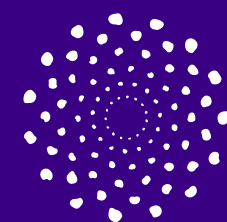


IFPA
FORUM
ASIA 2023

IFPA Asia Action Playbook

Advancing advocacy on psoriatic disease
in Asia and the Western Pacific



PsorAsia
IFPA Region Asia





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Cover image
Rocyie Wong
Psoriatic disease advocate,
Malaysia

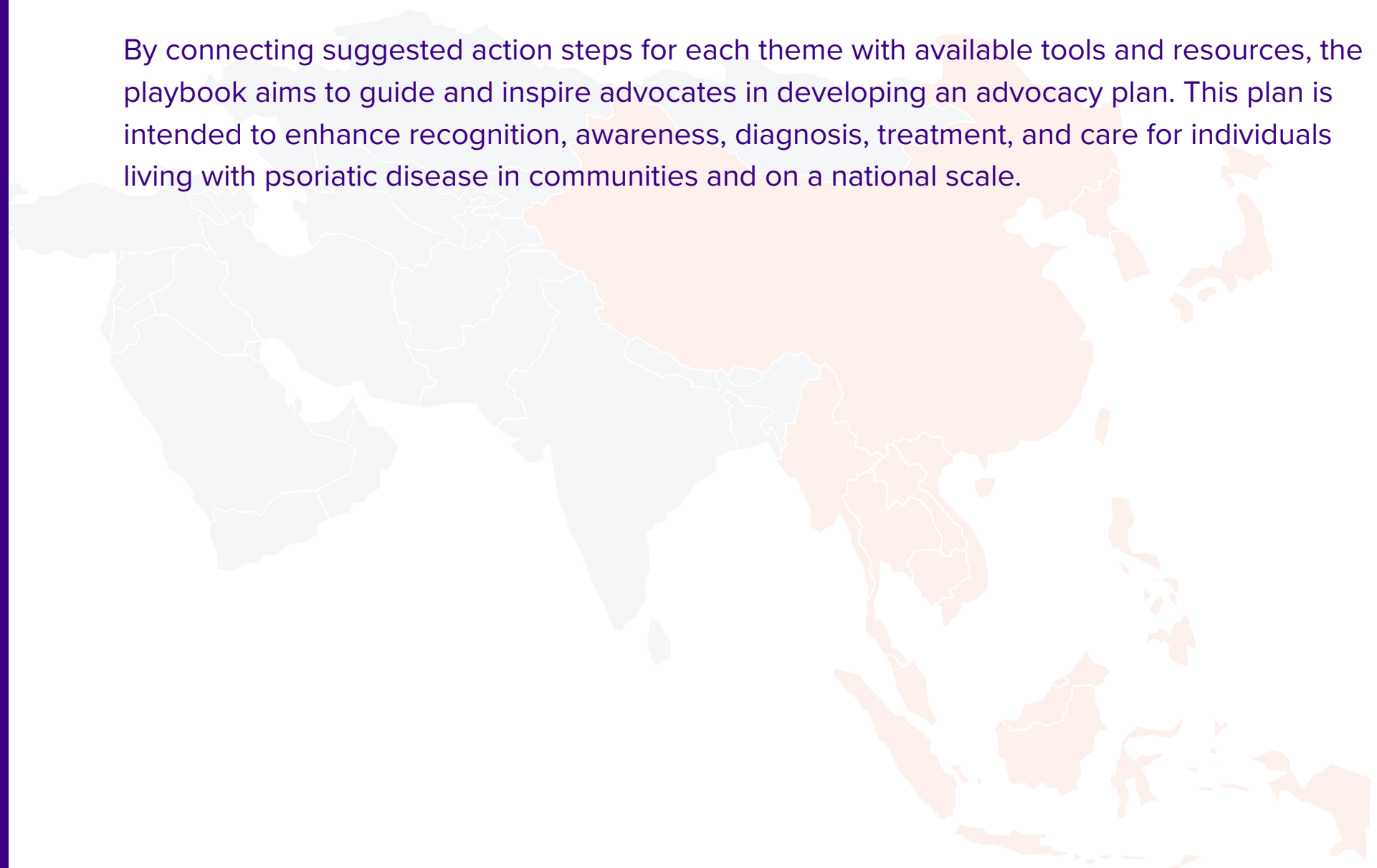
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A playbook for advancing advocacy

This playbook offers practical support for advocates and members of patient organizations, empowering them to raise awareness and visibility of psoriatic disease as a significant health concern that demands improved treatment and care. Its purpose is to assist patient associations in crafting tailored action plans at the local level.

The playbook is structured around four core themes that reflect areas where action must be advanced for people living with psoriatic disease in the region. The themes include enhancing access to care for individuals with psoriatic disease, prioritizing mental health, addressing comorbidities associated with psoriatic disease, and understanding the social and familial impact of the condition.

By connecting suggested action steps for each theme with available tools and resources, the playbook aims to guide and inspire advocates in developing an advocacy plan. This plan is intended to enhance recognition, awareness, diagnosis, treatment, and care for individuals living with psoriatic disease in communities and on a national scale.



Chiara Lionel Salim
Founder of Psoriasis Indonesia at
the IFPA Forum Asia 2023



INTRODUCTION

Building a better understanding of psoriatic disease in Asia

Addressing psoriatic disease has become a global priority because of the sustained efforts of IFPA and its members, who continue to campaign actively for its recognition as a serious non-communicable disease. The IFPA Forum Asia 2023 aimed to unite stakeholders from across the psoriatic community and promote regional and national action.

Before the forum, a variety of reading materials were created to involve IFPA members and encourage meaningful discussions during the event. The forum served as a crucial platform for dialogues that have since led to the formulation of specific advocacy initiatives suggested for patient associations to pursue in key areas requiring improvement.

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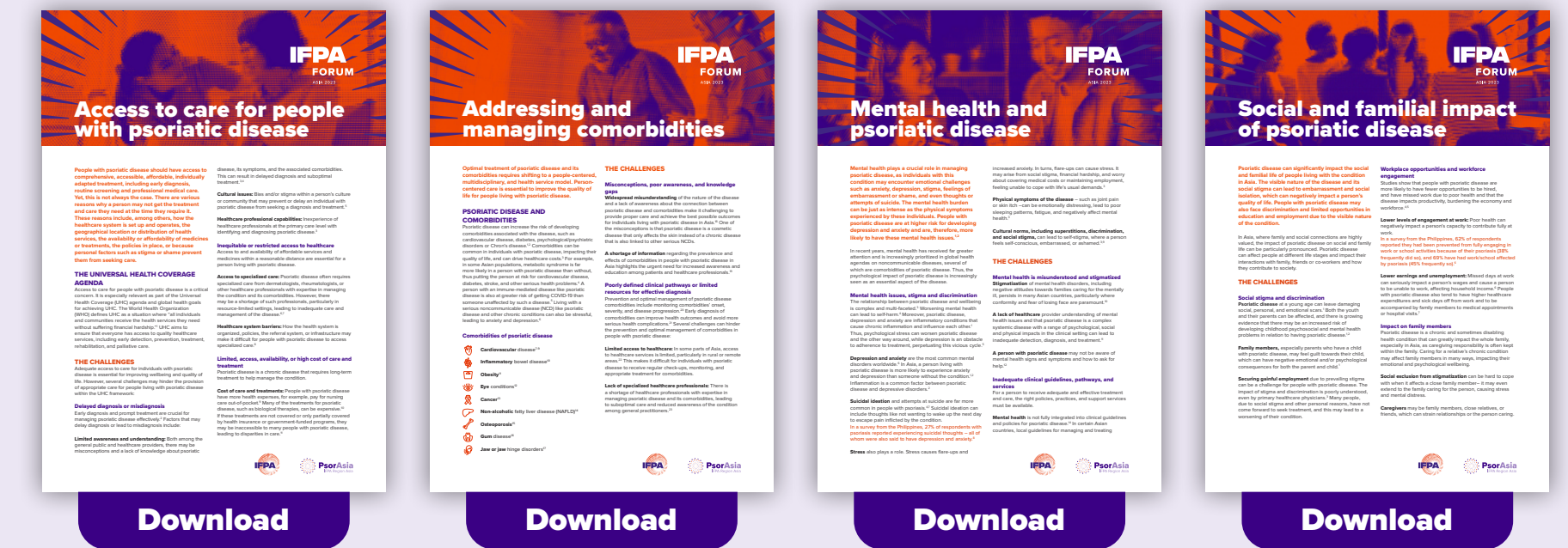
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IFPA Forum Asia 2023 resources

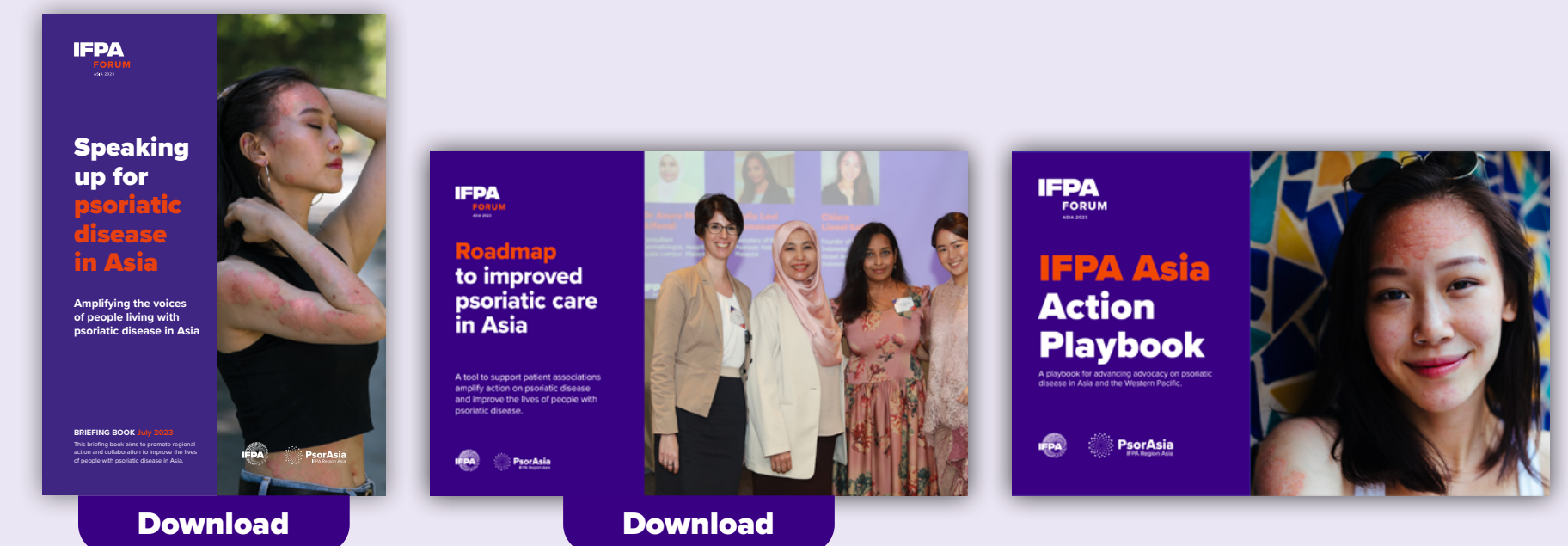
The **theme briefs** unfold the key challenges and priority asks for asserting policy action in four areas:



The **briefing book** highlights some key issues that need to be addressed to improve the lives of people living with psoriatic disease. The briefing book is available in six languages: [English](#), [Japanese](#), [Korean](#), [Traditional Chinese](#), [Malay](#), [Tagalog](#).

The **roadmap** provides a clear set of advocacy demands and practical strategies to guide efforts to improve psoriatic care in Asia.

The **playbook** provides examples from the region and internationally that illustrate how advocacy approaches have been applied in other contexts.





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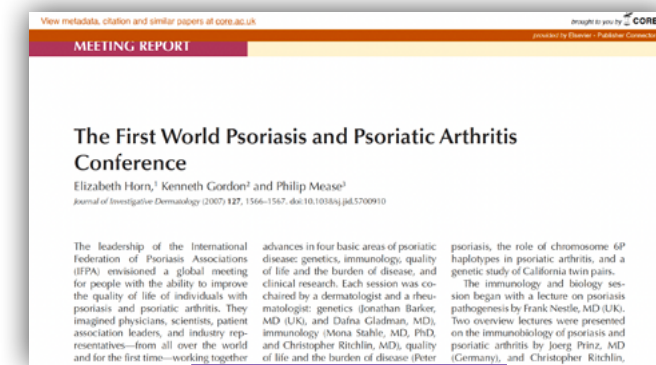
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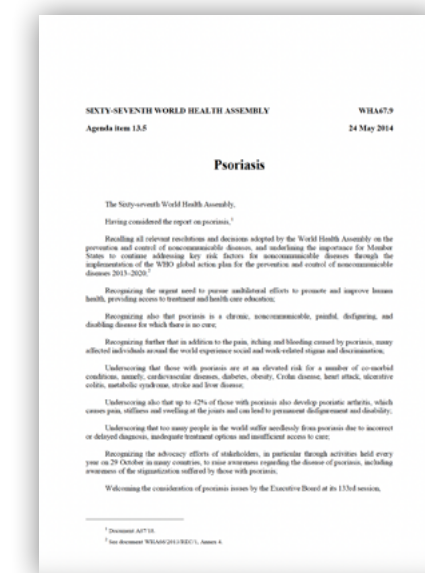
Global



Download

2006

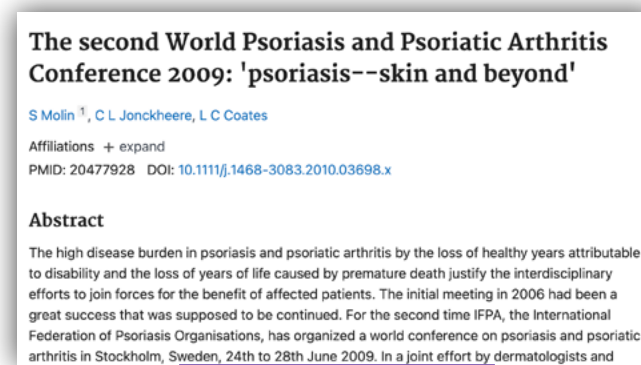
IFPA identifies a need to advocate for psoriasis on a national and international scale



Download

2014

The World Health Assembly adopts a resolution on psoriasis



Download

2009

New evidence prompts IFPA to draft and send a policy paper on psoriasis to the World Health Organization



Download

2016

The World Health Organization releases a report with recommended actions for advocates, health care decision-makers and policymakers

Regional



Learn more

2010

PsorAsia is established and becomes a member of IFPA to represent the interests of people living with psoriatic disease in the Asia-Pacific region



Learn more

2022

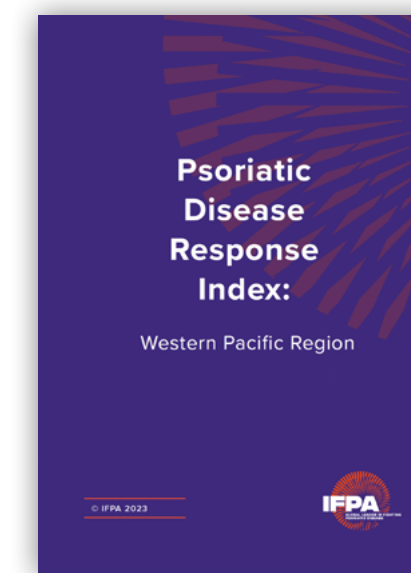
IFPA hosts the first regional IFPA Forum 2022 in Europe



Learn more

2023

IFPA, in partnership with PsorAsia, hosts the second regional forum: Speaking Up for Psoriatic Disease in Asia



Download

2023

The Psoriatic Disease Response Index - Western Pacific measures health systems' responses to psoriatic disease in five countries in the Asia-Pacific region



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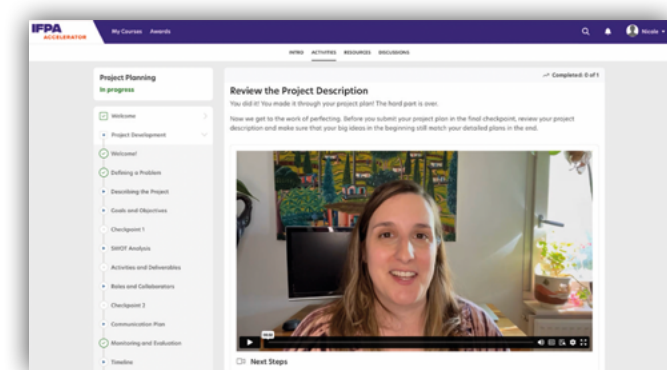
IFPA MEMBER SUPPORT

IFPA Member support

IFPA members can access a variety of information and resources, including project funding and training.

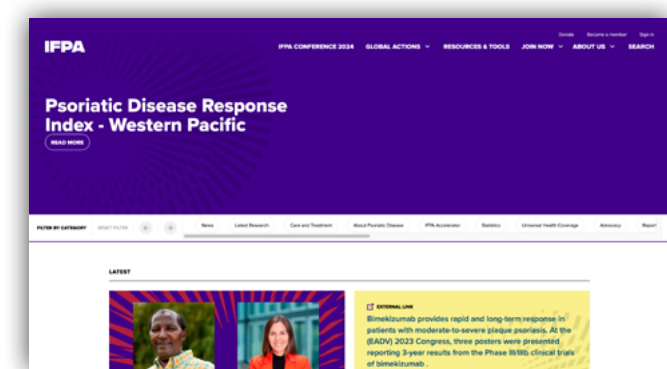
IFPA member training

Creating capacity-building opportunities for IFPA members is an important function of the organization.



Download

IFPA Accelerator is a skills-building program for patient advocates. The program includes a virtual project planning course for IFPA members with instructions, advice and helpful exercises for learning about each step of the project development process from conceptualization to completion.



Learn more

The **IFPA website** hosts a variety of resources to strengthen national advocacy, awareness, or peer support. Toolkits, webinar recordings, statements, white papers, or reports are openly available on the IFPA website under tools and resources.



Nguyen Tran Anh Thu
Reporter from Voice of Vietnam at the IFPA Forum Asia 2023



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IFPA MEMBER SUPPORT

Project funding

IFPA supports efforts worldwide to strengthen patient organization’s ability to act.

The Solidarity Fund

The IFPA Solidarity Fund was created to address the funding gap many members face by awarding grants to support psoriatic disease advocacy, education and awareness-raising. IFPA member organizations can apply. [Learn more.](#)

Project Rare GPP funding

Project Rare GPP’s vision is to improve associations ability to help meet the needs of those living with generalized pustular psoriasis (GPP), that are too often left behind, and who are most in need of relief. Funding is allocated for patient organizations that want to:

- connect and improve wellbeing and quality of life of those affected
- initiate projects to improve patient experience
- provide or support participation in education or networking events.

Patient associations can apply for funding through IFPA. Projects are prioritized according to impact, reach and collaboration and three-year program awards are granted on a regular basis. [Apply here.](#)



Better practice



Philippines: Psoriasis Philippines (PsorPhil) GPP CARE project

The project is a comprehensive initiative to enhance support for people living with GPP through consolidated assistance, research, and education. This involves building a network with patients, doctors, and researchers. It is designed to provide enhanced care to individuals with GPP through various initiatives, including a patient-powered registry, GPP support group, patient rescue activities, networking with hospitals, and collaboration with different trial sites.



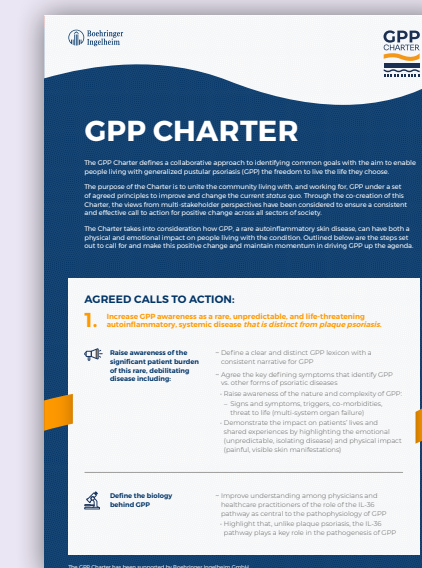
Malaysia: GPP Patient Support (GPS) Navigator Program

The program trains volunteer ‘Navigators’ to offer psychosocial, health literacy, and emotional support to individuals coping with GPP. It is a component of a collaborative effort involving patient organizations, GPP specialist centers, and medical societies, all working together to assist patients throughout their GPP journey. It focuses on fulfilling patients’ needs for emotional support, access to information, and a sense of community throughout their experience with GPP.

Tools and resources

The GPP Charter

The GPP Forum report



Download



Download



IFPA MEMBER SUPPORT



Watch

Uplift Innovation Program

The program is geared towards helping doctors and patients have more transparent conversations about plaque psoriasis and psoriatic arthritis. Grant awards are given to organizations to support projects encouraging open discussions about a patient's health and treatment objectives and enhancing collaboration.



Learn more

Start-up Fund

Advocates for psoriatic disease, individuals dedicated to supporting patients with psoriatic disease, and representatives from organizations that aid those with psoriatic disease in their countries can approach IFPA about the eligibility criteria for applying for funding when starting a new patient association.

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IFPA: The Good Care Initiative

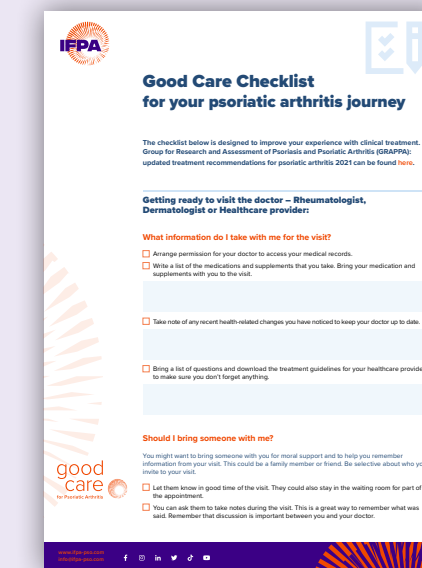
The Good Care initiative strives to promote advocacy and enhance understanding of psoriatic arthritis. In this initiative, IFPA aims to partner with rheumatologists and the patient community to raise awareness about new treatment guidelines, aiming to enhance the quality of life for individuals with psoriatic disease worldwide.

Tools and resources

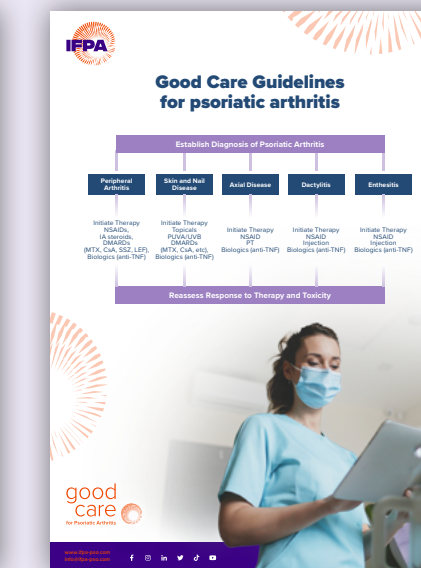
Living with psoriatic arthritis – checklist and toolkits

Treatment guidelines for psoriatic arthritis – what's new

Social media toolkit



Download



Download



Download

PSA and Mental Health

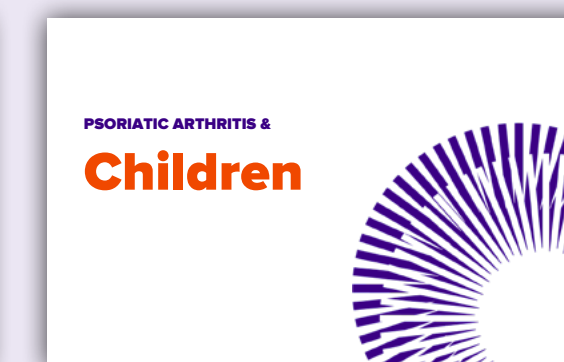
Reproductive Health booklet

PSA and childcare booklet

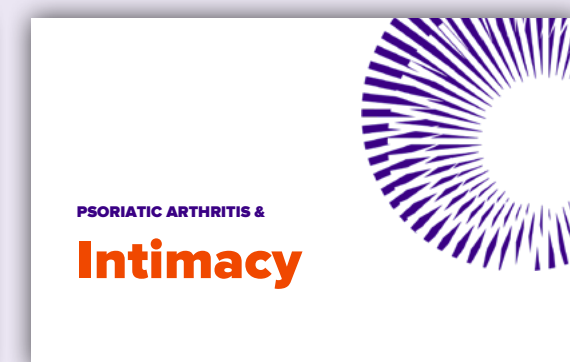
PSA and Intimacy booklet



Download



Download



Download



ROADMAP ACTIVATION

Getting started

The following section provides a variety of links to resources, tools, and good practices. These include good practice cases from the Asian Region and other countries and regions worldwide. The aim of sharing these resources, tools, and good practices is to spark inspiration for developing local strategies and action plans that align with the roadmap.

How to navigate this section

The section is set out as follows:



Themed section headers

There are four section:

- Access to care
- Managing and addressing comorbidities
- Mental health and psoriatic disease
- Social and familial impact of psoriatic disease

Priority asks

For each priority ask, a list of actions is proposed for advancing advocacy in relation the specific priority ask. A full list of priority asks is available in the IFPA Asia Roadmap document. Learn more.

Better practices/Tools and Resources

A selection of examples has been identified to illustrate how proposed asks/actions were manifested in other countries within the region or globally.

The IFPA Asia Roadmap and framework

The roadmap is the primary outcome document from the IFPA Forum Asia 2023. The purpose of the roadmap is to set the strategic direction for advocacy action in the Asian Region. In the roadmap, a framework sets out the goals and several priorities for each of the four thematic areas for focusing action. The priority asks emerged and were refined as part of the consultative process leading up to the IFPA Forum Asia 2023 and at the event itself.

Download a poster with the framework as outlined in the roadmap



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PRIORITY ASK 1

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

Advocacy actions

List the types of advocacy tools that would be beneficial to develop. Try to learn from what other patient associations have done.

Develop the education and communication materials for health care professionals identified as relevant in your context. If possible, involve one/several health care professionals close to your organization.

Plan and action your outreach to health care professionals with the tools and materials collated and developed.

Better practice

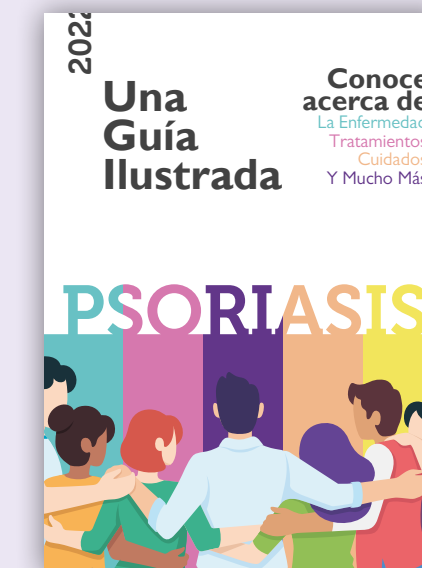


Vietnam: PsorViet Radio podcast

Four volunteers from the Vietnam Psoriasis Association began the PsorViet podcast “Da lieu & Suck hoe” (Skin disease and health) in 2021. With IFPA’s solidarity fund funding, the team expanded to 22 members, including dermatologists, nurses and patients. The podcast reaches thousands of people. [Learn more.](#)

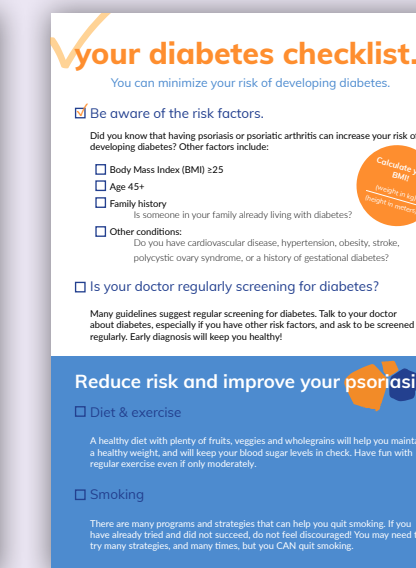
Tools and resources

Psoriasis: An illustrated guide in Spanish



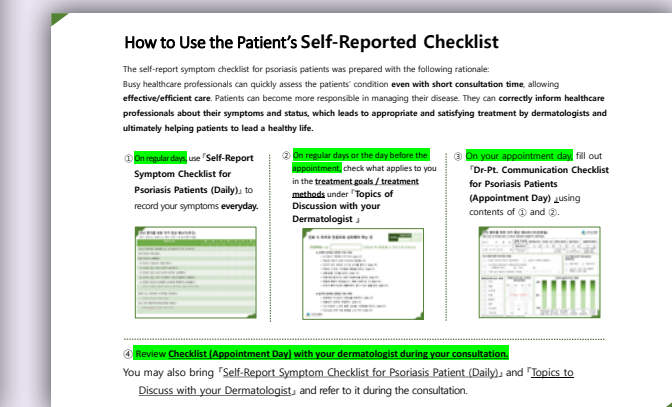
Download

The checklist on psoriatic disease and diabetes



Download

Self-report Symptom Checklist for Psoriasis patients



Download



ROADMAP ACTIVATION / ACCESS TO CARE

PRIORITY ASK 2

Support or encourage the development of guidelines and protocols for diagnosing and managing psoriatic disease

Advocacy actions

Identify other partners interested in developing national guidelines on psoriatic disease, where they are absent or need to be updated.

Establish a formal collaboration with partners identified and initiate guideline development.

Work with partners to produce a guideline document.



Dr Colin Theng
Dermatologist and President of the Singapore Psoriasis Association speaking at the IFPA forum

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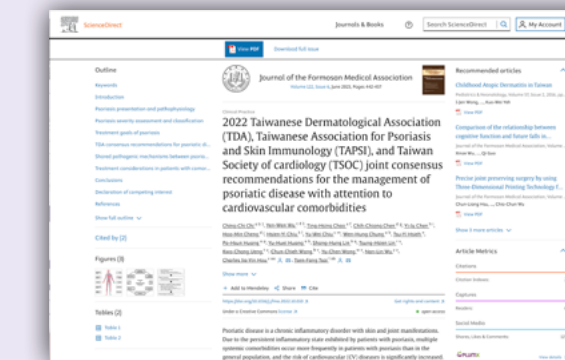
Tools and resources

Guidelines in the Asian Region

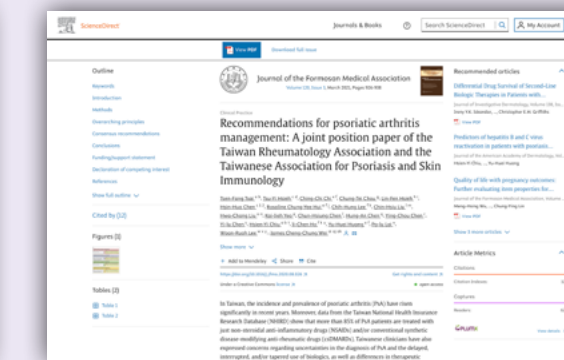
2022 Joint consensus recommendations for the management of psoriatic disease

Recommendations for psoriatic arthritis management

Guidelines for the Diagnosis and Treatment of Psoriasis in China: 2019 Concise Edition



Download



Download



Download

International guidelines

Key updates to the Group for Research Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) treatment recommendations for psoriatic arthritis



Learn more





ROADMAP ACTIVATION / ACCESS TO CARE

PRIORITY ASK 3

Address health care system challenges that prevent equitable access to treatment and care

Advocacy actions

Learn from the COVID-19 pandemic to identify ways of using digital technologies to improve access and address unequal or inequitable care.

Compile better practices and host discussions with different stakeholders about tele dermatology and inequity in access.

Promote tele dermatology at events, roundtable meetings and conferences to help bridge gaps in care in rural or underserved areas and provide equitable access to treatment.

Identify entry points and plan how to approach policymakers to motivate for the inclusion of legislation on psoriatic disease treatment and management within the Universal Health Coverage (UHC) framework to ensure health care access and protection of the most vulnerable.

Plan a campaign to include legislation on psoriatic disease treatment and management within UHC.

Action the campaign.

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Philippines: National Psoriasis Care Act

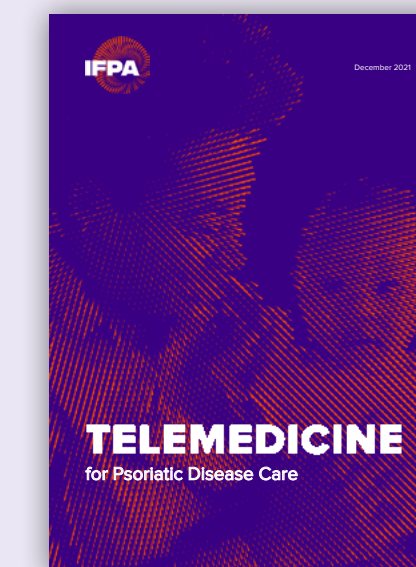
In 2021, House Resolution No. 9821, more commonly known as the National Psoriasis Care Act, was filed. The bill aims to ensure that Filipinos afflicted with psoriatic disease will have equitable and affordable access to medicine and treatment that could benefit almost 2 million people and their families. The patient association in the Philippines, PsorPhil, was critical in highlighting the stories of people affected by psoriatic disease to policymakers and providing input towards the draft legislation. [Learn more.](#)



Panama: Psoriasis Bill

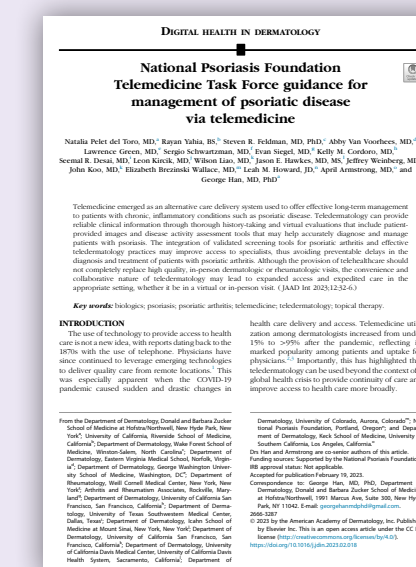
Members of the Panama Psoriasis Foundation of Panama have advocated for seventeen years for a Bill on psoriasis into law. They are now working on a Roadmap for the implementation of the law. [Read the interview.](#)

Tools and resources



Download

Telemedicine for Psoriatic Disease



Download

National Psoriasis Foundation Telemedicine Task Force guidance for the management of psoriatic disease via telemedicine



ROADMAP ACTIVATION / ACCESS TO CARE

PRIORITY ASK 4

Improve access to biologic therapies and other advanced treatments for psoriatic disease

Advocacy actions

Increase awareness of the barriers to access to biological treatment.

Work with partners to promote the inclusion of biological treatment in the National drug formulary

Develop a policy brief with a clear set of demands that can be presented to policymakers.

Establish how to identify gaps that may affect the future treatment supply and consider setting up a system with partners to track clinical research.

Use the data collected to support campaigns on improved access to biological treatments.

Support knowledge-building around biological treatments and precision medicine that can be used to support clinicians.

Determine whether working with partners in your country or region to build an investment case would be a feasible project for your patient association. Identify potential partners.

If an investment case is a longer term project your patient association is interested in, then start by learning from other countries.

Plan and develop the investment case.

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China: Patient advocates engaged with the media on psoriasis drug access

In a recent policy address, psoriatic disease advocates from China urged the government to make it easier to access biologics and to introduce more affordable mainland drugs, given that the same biologics in mainland China cost significantly less than in Hong Kong. [Read the article \[Chinese\]](#).



China: The Dandelion Web-based General Education project

A series of live broadcast sessions for clinicians were conducted to update clinicians on psoriasis research. These education sessions, which included topics on biological drugs and targeted treatment and took place once every two weeks, sought to popularize and interpret the science on psoriatic disease. [Access the PPT \[Chinese\]](#).



Philippines: A roundtable discussion on improving health care for psoriatic disease

The patient association PsorPhil held a roundtable discussion with policy decision-makers with the intention that the recommendations on biological treatments from the event would be included in the Philippine National Drug Formulary. [Learn more](#).

Europe: EUROPSEVATORY project

EUROPSO is the European Federation of Psoriasis Association that receives country-specific information data from its member European countries. The EUROPSEVATORY project aims to provide a comprehensive overview of psoriatic disease in Europe. [Read the article](#).

Tools and resources



Download

Evaluation of health technologies from a social perspective: Social Return on Investment in Psoriasis



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Addressing and managing comorbidities

PRIORITY ASK 1

Increase awareness among health care professionals

Advocacy actions

Share better practices on models of care with health care professionals as inspiration for how screening for comorbidities such as cardiovascular disease or diabetes is conducted elsewhere.

Ask health care providers for screening for metabolic diseases to be part of routine clinical practice through dermatologists and primary care.

Highlight opportunities to health care providers for routine screening of metabolic disease at the primary care level.

Better practice



Singapore: The National Skin Centre – Psoriasis Unit screens for metabolic syndrome. Two-thirds of patients who visit the psoriasis/photodermatology clinic were screened for metabolic syndrome. Reminders are also sent to doctors to screen psoriasis patients for metabolic syndrome every six months if patients have not done so, either in the National Skin Centre or through a general practitioner or polyclinic. [Visit the website.](#)

Tools and resources

Inflammation as a link between obesity, metabolic syndrome and type 2 diabetes



Download





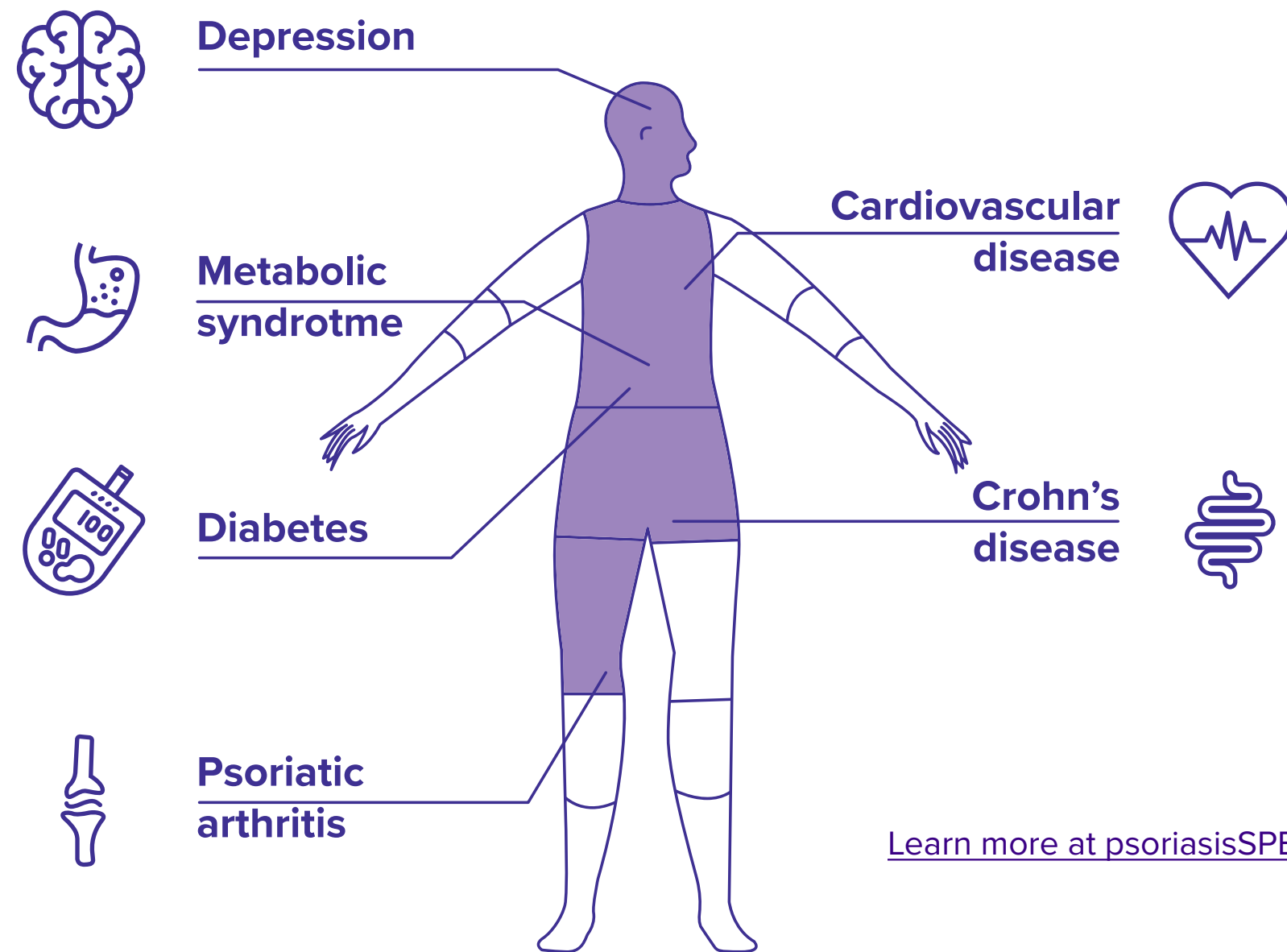
PRIORITY ASK 2 Promote patient education and awareness of comorbidities and their risk factors

Advocacy actions

Inform patient association members and other patients about the increased risks for comorbidities.

Consider novel ways to bring awareness and educational messaging across to people with the condition, including those at risk for comorbidities.

Develop a communication plan around the novel educational materials brainstormed.



[Learn more at psoriasisSPEAKS](#)

International better practice



Ireland: Let's talk psoriasis video and podcast series

People with psoriatic disease are experiencing some of Ireland's longest delays to access the specialist care they desperately need. This first series of its kind is designed to bridge this gap in support by providing access to expert guidance from leading Irish dermatologists and health care professionals to help people manage their psoriasis. At the same time, they wait to access specialist care. One episode is dedicated to psoriatic arthritis. [Listen to the podcast.](#)

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PRIORITY ASK 3 Improve access to care through health care professional training

Advocacy actions

Investigate funding opportunities or approaches to educate or train more health care professionals and potentially advocate for that within institutions or at a national level.

Identify partners with whom to develop training opportunities.

Collaborate with health departments and local or international partners to support or organize health care professional training.

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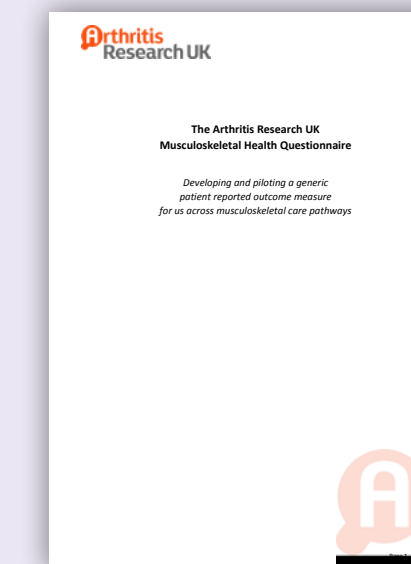


Global: Collaboration advancing research for individuals living with psoriatic disease. Psoriatic disease presents many unmet needs and challenges in care. Early diagnosis is crucial. Therefore, the International Dermatology Outcome Measures (IDEOM) and IFPA are working in collaboration to advance research and right access to care. IDEOM has identified the necessity of a validated musculoskeletal questionnaire (MSK-Q) instrument, a tool to help achieve this goal. IFPA will provide access and extend the tool's reach to their global member community through various channels and virtual educational workshops.

The research collaboration will enable IDEOM to engage directly with individuals affected by psoriatic disease, fostering a deeper understanding of their needs and concerns.

Tools and resources

Musculoskeletal Health Questionnaire brief



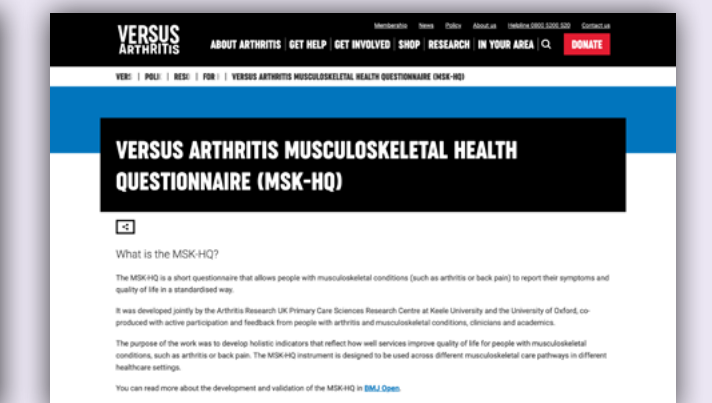
Download

Musculoskeletal Health Questionnaire Report



Download

Musculoskeletal health questionnaire (MSK-HQ)



Learn more



PRIORITY ASK 4 Encourage person-centered and multidisciplinary care

Advocacy actions

Emphasize the importance of holistic care for people with psoriatic disease and comorbidities as the best approach.

Explore digital health opportunities and determine if there are overlaps in other disease areas where patient associations are active.

Promote the use of digital health to facilitate access to a multidisciplinary care team or coordination between team members.

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China: Survey to understand the needs of people being treated for psoriatic disease
Physicians in China designed a survey to better understand the needs of people living with psoriatic disease. The Mutual Assistance Fund for Psoriasis in China is teaching patients to use the tool to understand and describe their needs.



Chile: A study on comorbidities in people with psoriasis living in Chile
The study aimed to see if there was a relationship between comorbidities and the severity of psoriasis among close to six hundred participants. The findings suggest assessing patients with psoriasis for comorbidities in a multidisciplinary setting is essential.

Tools and resources

Comorbidities in Chilean patients with psoriasis: a Global Healthcare Study on Psoriasis



Download



Mental health and psoriatic disease

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PRIORITY ASK 1

Help capacitate health care providers to identify and address mental health needs

Advocacy actions

Identify gaps in access to trained psychologists capable of identifying and treating mental health that patients can be referred to.

Speak with primary care staff, including general practitioners about how mental health issues affect people with psoriatic disease and how they can raise the conversation about mental health with a patient.

Support the development and use of digital health technology that improves access to consultations with primary care providers, psychological counseling, and other mental health services such as peer support.

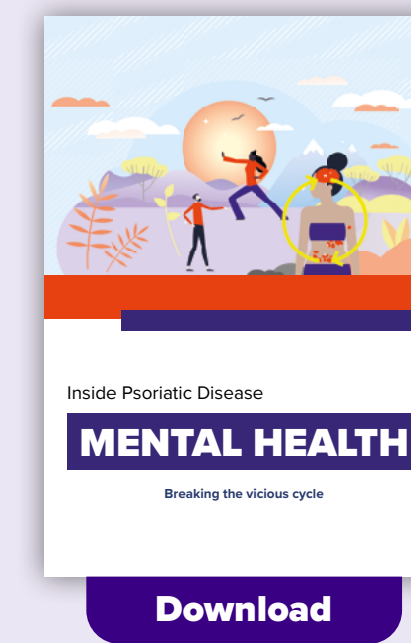
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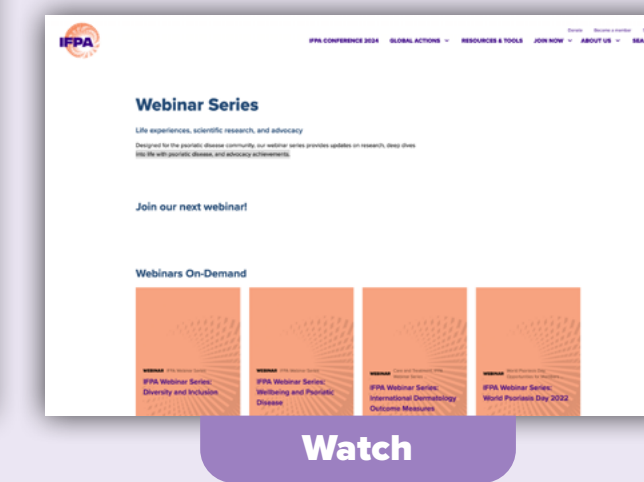
Peru: A program to provide psychological support
The patient association APAPSO is launching a new program that will enable patients to deploy their own human resources. The program, developed with the support of two psychologists and directed by 14 patients, will help people living with the disease learn to cope healthily with prejudices and come to terms with their illness.

Tools and resources

Inside Psoriatic Disease: Mental health

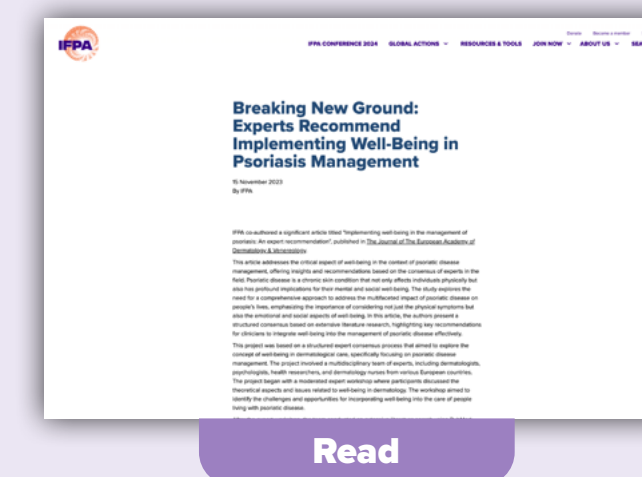


IFPA Webinar Series: Well-being and Psoriatic Disease



IFPA co-authored a significant peer-reviewed journal article that addresses the critical aspect of well-being in psoriatic disease.

Breaking New Ground article review



Implementing well-being in the management of psoriasis





PRIORITY ASK 2

Help capacitate health care providers to identify and address mental health needs

Advocacy actions

Provide inspiration, tools, and insights that will allow people with psoriatic disease to positively reframe their life purpose and take action needed to care for their health.

Educate people with psoriatic disease about the signs and symptoms of poor mental health, why it must be addressed and that they should proactively seek help.

Inspire individuals with psoriatic disease positively reframe their life purpose and take action needed to care for their health.



Jannarie Zarzoso
Miss Universe Philippines Finalist and President of the PsorPhil Youth Association at the IFPA Forum Asia 2023

Tools and resources

Psoriatic Disease and Mental Health



An interview with Jannarie Zarzoso about her journey with psoriatic disease



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PRIORITY ASK 3

Raise awareness about mental health, reduce stigma and discrimination

Advocacy actions

Conduct public awareness campaigns aimed at changing perceptions about the disease.

Recruit potential patient advocates willing to share their experience of living with psoriatic disease and how it has impacted their mental health and management of the condition.

Help patient advocates to identify platforms that allow them to tell people about psoriatic disease and mental health.



Stand-up comedian
Let's laugh it out! comedy show in China

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China: Laughing it out stand-up comedy

The medium of stand-up comedy is being used in China to help break the silence on psoriatic disease.



China: Hello, my perfect lover!

A first-of-its-kind movie based on a true story explores the theme of having a romantic relationship with and acceptance of living with psoriatic disease, which, with the correct treatment, can be effectively managed.



Japan: Music video for psoriasis patients “Hareyuku Michi – a way to be cleared”

The music video was created to inspire a deeper understanding of psoriatic disease and its impact on people living with it. [Watch the video.](#)



Malaysia: My Skin by Psoriasis Fighters

The psoriasis fighters went on a musical journey to inspire people living with psoriatic disease not to lose hope and raise awareness about access to treatment. [Watch the video.](#)

Tools and resources

The Shedding the Light on Psoriasis patient advocate campaign

Resources to get started with advocacy



Watch



Read



PRIORITY ASK 4

Campaign government and policymakers for increased funding and policy support

Advocacy actions

Highlight the financial burden for society when people with psoriatic disease suffer from mental health issues and cannot work, perform at work or contribute as community members.

Use the insights to develop health economic arguments that can be presented to policymakers.

Work with advocacy organizations from other disease areas to campaign for increased funding and policy support for integrated mental health care services and mental health professionals' education, including community-based professionals.

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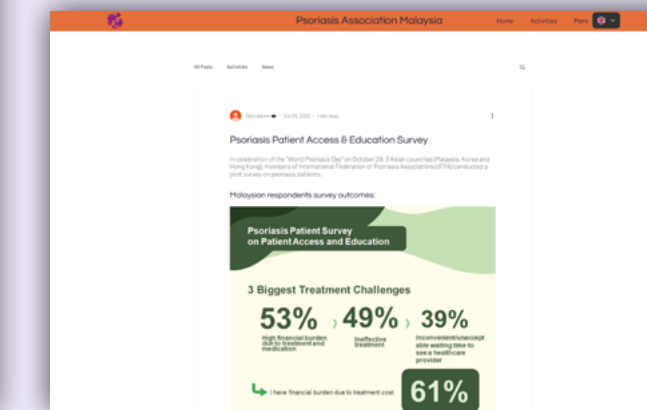
Tools and resources

Psoriasis – Lifting the burden of stigma and changing lives



Download

Take inspiration from the Patient Access and Education Survey



Download



Xingxiang Shi
China Mutual Assistance of Psoriasis Patients (Founder and Director) and Chronic Skin Disease Fund (Deputy Director and Secretary-General)





Social and familial impact of psoriatic disease

PRIORITY ASK 1

Educate employers about creating a supportive workplace

Advocacy actions

Develop a report on the experiences of people with psoriatic disease in the workplace.

Develop additional tools and promote the findings and actions proposed in the report to employers so that they can be informed about improving working conditions for people with psoriatic disease.

Use the report as a conversation-opener when meeting others to discuss the topic.

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Canada: Working it out

The Canadian Psoriasis Network (CPN), the Canadian Association of Psoriasis Patients (CAPP), and Unmasking Psoriasis, an awareness group in Saskatchewan, Canada, collaborated to develop an online survey to better understand and address the workplace challenges and needs of people living with psoriatic disease. The survey results were made available as part of the first phase of activities. Phase two focused on public policy, including a white paper, meetings with policymakers to share the findings and recommendations, and mapping policies and programs for employment and disability that affect people with psoriatic disease.

Tools and resources

Working it Out: A report on the experiences of Canadians in the workplace



Download



PRIORITY ASK 2

Highlight the need for policymakers to promote social and familial support

Advocacy actions

Adapt the findings from the workplace report into a policy brief/s or white paper analyzing the local policy landscape that can be used in advocacy with policymakers.

Set up meetings to share findings and recommendations with policymakers.

Map policies and programs related to employment and disability that affect people with psoriatic disease in the workplace

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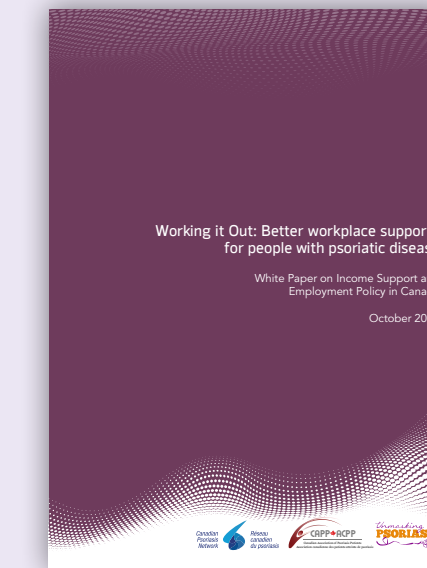


IFPA ambassadors
Stop the Stigma Now! campaign

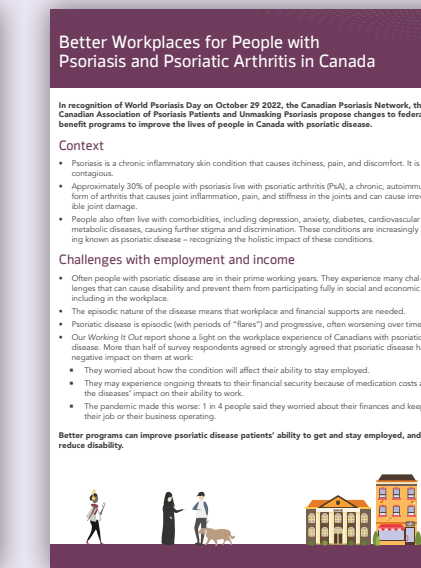
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Better workplace supports for people with psoriatic disease

Work it out: two-page policy brief

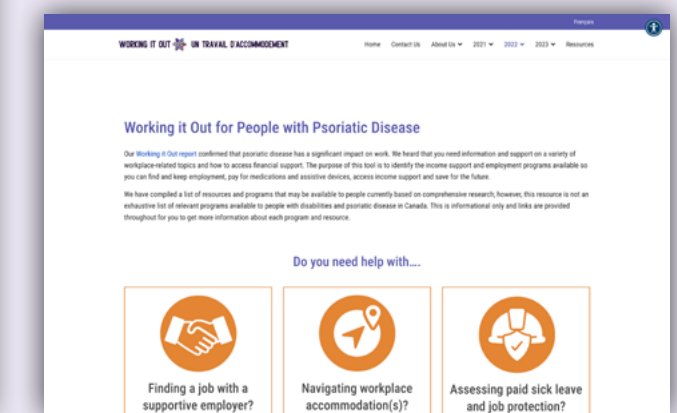


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Mapping of policies and programs



Download



PRIORITY ASK 3 Provide a community for patient association members

Advocacy actions

Identify patient advocates to tell their stories of hope/inspiration to build empathy and understanding with their audience.

Organize outreach to schools and/or communities to provide awareness of psoriatic disease invite a patient advocate.

Set up a community-based support group where patients, families, and caregivers can connect with one another.



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Philippines: Caravan of Hope Youth Outreach Program

PsorPhil's youth chapter visits schools and campuses to educate students of all ages about psoriatic conditions. The campaign focuses on unpacking the nature of psoriatic disease, its typical symptoms, and the associated challenges. A key component of this program is having a speaker living with psoriatic disease share their personal experience.



Philippines: PsorCoach Program and National Youth Summit

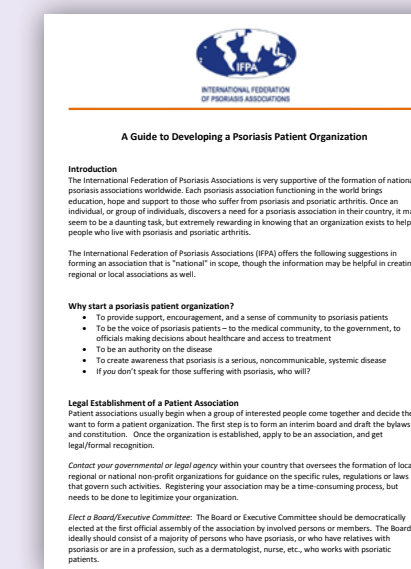
The annual program trains you with psoriatic disease to as coaches for other youth. In addition, PsorPhil hosts the "National Youth Summit" biennially to empower young individuals with psoriatic disease.



Singapore: National Skin Centre support group

The National Skin Centre provides a range of support groups tailored to the unique needs of the patients and caregivers attending the center. Support groups play a crucial role in offering psychosocial and emotional assistance for coping with psoriatic disease.

Tools and resources



A guide to developing a psoriasis patient organization



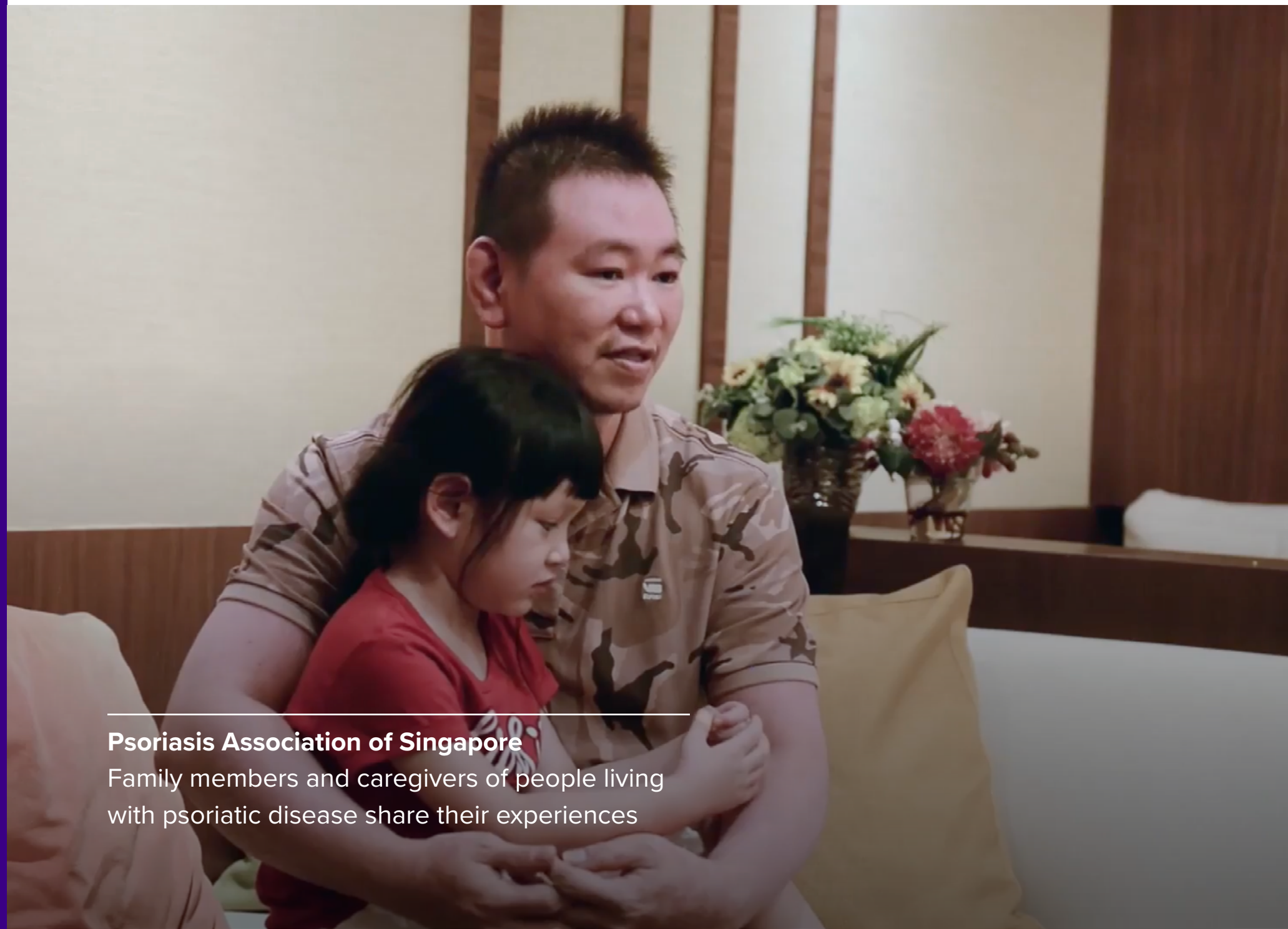
PRIORITY ASK 4 Encourage family members related to a person with psoriatic disease and friends to provide support

Advocacy actions

Develop educational materials for caregivers addressing issues and concerns they may have.

Establish peer support for caregivers/family members so that they can better cope with the demands of caregiving.

Invite caregivers to share their experiences of caring for a person with psoriatic disease as a way to encourage and support others in similar circumstances.



Psoriasis Association of Singapore
Family members and caregivers of people living with psoriatic disease share their experiences

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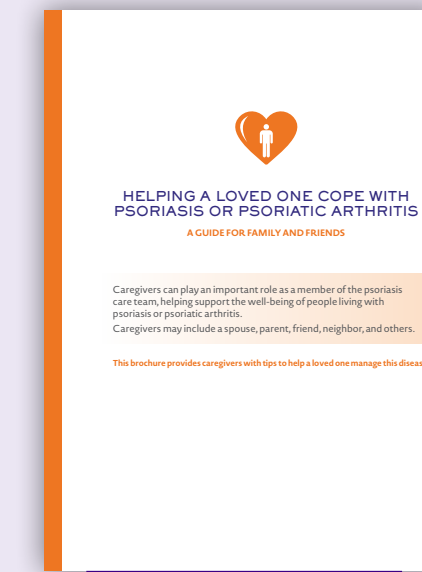
Better practice



Singapore: Caring for a person with psoriatic disease video
The patient association in Singapore interviewed caregivers about their experience of supporting someone with psoriatic disease. [Watch the video.](#)

Tools and resources

A guide for family and friends



Download

Supporting Loved Ones with Psoriatic Disease



Read



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Communication considerations

The approach for engaging with people living with psoriatic disease and policymakers varies depending on the country, stakeholder involvement, and specific topics at hand. The content and messaging recommendations provided serve as guidance and must be customized to align with your country or region's most fitting channels and tone.

By leveraging suitable communication channels and customizing messages to resonate with local contexts, a patient advocacy group can significantly bolster its efficacy in communicating and engaging with diverse audiences across Asia.

Digital Platforms and social media

In Asia, several social media channels and digital platforms are widely utilized, each offering unique advantages.

Here are a few examples:¹



WeChat (China): WeChat is the most used social media platform in China with more than 1.3 billion active users in 2023, offering features for content sharing and community building. The App's functionality and wide user base make it an effective tool for reaching a large audience in China.



LINE (Japan, Taiwan, Thailand, Indonesia): LINE is the preferred messaging app with countries such as Japan boasting 95 million active users and Thailand 51 million. Line has brand accounts for organizations and associations, making it an ideal platform for communication and community engagement.



Facebook and Instagram: These platforms are widely used across Asia for content sharing and community engagement. In India, there are more than 350 million active Facebook users, while Thailand has 99 million and Philippines has about 71 million. Instagram is used by 17 million people in South Korea. Their broad user base and versatile features make them effective for reaching diverse audiences.

Multi-channel approaches

How people receive and consume news and information varies with demographics, therefore consider a multi-channel approach to reach diverse groups. In the interests of equity and promoting access to information, treatment and care, be mindful that some groups might have limited internet access.

Direct communication

Attending conferences, seminars, and networking events relevant to the policy area of interest can provide opportunities to engage with policymakers, government officials, and key stakeholders. These can also be excellent platforms for sharing or promoting policy briefs and reports.

Policy briefs

Policy briefs can effectively communicate your message to policymakers. Distributing these through email or official channels can be impactful.

Guidelines and compliance

Prioritize adherence to local regulations, especially when engaging with audiences across different regions, ensuring awareness and compliance with health care communication regulations. Given the varying regulatory landscapes in different countries for healthcare communication, we strongly advise seeking specialized local legal counsel if there are uncertainties.

¹Dash Hudson. Popular APAC Social Media Platforms Marketers Should Know. <https://www.dashhudson.com/blog/apac-social-media-platforms>



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Arthritis Research UK

- Versus arthritis musculoskeletal health questionnaire (MSK-HQ)
- Arthritis Research UK Musculoskeletal Health Questionnaire brief
- Arthritis Research UK Musculoskeletal Health Questionnaire Final Report on Piloting study

The Good Care Initiative

- Living with psoriatic arthritis – checklist and toolkits
- PSA and Mental Health Reproductive Health booklet
- PSA and Intimacy booklet
- PSA and childcare booklet
- Treatment guidelines for psoriatic arthritis – what's new
- Social media toolkit and images

IFPA resources

- IFPA Forum 2022 in Europe Briefing book

IFPA Forum Asia 2023 briefing book

- English, Japanese, Korean, Traditional Chinese, Malay, Tagalog

IFPA Forum Asia 2023 theme briefs

- Access to care for people with psoriatic disease
- Addressing and managing comorbidities
- Mental health and psoriatic disease
- Social and familial impact of psoriatic disease

IFPA resources

- Psoriatic Disease and Mental fact sheet
- Inside Psoriatic Disease: Mental health
- Psoriatic Disease Response Index - Western Pacific/ Social media toolkit
- Telemedicine for Psoriatic Disease

Solidarity Fund

- Well-being and Psoriatic Disease

World Health Organization

- World Health Assembly 2014 Resolution (WHA 67.9)
- World Health Organization Global Report on Psoriasis

Working it out Canada

- Working it out: A report on the experiences of Canadians in the workplace
- Work it out: two-page policy brief
- Working it out: Better workplace supports for people with psoriatic disease – white paper on income support and employment policy in Canada
- Mapping of policies and programs: A list of resources and programs was compiled of what may be available to people currently based on comprehensive research



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Peer-reviewed articles

- Evaluation of health technologies from a social perspective “Social Return on Investment” applied to PSORIASIS
- Implementing well-being in the management of psoriasis: An expert recommendation
- Inflammation as a link between obesity, metabolic syndrome and type 2 diabetes
- Comorbidities in Chilean patients with psoriasis: a Global Healthcare Study on Psoriasis

Patient/HCP check-list

- Self-report Symptom Checklist for Psoriasis patients
- The checklist on psoriatic disease and diabetes

Surveys

- Patient Access and Education Survey

Webinars

- National Psoriasis Foundation webinar: Supporting Loved Ones with Psoriatic Disease

Videos

- My Skin by Psoriasis Fighters
- Psoriasis Patients “Hareyuku Michi – a way to be cleared” video
- The Uplift Innovation Program

Brochures

- National Psoriasis Foundation Telemedicine Task Force guidance for the management of psoriatic disease in telemedicine
- Psoriasis: An illustrated guide in Spanish

Guidelines

- 2022 Taiwanese Dermatological Association (TDA), Taiwanese Association for Psoriasis and Skin Immunology (TAPSI), and Taiwan Society of Cardiology (TSOC) joint consensus recommendations for the management of psoriatic disease with attention to cardiovascular comorbidities
- Recommendations for psoriatic arthritis management: A joint position paper of the Taiwan Rheumatology Association and the Taiwanese Association for Psoriasis and Skin Immunology

- Guidelines for the Diagnosis and Treatment of Psoriasis in China: 2019 Concise Edition
- Updated GRAPPA treatment guidelines for psoriatic arthritis/Key updates to the GRAPPA treatment recommendations for psoriatic arthritis



Tran Hong Truong
President of the Vietnam Psoriasis Network (PSORVIET) at the IFPA Forum Asia 2023



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Get in touch

IFPA

Founded in 1971, IFPA is the international federation of psoriatic disease associations. We are the psoriatic disease community. Our members represent over 60 million people living with psoriatic disease. Together, we advocate for a future where all people living with psoriatic disease enjoy good health and well-being, free from stigma and preventable disability and comorbidities.

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PsorAsia

Founded in 2012, PsorAsia is a regional organization in the Asia Pacific for psoriatic disease associations. PsorAsia is the regional arm of IFPA, and they represent the interests of millions of people living with psoriatic disease in the region.

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