



2022

Annual Report





Introduction

Throughout 2022, the Global Alliance for Patient Access advanced patient-centered care through raising awareness and advocating for policies that ensure patient access.

GAfPA convened and facilitated discussions among health care stakeholders across a variety of disease states, including:

- COVID-19
- Autoimmune diseases
- Atherosclerosis and cardiometabolic conditions
- Osteoporosis
- Rare conditions

In Asia, Africa and Europe, GAfPA translated discussion into action.



Raising Awareness

In South Africa, GAfPA worked to inform patients and health care providers about the need for osteoporotic screening and second-fracture prevention.



Expanding Understanding

In Australia GAfPA began replicating the LDL cholesterol awareness work it began in Europe and South Africa.

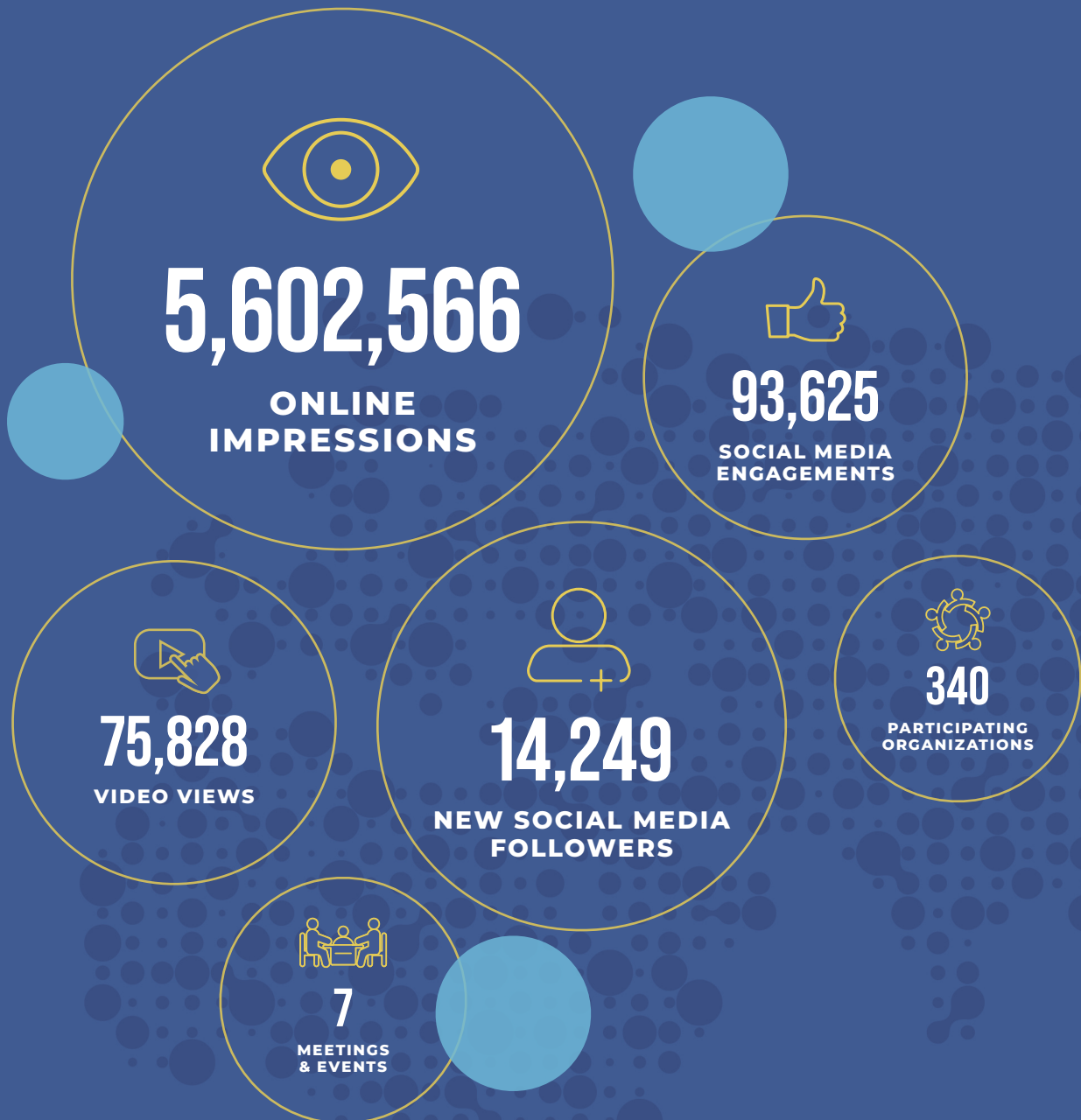


Updating Guidelines

In Europe, GAfPA convened stakeholders to work with medical societies in updating its treatment guidelines for patients with rare conditions.

Impact

Throughout the year, GAFPA spotlighted the global need for patient-centered care. Metrics from 2022 reflect global advocates' commitment to raising awareness, improving policy and empowering patients to meet today's health care challenges.





Cardiovascular Disease

The leading cause of death globally, cardiovascular disease remained a focus of GAFPA's education and advocacy efforts in 2022.

An Expanding Education Campaign

In 2022, GAFPA laid the groundwork for an awareness campaign in Australia to highlight the correlation between high LDL cholesterol and cardiovascular disease. The efforts build upon a 2021 campaign in South Africa with similar goals.

For the past several years, GAFPA has also collaborated with stakeholders to identify their country-specific unmet needs among patients living with high LDL cholesterol and the health care providers who diagnose and treat them.

The insights gleaned from these initiatives will be used to launch LDL cholesterol awareness campaigns and policy roundtables.

RESOURCES

Blog Posts

- ▶ HEARTS in the Americas
- ▶ New Tools Could Boost Patient-Centered Care
- ▶ Reclaiming Progress Against Non-Communicable Diseases



Clinical Trials Awareness

Every new treatment or breakthrough cure requires clinical trials, which GAfPA spotlighted this year as the earliest access barrier for many patients and disease states.

Identifying Access Barriers

Simultaneously with the meeting of the EULAR Congress, GAfPA hosted a meeting of representatives from European patient associations to explore clinical trials awareness and access challenges.

The group identified challenges that included:

- The public's lack of clinical trials awareness
- Costs incurred by participating patients
- Lack of engagement by health care providers
- Persistent health disparities

GAfPA subsequently published a report on the subject and offered some practical solutions to improve access.

Recommendations included:

- Helping patients navigate enrolment
- Making it easier for providers to connect patients with trial opportunities
- Providing additional financial support for trials that make participant diversity a priority
- Raising public awareness for trials
- Incentivizing greater private-sector investment in trials

RESOURCES

Reports

- ▶ Clinical Trials: Overcoming the First Barrier
- ▶ Improving Clinical Trials Awareness and Access: Insights from Rheumatic Disease Patient Advocates

Blogs

- ▶ Clinical Trials Access Barriers Delay & Derail New Treatments
- ▶ Making Clinical Trials Access a Global Priority



Innovation, Value & COVID-19

As the risk of COVID-19 lingered across the globe, medical innovation was as important as ever in 2022. So too were informed concepts of health care value.

Health Technology Assessment

To support GAfPA's European patient networks across different disease areas, GAfPA published a guide to help patient groups effectively engage with health technology assessment bodies in their own countries. The resource reflects the growing impact of health technology assessment on patients' ability to access new and innovative treatment options.

Innovation and Patient Access

GAfPA also developed resources to help patients and policymakers worldwide better understand COVID-19 vaccines. Materials included:

- A one-pager and video outlining the **different types of vaccines** that exist
- A “Fast Facts” examining **COVID-19 vaccination in developing countries**, taking care to highlight the most substantial barriers preventing patients in those countries from getting their jab
- An **international European survey and related report** highlighting autoimmune patients' need for COVID-related health information tailored to their specific condition and treatment regimen

RESOURCES

Videos

- ▶ Understanding COVID-19 Vaccines

Reports

- ▶ COVID-19 Vaccines in Developing Countries
- ▶ Autoimmune Disease and COVID-19

One-Pagers

- ▶ Giving Patient Advocates a Voice in Health Technology Assessment
- ▶ Immunising Yourself Against COVID-19

Blogs

- ▶ COVID-19 Vaccines in Developing Countries
- ▶ Autoimmune Patients Want Clear, Actionable Information COVID-19



Osteoporosis

The threat of a silent disease loomed large in 2022 in the Republic of South Africa.

Raising Awareness

In 2022, GAFPA partnered with the National Osteoporosis Foundation of South Africa to raise awareness about osteoporosis in the country and to highlight patients' unmet needs.

The campaign, *Know Your Bones*, aimed to:

- Help at-risk people understand their **risk of developing osteoporosis**
- Encourage at-risk people to **adopt practices** that reduce their risk for bone loss
- Highlight the **importance of screening**
- **Facilitate access to guideline-directed treatments** so patients can manage their condition and prevent fractures.

RESOURCES

▶ Videos

- ▶ Know Your Bones, Awareness Campaign

▶ Reports

- ▶ Mending Broken Bones: Challenges & Solutions for the Diagnosis and Treatment of Osteoporosis in South Africa



Rare Disease

This year, GAfPA forged ahead with the rare disease advocacy work it began in 2021.

Neuromyelitis Optica Spectrum Disorder

GAfPA hosted an advocacy meeting in Vienna coinciding with the European Academy of Neurology's annual congress. Participants acknowledged the importance of the European Academy of Neurology updating its treatment guidelines. Needed updates, stakeholders agreed, include incorporating patient perspectives into the guideline development process.

In Amsterdam, GAfPA convened patient advocates and disease experts to further explore patient perspectives and to discuss policy reforms to facilitate treatment access.

Hereditary ATTR Amyloidosis

GAfPA published a guide to help patients at risk for or diagnosed with hATTR amyloidosis navigate genetic testing. The resource describes the genetic tests available, as well as the role of genetic counselors in interpreting results to help patients decipher next steps.

Neurological Rare Diseases

This year GAfPA also convened a roundtable in Brussels at the European Parliament to discuss the need to revise current EU legislation related to neuromyelitis optica spectrum disorder and other rare neurological diseases. Advocates aim to use momentum around the revisions to increase awareness of unmet needs among patients with rare neurological conditions.

RESOURCES

Reports

- ▶ Unmet Needs in Neuromyelitis Optica Spectrum Disorder
- ▶ Genetic Testing: A Guide for Patients with Transthyretin Amyloidosis

Blogs

- ▶ Mission Possible for Rare Disease
- ▶ A New Rare Disease Action Plan for England
- ▶ Shining a Light on Unmet Needs for Rare Disease Patients



Moving Forward

In 2023, GAfPA continues its advocacy and education on issues related to clinical trials, chronic kidney disease, cardiovascular health, rheumatic and musculoskeletal diseases, rare diseases, COVID-19, RSV and more.

GAfPA will also build upon its clinical trials policy-focused programming to further education initiatives, raise awareness and foster collaboration among diverse stakeholders to improve clinical trials access.

Throughout 2022, advocates found unique opportunities to shape policies and improve access for patients across the globe. GAfPA looks toward 2023 as an opportunity to build partnerships, increase education and further the vision of patient-centered care for all people.



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

