

2018

YEAR IN REVIEW

GAfPA
Global Alliance for Patient Access



OVERVIEW

Building on a busy and successful 2017, the Global Alliance for Patient Access expanded its reach across Europe and Latin America in 2018, engaging hundreds of stakeholders. GAfPA hosted eight events in Latin America and three events in Europe. Along with meetings, GAfPA maintained a [blog](#), produced multiple event reports and issued “Fast Facts: Compulsory Licensing” in [English](#) and [Spanish](#).

GAfPA worked to empower patient advocates and expand the collaborative efforts of organizations that represent the best interest of patients. That included bringing to the forefront the latest information related to innovations in health, best practices in advocacy, and patient education.

The most important topic, however, remained patient access. GAfPA worked throughout 2018 to increase awareness about the importance of patient access to physician-prescribed therapies and to highlight the importance of the physician-patient relationship.



EUROPE

GAfPA hosted three meetings in Europe in 2018 through the European Alliance for Patient Access.



Meeting of Rheumatic and Musculoskeletal Diseases Patient Advocates

JUNE 15 • *Amsterdam, Netherlands*

There were 22 patient representatives in attendance at the meeting, representing organizations from across Europe.

Two presentations were given during the meeting relating to advocacy work in Europe and on the global scale. Attendees shared some of their current and planned advocacy activities during the meeting.

Meeting objectives:

- To provide patient advocates an update on relevant policy issues
- To learn about new topics of concern for the rheumatic and musculoskeletal diseases community.



Meeting of Rheumatoid Arthritis Patient Advocacy Groups

JUNE 25 • *Brussels, Belgium*

The meeting consisted of 10 patient advocates, representing patient groups active in rheumatoid arthritis from across Europe. The meeting discussions highlighted how patient empowerment, and patients, in partnership with their physicians, can impact policy.

Meeting objectives:

- To help delegates to consider the complex issues of unmet need in rheumatoid arthritis and co-morbidities
- To demonstrate how patient groups can be empowered to advocate on issues of importance.





Joint Workshop by EAfPA and Myeloma Croatia on Policy Issues Affecting Patient Access to Approved Therapies in Myeloma

NOVEMBER 9 & 10 • Zagreb, Croatia

This workshop brought together advocates to look at policy issues affecting patient access to approved myeloma therapies. The workshop included panels of health care professionals and patient advocates as well as presentations on effective advocacy and setting up regional patient networks.

Meeting objectives:

- To review policy issues affecting patient access to approved therapies in myeloma
- To discuss how to elevate the discussion around blood cancer
- To determine ways to overcome the challenges that are being faced by myeloma patients.

LATIN AMERICA

GAfPA hosted eight meetings in Latin America in 2018: three meetings of the Latin American Patient Academy, a series of three dialogues about access, innovation and intellectual property, and two additional meetings.



Health Journalist Educational Workshop on Biologics and Biosimilars

APRIL 9 • *Buenos Aires, Argentina*

The Health Journalist Educational Workshop was held during the Pan American League of Rheumatology Associations Meeting. The workshop brought together more than 25 journalists from seven countries to discuss key issues and progress related to the regulation of biologics and biosimilars. The journalists represented outlets in Brazil, Mexico, Colombia, Chile, Paraguay, Uruguay and Argentina.

Meeting objectives:

- To increase participants' knowledge of the biosimilar regulatory landscape in Latin America
- To provide a forum for participants to share experiences
- To discuss possible solutions for overcoming access barriers that keep patients from optimal care and treatment of their rheumatoid arthritis.

GAfPA released a summary report of the Health Journalist Educational Workshop on Biologics and Biosimilars in [English](#) and [Spanish](#).



Latin American Patient Academy

Module 1:

MAY 6

• *Miami, United States of America*

Module 2:

SEPTEMBER 7

• *Lima, Peru*

Module 3:

NOVEMBER 8

• *San Paolo, Brazil*

GAfPA assisted in hosting three face-to-face meetings of the Latin American Patient Academy in 2018. The program included about 22 patient representative leaders from across eight countries throughout Latin America. They represented the following disease states: cancer, diabetes, transplants, cardiovascular, rare diseases, autoimmune diseases, psoriasis, rheumatoid arthritis, multiple sclerosis, and HIV.

Module 1 covered regulations and **Module 2** covered health technology assessment, a way of evaluating the social, economic, organizational and ethical issues of a health intervention or a health technology. **Module 3** covered research and development, and clinical trials.

Meeting objectives:

- To create a dialogue on best practices
- To strengthen the patient advocacy community in the region
- To begin building a framework for continual collaboration among this community and throughout Latin America.

3rd Annual Latin American Conference on Biologics and Biosimilars

SEPTEMBER 6 & 7 • Lima, Peru

Over 60 patient advocates gathered from across Latin America to discuss patient access issues.

Meeting objectives:

- To highlight the attributes of advance specialty therapies and their use across disease states, their unique nature and the distinctions with conventional medicines that are reflected in policies governing approvals, prescribing and dispensing
- To provide attendees with diverse perspectives offering a robust discussion on policy issues such as therapeutic substitution, indication extrapolation and pharmacovigilance
- To provide a forum for patient advocates, representing many different disease states, to come together from across Latin America
- To give patient advocates and attendees the opportunity to discuss policies that directly impact patient access such as non-medical switching, biosimilar substitution and compulsory licensing.

GAfPA released a summary report of the 3rd Annual Latin American Conference on Biologics and Biosimilars in [English](#) and [Spanish](#).





La Alianza Global para el Acceso de Pacientes (GAIPA) es una red de médicos y defensores de pacientes con la misión compartida de promover políticas de salud que aseguren el acceso de los pacientes a cuidado clínico apropiado y a terapias aprobadas. GAIPA logra esta misión a través de la educación de médicos y pacientes sobre cuestiones de política de salud y el desarrollo de material educativo e iniciativas de promoción para promover la formulación de políticas informadas.

GAIPA

Access, Innovation and Intellectual Property: A Dialogue Series

OCTOBER 26

• *Bogota, Colombia*

NOVEMBER 12

• *Santiago, Chile*

DECEMBER 5

• *San Salvador, El Salvador*

Each of the meetings brought together 20-30 patient advocacy representatives from the host country.

Meeting objectives:

- To demonstrate a commitment to advancing the discussion in health, oriented towards improving policies of access, innovation, competitiveness and intellectual property
- To review the state of policies and regulations
- To identify challenges, opportunities and solutions
- To build a framework for continued sustainable collaboration among the patient advocacy community and national intellectual property agencies.

Attendees of each meeting received Fast Facts: Compulsory Licensing in [English](#) and [Spanish](#).

EDUCATIONAL MATERIALS & BLOGS

EUROPE

JANUARY 24 • Making Visible the Invisible on Headache Pain: Sharing Successful Experiences Across Europe

MARCH 6 • Europeans Work to Turn Health Care Rights into Realities

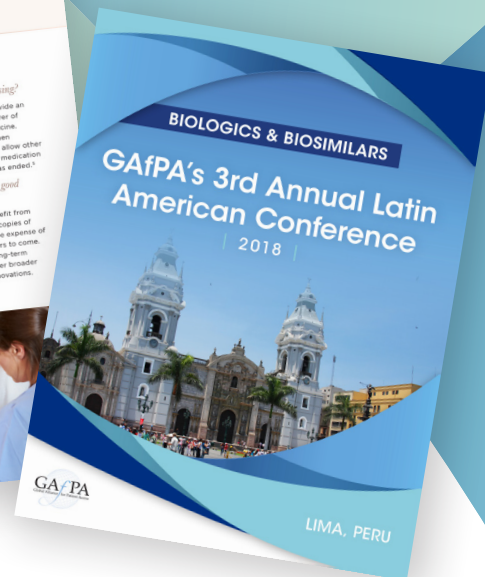
MARCH 26 • Mapping Report Reveals Access Disparities among European Patients

MAY 2 • From local to global: promoting societal impact of pain – 'Sine Dolore World Park'

MAY 3 • In Europe, Advocates Emphasize Role of Patient Voice

MAY 17 • Drug Approval Signals New Options for Stroke, Heart Attack Survivors in Europe

JUNE 5 • Portugal Confirms Patient Role in Treatment Decisions



LATIN AMERICA

FEBRUARY 19

- Upcoming Latin America Events
 - Eventos Latino Americanos
-

- Biologics & Biosimilars Health Journalist Educational Workshop 2018 – Buenos Aires
 - Biológicos y Biosimilares Taller Educativo de Periodistas de Salud 2018 – Buenos Aires
-

JUNE 15 • School's in Session at the Latin American Patient Academy

AUGUST 23

- How Latin America Can Avoid a Health Care Missstep
 - Fast Facts: Compulsory Licensing
 - Fast Facts: Licencia Obligatoria
-

• GAfPA's 3rd Annual Latin American Conference

• Biológicos y Biosimilares 3° Conferencia Anual GAfPA para América Latina

SEPTEMBER 17 • La farmacovigilancia como modo de reforzamiento de regulaciones

MOVING FORWARD

The Global Alliance for Patient Access plans to continue expanding its impact in the coming year. Goals for 2019 include:

- ▶ Working to host and collaborate on more regional advocacy workshops to share best practices among a wider population of patient advocates
- ▶ Developing and sharing relevant briefings and materials to help further education and provide patient advocates with helpful resources for their work towards patient access
- ▶ Strengthening and expanding GAfPA's network of patient advocates, physicians and partners
- ▶ Expanding the European Alliance for Patient Access' network across Europe by engaging with local partners on key policy issues that impact access to therapeutic treatments.



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

www.gapfa.org