

A global initiative to ensure people with psoriasis and psoriatic arthritis get the care and treatment they need to live full and healthy lives

Background

Psoriasis is a chronic, autoimmune disease that appears on the skin. Up to 30% of people with psoriasis will develop psoriatic arthritis, a form of inflammatory arthritis that attacks the joints and tendons.

The burden of psoriasis and psoriatic arthritis on the individuals who live with these diseases is significant.^{1,2} Psoriasis symptoms include itching, skin scaling and flaking, and pain.³ Psoriatic arthritis symptoms include fatigue, pain, and swelling around the joints.³ Moreover, psoriasis and psoriatic arthritis are associated with serious co-morbid conditions such as heart disease and diabetes, which can reduce life expectancy.^{4,5} The associated stigmas of these diseases lead to depression in many people and can heavily impact life choices, for example, career decisions and personal relationships.⁶

Despite the fact that psoriasis and psoriatic arthritis are serious and complex chronic conditions that have a significant impact on the body, patients struggle to get a correct diagnosis, have difficulties seeing the proper medical specialists and accessing life-changing medications, and are challenged by the symptoms and effects of psoriatic disease on their everyday life.⁷

It is therefore crucial we raise awareness on the impact of psoriasis and psoriatic arthritis and address the unmet needs of people living with these debilitating diseases.

Call to action

As national and international organizations dedicated to patients with psoriasis and psoriatic arthritis, we the:

- International Federation of Psoriasis Associations (IFPA), a global organization based in Sweden
- European Federation of Psoriasis Associations (EUROPSO), Europe
- National Psoriasis Foundation (NPF), United States
- The Arthritis Society, Canada

are **speaking out in unison for people living with psoriatic diseases**. In February 2014, we developed a consensus statement to address the common unmet needs faced by the millions of people around the globe dealing with psoriasis and psoriatic arthritis. This included:

1. Reducing the time to diagnosis of psoriasis and psoriatic arthritis
2. Improving treatment of psoriasis and psoriatic arthritis, including access to medical specialists and to the most appropriate medication
3. Assisting people living with psoriatic disease, caregivers and medical professionals in managing the burden of disease

Three documents relating to the unmet needs in psoriasis and psoriatic arthritis were used as a foundation for prioritizing our statement:

- **The Multinational Assessment of Psoriasis and Psoriatic Arthritis (MAPP)** survey published in the *Journal of the American Academy of Dermatology (JAAD)*, March 2014³
- **The Psoriasis White Paper** published in the *Journal of the European Academy of Dermatology and Venereology (JEADV)*, July 2012⁶
- **The Psoriatic Arthritis Forum** proceedings, October 2012

1. Reducing time to diagnosis of psoriasis and psoriatic arthritis

The education of health care providers and people living with psoriasis is essential to ensure early diagnosis of psoriasis and psoriatic arthritis.

Patient organizations can:

- a. Use social media and printed materials to communicate to patients and health care providers (i) the symptoms of psoriatic arthritis, and (ii) how joint pain could indicate psoriatic arthritis in a psoriasis patient
- b. Educate patients on the symptoms of psoriasis and psoriatic arthritis and help them actively and effectively engage in conversations with their health care provider

Other stakeholders can:

- a. Promote the use of standardized and effective diagnostic tools for psoriasis and psoriatic arthritis among health care providers
- b. Initiate training programs and web-based educational tools to help health care providers improve their knowledge of the symptoms of psoriasis and psoriatic arthritis

2. Improving treatment of psoriasis and psoriatic arthritis

Education can improve rates of under- or non-treatment.

Patient organizations can:

- a. Increase the amount of patient materials (specifically for psoriatic arthritis), information and support services that promote self-management, access to care, and treatment options
- b. Educate key stakeholders including policy-makers and health care providers about the benefits that early and effective treatment can bring to the patient

Other stakeholders can:

- a. Establish a multidisciplinary approach (e.g. rheumatologists, dermatologists, pediatricians, primary care providers, cardiologists and psychologists/psychiatrists) to treatment to ensure appropriate management of individual symptoms
- b. Support the continued development of psoriasis and psoriatic arthritis standards of care

3. Assisting patients, caregivers and medical professionals in managing the burden of disease

More support services are urgently needed to help people with psoriasis and psoriatic arthritis cope with the burden of their disease.

Patient organizations can:

- a. Raise awareness to people with psoriasis and psoriatic arthritis of the importance of treatment compliance and the negative ramifications that can result from discontinuing treatment
- b. Conduct further research into the burden of disease (particularly for psoriatic arthritis), and ensure that appropriate coping mechanisms and support systems are in place

Other stakeholders can:

- a. Recognize psoriasis and psoriatic arthritis as distinct serious diseases with many associated co-morbidities warranting more attention globally, e.g. the World Health Organization (WHO) resolution in May 2014 aims to get psoriasis recognized as a serious non-communicable disease*
- b. Recognize and understand the psychosocial impacts of psoriatic disease, and ensure appropriate support services are available, e.g. by policy-makers and health care providers

Get involved

This is the beginning of an urgently needed awareness campaign that seeks to communicate the seriousness of psoriasis and psoriatic arthritis to decision-makers in patient care and to address unmet patient needs on a global scale. We encourage any group or person dedicated to improving peoples' lives with psoriasis and psoriatic arthritis (e.g. additional patient organizations, health care providers, pharmaceutical companies, and policy-makers) to join us.

If you would like further information about the initiative and how to take action please contact:

Where	Society	Email address	Phone number
Global	International Federation of Psoriasis Associations	ifpa@pso.se	+46 8 556 109 18
Europe	European Federation of Psoriasis Associations	secretary@europso.eu	+49 1 722 907 752
US	National Psoriasis Foundation	getinfo@psoriasis.org	1.800.723.9166
Canada	The Arthritis Society	info@arthritis.ca	1.800.321.1433

* For information about the WHO resolution please contact the International Federation of Psoriasis Associations

References:

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2. Kimball AB, Jacobson C, Weiss S, *et al*. The psychosocial burden of psoriasis. *Am J Clin Dermatol*. 2005;6:383–92.
3. Lebwohl MG, Bachelez H, Barker J, *et al*. Patient perspectives in the management of psoriasis: Results from the population-based Multinational Assessment of Psoriasis and Psoriatic Arthritis Survey. *J Am Acad Dermatol*. 2014;70:871-881.
4. Gelfand JM, Troxel AB, Lewis JD, *et al*. The risk of mortality in patients with psoriasis: results from a population-based study. *Archives of Dermatology*. 2007;143:1493–9.
5. Gladman DD, Antoni C, Mease P, *et al*. Psoriatic arthritis: epidemiology, clinical features, course, and outcome. *Ann Rheum Dis*. 2005;64:Suppl.II:ii14–ii17.
6. Augustin M, Alvaro-Gracia JM, Bagot M, *et al*. A framework for improving the quality of care for people with psoriasis. *J Eur Acad Dermatol Venereol*. 2012;26:Suppl.4:1–16.
7. National Psoriasis Foundation. Statistics. Available at: https://www.psoriasis.org/learn_statistics.