IFPA

GLOBAL LEADER IN FIGHTING
PSORIATIC DISEASE

Annual Report
2022

Contents

IFPA

Founded in 1971, IFPA is the only global organization uniting all people living with psoriatic disease – regardless of where they live, what type of psoriatic disease they have, or how it impacts their lives.

IFPA's members are national and regional patient associations representing over 60 million people living with psoriatic disease.

Together we speak up for psoriatic disease

Vision

A future where all people living with psoriatic disease enjoy good health and well-being, free from stigma and preventable disability and comorbidities

Mission

Unite, strengthen and lead the global psoriatic disease community to improve the lives of all people affected by psoriatic disease

Strategic goals

Message from the Executive Director

2022 was IFPA's year of mental health. The aftermath of the COVID-19 pandemic coupled with trends on the global health agenda, war in Ukraine, and increasing climate tragedies made this the perfect time to address the connection between psoriatic disease and emotional well-being.

We began the year with a deep dive into the research. The statistics were staggering. Worldwide, 54% of people with psoriatic disease experience stress and anxiety that surpasses the general average. One in five have experienced stigma and discrimination. More than 80% reported an impact on their intimate and family relationships. In April, IFPA published a report titled "**Inside Psoriatic Disease: Mental Health**" exposing the biological and environmental factors that impact the brain-skin axis, and exploring proven strategies to combat anxiety and depression among people with psoriatic disease. This knowledge informed our actions in 2022, and remain the foundation of our advocacy platform regarding mental health.

In parallel with these efforts, IFPA continued to support our members. In February, we formally launched **IFPA Accelerator**. The training program guides new advocates in forming a patient association and supports existing patient associations as they continue to reach for new skills and ambitious targets. The library of trainings will continue to grow in coming years.

2022 also marked the first **IFPA Forum**, an annual advocacy meeting that pulls diverse stakeholders together to collaborate for regional progress. The first Forum was held in Milan, Italy on September 4th, and addressed unmet needs for Europeans living with psoriatic disease. 95 advocates joined forces to speak up, and form a united action plan.

World Psoriasis Day amplified the call to address mental health. With our theme "Unload Psoriatic Disease" we led the global community in raising awareness of the connection to depression and anxiety. We called upon advocates living with the disease to share messages of hope and healing. We expanded the website at psoriasisday.org, developing even more tools for supporters to create posters, print T-shirts, and more. The campaign reached a potential 2.7 billion people around the world.

October 29th further marked the climax of **IFPA Island**, a project addressing youth living with psoriatic disease through video games. IFPA Ambassador Joel Nelson spearheaded the project. Viewers tuned into his Twitch channel each week to watch him build IFPA Island inside Nintendo's Animal Crossing: New Horizons. The live streams chats covered topics ranging from pain to family. After the project's conclusion, IFPA released a toolkit for national associations to repeat and improve upon the idea.

IFPA concluded the year with a final project called "**All the Colors We Are**," showcasing diversity within the psoriatic disease community and advocating for more inclusive approaches to medical research, education, and treatment. IFPA's global community submitted photos of rare and non-rare psoriasis, psoriatic arthritis and other visible symptoms. A digital library of these images was made available for free download to raise awareness. In the first phase of the project, the medical community participated in discussions and activities, including joint webinars. Together with the International Psoriasis Council, IFPA held a consultative workshop to share best practices and discuss unmet medical needs as IFPA now moves into the second phase of the project.

Our team was glad to resume travels in 2022, assembling collaborators in the global fight against psoriatic disease. We warmly thank the incredible advocates and partners who have supported our growing ambitions throughout the year. We congratulate our IFPA members for their extraordinary initiative to effect change for everyone living with psoriatic disease. Finally, I want to say thank you to our sponsors for believing in the work that we do, without you we could not accomplish as much. We look forward to continuing the journey together in 2023.

Enjoy the report,

Frida Dunger Johnsson
Executive Director

THE ORGANIZATION

IFPA Board

Hoseah Waweru
President

Ingvar Ágúst Ingvarsson
Vice President

Kathleen L. Gallant
Secretary

Josef de Guzman
Treasurer

Silvia Fernandez Barrio
Board Member

Helen Crawford
Board Member (entering September 2022)

David Trigos Herraez
Board Member (exiting September 2022)

Leticia Lopez
Board Member (exiting September 2022)

Masanori Okuse
Board Member (entering September 2022)

IFPA Secretariat

Frida Dunger Johnsson
Executive Director

Janina Kostiukaite
Project Developer

Camille Lancelot
Communications Manager

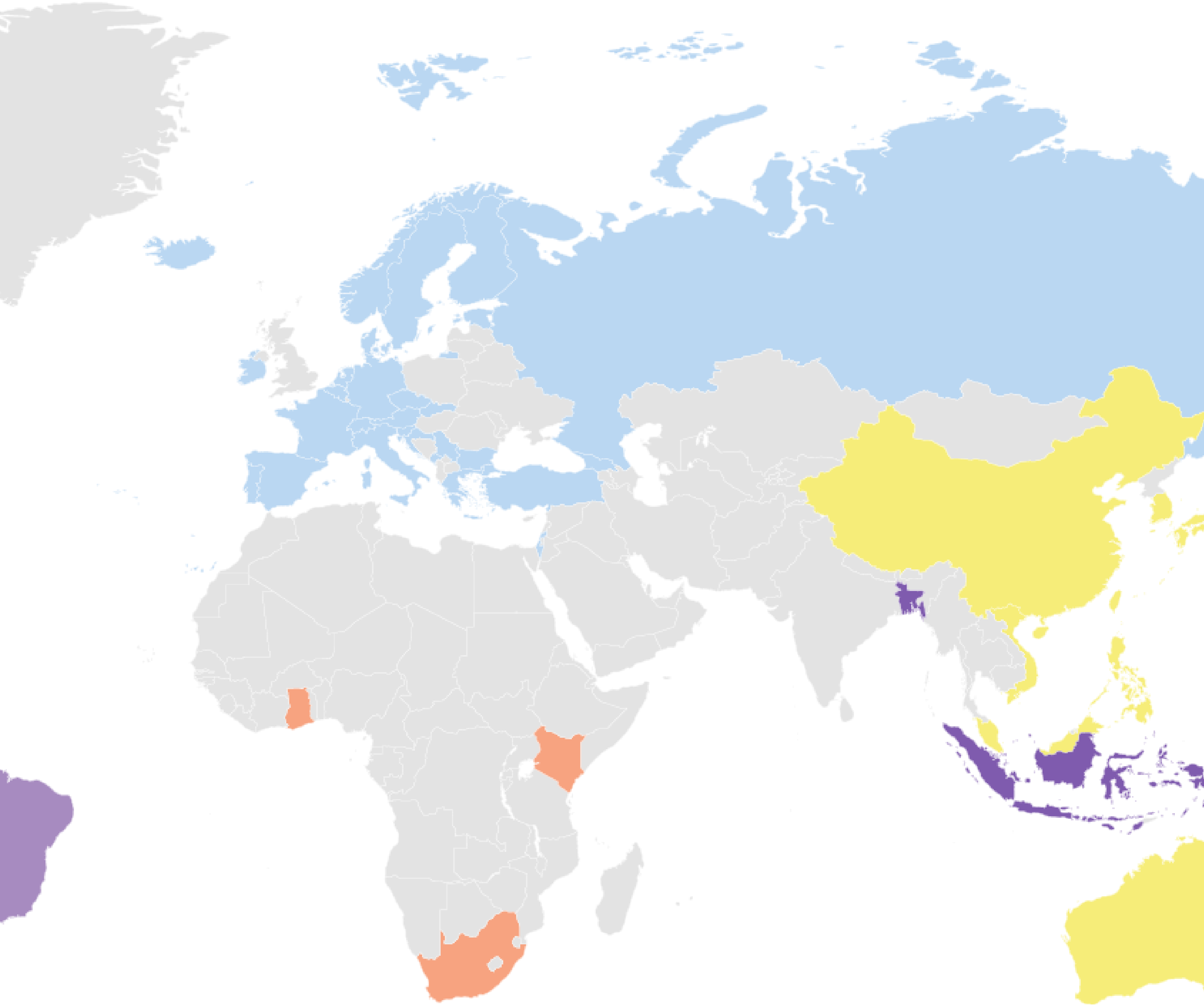
Elisa Martini
Program Officer - Advocacy and Policy

Sicily Mburu
Scientific Officer

Ida Mourjujärvi
Manager Administration and Events

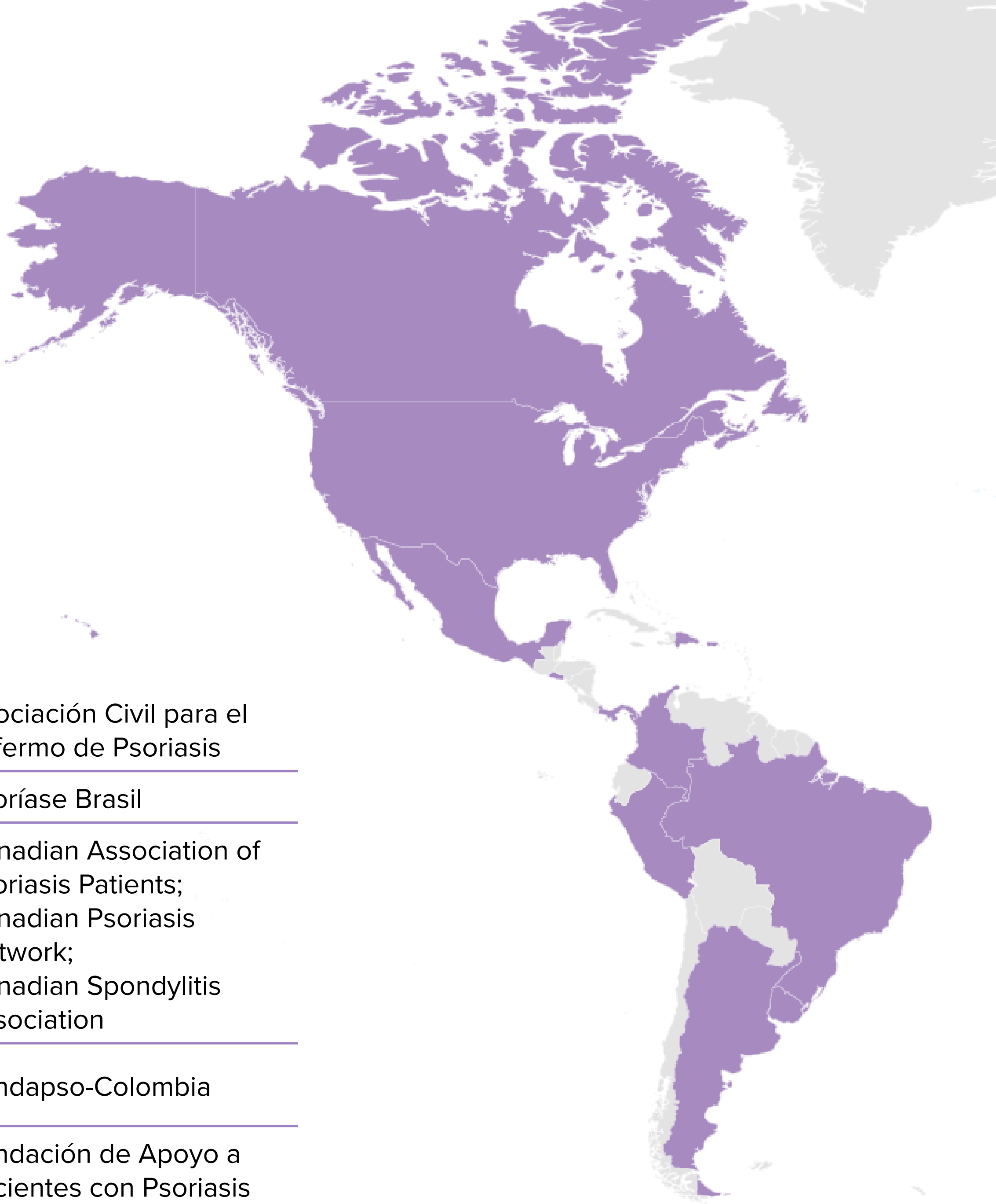
Annika Sjöberg
Marketing Manager

IFPA Membership



Africa

Regional Organization	PSORAFRICA
Ghana	Psoriasis Ghana
Kenya	Psoriasis Association of Kenya
South Africa	South African Psoriasis Association

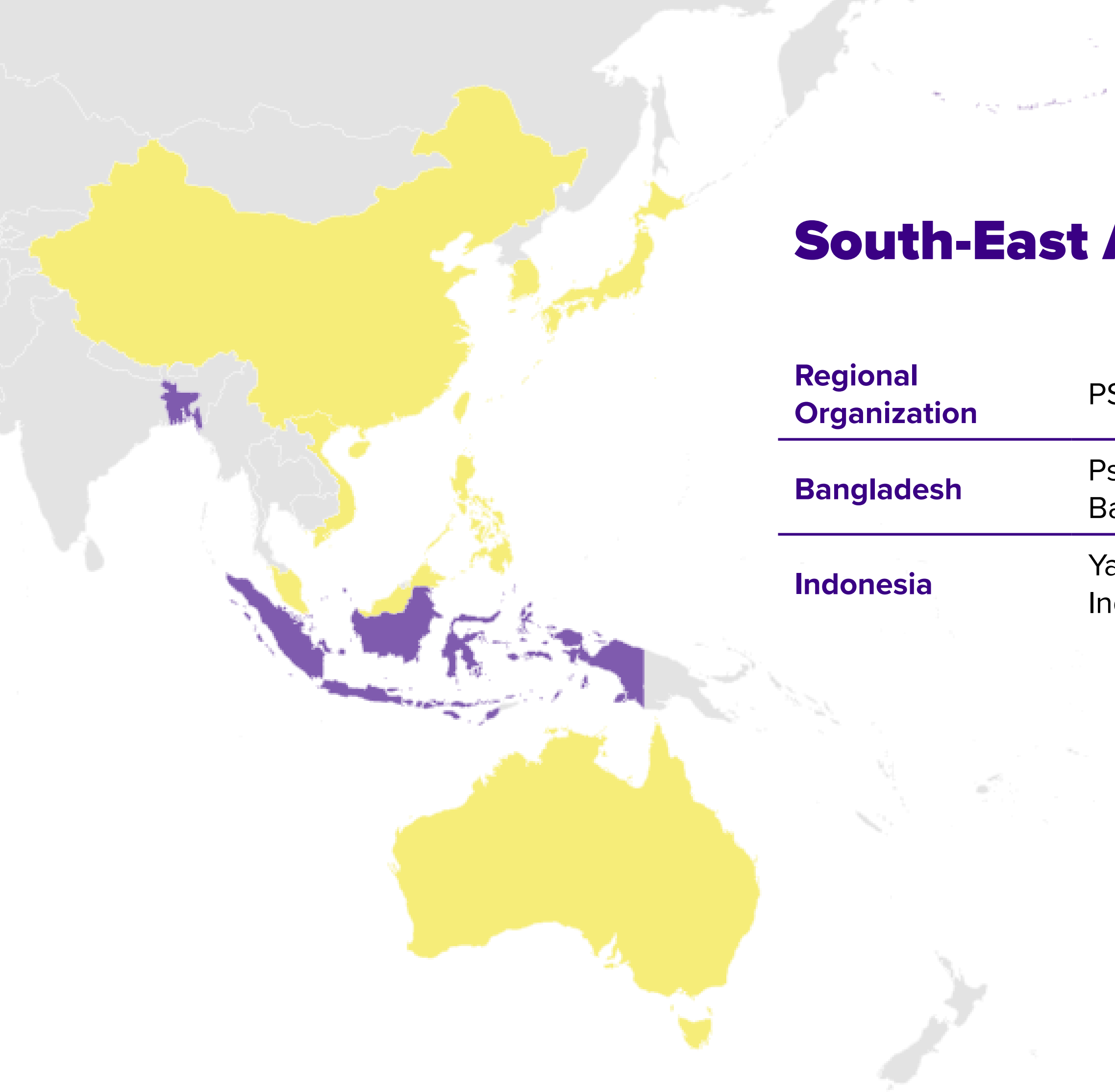


Americas

Argentina	Asociación Civil para el Enfermo de Psoriasis
Brazil	Psoríase Brasil
Canada	Canadian Association of Psoriasis Patients; Canadian Psoriasis Network; Canadian Spondylitis Association
Colombia	Fundapso-Colombia
Dominican Republic	Fundación de Apoyo a Pacientes con Psoriasis
El Salvador	Asociacion Psoriasis Nueva Vida El Salvador
Mexico	Asociación Mexicana contra la Psorias
Panama	Fundación Psoriasis de Panama
Peru	Asociación de Psoriasis y Arthritis Psoriásica - Perú
Puerto Rico	Asociación Puertorriqueña de Ayuda al Paciente de Psoriasis
United States	National Psoriasis Foundation
Uruguay	Asociación Psoriasis Uruguay

Europe

Regional Organization	EUROPSO
Austria	Pso-Austria Verein und Selbsthilfegruppe der PsoriatikerInnen in Österreich
Belgium	Groupe d’Aide à l’Information et à la Recherche sur le Psoriasis; Psoriasis Liga Vlaanderen
Bulgaria	Асоциация на хората с псориазис и псориатични усложнения
Croatia	Društvo psorijatičara Hrvatske
Czech Republic	Spolek psoriatiků a atopických ekzematiků
Denmark	Psoriasisforeningen
Estonia	Eesti Psoriaasiliit
Finland	Psoriasisliitto
France	France Psoriasis
Georgia	Psoriasis Association of Georgia; საქართველოს ფსორიაზით დაავადებულ პაციენტთა ასოციაცია
Germany	Deutscher Psoriasis Bund
Greece	Epidermia
Iceland	Samtök Psoriasis og Exemsjúklinga
Ireland	Irish Skin Foundation
Israel	Israel Psoriasis Association
Italy	Associazione Psoriasici Italiani Amici della Fondazione Corazza
Montenegro	Association for helping people with rheumatic diseases Montenegro
Norway	Psoriasis- og eksemforbundet
The Netherlands	Psoriasispatiënten Nederland
Portugal	PSOPortugal
Russia	Interregional Charitable Public Organization “Skin and Allergic Diseases”
Serbia	Udruzenje Pacijenti Protiv Psorijaze
Slovakia	Spolocnost Psoriatikov a Atopikov SR
Slovenia	Drustvo Psoriatikov Slovenije
Spain	Acción Psoriasis
Sweden	Psoriasisförbundet
Switzerland	Schweizerische Psoriasis und Vitiligo Gesellschaft
Turkey	Türkiye Sedef Hastalan Dayanisma Dernegi



South-East Asia

Regional Organization	PSORASIA
Bangladesh	Psoriasis Awareness Club Bangladesh
Indonesia	Yayasan Peduli Psoriasis Indonesia

Western Pacific

Australia	Psoriasis Australia
China	银屑病病友互助网
Hong Kong	香港銀屑病友會
Japan	Japan Psoriasis Association
Korea	Korea Psoriasis Association
Malaysia	Persatuan Psoriasis Malaysia
Philippines	Psoriasis Philippines
Singapore	The Psoriasis Association of Singapore
Taiwan	台灣乾癬協會
Vietnam	HỘI VẢY NẾN VIỆT NAM

Civil-Society Partners

csem
Civil Society Engagement Mechanism for UHC2030

ONGO

Global Health Council
The Collective Voice of the Global Health Community

GLOBALSKIN.ORG
International Alliance of Dermatology Patient Organizations

G P A
Global Psoriasis Atlas

GRAPPA
Group for Research and Assessment of Psoriasis and Psoriatic Arthritis

International Alliance of Patients' Organizations
A global voice for patients

ILDS

IPC
INTERNATIONAL PSORIASIS COUNCIL

NCDAlliance

Private Sector Partners

abbvie

almirall

AMGEN

Bristol Myers Squibb™

Boehringer Ingelheim

janssen

LEO

NOVARTIS

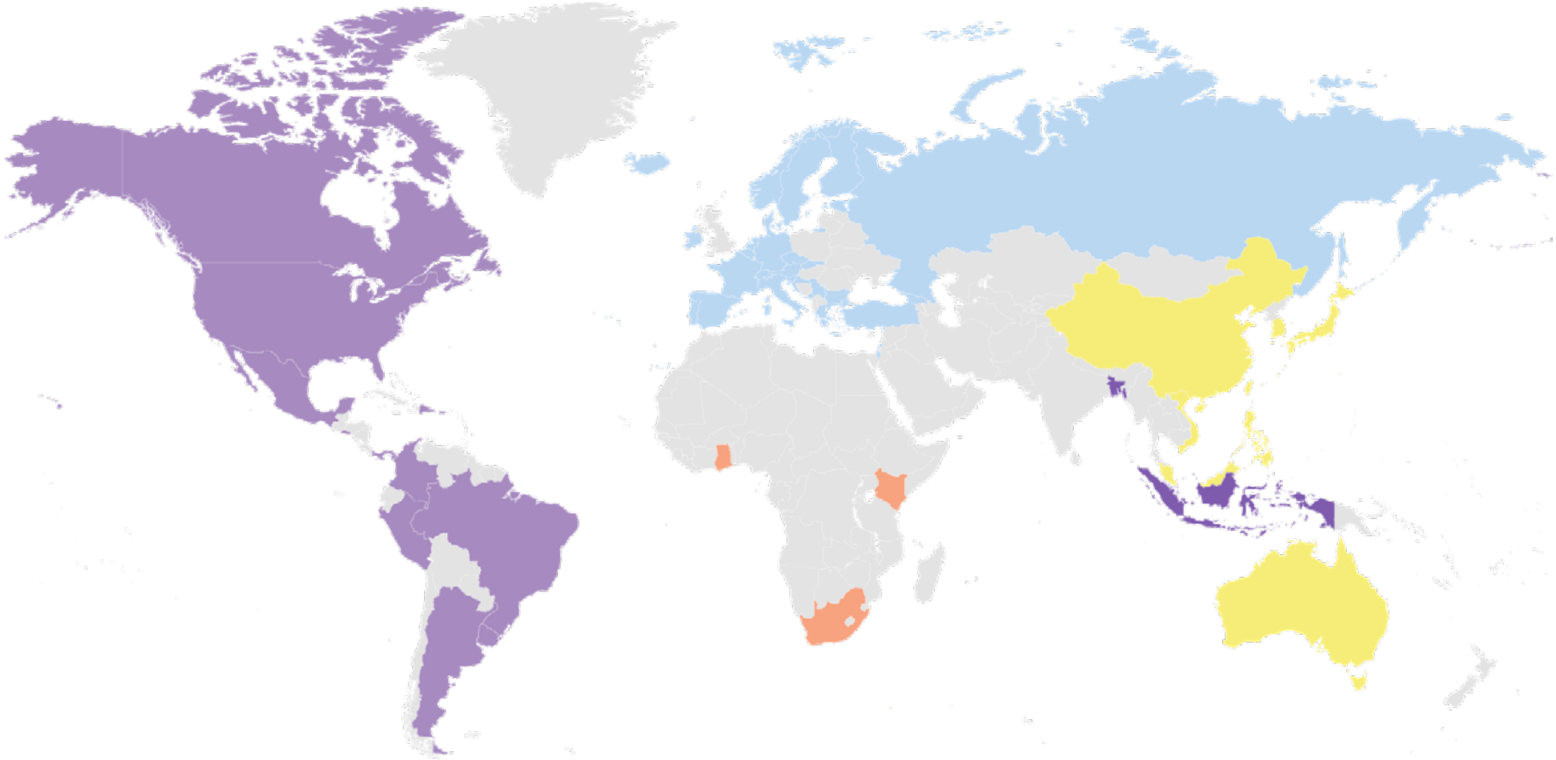
Lilly

Pfizer

ucb

PROGRESS TOWARD STRATEGIC GOALS

ENSURE GLOBAL REPRESENTATION



As a global organization, it is essential that IFPA represents everyone with psoriatic disease, no matter where they come from. IFPA is growing its membership, particularly in areas where there is not enough organized advocacy for people with psoriatic disease. Our goal is to have **133 national member associations by 2030**. Together, we will boost the voices of everyone living with psoriatic disease, everywhere.

To accomplish this ambitious goal, IFPA hired a Marketing Manager, Annika Sjöberg, in September. The Marketing Manager is responsible for outreach to prospective members, and for facilitating the creation of new patient associations.

59
national members

3
regional members

55
countries

IFPA plans to welcome 25 new members by 2024.

IFPA advocates for people living with psoriatic disease at the global level. By generating knowledge to support our advocacy platform, then attending and hosting advocacy meetings to promote our message, IFPA ensures the visibility and relevance of psoriatic disease in every action on the global health agenda. This year, IFPA put mental health in the spotlight.

IFPA's advocacy in 2022 included:

- *Inside Psoriatic Disease: Mental Health*, a report evaluating strategies to improve well-being for people with psoriatic disease
- Speaking up for regional needs at IFPA Forum Europe
- Development of indicators to measure national health system's management of psoriatic disease
- IFPA Coalition action plan

230
people trained in patient advocacy

70
patients participating in decision making groups

11
advocacy events

IFPA empowers people living with psoriatic disease to participate in the decisions that affect them. In 2022, 70 patient representatives from IFPA participated in advisory boards and advocacy task forces around the world.

IFPA joins forces with national member associations to implement change locally. IFPA's members are working together towards a better future for all people living with psoriatic disease. IFPA collects information from members about local needs and priorities, then provides resources to meet those needs.

Support for members comes in the form of training, grants, and networking opportunities and research. These resources are made available thanks to bidirectional cooperation between national members and IFPA's global team.

19

members consulting

21K €

amount distributed in grants

10

national projects sponsored

After several years of virtual meetings, IFPA's members finally gathered in Milan, Italy in September for the tri-annual General Assembly. The day was completed with workshops and trainings.

SHARE KNOWLEDGE

Diagnosis. Stigma. Discrimination. Equality. Justice. IFPA works to improve the lives of people living with psoriatic disease. Raising awareness is a powerful tool to dismantle some of the biggest challenges that this community faces.

IFPA continues to develop robust systems for sharing knowledge. From latest research to best practices in advocacy, knowledge is our greatest weapon.

Next, it's time to close the gap between knowledge and action. By actively participating in research, IFPA can uncover findings and trigger breakthroughs for everybody living with psoriatic disease.

210
people attending
IFPA events

87K
website views

14
published papers

In 2022, IFPA collaborated with medical researchers to investigate topics including comorbidities, COVID-19, rare forms of psoriatic disease, and diversity.

IFPA is dedicated to the visibility of psoriatic disease on the global stage. Through collaborations with member associations, NGOs, scientific organizations, medical associations, governments and the private sector, IFPA accelerates action towards positive change.

In addition to participating in research, IFPA hosts many events and campaigns uniting the global community. In 2022, IFPA hosted IFPA Forum Europe, World Psoriasis Day, and four IFPA Coalition meetings.

IFPA further participated in cross-sector initiatives to address rare diseases, non-communicable disease, and dermatological diseases. Through partnership with larger disease areas, IFPA can open new doors to progress.

11
private sector partnerships

10
civil society partnerships

IFPA joined the campaign for Rare Disease Day for the first time on February 28th.

2022 FLAGSHIP PROGRAMS

IFPA Accelerator

Boosting national leadership

IFPA Accelerator is a training program that supports organizations in expanding their work and reaching new audiences. The program also guides new advocates in establishing patient organizations.

February 2022 marked the official launch of IFPA Accelerator. The first virtual courses teach IFPA members how to:

- Found a patient organization
- Run a General Assembly
- Plan strategically
- Communications and campaigning

Learn more about IFPA Accelerator at **ifpaaccelerator.com**

35

registered participants

5

courses added

IFPA Goals

1 ENSURE GLOBAL REPRESENTATION

3 STRENGTHEN MEMBER CAPACITY

4 SHARE KNOWLEDGE

Sustainable Development Goals

3 GOOD HEALTH AND WELL-BEING

4 QUALITY EDUCATION

10 REDUCED INEQUALITIES

IFPA Forum

Speaking up for psoriatic disease

At the first IFPA Forum, patient advocates joined policymakers and allies from industry and civil society to speak up for psoriatic disease in Europe. Five pressing needs were investigated. These were:

- Access to early diagnosis and treatment
- Mental health, stigma and quality of life
- Health workforce shortages
- Digital transformation and telemedicine

Each of the topics was elaborated in a **Briefing Book** ahead of the event. Participants used the document to prepare their positions.

At the Forum, stakeholders from across sectors came together to participate in panel discussions, and collaborate in workshops. The outcome was a roadmap to spearhead progress in the region.

Read more about the first IFPA Forum at **ifpaforum.com**

95
attendees

75
people with psoriatic disease trained in advocacy

IFPA Goals

2 LEAD GLOBAL ADVOCACY

4 SHARE KNOWLEDGE

5 UNITE STAKEHOLDERS

Sustainable Development Goals

3 GOOD HEALTH AND WELL-BEING

10 REDUCED INEQUALITIES

16 PEACE, JUSTICE AND STRONG INSTITUTIONS

World Psoriasis Day

Uniting for action

World Psoriasis Day is celebrated every year on October 29th. The theme for 2022 was **Unload Psoriatic Disease**. IFPA's global community raised awareness of the mental health impact of psoriatic disease, and how to protect well-being for everyone living with it.

IFPA continued to build the World Psoriasis Day platform at psoriasisday.org. New tools like downloadable social media tiles, and a poster generator facilitate adaptation of campaign materials into different languages and contexts. The printable T-shirt design made it's way around the world.

Read the complete report at **psoriasisday.org**

64

countries participating

74

activities pinned on the World Psoriasis Day map

2.7B

potential press reach

IFPA Goals

2 LEAD GLOBAL ADVOCACY

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IFPA Conference

Calling for breakthroughs

Preparations are underway for the 7th IFPA Conference scheduled for 27-29 June, 2024 in Stockholm, Sweden. The theme and Scientific Executive Committee were selected in 2022.

Sign up for updates at **ifpaconference.com**

THEME

Uncovering the broad spectrum of psoriatic disease

Prof. April Armstrong
Chairperson

Prof. Laura Coates
Co-Chair in Rheumatology

Prof. Ulrich Mrowietz
Co-Chair in Dermatology

Barbra Bohannan
Secretary

IFPA Goals

4 SHARE KNOWLEDGE

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Sustainable Development Goals

3 GOOD HEALTH AND WELL-BEING

4 QUALITY EDUCATION

9 INDUSTRY, INNOVATION AND INFRASTRUCTURE

2022 PROJECTS

IFPA Coalition

Joining forces

12
member organizations

4
meetings

By collaborating across borders, sectors and disease areas, IFPA generates support to implement the recommendations outlined in the World Health Organization's 2016 Report on Psoriasis.

In 2022, the Coalition continued to work towards the triple A (AAA) Action Plan for the Coalition: Act, Amplify, and Align.

At quarterly meetings, Coalition members offered input to IFPA's mental health initiatives, and contributed to the report, **Inside Psoriatic Disease: Mental Health.**

The Coalition further developed **indicators** to measure implementation of the WHO Global Report on Psoriasis. These indicators will be used to produce the Psoriatic Disease Response Index Asia planned for 2023.

Learn more at **ifpa-pso.com/projects/ifpa-coalition**

IFPA Goals

2 LEAD GLOBAL ADVOCACY

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Sustainable Development Goals

3 GOOD HEALTH AND WELL-BEING

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10 REDUCED INEQUALITIES

On August 30th 2022, Panama approved a law declaring “of national interest medical attention, research, and professional training in the early detection, diagnosis and integral treatment of psoriasis.” After 17 years of advocacy, Monica Chapman, founder of the Panama Psoriasis Foundation, worked closely with Deputy Itzi Atencio to develop the two-page bill and introduce it to the National Assembly.

Chapman participated in two debates at the Assembly in front of the Ministry of Health and the Ministry of Economy. The bill was finally approved with no opposing votes. Now work for implementation begins.

IFPA Ambassadors

Representing psoriatic disease in all its complexity

As people with lived experience, IFPA Ambassadors are experts in psoriatic disease. Their valuable input amplifies global efforts to improve the lives of people living with psoriatic disease. The 2022 cohort of Ambassadors have every kind of psoriatic disease and live in each region of the world. They also represent different ages, genders, levels of psoriatic disease severity, experiences with healthcare systems and access to treatment.

20
training hours

124
advocacy hours

In the program, IFPA provides training for the Ambassadors in speech and advocacy. Ambassadors are then hired by IFPA and external partners to participate in campaigns, speaking engagements, and research panels.

In 2022, IFPA Ambassadors:

- Presented their stories at conferences and on panels
- Directed personal initiatives to address mental health
- Collaborated for World Psoriasis Day
- Spoke up at IFPA Forum
- Submitted photos to All the Colors We Are
- Ran IFPAisland video game and live stream

IFPA Goals

1 ENSURE GLOBAL REPRESENTATION

2 LEAD GLOBAL ADVOCACY

4 SHARE KNOWLEDGE

Sustainable Development Goals

3 GOOD HEALTH AND WELL-BEING

8 DECENT WORK AND ECONOMIC GROWTH

16 PEACE, JUSTICE AND STRONG INSTITUTIONS

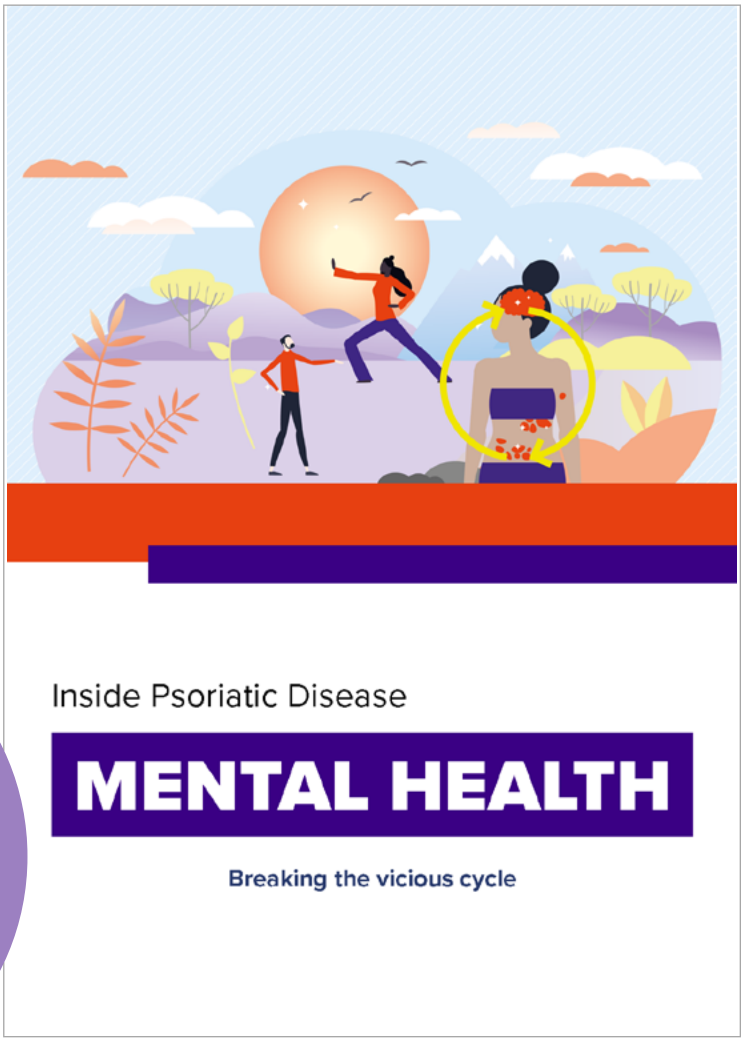
Inside Psoriatic Disease

Mental Health

IFPA continued its series on advocacy for comorbidities with the report titled “Inside Psoriatic Disease: Mental Health.”

Depression and anxiety are increasingly recognized as a significant part of psoriatic disease. In this report, IFPA uncovered the endogenous and exogenous reasons for this link, and outlined proven techniques to improve well-being for everyone living with psoriatic disease.

This mental health report built the foundation for IFPA’s actions in 2022, from infographics, to press releases, to campaigns, to video game awareness raising activities, and more



Inside Psoriatic Disease

MENTAL HEALTH

Breaking the vicious cycle

2.8 K
report views

Read the report at: **ifpa-pso.com/resources-tools/inside-psoriatic-disease-mentalhealth**

IFPA Goals

2 LEAD GLOBAL ADVOCACY

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3 GOOD HEALTH AND WELL-BEING

4 QUALITY EDUCATION

Solidarity Fund

Supporting IFPA Members

Across the world, IFPA members are actively working to improve the lives of the millions of people living with psoriatic disease. However, accessing financial support can be an enormous challenge. The IFPA Solidarity Fund was created to address the funding gap by awarding grants for advocacy, education and awareness-raising. IFPA is proud to support our heroes across the world that are truly making a difference. Learn more at **ifpa-pso.com/project-funding/**

In 2022, grants of up to 2,500 euros were awarded to 9 recipients:

Croatia
Education Program for Psoriasis Patients

Greece
Comorbidities Campaign with Focus on Depression

Hong Kong
Psoriasis Patients Registry

Kenya
Symposium for Patients and Caregivers

Russia
7-day Knowledge Marathon

South Africa
Poetry for Inclusion & Mental Health Webinars

Vietnam
Reporter Training for PsorViet Podcast

Iceland
EADV Attendance

Peru
Psychology and Coping Program

IFPA Goals

- 2 LEAD GLOBAL ADVOCACY
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Sustainable Development Goals

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- 9 INDUSTRY, INNOVATION AND INFRASTRUCTURE
- 10 REDUCED INEQUALITIES

Epidermia was awarded 20,000 EUR through Amgen and IFPA's 2022 UPLIFT Innovation Challenge to establish **Me and My Doctor**, a program educating people with psoriatic disease on communication techniques for medical appointments.

By fostering better communication, Epidermia increased trust between doctors and patients. The results: 17,000 participants in the program increased their adherance to treatment, achieved greater success in treatment goals.

IFPAisland

Gaming for awareness

Up to half of people with psoriatic disease develop it as children or young adults. To reach this demographic, IFPA was the first patient association to create an island inside Nintendo's Animal Crossings: New Horizons video game.

IFPA Island is a safe space for everyone, especially people living with psoriatic disease, to interact and have fun together. Everyone is invited to visit the island, take and share pictures in the psoriatic disease-themed spaces, participate to events, and learn more about psoriatic disease.

Joel Nelson – IFPA Ambassador and owner of the Twitch channel JoelvsArthritis – shared his story with psoriatic-associated Juvenile Idiopathic Arthritis while creating the IFPAisland. Joel livestreamed from events like EADV. The project culminated in an, 8-hour World Psoriasis Day marathon with live interviews and interactive gaming.

Learn more about IFPAisland at: **ifpa-pso.com/projects/ifpa-island**

viewed from
15
countries

500
minutes live

5K
minutes watched
on Twitch

IFPA Goals

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Global Psoriasis Atlas

Worldwide epidemiology of psoriatic disease

The GPA is a collaboration between three leading international organisations in world dermatology and psoriatic disease: IFPA; International League of Dermatological Societies (ILDS); and International Psoriasis Council (IPC). It is a long-term project collecting open-access information about worldwide epidemiology of psoriatic disease. In 2022, work focused on four key areas:

- Epidemiology of psoriasis
- Understand and characterize the economic impact of psoriasis
- Recognizing the comorbid disease burden of psoriatic disease
- Improving early diagnosis of psoriasis

Learn more at **globalpsoriasisatlas.org**

2022 Highlights

There have been no population-based epidemiological studies on psoriasis. To contribute to data in this area, the Global Psoriasis Atlas has been working with Dr. Choon Siew Eng to analyze trends in incidence and prevalence of psoriasis in Johor Bahru, **Malaysia**.

The Global Psoriasis Atlas used the Taiwan National Health Insurance claim database and national death certificates from 2006 to 2017 to determine trends in incidence, prevalence and mortality of people living with psoriatic disease in **Taiwan** to examine how these epidemiological factors changed over time.

A team from the Global Psoriasis Atlas conducted a field study in East **Greenland** to investigate discrepancies in studies of the prevalence of psoriasis in Inuit populations, and further knowledge of skin diseases among indigenous people in the Arctic region.

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In 2022, Psoriasis Association of Kenya developed a new website to showcase their organization. The site features images of psoriatic disease, quick facts about the illness, and messages of support. Members can use the site to learn about upcoming events and get involved with the community. The site marks a new level in PAK's activation. Visit **psoriasiskenya.co.ke** to see it for yourself!

All the Colors We Are

Raising awareness of diversity

There is a serious diagnosis gap in skin diseases. For too long, training materials have centered European images, shaping physician's understanding of psoriasis and related illnesses. People with non-white skin have more difficulty receiving a correct diagnosis. As a consequence, their treatment is delayed, often causing further health complications.

It's time to break these obstacles. It's time to represent all persons living with psoriatic disease irrespective of their gender and geographical location. Together with IFPA members, partners and supporters, IFPA will give the public a more balanced and accurate understanding of what psoriasis can look like among different skin colors. Contributors from around the world sent photos of their psoriatic disease. These images will be used to create awareness-raising materials, and improve training tools.

Learn more at **ifpa-pso.com/projects/all-the-colors-we-are**

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IFPA

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PSORIATIC DISEASE

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