



November 14, 2019

World Psoriasis Day 2019 Preliminary Report



INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

A Message from IFPA's president...

Dear friends around the world,

Congratulations on another vibrant World Psoriasis Day! I struggle to express my regards for the closing of our celebrations, because it doesn't feel like a closing at all. Rather, we are at the beginning of a new chapter for World Psoriasis Day and for our work advocating for psoriasis and psoriatic arthritis. This year we began the first in our new sequence of three-year cycles for World Psoriasis Day targets. In 2019 we got connected. We encouraged individuals to connect with psoriasis associations to access all the wonderful resources and support that these relationships can bring. Next year, we will continue the mission by calling on our friends in the psoriasis community to get informed and to spread that information to their constituents. Finally, in 2021 we will unite with the world at large to spread awareness and visibility of psoriasis.



This World Psoriasis Day, we also celebrated an important milestone in the Global Psoriasis Atlas. In the wake of the WHO Resolution, and the WHO Report, the GPA is the next chapter in improving the lives of people living with psoriasis and psoriatic arthritis. With their website launch on October 29th, people all over the world are now able to search for psoriasis data specific to their own country and to become informed about the experience of living with this disease. As research continues and the Atlas becomes ever more accurate, we look forward to the possibilities that this excellent resource has opened.

As always, it is heartening to witness the enthusiasm of our global psoriasis warriors. Thank you for continuing to make each World Psoriasis Day even better than the last. We are glad to be connected with you!

Warmest regards,

Hoseah Waweru, MD.
President of the IFPA Board

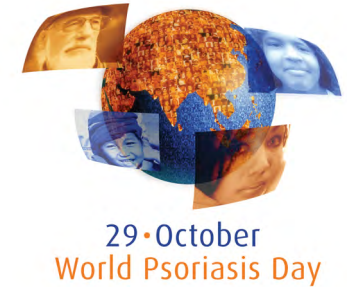
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Background

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 2019 theme is CONNECTED. It has been widely shared by IFPA members associations and adapted nationally and regionally to local languages and contexts.

Sponsors of World Psoriasis Day 2019

IFPA thanks the following sponsors for their role in making World Psoriasis Day 2019 possible:



World Psoriasis Day 2019: CONNECTED

On October 29, 2019, we celebrated the 15th annual World Psoriasis Day. This year's theme was CONNECTED. For the first time, the IFPA Secretariat, World Psoriasis Day Committee, and World Psoriasis Day Working Group collaborated to develop pillars and messages under our theme to explain all of the ways that psoriasis connects us. What does it mean to be CONNECTED? We feel that this is an important time to focus on how individuals living with psoriasis can become connected to a larger community, with all the resources and support that these relationships can bring. Over the past year, global health advocates have placed particular emphasis on mental health. We, in the psoriasis community, hoped to intersect with this theme by highlighting the essential role that connecting to other people living with psoriasis can play in mental health. As mental health is one of the major co-morbidities of psoriasis, we also hoped to highlight the connection between psoriasis and other disease areas during this World Psoriasis Day. Furthermore, the theme of World Health Day 2019 again stressed the importance of access to health care for everyone, everywhere. With this World Psoriasis Day theme, we stressed the importance of connecting people living with psoriasis to quality medical teams, representative research, necessary treatments, and supportive communities.

In addition to this year's theme, the World Psoriasis Day stakeholders also developed our first ever three-year strategy for upcoming World Psoriasis Days. We hope that by setting this precedent of working in three-year cycles, we will give our members the opportunity to plan further ahead and more deeply unite our messaging for World Psoriasis Days to come. The theme for World Psoriasis Day 2020 is INFORMED. The theme for World Psoriasis Day 2021 is UNITED. With this cycle we are hoping to focus first on the individual, then the psoriatic disease community, and finally the whole world.

Let's get connected!



[#worldpsoriasisday](#)

[#letsgetconnected](#)

[#estemosconectados](#)

CONNECTED

Psoriasis is connected to co-morbidities.

Pso & PsA are connected to other disease areas through co-morbidities. Yet another reason to treat psoriasis seriously!

Psoriasis patients should be screened for co-morbidities. Early detection is critical.

Psoriasis is connected to mental health and significantly impacts quality of life.

Co-morbidities are connected to an amplified cost burden for both the individual and society.

Patients must be able to get connected to quality healthcare and research.

No one should be left behind! All patients are equal and should have the same access to healthcare.

Take the first step towards your well-being – connect to healthcare professionals to stay happy and healthy.

Connecting patients to the scientific community helps to build understanding of the burden of disease from the patient perspective.

Patients should be involved in the medication development cycle.

We become empowered by connecting to supportive communities.

You are not alone with psoriasis. We are many and we are stronger when we connect together.

Psoriasis has real impacts on mental health. Let's combat these by connecting to supportive communities.

By sharing your experience, you can help fight stigma and discrimination.

Awareness is empowerment. Get connected with a psoriasis association in your country to learn more.

Connected organizations can fight more effectively for people living with psoriasis and psoriatic arthritis.

By connecting all the strength, capacity, and experience in our networks, we can maximize impact.

Let's connect our global, regional, and national advocacy efforts!

Connecting psoriasis to other disease areas makes our work more powerful.

Every project represents a different piece in the psoriasis puzzle. Let's get connected!

World Psoriasis Day in Perspective

My heart is filled with joy as I witness the efforts put by different communities and patient organizations worldwide to give psoriasis and Psoriatic Arthritis ONE strong and united voice. Staying true to the theme of the World Psoriasis Day for 2019: Let's Get Connected, the show of force of different nations is the most powerful I've seen in the many years that I've been the chairman of the WPD Steering Committee. With all the national leaders of psoriasis advocacy, we call on the various States to keep their promise of improving the lives of patients with psoriasis as they did when they unanimously approved the Psoriasis resolution at the World Health Assembly in 2014.

To the Psoriasis community worldwide, IFPA and its hard-working Secretariat will continue to set the stage as we lift our collective voices to better the lives of every patients challenged by psoriasis and Psoriatic Arthritis.

Let's get connected, and happy World Psoriasis Day to all of you.



Josef de Guzman

Chairman, World Psoriasis Day Steering Committee
Treasurer, IFPA Board

World Psoriasis Day takes place on 29th October every year and is the world's biggest platform for raising awareness about psoriasis and psoriatic arthritis.

Today, IFPA is in an exemplary position thanks to the skills and commitment of our members across the world who have the same spirit of solidarity anchored within them. In order for them to give the best of themselves it was essential to create a WPD Working Group which allowed us to ensure the most comprehensive theme #Let'sGetConncted with 16 empowering messages. All of this did not happen by waving a magic wand – numerous Secretariat meetings, conversations with the Board, teleconferences with the working group and hours of planning were required. I am pleased to say that all this effort resulted in the most successful WPD campaign so far and there is no denying the fact that we have reached millions of people by sharing our messages about psoriasis and psoriatic arthritis.



Janina Kostiukaite

Secretariat Lead Project Lead for World Psoriasis Day
Project Developer, IFPA

We need to keep up this work, day after day. We need to reinforce our position while remaining CONNECTED and committed to our mission. At the same time, we must keep in mind that we achieve bigger results through the interaction and integration of the people who are the most important part of it – people living with psoriasis and psoriatic arthritis. Let's get them INFORMED and let's get UNITED with everyone who trusts us, who supports and funds us. With our employees, volunteers and collaborators around the world for a louder voice of psoriasis globally. Thanks to all of you, around 60 million people benefitted from the campaign this year.

Hashtags by the Numbers

The following results reflect the performance of the official World Psoriasis Day 2019 hashtags on Twitter from October 27 until November 5.

#worldpsoriasisday

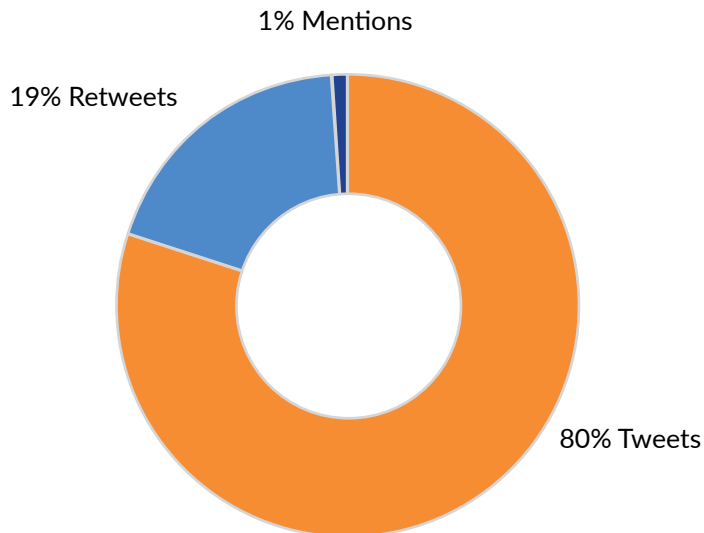
2,716 Tweets
409 Contributors
8,936,972 Potential Reach

#letsgetconnected

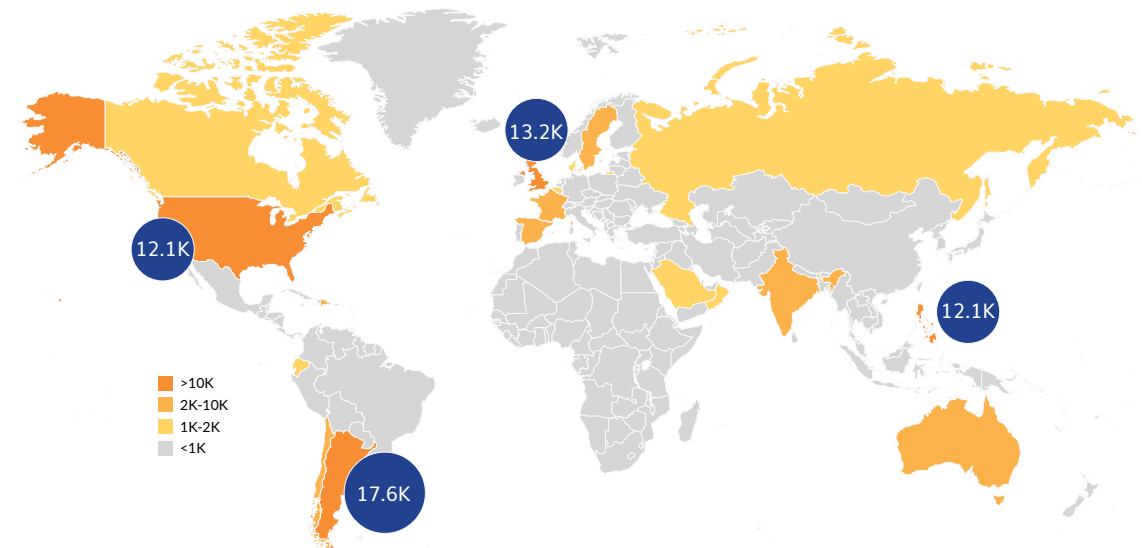
1,788 Tweets
281 Contributors
4,165,288 Potential Reach

#estemosconectados

956 Tweets
128 Contributors
3,019,200 Potential Reach



Number of hashtagged tweets by country



*Hashtag tracking with the help of Tweepmap and BrandMaxima

IFPA's World Psoriasis Day Campaign



The World Psoriasis Day campaign is one of IFPA's biggest projects each year. It is also a great opportunity to come together as a community to learn from each other and build capacity. This year IFPA contributed to capacity building in connection to World Psoriasis Day through offering workshops on social media skills hosted by external experts in collaboration with Celgene and Novartis. In September, two webinars were hosted by the **W2O agency** with the aim to strengthen IFPA members' capacity to prepare strong social media strategies. After the webinars all IFPA members also received a social media toolkit, which was developed to be used as a guide for strategic planning and a tool for measuring success.

Alice Titalii

Capacity Development Officer, IFPA

This year, we were pleased to debut a new format for the World Psoriasis Day theme. For the first time, our message was subdivided into four core pillars with sub-messages within each. The goal of this strategy was to make this year's theme even more relevant for the different audiences and contexts that our members and partners engage with worldwide. With the same intention, IFPA designed our World Psoriasis Day campaign to be as useful and helpful to our members and partners as possible. By sharing our materials, we were able to unite our stakeholders even more deeply around our common theme: **CONNECTED**.



Camille Lancelot

Communications Manager, IFPA

Pso and PsA are connected to other disease areas by co-morbidities.

Let's get

CONNECTED

WORLD PSORIASIS DAY
OCTOBER 29

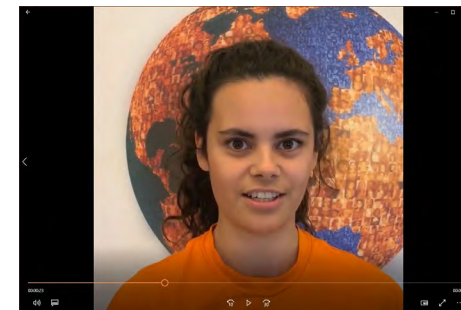


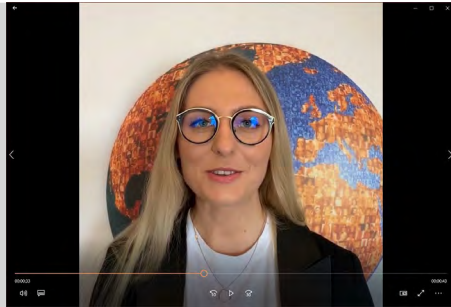
Social Media Messages

A series of 20 images and text was created for use on our own social media channels as well as those of our members, partners, and supporters. Designed to be easy to copy and paste, there was one image for each message under our **CONNECTED** theme. [Click Here](#) for the complete collection.

Video: Psoriasis is connected to comorbidities

This video featured all the members of the IFPA Secretariat. It is intended to highlight the first pillar of our **CONNECTED** theme, explaining the connection between psoriasis and comorbidities. Early detection is key to managing these risks! [Click Here](#) to watch the full video.



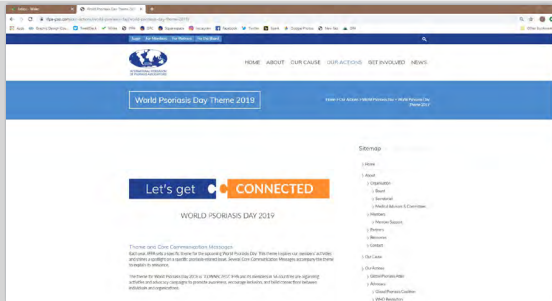
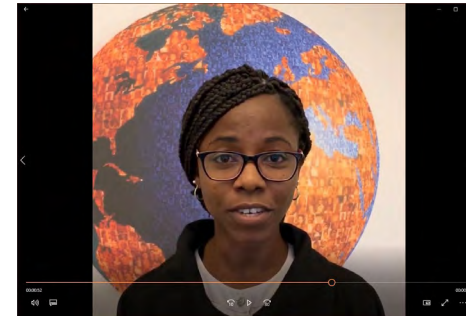


Video: Connect to a psoriasis community

This video featured all the members of the IFPA Secretariat. It is intended to highlight the second pillar of our CONNECTED theme, encouraging individuals living with psoriasis and/or psoriatic arthritis to get connected to an association or other people who also have the same disease. We are stronger when we connect! [Click here](#) to watch the full video.

Video: Let's get connected for World Psoriasis Day 2019!

This video featured all the members of the IFPA Secretariat. It was conceived to encourage our members and supporters to connect their efforts on World Psoriasis Day. By sharing materials and photos among our community, we can amplify our messages and get greater reach. [Click Here](#) to watch the full video.



Theme Page on the IFPA Website

On the IFPA website, we created a page to explain this year's theme. Through this page we also gave access to those WPD materials which could be made public. To visit the page, [Click Here](#).

Promoting the Global Psoriasis Atlas

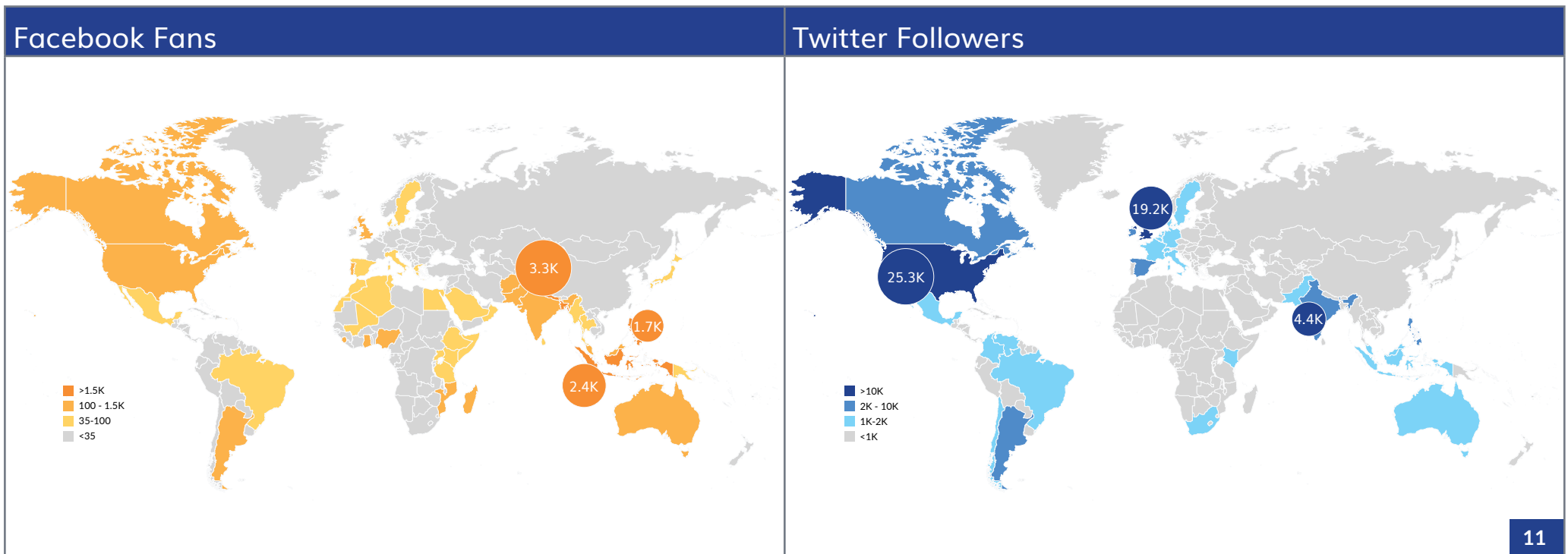
The launch of the Global Psoriasis Atlas was a tremendous milestone for World Psoriasis Day 2019. To promote the launch, IFPA invited the Atlas team to host a webinar with our members explaining the tool and how to promote its debut. When the Atlas launched on October 29, we followed their campaigns on Twitter and Facebook and promoted them on our social media channels too.



IFPA Campaign by the Numbers

The following data represents four of IFPA's social media channels: Twitter ([@psoriasisIFPA](#) and [@PSOCoalition](#)), Facebook ([International Federation of Psoriasis Associations](#)), and Instagram ([@psoriasisIFPA](#)).

Oct 1 - Nov 5	Twitter	Facebook	Instagram
Followers (Nov 5)	5.6K	15K	612
New Followers	155 (2.7% increase)	212 (1.4% increase)	87 (14.2% increase)
Posts	74	35	9
Impressions	362K	266K	11K
Engagement	1.5K	35K	422



World Psoriasis Day Engagement

Engagement is defined as any action taken on a post, including likes, reactions, comments, shares, retweets, link clicks, and content clicks.

Twitter Engagement



Total:

1.5K

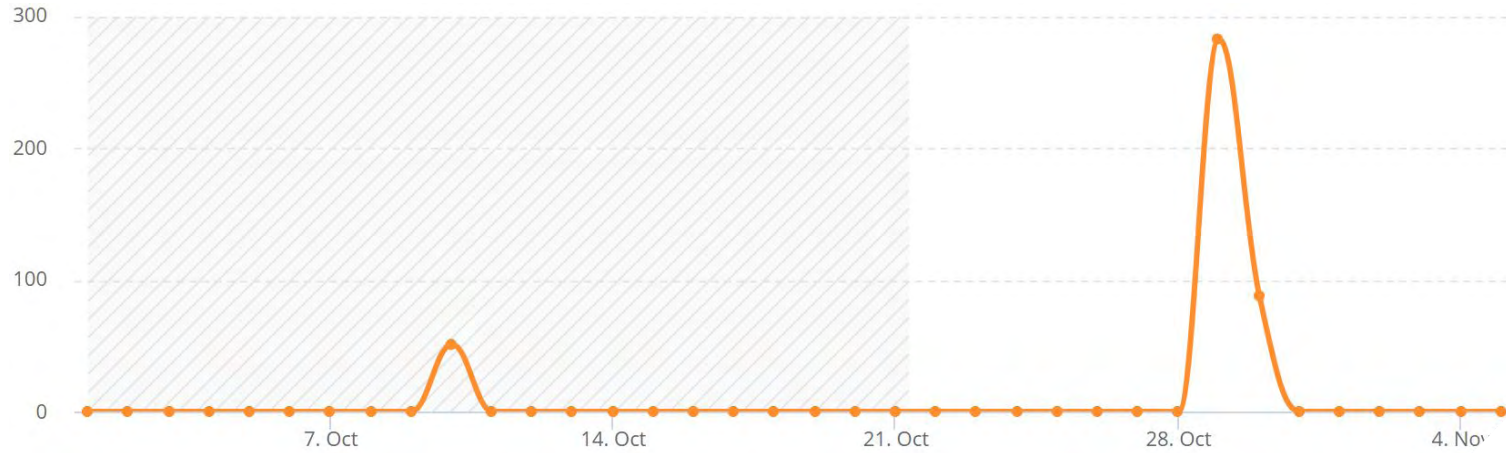
Facebook Engagement



Total:

35K

Instagram Engagement



Total:

422

*Social media analysis with the help of Hootsuite and Tweepstat

Top Tweet

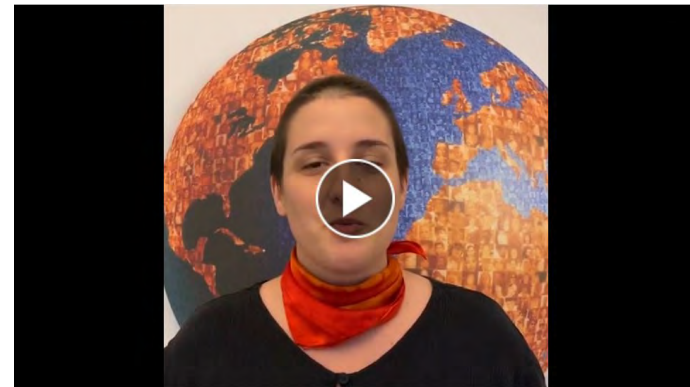
We are many and we are stronger when we connect together! **#psoriasis #psoriaticarthritis #letsgetconnected #worldpsoriasisday #estemosconectados**



13 retweets, 17 likes, 5 790 impressions

Top Facebook Post

Psoriasis is connected to co-morbidities **#letsgetconnected #worldpsoriasisday #estemosconectados**



165 engagements, 63 900 reach, 10 026 10-second views

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 2019. 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 **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. We celebrate the entire **Global Psoriasis Atlas** team for their remarkable achievement launching the Atlas website on World Psoriasis Day 2019.



Finally, we would like to thank our partners at **Almirall, Bristol-Myers Squibb, Celgene, LEO, Novartis, UCB** and particularly the **High Lantern Group** for their crucial participation in the development of the **Global Psoriasis Coalition**. Our tireless work is helping to further the global advocacy agenda on psoriasis and psoriatic arthritis. The Coalition has reinforced the messages of this year's theme through their web presence (www.globalpsoriasiscoalition.org) and social media activities ([@PSOCoalition](https://twitter.com/PSOCoalition)). [Visit their website](#) to explore the white papers and reports on these important topics.



World Psoriasis Day Activities: Globally Connected

World Psoriasis Day is a special day each year when we can let people see what psoriasis is, and learn more about it. When we are dealing with a disease that affects all parts of our life, both personal and professional, it is important that people are aware so that they can have compassion. We don't have to shy away from living a healthy, full life. World Psoriasis Day is a time where we can surround ourselves with people who have our same level of compassion and understanding. When we treat our minds and bodies well, our minds and bodies will help us in return. Finding supportive people is a big step towards that.

-Ingvar Ágúst Ingvarsson
Vice President, IFPA Board



October 29 is the day when psoriasis patients have a voice to communicate to the world about the seriousness of the disease and the needs they have to achieve a quality of life. On World Psoriasis Day, every member of IFPA had the opportunity to express to the leaders of their nations the necessities and the importance of working together, as a team, for the wellness of the patients. It's a day for the patients to feel...free!

-Leticia Lopez
Secretary, IFPA Board

To me, today, "connected" means promoting connections between my various health care practitioners into a team to help me manage and thrive with psoriatic disease and fibromyalgia. As I get older and my conditions progress, I need my "team" to help support and care for me through the flare ups, care for my health and well-being in between, and prevent/manage additional comorbidities. I encourage everyone struggling with psoriatic and noncommunicable chronic diseases to do the same, starting with their primary care provider.

-Kathleen L. Gallant
Member at Large, IFPA Board





On World Psoriasis Day, we can finally connect all our countries and regions and speak with one voice. For years, we have been using October 29th as an occasion to spread important messages about psoriasis and psoriatic arthritis. This year, we celebrate everything that links us. In the end, the world is not that big. We are together, supporting each other through the highs and lows that psoriasis brings.

-David Trigos Herraes
Substitute, IFPA Board

Some people ask about the importance of a certain word: "Disease Day." I say to myself, thank God there is a World Psoriasis Day. It is the one day when we put much more strength than what we do every day in our organization to make our disease visible. On that particular day, week, month, we really get connected to media, doctors, agencies, politicians, healthcare legislators, and whoever can help us change the vision of the disease. It is the day of our utmost strength and creation. It is the day to get to our patients, to look for the ones we could not find during the year. And we find them because everybody in those days and weeks works together towards one goal: to make the disease visible. We do this to get to more patients, even in the most remote places, and we create consciousness of the burden and danger. Year after year the understanding about psoriasis gets bigger, rights for the patients are better understood, access improves, and better doctors can be found. But many more WPDs are needed to get to the real changes of a world without suffering from psoriasis.



-Silvia Fernandez Barrio
Substitute, IFPA Board



GLOBAL PSORIASIS COALITION

Global Psoriasis Coalition

The Global Psoriasis Coalition participated in World Psoriasis Day with a social media campaign on Twitter focused on psoriasis co-morbidities and on universal health coverage (UHC), both part of the messages of this year's campaign. The messages on co-morbidities were aimed at raising awareness that psoriasis is not just a skin disease, therefore it is important that patients and doctors treat psoriasis seriously. The messages on universal health coverage aimed at placing psoriasis in the global conversation on UHC, and focused on the importance of primary healthcare in the management of psoriasis and access to care (you can access the white paper on psoriasis and primary healthcare at globalpsoriasiscoalition.org). Many members of the Global Psoriasis Coalition



actively participated in WPD: corporate partners organized activities to raise awareness on psoriasis within their corporation, supported IFPA members activities all over the world or promoted psoriasis on social media. Civil society organizations part of the Global Psoriasis Coalition supported IFPA's campaign by spreading the messages on social media. The engagement of the Global Psoriasis Coalition and its members for WPD will help our psoriasis advocacy reach a broader audience and will begin to give psoriasis the visibility it deserves..

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 that calls on civil society to advocate for a people-centered and integrated response to psoriasis.

globalpsoriasiscoalition.org



Psoriasis & Primary Care Report

Beyond Gatekeeping:
Effective Primary Care Support
in the Management of Psoriasis
& Psoriatic Arthritis

Global Psoriasis Coalition | September 2019





Global Psoriasis Atlas

On the World Psoriasis Day 2019, the Global Psoriasis Atlas (GPA) website was launched. The GPA aims to improve the understanding of psoriasis among different groups of people in different regions worldwide, while meeting the highest scientific standards of epidemiological data collection and estimation. On October 29, the three leading organisations- the **International Federation of Psoriasis (IFPA)**, the **International League of Dermatological Societies (ILDS)** and the **International Psoriasis Council (IPC)**- presented the web interactive platform to audiences around the globe. Through support by researchers and experts at the University of Manchester and University Medical Centre Hamburg-Eppendorf, the GPA provides the best available data to date on psoriasis.

Though there has been previous data on Psoriasis in the past, this first edition of the GPA serves as a scientific tool containing data on the prevalence of psoriasis among adults and children, as well as healthcare data. It also goes one step further and presents the human face of psoriasis by sharing first-hand compelling stories from people around the world who live with psoriasis.

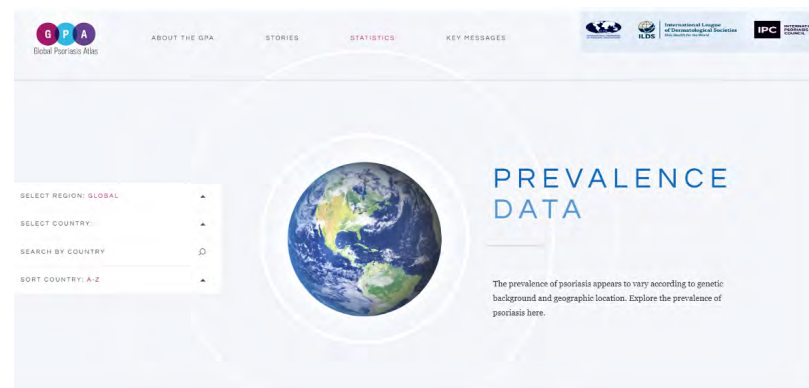
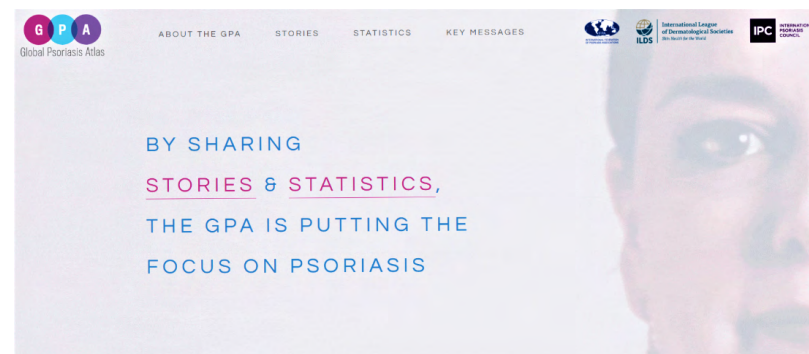
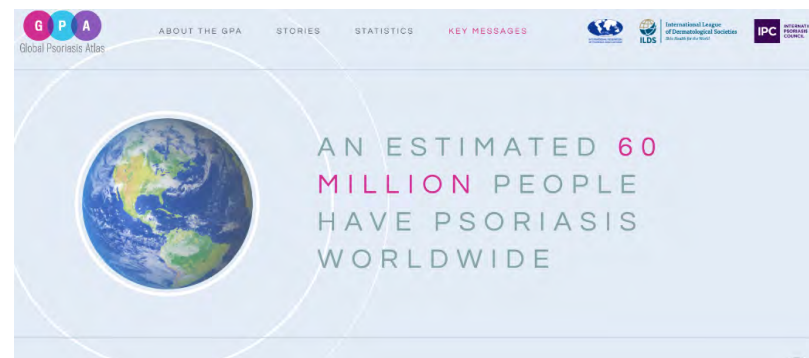
Future editions will include data on access to treatment, comorbidities and cost to society. As part of the collaborating organisations, the IFPA team received wonderful feedback from member organisations globally after the GPA went online. We shared the global messages in all social media platforms and watched video stories as the day's events unfolded.



Sicily Mburu
Scientific Officer, IFPA

The launch of the Global Psoriasis Atlas website is a landmark event for psoriasis advocacy. Visit their website to access data and testimonials on psoriasis in your country.

globalpsoriasisatlas.org



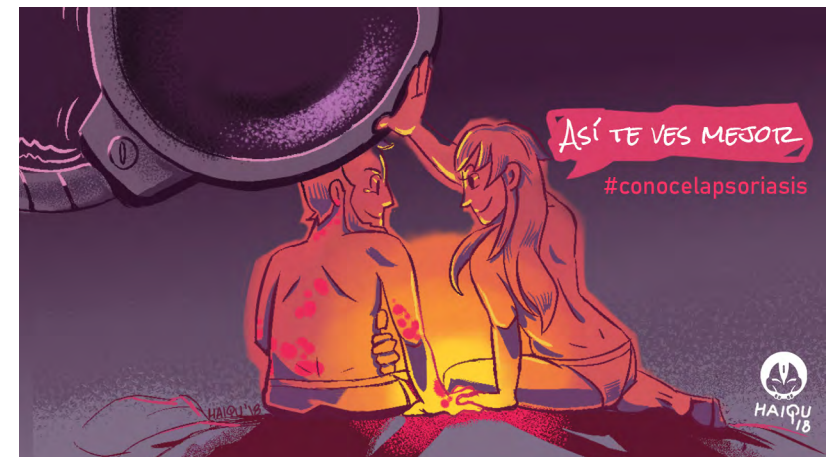
Asociación de Psoriasis y Artritis Psoriásica- Peru

For World Psoriasis Day, APAPSO Peru developed the #ConoceLaPsoriasis campaign which aims to raise public awareness of psoriasis, and also seeks to encourage those suffering to uncover and leave their fears behind. Outstanding Peruvian illustrators and designers have collaborated with this awareness campaign to create original illustrations and graphics in solidarity with those living with psoriasis, and for the sake of spreading information. These illustrations were shared digitally and on social networks throughout the month of October.

To see the campaign, visit www.psoriasis.org.pe

APAPSO Peru is a nonprofit organization aimed at promoting the rights of people suffering from psoriasis and psoriatic arthritis. The main purpose of this venture is to help improve the quality of life of the sick, providing them with the support they need so they will not get lost on the road to finding adequate treatment.

www.psoriasis.org.pe





Inspire Japan WPD

When Japanese model Angelica Michibata revealed that she has psoriasis, music creator Hyadain was inspired to create a cheerful song that would encourage people living with psoriasis. In cooperation with **Inspire Japan**, Hyadain created a wonderful song with mobilizing lyrics. The touching song is fun and emotional, all at the same time.

The music video has been shared on social media and youtube. It features healthcare workers, activists, and people living with psoriasis, in addition to the energetic performers. Inspire Japan released translated subtitles of this masterpiece for World Psoriasis Day.

Watch the music video at www.inspirejapan-wpd.net

Inspire Japan WPD was born in 2017 as a project in which members of the Psoriasis Patient Association gathered to raise awareness of Psoriasis in Japan and connect with those individuals who are suffering alone.

www.inspirejapan-wpd.net





South African Psoriasis Association

The South African Psoriasis Association uses World Psoriasis Day to target the needs of people living with psoriasis and psoriatic arthritis in South Africa. Namely, they dedicate their efforts to raising awareness, spreading information, improving access to treatment, and giving people with psoriasis a voice.

To that end, this year the South African Psoriasis Association organised a patient meeting to celebrate World Psoriasis Day. In dedication of their members, SAPSA orchestrated a day of activities including talks on dermatology, rheumatology, and management of psoriasis, in addition to joyful entertainment.

The South African Psoriasis Association is a volunteer organisation that offers information, inspires confidence, and encourages engagement among its members. SAPSA believes strongly that people with psoriasis need to know that they are not alone. That is why each of their volunteers has some form of psoriasis themselves. To learn more, visit:

www.psoriasis.org.za



Associazione Amici Della "Fondazione Natalino Corazza Onlus"

In their first year with IFPA's membership, the Fondazione Corazza celebrated World Psoriasis Day with a bang. They made noise with a maxi outdoor photographic installation and accompanying flashmob dance synchronised in five cities across Italy, including Bologna, Naples, Rome, Milan, and Turin. The foundation worked with the Almadanza Academy of Choreographic Arts to choreograph a dance and teach it to participants with online videos. The flashmob surprised and delighted passers-by. Their performance called attention to a series of photographs on public display illustrating psoriasis in all its beauty. Clinical dermatologists were also present at the events to answer any questions about the pathology of psoriasis.

Learn more about the event at the Fondazione Corazza's Facebook page: [@fondazionecorazza](https://www.facebook.com/fondazione.corazza)

The Associazione Amici Della "Fondazione Natalino Corazza Onlus" is an associated member of IFPA. The organisation is the membership component of the Fondazione Corazza, a foundation that has dedicated itself to the study of psoriasis and its complications.

www.fondazionecorazza.org



Letter from the Executive Director

Dear friends,

This World Psoriasis Day was an inspiring event where patient advocates, family members, friends, patients, doctors, nurses and other healthcare professionals, government officials, civil society, corporate representatives, and many others came together all over the world to provide a united message: Let's get connected!

I would like to take this opportunity to express sincere thanks and appreciation from IFPA for all those who have spent days, weeks or even months to make World Psoriasis Day 2019 such a success! Many are still continuing this month. We will be publishing a complete report for World Psoriasis Day 2019 at the start of the next year, with further statements from the IFPA Board and more in-depth reports on IFPA member activities. Meanwhile, the IFPA Secretariat is pleased to provide this preliminary report to quickly follow up WPD 2019 with highlights of the day. We were enormously inspired and impressed as we monitored activities across the world!

Once more, thanks to all who have labored to make this possible, and particularly to IFPA members, supporters and partners, our wonderful IFPA Board and Secretariat team, and particularly the official sponsors of World Psoriasis Day.

Patrik Vuorio

Executive Director, IFPA





INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

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