

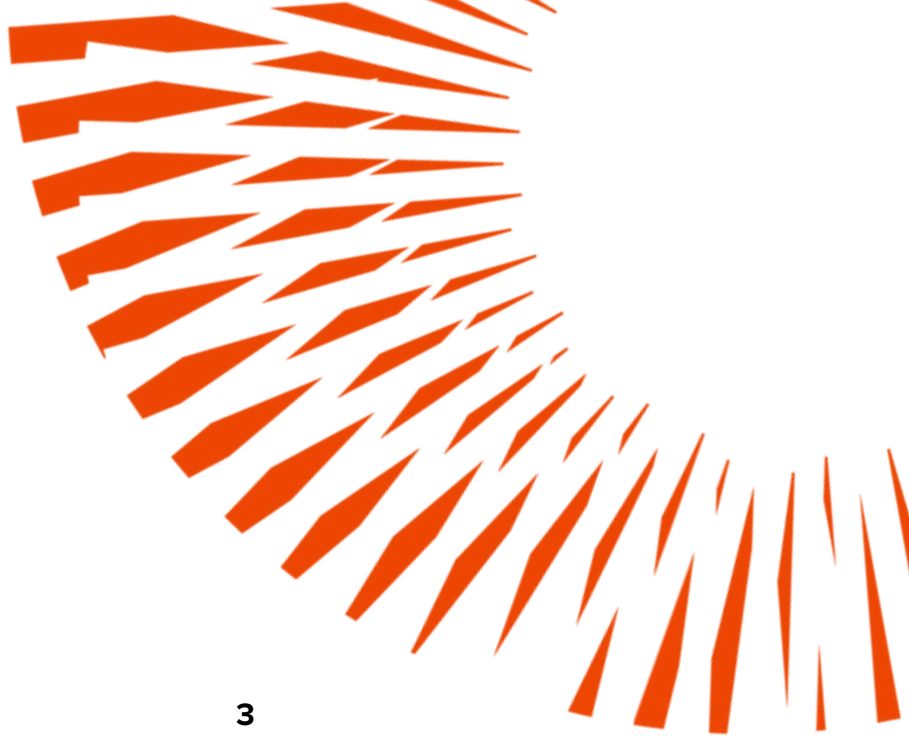


**IFPA**

GLOBAL LEADER IN FIGHTING  
PSORIATIC DISEASE

**ANNUAL REPORT**

**2023**



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# IFPA

Founded in 1971, IFPA is the 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.

## 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

As we reflect on 2023, we recognize it as a year marked by significant global challenges. Wars and health crises have cast long shadows over the world, creating an environment of uncertainty and hardship for many. Despite these difficulties, IFPA has remained steadfast in our vision and conviction that progress is possible. Our commitment to improving the lives of those affected by psoriatic disease has never wavered, even in the face of adversity.

One of the significant highlights of 2023 was our focused efforts in the IFPA Forum Asia. This initiative facilitated follow-up activities that have begun to reshape the understanding and management of psoriatic disease in the region. By engaging with local stakeholders and healthcare providers, we have laid the groundwork for lasting improvements in patient care and support.

One of our key focuses in 2023 was on strengthening global commitments to Universal Health Coverage (UHC) for psoriatic disease where everyone, irrespective of their age, sex, financial situation, or living standards can access the health services they need, without experiencing financial hardship. Our efforts culminated in the publication of a comprehensive report named “Strengthening Global Commitments to UHC for Psoriatic Disease”. This report underscores the critical importance of strengthening primary care, addressing the shortage of healthcare professionals, and considering mental health as a part of health.

Our theme for this year, UHC & Access for All, resonates deeply as we continue to champion the cause of equitable healthcare. Recognizing that we have a long way to that all people with psoriatic disease will receive the healthcare they need and are entitled to.

This report not only details our key activities and accomplishments over the past year but also provides our financial statements and an overview of our funding.



Since the inception of our Global Strategy 2021-2030 our efforts has focused on achieving advancement against five main goals: ensuring global representation, leading global advocacy, strengthening member capacity, sharing knowledge, and uniting stakeholders. In the following pages, you will find comprehensive insights into our successes, the progress we have made, and the valuable learnings we have gathered along the way.

Our achievements would not have been possible without the unwavering support of our members and partners. Thank you for your continued support and partnership. Together, we continue to drive the highest quality and strive for a world where everyone affected by psoriatic disease has access to the care and support they need. The IFPA team are always keen to engage with and explore opportunities for collaborations, research and advocacy, please do get in contact. I wish you all a safe and productive 2024.

Enjoy the report,

**Frida Dunger**

*Executive Director*



# **THE ORGANIZATION**

# IFPA BOARD



**Hoseah Waweru, M.D.**  
President



**Ingvar Ágúst Ingvarsson**  
Vice President



**Kathleen L. Gallant**  
Secretary



**Josef de Guzman**  
Treasurer



**Silvia Fernandez Barrio**  
Board Member



**Helen Crawford**  
Board Member



**Masanori Okuse**  
Board Member

# IFPA SECRETARIAT



**Frida Dunger**

Executive Director

**Ida Mourujärvi**

Finance and Administration Manager

**Janina Kostiukaite**

Fundraising Manager

**Annika Sjöberg**

Marketing and Communications Manager

**Camille Lancelot**

Community Manager

**Tanjia Nishi**

Global Communicator

**Elisa Martini**

Policy and Advocacy Manager

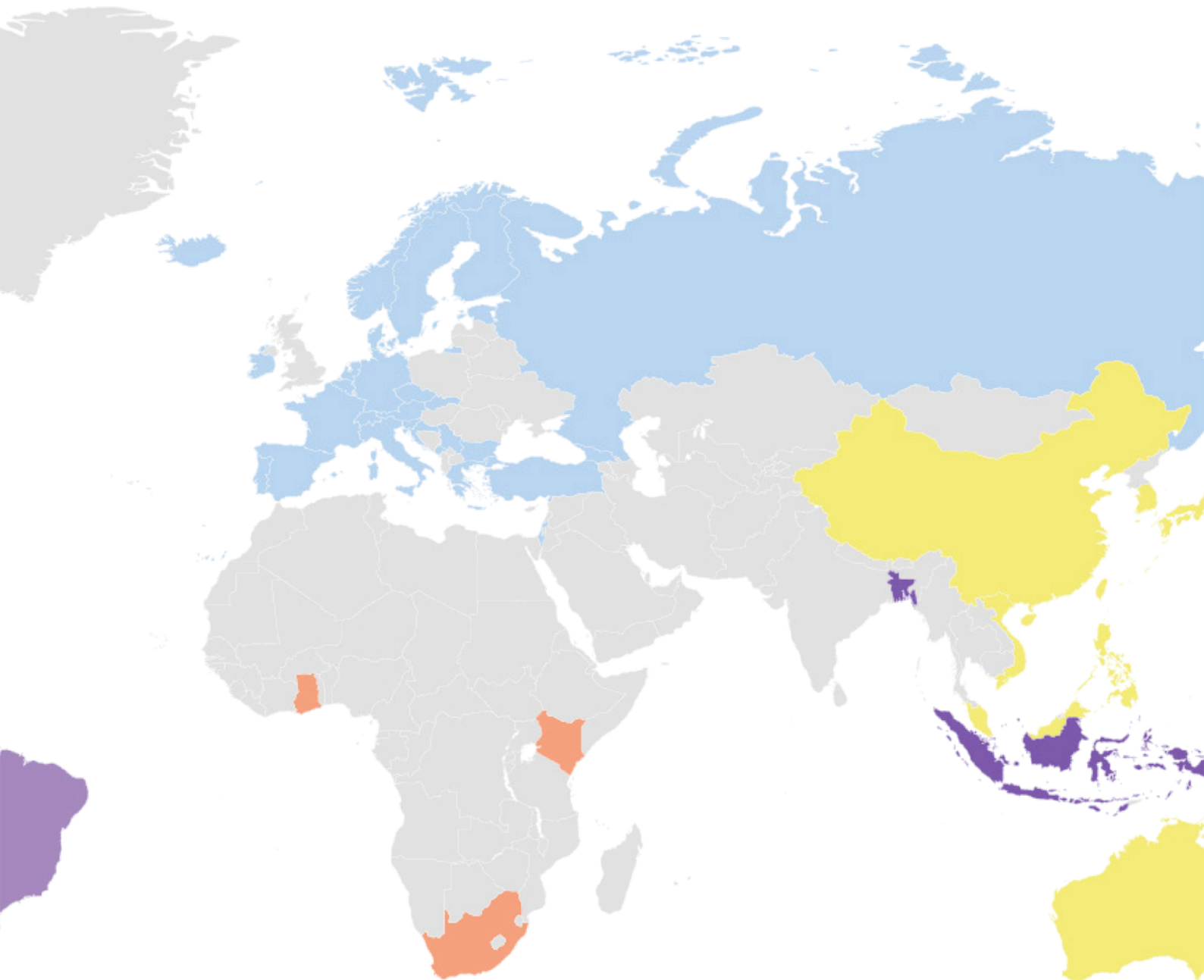
**Raquel Vaz**

Scientific Project Leader

**Sicily Mburu**

Scientific Officer

# IFPA MEMBERSHIP



## Africa

**Regional Organization**

PSORAFRICA

**Ghana**

Psoriasis Ghana

**Kenya**

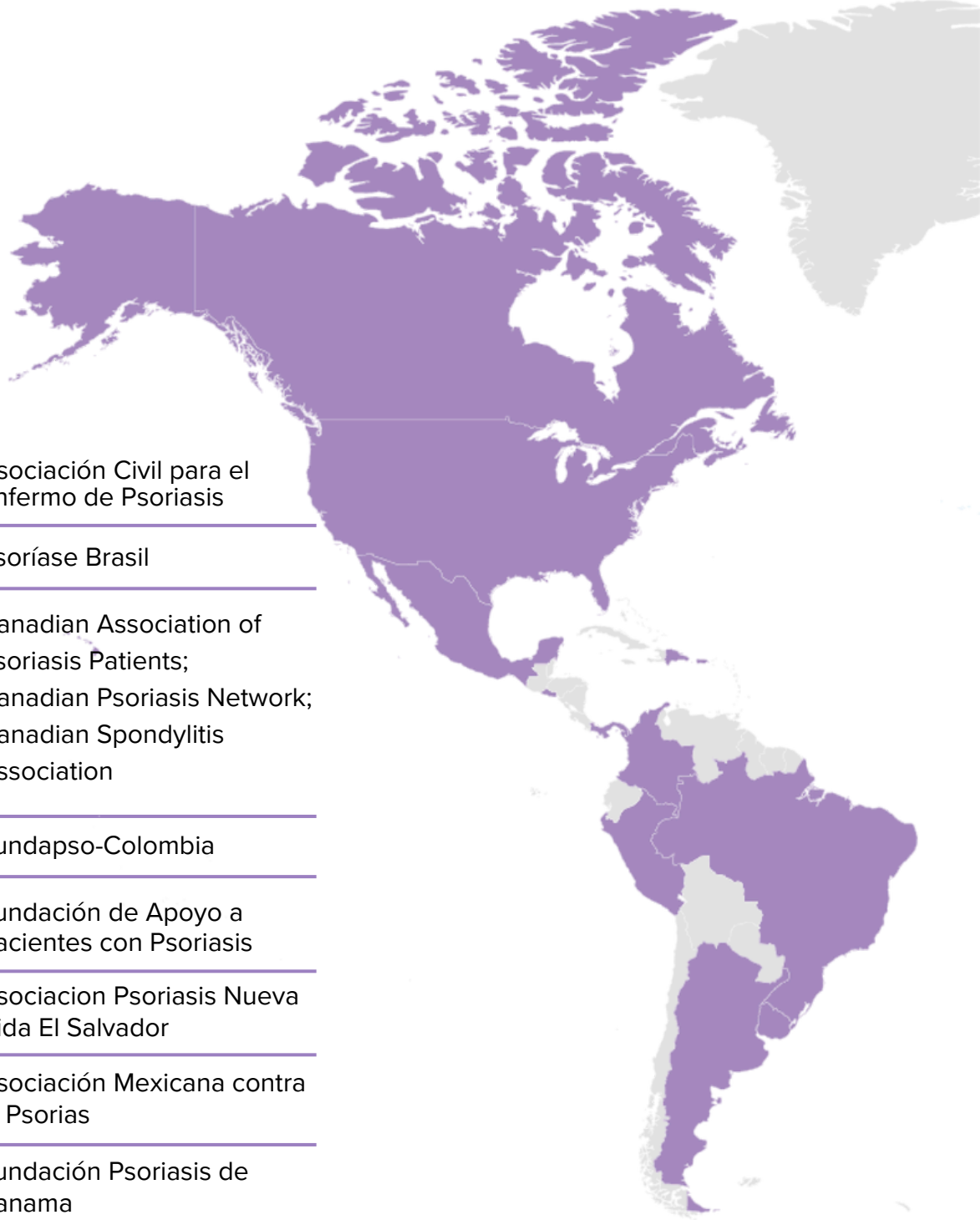
Psoriasis Association of Kenya

**South Africa**

South African Psoriasis Association

# Americas

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



# Europe

Regional Organization	EUROPSO
<b>Austria</b>	Pso-Austria Verein und Selbsthilfegruppe der PsoriatikerInnen in Österreich
<b>Belgium</b>	Groupe d'Aide à l'Information et à la Recherche sur le Psoriasis, asbl
<b>Bulgaria</b>	Асоциация на хората с псориазис и псориатични усложнения
<b>Croatia</b>	Društvo psorijatičara Hrvatske
<b>Czech Republic</b>	Spolek psoriatiků a atopických ekzematiků
<b>Denmark</b>	Psoriasisforeningen
<b>Estonia</b>	EPsoL- Eesti Psoriaasiliit
<b>Finland</b>	Psoriasisliitto
<b>France</b>	France Psoriasis
<b>Georgia</b>	Psoriasis Association of Georgia; საქართველოს ფსორიაზით დაავადებულ პაციენტთა ასოციაცია
<b>Germany</b>	Deutscher Psoriasis Bund
<b>Greece</b>	Epidermia
<b>Hungary</b>	Association of Hungarian Psoriasis Clubs
<b>Iceland</b>	Samtök Psoriasis og Exemsjúklinga
<b>Ireland</b>	Irish Skin Foundation
<b>Israel</b>	Israel Psoriasis Association
<b>Italy</b>	APIAFCO Associazione Psoriasici Italiani Amici della Fondazione Corazza
<b>Montenegro</b>	Association for helping people with rheumatic diseases Montenegro
<b>Norway</b>	PEF, Psoriasis- og eksemforbundet
<b>The Netherlands</b>	Psoriasispatiënten Nederland
<b>Portugal</b>	Associação Portuguesa da Psoríase
<b>Russia</b>	Interregional Charitable Public Organization "Skin and Allergic Diseases"
<b>Romania</b>	Asociația Pacienților cu Afecțiuni Autoimune
<b>Serbia</b>	Pacijenti protiv psorijaze
<b>Slovakia</b>	Spoločnosť Psoriatikov a Atopikov SR
<b>Slovenia</b>	Društvo Psoriatikov Slovenije
<b>Spain</b>	Acción Psoriasis
<b>Sweden</b>	Psoriasisförbundet
<b>Switzerland</b>	Schweizerische Psoriasis und Vitiligo Gesellschaft
<b>Turkey</b>	Türkiye Sedef Hastalan Dayanisma Dernegi



## South-East Asia

<b>Regional Organization</b>	PSORASIA
<b>Bangladesh</b>	Psoriasis Awareness Club Bangladesh
<b>Indonesia</b>	Yayasan Peduli Psoriasis Indonesia

## Western Pacific

<b>Australia</b>	Psoriasis Australia Inc.
<b>China</b>	银屑病病友互助网 中国慢性皮肤病关爱公益基金
<b>Hong Kong</b>	香港银屑病友會
<b>Japan</b>	Japan Psoriasis Association
<b>Korea</b>	대한건선협회
<b>Malaysia</b>	Persatuan Psoriasis Malaysia
<b>Philippines</b>	Psoriasis Philippines
<b>Singapore</b>	The Psoriasis Association of Singapore
<b>Taiwan</b>	台灣乾癬協會
<b>Vietnam</b>	HỘI VẢY NẾN VIỆT NAM

# Civil & Medical- Society Partners



# Private Sector Partners



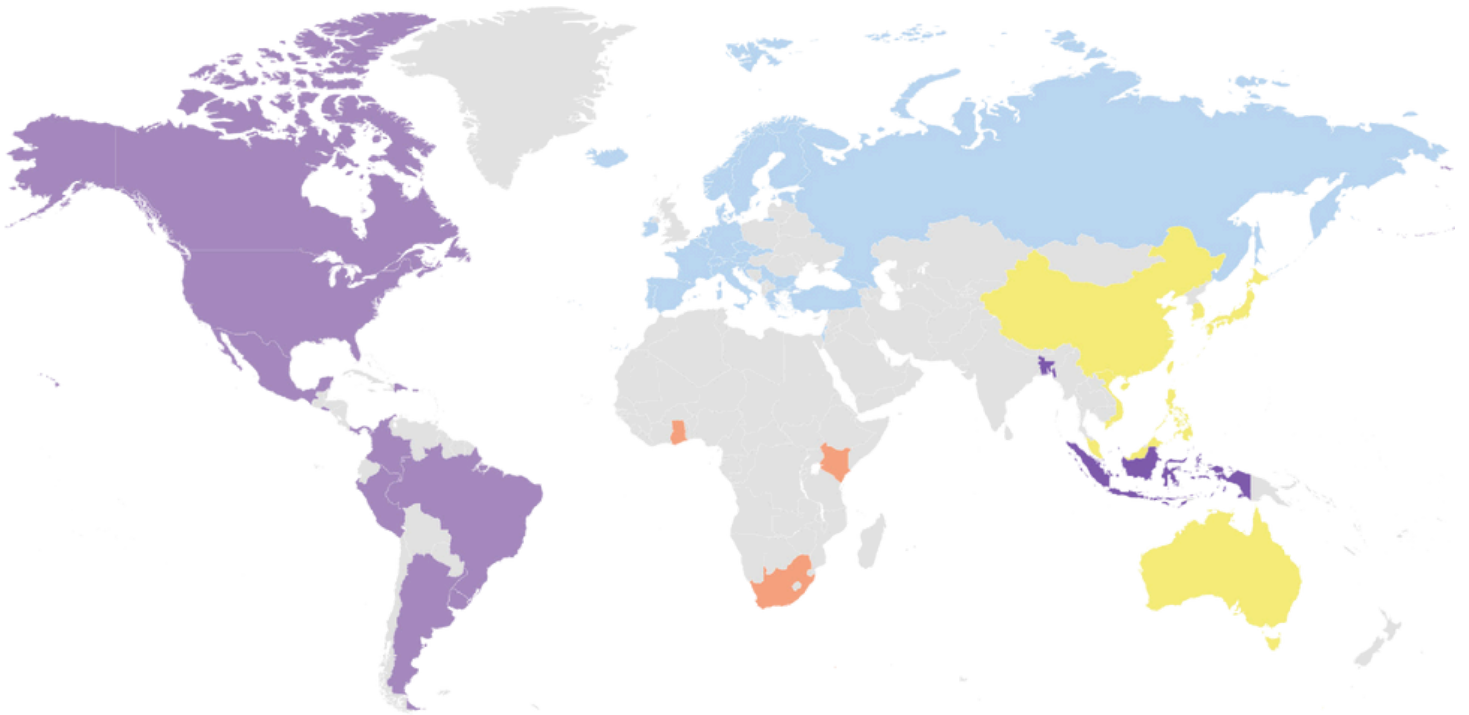






**PROGRESS  
TOWARD  
STRATEGIC  
GOALS**

# ENSURE GLOBAL REPRESENTATION



As a global federation, IFPA is committed to representing everyone living with psoriatic disease, leaving no one behind. We are expanding our membership with the aim to reach **133 national member associations by 2030**. United, we will amplify the voices of everyone living with psoriatic disease, across the globe.

This year, we welcomed new members from China, Hungary, and Romania. By December 31, 2023, IFPA had expanded to include 61 national member organizations across 57 countries, along with 3 regional member organizations.

**61**

**National members**

**3**

**Regional members**

**57**

**Countries**

# LEAD GLOBAL ADVOCACY



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 universal health coverage in the spotlight.

## IFPA's advocacy in 2023 included:

- A report titled "Strengthening Global Commitments to UHC for Psoriatic Disease," highlighting the essential push for inclusive and comprehensive healthcare solutions
- IFPA's Film: A Right to Health on Universal Health Coverage
- Psoriatic Disease Response Index: Western Pacific, was launched at the Forum Asia, translated into 3 different languages

# 73

**People trained in patient advocacy**

# 70

**Patients participating in decision making groups**

# 17

**Advocacy events**

# STRENGTHEN MEMBER CAPACITY



IFPA collaborates with our national member associations to drive local change. By uniting our efforts, we strive to create a better future for individuals affected by psoriatic disease. IFPA gather insights from our members about local needs and priorities, then create and distribute the necessary resources addressing these issues.

This support includes training, funding opportunities, networking opportunities, and research.

**20**

**Members consulting**

**187.5K €**

**Amount distributed in grants**

**18**

**National projects sponsored**

# SHARE KNOWLEDGE



Diagnosis. Stigma. Discrimination. Equality. Justice. IFPA is dedicated to enhancing the lives of those living with psoriatic disease. Raising awareness is key to overcoming the significant challenges this community encounters.

IFPA is committed to building effective systems for knowledge sharing and contributing to research to enhance advocacy. In line with this, IFPA is also organizing a scientific conference in 2024, bringing together experts and stakeholders to advance the field through collaborative learning and innovative discussions.

We must bridge the gap between knowledge and action. By engaging in research, IFPA aims to discover insights and drive breakthroughs that benefit everyone living with psoriatic disease.

**55**

**People attending  
IFPA events**

**41K**

**Website views**

**15**

**Published papers**

# UNITE STAKEHOLDERS



IFPA is dedicated to the visibility of psoriatic disease on the global arena. By collaborating with member associations, NGOs, scientific organizations, medical groups, governments, and the private sector, IFPA drives initiatives for meaningful change.

In addition to participating in research, IFPA hosts many events and campaigns uniting the global community. In 2023, IFPA hosted IFPA Forum Asia and World Psoriasis Day. The Coalition convened four times in 2023: March, July, October and December.

Additionally, IFPA participated in cross-sector initiatives focusing on rare diseases, non-communicable diseases, and dermatological conditions. By partnering with broader disease areas, IFPA increase its impact.

## 12

**Private sector  
partnerships**

## 12

**Civil & medical  
society partners**



**2023  
FLAGSHIP  
PROGRAMS**

# IFPA ACCELERATOR

Boosting national leadership

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

## The program aims to:

- Accelerate the growth of IFPA
- Leverage the skills and capacities of member associations
- Strengthen regional alliances and facilitate best practice sharing within regions

## In 2023, trainings were developed on topics like:

- Community Mobilization
- GPP and Advocating for Rare Diseases
- Measuring Health System Response to Psoriatic Disease
- Project Planning

Learn more about IFPA Accelerator at [ifpaaccelerator.com](https://ifpaaccelerator.com)

**78**

**Registered participants**

**14**

**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

The IFPA Forum is a Flagship program of IFPA designed to put the needs of people living with psoriatic disease at the center of the policy discourse at the regional level. In 2023, the IFPA Forum united stakeholders from the psoriatic community, focusing on Asia. It brought associations, thought leaders, and those with psoriatic disease into collaborative efforts.

In this year's forum a **Briefing Book** and four theme briefs were developed to investigate four pressing needs for people living with psoriatic disease in Asia and Western Pacific. The Briefing Book is available in **6 languages**.

At the Forum, the Psoriatic Disease Response Index: Western Pacific Region was launched. The IFPA Forum Europe Action Playbook, created after the IFPA Forum Europe (2022), was presented to European members during European Psoriasis Week in May. This resulted in a roadmap, action plan, and playbook, along with collaboration with PsorAsia.

Read more about the IFPA Forum at [ifpaforum.com](https://ifpaforum.com)



**118**  
Attendees

**73**  
People with  
psoriatic disease  
trained in advocacy

### IFPA Goals



### Sustainable Development Goals



# WORLD PSORIASIS DAY

## Access For All

World Psoriasis Day is celebrated every year on October 29th. World Psoriasis Day 2023 was marked by a global commitment to promoting inclusivity and accessibility for individuals living with psoriatic disease. The theme "Access for All" emphasized the importance of ensuring that individuals with psoriatic disease, regardless of their geographical location, economic status, or other barriers, have equitable access to quality healthcare and resources.

IFPA continued to build the World Psoriasis Day platform at [psoriasisday.org](https://psoriasisday.org). New tools like downloadable social media tiles, and a poster generator facilitate adaptation of campaign materials into different languages and contexts.

Learn more in IFPA's World Psoriasis Day 2023 Impact Report at [psoriasisday.org](https://psoriasisday.org)



# 94

Countries participating

# 38.3M

Hashtag reach

# 1.6B

Potential press reach

### IFPA Goals



### Sustainable Development Goals



# IFPA CONFERENCE

Calling for breakthroughs

By conducting the multidisciplinary IFPA Conference on psoriatic disease every third year, since 2006, IFPA drives global scientific research. Medical and healthcare professionals present frontline clinical research in dermatology, rheumatology and beyond.

The 7th IFPA Conference will take place **June 27-29**, 2024 in **Stockholm, Sweden**, with the theme: **Uncovering the broad spectrum of psoriatic disease**.

The press release in connections with opening of registration gained **21.2K** recorded views and a potential reach of **1.1B**. The planning for the Conference, addressing psoriasis and psoriatic arthritis, continued during the year.

To know more visit at [ifpaconference.com](https://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



**5** UNITE  
STAKEHOLDERS



## Sustainable Development Goals

**3** GOOD HEALTH  
AND WELL-BEING



**4** QUALITY  
EDUCATION



**9** INDUSTRY, INNOVATION  
AND INFRASTRUCTURE





**2023**

**PROJECTS**

# IFPA COALITION

Joining forces



By collaborating across borders, sectors and disease areas, IFPA uses the Coalition to generate support to implement the recommendations outlined in the Global Report on Psoriasis, developed by the World Health Organization in 2016.

To reach its goal to lead global advocacy, IFPA has defined a triple A (AAA) Action plan: Act, Amplify, and Align.

Coalition members gave helpful input and contributions to discussions to further amplify IFPA's advocacy work. In 2023, the IFPA Coalition counted 15 members from civil society, industry, and medical professionals' organizations.

Learn more at [ifpa-pso.com/projects/ifpa-coalition](https://ifpa-pso.com/projects/ifpa-coalition)

## IFPA Goals



## Sustainable Development Goals





IFPA representatives followed the 76th World Health Assembly. IFPA contributed to the proceedings of the assembly by joining in the submission of a statement together with other organizations, as part of the Global Health Council delegation.

IFPA connected to a new representative in the WHO headquarters, had three meetings with the new contact and agreed on a project to conduct in 2024.

# 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. In 2023, IFPA continuously received requests to contribute patient testimonials, survey participants, and stars for photo and video assets.

**21**  
Training hours



**265**  
Advocacy hours

In the program, IFPA provides training for the Ambassadors in speech and advocacy. The aims of the program are to unite a team of skilled ambassadors, reliable and ready to speak up for psoriatic disease and its comorbidities in the global arena. Their expert perspectives boost the diverse needs and experiences of people living with psoriatic disease, everywhere.

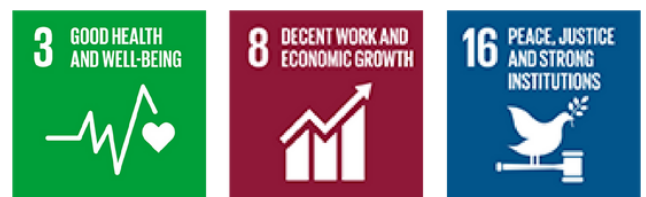
## In 2023 the Ambassadors:

- Received training on project development for awareness raising
- Presented their stories at conferences and on panels
- Directed personal initiatives to address universal health coverage
- Appeared in the film Psoriatic Disease Reflections: A Right to Health
- Collaborated for World Psoriasis Day
- Spoke up at IFPA Forum
- Served on steering committees and participated in projects with civil society organizations and industry partners to raise awareness of patient priorities globally

## IFPA Goals



## Sustainable Development Goals



# GLOBAL PSORIASIS ATLAS

## Worldwide epidemiology of psoriasis

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 psoriasis.

The GPA website is the first-ever comprehensive online epidemiological resource database tool. It contains data on the number of psoriasis cases, healthcare data and looks in depth at the experiences and faces behind people living with psoriasis.

### In 2023 the Global Psoriasis Atlas advanced epidemiological data with:

- 6 publications
- The GPA website translated into Arabic and Spanish
- A field study to the East Cape of South Africa in December

Further information is available on [globalpsoriasisatlas.org](https://globalpsoriasisatlas.org)

### IFPA Goals



### Sustainable Development Goals



# PSORIASIS AND BEYOND

## The global psoriasis disease survey

Psoriasis and Beyond is overseen by a Steering Committee of patient advocates, dermatologists and rheumatologists. By understanding the patient experience, including patient awareness of their own disease, our community will be better equipped to design meaningful interventions. The results of the study are hosted on IFPA’s website for easy access to patient advocates.

In 2023, IFPA continued to use data for evidence-based policy advocacy, focusing on addressing global gaps identified by the study. France, India, and the US have published national patient data at global medical congresses, with Canada, Japan, and the US preparing submissions for peer-reviewed journals. This will enhance evidence-based discussions with policymakers. Additionally, IFPA launched an online educational portal on their website for ongoing education on psoriatic disease.

Learn more at [ifpa-pso.com/projects/psoriasis-and-beyond](https://ifpa-pso.com/projects/psoriasis-and-beyond)



### IFPA Goals



### Sustainable Development Goals



# GOOD CARE

## For psoriatic arthritis

In 2023, IFPA intensified the efforts of increasing awareness of Psoriatic Arthritis— a joint manifestation of Psoriatic Disease associated with high burden and significant comorbidities. Recent progress in understanding the course of psoriatic arthritis (PsA) has led to breakthroughs in therapies.

Through the project, “Good Care for Psoriatic Arthritis” IFPA aims to join forces with rheumatologists and the patient community to raise awareness of new treatment guidelines, and ultimately improve quality of life for people with PsA around the world.

### The outcome of the project consisted of:

- 3 educational videos
- 16 articles
- 1 illustration book

It was presented at three congresses: ACR, WCD and EULAR. The project had a global committee existing of member organizations and Ambassadors.



### IFPA Goals



### Sustainable Development Goals



# 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.

In 2023, IFPA engaged with our members in Singapore on the project, partnered with IPC for a workshop on skin of color and partnered with GPA to start working on a skin of color atlas.

Learn more at [ifpa-pso.com/projects/all-the-colors-we-are](https://ifpa-pso.com/projects/all-the-colors-we-are)

450  
Images



15  
Stories

## IFPA Goals

1 ENSURE GLOBAL REPRESENTATION



4 SHARE KNOWLEDGE



## Sustainable Development Goals

3 GOOD HEALTH AND WELL-BEING



10 REDUCED INEQUALITIES



16 PEACE, JUSTICE AND STRONG INSTITUTIONS



# IFPA FUNDS

## Solidarity Fund

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 established 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/solidarity-fund](https://ifpa-pso.com/project-funding/solidarity-fund)

During 2023, the Solidarity Fund had one call for application. 6 out of 6 applying organizations were elected to share 17,521 EUR.



### IFPA Goals



### Sustainable Development Goals



# IFPA FUNDS

## IFPA Start-Up Fund

The IFPA Start-Up Fund was developed in 2023 to support individuals or groups who reside in a country where there doesn't exist a patient association, and who has the ability to start one. For this reason, the Start-Up funding is connected to specific projects, Start-Up projects, with the purpose of starting new patient associations.

In 2023, Start-Up projects were initiated in **Afghanistan** and **Rwanda**.

## Project Rare GPP

The Project Rare GPP fund is an opportunity for patient organizations to reach those in their region living with GPP (Generalized Pustular Psoriasis). National patient organizations are crucial to the fight against psoriatic disease, and often lack resources to carry out all the projects they wish for. With the financial assistance from this fund, they can realize some of these projects.

During 2023, the Fund had two calls for application, where 9 applications of 25 shared 100,000 EUR.

## UPLIFT Innovation Program

The UPLIFT Innovation Program promotes an open dialogue about a patient's health and treatment goals and strengthens cooperation. Organizations around the world are awarded donations for projects that promote an open dialogue about a patient's health and treatment goals and strengthens cooperation.

In October, 4 organizations, out of 17, were awarded donations to execute their vision to respond to this question, to the total amount of 70,000 USD.

### IFPA Goals



### Sustainable Development Goals





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