

# PSORIASIS Be Informed

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World Psoriasis Day 2020



29 • October  
World Psoriasis Day



INTERNATIONAL FEDERATION  
OF PSORIASIS ASSOCIATIONS

THEME DOCUMENT

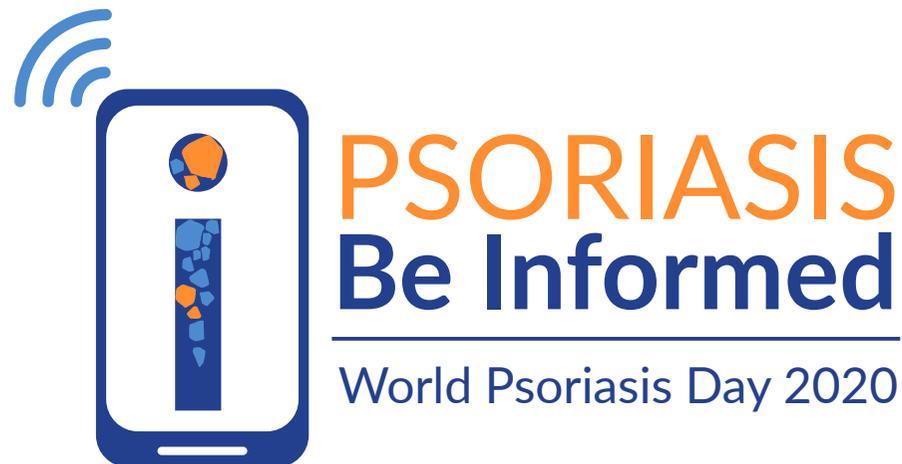
# PSORIASIS. BE INFORMED.

Information is a key ingredient in the recipe for empowerment. We knew this in 2019 when we launched our three-year campaign: *Connected, Informed, United*. Still, the events of 2020 have reinforced our commitment to the theme. There has never been a more important time to **be informed**. COVID-19 emphasizes the need in highlight, bold, and underline. People with psoriasis and psoriatic arthritis have many doubts in this crisis. Lack of knowledge about the disease and uncertainty about access to care and medicine make us even more vulnerable. As we build knowledge about the impact of COVID-19 on individuals with psoriasis, we also build hope, protection, and purpose for those same people. This is the power of being informed.

Informed individuals can manage their psoriasis better, and motivate behavior change in their communities. In the same way, informed patient associations, advocates, medical professionals, and scientists are more effective in their work. Everyone is invited to use this document and its separate toolkit to outline your World Psoriasis Day 2020 campaign. In these modern times, we access information in a digital form. This has become even more true during global lockdowns and social distancing. Through our handheld devices, we have an ocean of information at our fingertips, as well as a tool to engage with what we learn and get connected. For this reason, we have selected the cell phone to represent this year's World Psoriasis Day. We hope you will use your own device to follow the campaign. It is time to **be informed** about psoriasis and psoriatic arthritis.

IFPA is pleased to present the theme of World Psoriasis Day 2020.

## World Psoriasis Day Logo 2020



# INFORMED Pillars

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# EMPOWERMENT

## Being informed leads to empowerment.

Seemingly, we are experiencing a new wave of empowering technology these days. Digital innovations have been used to improve the quality of healthcare delivery, improve patient safety, and decrease medical errors. The starting point, as ever, is acquiring knowledge and education. Now more than ever, people are using the internet for information and advice. In this way, millions of people are empowered to use available resources to improve their own lives and the lives of others. Let's use these resources to get informed about psoriasis and psoriatic arthritis.

IFPA believes that the secret to positive change is to empower others. Get involved in this year's WPD campaign by engaging with us. Follow @psoriasisIFPA on Twitter, Facebook, Instagram, and Youtube to join the action. Approach your local patient association to participate in WPD activities in your area. In 2019 we got connected. Now, we seize the opportunity to develop an even more informed and empowered psoriasis and psoriatic arthritis community.

## Be informed, be empowered.

### Examples of Key Targets

- Informed patients can manage their condition better and motivate behavior change in their communities.
- Informed patient associations are effective in advocating the needs of psoriasis patients and helping them with social and psychological issues, something physicians have little time to do.
- Informed medical professionals have the ability to deliver positive, solid information about psoriasis and its treatments.
- Informed society will know that psoriasis is not transmittable to/from another person by touch or close contact, which will help to lessen the stigma, discrimination and exclusion of people living with psoriasis.
- Informed decision makers will be empowered to implement the recommendations stated in the WHO Resolution on Psoriasis, to create national guidelines/action plans and devote resources to support early screening of psoriasis patients.

# JOURNEY

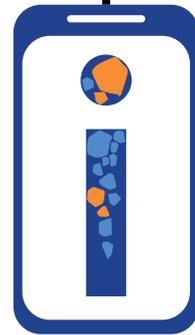
## We have made tremendous progress.

The history of psoriasis predates ancient Egypt. In early days, psoriasis was frequently confused with contagious leprosy, which did nothing to help the stigma of the disease. Through the ages, people with psoriasis faced isolation and shunning. Their condition was treated, or rather mistreated, with any number of remedies including animal dung, fresh oil, onions mixed with sea salt and urine, nitrate, sulfur, and mercury.

We have come a long way from the days of smelly and harmful management plans for psoriasis. In the 1800s, psoriasis was officially recognized as a non-communicable disease, and we began to work against stigma. In the 1900s, psoriasis started to be researched as an immune-mediated condition and linked it to co-morbidities like psoriatic arthritis. Cutting edge treatments like biologics became available at the end of the 20th century. Today, the broader choice of treatments allows more and more people around the world to keep the disease well under control.

The first World Psoriasis Day was celebrated on October 29, 2004. The WHO Resolution on Psoriasis (2014), and the subsequent Global Report on Psoriasis (2016) were landmark events in international advocacy. What are some important events in your country's psoriasis journey? Let's highlight these milestones, and **be informed** about the major opportunities that exist today for World Psoriasis Day 2020.

## Celebrate the journey. Be informed.



## Examples of Global Milestones

- IFPA was founded in 1971. Today we unite 62 associations from 58 countries in the mission to create a world free of suffering from psoriasis and psoriatic arthritis.
- The first World Psoriasis Day took place on October 29th, 2004 to focus people's attention on psoriasis.
- Following IFPA's efforts, the WHO Resolution on Psoriasis (2014) recognized psoriasis as a chronic, painful, non-communicable disease. This was followed by the WHO Global Report on Psoriasis (2016) which proposed key risk areas that need to be addressed to improve the lives of people with psoriasis and psoriatic arthritis.
- The Global Psoriasis Coalition (GPC) was founded by IFPA in 2017 to unite multiple sectors and stakeholders in global psoriasis advocacy.
- The Global Psoriasis Atlas (a collaboration between IFPA, ILDS, and IPC) publicly published early epidemiological findings in 2019.

## Resources are the tools of change.

We would all like to be walking wikis, with unlimited knowledge of psoriasis and psoriatic arthritis. However, until we discover a way to become omniscient, we rely on ever more expansive and precise resources to learn about psoriasis science and advocacy.

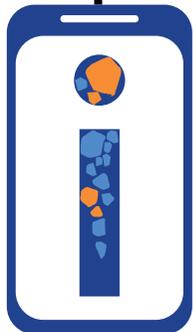
World Psoriasis Day 2020 is focused on **information**. Let's point our stakeholders towards reliable and useful tools they can use to **become informed!** Where can people who have psoriasis and psoriatic arthritis go to find out more about their condition? Which websites or events can the general public access to learn more about Pso and PsA? How can advocates find evidence to support their messaging and initiatives? What are these information services on global, regional, and national levels?

This World Psoriasis Day is an opportunity to highlight reliable resources and combine our efforts for maximum impact. Where resources don't exist, let's take action to fill in the gaps!

## Resources lead us forward.

### Examples of Global Resources

- The Global Psoriasis Atlas is an epidemiological resource that provides data on the global burden of psoriasis. It is a world-class database designed to help decision makers, the media, NGOs, healthcare professionals, and, of course, people living with psoriasis. Visit [globalpsoriasisatlas.org](http://globalpsoriasisatlas.org)
- IFPA provides important resources that member associations can use for their work in their countries. These include the World Health Organization (WHO) Resolution and Report, in addition to brochures, white papers, and toolkits. Visit [ifpa-pso.com](http://ifpa-pso.com) and [globalpsoriasiscoalition.org](http://globalpsoriasiscoalition.org)
- The World Psoriasis Day website highlights the actions of IFPA members and all our global community to celebrate October 29th and raise awareness of psoriasis and psoriatic arthritis. Visit [ifpa-pso.com/our-actions](http://ifpa-pso.com/our-actions)
- World Psoriasis and Psoriatic Arthritis Conference (WPPAC) website contains links to the latest developments in psoriasis and psoriatic arthritis research. These include abstracts and the conference program. [ifpaworldconference.com](http://ifpaworldconference.com)
- IFPA's position papers on biosimilars address the concerns of the psoriasis and psoriatic arthritis patient community with regards to the value of treatment options like biosimilars. IFPA's position paper raises the importance of an informed patient-provider relationship, while advocating that all patients have access to treatment solutions. [ifpa-pso.com/our-cause/resources](http://ifpa-pso.com/our-cause/resources)



# COVID-19

## There has never been a more important time to be informed.

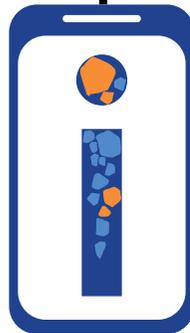
Facing the COVID-19 pandemic, people with psoriasis and psoriatic arthritis are wrestling with particular concerns. *Will I be able to see my doctor? Am I at heightened risk? Should I make adjustments to my treatment? How can I access my medicines in case of shortages?* These are just a few questions. People living with psoriasis and psoriatic arthritis are searching for answers.

While the world manages a communicable disease crisis, we cannot forget that people living with non-communicable diseases continue to be vulnerable. It is clear that our health systems need to become more resilient. To confront these uncertain times, we are all responsible for getting **informed** about reliable advice and advocacy targets for people living with psoriasis and psoriatic arthritis during the COVID-19 pandemic. With this **information**, we can feel reassured, behave safely, and protect others.

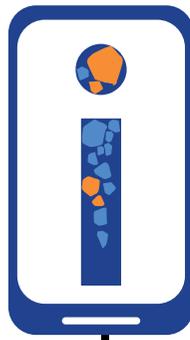
## With information, we can act.

### Examples of Key Actions

- Participate in PsoProtect. Whether or not you have experienced symptoms of COVID-19, if you have psoriasis you are invited to complete the PsoProtectMe survey at [psoprotectme.org](https://psoprotectme.org). Your answers will help us all understand the burden of COVID-19 on people with psoriasis.
- Talk to your psoriasis care provider about PsoProtect. Clinicians are requested to fill out the PsoProtect survey for any psoriasis patients who are confirmed or suspected of having COVID-19. Answers will help us develop recommendations for best treatment. Visit [psoprotect.org](https://psoprotect.org).
- Refer to the WHO and your local health authorities for the most updated advice regarding COVID-19.
- Visit [ifpa-pso.com](https://ifpa-pso.com) for global recommendations and resources for people with psoriasis and psoriatic arthritis during COVID-19.
- Get involved in global advocacy for people living with NCDs during COVID-19.



# More Information



## Global Psoriasis Atlas

The Global Psoriasis Atlas is a leading epidemiological resource which aims to provide data on the global burden of psoriasis. It was launched on the 30th of September 2016 by the founding organizations—the International Federation of Psoriasis Associations (IFPA), the International League of Dermatological Societies (ILDS) and the International Psoriasis Council (IPC)—based on recommendations in the WHO Report on Psoriasis. The World Health Organization report recognized psoriasis as a chronic, disfiguring, disabling, non-communicable disease that deserved global attention. Yet, the report noted, knowledge regarding the global burden of psoriasis is limited.

The Global Psoriasis Atlas's web-based atlas was ultimately launched on World Psoriasis Day 2019. It is a unique, world-class database designed to help decision makers, media, non-governmental organizations, healthcare professionals, and, of course, people living with psoriasis. This tool—which contains the latest information on the epidemiology, health services and outcomes in psoriasis care across different geographical zones—is a publicly accessible interactive database. It was envisioned to inform research policy and healthcare. To help you share your story, the Atlas emphasizes patient perspectives and experiences. Once complete, the Atlas will provide the first complete global snapshot of the disease burden of psoriasis and provide a framework for future studies and international collaboration. It aims to be a resource that will help improve treatment and patients' access to care worldwide, as well as recognize psoriasis as a health care priority.

[globalpsoriasisatlas.org](http://globalpsoriasisatlas.org)

## Position Papers

To improve patient health outcomes and raise awareness of new treatment options, IFPA published its position paper on biosimilars. The position paper addresses concerns from the psoriasis patient community regarding treatment options such as biosimilars. The paper offers an introduction to biosimilars, explaining the difference between biologics and biosimilars and outlining important priorities for including biosimilars among the treatment options for all psoriasis patients.

IFPA welcomes the introduction of safe and effective biosimilars that have the potential to improve access to treatment and increase treatment options for people living with psoriasis. These biosimilars must be proven to be as safe and as effective as their biologic originators with sufficient clinical and nonclinical testing before they can be used to treat patients. Furthermore, IFPA continues to stress the importance of the patient-provider relationship when making any treatment decisions. The patient should remain at the center of decision-making processes.

[ifpa-pso.com](http://ifpa-pso.com)

## IFPA and Coalition and WPPAC Websites

Having plenty of updated resources is the best way to be informed. One of IFPA's main goals is to provide our member associations with material they can use for their work in their countries. We are proud to share a WHO resolution and report in our resource library, as well as the newly released Global Psoriasis Atlas. We also have different kinds of material available to our membership, from brochures and poster layouts to white papers and toolkits. We know that IFPA member associations have many resources available for their members, members' families and the general public. Let's take advantage of these opportunities to become better educated about psoriasis! In addition, all are invited to be informed about developments leading up to the 6th World Psoriasis and Psoriatic Arthritis Conference (WPPAC) which will be organized by IFPA in July 2021. The latest developments in psoriasis and psoriatic arthritis research and advocacy will be discussed there. This year's theme 'be informed' is the perfect chance to promote your material as well as IFPA's material, to raise awareness on the burden of psoriasis, to unify our messages and to make our advocacy actions more effective.

[ifpa-pso.com](http://ifpa-pso.com)  
[globalpsoriasiscoalition.org](http://globalpsoriasiscoalition.org)  
[ifpaworldconference.com](http://ifpaworldconference.com)

## PsoProtect

PsoProtect is a global initiative to collect data so that we can better understand the impact of COVID-19 on people living with psoriasis. The data is de-identified and the surveys take only 5-10 minutes to complete! Clinicians are encouraged to report outcomes of COVID-19 in their patients at using the PsoProtect survey. Individuals with psoriasis also have an important role to play. Everyone with psoriasis, whether or not you have experienced symptoms of COVID-19, is invited to report using the PsoProtectMe survey. The information collected will help healthcare professionals make important decisions about the clinical care of people with psoriasis during the pandemic.

[psoprotect.org](http://psoprotect.org)  
[psoprotectme.org](http://psoprotectme.org)



What information does your country make available? Send links to [info@ifpa-pso.com](mailto:info@ifpa-pso.com) so that we can cross-promote your resources on our channels!

# HOW TO GET STARTED?

