

The IFPA logo is rendered in a bold, white, sans-serif font. The letters are thick and closely spaced, with a slight shadow effect that makes them stand out against the dark blue background. The background itself is a vibrant blue with a pattern of orange, jagged, sunburst-like rays radiating from the top left towards the bottom right.

IFPA

GLOBAL LEADER IN FIGHTING
PSORIATIC DISEASE

Annual Report 2021

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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

This past year has been a time of growth and energy for IFPA. 2021 marked the 50th anniversary of IFPA's founding. We celebrated the landmark with appropriate fanfare, but also took it as an opportunity to re-evaluate priorities and chart the next 10-year path. IFPA's 2030 Strategy is the product of close collaboration with IFPA's global membership, and input from diverse stakeholders. With new targets, IFPA is taking on a bold, ambitious future leading the global fight against psoriatic disease.

IFPA's projects are designed to provoke progress towards our strategic goals. For example, the World Psoriasis & Psoriatic Arthritis Conference – now dubbed the IFPA Conference – unites stakeholders from diverse medical specialties and related industries. It shares cutting-edge knowledge and research in psoriatic disease. The 6th IFPA Conference was held virtually, due to the COVID-19 pandemic. Caregivers of people with psoriatic disease gained new understanding of nutrition, psychology, inflammation, comorbidities, and more. By working together with the scientific community, IFPA addresses priorities like early diagnosis, multidisciplinary care, and improved perception of psoriatic disease.

World Psoriasis Day is another IFPA-lead initiative that develops strategic goals to increase global representation in the psoriatic disease space, supercharge global advocacy initiatives, raise awareness and unite stakeholders, including the general public. The theme of World Psoriasis Day 2021 was *United*. Participants from 72 countries came together to share challenges and successes with psoriatic disease. IFPA launched a petition to demand change. Uniting for action, we take steps towards our common goal.

In 2021, IFPA also started development of two important new programs: IFPA Accelerator and IFPA Forum. IFPA Accelerator is designed to encourage new advocates to build new patient associations, and to support existing associations in expanding their operations. The program will strengthen IFPA's member associations and ensure global representation to accelerate progress for people living with psoriatic disease worldwide. The IFPA Forum is a much-awaited space for people with psoriatic disease to gather, developing consensus on global priorities and road maps, and addressing policymakers. The Forum will generate powerful steps forward.

Progress for people living with psoriatic disease is progress for all. The Sustainable Development Goals and NCD targets permeate IFPA's projects and initiatives. People living with psoriatic disease are citizens of this planet. They are equally important and deserve the same opportunities to good health and wellbeing.



The fight for our future is aligned with the battle of the NCD community. Many comorbidities of psoriatic disease are life-threatening NCDs such as diabetes, cardiovascular disease, and poor mental health. Progress in any of these areas will benefit all.

IFPA contributes to SDG3, target 4 on reducing premature mortality from NCDs through prevention, and 8 on achieving universal health coverage. Moreover, IFPA supports the NCD objectives by monitoring and evaluating progress in prevention and control, providing resources that support the strengthening and orienting of health systems to address NCDs.

IFPA's successes in 2021 were made possible by the powerful support of our members. This community's devotion and expertise is accelerating every year. Millions of people are breaking barriers in awareness and care thanks to your skilled effort. We sincerely thank our partners in civil society and private industry for your valuable contributions to IFPA's projects. We look forward to rising to new challenges together in 2022.

Enjoy the report,

Frida Dunger Johansson
Executive Director

THE ORGANIZATION



IFPA Board

Hoseah Waweru

President

Ingvar Ágúst Ingvarsson

Vice President

Leticia Lopez

Secretary

Josef de Guzman

Treasurer

Kathleen L. Gallant

Board Member

Silvia Fernandez Barrio

Board Member

David Trigos Herraes

Board Member



IFPA Secretariat

Frida Dunger Johnsson

Executive Director

Janina Kostiuikaite

Project Developer

Camille Lancelot

Communications Manager

Maxine Lancelot

Scientific Coordinator

Elisa Martini

Program Officer - Advocacy and Policy

Sicily Mburu

Scientific Officer

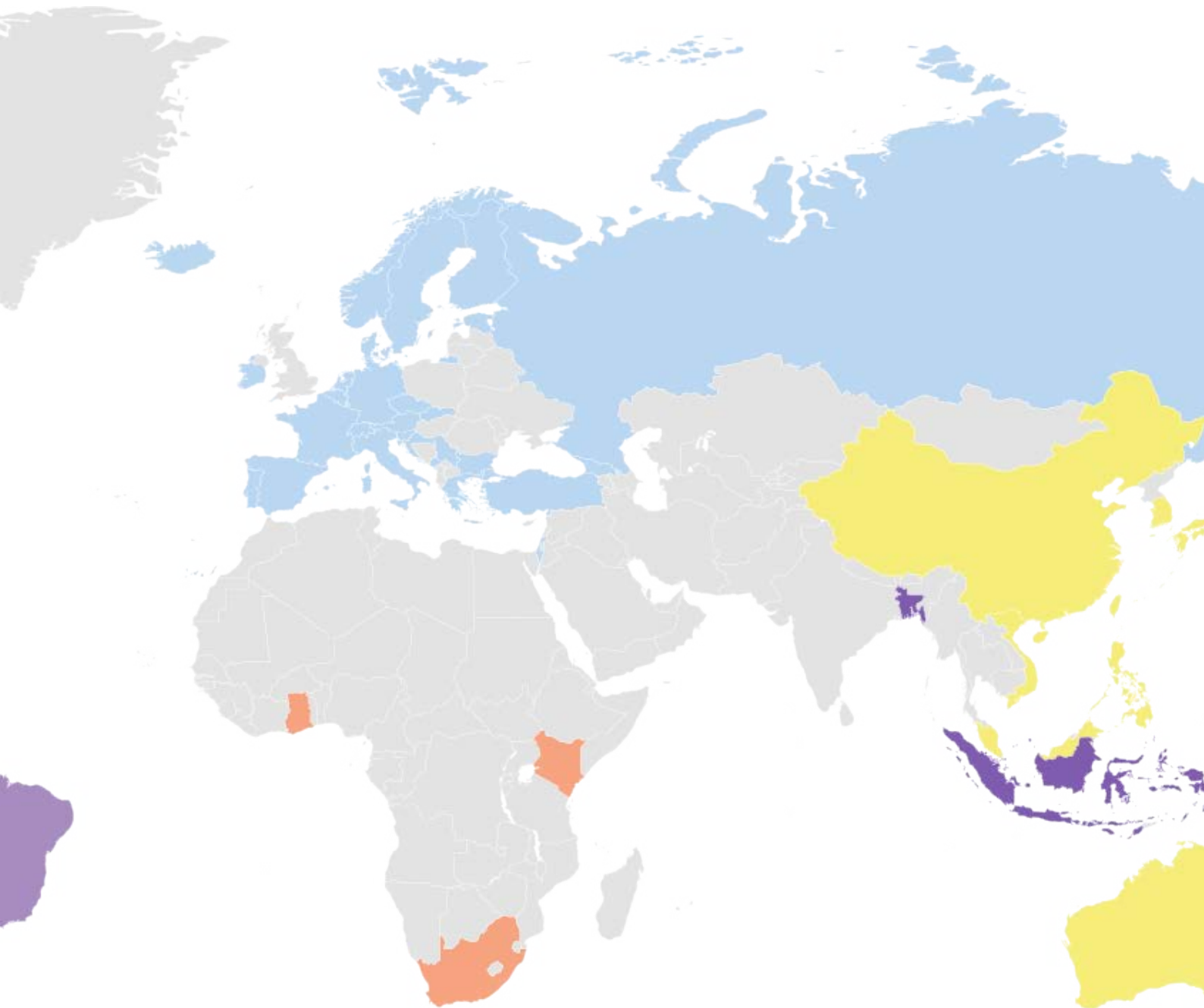
Ida Mourjujärvi

Manager Administration and Events

Alice Titalii

Program Officer - Capacity Development

IFPA Membership



Africa

Regional Organization

PSORAFRICA

Ghana

Psoriasis Ghana

Kenya

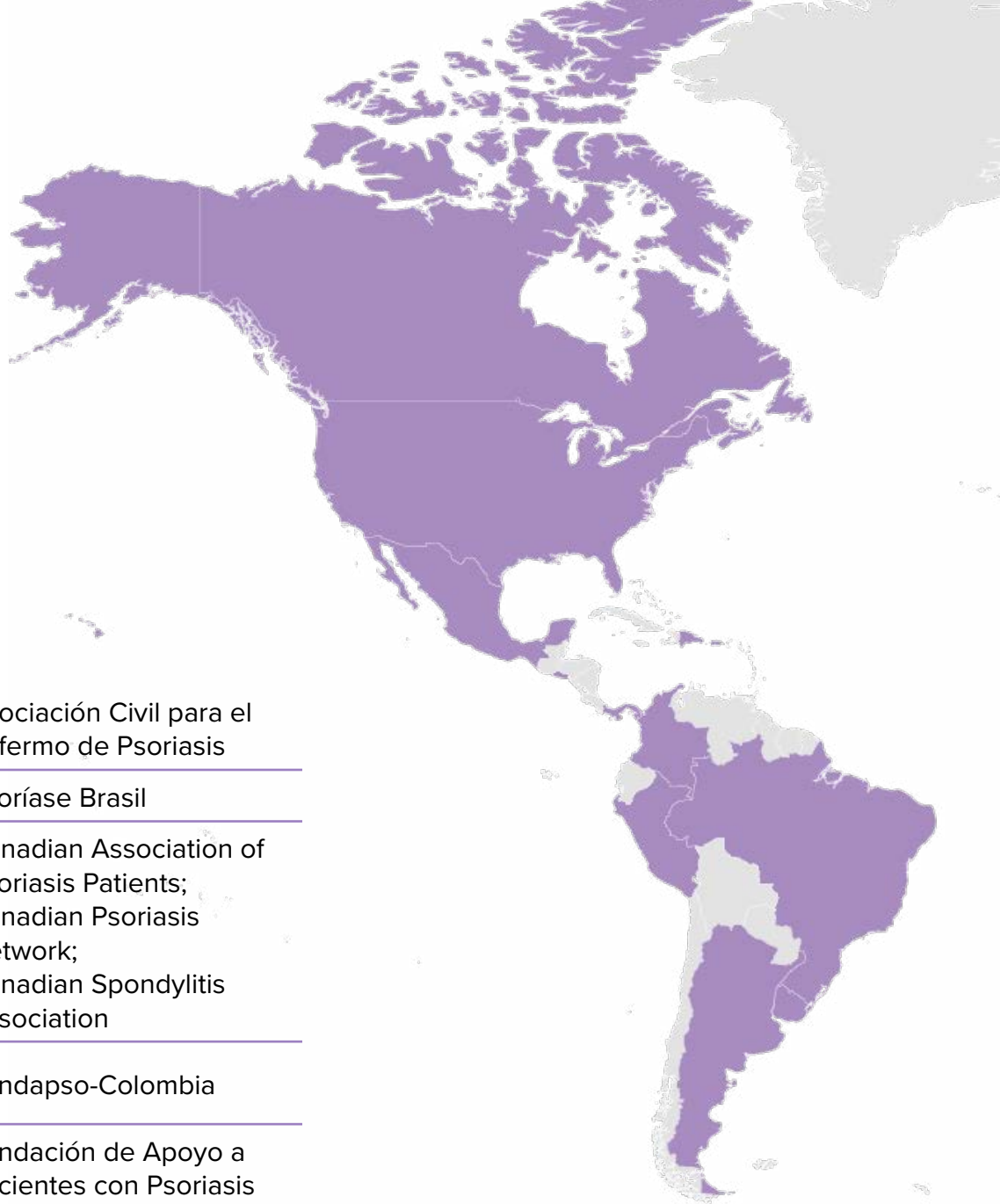
Psoriasis Association of Kenya

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	Asociación Psoriasis Nueva Vida El Salvador
Mexico	Asociación Mexicana contra la Psoriasis
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 псориаатични 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

Društvo Psoriatikov Slovenije

Spain

Acción Psoriasis

Sweden

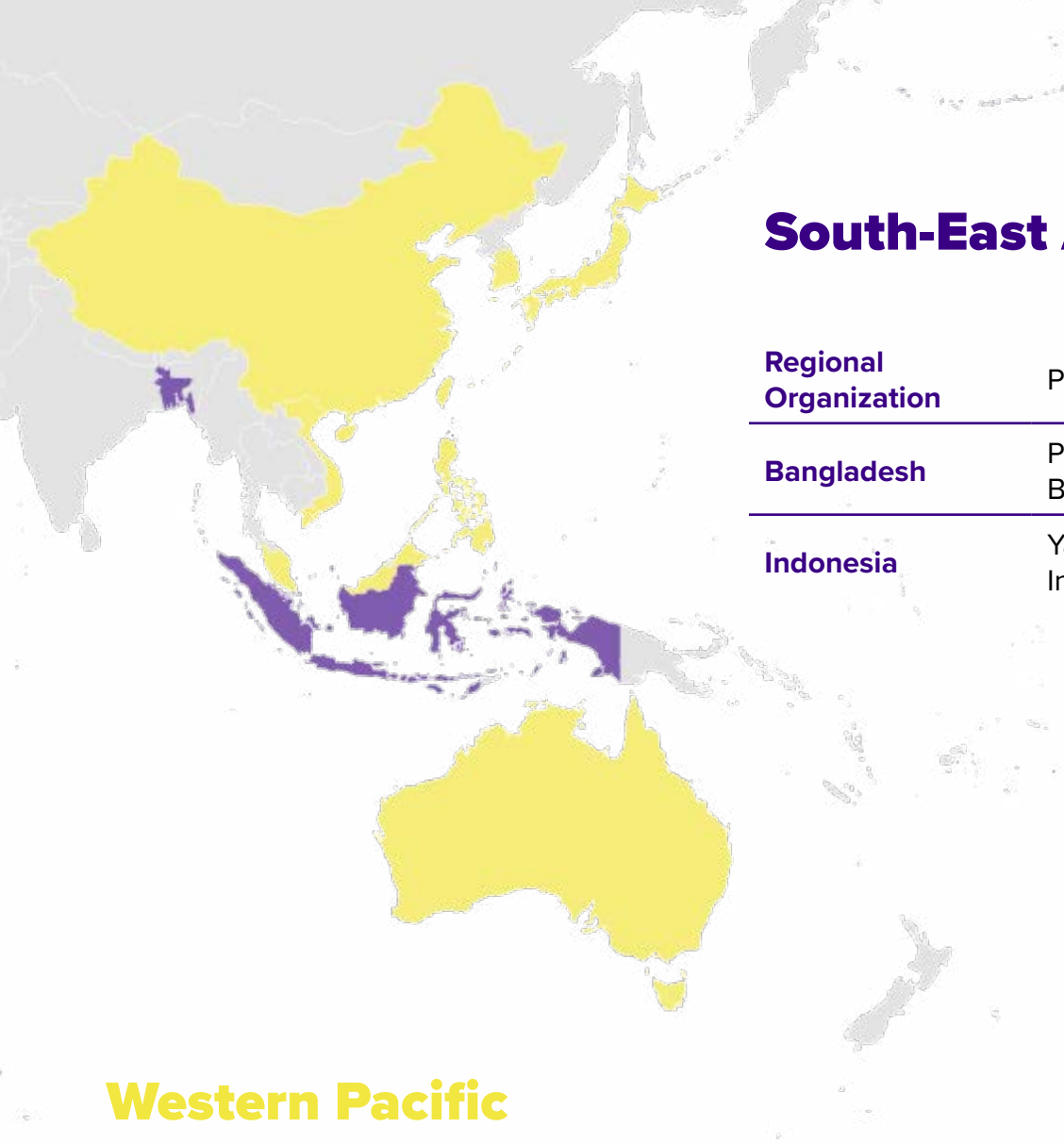
Psoriasisförbundet

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	银屑病患者互助网
Hong Kong	香港银屑病友會
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 VÂY NẾN VIỆT NAM

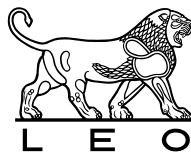
Network



International Alliance of Dermatology Patient Organizations



Industry Partners







50 Years of IFPA

2021 marked IFPA's 50th anniversary. Founded in 1971, IFPA has grown from a small collection of European organizations into a truly international federation comprised of more than **60 organizations** in over **55 countries** and with a legacy of meaningful advocacy achievements. IFPA celebrated the milestone with appropriate fanfare, including a short film to document the organization's history.

IFPA also took the opportunity to analyze persistent gaps in the needs of people with psoriatic disease, and reflect upon the most effective actions to improve their lives. IFPA's **2021-2030 Strategy** was born of extensive collaboration with IFPA members and other stakeholders in the psoriatic disease space. It highlights **8 priority issues** raised by the members, and **5 goals** to achieve IFPA's vision of a future where all people living with psoriatic disease enjoy good health and well-being.

Now it is time to act and implement. IFPA will advocate for greater psoriatic disease recognition and push for national governments to deliver on the recommendations set out in the Global Report on Psoriasis.



Priority Issues

Equal access to treatment

Early diagnosis

Raise awareness among healthcare providers

Stop stigma

Change perception of psoriatic disease

Multidisciplinary care

Link with mental health

Join forces with family and community

GLOBAL LEADER IN FIGHTING PSORIATIC DISEASE

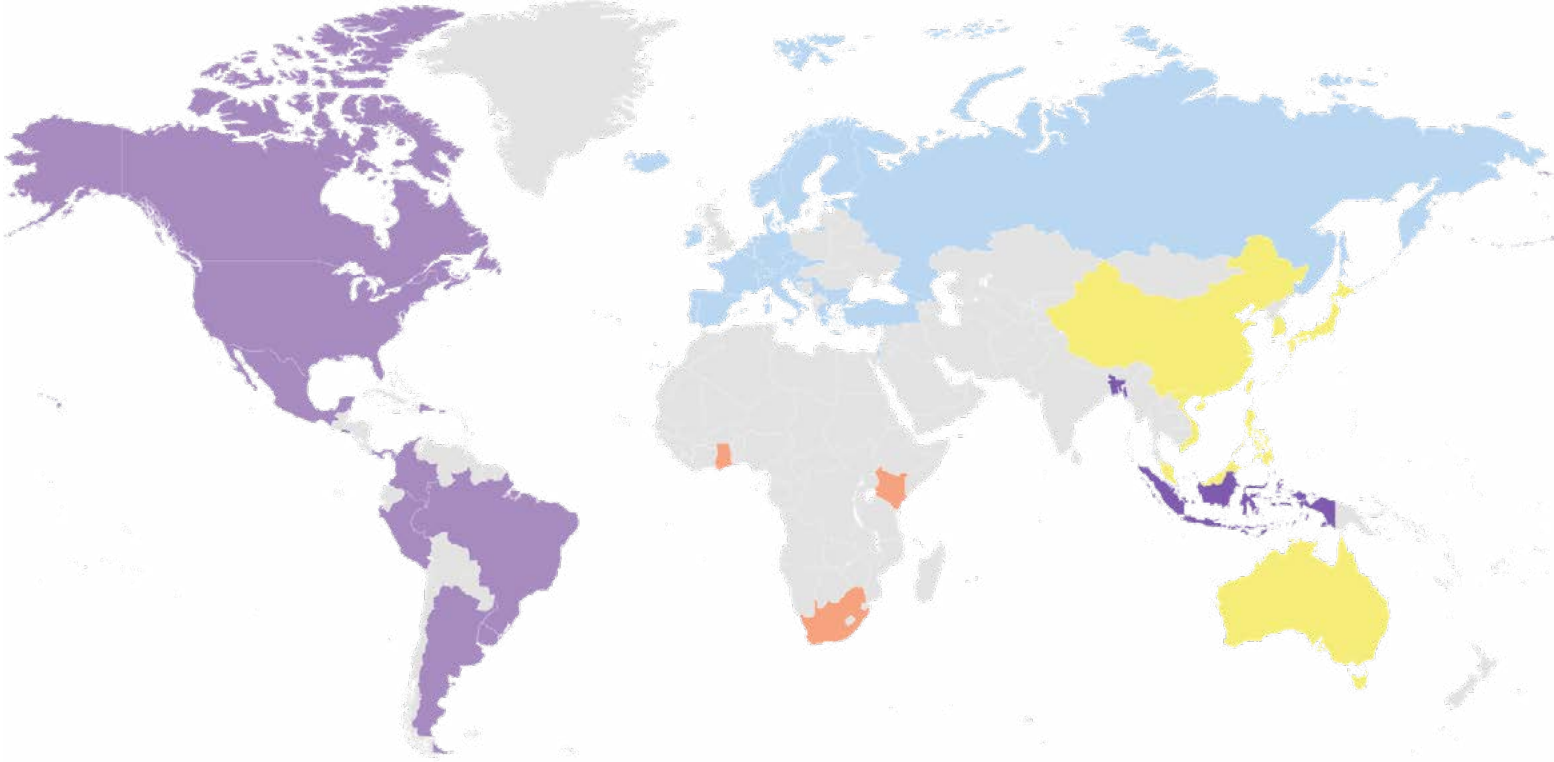
Design is a powerful marker of change. IFPA's next act is visualized with a new graphical profile. The re-branding signals a new era of IFPA, in which we will unite, strengthen, and lead. The new logo, colors, design, and tone of voice capture the organization's fighting spirit. IFPA is activating, inclusive, and bold.





**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 has created a training program for individuals to establish and run a successful patient association. **IFPA Accelerator** was developed in 2021, and will launch in February 2022.

59

national members

3

regional members

55

countries

In 2021, IFPA welcomed new members in Canada, China, Ghana, and Montenegro.



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.

Pressing topics covered by IFPA in 2021 included:

- Definition of the term *psoriatic disease*
- Comorbidities of psoriatic disease
- Valuation of experts with lived experience
- Implementation of the recommendations from the WHO Global Report on Psoriasis
- Telemedicine

2

advocacy reports

1

global petition

13

advocacy events

In October 2021, IFPA met with the NCD Department at World Health Organization headquarters to discuss partnership in regional implementation of recommendations from the Global Report on Psoriasis.

Solidarity Fund

Across the world, IFPA's members are actively working to improve the lives of millions of people living with psoriatic disease. The IFPA's Solidarity Fund closes the funding gap and makes these projects possible. Grants are awarded to projects that support psoriatic disease advocacy and education. Preference is given to members with scarce financial resources and special challenges.

In 2021, **12,000 Euros** were awarded to **6 associations**.



87%

of IFPA members rated their membership as Very Good or Excellent

Training

In 2021, the Mentorship Program and Coaching Programs were combined into one initiative called IFPA Accelerator. Launched in February 2022, IFPA Accelerator addresses both new and existing patient associations in a multi-level training platform.

12

Mentorship Program participants

5

Coaching Program participants

IFPA Webinar Series

The IFPA Webinar Series educates advocates in the psoriatic disease space. Attendees sharpen their skills and learn the latest information on psoriatic disease. This year, topics included:

Research updates and the future of psoriatic disease

Psoriatic disease, COVID-19, and vaccinations

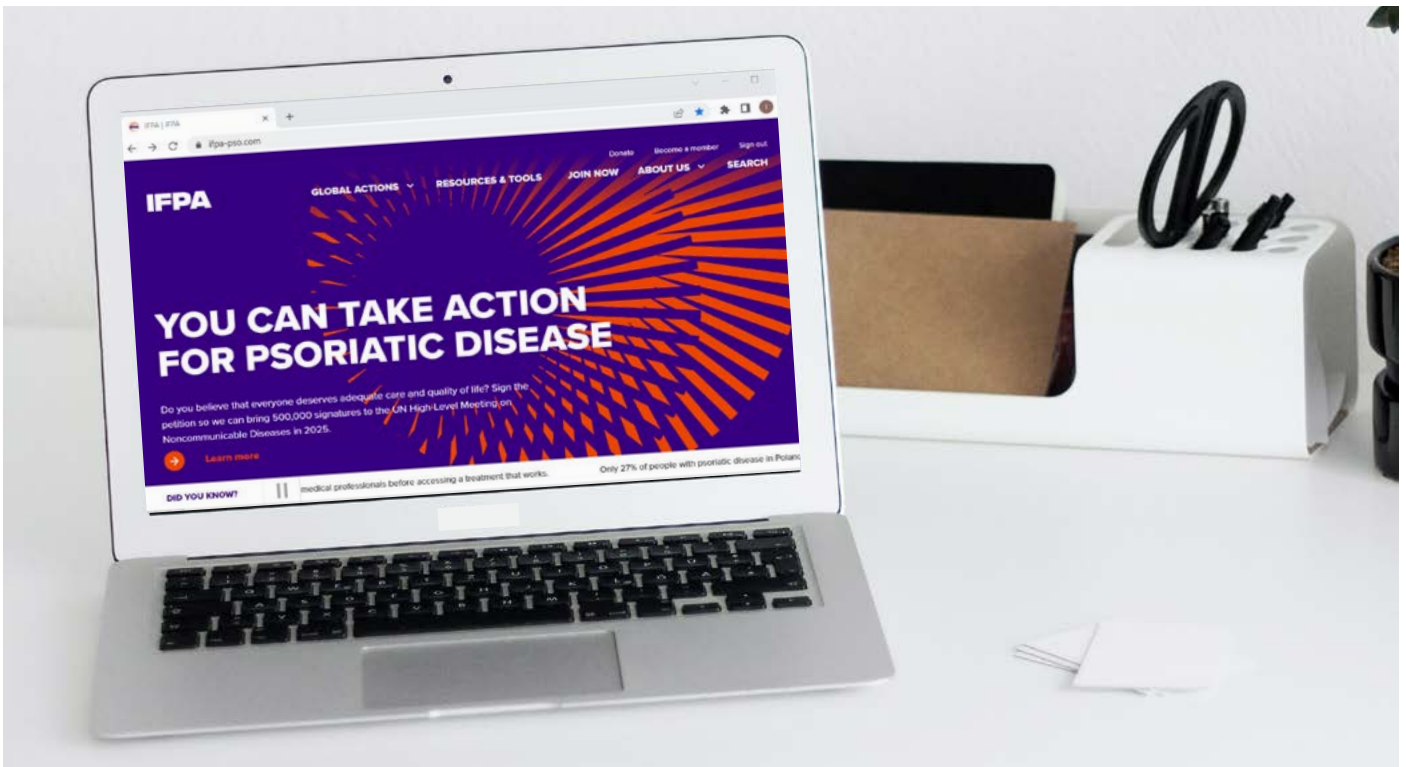
World Psoriasis Day

European psoriasis treatment guidelines

Generalized Pustular Psoriasis (GPP)

Telemedicine

300
advocates attending



New IFPA Website

In conjunction with the new strategy and branding, IFPA launched a brand new webpage. The site reflects the vast and diverse activities happening at IFPA and within the membership. The **Resources & Tools** page collects the most important information from across the psoriatic disease space into one, easy-access knowledge hub. The site also features a password-protected **Member Portal**. The portal is a growing forum and safe space to share exclusive information and discuss strategies to address the psoriatic disease community's most urgent needs.

UNITE STAKEHOLDERS



IFPA is dedicated to the visibility of psoriatic disease on the global stage. Despite the obstacles of COVID-19, IFPA represented the psoriatic disease community at 30 global and regional events in 2021. These included the **World Health Assembly**, the **World Health Summit**, the **United Nations General Assembly**, and many scientific conferences in dermatology and rheumatology. IFPA's community of people with lived experience are experts in psoriatic disease and must be genuinely involved in every decision making process and research initiative.

IFPA is equally active in creating spaces for where stakeholders from diverse sectors can come together to tackle the issues related to psoriatic disease. In 2021, IFPA's meetings and events included the **6th IFPA Conference**, and five **IFPA Coalition** meetings. With diverse minds and expert collaboration engaged in these settings, our goals of fighting psoriatic disease are achievable.

23

meetings and events
attended

7

meetings and events
hosted

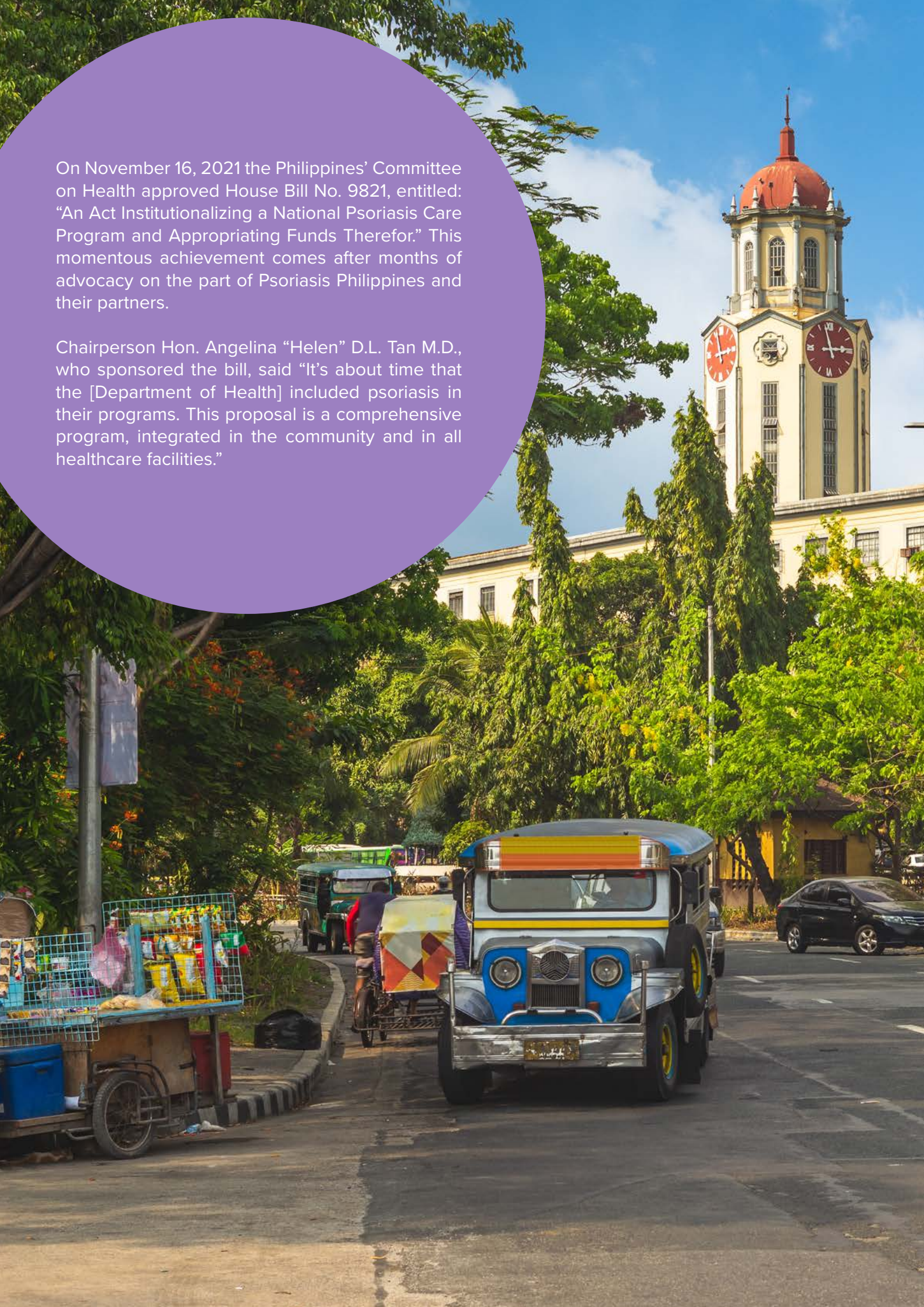
IFPA represents people living with psoriatic disease at global health policy and research meetings including the World Health Assembly, the World Health Summit, and the United Nations General Assembly.



2021 PROJECTS

On November 16, 2021 the Philippines' Committee on Health approved House Bill No. 9821, entitled: "An Act Institutionalizing a National Psoriasis Care Program and Appropriating Funds Therefor." This momentous achievement comes after months of advocacy on the part of Psoriasis Philippines and their partners.

Chairperson Hon. Angelina "Helen" D.L. Tan M.D., who sponsored the bill, said "It's about time that the [Department of Health] included psoriasis in their programs. This proposal is a comprehensive program, integrated in the community and in all healthcare facilities."



IFPA Conference

Calling for breakthroughs



The 6th IFPA Conference, also known as the World Psoriasis & Psoriatic Arthritis Conference, took place June 30 - July 3. The first virtual edition of the conference successfully welcomed delegates from **67 countries** and many medical disciplines. The theme of the conference was *CONNECTED, INFORMED, and UNITED to improve multidisciplinary care for psoriatic disease.*

Read the complete report at ifpaconference.com

800

registered delegates

60

top-tier presentations

40+

hours of live and on-demand content

IFPA Goals



Sustainable Development Goals





The Covid-19 pandemic has exacerbated many cases of psoriatic disease and individuals' stress levels. To provide emotional support to its members, the South African Psoriasis Association (SAPSA) organized virtual mental health sessions. SAPSA invited health experts to explore multiple perspectives of anxiety and stress related to living with psoriasis and coping with the Covid-19 pandemic. Funding was provided by the IFPA Solidarity Fund.

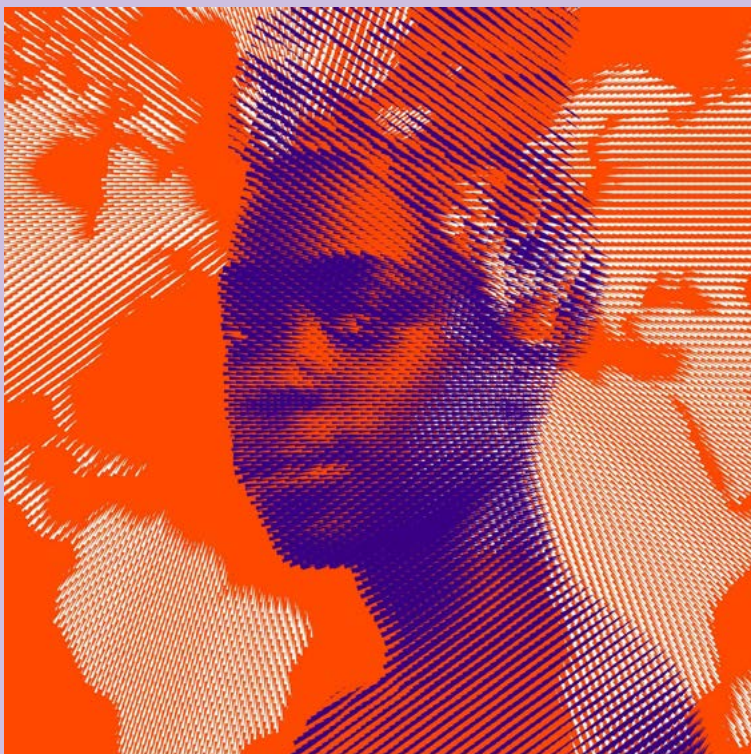
World Psoriasis Day

Uniting for action

World Psoriasis Day is celebrated every year on October 29th. The theme for 2021 was **United**. Psoriatic disease advocates around the world joined forces to raise awareness, and demand change.

IFPA launched the Now Act Petition on World Psoriasis Day. The petition calls for concrete steps to be taken towards implementation of the recommendations from the WHO Global Report on Psoriasis. IFPA set an ambitious target to bring 500,000 petition signatures to the UN High Level Meeting on Noncommunicable Diseases in 2025.

Read the complete report at psoriasisday.org



72

countries participating

76

activities pinned on the
World Psoriasis Day
map

6K

website visits

IFPA Goals



Sustainable Development Goals



IFPA Ambassadors

Representing psoriatic disease in all its complexity

IFPA Ambassadors are skilled spokespeople who have personal experience with psoriatic disease. In 2021, a pilot group of **16 ambassadors** were selected for their diverse and inclusive perspectives on the illness. Between them, the 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.

126
training hours



114
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.

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.

IFPA Goals



Sustainable Development Goals





Childhood can be a challenging time for many, and even more so for people living with psoriatic disease. The Danish Psoriasis Association believes that no young person should be left alone with psoriasis. Their initiative, PsoUng (meaning PsoYoung), organizes social events for children and young adults with psoriatic disease to combat loneliness and isolation.

Now Act Petition

More than promises, we demand progress



The NOW ACT Petition was launched on World Psoriasis Day. On behalf of the psoriatic disease community, the petition lists five demands that will make a difference. IFPA aims to bring 500,000 signatures to the UN High-Level Meeting on Noncommunicable Diseases in 2025. Signatories insist that national governments deliver on their promise to improve the lives of people living with psoriatic disease.

1,200
signatures

6
translations

Sign the petition at: ifpa-pso.com/projects/petition

IFPA Goals



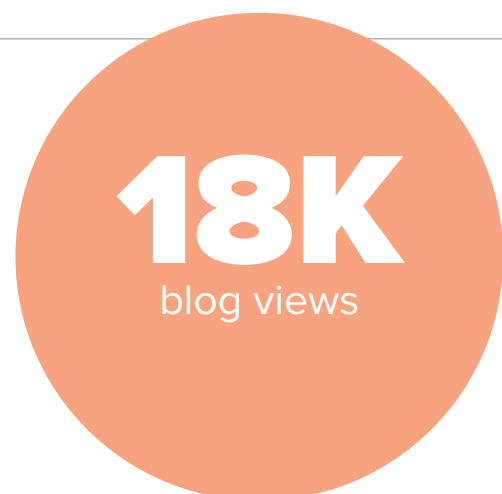
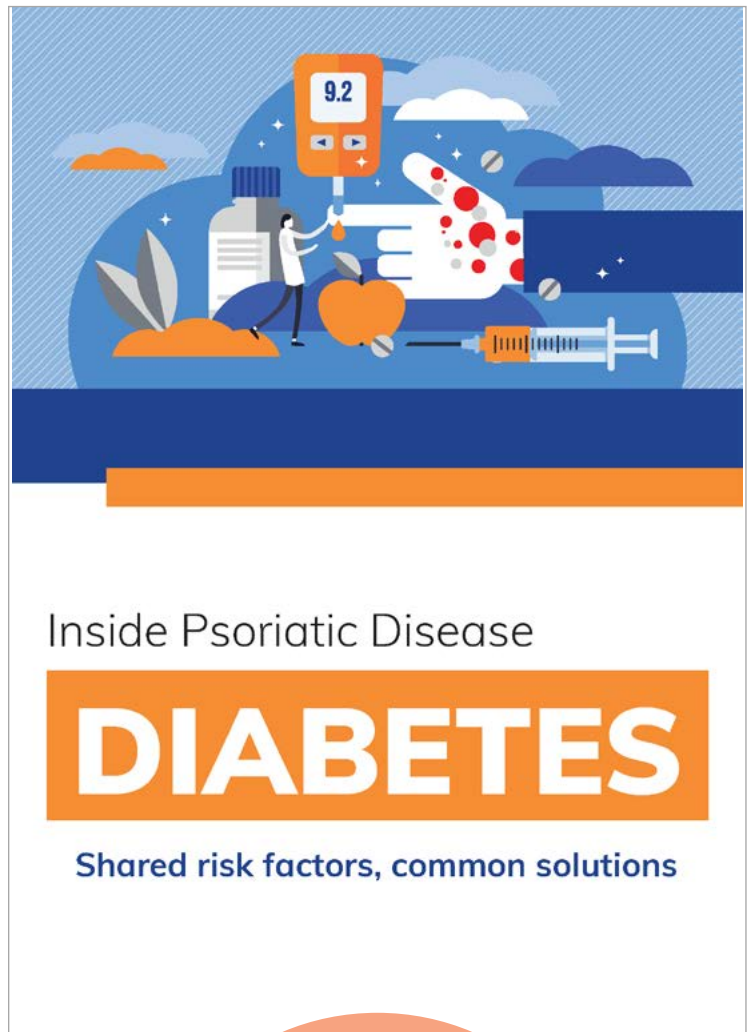
Sustainable Development Goals



Inside Psoriatic Disease

Diabetes

The diabetes report was the first in a series on comorbidities of psoriatic disease. The report details the shared risk factors and common solutions that unite psoriatic disease and diabetes, tackling the issue from both a scientific and an advocacy perspective. Among other promotions, the report appeared in the blog of the International Diabetes Federation. Over the coming years, future reports will raise awareness of the full-body involvement of psoriatic disease..



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

IFPA Goals

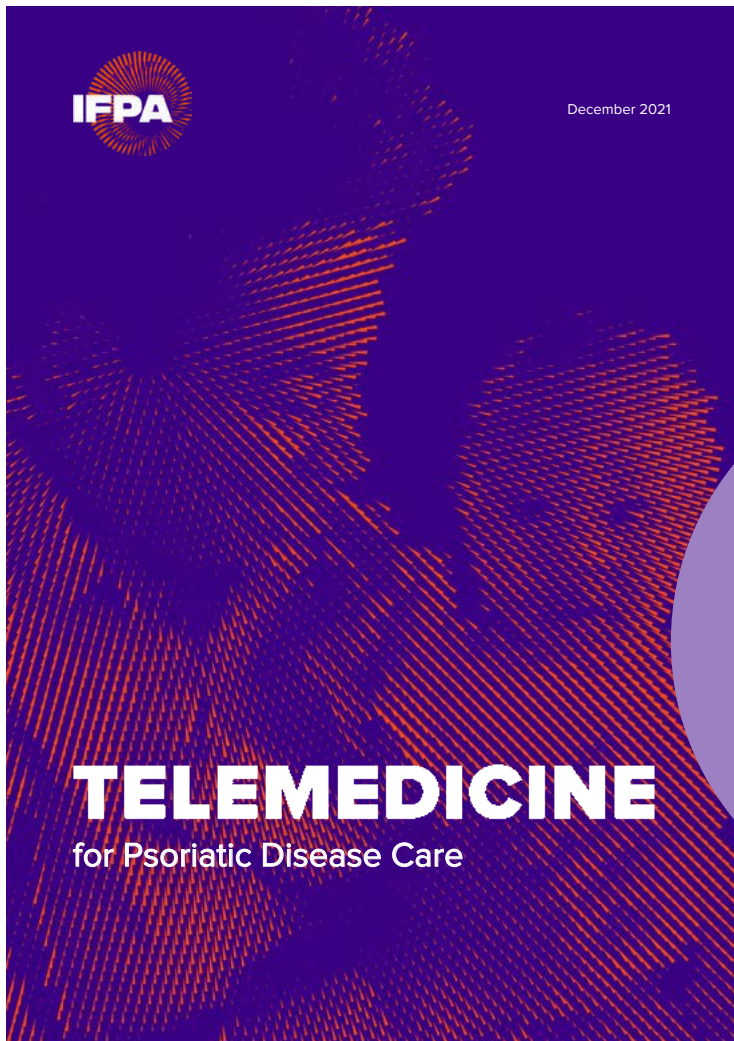


Sustainable Development Goals



Telemedicine Report

Adapting and preserving care



During the COVID-19 pandemic, people living with psoriatic disease adjusted to new solutions for care, including telemedicine. IFPA's report explores the opportunities and challenges of digital healthcare. Its insight will guide policymakers as they learn from the COVID-19 pandemic and prepare for the future of healthcare. The report was launched in December 2021.

380
report views

3
seminars

Read the report at: ifpa-pso.com/resources-tools/telemedicine-for-psd

IFPA Goals



Sustainable Development Goals

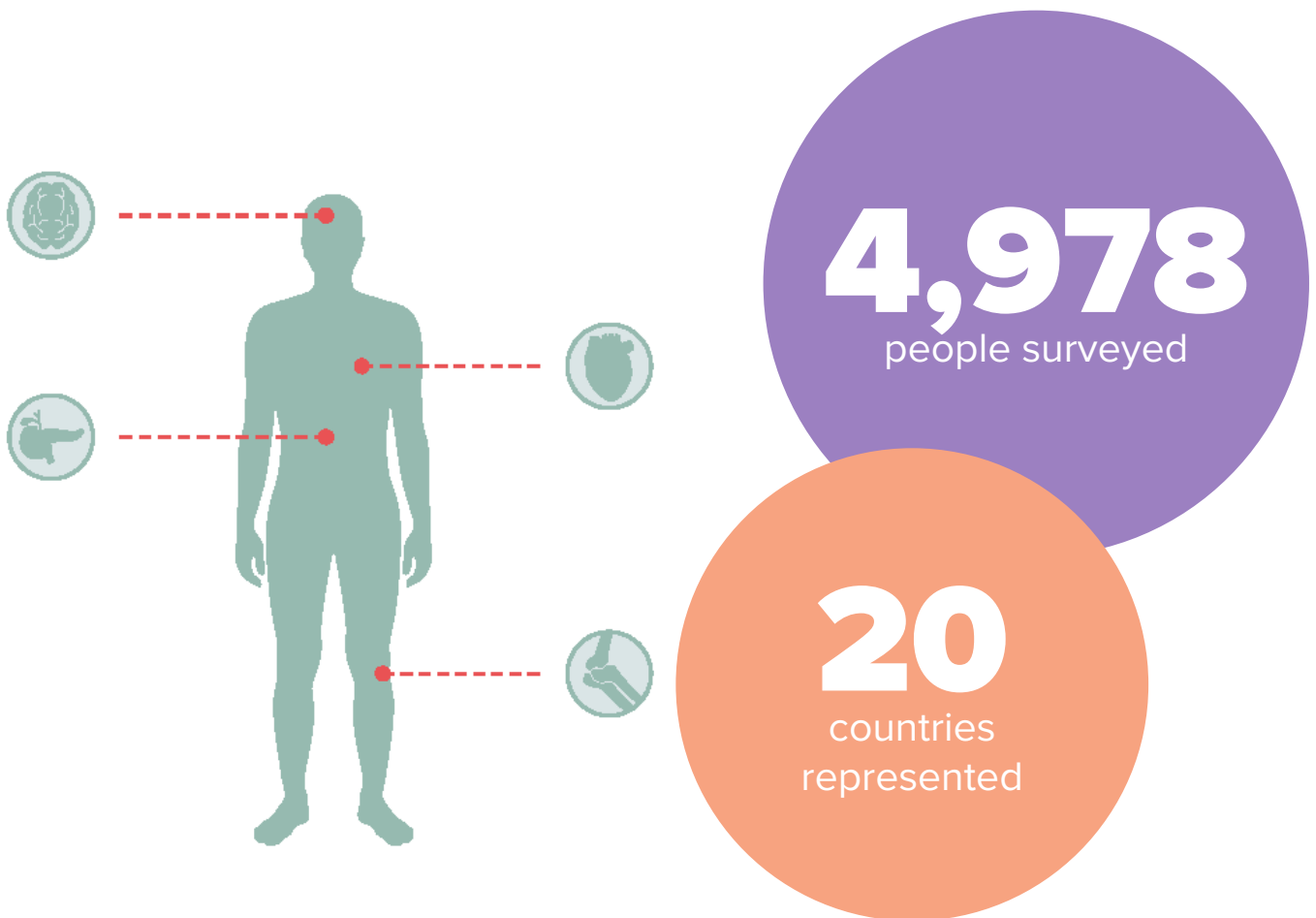


Psoriasis & Beyond

The global psoriatic disease study

The Psoriasis and Beyond study surveyed 4,978 people with psoriatic disease from 20 countries to assess their understanding of the illness and its broader impact. The study published first insights just before World Psoriasis Day 2021. Results will continue to be published in 2022, revealing awareness of comorbidities, impact on quality of life, satisfaction with care, and more.

Learn more at ifpa-psy.com/projects/psoriasis-and-beyond



IFPA Goals



Sustainable Development Goals



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 2021, 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

2021 Highlights

Development of **clinical diagnostic criteria** for chronic plaque psoriasis which will address issues faced by field workers in epidemiology studies and aid in preventing misdiagnosis.

Launch of **Spanish** version of the GPA website:
globalpsoriasisatlas.org/es

The **first psoriasis incidence data ever obtained in Chile**. Work led by Claudia De la Cruz and Cristobal Lecaros examining the incidence of psoriasis in Chile, published in Clinical and Experimental Dermatology.

Collaboration with **IRASPEN** study on pustular psoriasis.

IFPA Goals



Sustainable Development Goals



APAPSO Perú collaborated with Peruvian illustrators to raise awareness for psoriatic disease, clarify misconceptions, and highlight the impact it has on people living with it. In addition, the project supported those affected. Illustrations were shared through a social media campaign so more people will be aware of psoriatic disease, show solidarity to those who suffer from it and little by little eliminate stigmas and prejudices.



PsoProtectMe

Investigating psoriatic disease and COVID-19

4,791
individual reports to
PsoProtectMe

30+
countries
represented

5
publications
in 2021

PsoProtect is a registry healthcare providers to report outcomes, therapy, and epidemiology of COVID-19 infection in people with psoriasis.

Learn more at psoprotect.org



PsoProtect



PsoProtectMe

PsoProtectMe is a self-reported survey to help understand how the COVID-19 pandemic is affecting people with psoriasis.

Learn more at psoprotectme.org

IFPA's is active in patient recruitment, and diffusion of scientific results. Together with our partners at PsoProtect, we are making the psoriatic disease community, their caregivers, and their policymakers more aware of the broad impact of COVID-19.

IFPA Goals



Sustainable Development Goals



IFPA Coalition

Joining forces

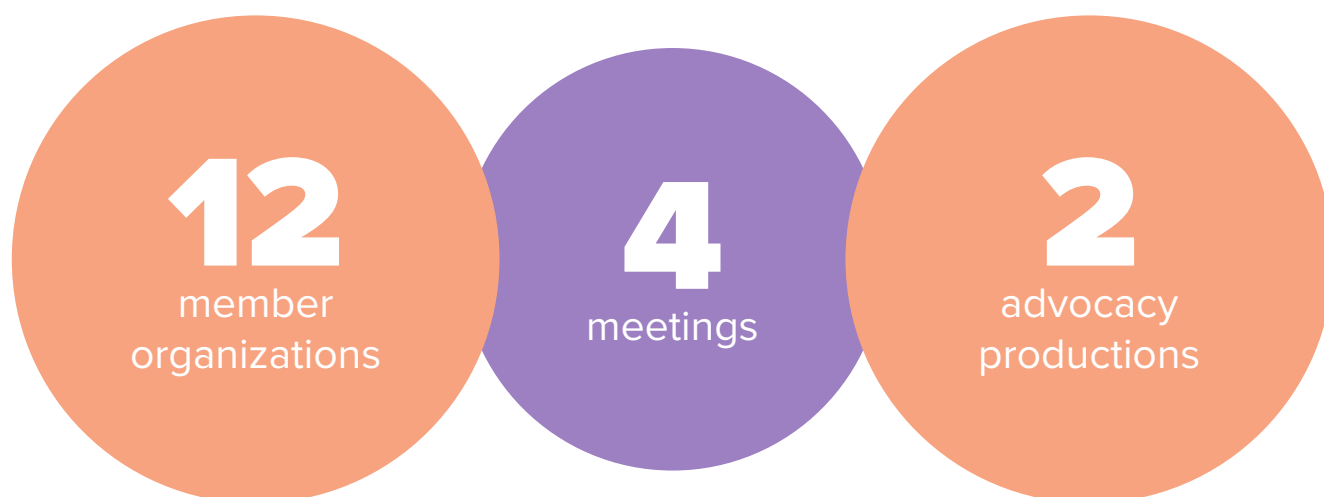
By collaborating across borders, sectors and disease areas, IFPA generates support to implement the recommendations outlined in the World Health Organization's 2016 Report on Psoriasis.

In 2021, IFPA has defined a triple A (AAA) Action Plan for the Coalition: Act, Amplify, and Align. The action plan defines working structures and targets to extract maximum value from Coalition meetings.

The **Psoriatic Disease Response Index**, a resource produced by the Coalition in 2020, was presented at the 6th World Psoriasis and Psoriatic Arthritis Conference (WPPAC).

The Coalition further contributed to two advocacy initiatives published by IFPA in 2021: the **Now Act Petition** demanding action in implementing the recommendations of the Global Report on Psoriasis, and the **Telemedicine Report** exploring the pros and cons of digital healthcare.

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



IFPA Goals



Sustainable Development Goals





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