IFPA
FORUM
ASIA 2023

Speaking up for psoriatic disease in Asia

Amplifying the voices of people living with psoriatic disease in Asia

BRIEFING BOOK July 2023

This briefing book aims to promote regional action and collaboration to improve the lives of people with psoriatic disease in Asia.

IFPA

PsorAsia
IFPA Region Asia

In this briefing document, "Asia" refers to the World Health Organization (WHO) South-East Asia and Western Pacific regions. The WHO South-East Asia region comprises 11 United Nations Member States and represents more than 25% of the global population. Meanwhile, the WHO Western Pacific region includes 37 Member States and is home to approximately 1.9 billion individuals.

Contents

IFPA FORUM

The IFPA Forum provides a platform for stakeholders in the psoriatic disease community to collaborate, share knowledge and tackle the challenges faced by people living with psoriatic disease. By fostering dialogues, we strive to drive policy and increase awareness, ultimately reaching a broader audience to improve the well-being of those affected by psoriatic disease.

Recently, IFPA has expanded its efforts by organizing regional forums, with the IFPA Asia Forum being the second forum to take place. These regional forums provide an opportunity for stakeholders in specific regions to come together and discuss the unique challenges faced by people with psoriatic disease in those areas. In 2022, a regional forum was held in Europe, which brought together experts and advocates from the region to collaborate and address the challenges faced by people living with psoriatic disease in Europe.

LEARN MORE about the IFPA Forum and the outcome from IFPA Forum Europe 2022

IFPA has facilitated the development of this briefing book.

Speaking up with one voice

The IFPA Forum in Asia 2023 represents a unique opportunity for the psoriatic disease community to come together and speak up with one voice about the challenges faced in the region. This event symbolizes a new chapter in our collective pursuit of better understanding, support and care for those living with psoriatic disease. By uniting our efforts and addressing the unique challenges faced in Asia, we can foster hope and spark lasting change for countless lives.

The IFPA Regional Forums are critical for elevating the conversation about psoriatic disease globally and, specifically, in the Asia-Pacific region. Through these dialogues, we can reach more people, drive policy and take more action to improve the well-being of people living with psoriatic disease. By speaking up with one voice, we can advocate for change and ensure that the needs of people with psoriatic disease in Asia are prioritized.

This briefing book highlights some key issues that need to be addressed to improve the lives of people living with psoriatic disease in Asia. Ensuring access to care, addressing and managing comorbidities, prioritizing mental health care, and combating the social and familial impacts of the disease are among our top priorities. We need to work towards early diagnosis, comprehensive treatment options, people-centered care and mental health support to help those affected to lead fulfilling lives.

By improving awareness and education about psoriatic disease, we can combat the discrimination, stigma, shaming and bullying that often affects people with this condition. This can only be achieved by collaborating with stakeholders from across the region and speaking up with one voice.

We are confident that by working together, speaking up and advocating for change, we can **ensure better lives for people with psoriatic disease in Asia**.

IFPA
GLOBAL LEADER IN FIGHTING PSORIATIC DISEASE

Frida Dunger Johnsson
Executive Director, IFPA

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Key themes

This briefing book focuses on four key themes central to discussions at IFPA Forum Asia. The themes were identified in consultation with national psoriatic disease patient associations as priority areas for action.

THE THEMES ARE:

- **Access to care**
- **Comorbidities of psoriatic disease**
- **Mental health**
- **Social and familial impact of psoriatic disease**

By prioritizing these areas, we can work to address the unmet needs of people living with psoriatic disease in Asia and, ultimately, towards improving the lives of those affected by psoriatic disease.

2023 is the year of universal health coverage

Everyone, everywhere should have access to quality, people-centered care

Universal health coverage (UHC) is critical to ensure access to quality healthcare services and treatments for people with psoriatic disease.[1] UHC aims to ensure that all individuals and communities have access to quality health services without experiencing financial hardship. By expanding coverage for essential health services, including those related to the prevention, diagnosis and treatment of psoriatic disease, UHC can help to reduce financial barriers to care and ensure that people with psoriatic disease receive the support they need to manage their condition effectively.[1]

Strengthening health systems: investing in healthcare infrastructure, training healthcare workers, and developing policies and guidelines

Achieving UHC by 2030 (Sustainable Development Goal Target 3.8) requires a strong health system. UHC can help to strengthen health systems and improve access to specialized care for psoriatic disease. By investing in healthcare infrastructure, training healthcare workers, and developing policies and guidelines for managing chronic conditions such as psoriatic disease, UHC can help ensure that people with psoriatic disease receive comprehensive and coordinated care that addresses all aspects of their health needs.

Effective primary care support in the management of psoriatic disease

Primary care is often said to be the cornerstone of UHC. Psoriatic disease requires a comprehensive approach that includes different healthcare disciplines and links to social support for addressing the skin and joint symptoms and associated comorbidities. This holistic approach, coordinated at primary care level, could serve as a benchmark model for managing other chronic diseases that similarly necessitate addressing multiple aspects of a person's health.

WORLD PSORIASIS DAY 2023

World Psoriasis Day on 29 October provides an opportunity to raise awareness of the importance of UHC for people with psoriatic disease. It offers a platform to advocate for policy changes that promote greater access to quality healthcare services, health equity and treatments for this community, to ensure better health outcomes for all.[2]

3 GOOD HEALTH AND WELL BEING

LEARN MORE about psoriatic disease and universal health coverage. Access IFPA's tools and resources here.

What is psoriatic disease?

In individuals with psoriatic disease, which encompasses psoriasis and psoriatic arthritis, the immune system is triggered and activated.[3] This overactive immune system can lead to inflammation in other parts of the body, including the organs, where it may not be visible and can cause other health issues. Psoriatic disease is associated with several related health-harming diseases, also known as comorbidities.[4,5]

A visible and non-visible disease

Psoriatic disease can cause severe, uncomfortable and noticeable physical symptoms visible on the skin, such as itching, pain and lesions.[4] Joint symptoms of psoriatic disease usually develop several years after skin symptoms arise, and can be painful and limit mobility.[5]

Psoriasis – affects the skin and may be highly visible, appearing as thickened, red or dark patches of skin covered by a silvery scale or crust. It can occur on various parts of the body, including the scalp, elbows, knees and back. There are multiple subtypes of psoriasis, including plaque psoriasis (the most common type of psoriasis), guttate psoriasis, inverse psoriasis, pustular psoriasis, erythrodermic psoriasis and rarer forms, such as generalized pustular psoriasis.

Psoriatic arthritis – is a type of inflammatory arthritis that can cause joint pain and stiffness and damage to joints and surrounding tissues. Global estimates indicate that psoriatic arthritis affects one-third of people with psoriasis although, proportionally, fewer Asians develop it.[6-10] The chronic fatigue or joint pain associated with psoriatic arthritis may not be visible; however, it can cause disfigurement and debilitation over time.

A disease that needs ongoing management

Psoriatic disease is a serious and even life-ruining noncommunicable disease found worldwide.[11] It is a chronic immune-mediated systemic inflammatory disorder that affects the skin, joints and, sometimes, other organs. Because there is no cure, treatment options consist of symptom control, prevention of flare-ups and joint damage, and disease remission.

> ***"Scalp problems – dandruff and rashes – are very common, so why isn't it talked about openly?*** *It breaks my heart to know that so many people refuse to get a haircut because of their scalp psoriasis. I usually take the initiative to explain and educate the hairdressers about my condition.* ***Once they understand, they're OK with it."***
>
> **Rocyie Wong**
> Malaysia

What causes it?

The causes of psoriatic disease are not known, but researchers believe that genetic and environmental factors play a role in the development of the disease.[12] Common triggers for the initial onset of the disease and subsequent flare-ups include stress, skin trauma (cuts, scrapes or tattoos), dry skin, certain medications, climate, alcohol consumption, smoking and infections.

The burden of psoriatic disease in Asia

~ 10.7m people are estimated to be **living with psoriatic disease** in Asia.[14]

Estimates of the prevalence of psoriatic disease tell healthcare decision-makers about the scale of the burden and provide data that can help identify health priorities and inform policies. The prevalence of psoriatic disease varies by region, with higher rates reported in developed countries.

In Asia, the prevalence of psoriatic disease is estimated to be between 0.1% and 0.5%, although this may be underestimated due to underreporting and misdiagnosis.[13]

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GPA
Global Psoriasis Atlas

Mapping the burden – work in progress

Studies on psoriasis prevalence and incidence improve our understanding of the disease burden, aiding healthcare resource allocation.[13] However, obtaining reliable, country-specific and comparable regional population-based estimates is challenging.

The **Global Psoriasis Atlas (GPA)** aims to deepen our understanding of psoriasis, but it does not cover other forms, such as psoriatic arthritis, making it difficult to estimate the total burden of psoriatic disease. While efforts are ongoing to expand our knowledge, more work is needed to fully comprehend the impact of the disease on those affected.

LEARN MORE about the work of the GPA and the prevalence of psoriasis

The prevalence and estimated figures of individuals living with psoriasis are derived from the GPA. It is important to note that these numbers may differ from other sources, as they are intended to provide a broad understanding of the burden of psoriasis and highlight the necessity for further data collection.

Estimated prevalence and number of people living with psoriasis across the Asia-Pacific region
Data from the Global Psoriasis Atlas[14] *

COUNTRY, REGION OR TERRITORY	NUMBER OF PEOPLE	PREVALENCE LOWER & UPPER OVERALL LIMIT %**
Australia	460,860	0.59–6.1
Bangladesh	466,670	0.09–0.97
Brunei	2,570	0.16–1.91
Bhutan	2,280	0.09–0.97
Cambodia	48,350	0.06–1.65
China	2,360,000	0.07–0.42
Fiji	2,460	0.06–1.04
India	3,590,000	0.08–0.92
Indonesia	797,380	0.06–1.65
Japan	690,230	0.14–1.94
Laos	20,720	0.06–1.65
Malaysia	95,520	0.06–1.65
Mongolia	20,840	0.22–2.18
Myanmar	161,200	0.06–0.165
Nepal	80,920	0.07–0.98
New Zealand	85,020	0.5–5.73
North Korea	28,180	0.04–0.3
Pakistan	558,340	0.09–0.97
Papua New Guinea	22,440	0.06–1.04
Philippines	316,900	0.06–1.65
Solomon Islands	1,660	0.06–1.04
South Korea	281,770	0.17–null
Sri Lanka	66,680	0.06–1.68
Taiwan	12,800	0.02–0.16
Thailand	208,530	0.06–1.65
Timor-Leste	3,910	0.06–1.65
Vanuatu	750	0.06–1.04
Vietnam	288,580	0.06–1.65

DISCLAIMER: The country, region, and territory names, as well as the maps, included in this briefing book, are intended for general informational purposes only and should not be relied upon as a reference. The depiction of political boundaries does not indicate the stance of IFPA or any of its partners on matters of recognition, sovereignty, or jurisdiction.

* The GPA does not currently include data for several countries and areas listed in the WHO SEAR and WPR regions. These include Cook Islands, Hong Kong SAR (China), Kiribati, Macao SAR (China), Maldives, Marshall Islands, Micronesia, Nauru, Niue, Palau, Samoa, Singapore, Tokelau (New Zealand), Tonga, Tuvalu, and Wallis and Futuna (France).
** The lower and upper limit (%) of prevalence data includes estimates for adults and children. Visit the GPA website to learn more about how prevalence is calculated.

A high and rising burden

The burden of psoriatic disease is regarded as significant, given that so many people are affected and its prevalence among adults appears to be steadily rising.[15,16] An increase in underlying health-related conditions, such as obesity in certain Asian populations, puts people at higher risk for psoriatic disease, increasing prevalence rates.[15,16] Other drivers include more individuals seeking treatment after COVID-19, when restrictions on movement prevented many people with chronic conditions from accessing routine healthcare services.[16] In China, one of the most populated countries, estimates on the burden of psoriasis suggest that as many as 7.65 million people may be affected.[17] Experts also say the incidence rate (new cases per year) is progressively affecting younger people. This could be related to various factors, such as climate variability, air purity, diet, psychological stress and other environmental causes.

Individual impact

Psoriatic disease can affect a person's physical, mental and emotional well-being, overall quality of life and relationships. In some Asian countries, cultural norms and societal discrimination may worsen the psychosocial effects of the condition.[18] It can also be a major financial burden for the person with the condition and their families due to medical bills, days off work because of doctors' appointments or illness, and time spent as caregivers. In Korea, for example, individuals with severe psoriasis struggle to afford high treatment costs, and discontinuing treatment as a result is common.[19]

Economic and societal impact

Higher healthcare costs and lost productivity contribute to the economic burden on society.[20] In Asia, the economic burden is not well documented. However, estimates from Australia and Japan indicate that these countries spend around 0.17% and 0.44% respectively of their gross domestic product (GDP) on treating psoriasis.[21–23] Health expenditure on psoriatic disease care reflects State investment in the well-being of people living with the condition.

The global burden of psoriasis

Psoriasis affects about 60 million people.[13] The Global Psoriasis Atlas (GPA) data show that prevalence varies widely, from less than 0.1% in some African countries to more than 4% in some European countries.[14] Globally, psoriasis presents a high economic burden in terms of direct and indirect costs, comparable to costs associated with other serious illnesses, such as, pancreatic cancer, melanoma, prostate cancer and asthma[24]

Earlier detection and better management can reduce the burden

The impact of psoriatic disease can be mitigated with timely diagnosis, proper treatment and ongoing management. However, limited access to healthcare and treatments complicates the burden of psoriatic disease in Asia. Dermatologists and rheumatologists, who play a crucial role in managing the disease, are in short supply in many countries, leading to delayed or incorrect diagnoses and suboptimal disease management.[25] Moreover, people with the disease have suffered from a lack of treatment choices due to poor understanding of the condition, although there has been progress in this area recently.[26] To reduce the high burden of the disease, it is necessary to prioritize psoriatic disease and improve access to healthcare and treatments. Increasing awareness of the disease among healthcare providers and the general public is essential for improving the diagnosis and management of the disease.[18]

Studies from the region report that at least one in 10 people with psoriasis in Asia have psoriatic arthritis.[7–10] To put this in perspective, in China, potentially half a million people are living with psoriatic arthritis (based on the reported prevalence of psoriatic arthritis of 0.01–0.1%).[5,27]

Progress on recommendations from the WHO Global Report on Psoriasis

In 2016, the World Health Organization released the WHO Global Report on Psoriasis with actionable recommendations. To monitor countries' achievement in implementing the recommendations from the WHO report, IFPA commissioned the Western Pacific Region Index report.

The Index report reviews progress across five countries, namely Australia, China, Japan, the Philippines and Singapore, using an Index scoring system.[28]

PERCEIVED DISCRIMINATION AND STIGMATIZATION

3 out of 4 Australians with psoriatic disease reported hiding their condition from colleagues, friends and even family members.[29]

30%

30% of people surveyed in the Philippines experience stigmatization in workplaces and common areas.

AVAILABILITY OF TREATMENT GUIDELINES

Australia, **China**, **Japan** and **Singapore** have recently updated their guidelines on psoriasis or psoriatic arthritis. In the **Philippines**, there are no locally authored treatment guidelines.

PATIENT-CENTRIC INVESTIGATION OF WELL-BEING

Healthcare professionals in all five countries confirm that they check the physical health of their patients with psoriatic disease, but **mental health is not always consistently followed up on**.

HEALTHCARE EXPENDITURE DATA

Healthcare expenditure data was **limited for countries** other than Australia and Japan.

Five categories and 10 indicators

Public awareness

- Existence of a public awareness campaign
- Perceived discrimination and stigmatization

Provider awareness

- Training for general practitioners
- Availability of treatment guidelines

Patient engagement

- Tools or support for medication adherence
- Patient-centric investigation of well-being

Health systems

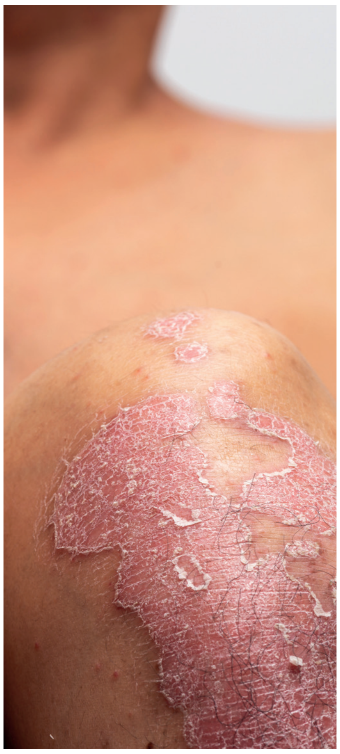
- Time to diagnosis
- Access to medicines
- Access to specialist care

Enabling environment

- Direct and indirect costs for patients and the system

Priority areas for action

To improve the situation for people living with psoriatic disease in Asia, key priorities across the region include ensuring access to care, managing comorbidities, prioritizing mental healthcare, and addressing the social and familial impacts of the disease. To achieve these goals, we must focus on early diagnosis, comprehensive treatment options, patient-centered care and mental health support, all of which are crucial in helping affected individuals lead fulfilling lives.



Access to care

Psoriatic disease may not be curable yet, but it can be controlled with standardized treatment and, in a small number of cases, recurrence can be avoided with effective treatment.[30] Even with improvements in treatment, chronic and life-long care is needed.[30] People with psoriatic disease should have access to comprehensive and affordable professional medical care. However, a broad range of barriers may inhibit access to care at all levels of healthcare. These range from health system factors, such as workforce shortages and inadequate knowledge, to supply, access to reimbursement of medicines affecting affordability and health inequities.

KEY CHALLENGES

Delayed diagnosis or misdiagnosis

Early detection of psoriatic disease enhances treatment effectiveness, but diagnosis delays are common in Asia and globally.[31–33] Delays in diagnosis and treatment greatly impact disease progression and severity, ultimately worsening long-term outcomes and leading to reduced quality of life.[31–34] Delays are often tied to poor awareness among the public and healthcare professionals, with treatment delays of up to five years reported in primary care.[31,35–38]
In some Asian countries, cultural factors, such as stigma around skin conditions and conceptions of psoriasis by the person affected or family members that the disease is neither curable nor life-threatening, further challenge awareness-raising, seeking referral and access to care.[18,38]

Inequitable or restricted access to healthcare

Geography, poverty and insurance limitations can be major obstacles in accessing care for people with psoriatic disease in Asia.[39] In addition, healthcare systems may lack resources, causing long waiting times, limited specialist availability and inadequate follow-up care.[38] Dermatologist accessibility is also a concern, with diagnostic delays and misdiagnoses due to insufficient knowledge among rheumatologists and a shortage of specialists constraining access to specialized care.[38,40]

+

Access to care priority asks

Increase awareness of psoriatic disease among healthcare professionals, especially primary care frontline health workers.

Develop guidelines and protocols for diagnosing and managing psoriatic disease, including recommendations for early diagnosis, routine screening and appropriate, adequate and timely treatment.

Address healthcare system challenges preventing equitable access to treatment and care.

Improve access to biologic therapies and other advanced treatments for psoriatic disease, including reducing barriers to reimbursement and increasing the availability of these therapies in Asia.

43% of people

with psoriatic disease surveyed in the region (Australia, Japan, South Korea and Taiwan) say that affordability drives their treatment choice.[41]

Biologics

Improving access to biologic treatments for psoriatic disease in Asia is crucial for enhancing health outcomes and reducing the psoriatic disease burden.

Biologic treatments for psoriasis or psoriatic arthritis can be transformative for people living with psoriatic disease.[43] By targeting specific overactive parts of the immune system, biologics differ from systemic treatments that affect the entire immune system. They may have lower risks of organ damage compared to other types of systemic treatment. Although biologic use has risen, access remains limited in many Asian regions due to high costs, limited availability and restrictions placed by insurance and government programs. People with psoriatic disease in South Korea, Taiwan, Australia and Japan must often undergo conventional therapies before qualifying for biologic treatment reimbursements.[41,44-47] However, recent Japanese research suggests that initiating newer therapies or biologics may reduce hospital costs and stays.[48]

Limited access and availability, and high cost of treatments

Regulatory barriers, provider awareness and treatment availability inhibit effective psoriatic disease treatment in parts of Asia. The WHO highlights challenges in affordable access to healthcare and medications for chronic diseases in the Asia-Pacific region.[39] Patients may lack access to basic treatments or face high costs, particularly for newer treatments, resulting in choices based on affordability and leading to a high risk of under-treatment and avoidable patient burden.[41] Newer treatments are available but, for economic reasons, some countries are not able to prioritize access to these medicines.

Stigma and discrimination

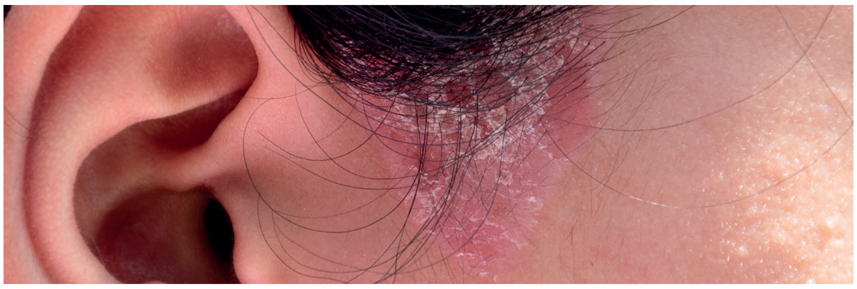
Stigma and discrimination against people with psoriatic disease can hinder care. Visible skin lesions may lead to discrimination in social, work and even healthcare settings, affecting mental health and deterring patients from seeking care. A study found that Chinese patients with psoriatic disease face significant stigma and psychological distress, encountering negative attitudes from family, friends and healthcare providers.[42]

The Philippines makes groundbreaking policy move to ensure equitable access to treatment: the Philippines psoriasis bill approved

The Philippines' Committee on Health has passed a bill establishing a National Integrated Program to prevent and treat psoriasis as a public health problem.[49] The bill aims to provide equitable and affordable access to medicines and treatment for nearly 2 million Filipinos with psoriatic disease. It emphasizes an integrated, comprehensive approach to health development, focusing on integrative, multidisciplinary, patient and family-centered policies, programs and services for people living with psoriatic disease.[50]

Panama has recently followed in the footsteps of the Philippines, with the approval of a law declaring the medical attention, research and professional training in the early detection, diagnosis and integral treatment of psoriasis to be of national interest. These two countries take inspiration from the German National Program on Psoriasis Healthcare 2005–2015, which yielded tremendous improvements in patient outcomes as well as addressing regional disparities.[51]

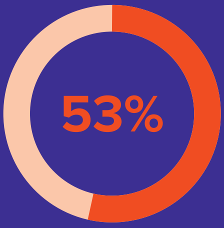
> ***"It's about time that the [Department of Health] included psoriasis in their programs. This proposal is a comprehensive program, integrated in the community and in all healthcare facilities."***
>
> Former Chair of the Committee on Health Hon. Angelina Helen D.L. Tan M.D, who was the original proponent of the bill in 2021



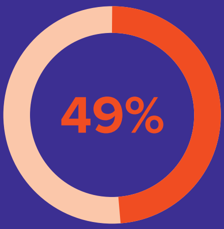
Cost of treatment is a major burden for people with psoriatic disease

In 2022, a joint survey of people living with psoriasis in Malaysia, Hong Kong and Korea revealed the impact of the high financial burden of psoriasis treatment.

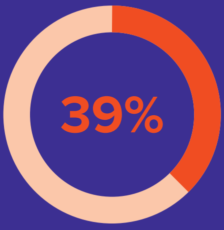
Biggest treatment challenges
in Malaysia



High financial burden of treatment

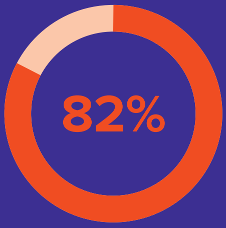


Ineffective treatment



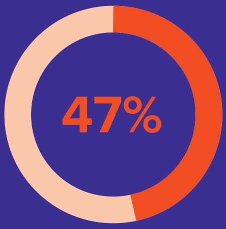
Unacceptable waiting time to see a healthcare provider

Biggest treatment challenges
in Hong Kong



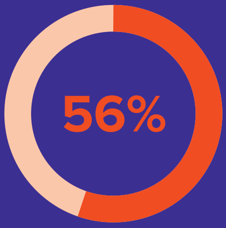
High financial burden of treatment

Ineffective treatment

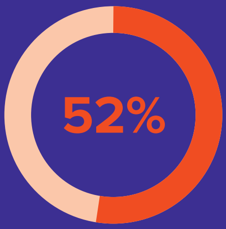


Unacceptable waiting time to see a healthcare provider

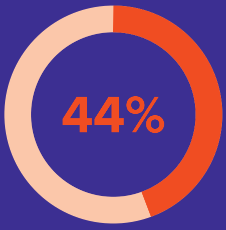
Biggest treatment challenges
in Korea



Ineffective treatment



High financial burden of treatment



Strict insurance eligibility

Psoriatic disease and comorbidities

People with psoriatic disease are at higher risk of comorbidities such as cardiovascular disease, metabolic syndrome, and depression, therefore early screening and management are crucial.[52-54] Higher mortality and hospitalization rates are associated with comorbidities, and a person with psoriatic disease may have multiple comorbid conditions, adding to the complexity of management.[52] Early screening can help address comorbidities by reducing missed diagnoses or misdiagnoses.[38] Appropriate management consists of person-centered, comprehensive and coordinated care and an individually adapted treatment plan aimed at enhancing the quality of life of the person living with psoriatic disease.

KEY CHALLENGES

Misconceptions, poor awareness and knowledge

Psoriatic disease is not just a skin condition but a non-communicable disease with comorbidities.[18,38] Lack of awareness of this relationship hinders proper care and outcomes. Healthcare professionals in Asia require data and knowledge on the prevalence, treatment and impact of comorbidities to aid diagnosis and treatment in people with psoriatic disease.[55] At the same time, patient education and empowerment are critical for reducing the impacts of comorbidities, improving treatment adherence and preventing misinformation about medication and its potential side effects.[18]

Poorly defined clinical pathways or limited resources for effective diagnosis

The Taiwan Rheumatology Association and the Taiwanese Association for Psoriasis and Skin Immunology recommend monitoring comorbidities in psoriatic arthritis management, including regular checks of blood pressure, blood glucose, cholesterol, weight and other risk factors.[10]

Treatment effects on common comorbidities should be considered.[10] Factors challenging the availability of health checks include shortages of diagnostic equipment, supplies and healthcare professionals trained in managing psoriatic disease in the region, especially in remote and rural areas.[56] Suboptimal outcomes can result from a lack of coordination among healthcare professionals.[59] Inadequate infrastructure and, high healthcare and medication costs are additional barriers for individuals and the health system.[46,58,59]

RECOMMENDED APPROACHES TO CARE

In addition to timely physician intervention and increased awareness of comorbidities to prevent long-term damage to health and improve quality of life, two approaches or models of care ensure effective management of psoriatic disease and comorbidities:[10,18,52,60,61]

Person-centered care

Patient involvement in clinical decision-making is crucial in a person-centered care model, as it improves treatment adherence, quality of life and patient satisfaction.[18,62,63] Unfortunately, healthcare professionals have a limited understanding of this approach, leading to its underutilization. Providers must receive education and training on effective patient communication to promote person-centered care. Information booklets, educational programs, social media activities, psychosocial support programs and patient support services

Comorbidities priority asks

Increase awareness among healthcare professionals
Train healthcare professionals to recognize comorbidities in psoriatic disease patients and to refer them for treatment when necessary.

Promote patient education and awareness of comorbidities and their risk factors
Educate patients about regular check-ups, screening for comorbidities, the importance of early detection and lifestyle modifications and risk reduction strategies.

Improve access to care
Improve access to care, especially in rural and underserved areas, by increasing the number of trained healthcare professionals, improving diagnostic and treatment facilities, and using digital technologies.

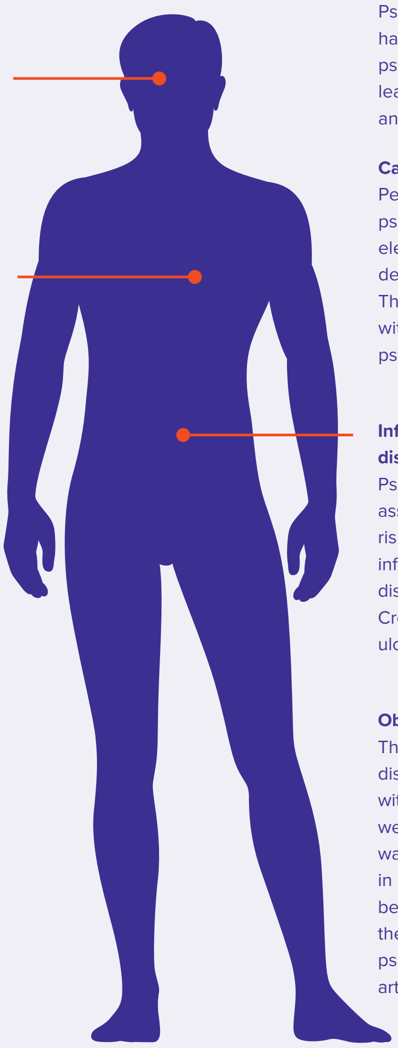
Encourage person-centered and multidisciplinary care
Encourage a multidisciplinary approach to care that includes patients in treatment decisions, involving collaboration between specialists to address the physical and psychological aspects of the disease.

can enhance patient knowledge and involvement. Successful online education support programs in South Korea, Singapore and Malaysia have led to higher patient engagement in managing psoriasis.[18]

Multidisciplinary, coordinated and continued care

Psoriatic disease is a complex condition that affects multiple organ systems, requiring a holistic approach from healthcare professionals.[64-66] A multidisciplinary team of experts from various fields, such as dermatology, psychiatry, psychology and social work, is necessary to assess the patient's condition, develop a comprehensive treatment plan and address comorbidities. A multidisciplinary approach can meet physical and mental health needs, leading to more effective management, improved quality of life and better health outcomes for people with psoriatic disease in Asia.

The most common comorbidities associated with psoriatic disease include:



Eye conditions
Psoriatic disease is associated with an increased risk of developing eye conditions such as uveitis and conjunctivitis.[67]

Cardiovascular disease
Individuals with psoriatic disease are at increased risk of developing cardiovascular disease, including high blood pressure, heart attack and stroke.[60,68-72]

Metabolic syndrome
Metabolic syndrome is a group of risk factors that increase the risk of developing heart disease, stroke and type 2 diabetes. People with psoriatic disease have a higher prevalence of metabolic syndrome.[60,73-75]

Osteoporosis
Psoriatic disease can lead to reduced bone density and an increased risk of osteoporosis.[76]

Depression and anxiety
Psoriatic disease can have a significant psychological impact, leading to depression and anxiety.[77-80]

Cancers
People living with psoriasis have an elevated risk of developing all cancers. This risk increases with the severity of the psoriasis.[12]

Inflammatory bowel disease
Psoriatic disease is associated with a higher risk of developing inflammatory bowel disease, including Crohn's disease and ulcerative colitis.[81,82]

Obesity
The odds of psoriatic disease increase with increase in body weight.[83,84] Obesity was determined in some studies to be a key factor in the transition from psoriasis to psoriatic arthritis.[85,86]

> ***"Many individuals with psoriatic disease have one or more comorbidities. These conditions are complex and chronic and can impact the choice of treatment for psoriasis.*** *Without treatment and management, patients risk serious damage to their health. Holistic management is important for early detection, diagnosis and management of these comorbidities to avoid further harm to health."*
>
> **Dr Colin Theng**
> Dermatologist and President of the Psoriasis Association in Singapore

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24%

of people with psoriasis treated at dermatology clinics in Malaysia over a 10-year period had obesity and, 17% had diabetes.[87]

Psoriatic disease and mental health

Psoriatic disease can severely affect mental health, as individuals struggle to cope with visible skin lesions, chronic pain and disability, leading to psychological effects such as anxiety, depression, embarrassment and shame.[88,89] Stigma and discrimination caused by false beliefs of contagion can also exacerbate these negative effects. Managing mental health, including stress, is crucial, due to its impact on physical symptoms. Individuals living with psoriatic disease may face further challenges, such as coexisting inflammatory conditions and difficulties adhering to long-term treatment, which can lower their quality of life.[90-93] Distress and recurrent depression may even lead to suicidal ideation or actions.[94,95]

KEY CHALLENGES

Stigma, shame and cultural attitudes related to mental health issues

Individuals with psoriatic disease in Asian countries such as China, India and Malaysia are at a greater risk of experiencing depression and anxiety compared to those without the disease.[53,92,96] However, accessing mental health care can be hindered by mental health stigma, cultural beliefs and misunderstandings about mental illness. Although cultural influences have been linked to lower rates of depression in Asian culture, cultural attitudes and stigma can discourage patients from seeking help.[96,97] Sharing one's mental illness or chronic disease can be perceived as bringing shame to the family or a sign of weakness.[98] This can lead to affected individuals keeping their problems hidden, avoiding using health services, and struggling with personal and financial resources to cope with the stigma.[98]

Psychosocial care needs to be integrated in guidelines, models of care and referral pathways

According to the Guidelines for the Diagnosis and Treatment of Psoriasis in China (2019), psychological factors are crucial in the development, progression and treatment of psoriatic disease.[93] The guidelines highlight the importance of psychotherapy, which involves psychological methods such as communication and education to reduce physical symptoms and improve psychological well-being.[93]

Psoriasis patients are at higher risk of depression, anxiety, psychiatric disorders and suicide ideation, making it crucial for clinicians to conduct routine screenings for these conditions.[99] Around 5% of patients in China were found to have committed suicide, with higher rates of suicide among those who had severe disease.[100] However, mental health issues are not always recognized as serious comorbidities of the condition in Asia. Collaboration between dermatologists, psychiatrists and primary care physicians is necessary to support emotional and clinical outcomes for patients with psoriatic disease.[99]

RECOMMENDED APPROACH TO CARE

Integration of psychosocial care

Psoriatic disease management must integrate psychosocial care to meet the mental health needs of affected individuals.[101,102] This intervention can greatly enhance treatment outcomes and quality of life by providing patient education, counseling and support groups. However, there is a lack of awareness and understanding surrounding the importance of psychosocial care.[18] To close this gap, greater research, education and support for patients and their families is required, including access to mental health professionals and support groups.

Mental health priority asks

Healthcare providers
Identify and address mental health needs by screening patients, providing counseling, psychiatric treatment referrals and integrating mental health care into treatment plans.

People living with the disease
Seek out mental health care and support by participating in support groups, talking to healthcare providers, exploring therapy options and advocating for their own mental health needs.

Advocacy organizations
Raise awareness, reduce stigma and discrimination, and advocate for increased access to mental health care and support for people with psoriatic disease.

Government and policymakers
Increase funding, develop policies to support integrated mental health care and implement public education campaigns to reduce stigma and increase awareness about the mental health impact of psoriatic disease.

Stigma and discrimination caused by false beliefs of contagion can also exacerbate these negative effects

Addressing mental health at the clinic
Interviews with healthcare providers in three countries found that factors preventing mental health assessment in clinical practice include:[28]

AUSTRALIA
Limited consultation time

CHINA
High patient volume

JAPAN
Provider and patient willingness

In a survey from the Philippines,

27%

of respondents with psoriasis reported experiencing suicidal thoughts – all of whom were also said to have depression and anxiety.[103]

68%

reported having anxiety, yet only 26% are being treated.

PATIENT STORY

Mental health

Chiara Lionel Salim
Jakarta, Indonesia

Chiara, founder of Psoriasis Indonesia and an IFPA Ambassador, has a life-threatening rare form of the condition called erythrodermic psoriasis, and recently began developing psoriatic arthritis. The physical and emotional toll has been significant, but Chiara turned to blogging and social media to share her experiences, express her emotions, and address taboos and misunderstandings around psoriatic disease. She advises others battling rare diseases that “it’s OK to not be OK” and encourages them to appreciate their strength and resilience as warriors.

WATCH THE VIDEO

Watch Chiara’s story about living with erythrodermic psoriasis

Social and familial impact of psoriatic disease

Psoriatic disease can greatly impact the social and familial lives of those living with the condition, especially in Asia, where these connections are highly valued. As the disease can affect people at different life stages, it is important for healthcare providers and employers to consider necessary accommodations to facilitate their active role in society. Discrimination and limited opportunities in education and employment may also be present, due to the visibility and impacts of the condition. Raising awareness and providing support through public outreach, healthcare, communities, workplaces, schools and families can overcome these obstacles.

KEY CHALLENGES

Stigma and discrimination among young people

Living with psoriatic disease in childhood can have various negative impacts on the child or young person and their parents. These impacts include an increased risk of developing mental health problems such as anxiety or depression caused by experiences of shame, teasing, bullying, misaligned body image and social isolation.[104] Such impacts can continue into adulthood and affect how the individual integrates into society. In addition, parents with a child affected by psoriatic disease may experience guilt and negative emotional and psychological consequences.

Lack of understanding of psoriatic disease in the workplace

Research shows that psoriatic disease causes individuals to miss work more frequently and reduces their productivity, ultimately putting a strain on the economy and the workforce.[105,106] They might also need special accommodations in the work environment. In a survey from China, 50% of individuals with severe psoriasis were unemployed. The unemployment rate for those with mild or moderate disease was 37%.[100] Thus, it is crucial for employers to be flexible and responsive to their employees with psoriatic disease. In addition, initiatives are required to educate employers, human resource staff and unions about the impact of these diseases on individuals and families.[107]

Impact on family members underrecognized

Psoriatic disease is a long-term condition that can have a significant impact on families in Asia, with family members often serving as primary caregivers. This can take a toll on their mental health, leading to psychological distress, depression and social isolation.[108] The burden is further compounded by anxiety and depression in the person with psoriatic disease. Financial strain also adds to the challenge, especially for low-income households, with some caregivers having to change jobs or reduce hours to provide care.

Women and their families require consideration

Psoriatic disease can have a greater impact on women, affecting their quality of life and outcomes.[109,110] Those planning or caring for a family often struggle the most, experiencing greater psychological implications compared to men. Women also report negative effects on their social relationships, mental health and career, as well as concerns around family planning. To better support women with psoriatic disease, healthcare providers should offer tailored information, training and shared decision-making opportunities between patients and professionals.[109]

Social and familial impact priority asks

Employers
Provide a flexible work environment with accommodations such as flexible working hours, remote work options and ergonomic equipment. Raise awareness about the disease and its impact on employees and their families.

Policymakers
Promote social and familial support by ensuring access to affordable healthcare and mental health services, promoting workplace accommodations and allocating resources to reduce stigma and discrimination.

Patient organizations
Provide community support and reduce social isolation for people with psoriatic disease. Offer opportunities for learning, sharing experiences and emotional support with support groups for people with psoriatic disease as well as caregivers/family members.

Family and friends
Offer understanding, empathy and emotional support, and encourage seeking professional help. Help reduce social isolation by inviting loved ones to social events and activities.

Psoriatic disease can have a greater impact on women, affecting their quality of life and outcomes.[109,110]

Psoriasis Campus Caravan of Hope

The youth chapter of PsorPhil is doing a fantastic job in raising awareness about psoriatic disease. By visiting schools and campuses, they are able to educate young people of all ages about the disease and its impact on those living with it. As part of the campaign, the youth chapter discusses what psoriatic disease is, its usual manifestations and the hardships that often accompany it. The speaker living with psoriatic disease shares their personal experience, which helps to build empathy with the students. The topics covered in the campaign are crucial as they highlight the challenges encountered during childhood and school years, such as bullying, stigma and judgment from others, or feelings of detachment and isolation due to their condition.

PATIENT STORY

Diagnosed with generalized pustular psoriasis

Emmylou Casanova
Philippines

17 years ago, Emmylou was diagnosed with rare and severe generalized pustular psoriasis (GPP) after experiencing lesions and pain. Misdiagnosed with Stevens-Johnson syndrome, she was prescribed topical steroids, which helped, but required hospitalizations for subsequent flare-ups. Emmylou has faced discrimination in public transport, pools, salons and spas. She advises learning about the condition, finding support and being kind to yourself during flare-ups.

WATCH THE VIDEO

Watch Emmylou's interview on the IFPA's YouTube channel psoriasisIFPA

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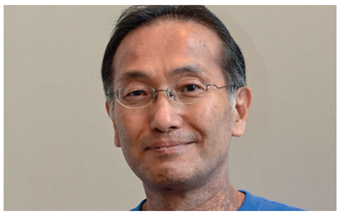

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Our vision

Founded in 1971, IFPA is the international federation of psoriatic disease associations. IFPA's members represent more than 60 million people living with psoriatic disease.

IFPA is the only global organization representing and uniting all people living with psoriatic disease – regardless of where they live, the type of psoriatic disease they have or how it impacts their lives.

Vision

A future where all people living with psoriatic disease enjoy good health and wellbeing, free from stigma and preventable disability and comorbidities

Mission

Unite, strengthen and lead the global psoriatic disease community to improve the lives of all people affected by psoriatic disease

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OUR MEMBERS IN ASIA

REGIONAL	PsorAsia Pacific
AUSTRALIA	Psoriasis Asia Inc.
BANGLADESH	Psoriasis Awareness Club Bangladesh
CHINA	Mutual Assistance of Psoriasis Patients 银屑病病友互助网
HONG KONG	Hong Kong Psoriasis Patients Association
INDONESIA	Psoriasis Care of Indonesia Foundation / Yayasan Peduli Psoriasis Indonesia, YPPI
JAPAN	Japan Psoriasis Association
MALAYSIA	Psoriasis Association of Malaysia / Persatuan Psoriasis Malaysia
PHILIPPINES	Psoriasis Philippines (PsorPhil)
SINGAPORE	The Psoriasis Association of Singapore
SOUTH KOREA	Korea Psoriasis Association 대한건선협회
TAIWAN	Psoriasis Association Taiwan 台灣乾癬協會
VIETNAM	PsorViet / HỘI VẢY NẾN VIỆT NAM (PsorViet)

IFPA
GLOBAL LEADER IN FIGHTING
PSORIATIC DISEASE

WHAT DO LOCALS CALL PSORIASIS?

AUSTRALIA	psoriasis
BANGLADESH	সোরিয়াসিস
CHINA	[Mandarin] 牛皮癬 (Niu Bi Xien), 白疕和松皮癬 (psoriasis in modern medicine)
HONG KONG	銀屑病 / 牛皮癬
INDONESIA	psoriasis
JAPAN	乾癬
MALAYSIA	psoriasis
PHILIPPINES	soryasis
SINGAPORE	银屑廯 / 牛皮癬
SOUTH KOREA	건선 (geon-seon)
TAIWAN	乾癬
VIETNAM	Bệnh vảy nến