

January 2021

World Psoriasis Day Report 2020



INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

A Message from IFPA's President...

Dear friends around the world,

At the close of another World Psoriasis Day, I must once again marvel at our collective ambition. While the turbulence of this year's pandemic impacted the health sector and each of our personal lives, a surge of innovation touched each country's World Psoriasis Day 2020 celebrations, as well as the outcomes of the campaign.



Since the arrival of COVID-19, we have been emphasizing the importance of resilient health systems to accommodate people with psoriasis and psoriatic arthritis, even in times of crisis. We should also not underestimate the powerful resilience of the human spirit. Our community has proved highly adaptive. From online dance parties in the Philippines, to polka dot dress-up in Czech Republic, to face-to-face meetings and virtual webinars in Kenya, on World Psoriasis Day we used every available tool to persevere in spreading joy, support, information, and connection. This should come as no surprise. Our psoriasis community is practiced in facing adversity, changing perspective, and growing new and beautiful opportunities out of hardship.

Notably, this year's World Psoriasis Day campaign was celebrated by many external parties. Following efforts to make World Psoriasis Day more accessible, it seems that private individuals, non-profit organizations, industry stakeholders, advocacy groups, and governmental bodies have all included World Psoriasis Day on their calendars. They engaged with our website, toolkit, and theme document to actively participate in the campaign. It is a new outcome that has increased the reach of our message by an estimated three-fold.* There is no end to what we can accomplish together. I look forward to building upon this success in next year's UNITED campaign.

Warmest regards,

Hoseah Waweru, MD.
President of the IFPA Board

*This estimation is according to hashtag analytics. See pages 8, 9 & 11.

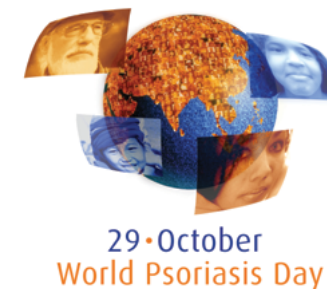
Table of Contents

A Message from IFPA's President	2
Background	4
Sponsors of World Psoriasis Day 2019	4
World Psoriasis Day 2020: INFORMED	5
Be Informed	6
World Psoriasis Day in Perspective	7
Hashtag Impact	9
IFPA Campaign	10
Noteworthy Numbers	11
Partners of IFPA	13
Around the World	15
Letter from the Executive Director	20

Background

World Psoriasis Day (WPD) is an annual day dedicated to people living with psoriasis and psoriatic arthritis, celebrated on October 29th. The overall aims of WPD are:

- Raise awareness on the severity of the disease and on the everyday challenges faced by people living with psoriasis and psoriatic arthritis
- Spread information about psoriasis, refute common misconceptions and increase patients' knowledge
- Improve access to treatment by targeting health ministers, governments and decision-makers
- Give the psoriasis community a voice, to empower people living with psoriasis.



Since its establishment in 2004, IFPA members associations have put extraordinary effort in organizing events, engaging with national policy-makers and, more recently, campaigning on social media.

The WPD 2020 theme is INFORMED. It has been widely shared by IFPA members associations and adapted nationally and regionally to local languages and contexts.

Sponsors of World Psoriasis Day 2020

IFPA thanks the following sponsors for their role in making World Psoriasis Day 2020 possible:



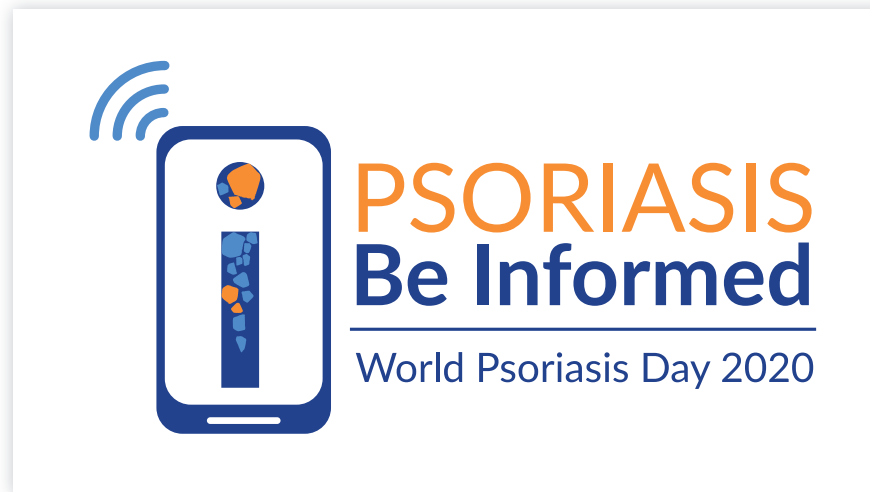
World Psoriasis Day 2020: INFORMED

On October 29, 2020, we celebrated the 16th annual World Psoriasis Day. This year's theme was INFORMED. When IFPA developed the campaign, we felt called to emphasize the importance of credible, abundant, and new information for the best treatment of psoriasis and psoriatic arthritis. People living with these chronic inflammatory illnesses are further burdened by the necessity of sifting through unreliable, and sometimes predatory information before arriving at reliable resources that can truly help. IFPA and our members are devoted to making the journey simpler. Furthermore, the psoriasis community hosts a wealth of knowledge and best practices with regards to treatment, support, advocacy, and many other diverse topics. World Psoriasis Day was the perfect opportunity to highlight these assets for the benefit of patient organizations everywhere. Finally, research into new treatments and better systems are critical for both health care professionals and policy advocates to achieve the high standards we all hope for. Good information supports us all.

Psoriasis. Be informed.

What we could not have predicted when we designed the 2020 campaign was the arrival of the COVID-19 pandemic. Uncertainty about the possible impact of COVID-19 on people living with psoriasis and psoriatic arthritis highlighted the urgency of reliable, helpful information. Lockdowns and isolation orders changed the shape of our regular World Psoriasis Day activities. Grief and anxiety made mental health burdens heavier. At the same time, we discovered new opportunities to maximize World Psoriasis Day. We transformed the campaign into a digital one, which allowed us to connect globally more than ever. Webinars, videos, infographics, websites, and apps offered beautiful solutions to transmit the information we praised. In the end, our global campaign was changed, and in many ways enhanced by the special circumstances.

Our message was heard.



#worldpsoriasisday #beinformed #WPD2020

Be Informed

Empowerment

Information is the key to positive change

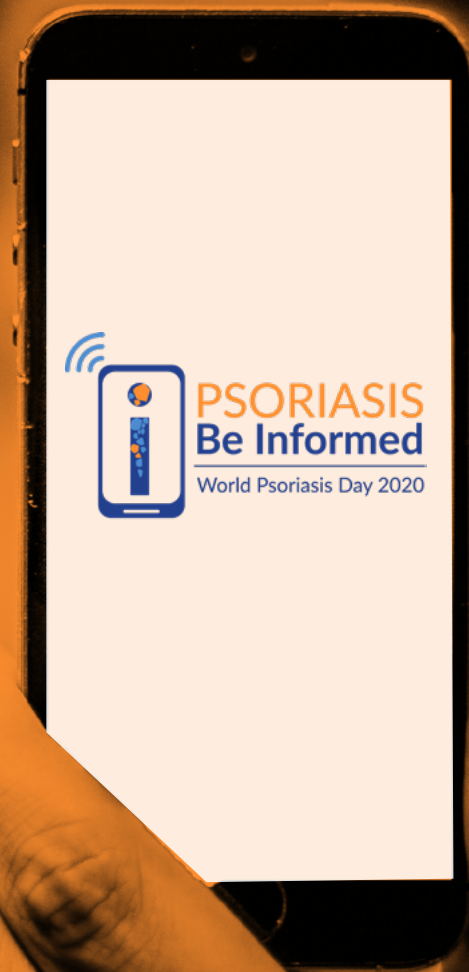
Journey

Highlight major events in the history of psoriasis advocacy

Resources

Point stakeholders toward reliable and useful tools

Are you informed about psoriasis and psoriatic arthritis?



World Psoriasis Day in Perspective

World Psoriasis Day is the beating heart of IFPA. Interaction with our members is the soul of the organization. So when the emerging COVID-19 pandemic challenged us with physical, emotional and economic toll, we understood this year was going to be special.



And it was! World Psoriasis Day 2020 was unlike any before. It took place in the new surroundings, and invited IFPA members, partner organizations, corporate partners, social media influencers, and general public to follow the “Be Informed” campaign through a series of Zoom Webinars, Instagram stories, and Facebook Live broadcasts.

It was impressive to see how individuals and communities across the world came together united in raising awareness and spreading information about psoriasis and psoriatic arthritis. The campaign “Be Informed” reminded us that despite any unfavorable circumstances our hearts beat stronger when we are together.

We are diverse; we always have been and always will be. However, diversity shouldn’t divide us, but unify us because diversity is an asset. We look forward to celebrating our unity in next year’s campaign: UNITED.

Janina Kostiukaite

Project Lead for World Psoriasis Day
Project Developer, IFPA

BE INFORMED!

What a very apt theme to mark and celebrate World Psoriasis Day for 2020. Covid19 has been changing the way we live. The information that we need for psoriasis and psoriatic arthritis has been more important than ever for patients and doctors alike. The uncertainties that this pandemic has brought upon us made us look deeper and wider into the spectrum of psoriatic disease. This year, we celebrate World Psoriasis Day around the world with more deep introspect about our condition.



Josef de Guzman

Chairman, World Psoriasis Day Steering Committee
Treasurer, IFPA Board



An adaptive year

Like many IFPA members, **PsorViet** used digital solutions to safely gather for World Psoriasis Day during the global pandemic.

Hashtag Impact

The following results reflect the performance of the official World Psoriasis Day 2020 hashtags on Twitter from October 4 until November 4. Impressively, we recorded a 46% increase in Mentions on Twitter when compared with World Psoriasis Day 2019. This indicates that individuals were visiting the World Psoriasis Day website and Toolkit, engaging with our campaign messages, and creating their own posts to actively participate in World Psoriasis Day with us.

#worldpsoriasisday

#beinformed

#WPD2020

6.7K Tweets

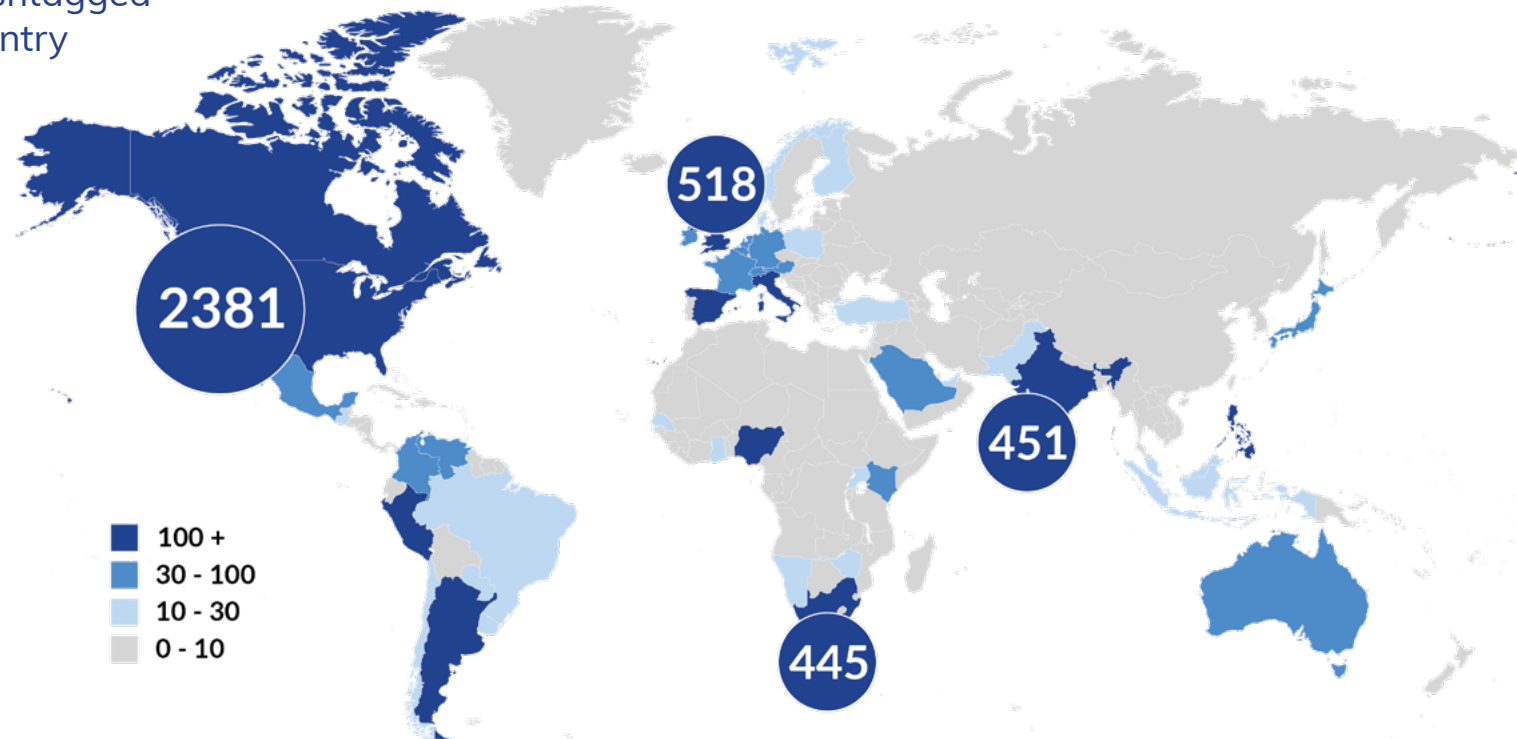
4,112 Contributors

102 Countries

732 Cities

43.8M Reach

Number of Hashtagged Tweets by Country



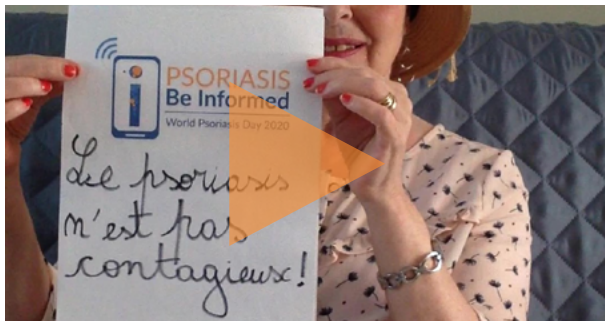
*Hashtag analytics by Tweepmap

IFPA Campaign

In an effort to combat the social isolation necessitated by COVID-19 as well as take advantage of unprecedented online presence caused by the pandemic, IFPA chose to focus on digital interactive actions for the World Psoriasis Day 2020 campaign.

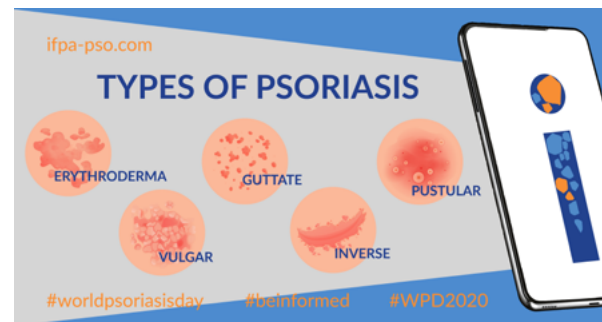
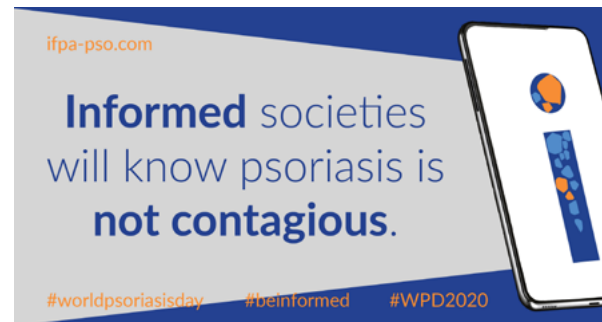
“Be Informed” Videos

The “Be Informed” video campaign invited participants around the globe to send in informative and inspiring messages about psoriasis and psoriatic arthritis. Dozens of participants submitted recordings. The result: 5 compiled videos displaying messages from **10** countries across **4** continents in **6** languages.



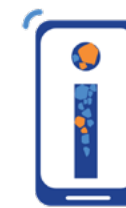
Social Media Tiles

IFPA designed informational social media tiles to spread credible information about psoriasis and psoriatic arthritis to our target audiences. Blank tiles were made available to IFPA members who could translate those messages into local languages, and compliment the content with even more scientific facts.



GIFs

IFPA designed a handful of attention-grabbing GIFs that were integrated into platforms such as Instagram, Whatsapp, and Facebook. These GIFs sparked a fun, easy way to instantly participate in the global campaign.



Noteworthy Numbers

IFPA's online campaign was promoted across IFPA's social media channels: Twitter ([@psoriasisIFPA](#) and [@PSOCoalition](#)), Facebook ([International Federation of Psoriasis Associations](#)), Instagram ([@psoriasisIFPA](#)), Youtube ([psoriasisIFPA](#)), and LinkedIn ([International Federation of Psoriasis Associations](#))

45.6%
increase in mentions

This year, IFPA measured a 45.6% increase in mentions of IFPA on Twitter, in addition to marked increases in tagged posts across all platforms. This trend suggests that individuals and organizations are planning ahead to participate in World Psoriasis Day. They have taken the time to explore the World Psoriasis Day Toolkit and website so that they can create their own content to engage with the global campaign.

331K
GIF and sticker views

IFPA's first production of GIFs and stickers received high numbers of engagement. This performance reflects IFPA's efforts to make World Psoriasis Day more accessible and interactive. These GIFS are visible not only to our members, but even those who may not know very much about psoriasis.

1.1K
downloads of the
WPD Toolkit

The 2020 World Psoriasis Day Toolkit was designed to be more accessible to a wider audience. The Toolkit was filled with links to World Psoriasis Day materials, and listed several ways to participate in the campaign. We attribute 2020's increase in global engagement to efforts like the World Psoriasis Day Toolkit that made it possible for more stakeholders to participate in a unified campaign.



Belonging in community

For those who feel isolated by their condition, World Psoriasis Day is an important celebration of togetherness. Inspire Japan WPD built community by sharing T-shirts!



Partners of IFPA

We would like to acknowledge IFPA's partners and the networks of which IFPA is a part for appreciated collaboration during World Psoriasis Day 2020. Working together, we were able to highlight psoriasis and psoriatic arthritis on the stage of global health advocacy for World Psoriasis Day.

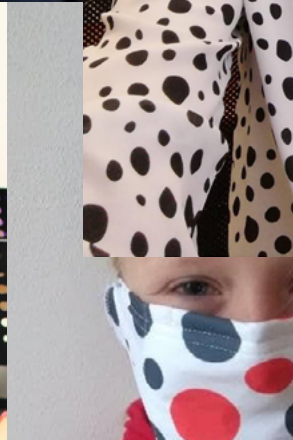


We would also like to acknowledge the **PsoProtect** and **PsoProtectMe** for exceptional effort to collect data that will help us better understand the impact of COVID-19 on people living with psoriasis and psoriatic arthritis. IFPA was honored to collaborate with the **Global Psoriasis Atlas** and PsoProtect on a World Psoriasis Day video series to promote participation in these two important research projects. We recognize the **International Psoriasis Council** and the **International League of Dermatological Societies** who we are glad to partner with on the development of the Global Psoriasis Atlas

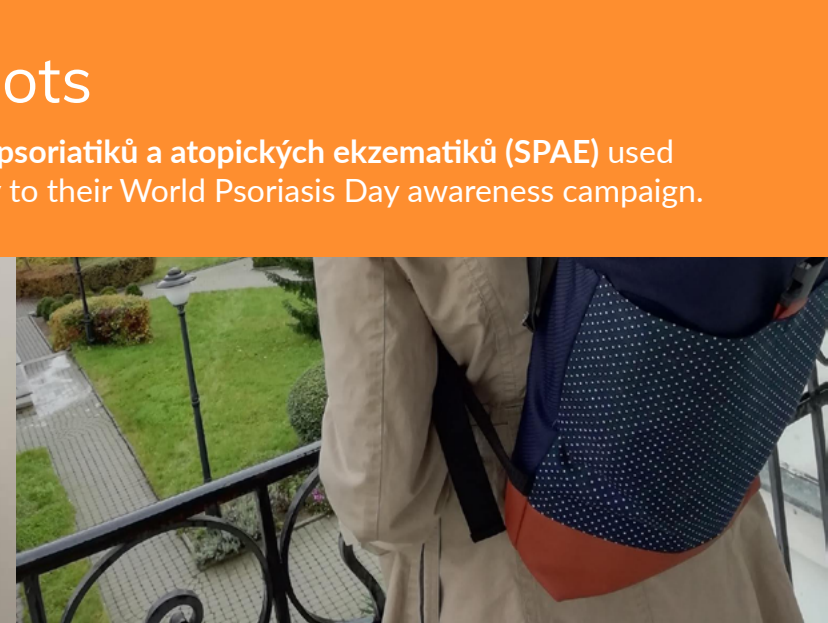


Finally, we would like to thank our partners **Abbvie, Amgen, Bristol Myers Squibb, Janssen, Leo Pharma, Eli Lilly, Novartis, UCB**, and the **High Lantern Group** for their participation in IFPA's **Global Psoriasis Coalition**. Our work together is helping to further the global advocacy agenda on psoriasis and psoriatic arthritis. On October 29th, the Coalition launched the Psoriatic Disease Response Index – the first-ever effort to comprehensively measure health system's responses to psoriatic disease. Visit www.globalpsoriasiscoalition.org to discover this ground-breaking project.





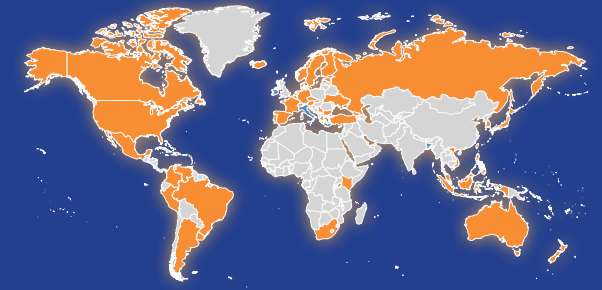
Celebrating spots
In the Czech Republic, Spolek psoriatiků a atopických ekzematiků (SPAĚ) used polka dots to bring fun and joy to their World Psoriasis Day awareness campaign.



Around the World

55
countries

World Psoriasis Day activities were hosted in each of IFPA's 55 member countries.

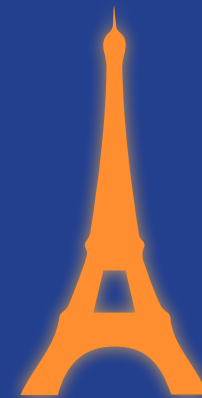


IFPA associations held an average of 20 webinars to spread public awareness of psoriasis.

20
webinars

15
monuments

15 monuments were lit orange for World Psoriasis Day in Vietnam, Peru, Turkey, Uruguay, Brazil, Japan, and Argentina.





European Academy of Dermatology and Venereology

Coinciding with World Psoriasis Day, IFPA participated at the European Academy of Dermatology and Venereology Congress October 29th-31st. This year's plenary session engaged experts on inflammatory skin diseases and their comorbidities. Psoriasis was not left behind.

The conference offered a great opportunity to involve the dermatology community. Attendees passed by the first-ever IFPA World Psoriasis Day Virtual Booth where we highlighted our cause, actions and advocacy on behalf of our members. A fun quiz in the booth showed that participants understand psoriasis impacts more than just the skin, but are somewhat less familiar with possible co-morbidities.*

At the scientific meetings there were key presentations in psoriasis care such as recent developments in biologics, biosimilars, the use of treatments in combination, and early findings on the impact of COVID-19 on people with psoriasis (presented by PsoProtect). More importantly, through advocacy efforts patients' voices have been listened to physicians and experts are now more and more keen to connect psoriasis with comorbidities in multidisciplinary care.



Sicily Mburu
Scientific Officer, IFPA

The European Academy of Dermatology and Venereology (EADV) is a non-profit founded with the aim of harmonizing specialist training, improving quality patient care, and continuing medical education for all Dermato-Venereologists within Europe. EADV hosts a yearly congress.

eadv.org





Global Psoriasis Coalition

The International Federation of Psoriasis Associations and the Global Psoriasis Coalition are pleased to present the Psoriatic Disease Response Index—the first-ever effort to comprehensively survey, quantify, and analyse health systems’ responses to psoriatic disease. As psoriatic disease constitutes a complex and burdensome health condition. Its management is a model to gauge the overall well-being of a health system.

Through our valuation of selected enablers and barriers, the Global Psoriasis Coalition identified opportunities of how each country can identify, treat, and support people living with psoriatic disease, including mitigating the negative individual, societal and economic costs. The analysis compiles and weighs indicators to create an assessment of the five countries’ performance in each category.

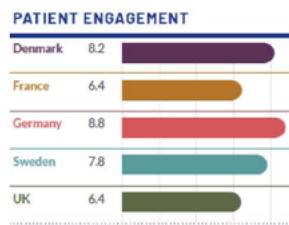
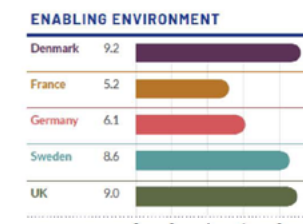
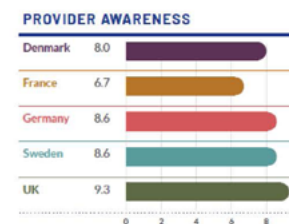
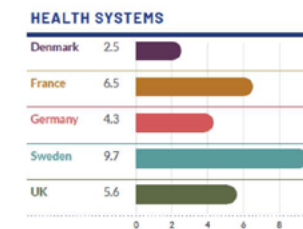
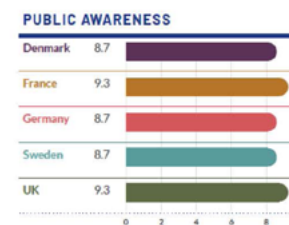
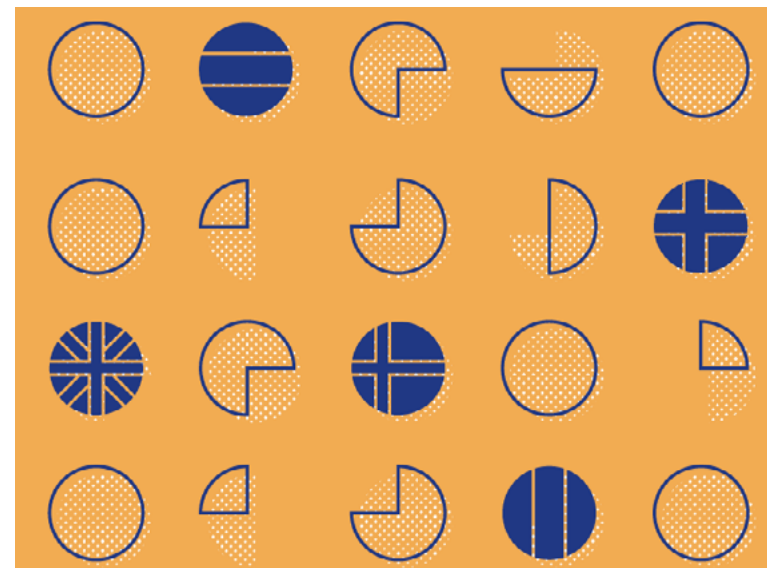


The Psoriatic Disease Response Index was launched at EADV on October 29th in celebration of World Psoriasis Day 2020’s theme: Be Informed. The Index was made possible by Abbvie, Amgen, Bristol Myers Squibb, Janssen, Leo Pharma, Novartis, and UCB

Elisa Martini
Advocacy and Policy Officer, IFPA

The Global Psoriasis Coalition is a program of the International Federation of Psoriasis Associations. Inspired by developments in the non-communicable diseases (NCD) policy agenda, the Coalition calls on civil society to advocate for a people-centered and integrated response to psoriasis.

globalpsoriasiscoalition.org



The full Psoriatic Disease Response Index report is available at:
<https://www.globalpsoriasiscoalition.org/>



Global Psoriasis Atlas



PsoProtect



PsoProtectMe

Global Psoriasis Atlas & PsoProtect & PsoProtectMe

In the spirit of spreading information, the Global Psoriasis Atlas, PsoProtect, and IFPA collaborated for World Psoriasis Day. Video testimonials were collected from around the world to illustrate the varied experiences of living with psoriasis and psoriatic arthritis during COVID-19. Respondents further highlighted the value of participating in research projects like PsoProtectMe to so that we can all gain an improved understanding of psoriasis. The original cast of the Global Psoriasis Atlas website's testimonials reappeared to share updates from the past year. People living with psoriasis and psoriatic arthritis can see their own story reflected in these voices and find belonging in shared experience.



In addition, PsoProtect celebrated the first publication of early insights from the registry's data. A paper titled "Factors associated with adverse COVID-19 outcomes in patients with psoriasis" was published in the Journal of Allergy and Clinical Immunology. PsoProtect presented the findings at EADV.

Camille Lancelot
Communications Manager, IFPA

The Global Psoriasis Atlas is a long-term epidemiological research project into the prevalence and incidence of psoriasis and its comorbidities.

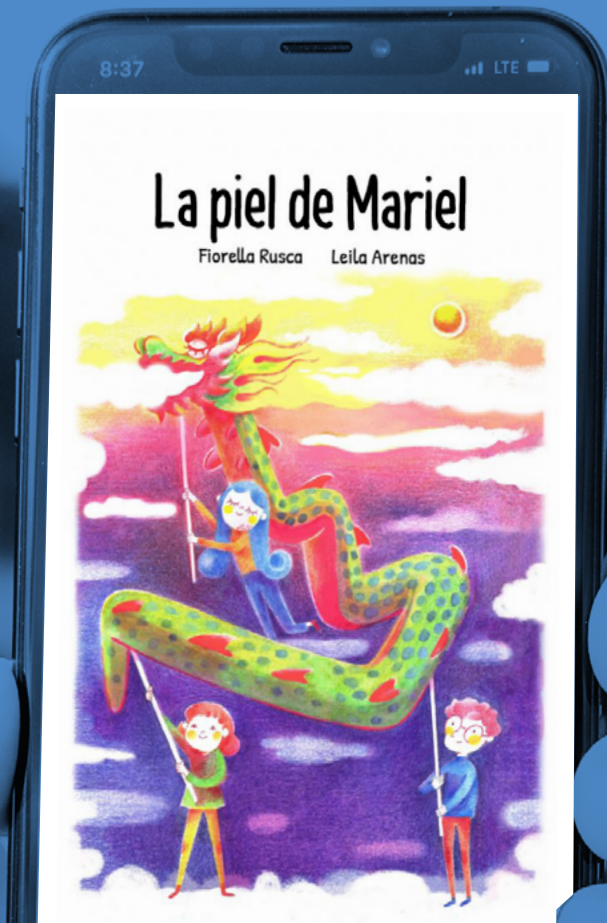
globalpsoriasisatlas.org

PsoProtect is an international registry for healthcare providers to report outcomes of COVID-19 in individuals who have psoriasis. PsoProtectMe is a patient-reported survey into the impact of the pandemic on people living with psoriasis, whether or not they have been infected.

psoprotect.org

psoprotectme.org





Psoriasis and children

APAPSO Peru engaged children with psoriasis, writing a children's book called "the skin of Mariel." The book and accompanying doll give confidence to young people with psoriasis, and spreads understanding among their peers.

Letter from the Executive Director

Dear friends,

It is a privilege to arrive at IFPA just in time to participate in our community's joyful World Psoriasis Day celebrations. Your colorful campaigns are the perfect inspiration for the next phase in our global mission. I am honored and excited to harness your dedication towards positive change for people living with psoriasis and psoriatic arthritis around the world.

Our network's high level of capacity is obvious. In the spirit of being informed, I look forward to spending these next few months meeting IFPA's many members, partners, and supporters to collect your input. The next steps in IFPA's journey will be informed by a balanced understanding of global advocacy needs and available assets. United, we will improve conditions for everyone living with psoriasis and psoriatic arthritis.

I would like to express my sincere appreciation to everyone who contributed to the World Psoriasis Day Campaign, including the official sponsors of World Psoriasis Day 2020: Amgen, Boehringer Ingelheim, Bristol Myers Squibb, Janssen, Leo Pharma, Eli Lilly, Novartis, Pfizer, and UCB. We further thank the impressive number of teachers, doctors, researchers, companies, non-profits, government agencies, and private individuals who engaged with our campaign. Awareness is not a solitary task. When the entire community is informed, we can produce valuable cultural and political gains that will truly make a difference to those living with psoriasis and psoriatic arthritis. Thank you for joining your force with ours.



Frida Dunger Johnson
Executive Director, IFPA

World Psoriasis Day is sponsored by:



INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

Gustavslundsvägen 143
16751 Bromma
SWEDEN

ifpa-pso.com
@psoriasisIFPA