer Diagnostics
The groups’ efforts took the shape of several advocacy and education initiatives:

• Against the backdrop of the pandemic, advocates highlighted the importance of the Pain Management Inter-Agency Task Force Recommendations as the model for optimal policy—and optimal care.

• The organization spotlighted the value of patient-centered pain care for people living with arthritis, including veterans and Armed Services members, who have a disproportionately high rate of osteoarthritis.

• When the Centers for Medicare and Medicaid Services proposed a physician fee schedule that would discourage providers from using opioid alternatives in treating pain, advocates pushed back. The agency ultimately backed down from the proposal.
Patient Protections

As the COVID-19 pandemic heightened vulnerabilities for many Americans, protection from misleading “bad drugs” ads took on a new importance.

During 2020:

- The Partnership to Protect Patient Health urged policymakers to consider the dangers of patients who discontinue their prescribed medication without first talking with their health care provider.
- Several state legislatures took up the issue during their 2020 session, including a bill that was signed into law in West Virginia.
- Members of the U.S. House of Representatives reiterated the need for the Federal Trade Commission to take a decisive stance on misleading “bad drug” ads. The agency reported making progress with a key perpetrator of misleading lawsuit advertising and concurred that the public deserves to be shielded from these practices.
In 2020, the Rare Diseases Working Group honed in on patient-centered health care by advocating for better access to treatment and fewer barriers to diagnosis.

The newly launched Rare Diseases Working Group used 2020 to establish itself as a platform for convening on both broad rare disease challenges and barriers facing patients with specific rare diseases.

The working group:

- Hosted its first-ever meeting, where clinician members focused on hATTR amyloidosis and the challenges that patients face in accessing different treatment options
- Explored how COVID-19 impacted access to treatment for patients with a rare disease
- Issued a series of educational infographics outlining common access barriers
- Advocated for improved health coverage policies for patients with amyloidosis
- Used policy papers to examine both health system barriers and diagnosis guidelines for hATTR amyloidosis patients.

RESOURCES

VIDEOS
- Challenges in Rare Disease Treatment

PAPERS
- Health System Barriers for Amyloidosis Patients
- Fast Facts: Clinical Diagnosis Guidelines for Transthyretin Amyloidosis

BLOG POSTS
- COVID-19 Anxiety Burdens Rare Disease Community
- When Rare Disease is a Family Affair

GRAPHICS
- Challenges in Diagnosing Rare Diseases
- Access Barriers for Patients with Rare Diseases
As COVID-19 drew national attention to respiratory health, AfPA’s Respiratory Therapy Access Working Group embraced the opportunity to advocate for patient-centered care.

Efforts included:

- **Raising awareness about access barriers** facing Medicare patients who need ventilators
- **Exploring the proper use of oral corticosteroid therapy** for asthma patients
- **Increasing public awareness** about the benefits of telemedicine
- **Spotlighting the need for continuity of respiratory care** during the COVID-19 pandemic
- **Highlighting the value of new medical technology**, including “smart” digital inhalers, for tailoring care for individual patients.
Skin Conditions

While the stress of the COVID-19 pandemic exacerbated skin conditions for some patients, it also led to gaps in care. Some patients missed out on crucial screenings while others struggled to keep up with treatment.

Through educational content and programming, the Derma Care Access Network:

- **Highlighted the need for continued access to care**, including telemedicine capabilities
- **Rallied the advocacy community during COVID-19**, spotlighting insights from dermatologists and convening stakeholders for a webinar on maintaining care during COVID-19
- **Continued to champion reform on step therapy**, a long-standing barrier for patients with skin conditions. The Derma Care Access Network dedicated a new educational video to defining the widespread challenge—and what policymakers can do to help.

This year, the Derma Care Access Network emphasized a core message: Skin conditions aren’t just skin deep.
Utilization Management & Access Barriers

Sustained national attention on health care this year offered critical opportunities to educate and advocate on access barriers.

The Patient Access Collaborative created new educational resources on the most common, and most challenging, utilization management tools. The group also explored the growing problem of co-pay accumulator adjustment programs. And the collaborative’s webinar series united and empowered advocates this year by exploring best practices and highlighting expert voices.

Meanwhile, the Keep My Rx campaign doubled down on the need to protect patients from non-medical switching. When health plans announced they were willing to suspend some barriers for people with COVID-19, Keep My Rx advocates made clear that impeding access and pushing stable patients off of their medicine was bad for all patients, not just those with the coronavirus.

And the National Council of Physician Legislators continued its work to unite health care providers who also serve in statehouses around the country. Through virtual meetings and ongoing communication, the group explored the diverse challenges facing physician legislators in 2020.
In 2020, the Vision Health Advocacy Coalition worked to raise awareness and improve treatment access for the 14 million Americans living with vision conditions.

Education and advocacy efforts included:

- A range of educational materials on the global impact of vision conditions
- A series of patient empowerment webinars
- A collection of “Spotlight” videos designed to increase awareness about specific vision conditions
- A national survey exploring the potential value of home infusion for Medicare beneficiaries living with thyroid eye disease
- The use of social media graphics and blog posts to highlight vision-related awareness days and to increase public understanding of the need for access to patient-centered care.
Moving Forward

Patient & Provider Advocates for Telehealth
A new stakeholder coalition will spotlight one of the fastest-growing access issues to arise from 2020—telehealth. Patient & Provider Advocates for Telehealth is a national coalition of stakeholders who recognize that telehealth helps patients manage chronic diseases, provides for better outcomes and supports overall cost containment.

AfPA’s Mental Health Working Group
A new Alliance for Patient Access working group will bring together health care providers committed to optimal, patient-centered mental health care. The group will build upon AfPA’s past advocacy on mental illness as a comorbidity of a range of diseases.

Obesity Awareness & Advocacy Initiative
A cross-coalition initiative will explore obesity’s role as a root cause of diabetes, cardiovascular conditions and chronic disease. AfPA working groups, coalitions and affiliates will work together to raise awareness about obesity’s far-reaching impact and to advocate for improved access to care for patients living with obesity.

The new year will welcome several new initiatives.
Signing Off

At times, this year felt virtually impossible. But with your help and support, we did it.
Stay connected in 2021!

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