



# 2019

YEAR IN REVIEW





## OVERVIEW

**For the Global Alliance for Patient Access, 2019 was a year of strategic growth and global impact. GAfPA participated in events and engaged with a range of partners to support its mission of advancing patient-centered care.**

To this end, leadership presented about patient-centered care in the European Parliament and facilitated advocacy workshops at a meeting of the European Federation of Neurological Associations.

Also in Europe, GAfPA worked to raise awareness about living with rheumatoid arthritis and managing high cholesterol through the release of new materials, including:

- The European Alliance for Patient Access' first "Patient Essentials" [video](#), which guides patients on how to talk to their health care provider about rheumatoid arthritis
- A cross-organizational [consensus statement](#) signaling advocacy groups' commitment to highlighting key messages from [new lipid management guidelines](#).
- A "Fast Facts" and an eight-[blog](#) series highlighting how high cholesterol and heart disease affect patients, [workplaces](#) and the [population](#) writ large.

But GAfPA's 2019 efforts transcended patient education about chronic diseases. Teams worked around the globe to increase patients' access to approved therapies and innovations in health care. Broadening awareness about the benefits of innovative biologics and biosimilars, and the harmful impact of [compulsory licensing](#), were also among this year's efforts.

GAfPA delivered these messages on two new continents—Asia and Africa—while expanding efforts in South and Central America. Among the year's key events were:

- [Biosimilar briefings](#) in Turkey, the United Arab Emirates and Egypt, after kicking off the series with three meetings in South America
- Patient access discussions, including at the ChinaBio Partnering Forum in Shanghai
- Workshops in [India](#) and Cyprus on the topics on advocacy and policy.

# AT A GLANCE: GfPA's Global Reach

The Global Alliance for Patient Access participated in workshops or meetings in the following locations. Patient and patient-advocacy organizations from countries that are shaded participated in GfPA-administered questionnaires and surveys in 2019.





# RHEUMATOID ARTHRITIS

More than 2.3 million Europeans live with rheumatoid arthritis, but an EAfPA [patient questionnaire](#) revealed half of patients didn't fully understand the disease. This was just one of many insights gained from questionnaire participants in the United Kingdom, Germany and Portugal. Participants also indicated a desire for resources on how to engage more fully in treatment decisions. The questionnaire results helped inform EAfPA's outreach efforts for the year and were also highlighted in a [blog post](#).

The European Alliance for Patient Access held its annual meeting of rheumatic and musculoskeletal disease patient advocates as part of the EULAR 2019 meeting in Madrid, Spain in June. About 15 patient advocates joined with experts to discuss access issues and how to communicate with their health care providers about rheumatoid arthritis.

The European Alliance for Patient Access's first "Patient Essentials" video, "[How to Talk to Your Health Care Provider about Rheumatoid Arthritis](#)," debuted at the meeting. Since then it has been translated into nine languages and has been viewed more than 27,000 times.



# CHOLESTEROL MANAGEMENT



Cardiovascular disease is both preventable and treatable, yet it remains a significant and growing concern across Europe. More than half of Europeans live with raised cholesterol, a leading risk factor for heart disease. Early in the year, EAfPA released “[Fast Facts: Impact of High Cholesterol](#)” to help answer basic questions for patients. A video, “[High Cholesterol in Europe](#),” followed in April. Related blog posts covered the need for [personalized treatment plans](#), the [value of prevention](#) and the importance of [prioritizing heart health](#), among other topics.

In the fall, the European Society of Cardiology and the European Atherosclerosis Society issued new guidelines on lipid management. EAfPA’s “[Fast Facts: 2019 Guidelines on Cholesterol Management](#)” provides an overview and outlines what patients and health care providers can do to address this silent killer.

To assess patients’ perspective and knowledge about high cholesterol and cardiovascular disease, the European Alliance for Patient Access developed a [patient questionnaire](#). Released in November, the results show not all patients have enough information to protect themselves from preventable heart attacks and strokes, and that patients need more educational materials. EAfPA released its second “Patient Essentials” video in December. “[How to Talk to Your Health Care Provider about High Cholesterol](#)” was translated into four languages and has been viewed more than 13,400 times. Findings from the patient questionnaire will continue to guide EAfPA’s education efforts on this topic in 2020.







# INNOVATION & ACCESS

GAfPA's work this year also touched on the importance of innovation in clinics across the globe.

"[Innovation: Priorities and Challenges in Health Systems in Latin America](#)," captured the opinions of 50 patient advocacy organization representatives from across Central and South America. It demonstrated that patients and patient-advocacy organizations understand the many benefits of medical innovation. Despite their desire for new treatments, however, patients encounter a range of threats and challenges: fragmentation of the health care system, financing and out-of-pocket costs. Survey results, recapped in [English](#) and [Spanish](#)-language blog posts, demonstrate the importance of pro-innovation policies and programs that promote medication access.

The survey results were also discussed by more than 40 patient advocates from across Latin America during the fourth annual Latin American Summit. Titled "Innovation, Access, IP and Patient-Centered Care," the August gathering served as an opportunity to discuss best practices for improving access to biologic therapies, improving the patient experience and overcoming harmful policies.

GAfPA continued to raise awareness this year of compulsory licensing, a drastic policy that breaks patents on new drugs. The practice threatens to stifle innovation, as GAfPA's "Understanding Compulsory Licensing" video explains. Released in English, Spanish and Portuguese, the [video](#) has been viewed more than 68,800 times.

Meanwhile, in a [series of briefings](#) that began in Sao Paulo, Brazil and Buenos Aires, Argentina, clinicians who practice rheumatology, dermatology and oncology got up to speed on the science and policy behind biosimilars, follow-on versions of original biologic drugs. GAfPA and the [Biologics Prescribers Collaborative](#) co-hosted subsequent meetings in the UAE, Turkey, Colombia and Egypt, with nearly 100 physicians investing time to discuss the nature of biosimilars and the impact they can have on patient access to treatment. [Biosimilar regulation](#) was covered in the GAfPA policy blog.

GAfPA and its partners also worked to empower patients with advocacy skills. In March, GAfPA, along with POSPF, hosted a policy workshop in Nicosia, Cyprus with 15 patient advocates from across the region in attendance. The meeting worked to educate patients on therapeutic options and biosimilars, increase awareness about the importance of patient access, improve patient knowledge about the regulation of biologics and biosimilars in Cyprus, and train patients in making their voices heard by policymakers.

Also in March, GAfPA co-hosted a [Patient Access Advocacy Workshop](#) in New Delhi, India with IIMR Delhi, IAPO and IAPG. More than 50 patient advocates from across India spent the day exploring the challenges and opportunities surrounding patient access in India and discussing the role of innovation in increasing access for individual patients and the population at large.



# LOOKING AHEAD

Meaningful partnerships and support enabled GAfPA to broaden its reach this year, empowering advocates for advanced medicine and patient access. GAfPA looks forward to continuing this important work in 2020.



**The Global Alliance for Patient Access** is a network of physicians and patient advocates with the shared mission of promoting health policy that ensures patient-centered care. GAfPA accomplishes this mission through educating physicians and patients on health policy issues and developing education material and advocacy initiatives to promote informed policymaking.

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