



INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

PSORIASIS IS A SERIOUS DISEASE DESERVING GLOBAL ATTENTION

A report by the International Federation of
Psoriasis Associations



EXECUTIVE SUMMARY

This paper seeks to inform the United Nations and other international organizations, Governments, Ministers of Health, donor countries and global philanthropic institutions, civil society, insurers/payers, health workers and psoriasis patients and their families that psoriasis is a serious inflammatory, noncommunicable autoimmune disease which carries severe physical, mental and socioeconomic burdens on over 125 million people worldwide.

THE BURDEN OF PSORIASIS

Psoriasis is not a genuine “skin problem.” It is a chronic, noncommunicable inflammatory disease which is often mistaken for contagious diseases, such as leprosy, syphilis and even HIV/AIDS. People who suffer from psoriasis can be male or female, of any race or age, and across all socioeconomic backgrounds.

Psoriasis has an overwhelming impact on the patient. Recent studies (included in this report) have shown that people with psoriasis are at an increased risk for other inflammatory diseases, such as psoriatic arthritis, cardiovascular disease, diabetes, Crohn’s disease, hypertension, irritable bowel syndrome, lupus, and obesity, and can result in early death. Mounting data show that it is critical that the inflammatory state of psoriasis be managed and diagnosed early.

Physically, psoriasis is uncomfortable, itchy and painful, with inflamed, cracked and bleeding skin lesions or pain from joints and other internal organs. Psoriasis patients are embarrassed, humiliated, and tend to hide their skin from the critical public. The psychological impacts are feelings of self-consciousness, frustration and shame, often leading to depression and alcoholism, and causing severe mental trauma and thoughts of suicide. Economically, in the U.S. alone, impact is estimated that Americans with psoriasis lose approximately 56 million hours of work and spend \$2 to \$3 billion to treat the disease every year.

Developing countries with less resources and health-care have an even greater economic burden due to the lack of access to reliable diagnosis or risk for misdiagnosis of the disease, stigmatization and discrimination, and little-to-no access to affective treatments. People with psoriasis are often ostracized and barred from positions in the job market where people can “see” them, linking psoriasis with contagious diseases and/or low income and a poor quality of life. The humanitarian, social and economic costs are immense.

The International Federation of Psoriasis Associations (IFPA) unites national psoriasis organizations in a global campaign for improved medical care, greater public understanding and increased research, and conducts programs like World Psoriasis Day. World Psoriasis Day focuses on awareness-raising activities, media-attracting activities and advocacy to health ministries. Examples of activities reported from 2010 include a psoriasis conference tour in Spain, a road show with the theme “Will you hold my hand” in Singapore, a photo project on youths with psoriasis in Norway and a “Hug-me, I’m not Contagious” campaign in the Philippines. World Psoriasis Day was celebrated on every inhabited continent in 2010.

Despite the efforts of IFPA and national patient organizations, psoriasis continues to be a serious disease worldwide. Patient organizations alone do not have the scope to mobilize significant support and attention. Psoriasis continues to be a problem – first because there is no known cure – but also because there is a severe lack of recognition and awareness, a lack of correct diagnosis, and a lack of understanding the nature of the disease – both by the patient and the public. More than 125 million people need the help and support of all stakeholders, including the World Health Organization (WHO), the world’s leading international organization that has the power and influence to make a tremendous and positive impact in the lives of those suffering with psoriasis.

Together, all stakeholders can help psoriasis patients to recognize their own disease and seek treatment, will enable the public to realize psoriasis is not contagious and halt discriminating behavior, and will facilitate the medical community to properly diagnose and treat the disease. In small but effective steps, this policy will help lift the heavy burden of psoriasis worldwide and allow for a better quality of life.

INTRODUCTION:

PSORIASIS IS A SERIOUS DISEASE DESERVING GLOBAL ATTENTION

There are **more than 125 million people**, or nearly three percent of the world's population, men, women, and children, even newborn babies, who endure the symptoms of psoriasis [pronounced sore-EYE-ah-sis].¹ It is estimated that at least 10 percent of psoriasis sufferers have a severe form that causes disability and exclusion from a normal life. Many tolerate constant pain from cracking and bleeding lesions, and bear the humiliation and discomfort of continually flaking skin.

Although there are numerous treatments for psoriasis, many still face a very poor quality of life because the treatments do not work, work poorly, are too expensive, or are not available to them. Especially in developing countries, people with psoriasis have to face severe problems with stigmatisation, discrimination and negative attitudes in general among the public, and often bear the brunt of public rejection. Many people with psoriasis isolate themselves because of such a deep sense of shame, embarrassment and low self-esteem.

It is often wrongly presumed that psoriasis sufferers are contagious or have a transmittable disease. The general public confuses psoriasis with un-cleanliness, leprosy, syphilis and sometimes HIV/AIDS.² People with psoriasis can be ostracized at school and in the community, and prevented from working. The socio-economic impacts, in both the developed and developing world, place severe strains on the individual and the household. Yet, much of the world's population finds psoriasis a trivial matter requiring little understanding or sympathy. Because the disease is so difficult and costly to treat (when correctly identified), some dermatologists do not even want to see people who have psoriasis. Psoriasis takes a back seat to other more chronic and more deadly diseases.

However, this viewpoint must change. Recent studies have shown that people with psoriasis are at an increased risk for other inflammatory diseases, such as arthritis, heart disease/hypertension, diabetes, Crohn's Disease, lupus, irritable bowel syndrome, depression, and obesity. Between 6% and 42% of people with psoriasis, depending on the population studied, also get psoriatic (sore-ee-attic) arthritis, which causes pain, stiffness and swelling in and around the joints, and erosive or deformed joint damage.³ This type of arthritis can be disabling and most often affects the neck, hands, feet, wrists, ankles and lower back.

Professor Jörg C. Prinz, President of the IFPA Scientific Committee for the 2nd World Psoriasis and Psoriasis Arthritis Conference 2009 and Professor of Dermatology at the University of Munich, states that "due to the early onset of the disease psoriasis patients are exposed to lifelong suffering."⁴ Professor Prinz points out that psoriasis is a disease, which according to the World Health Organization definition of health, is associated with major social, physical and mental restrictions and thus fulfils the criteria for the absence of health much more than many other severe medical disorders. According to the definition of disease burden, psoriasis patients are facing many years of healthy life lost by virtue of being in states of poor health and disability, and they lose a number of years of life due to premature death resulting from psoriasis and its co-morbidities.⁵

Drs. Lotus Mallbris, Olof Akre, Fredrik Granath, Li Yin, Bernt Lindelöf, Anders Ekbom, and Mona Ståhle compared, using the Swedish Inpatient Registry, inpatients in general with psoriasis inpatients, and found that psoriasis patients, admitted to the hospital with severe psoriasis, had a shorter lifespan due to cardiovascular disease:

The overall risk among inpatients admitted at least once was increased by 50% (SMR 1.52; 95% CI: 1.44–1.60). The excess risk increased with increasing number of hospital admissions (p for trend <0.001). Cardiovascular mortality was higher among those admitted at younger ages (p for trend <0.001; SMR 2.62, 95% CI: 1.91–3.49, for patients aged 20 to 39 years at first admission). Young age at first admission appeared to further increase the risk among those who were repeatedly

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Severe psoriasis...is associated with increased risk for cardiovascular death

admitted. We conclude that a diagnosis of psoriasis per se does not appear to increase the risk for cardiovascular mortality. Severe psoriasis, however, here measured as repeated admissions, and early age at first admission, is associated with increased risk for cardiovascular death.⁶

An alarming study released in December 2007 also shows a link between severe psoriasis and an increased risk of early death.⁷ Dr. Bruce Strober, Department of Dermatology at New York University School of Medicine, states:

Mounting data suggest that psoriasis is a component of an inflammatory state that nurtures significant co-morbidities. It is likely that in some patients both psoriasis and obesity are co-dependent manifestations of an underlying dysfunctional pathophysiologic state. It is important that the overall management of psoriasis is significantly improved to ensure that patients are diagnosed early, appropriately treated and regularly monitored for signs of co-morbidity.⁸

Data collected by Dr. Wayne P. Gulliver, New Lab Clinical Research Inc. St John's, Newfoundland, Canada, further highlights the severity of psoriasis:

In our study of psoriasis patients from Newfoundland and Labrador populations we have confirmed increased rates of arthritis, heart disease, diabetes and hypertension. Along with the increased risk of co-morbidity we found that 68% (2220 of 3228 patients) required hospitalization at least once during the past 10 years. Of the patients hospitalized 56% had an associated cardiovascular co-morbidity and 18% had diabetes. This compares to approximately 4% prevalence of these common complex diseases in the general population. We also found that in our psoriasis population they were more likely to die of cardiovascular disease than the general population (44% versus 36%). On average the age of mortality for psoriasis patients was approximately 10 years less than the general population (68.8 years versus 77.4 years for males, 72.2 years versus 82.5 years for females).⁹

Dr. Gulliver's data includes an alarming statement of mortality rates of patients who have severe psoriasis at a young age: "In patients whose age of onset was less than 25 years the mean age of mortality was also almost 20 years less than the general population (60 years versus 80 years)."

Patients suffering from psoriasis critically need access to regular high quality treatment and care, and actions should be taken to encourage awareness and early diagnosis, as well as helping them with discrimination and mental health.



WHAT IS AND WHAT CAUSES PSORIASIS

Psoriasis is an immune-mediated, genetic disease manifesting in the skin and/or the joints.¹⁰ According to the U.S. National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a division of the National Institutes of Health (NIH):

Psoriasis is driven by the immune system, especially involving a type of white blood cell called a T cell. Normally, T cells help protect the body against infection and disease. In the case of psoriasis, T cells are put into action by mistake and become so active that they trigger other immune responses, which lead to inflammation and to rapid turnover of skin cells.¹¹

In *Plaque* psoriasis, the most common type, patches of skin called “lesions” or “plaques” become red and inflamed, and are covered by a white scale. Psoriasis can be limited to a few lesions or can involve moderate to large areas of skin and scalp. The severity of psoriasis can vary from person to person; however, for most people, psoriasis tends to be mild.¹²

Other forms of psoriasis include:

- *Guttate* psoriasis, which is also fairly common, is characterized by red, small, dot-like lesions covered with silvery white scale;
- *Pustular* psoriasis has blister-like lesions of fluid, which is not infectious, and intense scaling. It can appear anywhere on the body, but often it appears on the palms of the hands and the soles of the feet.
- *Inverse* psoriasis has very red lesions with little or no scales and appears in the skin folds, such as the arm pits, creases in the groin and under the breasts.¹³
- *Erythrodermic* psoriasis is a particularly inflammatory form of psoriasis that often affects most of the body surface. It is characterized by periodic, widespread, fiery redness of the skin, and erythema (reddening) and exfoliation (shedding) of the skin are often accompanied by severe itching and pain. Patients having an erythrodermic psoriasis flare must seek medical attention and be hospitalized immediately because protein and fluid loss can lead to severe illness. Infection, pneumonia and congestive heart failure brought on by erythrodermic psoriasis can be life threatening.¹⁴

WHO GETS PSORIASIS?

Psoriasis affects more than 125 million or nearly three percent of the world’s population. It can develop in males or females of any race or age, across all socioeconomic groups. It often appears between the ages of 15 and 35, although it can strike at any age including infants and the elderly.¹⁵

According to the NIH, as many as 7,5 million, 1 in 49, or 2,02%, of Americans have psoriasis. Statistics for other countries are unknown, but are estimated to be similar to the diverse population of the United States.

HOW IS PSORIASIS TREATED?

Psoriasis has no known cure, but many different therapies can reduce, or nearly stop, their symptoms, although no single treatment works for everyone. Many psoriasis patients report using various treatments at the same time.

The most common treatment for psoriasis are topicals, which are rubbed into the skin, and other over-the-counter products such as various moisturizers and Vaseline. Moisturizers are an important part of caring for psoriasis lesions and can be any kind of cream, lotion or ointment made to provide relief from dry, itchy skin. Prescription topicals include Dovonex/ Daivonex (a form of Vitamin D), steroid creams and ointments of various potencies (to slow the growth of skin cells and decrease inflammation), coal tar (used to reduce scaling, inflammation, and itching), Dithranol or Anthralin, and Tazorac (a form of Vitamin A). Often times the psoriatic plaques grow so quickly that they become very thick and the topical treatments cannot penetrate the skin. The patient must soak in a tub of warm water to soften and loosen the plaques, and then apply a topical medication. Depending of the severity, it is not uncommon that it can take up to two hours every day to care for psoriasis, including applying topical solutions or ointment to each psoriasis plaque every day and soaking in soothing medicated baths. This type of therapy often helps tame the inflammation and thin the plaques, but with chronic psoriasis, they rarely disappear.

Sunlight and Phototherapy (ultraviolet light or UVA UVB) is used by patients with moderate-to-severe psoriasis and is often combined with topical treatments. UVA and UVB rays, found in natural sunlight which are reproduced in phototherapy units, penetrate the skin and slow the abnormally rapid growth of skin cells associated with psoriasis. Phototherapy treatment involves exposing the skin to an artificial UVA or narrow band UVB light source for a set length of time on a regular schedule, either under a doctor's direction in a medical setting or with a home unit purchased with a doctor's prescription. Treatment normally takes between 20 and 30 exposures over a 3-to-4 month period to achieve partial clearing of plaques. The clearing may last a few weeks or months, and then the psoriasis will reoccur, prompting the light-therapy cycle again. Laser treatment is also used to deliver a narrow beam of ultraviolet light to smaller areas of skin.

Systemic treatments, such as Methotrexate and Cyclosporine, are prescription drugs used to treat severe psoriasis, and are given in the form of a pill or an injection. These treatments suppress the immune system, slow the growth of skin cells, and can be highly effective in reducing psoriasis and the painful symptoms of psoriatic arthritis. Methotrexate, used to treatment psoriasis since the 1950s, is inexpensive and is therefore available to people in developing countries. Systemic treatments can have serious potential risks on other parts of the body, including the liver (Methotrexate) and kidneys (Cyclosporine), and patients commonly report nausea, hair loss and flu-like symptoms. Oral retinoids, like Acitretin or Soriatane, are manufactured drugs related to Vitamin A that can slow down the growth of skin cells. However, many psoriasis patients worldwide are on systemic drugs, including Methotrexate, and many have had a good life for many years.

Biologics are the newest class of treatments for moderate-to-severe psoriasis and are also used to treat psoriatic arthritis. The Biologics are made from proteins produced by live human and animal cells. Biologics, such as Enbrel, Stelara and Humira, are given by injection, and Remicade (also used to treat Crohn's Disease) is administered intravenously. These drugs block parts of the immune-system process that drives psoriasis and arthritis by targeting types of



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immune cells, such as T cells or interleukines.¹⁶ The Biologics carry the risk of serious side effects, the most common being risk of infection. Although thought to be safe, the new drugs have been in use for less than 10 years and, in the long run, the effects of regulating the immune system is unknown.

According to the National Psoriasis Foundation, in 2010 there were 34 drugs in the psoriasis-treatment pipeline in various clinical stages of the approval process.¹⁷ Many of the new drugs are Biologics and inhibit the immune system from over-reacting or over-producing certain cells. Each Biologic product costs on average about \$800 million U.S. dollars for pharmaceutical companies to produce, from conception-to-the-shelf, and once released to the public, cost on average around \$11,000 to \$18,000 a year, depending on the dose and the drug.¹⁸ The extremely high cost of biologic medications for the national social security / health systems

or the patients is one of the reasons why psoriasis is under-treated, yet many of the new treatments are biologic.

Despite the dearth of medications available to treat psoriasis, a study by the National Psoriasis Foundation and Amgen reported that “nearly 40% of the 1,142 patients surveyed with chronic moderate or severe psoriasis are not currently receiving any treatment,” and more than half of the patients are not be treated as recommended by American Academy of Dermatology guidelines.¹⁹ 73% were only using topical treatments. Factors for lack or low treatment are health insurance issues, fear of the biologics (because the immune system is comprised), increased risk of side effects from the systemic and biologics, very high cost, low efficacy of the systemic, and lack of access to health care.

Globally, not all of these medicines have the same brand name or have been approved in all countries, and many developing countries do not have access to the more expensive treatments, such as the biologics and cortisone creams.²⁰ Dr. Hoseah Waweru, Dermatologist and Vice-President of the International Federation of Psoriasis Associations, reports that in Kenya, the only available treatment for psoriasis is coal tar, Dithranol and Methotrexate, and getting more effective therapies, like the Biologics, is impossible.²¹

EXAMPLES OF TREATMENTS

TOPICALS

- Moisturizers
- Steroid creams
- Ointments
- Coal tar
- Vitamin A or D creams

PHOTOTHERAPY

- Sunlight
- Artificial UVA
- Narrow band UVB
- Laser treatment

SYSTEMIC

- Methotrexate
- Cyclosporine
- Retinoids

BIOLOGICS

- Enbrel
- Stelara
- Humira
- Remicade

WHAT IS THE IMPACT OF PSORIASIS?

PHYSICAL IMPACT

Physically, psoriasis is uncomfortable and painful. Wearing certain fabrics against the skin can be irritating and hurt. Psoriasis plaques can get caught on rough fabric fibers and can rip off, causing oozing and bleeding. Perspiration can cause the plaques and open wounds to burn, becoming more irritated; prompting the immune system to build-up more skin cells. Open wounds are also susceptible to infection. Psoriasis patients tend to wear loose clothing and avoid activities that cause perspiration. Due to embarrassment, psoriasis patients attempt to completely cover their skin and many report not wearing shorts or short-sleeved tops for 10, 20, even 40 years.

Psoriasis can cause extreme itching, but psoriasis patients are told not to scratch because of possible dirt or bacteria under the fingernail. Scratching can pull off the psoriasis scale, cause bleeding, and injure the underlying skin, leading to the “Koebner phenomenon,” which actually causes the psoriasis to worsen.

Psoriasis can negatively impact most daily activities, such as using the hands, walking, sitting and standing for long periods of time, and interferes with sexual activity.²² Itching and pain interferes with periods of rest and sleeping. Embarrassment from psoriasis interferes with socializing, particularly activities associated with being physically active. An Irish study of psoriasis patients report that 40% avoid playing sports and 72% avoid swimming.²³



...psoriasis patients are twice as likely to have thoughts of suicide, compared with others who suffer from chronic diseases

PSYCHOLOGICAL IMPACT

A National Psoriasis Foundation Mental Health Issue Brief estimated that as many as 52% of psoriasis patients report clinically significant psychiatric symptoms and are likely to receive a psychiatric diagnosis. Approximately one-half of patients report strong feelings of anger, frustration, self-consciousness and embarrassment. Contributing to feelings of shame and isolation, people with psoriasis experience social discrimination and humiliation (refusal of service, admittance to the gym, to the pool, etc).²⁴ People suffering with psoriasis in the developing world are often ostracized because they are presumed to have HIV/AIDS, leprosy or syphilis, and this discrimination can cause severe psychological trauma.

The European Federation of Psoriasis Patient Associations (EUROPSO) undertook a Europe-wide survey to examine the quality of life and patients' perspectives on treatment and their disease and found that of the 17,990 respondents that had psoriasis,

The greatest impact was on activities of daily living, especially affecting clothing choice, bathing routine and sporting activities. Overall, 77% replied that psoriasis was a problem or a significant problem. While patients were satisfied with the information and care from their dermatologist (40% highly satisfied), available treatment options were less satisfactory, with over 70% reporting only low to moderate satisfaction.²⁵

Also of concern is the finding that psoriasis patients are twice as likely to have thoughts of suicide, compared with others who suffer from chronic diseases. A study done by the U.S. University of Michigan Medical School reports that of the 217 psoriasis patients in the study, 9.7% of patients wish to be dead, and 5.5% reported active suicidal ideation at the time of the study. The death wish and suicidal ideation were associated with higher depression scores and higher patient self-ratings of psoriasis severity.²⁶ A surveyed conducted

by the Royal College of Physicians and the British Association of Dermatologists reveal that as many as one in 10 patients being treated in UK dermatology units are "so distressed by their condition that they consider suicide."²⁷

SOCIOECONOMIC IMPACT

A survey completed by the Swedish Psoriasis Association reports that psoriasis limits employment opportunities and imposes a serious barrier in the job market. One in four people believe that it is harder to get work if you have psoriasis, and the same say they cannot choose the work they want, feeling discriminated against. High rates of absence through psoriasis-related illness are also reported, and people with psoriatic arthritis often work part-time because of it.²⁸

In the United States, severe psoriasis is associated with lower income: Dr. Liz Horn states "Psoriasis is a serious disease that can significantly impact a patient's life by interfering with everyday activities, including work,"²⁹ and data from a National Psoriasis Foundation survey panel report shows that there is a relationship between psoriasis severity and household income. According to survey findings, data showed that "21 percent of patients with severe psoriasis (n-179) had a low household income (<\$30,000), compared to 13 percent for patients with mild psoriasis (n-180)."³⁰ Patients surveyed reported that psoriasis negatively affected their job, directly due to their health, and Dr. Mark Lebwohl, President of the Foundation Medical Board, states that psoriasis can have a "profound negative impact of a person's ability to function."³¹



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



WHY DOES PSORIASIS CONTINUE?

Psoriasis continues because there is no known cure.

Psoriasis continues because of the lack of education, in both health-care providers and psoriasis patients, on the nature of the disease. As previously stated, psoriasis is still mistaken for numerous other diseases, including leprosy, or as a cosmetic topical skin rash.

Psoriasis continues because of the lack of interest and of funding for genetic and clinical research into the causes of and the cure for psoriasis and other inflammatory noncommunicable diseases (NCDs).

Psoriasis continues because of the lack of dermatological care, especially in least-developed countries where the majority of health-related aid goes to more deadly communicable diseases.

Psoriasis continues because stigmatization, embarrassment and discrimination force psoriasis patients to hide their skin and isolate themselves from the general public, often resulting in severe psychological and poor socio-economic conditions.

Psoriasis continues because, when diagnosed properly, it is under-treated and dismissed as a psoriasis health concern. New medications that significantly reduce psoriasis and other inflammatory diseases are often not available, are very expensive, and not covered by all health care plans. Often when coverage is provided, there are stipulations that a psoriasis patient must try and fail certain medications first, like topicals and systemics, and sometimes this can take over a year or more.

Psoriasis continues because there are barriers to policies that could greatly change the impact of psoriasis. Politically, there is a general lack of attention to psoriasis because psoriasis, if it is recognized and properly diagnosed, is considered a “cosmetic” or skin disease, not a disease of the immune system that has serious implications and causes severe physical, mental and socio-economic disabilities. If psoriasis is continuously looked at as a cosmetic disease or isn’t even identified as a disease, how can policies be written in support of psoriasis patients?

PSORIASIS CONTINUES TO BE UNDER-RECOGNIZED AND UNDER-TREATED

Despite the efforts of IFPA and national psoriasis associations, psoriasis continues to be a serious disease worldwide affecting over 125 million people, with no known cure. The lack of a broad reach from national efforts and World Psoriasis Day still finds that the general public is not aware of what psoriasis is, and continues to regard it as a cosmetic or communicable skin disease. Insurers, employers and the public incorrectly consider psoriasis to be a superficial problem.³²

Psoriasis patients are under-educated about their disease, under-treated, and, in general, lack access to affective effective treatments. Because the majority of patients do not understand the nature of psoriasis and they are unaware that they are at an elevated risk for other chronic and serious health conditions. The physical, mental and socioeconomic impact of psoriasis is still severe.

NEEDED CHANGES

What must change is individual, local, national, and global awareness that:

- psoriasis is a serious and chronic immune-related disease
- psoriasis is not communicable, is not HIV/AIDs, leprosy or syphilis
- psoriasis can be treated effectively

Medical practitioners must be informed so that they can properly diagnose and treat psoriasis.

Universal access to effective and affordable treatments for psoriasis and psoriatic arthritis must be made available, especially in least- and middle-developed countries.

There must be awareness that if psoriasis is not treated effectively and early, the inflammatory process can lead to serious co-morbidities, such as an increase in cardiovascular disease, arthritis, depression, diabetes, alcoholism, obesity, metabolic syndrome, Crohn's Disease, and early death.

HOW ALL STAKEHOLDERS CAN HELP PSORIASIS PATIENTS: A CALL TO ACTION

UNITED NATION AGENCIES

- Make NCDs central to the global health and development goals and targets that succeed the Millennium Development Goals (MDGs) in 2015
- Provide leadership and raise awareness about the seriousness of psoriasis and the high risk of inflammatory co-morbidities by developing messaging to support psoriasis awareness and education and by including psoriasis in forums regarding chronic, noncommunicable diseases
- Acknowledge that moderate-to-severe psoriasis/psoriatic arthritis can be disabling and psoriatics are often socially excluded and ostracized by society. UN agencies can include psoriasis/psoriatic arthritis in disability forums and policy

GOVERNMENT AND MINISTERS OF HEALTH

- Implement recommendations for governments in the WHO 2008-2013 Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable Diseases (NCDs) .
- Include psoriasis and psoriatic arthritis within national health plans to control and prevent chronic disease.
- Establish or strengthen national policies and health development plans for the treatment and control of psoriasis and NCDs, enabling them to respond to the health-care needs of people with psoriasis and co-morbidities, which have a large socio-economic impact.
- Engage in the UN Summit on NCDs in September 2011 and implement outcomes.

DONOR COUNTRIES AND GLOBAL PHILANTHROPIC INSTITUTIONS

- Provide funding to low- and middle-income countries for NCDs, including psoriasis and diagnosis and treatment
- Support integration of NCDs into health system
- Provide funding for research into the links between psoriasis and comorbid metabolic disorders in particular diabetes, heart diseases, respiratory diseases and cancers

CIVIL SOCIETY

- Develop new psoriasis patient-led organizations to educate psoriasis patients and the public about the disease and World Psoriasis Day, and advocate for psoriasis and NCD health policy in their country or region;
- Influence decision-makers in government and the private sector to provide valuable resources to chronic disease programmes
- Join with related chronic disease organizations and unite for prevention and control of chronic disease

INSURERS/PAYERS

- Provide low-cost coverage for psoriasis treatments, such as Methotrexate, coal-tar and corticosteroid topicals and phototherapy.
- Include biologic treatments for moderate and severe psoriasis and psoriatic arthritis.

HEALTH WORKERS

- Diagnose and seek treatment options relative to availability into their area/region/country, including early screening for co-morbid conditions
- Seek to understand the cause of psoriasis and other inflammatory diseases, and seek a cure
- Take a holistic, life-course approach to understanding the impacts of psoriasis on the patient, including psychosocial challenges and healthy lifestyles options

RESEARCHERS

- Given the significant and growing link between psoriasis and myriad other disabling, life-threatening and costly chronic condition, conduct research into psoriasis and the connections with other comorbid conditions.

PHARMACEUTICAL INDUSTRY

- Develop effective psoriasis treatments and less expensive options for a broader patient population
- Support least-developed countries to gain access to new, safe and effective treatments

MASS MEDIA

- Disseminate information aimed at increasing public awareness of the physical, psychosocial and socioeconomic impacts psoriasis and psoriatic arthritis, the association with comorbid inflammatory diseases (NCDs), as well as the importance of leading a healthy lifestyle.

PSORIASIS PATIENTS AND CAREGIVERS

- Seek support, information and treatment of psoriasis and lead a healthier lifestyle, both physically and emotionally, which will contribute to feeling more comfortable in their own skin and in society.
- Take action! Become an advocate for psoriasis in your country. Support psoriasis patient organizations, spread awareness about psoriasis and impacts of the diseases, and participate in World Psoriasis Day campaigns

CONCLUSION

All stakeholders, including United Nations agencies, Governments, Ministers of Health, donor countries and global philanthropic institutions, civil society, insurers/payers, health workers and mass media have the power to make a tremendous impact on the lives of people living with and suffering from psoriasis.



REFERENCES

- ¹ National Psoriasis Foundation, “What is Psoriasis?” www.psoriasis.org
- ² Ettarp, Lars. President of the International Federation of Psoriasis Associations, Stockholm, June 2005.
- ³ Pariser, David M., MD; Jerry Bagel, MD; Joel M. Gelfand, MD, MSCE; Neil J. Korman, MD, PhD; Christopher T. Ritchlin, MD; Bruce E. Strober, MD, PhD; Abby S. Van Voorhees, MD; Melodie Young, MSN, RN, ANP; Sheila Rittenberg, BA; Mark G. Lebwohl, MD; Elizabeth J. Horn, PhD. “National Psoriasis Foundation Clinical Consensus on Disease Severity”. *ARCH DERMATOL.* Vol. 143, Feb. 2007.
- ⁴ Prinz, Professor Jörg C. Statement about psoriasis to the International Federation of Psoriasis Associations. 13 October 2009.
- ⁵ Prinz, Professor Jörg C. Statement about psoriasis to the International Federation of Psoriasis Associations. 13 October 2009.
- ⁶ Mallbris, Lotus, Olof Akre, Fredrik Granath, Li Yin, Bernt Lindelöf, Anders Ekbom and Mona Ståhle, “Increased risk for cardiovascular mortality in psoriasis inpatients but not in outpatients.” *European Journal of Epidemiology*, Vol. 19, No. 3/March 2004 (Online). <http://www.springerlink.com/content/j663212003m26732/>, August 4, 2008.
- ⁷ Gelfand, Joel M., MD, MSCE; Andrea B. Troxel, ScD; James D. Lewis, MD, MSCE; Shanu Kohli Kurd, MHS; Daniel B. Shin, BA; Xingmei Wang, MS; David J. Margolis, MD, PhD; Brian L. Strom, MD, MPH. “The Risk of Mortality in Patients with Psoriasis.” *ARCH DERMATOL.* Vol 143 (NO. 12), December 2007 www.arch-dermatol.com
- ⁸ International Psoriasis Council. “Psoriasis: Skin Symptoms may be Just the Tip of the Iceberg.” *PRNewswire*, New York, 10/24/06.
- ⁹ Gulliver, Wayne P. Abstract: “Long-term Prognosis of Psoriasis. Serono Symposia International Foundation Conference on: Treating Psoriasis as a Chronic Inflammatory Systemic Disease.” Athens, Greece. 29 February to 02 March 2008. Final Program PDF, p. 22-23.
- ¹⁰ National Psoriasis Foundation, www.psoriasis.org
- ¹¹ National Institutes of Arthritis and Musculoskeletal and Skin Diseases. “What Causes Psoriasis?” 1-25-08. http://www.niams.nih.gov/Health_Info/Psoriasis/default.asp
- ¹² National Psoriasis Foundation. “What is Psoriasis?” www.psoriasis.org.
- ¹³ International Federation of Psoriasis Associations, www.ifpa-pso.org.
- ¹⁴ National Psoriasis Foundation, www.psoriasis.org.
- ¹⁵ *Ibid.*
- ¹⁶ National Psoriasis Foundation, An Overview of Psoriasis and Psoriatic Arthritis. Jan. 2008, p. 17.
- ¹⁷ “Research Pipeline.” National Psoriasis Foundation. http://www.psoriasis.org/netcommunity/treating_psoriasis, Jan. 2011.
- ¹⁸ Morrow, Thomas, M.D. “Cost-Effective Psoriasis Treatment May Demand Creative Coverage Rules; Managed Care, May 2006. <http://www.natbiocorp.com/pdfs/managed-care-May06.pdf>
- ¹⁹ National Psoriasis Foundation. “Survey indicates people with chronic moderate to severe plaque psoriasis may be under-treated.” http://www.psoriasis.org/news/press/2007/20070202_survey.php.
- ²⁰ International Federation of Psoriasis Associations. “Treatment-Psoriasis.” www.ifpa-pso.org.
- ²¹ Waweru, Hoseah. Interview of Feb. 2, 2008.
- ²² Horn, Elizabeth J., PhD, and Jennifer C. Cather, MD. “Psoriasis Affects Daily Activities.” National Psoriasis Foundation Survey Panels, 2007.
- ²³ “Image Matters.” Psoriasis. Media Planet, October 2007, pg. 5.
- ²⁴ National Psoriasis Foundation. “Psoriasis and Mental Health Issue Brief” February 2007
- ²⁵ L. Dubertret, L.; U. Mrowietz; A. Ranki; P.C.M. van de Kerkhof; S. Chimenti; T. Lotti; G. Schäfer “European Patient Perspectives on the Impact of Psoriasis: the EUROPSO Patient Membership Survey”. *The British Journal of Dermatology*, Vol. 155 Issue 4, Pages 729-736, <http://www3.interscience.wiley.com/journal/118568777/abstract>. August. 4, 2008
- ²⁶ Gupta, Madhulika A, M.D., F.R.C.P.; Aditya K. Gupta, M.D., F.R.C.P.; Sueann Kirkby, B.S.N., and Charles N. Ellis, M.D., University of Michigan Medical School, Ann Arbor, Michigan. “Suicidal Ideation in Psoriasis.” *International Journal of Dermatology*, Vol. 32, March 1993.

²⁷ “NHS psoriasis care ‘inconsistent.’ BBC News. 19 Feb 2008. <http://newsvote.bbc.co.uk>

²⁸ “Summary of the Swedish Psoriasis Association’s 2006 Membership Survey.” IFPA Newsletter, Jan/Feb 2007, Vol. 12, No 1.

²⁹ “Survey indicates people with chronic moderate to severe plaque psoriasis may be under-treated.” National Psoriasis Foundation, http://www.psoriasis.org/news/press/2007/20070202_survey.php.

³⁰ “Survey indicates people with chronic moderate to severe plaque psoriasis may be under-treated.” National Psoriasis Foundation, http://www.psoriasis.org/news/press/2007/20070202_survey.php.

³¹ “Survey indicates people with chronic moderate to severe plaque psoriasis may be under-treated.” National Psoriasis Foundation, http://www.psoriasis.org/news/press/2007/20070202_survey.php.

³² National Psoriasis Foundation: Advocacy: Access to Care Issue Brief, February 2007. 2/7/08. http://www.psoriasis.org/files/pdfs/advocacy/chd2007/200702_access_issue_brief.pdf

³³ World Health Organization. 2008-2013 Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable Diseases. World Health Organization. Geneva, 2008.

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**INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS**

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.

IFPA Vision

A world without human suffering from psoriasis

IFPA Mission

To be the unifying global voice of all psoriasis associations, supporting strengthening and promoting their cause at an international level

**For more information about IFPA and our activities, please visit
www.ifpa-pso.org and www.worldpsoriasisday.com.**

