WORLD PSORIASIS DAY 2018

PRELIMINARY REPORT

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International Federation of Psoriasis Associations
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Introduction

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 2018 theme is “**Treat psoriasis seriously – our lives depend on it**”, and it has been widely shared by IFPA members associations and adapted nationally and regionally to local languages and needs. The theme focuses on the magnitude of psoriasis, including the increased risk of developing other non-communicable diseases, and calls for early diagnosis, access to treatment and comprehensive care.

The activities around WPD started worldwide at the beginning of October and are still ongoing in some countries during the week and month following WPD.

*This is a preliminary operational report published by the IFPA Secretariat as an early follow-up to WPD 2018. A full report and booklet will be published in December 2018.*
A message from the IFPA President on WPD

A statement from IFPA president Dr. Hoseah Waweru on WPD 2018 was released on October 29th and is available for download here. Further greetings and remarks from the IFPA Board will be published in the upcoming full IFPA report on WPD 2018.

Executive Director’s notes following WPD

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: Treat Psoriasis Seriously – Our Lives Depend On It!

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 #WPD18 such a success! Many are still continuing this week and month. We will be publishing a complete report for World Psoriasis Day 2018 by the end of this 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 2018 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 (listed here.)

Patrik Vuorio
Executive Director, IFPA
IFPA core communications materials on WPD 2018

We are pleased to see the global 2018 WPD theme, PsoSerious (available on our internal web), adapted in so many creative ways by our members and partners around the world. In addition, IFPA released the following resources on October 29th.

IFPA Press Release on WPD 2018

An IFPA Press Release regarding World Psoriasis Day 2018 was forwarded to news outlets globally on October 29th.

Releases of new resources on WPD 2018

World Psoriasis Day activities website
www.worldpsoriasisday2018.com

Will be continuously updated with activities organized around WPD 2018 by IFPA members

Global Psoriasis Coalition website
www.globalpsoriasiscoalition.org

The new official website of the Global Psoriasis Coalition, launched on October 29th, 2018

IFPA Instagram account
@psoriasisIFPA

New IFPA Instagram account sharing IFPA news, and photos from member activities
<table>
<thead>
<tr>
<th>Video Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Official WPD 2018 video</td>
<td>Greeting videos released by IFPA around WPD 2018</td>
</tr>
<tr>
<td>Message from Lars Fogt Werner</td>
<td>A message from Lars Fogt Werner from Psoriasisforeningen (Denmark)</td>
</tr>
<tr>
<td>Message from Antoinette Romeo</td>
<td>A message from Antoinette Romeo from GIPSO (Belgium - Wallonia)</td>
</tr>
<tr>
<td>Message from Tina Koukopoulou</td>
<td>A message from Tina Koukopoulou from Epidermia (Greece)</td>
</tr>
<tr>
<td>Message ahead of WPD from Europsso members</td>
<td>A message ahead of WPD from Europsso members</td>
</tr>
<tr>
<td>Message from the IFPA Secretariat</td>
<td>A message from the IFPA Secretariat on WPD 2018</td>
</tr>
<tr>
<td>WPD message from CariDee English</td>
<td>A WPD message from CariDee English, psoriasis advocate (US)</td>
</tr>
</tbody>
</table>
Official sponsors of WPD 2018

IFPA would like to acknowledge and thank the official sponsors of WPD 2018:

Related activities around WPD 2018

We are aware that our partners and sponsors have been carrying out extensive efforts in connection to the global WPD theme for 2018 and WPD. We look forward to being able to share more extensive details in the upcoming complete WPD 2018 report. We would however like to already highlight some efforts where IFPA has been directly requested to engage and where there have been active operational collaboration in preparations around WPD (the list is not to be viewed as all-encompassing):

**The World Psoriasis Happiness Report 2018** – produced by the Happiness Research Institute and LEO Innovation Lab, and powered by PsoHappy, this resource focuses on mental health as a serious and important aspect of psoriasis and psoriatic arthritis. The report was released in the weeks prior to, and used as a resource on, WPD.

**The Six Domains campaign** – developed by Celgene, this new online resource for patients and healthcare providers helps create a stronger understanding and communication regarding symptoms of psoriatic arthritis, under the slogan “What’s your combination?”. The campaign was launched around WPD.

**Blog post by Lilly through LillyPad EU** - in continued practice from previous years in our ongoing partnership with Lilly, this post was published in collaboration around WPD.

**Blog post by Bristol-Myers Squibb** - IFPA is pleased to welcome Bristol-Myers Squibb (as well as UCB) among our new partners and WPD sponsors for 2018. This post was published in collaboration between Bristol-Myers Squibb and IFPA in connection with WPD.
Partners of IFPA

We would like to acknowledge partners of IFPA and networks of which IFPA is a part, both for appreciated collaboration during 2018 overall and for support around WPD:

Thank you particularly to NCD Alliance for highlighting psoriasis and psoriatic arthritis as a part of the global NCD message on WPD.

We would also like to acknowledge the International Psoriasis Council and the International League of Dermatological Societies, both of whom we are glad to partner with on the development on the Global Psoriasis Atlas.

The Global Psoriasis Atlas reinforced its online presence on the web (www.globalpsoriasisatlas.com) and social media (@PsoriasisAtlas) in connection with WPD and we would like to send a note of particular appreciation to the GPA team as part of this report.

We would also like to thank our partners in the Global Psoriasis Coalition (Almirall, Celgene, LEO, Lilly, Novartis, and SUN Pharma) for helping further our global advocacy agenda on psoriasis and psoriatic arthritis, and the High Lantern Group for key assistance in development of the Coalition. Read more on www.globalpsoriasiscoalition.org.
Examples of IFPA member activities

We have been tremendously impressed by all the activities taking place across the world on and around WPD 2018! Ahead of our upcoming complete WPD 2018 report, we will list a few examples of national and regional activities and adaptations of #PSOserious:
Asia and the Pacific

The Bike Caravan of Hope

Psoriasis Philippines arranged a bike caravan across the Philippines in order to raise awareness and educate about psoriasis and psoriatic arthritis – a journey which stretched 612 kilometers! In addition, a WPD event with over 1,000 attendees took place on WPD weekend.
School children educated and sending messages of hope

PsorViet in Vietnam arranged, among other things, an educational campaign informing school children about psoriasis, culminating with the children writing and sending postcards to people living with psoriasis in Vietnam.
Europe

Information campaign with a clear message

PsoriasisLiitto, our Finnish psoriasis association member, created this beautiful campaign with the message “Psoriasis is not contagious – not even in water”.

The campaign included both images like this one, and an impactful video. The campaign was translated to both Finnish and Swedish.

Finding the way

Acción Psoriasis, our member association in Spain, have been highly active on social media and with a number of campaigns and initiatives, including communicating around one of their major campaigns, Buen Camino, with interviews filmed on the pilgrimage path of Camino de Santiago. Another campaign, on psoriatic arthritis, is https://artritispsoriasica.org/
Africa

WPD celebrations in Kenya and South Africa

Our member associations in Africa have been active with a number of activities in Kenya and South Africa.

Here, we see a photo from a presentation on WPD about psoriasis and psoriatic arthritis for doctors in Kenya by Dr. Hoseah Waweru (president of IFPA) on behalf of the Psoriasis Association of Kenya.

South America

Asociación Civil para el Enfermo de Psoriasis (AEPSO) in Argentina organized a range of activities leading up to WPD. Among these were an extensive media campaign, and this high-impact video with Argentinian key social media influencers spreading the message on WPD about psoriasis and psoriatic arthritis – which affect more than 800,000 people in Argentina.
Central America

Asociación Puertorriqueña de Ayuda al Paciente de Psoriasis (APAPP) in Puerto Rico arranged a wide range of activities that included, among other things, information campaigns with school children, media appearances on major television channels and this adapted version of this year’s WPD theme.

North America

The National Psoriasis Foundation (NPF) in the United States organized a major campaign this year. Among a number of other initiatives around the time of WPD were an online series exploring how medical costs, treatment options and cultural stigmas for people living with psoriasis vary across the globe.

NPF volunteers also participated in a Marine Marathon to raise awareness about psoriasis and psoriatic arthritis.
IFPA social media communications on WPD 2018

IFPA’s social media strategy this year was based on a combination of pre-prepared messaging designed around the theme of “PsoSerious” and interacting with members and partners. The main social media channels used this year were our Facebook and Twitter feeds (mainly @psoriasisIFPA). The below table summarizes the number of posts on each of those channels in the weeks leading up to WPD 2018 (from October 1 to October 28) as well as the spike in activity on the day itself (October 29).

<table>
<thead>
<tr>
<th>Number of Posts</th>
<th>Facebook</th>
<th>Twitter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lead-up (Oct 1-28)</td>
<td>16</td>
<td>45</td>
</tr>
<tr>
<td>WPD (Oct 29)</td>
<td>9</td>
<td>15</td>
</tr>
<tr>
<td>Total (% on WPD)</td>
<td>25 (36%)</td>
<td>60 (25%)</td>
</tr>
</tbody>
</table>

IFPA social media statistics - Twitter

On Twitter, the strategy was to balance IFPA-produced content with sharing activities and events of our members and partners around the world. The below table gives an overview of this balance, wherein about 40% of tweets were sent out as original tweets by IFPA and about 60% were re-tweets of content sent out by others.

<table>
<thead>
<tr>
<th>Tweets on October 29</th>
<th>IFPA Tweets</th>
<th>Re-Tweets</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Original</td>
<td>On behalf of partner</td>
<td>IFPA Member</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>Total from IFPA</td>
<td>15 (40%)</td>
<td>Total Re-Tweets</td>
<td>23 (60%)</td>
</tr>
</tbody>
</table>
On Twitter, a way of measuring impact is by “impressions”, which is the number of times a tweet appears on someone’s screen. In the period October 1 – October 29, tweets by IFPA from the @psoriasisIFPA account earned 301,100 impressions in total. Below is a breakdown of impressions by day. The peak in impressions was for the 15 tweets sent out on WPD, which earned a collective total of 48,226 impressions, which was about 16% of the impressions for the period October 1 – October 29.

Impressions and tweets per day (October 1 – October 29)

Here are the top tweets from the month leading up to WPD 2018:

Common Myths infographic tweet from 28/10

- 236 replies, re-tweets, and likes
WPD 2018 video from 26/10

- 221 replies, re-tweets, and likes

Today is WPD! Tweet with pin photo from 29/10

- 97 replies, re-tweets, and likes
IFPA social media statistics - Facebook

On Facebook, one way of measuring impact is by “reach”, which is the number of unique users who have content from the IFPA page appear on their screens. Below is a breakdown of the reach on Facebook leading up to WPD (October 1-28) and on the day itself (October 29):

<table>
<thead>
<tr>
<th></th>
<th>Reach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lead up (Oct 1-28)</td>
<td>275123</td>
</tr>
<tr>
<td>WPD (Oct 29)</td>
<td>61283</td>
</tr>
<tr>
<td>Total (Oct 1-29)</td>
<td>336406</td>
</tr>
<tr>
<td></td>
<td>(18% on WPD)</td>
</tr>
</tbody>
</table>

Here are the top posts on Facebook, as measured by views or reactions:

**WPD 2018 video** posted 26/10
- 27,761 3-second views
- 596 reactions
Infographic video posted 18/10

- 16,336 3-second views
- 312 reactions

2018 theme poster posted 21/10

- 16,587 people reached
- 9,940 reactions
Lastly, to gauge initial impact of the WPD campaign this year, we tracked the number of followers gained on each account. On Twitter, the IFPA account gained a net total of 102 followers in the ten days leading up to WPD, October 19-October 29. On Facebook, the IFPA page gained a net total of 96 followers in the week leading up to WPD, October 22-October 29.

**New Instagram account for IFPA**

In order to be able to better showcase examples of all of the inspired efforts taking place on, around and after WPD 2018, we combined the launch on October 29th of our new activities website, [www.worldpsoriasisd2018.com](http://www.worldpsoriasisd2018.com), with expanding the IFPA social media presence to Instagram, meaning we will from now on post examples of member associations’ activities on [@psoriasisIFPA](https://www.instagram.com/psoriasisIFPA) on Instagram in order to show a representation of the tireless efforts by psoriasis and psoriatic arthritis advocates around the world.

On Instagram, the new IFPA account gained over 120 initial followers by end of October 30th.
#WPD18 hashtag social media statistics – Twitter

We are monitoring the #WPD18, #PSOserious and #PSAserious hashtags using FollowTheHashtag in the time period before, during and after WPD.

While we will publish our findings more in detail in the complete WPD report which will be released by end of year, here is an overview of the #WPD18 official World Psoriasis Day hashtag, its global impact, distribution geographically and intensity on the days around and on WPD.
A few words from the IFPA team...

The IFPA Board

Dr. Hoseah Waweru  
President of IFPA

Ingvar Ágúst Ingvarsson  
Vice president of IFPA

Silvia Fernandez Barrio  
Secretary of the Board

Josef de Guzman  
Treasurer  
Chairman of the WPD committee

Kathleen L. Gallant  
Member at Large

Leticia Lopez  
Substitute

The IFPA Secretariat (as per WPD 2018, additional team members joining soon)

From left to right Maxine Lancelot (Scientific Officer), Patrik Vuorio (Executive Director), Elisa Martini (Program Officer – Advocacy and Policy), Alice Titialii (Program Officer – Capacity Development)
A few words in summary from the IFPA team after WPD

Dear all,

It has been amazing to see the fantastic activities, variety, creativity, unity, and inspired energy around the world on and around World Psoriasis Day 2018. Our sincere thanks to everyone that has contributed to this day, and to those who will continue doing so in the weeks following.

We are delighted to present this initial report, prepared by the IFPA Secretariat, at this moment shortly after October 29th. We will look forward to sharing with the full report by the end of 2018.

It is indeed time to treat psoriasis seriously – our lives depend on it! On WPD18, our community came together to strongly deliver that message.

Together, we are all in for the 125 million!

Much respect and appreciation to all,

The IFPA Board and Secretariat
Contact information – IFPA

We hope to receive more photos, videos, reports and information about our members’ activities as we gather data for the complete World Psoriasis Day 2018 report and booklet, and IFPA 2018 Annual Report. Please send us materials to info@ifpa-pso.com.

For general inquiries, welcome to contact us on info@ifpa-pso.com.

To contact members of the IFPA Board: https://ifpa-pso.com/about/organisation/board/

To contact the IFPA Secretariat: https://ifpa-pso.com/about/organisation/secretariat/

IFPA website: www.ifpa-pso.com
Global Psoriasis Coalition website: www.globalpsoriasiscoalition.org
Information about World Psoriasis Day: www.worldpsoriasisday.com
IFPA members activities website following WPD18: www.worldpsoriasisday2018.com

Facebook: IFPA International Federation of Psoriasis Associations
Twitter: @psoriasisIFPA (IFPA global account) and @PSOCoalition (Global Psoriasis Coalition)
Instagram: @psoriasisIFPA