



2021

YEAR IN REVIEW



Introduction

Despite ongoing public health challenges, the Global Alliance for Patient Access continued partnering with advocates to advance patient-centered care in 2021.

GAfPA facilitated stakeholder discussions about a range of conditions, such as:

- **Cardiovascular Disease**
- **Osteoporosis**
- **Rheumatic Diseases**
- **Amyloidosis**
- **Neuromyelitis Optica Spectrum Disorders.**

In Africa and Europe, GAfPA and its partners channeled those discussions into action. Advocacy concentrated on:



Care pathway development

GAfPA convened stakeholders – patients, providers and parliamentarians – to chart a clear care path for patients living with osteoporosis.



Treatment guideline modernization

GAfPA launched a campaign to educate South Africans about the risks of cardiovascular disease and the need to update treatment guidelines.



Rare disease awareness

GAfPA drew attention to unmet needs among people living with rare diseases.



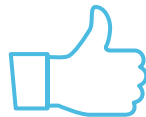
Digital Impact

Despite the uncertainty of an ongoing pandemic, GAFPA remained steadfast in spotlighting the global need for patient-centered care. Metrics from 2021 reflect global advocates' commitment to finding policy solutions for today's health challenges.



5,341,488

IMPRESSIONS



227,832

ENGAGEMENTS



300,000

VIDEO VIEWS



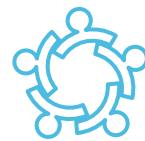
16,952

NEW FOLLOWERS



7

MEETINGS
& EVENTS



340

PARTICIPATING
ORGANIZATIONS



Cardiovascular Disease

In 2021 GAfPA worked to heighten patient awareness of the link between high LDL cholesterol and cardiovascular disease.

A New Working Group

Over a series of meetings, GAfPA's new South Africa Cardiovascular Disease Working Group identified advocacy priorities and developed education strategies to improve cholesterol care.

Priorities included:

- Raising awareness of the dangers of unmanaged high LDL cholesterol
- Aligning the South African Heart Association/Lipid and Atherosclerosis Society of Southern Africa Cardiovascular Disease Guidelines with the National Department of Health Guidelines
- Improving access to tailored cholesterol management.

An Education Campaign

GAfPA partnered with the Heart and Stroke Foundation of South Africa, the South African Heart Association, and the Lipid and Atherosclerosis Society of Southern Africa to launch a digital public awareness campaign: [Know Your Risk, Treat Your Numbers](#).

The campaign educated South Africans about the links between high LDL cholesterol and cardiovascular disease. It garnered more than 1 million impressions across social media and over 300,000 views on YouTube.

In 2022, GAfPA will:

- Enhance working group engagement with policymakers
- Establish a patient advocacy council
- Relaunch the Know Your Risk, Treat Your Numbers Campaign with renewed resources.

RESOURCES



REPORTS

- ▶ Cholesterol Management in South Africa



BLOG POSTS

- ▶ Heart Disease & COVID-19 Are a Dangerous Mix for EU Patients
- ▶ South Africa Faces Dangerous Gaps in Cholesterol Management
- ▶ The “Little” Heart Health Risk that Poses Big Problems
- ▶ High Blood Pressure Tops 1 Billion People Across the Globe



Osteoporosis

Expanding patient-centered care for osteoporosis was also a priority for GAFPA in 2021.

In October the European Alliance for Patient Access hosted a policy roundtable meeting in Brussels to discuss developing an integrated, patient-centered care pathway for osteoporosis patients in Belgium. Discussions explored:

- The most effective care pathway for osteoporosis patients
- Current barriers in Belgium’s health care system that hinder progress on that pathway
- The stakeholders who are essential to developing and implementing the care pathway at a policy level.

Dialogue revealed several pressing needs:



A formalized communication pathway



An integrated health data ecosystem



A stronger focus on primary prevention



A greater priority on patient education



A streamlined referral process



A reimbursement model that incentivizes improved health outcomes.

In 2022, GAFPA will continue engagement with Members of Parliament, convene additional meetings with stakeholders, and advance policy solutions into measurable gains in Belgium.

RESOURCES



REPORTS

- ▶ Developing an Osteoporosis Care Pathway for Belgium
- ▶ De Ontwikkeling van een Ozorgtraject voor Osteoporose in België
- ▶ Élaborer un Parcours de Soins de L’ostéoporose en Belgique



Rare Diseases

This year GAFPA expanded advocacy efforts into rare disease issues. GAFPA worked alongside its rare disease partners to shed light on patients' experiences and to chart solutions to address their unmet needs.

Hereditary Transthyretin Amyloidosis

GAFPA convened amyloidosis advocates and stakeholders across Europe to discuss the unmet needs of patients and their families. Identified unmet needs included: early, accurate diagnosis; equitable access to treatment; guidance on genetic testing; support for families and careers; and broad access to guidelines.

Following the meeting, GAFPA published a policy paper that captured the views and experiences of the amyloidosis community in Europe and encouraged policy action to address unmet needs.

Neuromyelitis Optica Spectrum Disorder

GAFPA gathered advocates and stakeholders to discuss the needs of patients living with Neuromyelitis optica spectrum disorder, or NMOSD.

Conversation explored patients' care burdens, unmet needs and access barriers. It also identified advocacy opportunities. Lack of disease awareness and access to specialists and care predominated participants' concerns. Participants also highlighted the support needs and barriers that both caregivers and patients face in accessing and affording treatment.

RESOURCES



REPORTS

- ▶ Unmet Needs in hATTR Amyloidosis in Europe



BLOG POSTS

- ▶ Bringing Rare Disease to the Forefront
- ▶ Youth Advocates Aren't Waiting to Shape Health Policy
- ▶ Unmet Needs Persist for Amyloidosis Patients in Europe
- ▶ Can Primary Care Physicians Diagnose Rare Diseases?
- ▶ This World Amyloidosis Day, Be the Link
- ▶ #30Million Reasons for Europe to Take Action on Rare Diseases



Innovation & Value

Though in-person gatherings were not always feasible, the patient voice remained integral to global dialogue on innovation and value this year.

Innovation & Patient Access

As nations worked toward widespread vaccination, some policymakers struggled to find the balance between innovation and access.

The issue of compulsory licensing rose once again to the world stage, with policymakers questioning whether waiving patent rights could hasten access to treatment. GAFPA highlighted why continued innovation matters to patients and encouraged policymakers to keep safety and long-term access top of mind.

Health Technology Assessment

As the ongoing COVID-19 pandemic kept the value of innovative treatments front and center, advocates also explored how to effectively engage in health technology assessments.

The European Alliance for Patient Access virtually convened rheumatic and musculoskeletal disease patient advocacy groups to discuss the issue during a Related Meeting of the EULAR Congress. Their discussion explored the need for the patient perspective in decision-making about health care value and access. It also pinpointed the challenges patient groups encounter when it comes to engaging in the health technology assessment process.

The dialogue built upon a [2020 GAFPA report](#) on the challenges that prevent patients and advocates from fully engaging in health technology assessments.

RESOURCES



REPORTS

- ▶ Elevating the Voices of Patients with Rheumatic and Musculoskeletal Diseases



BLOG POSTS

- ▶ Patents, Patients & COVID-19
- ▶ Why Patients are Prepared to Fight for a Voice in the Value Debate
- ▶ Europe Gets Real on Health Care Evidence
- ▶ Brazil's COVID-19 Vaccine Overreach
- ▶ Patients in England Brace for Crackdown on Common Pain Medications



Moving Forward

The new year will bring new opportunities for GAfPA to amplify the voices of patients and advocates.

In 2022, GAfPA will continue its advocacy on issues related to cancer, cardiovascular health, rheumatic and musculoskeletal diseases, rare diseases, and more. It will apply the success of this year's high cholesterol awareness campaign in South Africa to other regions of the world. GAfPA will also undertake an international survey to better understand the struggles autoimmune patients face during the COVID-19 pandemic – and how policymakers can help.

Health care remains a priority for many policymakers, giving advocates a unique opportunity to shape policies and improve access for their communities. GAfPA looks toward 2022 with renewed commitment to forging meaningful partnerships and building more patient-centered health care systems across the globe.



About the Global Alliance for Patient Access

The Global Alliance for Patient Access is an international platform for health care providers and patient advocates to inform policy dialogue about patient-centered care.

[GAfPA.org](https://www.gafpa.org)

