World Psoriasis Day – How the psoriasis community gave meaning to 29th of October

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World Psoriasis Day 2016 being celebrated in the Philippines © Aydin Mammadov/IFPA

Since 2004, October 29th has been dedicated to raising awareness on psoriasis and psoriatic arthritis. Conceived by patients, for patients, World Psoriasis Day stands as a reminder of the many achievements, but also of the many challenges still faced by people with psoriasis and psoriatic arthritis. In 2016, activities on World Psoriasis Day reached a record high. 2017 is aimed at debunking myths: did you know that psoriasis is an NCD?

Why World Psoriasis Day?

Psoriasis is a severe, chronic, disabling and disfiguring, non-communicable disease (NCD), for which there is no cure. Globally, there are 125 million people living with psoriasis[1]. Psoriasis symptoms are mostly visible on the skin, which can become inflamed, irritated, itchy or scaled. Visually, it may look like psoriasis is contagious or the result of bad hygiene. But the reality cannot be further than that. The 'usual suspects' for a psoriasis outbreak are one's genes, immune system, risk factors such as diet, physical activity, tobacco and alcohol use, and triggers such as stress or infection.

Throughout IFPA's longstanding work, we have observed the different realities that people with psoriasis face, in different countries, from lowered quality of life and expensive treatments, to exclusion from the community and discrimination. World Psoriasis Day was born as an attempt to shift the focus to celebrating the strength of people with psoriasis and to better inform communities of the disease and the needs of people with psoriasis. Over a decade later, World Psoriasis Day is observed in more than 50 countries, all over the world, with activities whose silver lining is simple – inclusion.

'Breaking Barriers' in 2016

Every day, people with psoriasis face immense barriers in society, including in the healthcare system, school or work, social relations and in their community. Their struggles include getting the correct diagnosis, affording treatment,

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attending work and school and establishing healthy and supportive relations with peers, family and the wider community.

Knowing that 'struggle' was the key word to describe everyday life, World Psoriasis Day 2016 focused on breaking the barriers, and bringing new words into the lives of people with psoriasis:

- FIGHT prejudice, stigmatisation and discrimination
- RAISE awareness, understanding and hope
- GAIN access to proper diagnosis, treatment and improved quality of life

The new approach echoed among the psoriasis communities and associations, which jointly created over 200 various activities worldwide – from awareness campaigns in Portugal, El Salvador, Ireland and Korea; to organising events and conferences in Russia, Austria and Malaysia; and media appearances in Argentina, Hong Kong, Japan and the Philippines. IFPA amplified their voices further, by creating an animated film, 'Breaking Barriers', as well as organising global social media campaigns.

2017 to bring increased focus on NCDs

One of the biggest myths we hear every day is that psoriasis is solely a skin disease. While in most cases it has a skin manifestation, psoriasis is in fact an NCD (recognised as such through the WHO Resolution on Psoriasis[2]). Furthermore, there are direct connections between psoriasis and other major NCDs, such as diabetes and cardiovascular diseases[3]. Recent research has identified ties between psoriasis and cancer and chronic respiratory diseases, as well[4].

Motivated by these research findings, the theme for World Psoriasis Day 2017 is '**Psoriasis Inside Out**'. We will aim to show the 'pso many sides' of everyday life with psoriasis, and listen to 'pso me' experiences from people affected by psoriasis, as patients, family members, partners, friends or colleagues.

World Psoriasis Day 2017 brings forth the need to look at psoriasis NCD co-morbidities and also shifts the focus from considering the physical burden only to look into the psychosocial impairments as well: how psoriasis affects interpersonal relationships, community belonging and school and work life on a daily basis.

Given the right environment, people with psoriasis can excel at whatever they want. Defy the odds, chase their dreams, reach their goals.

I think that given the right environment, people with psoriasis can excel at whatever they want. Defy the odds, chase their dreams, reach their goals. This is why I see great potential in World Psoriasis Day – to open the discussion about bringing people with psoriasis one step closer to no longer missing out on life because of their condition. I am optimistic enough to think that 2017 is the year when the wider NCD community will join us in this global exercise of understanding, activism and creating better lives for people with psoriasis.

To support the work on psoriasis and feed the voices of psoriasis patients in the global NCD discussions, IFPA has recently launched the Global Psoriasis Coalition[5], creating one more opportunity for non-governmental organizations, medical societies, foundations, researchers, corporate partners and decision makers to join forces and stand together for the 125 million people with psoriasis worldwide. We hope you will consider joining us.

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This is an extended version of a blog appearing on the International Federation of Psoriasis Associations website <u>HERE</u> [1].

About the Author:

Josef de Guzman carries out the role of a Treasurer in the Board of the International Federation of Psoriasis Associations (IFPA) (@PsoriasisIFPA [2]) and is Chairman of the World Psoriasis Day Steering Committee. To Josef, psoriasis has been part of everyday life, since his first psoriasis outbreak in 1996. Affected, but also motivated by the reality of being a psoriasis patient, Josef has taken a successful health advocacy career path, ultimately transforming the awareness, support and knowledge of psoriasis in the Philippines with the creation of PsorPhil in 2005. Starting as an online support group, PsorPhil is now leading national psoriasis advocacy in the Philippines. Currently, Josef mentors people in other countries on launching patient organizations and gives lectures on the patient perspective at medical congresses in Asia, the EU and the Middle East.

- [1] National Psoriasis Foundation, "Psoriasis Media Kit" www.psoriasis.org [3]
- [2] The full text of the WHO Resolution is available HERE [4]:
- [3] Azfar AS at al. Increased Risk of Diabetes and Likelihood of Receiving Diabetes Treatment in Patients with Psoriasis. Archives of Dermatology 18: 1 6 Jun 2012 and Mehta NN et al. Attributable Risk Estimate of Severe Psoriasis on Major Cardiovascular Events. Am J Med. 2011 Aug; 124(8): 775.e1–775.e6
- [4] Chiesa Fuxench ZC et al. The Risk of Cancer in Patients With Psoriasis: A Population-Based Cohort Study in the Health Improvement Network. JAMA Dermatol. 2016 Mar;152(3):282-90 and Li X et al. Association between Psoriasis and Chronic Obstructive Pulmonary Disease: A Systematic Review and Meta-analysis. PLoS One. 2015 Dec 23;10(12):e0145221
- [5] More information about the Global Psoriasis Coalition is available HERE [4]

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Related Resource: Addressing NCDs: Psoriasis and its Co-morbidities [5]

Related Link: World Psoriasis Day - 29th October [6]

Tags: psoriasis [7]

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Links

- [1] https://ifpa-pso.com/2017/10/11/world-psoriasis-day-how-the-psoriasis-community-gave-meaning-to-29-october/
- [2] http://twitter.com/PsoriasisIFPA
- [3] http://www.psoriasis.org
- [4] https://ifpa-pso.com/our-actions/advocacy/global-psoriasis-coalition/
- [5] https://old.ncdalliance.org/resources/addressing-ncds-psoriasis-and-its-co-morbidities
- [6] http://www.ifpa-pso.com/our-actions/world-psoriasis-day/
- [7] https://old.ncdalliance.org/taxonomy/term/184

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