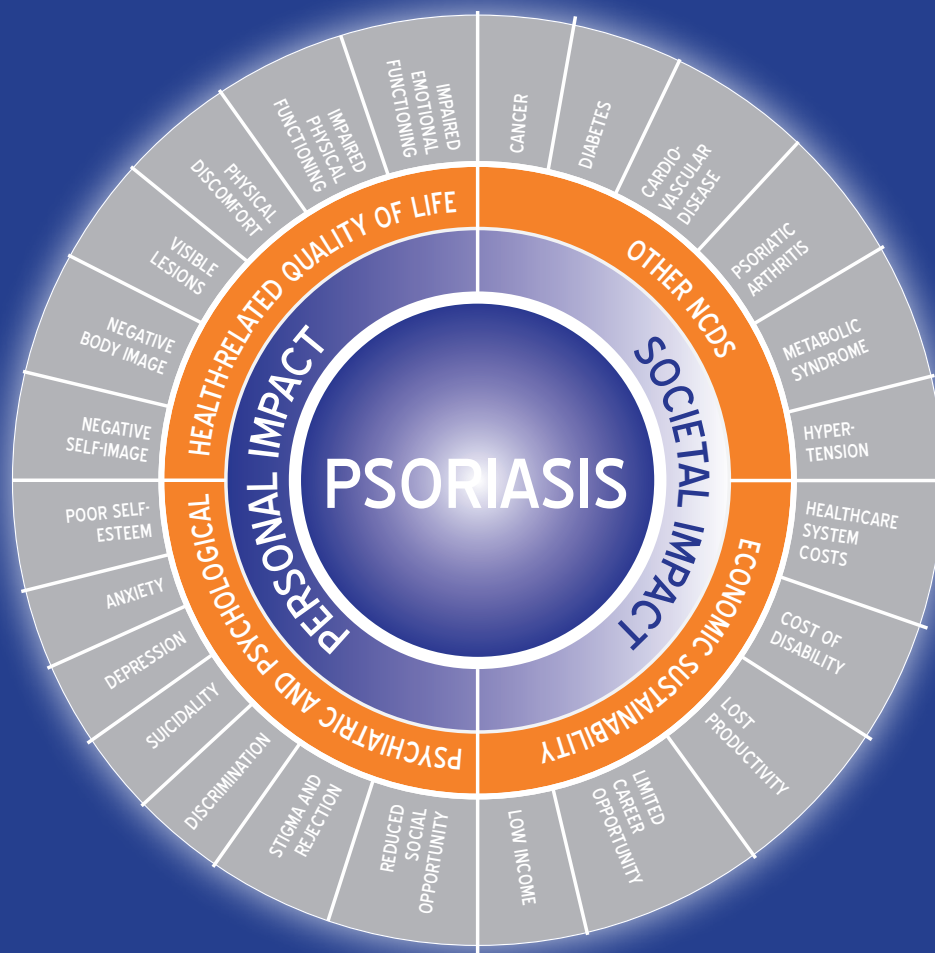




INTERNATIONAL FEDERATION  
OF PSORIASIS ASSOCIATIONS

# PSORIASIS CAN BE DISABLING

but shouldn't be a barrier to full participation in society



An issue brief by the International Federation of  
Psoriasis Associations, IFPA

# PSORIASIS CAN BE DISABLING

but shouldn't be a barrier to full participation in society

## Summary

The International Federation of Psoriasis Associations, IFPA, asks for more understanding of psoriasis as a disability and its impact on individuals and society. This issue brief highlights the different barriers and challenges that people with psoriasis face and calls governments around the world to action. The more than 125 million people suffering from psoriasis should not have to face discrimination, stigma, denied access to health care or fewer economic opportunities due to having psoriasis. It is therefore significant that the international community understands and acknowledges psoriasis as a disability and that governments include psoriasis in their national disability policies and health care plans.

## Psoriasis is a disability but should not be a barrier to participation in society

Confronted by the burden of pain, discomfort, stigma and discrimination, missed opportunities are common among people with psoriasis, due to the exclusion from society or that which is self-imposed.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international agreement that requires governments around the world to uphold the rights of people with disabilities. According to the UNCRPD, persons with disabilities include "those who have long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."<sup>1</sup>

## Psoriasis as a physical disability

Psoriasis is a serious chronic, non-communicable inflammatory disease for which there is no cure. At the 67<sup>th</sup> World Health Assembly, the WHO member states recognized that psoriasis is not only a serious non-communicable disease, but also a disabling one.<sup>2</sup> Painful, itchy and uncomfortable, psoriasis negatively affects most daily activities when using the hands, walking, sitting, and standing for long periods of time, and even disrupts resting and sleeping. Many who have psoriasis endure constant pain from cracking and bleeding lesions, and suffer the humiliation of continuously flaking skin.<sup>3</sup>

Approximately a third of people with psoriasis also suffer from psoriatic arthritis<sup>4</sup>, an inflammatory joint disease that can be extremely painful and severely disabling. It has been shown that people with psoriatic arthritis have similar or worse disability than men older than 75 years of age.<sup>5</sup> Physical impairments hinder individuals in attaining their full potential and limit their opportunities to live their life in the way that fits their own preference.

## Psoriasis as a psychosocial disability

Not only are the physical challenges daunting, people with psoriasis also have to face social barriers, such as stigmatization, discrimination and negative attitudes among the public, creating further hindrances to their full and effective participation in society on an equal basis with others. The stigma and discrimination are generally caused by the physical, highly visible, manifestation of psoriasis on the skin either pushing patients into self-imposed isolation due to embarrassment and shame, or societally imposed isolation, due to the public's misconceptions and fear of contagion.

In a Turkish study, 94.5 percent of the patients with psoriasis regarded psoriasis as a socially troubling disease.<sup>6</sup> In a survey made by the National Psoriasis Foundation, 40 percent reported that they do not receive equal service at various service establishments such as hair salons, public pools and health clubs as those without psoriasis.<sup>7</sup> A survey carried out by the International Federation of Psoriasis Associations and 15 of its national member associations, clearly shows the impact psoriasis has on an individual's life. Of the survey respondents, 65 percent reported discrimination at work, in school and other places<sup>8</sup> and 77 percent had experienced stigmatization.<sup>9</sup>



Severe psoriasis and psoriatic arthritis can make it difficult, or even impossible, to work.

A survey by the Swedish Psoriasis Association reported that one in four believes it is harder to get work if you have psoriasis and that they cannot choose the career they want.<sup>10</sup>

The fear of rejection and humiliation commonly present among people with psoriasis may lead to other psychosocial issues such as anxiety, low self-esteem, depression, intimacy problems, and even thoughts of suicide ideation.<sup>11</sup>

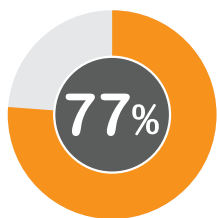
## Psoriasis: challenges and opportunities

Commonly perceived as not being a direct threat to life, psoriasis often takes a back seat to other diseases, even if recent studies show that severe psoriasis not only has a high impact on the quality of life, but also shortens life expectancy.<sup>12</sup> Many people with psoriasis also face barriers to a good quality of life due to treatments that are ineffective or not accessible. Nontreatment and undertreatment are significant problems for people with psoriasis<sup>13</sup> and a recent multinational survey demonstrates that almost 60 percent of people with psoriatic arthritis are not being treated for their joint disease.<sup>14</sup>

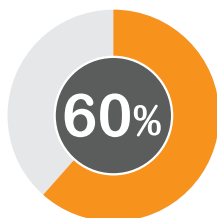
As has been shown, the burden of psoriasis can lead to negative socio-economic impacts, in both the developed and developing world. People with psoriasis are being ostracized not accepted at school and in the community and prevented from working in job positions where people can “see” them or because the employers fear frequent absenteeism or heightened social costs, due to their disease.<sup>15</sup> For society, psoriasis implies a huge economic burden. Data from the National Psoriasis Foundation shows that 92 percent of people with psoriasis surveyed who were unemployed responded that it was due solely to their psoriasis or psoriatic arthritis.<sup>16</sup>

Even with the physical and social challenges and barriers confronting people with psoriasis, they often find themselves excluded in national disability programs. This exacerbates the difficulty for people with psoriasis to have a full and equal participation in society. The UNCRPD requires all member states to provide persons with disabilities with assistive devices and reasonable accommodations as basic human rights to allow them to be fully participative in society.<sup>17</sup> Just as people with disabilities may need a ramp to enable them to access a public facility or specially adapted information to be able to participate in society, people with psoriasis need access to medical treatment to manage their disease and reduce both physical and social challenges and barriers that might otherwise exclude them from equal participation in society.

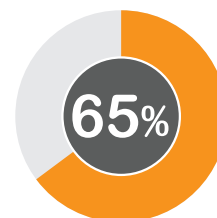
### The daily impact of psoriasis



see their psoriasis as a problem or a significant problem



say that the disease affects their everyday life



have reported discrimination at work, in school and other places

### Calls for action:

The International Federation of Psoriasis Associations, a non-profit organization made up of psoriasis associations from around the world, urges the international community to:

- **Acknowledge** that psoriasis, regardless of its severity, continues to hinder people with the disease from their full and effective participation in society, and that governments, the United Nations agencies and other international organizations include psoriasis and psoriatic arthritis in disability forums and policy;
- **Include** the rights of persons with disabilities in the post-2015 agenda on disability and development;
- **Encourage governments** to integrate psoriasis and psoriatic arthritis in their national health and disability plans;
- **Raise awareness** of the serious nature of psoriasis to help fight stigma and discrimination and remove barriers that hinder people with psoriasis from participating fully and equally in society; and,

**Encourage member states** to initiate mechanisms that will protect people with psoriasis from discrimination, stigmatization and vilification.

## Sources

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Image on page 1 reprinted with the courtesy of Anne Stiernquist, Psoriasisförbundet.

## About IFPA

The International Federation of Psoriasis Associations (IFPA) is a non profit organization made up of psoriasis associations from around the world.

IFPA unites psoriasis associations so that their global campaign for improved medical care, greater public understanding and increased research will improve the lives of people who live with psoriasis and psoriatic arthritis and explore the challenges psoriasis presents to the international psoriasis community.

## Worldwide unity for people living with psoriasis

IFPA gives nonprofit psoriasis associations a global voice to campaign on behalf of people who have psoriasis and psoriatic arthritis. IFPA provides the unity that strengthens everyone's ability to support research that will someday find a cause and a cure for these diseases.

**For more information about IFPA and our activities, please visit  
[www.ifpa-pso.org](http://www.ifpa-pso.org) and [www.worldpsoriasisday.com](http://www.worldpsoriasisday.com).**



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