IFPA FORUM
AFRICA 2026

ACTION PLAYBOOK

Guidance and tools to strengthen advocacy on psoriatic disease

INTRODUCTION

Welcome to the Playbook

The IFPA Forum Africa Roadmap sets out a shared vision and strategic direction for advancing psoriatic disease advocacy across the continent. This Playbook is its practical companion, it is a guide to help you turn that vision into action.

Structured around the Roadmap's three themes – Research, Rights, and Representation – it bridges the strategic priorities agreed at the Forum in Nairobi with the tools, tactics, and real-world examples you need to move forward. Adapt the tools to your circumstances, and draw on the examples from within and beyond Africa to find what works for you. As your advocacy develops, return to the Playbook. The further you go, the more of it will become relevant.

You do not need to start everywhere at once. Progress begins with one conversation, one relationship, one ask, consistently repeated.

IFPA and PsorAfrica are with you at every step.

What this Playbook covers

INTRODUCTION

Practical advice for advocates

Advocacy is the work of creating change in policy, practice, and public understanding. For patient associations, it means making the case to governments, health authorities, and the public that psoriatic disease is a serious, chronic non-communicable disease (NCD) that is treatable, and in need of better care.

It can take many forms, such as a meeting with a policymaker, sharing a patient story, joining a coalition, or submitting evidence to a national committee. In many African countries, psoriatic disease is still absent from health strategies and medicines lists, and Africa is often not mentioned at all on global agendas. Advocacy changes that. It gives policymakers the evidence to act and drives the decisions that determine whether people receive the care they deserve.

Plan your next steps

Good planning is half the work done. The Strategic Advocacy Planning Toolkit guides stakeholder mapping, links advocacy activities to objectives, and helps determine timelines and goals.

Access the Toolkit →

Research

Data on every aspect of psoriatic disease in African populations is urgently needed to support informed, evidence-based decisions that promote well-being for all.

ADVOCACY IN ACTION **RESEARCH**

Reliable data that puts people at the center

Data helps change perceptions and build the case for action. Evidence on burden and unmet need shows policymakers, funders, and health systems why psoriatic disease deserves attention and resources. Registries, prevalence studies, and real-world evidence strengthen the understanding of the disease, especially when research represents those living with it.

Guidance for advocates

Advocates must become familiar with the research landscape, build the evidence they need, and use data as a tool for change.

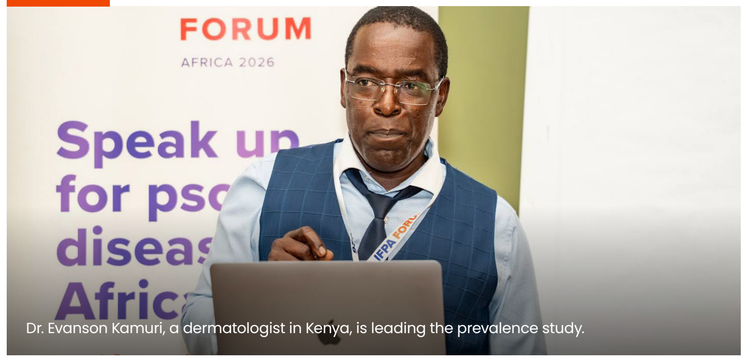
- **Start with existing resources** like surveys, clinic partnerships, and patient stories to build credibility.
- **Link data to specific policy asks** and real-world evidence gaps to influence decision-makers.
- **Position patient associations** as co-creators and use simple co-designed frameworks to enable feasible participation.

BETTER PRACTICES

Putting the needs of people living with psoriatic disease at the center of research

Effective dermatology care depends on research that reflects the full diversity of people living with psoriatic disease. Nonetheless, data gaps and barriers to participation mean that too many communities remain invisible in the evidence base.

KENYA



Dr. Evanson Kamuri, a dermatologist in Kenya, is leading the prevalence study.

Psoriasis registry and prevalence study

Kenya is advancing psoriatic disease research through two projects supported by international partnerships. Funded by the National Psoriasis Foundation, the Psoriasis Association Kenya (PAK) is creating the country's first **psoriasis registry** to study key factors affecting patients. Registries for psoriatic disease focus on observational real-world data and demand rigorous clinical methodology. A **psoriasis prevalence study**, backed by IFPA member the Danish Psoriasis Association, and funded by the Dr. Hoseah Waweru Solidarity Fund, is also pending ethical approval. **These efforts highlight how global funding and collaboration enable local associations to start high-quality research and advocacy projects.**

Read the full story →

IFPA

Breaking Barriers – patient participation in research

Breaking Barriers is a global initiative established by IFPA to uncover and overcome the barriers that prevent diverse communities from participating in research and care. **People living with psoriatic disease and healthcare professionals are invited to utilize and share the material created for this project.** Promoting diversity in research is relevant because when people are excluded from research, or feel under- or misrepresented, treatments risk being less effective for everyone. A case in point is clinical trials that draw on only a narrow demographic group; these risk producing results that do not reflect the broader population, leading to treatments that are less effective, or even harmful, for the groups left out.

Learn more →

ADVOCACY IN ACTION **RESEARCH**

Community evidence for better access

Community evidence reveals who is being left behind and why. In rural and under-resourced settings, local data can expose gaps in access to diagnosis, care, and treatment that national datasets often miss. By documenting lived experience and care barriers, advocates can make a stronger case for equitable, people-centered improvements.

Guidance for advocates

Turning an idea into a research project may feel overwhelming, but a simple four-step framework can help you move from question to action.

- **Question:** What is the clear, answerable research question grounded in both clinical need and patient experience?
- **Population and outcomes:** Who does this matter to, and what outcomes are most meaningful to people living with the disease?
- **Approach**: What is the most feasible way to study this, for example, a registry, survey, observational study, or multicenter collaboration?
- **Next step:** What is one realistic action you could take in the next 6-12 months to move this forward?

BETTER PRACTICES

From evidence to action

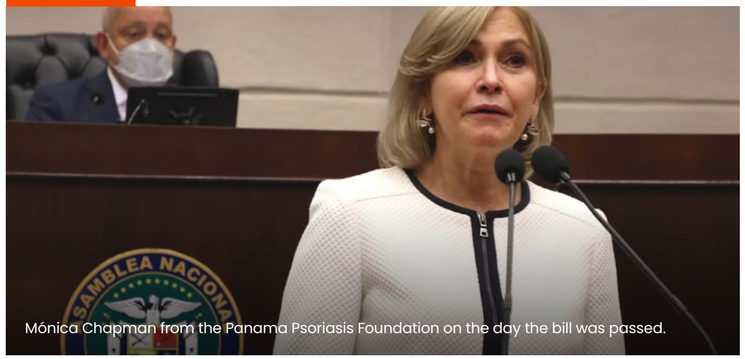
Sustained research is what turns policy commitments into measurable improvements in care for people living with psoriatic disease. The example from Canada demonstrates the value of longitudinal data tracking, while in Panama, a key component of policy implementation is ensuring that national epidemiological systems are in place.

CANADA

Pso Serious reports – a decade of research on access to care

Where you live can severely impact your ability to access care for psoriatic disease. In rural areas, waiting months to see a dermatologist or traveling long distances to an appointment is common. The province you live in can also determine which treatments are covered under public drug plans. These are key findings from Psoriasis Canada's Pso Serious 2024 report, which builds on a decade of research tracking progress on access to care and treatment. **A central takeaway from the latest report is its value as a roadmap for advocacy efforts addressing these ongoing concerns.**

PANAMA



Mónica Chapman from the Panama Psoriasis Foundation on the day the bill was passed.

From policy to access

In Panama, Law 322 declares psoriasis a disease of national interest, mandating public medical attention, research, and professional training for early detection and comprehensive treatment. Implementation now centers on a multistakeholder model that involves government entities. The model will focus on several core components, including establishing a national epidemiological data system to build the evidence base. As part of the pilot phase, initial field-based epidemiological data is being collected, with a national scale-up to follow once validated. **A key learning is that strong implementation architecture is critical, and community outreach accelerates impact.**

Key insights →

ADVOCACY IN ACTION **RESEARCH**

Exploring unmet needs with real-world evidence

Policymakers and health systems respond to evidence. Real-world data from patient surveys and lived experience give advocates local credibility, identify gaps in diagnosis and care, and guide association priorities. In Africa, where psoriatic disease data is scarce, documenting basic evidence on who is affected and what they need is advocacy in itself.

Guidance for advocates

Generative AI tools such as ChatGPT are transforming productivity, research, communication, and advocacy work.

AI can help:

- Draft neutral survey questions
- Remove ambiguity
- Standardize and organize responses
- Identify missing or duplicate data
- Categorize testimonials into themes
- Summarize patterns and trends
- Present findings to non-technical audiences

BETTER PRACTICES

Locally gathered survey data can drive regional advocacy and shape more responsive care

Understanding the true burden of psoriatic disease starts with listening to the people who live with it. Member-led surveys do exactly that, turning lived experience into evidence that can inform advocacy and guide policy decisions.

LATIN AMERICA

Regional survey on the unmet needs of people living with skin disease

A multicountry survey highlights the value of patient insights in understanding psoriatic disease. In Latin America, COLAPPIEL surveyed over 3,500 individuals with skin diseases across 14 countries, yielding key data on demographics, treatments, and patient experiences.

AI tools are a useful resource in developing a research project. However, a key message for advocates from the IFPA Forum Africa is that human oversight remains essential for interpretation, validation, ethics, and decision-making.

ADVOCACY IN ACTION **RESEARCH**

Resources and tools

The resources and tools listed are intended to offer patient advocates inspiration to build their own catalog of ideas for possible initiatives.

Reliable data that puts people at the center

Booklets:

Breaking the myths: clinical trials and psoriatic disease

Before you join a study: a practical guide for participation

Glossary of common terms in clinical research

Checklist:

Design it right: a checklist for diverse, equitable, patient-first trials

Websites:

Global Psoriasis Atlas (data on prevalence)

Embracing Diversity: The Imperative for Inclusive Clinical Trials

Peer-reviewed articles:

Establishment of the Kenyan Psoriasis Registry: A Case–Control Cohort

P16 Journey of psoriasis registry in Nigeria (Prince study)

Community evidence for better access

Report:

Pso Serious 2024: A report on access to care and treatment for psoriatic disease in Canada

Legal document:

Panama's Law 322 on Psoriasis

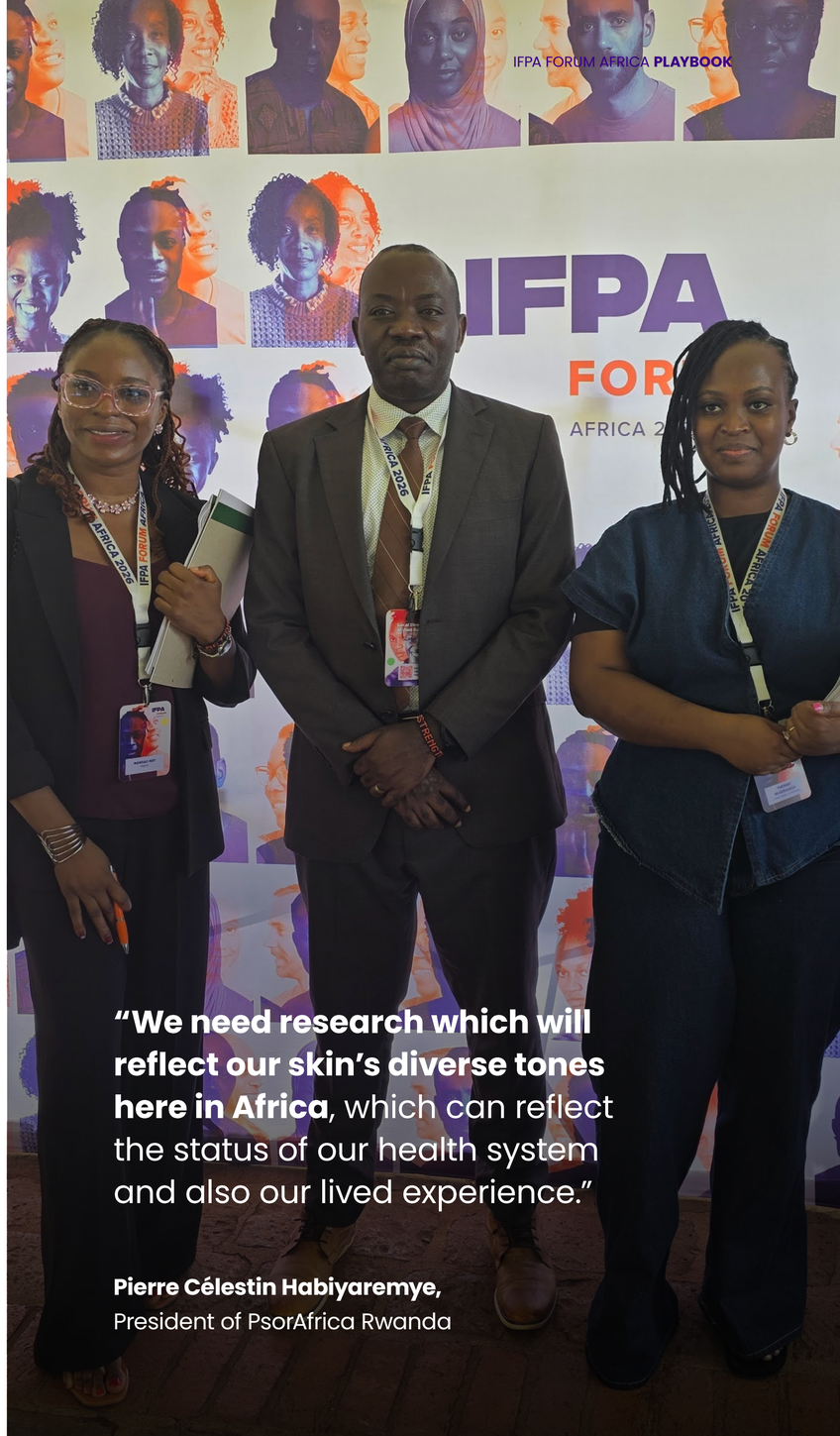
Uncovering unmet needs with real-world evidence

Report:

The Psoriatic response disease index for Africa on managing the disease (Ghana, Kenya, Rwanda, and South Africa)

Infographic:

Psoriasis Patient Access & Education Survey
Malaysia World Psoriasis Day 2022



"We need research which will reflect our skin's diverse tones here in Africa, which can reflect the status of our health system and also our lived experience."

Pierre Célestin Habiyaremye,
President of PsorAfrica Rwanda

Rights

Access, equity, and quality care – ensuring appropriate medicine availability, affordability, and acceptable quality of care for everyone with psoriatic disease.

ADVOCACY IN ACTION **RIGHTS**

Protecting the rights of your community

A rights-based approach to health starts from a simple premise that access to care is not a privilege; it is something everyone is entitled to, regardless of where they live, what they earn, or their condition. For advocates, this means understanding the specific barriers that prevent people living with psoriatic disease from getting the care they need, and knowing which levers can be pushed to remove them.

Guidance for advocates

Pointers for putting together your advocacy plan and activities:

- **Ground your advocacy in rights principles** to demand equity and accountability from policymakers.
- **Connect personal stories to policy gaps** to move decision-makers from awareness to action.
- **Use the right language** for your audience, and document everything to hold stakeholders accountable.

BETTER PRACTICES

Advocating for patients' rights

Protecting the rights of your community often requires direct engagement with policymakers and health authorities. Advocates can take different approaches. These include mobilizing rapidly in response to a specific policy threat and building sustained dialogue with the government through long-term advocacy platforms, as evidenced in Taiwan and Russia.

TAIWAN

Wang Ya Hsin from the Psoriasis Association of Taiwan helped lead the campaign.

Health is a human right

When Taiwan's government proposed policy changes that would have significantly restricted access to biologic therapies for thousands of people living with psoriatic disease, the Psoriasis Association of Taiwan mobilized quickly. It surveyed over 350 people living with psoriatic disease, compiled evidence from medical literature, and submitted a formal petition to legislators across party lines and to the Minister for Health, successfully halting the proposal. **Their experience is a powerful example of how patient associations can influence national reimbursement and medicines policy.**

Read the full story →

RUSSIA

Patient advocates attending the All-Russian Patient Protection Forum.

All-Russian patient protection forum

The Russian association Way to Health attended the annual patient rights forum on skin, pulmonological, and allergic diseases. The forum brings together experts from the medical community and government agencies. **In preparation, the association develops proposals for government agencies and encourages them to incorporate these recommendations into their care programs.** Over the past seven years, the forum has attracted around 9,000 participants from across the country.

Access to Care Statement →

ADVOCACY IN ACTION **RIGHTS**

The right to essential medicines

Essential medicines lists (EMLs) are vital tools that ensure people living with psoriatic disease have access to safe, effective, and affordable treatments. These lists, which include key medicines – such as topical corticosteroids, vitamin D analogs, systemic agents, and, more recently, biologics – set a global baseline for managing psoriatic disease. By standardizing care, EMLs help reduce treatment costs and improve people's quality of life.

Guidance for advocates

EMLs influence decisions around treatment, from global recommendations to local clinical practice.

- **The World Health Organization (WHO) Model List of Essential Medicines (EML)** provides an evidence-based benchmark.
- **The National Essential Medicines List (NEML)**, developed locally by countries, uses the WHO Model List as a starting point.
- **National formularies and procurement/reimbursement systems** are often used to guide what gets stocked, authorized, and funded in the public/insured system.
- **Clinical practice guidelines** commonly recommend medicines that are available and prioritized on NEMLs.

BETTER PRACTICES

From global policy to local practice: expanding access to treatment

When the WHO updates its Model EML, the ripple effects can reach patients in even the most resource-limited settings, but only when countries develop the capacity to act on that guidance.

GLOBAL HEALTH

Dr. Edwin Kojo Ogara of the WHO Kenya Country Office shared his insights on EMLs at the Forum..

The WHO adds biologics for psoriasis to the Model EML

In 2025, the WHO Expert Committee made a historic advancement by adding biologic therapies for psoriasis (namely adalimumab and ustekinumab) to the WHO Model EML. The addition of these two therapies, supported by leading dermatology and patient organizations, marks a groundbreaking development in the global fight against psoriatic disease. **The EML guides countries in prioritizing medicines, thereby paving the way for broader access to these effective treatments worldwide.**

Read the full story →

TANZANIA

Dr. Nancy John Kimario is involved in training graduate healthcare professionals in Tanzania.

Dermatovenerology training enables pharmacists to develop topical medicines

Diploma and Masters programs in dermatology and venerology, training skilled clinicians and pharmacists, are available through the Regional Dermatology Training Center, a supra-regional training, research, and clinical center located in Tanzania. The training includes a module on compounding topical medicines. **This initiative has already enabled four hospitals to start producing selected topical medications themselves**, greatly improving access to medicine and reducing costs for patients.

Learn more about the Advanced Diploma program →
Learn more about the Masters program →

ADVOCACY IN ACTION **RIGHTS**

The right to early and accurate detection

Early and accurate diagnosis is a fundamental right, enabling timely, effective care. Detecting psoriatic disease as early as possible helps prevent complications, reduce treatment costs, and improve health outcomes. Accessible technologies, training, and programs are essential to support reliable diagnosis for all populations, especially in underserved and rural areas.

Guidance for advocates

Recommended advocacy and policy actions to overcome barriers that prevent people in rural areas from accessing suitable care for psoriatic disease:

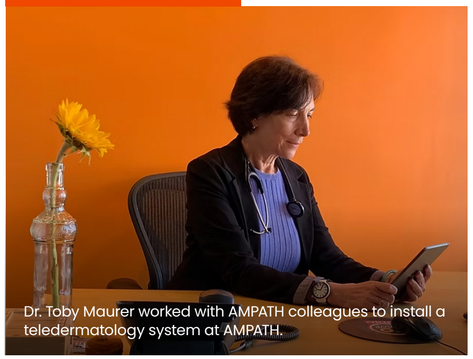
- **Prepare national treatment guidelines**, including psoriatic disease in NCD programs.
- **Work with the Ministry of Health**, and collaborate with different international societies, NGOs, and local societies.
- **Standardize referral guidelines** and have direct communication between primary care and dermatologists.
- **Increase access to essential treatments**, advocating for inclusion in NEMLs and ensuring the availability of basic medicines.

BETTER PRACTICES

Technology and training bring dermatology care closer to patients

Quality dermatology care has long been concentrated in specialist centers, leaving people living in rural and remote communities to bear the burden of distance, cost, and delayed diagnosis. Through technology that brings the specialist to the patient, and training that equips frontline healthcare workers to act with greater confidence, that gap is closing.

KENYA & UGANDA



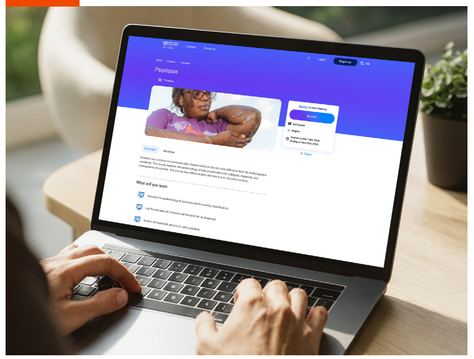
Dr. Toby Maurer worked with AMPATH colleagues to install a teledermatology system at AMPATH.

Technology expands AMPATH dermatology care

New technology is expanding AMPATH's dermatology care by enabling remote screening, triage, and treatment for people in rural western Kenya, eliminating the need for costly travel to referral hospitals. AMPATH is implementing its teledermatology system, which has also been extended to Uganda's Infectious Disease Institute.

Read the full story →

IFPA



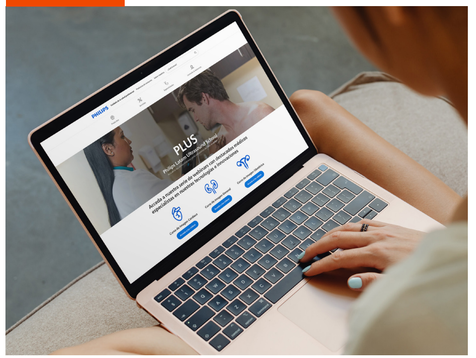
WHO Academy psoriasis course

The WHO Academy course on psoriasis provides comprehensive two-hour, self-paced training to healthcare workers at all levels, especially non-dermatologists and those in low-resource settings. IFPA, the International Psoriasis Council, and the WHO collaborated to create the course. The course is also available on the ILDS Skin Health Training Hub.

Access the course on WHO Academy →

Access the course on the ILDS Skin Health Training Hub →

MEXICO



Continuous medical education for healthcare professionals

A 120-hour diploma course that combines virtual and face-to-face training in pathologies such as psoriasis, atopic dermatitis, and other immune-mediated diseases is available in Mexico.

Learn more →

ADVOCACY IN ACTION **RIGHTS**

Resources and tools

The resources and tools listed are intended to offer patient advocates inspiration to build their own catalog of ideas for possible initiatives.

Protecting the rights of your community

Document:
Access to Care Statement guiding National Psoriasis Foundation advocacy

The right to early and accurate detection

News stories:
Africa Scales Up Integrated Community Healthcare Worker Programs

Psoriasis: The skin condition Kenya's health system continues to ignore

More than a skin condition: The silent threat of psoriatic arthritis

Peer-reviewed article:
Using artificial intelligence on dermatology conditions in Uganda: a case for diversity in training data sets for machine learning

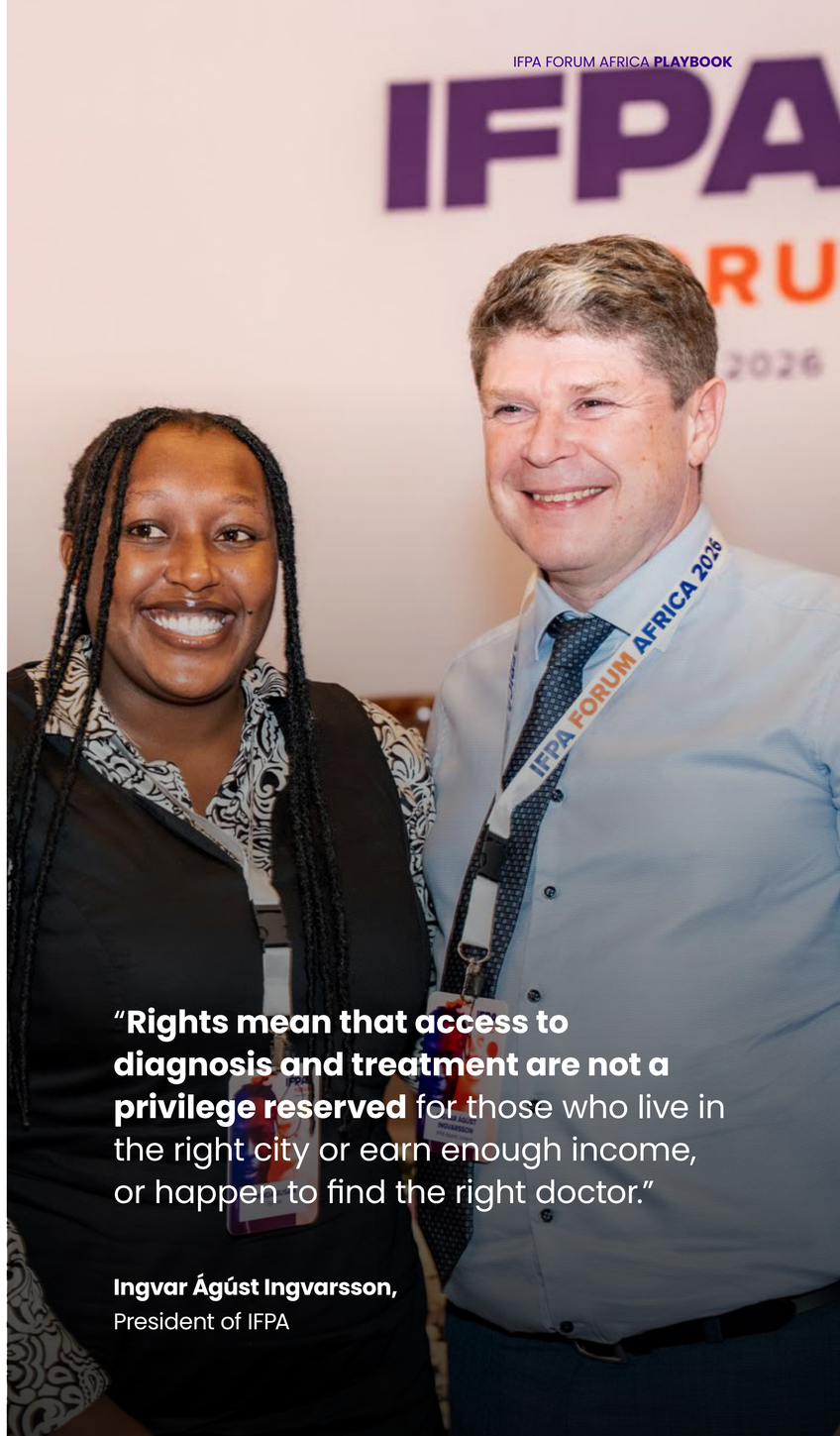
The right to essential medicines

WHO Model List of Essential Medicines:
Psoriasis and psoriatic arthritis

News story:
Our battle with a skin condition that keeps coming back

Peer-reviewed article:
SPIN-RFT expert consensus recommendations on the treatment of psoriasis and TB with targeted treatment

Tool:
Guidance to support advocacy for inclusion of psoriatic disease treatments in a National Essential Medicines List



"**Rights mean that access to diagnosis and treatment are not a privilege reserved** for those who live in the right city or earn enough income, or happen to find the right doctor."

Ingvar Ágúst Ingvarsson,
President of IFPA

Representation

People living with psoriatic disease must be included and participate in decisions about research, policy, and leadership on NCDs.

Recognition of psoriatic disease in global health →

Driving advocacy through partnership →

Young voices, stronger psoriatic disease systems →

Resources and tools →

ADVOCACY IN ACTION **REPRESENTATION**

Recognition of psoriatic disease in global health

Global recognition of psoriatic disease as a serious NCD is a crucial step toward ensuring equitable access to care for people living with this disease worldwide. Advocacy at international level matters because it elevates psoriatic disease on health agendas, drives policy change, and unlocks pathways to make essential treatments more widely available and affordable.

Guidance for advocates

Advocacy for overlooked NCDs must be intentional, people-centered, and policy-oriented:

- **Do not leave overlooked conditions behind**: Diseases such as psoriatic disease need to be intentionally integrated into broader NCD agendas and frameworks rather than treated as side issues.
- **Think beyond one disease:** Integrated, cross-cutting approaches improve outcomes and system efficiency.
- **Data is needed** to support policy asks, inclusion in benefits packages, and investment decisions.

BETTER PRACTICES

A decade of advocacy yields success: from landmark recognition to strategic partnership

Global change in psoriatic disease care is built milestone by milestone, through sustained advocacy, coalition-building, and the collective voice of people living with psoriatic disease worldwide. As the IFPA milestones highlight, patient-led advocacy, pursued consistently over time, can shape the institutions and policies that determine care for millions of people.

GLOBAL HEALTH

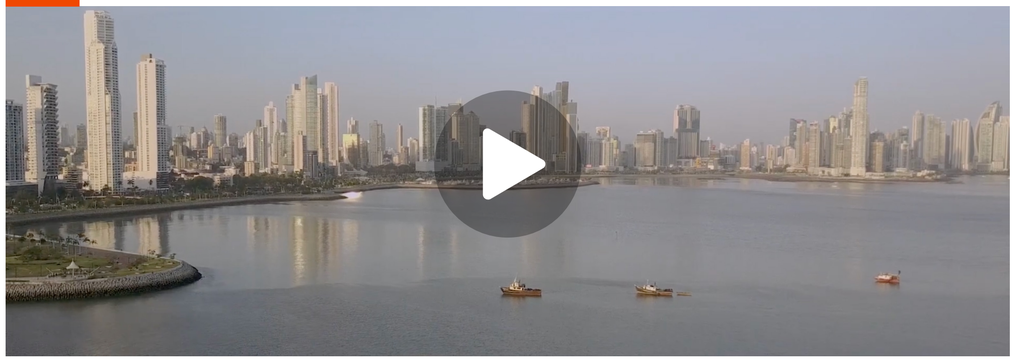
Anil Soni of the WHO Foundation and Frida Dunger of IFPA sign a multiyear collaboration to improve psoriasis diagnosis and care.

IFPA and the WHO Foundation launch a strategic collaboration to strengthen global psoriasis care

In 2026, IFPA and the WHO Foundation launched a multiyear collaboration to improve global care for psoriatic disease. The agreement marks an important milestone in IFPA's engagement with global health partners and supports WHO-led efforts to strengthen the understanding and management of the disease.

Read the full story →

IFPA



Achieving global recognition of psoriatic disease one milestone at a time

Building strong, functioning regional and national patient associations gives international bodies like IFPA legitimacy to represent people with psoriatic disease on the global stage and the power to hold healthcare decision-makers accountable.

Milestones

2014: Resolution WHA 67.9, recognizing psoriasis as an NCD, was officially adopted

2016: The WHO Global report on psoriasis was published, offering recommendations for stakeholders

2024: WHA 77 side event marks 10 years of advocacy and commitment for an update to the WHO Global report

2025: IFPA's policy conversation at Devex Impact House on the sidelines of UNGA 80 and the the High-Level Meeting on NCDs and mental health

2026: WHO Foundation collaboration

ADVOCACY IN ACTION **REPRESENTATION**

Driving advocacy through partnership

Effective advocacy for psoriatic disease depends on building strong partnerships that unite people with lived experiences, healthcare professionals, researchers, and policymakers. Representation ensures that people living with psoriatic disease are heard and that their needs shape policy and care. Advocates must strategically foster regional and global alliances with diverse stakeholders to advance people-centered, equitable, and integrated care.

Guidance for advocates

Successful advocacy partnerships should:

- **Start from shared goals**, not the individual agendas of the various partners.
- **Bring people living with psoriatic disease** into the discussion and decision-making process from the beginning.
- **Treat lived experience as evidence** – patient stories reveal gaps that data alone may miss.
- **Build trust before taking action** – meaningful partnerships require listening, follow-up, and clarity.

BETTER PRACTICES

Driving collaboration through regional discussions and novel approaches

In-person conversations at the IFPA Forum Americas and a roundtable discussion helped build momentum to advance the partnership in Latin America, highlighting the value of bringing stakeholders together in one place. Meanwhile, in Malaysia, the local patient association took the conversation directly to policymakers.

LATIN AMERICA

Psoriasis and psoriatic arthritis (PSA): improving care through collaboration

Regional partners, the International Psoriasis Council (IPC), the Pan American League of Associations for Rheumatology (PANLAR), the Latin American Psoriasis Society (SOLAPSO), the Coalition for Autoinflammatory and Psoriatic Disease Patient Associations (COLAPPIEL), and IFPA signed a mutual agreement to enhance psoriatic disease care across Latin America.

Read the full story →

MALAYSIA

30 MPs unite for psoriasis awareness at a historic parliament exhibition

In a powerful show of cross-party support, parliamentarians pledged to improve psoriatic care in Malaysia during a special three-day exhibition organized by the Psoriasis Association of Malaysia in conjunction with World Psoriasis Day 2025. It was the first time the exhibition had been held at the parliament building.

Read the full story →

ADVOCACY IN ACTION **REPRESENTATION**

Young voices, stronger psoriatic disease systems

Across IFPA's global membership, only about one in three patient associations actively involve young people. Young people are seldom truly consulted in program and policy design, often being included only as token representatives. A vital mindset shift is needed to reframe the perspective on young people, from seeing them as future members to recognizing them as genuine partners today.

Guidance for advocates

Patient associations should:

- **Start by listening** to young people through surveys or conversations, or co-design before acting, and focus on being engaging rather than blaming young people for their lack of interest.
- **Create meaningful roles** with real responsibility, giving young people genuine decision-making power and leadership opportunities.
- **Clearly communicate tangible benefits** of involvement, such as skill-building, networking, and visible impact.
- **Provide ongoing mentorship**, maintain feedback loops, and ensure logistical support to sustain authentic engagement among young people.

BETTER PRACTICES

Look beyond my skin: psoriatic disease and young people

Young people living with psoriatic disease deserve to be seen, heard, and represented on their own terms, and both World Psoriasis Day 2026 and a psoriasis association's youth-led initiatives in Norway show what it looks like when the community commits to making that a reality.

IFPA

WORLD PSORIASIS DAY 2026

World Psoriasis Day

Young adulthood is a critical period in life when individuals discover who they are, build relationships, and make important decisions about their future. This year's World Psoriasis Day 2026 slogan brings attention to young people living with psoriatic disease. **The "Look beyond my skin" slogan calls for a shift in perspective – for people to see the young person behind the disease, to listen to their experience, to embrace their identity, and to foster greater understanding of psoriatic disease.**

Read the full story →

NORWAY

Psoriasis and skin diseases youth patient association (PEF-Ung)

PEF-Ung is a children's youth organization working to improve quality of life for children, adolescents, and young adults with skin diseases. The **organization has taken a youth-first approach to its social media presence by putting young members in charge of its Instagram channel.** Because the people creating the content are themselves the audience, the output is authentic, resonant, and visually appealing to their peers. The association has complemented this with practical, co-created tools such as a yearly calendar and a fundraising program in which young participants design and sell products.

Learn more →

ADVOCACY IN ACTION **REPRESENTATION**

Resources and tools

The resources and tools listed are intended to offer patient advocates inspiration to build their own catalog of ideas for possible initiatives.

Recognition of psoriatic disease in global health

Blog:

Celebrating a decade of global action on psoriatic disease – Global week for action on NCDs

Press release:

Psoriatic Disease To Take Center Stage at the UN General Assembly: IFPA

Videos:

Psoriatic disease and NCD: Putting lived experience at the heart of policy (IFPA @ Devex Impact House)

A Decade of Action Since the World Health Assembly Resolution on Psoriasis - Success Stories

Driving advocacy through partnership

News update:

IFPA and IPC announced their official partnership in 2022

Psoriasis and PsA:

Improving care in Latin America through a mutual agreement signed between IPC, PANLAR, SOLAPSO, COLAPPIEL, and IFPA

Young voices, stronger psoriatic disease systems

Website:

PEF-Ung is a children's youth organization working to improve quality of life for children, adolescents and young adults with skin diseases

Booklet:

PsA in children, as part of IFPA's Good Care project

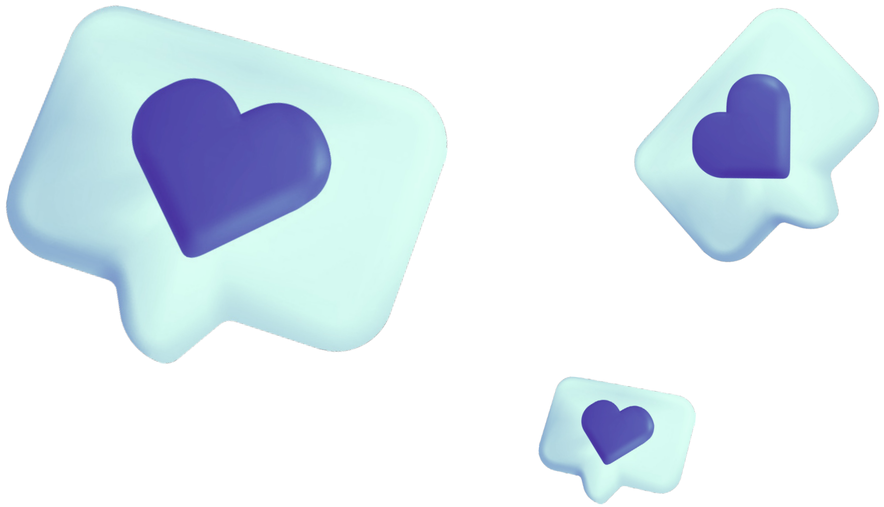
"You don't have to wear the banner of advocacy everywhere. You can ask one simple question at every meeting: '**Where's psoriasis on this list?**'"

Dr. Mary Nyamongo,
NCD Alliance Kenya

SUPPORT AND FUNDING

IFPA support and funding

Patient associations give people living with psoriatic disease collective representation – representation that carries far more weight with governments, health authorities, and industry than any individual can alone. IFPA is committed to supporting efforts in Africa and around the world to strengthen patient associations' ability to act. Guidance, funding, and access to IFPA's broad global network are among the benefits of membership.



01

Develop a patient association

A patient association is the foundation of effective advocacy. It brings people together to provide peer support, raise awareness, build relationships with healthcare providers, and ensure the voices of people living with psoriatic disease are heard where decisions are made.

Read IFPA's step-by-step guide →

02

Become an IFPA member

IFPA membership connects your association to a worldwide network of patient organizations and provides access to exclusive resources and materials.

Apply to become a new member →

03

Boost your leadership skills

IFPA provides training for patient advocates through its IFPA Accelerator program. The program is suitable for advocates who are starting out or are already IFPA members.

Register for the program →

04

Access funding

IFPA members can apply for IFPA grant funding. Each fund has its own requirements and application deadlines.

Learn more →

SUPPORT AND FUNDING

Dr. Hoseah Waweru Solidarity Fund projects in Africa

The Dr. Hoseah Waweru Solidarity Fund awards grants to support advocacy, education, and awareness-raising efforts related to psoriatic disease.

South Africa

Educational materials for beauty practitioners were developed, and in-person sessions with dermatologists and people living with psoriatic disease were held. IFPA's Good Care videos and booklets were adapted for multiple local languages.

Ghana

The groundwork was laid for the first Genome-Wide Association Study (GWAS) in Africa, in partnership with the University of Milan and Dr. Giovanni Damiani.

Kenya

IFPA's Good Care material was translated into Swahili, and a forum was held with rheumatologists. A simple checklist was developed for women of childbearing age and pregnant women, and a study on the prevalence of psoriasis in Kenya is being conducted.

Download the checklist, Embracing Motherhood: A Guide for Women with Psoriatic Disease →

GoodCare: a psoriatic arthritis project

The GoodCare Project for psoriatic arthritis unites IFPA with rheumatologists and the PsA community to **promote global awareness of the latest treatment guidelines.** Together, IFPA and its partners developed educational resources, podcasts, and a patient checklist to aid treatment planning and encourage shared decision-making, available in nine languages.

Access the materials →

Glossary

Terms explained for new advocates

Advocacy: Actions aimed at raising awareness, influencing policy, and securing resources to improve care and support for people with psoriatic disease.

Alliance/coalition: A formal partnership of patient groups, healthcare professionals, researchers, and other stakeholders working together toward shared advocacy goals.

Burden of disease: The impact of psoriatic disease on individuals and society, including health, social, psychological, and economic aspects.

Capacity building: Training and resources provided to patient associations or advocates to strengthen their ability to engage and influence policy and health systems.

Clinical trial: A research study in which experts evaluate potential treatments.

Comorbidities: Additional health conditions commonly associated with psoriatic disease, such as cardiovascular disease and diabetes.

Continuum of care: An integrated approach that ensures coordinated management of psoriatic disease across specialties and disease stages.

Disease prevalence: The number or proportion of individuals living with psoriatic disease within a given community or population.

Equitable care: Healthcare that is fair and accessible to all, regardless of geographic, economic, or social factors.

Formal patient representation: Official participation of patient groups in national or regional health policy forums and decision-making processes.

Integrated care: Coordination between medical specialties, such as dermatology and rheumatology, to provide comprehensive treatment.

People-centered care: Where healthcare services are tailored to people's needs and provided in partnership with them.

Real-world evidence: Insights into the usage and potential benefits or risks of a medical product in routine healthcare.

Registry: Database collecting detailed information about patients with psoriatic disease to support research and improve care.

Research inclusion: Ensuring that diverse populations affected by psoriatic disease are represented in clinical studies and research.

Stigma: Negative social attitudes and discrimination faced by people living with psoriatic disease.

Sustainable resources: The long-term funding and support needed to maintain advocacy programs and patient care initiatives.

Youth advocacy: Efforts to include and empower young people living with psoriatic disease to lead and participate meaningfully in advocacy.

Contact

IFPA member associations in Africa

PsorAfrica

PsorAfrica champions dignity, access to care, and inclusion for people living with psoriatic disease in Africa, moving from silence and stigma toward visibility and access to treatment.

Members

Ghana
Psoriasis Association of Ghana

Kenya
Psoriasis Association of Kenya

Rwanda
Rwanda Psoriasis and Psoriatic Arthritis Organization

South Africa
South African Psoriasis Association

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IFPA

Founded in 1971, IFPA is the International Federation of Psoriasis Associations. We are the psoriatic disease community. Our members represent over 100 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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