IFPA
FORUM
AMERICAS 2025

Roadmap for improving the lives of people living with psoriatic disease

A strategic plan to guide regional and national advocacy actions related to psoriatic disease.

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INTRODUCTION

Foreword

It is my great honor to address you as the newly elected President of IFPA.

The IFPA Forum Americas is part of IFPA's regional series, which gathers together our vibrant community, puts a spotlight on local challenges close to home, fosters stronger collaborations between different stakeholders, and pushes for concrete national and regional action.

We are a growing movement – stronger, louder, and more connected across regions than ever. Still, transforming global recommendations into local solutions is a mighty task, and the burden is heavy.

According to the Global Psoriasis Atlas, an estimated 60 million people live with psoriasis, including more than 8 million in the Americas. As in many other parts of the world, the burden of psoriatic disease in the Americas is marked by significant regional and demographic differences, further complicated by gaps in available data. People living with psoriatic disease in the Americas often face challenges in accessing proper healthcare. These challenges are influenced by income level, race and insurance coverage. For real people living with the disease, this may mean that people with lower incomes, or insufficient insurance, are more likely to be hospitalized due to their condition. That is unacceptable, and together we must work to change this. Access to the care we need is not a privilege; it is a human right for all.

IFPA Forum Americas reminds me of why IFPA exists, as it amplifies perspectives that might otherwise go unheard. Only by listening, learning and leading our shared fight can we make sure no one is left behind.

This Roadmap compiles conclusions from all the different Forum dialogues, which brought together our movement of advocates, clinicians, policymakers and partner organizations from across the globe, united by a vision to elevate the needs of everyone living with psoriatic disease. Looking ahead, I call upon all of you to carry forward the momentum of the IFPA Forum Americas into the coming year. Let us continue with the dialogues we have begun. Together, we can ensure that psoriatic disease remains visible on the political agenda, from national health plans to the global debate on non-communicable diseases.

Finally, I extend my deepest thanks to you, our remarkable IFPA community. Your unwavering commitment fuels our mission to unite, strengthen and lead the global psoriatic disease community. As we reflect on the Forum, let us reaffirm our promise to each other, to lift every voice, spark every action and, ultimately, transform lives.

Let's get to work.

Ingvar Ágúst Ingvarsson,
President of IFPA

INTRODUCTION

Uniting for change

The 2025 IFPA Forum Americas brought together patient advocates, healthcare professionals, policymakers and industry leaders to confront one of the region's most pressing challenges: equitable access to care. The Forum's central message was clear – lasting change requires collective action. By working together, stakeholders can dismantle systemic inequities and transform outcomes for people living with psoriatic disease across the Americas.

While each country faces distinct healthcare challenges, many barriers are shared, not only across borders but also with other non-communicable diseases (NCDs). Common obstacles include fragmented health systems, inconsistent treatment pathways and limited awareness of psoriatic disease among primary care providers, which often leads to delayed diagnosis. Additional hurdles involve gaps in data quality and regulatory complexities around access to new treatments.

A ROADMAP FOR ACTION

IFPA has created a Roadmap that captures the Forum's insights into clear and actionable steps. This Roadmap supports IFPA's vision by providing patient organizations and partners with a common framework to promote equitable access to high-quality care for everyone living with psoriatic disease.

The Roadmap emphasizes **three strategic priorities**, each accompanied by specific asks to support advancing the agenda for psoriatic disease across the Americas.

01

Equitable access to early diagnosis and treatment

- Early diagnosis and integrated care
- Empowerment and public awareness
- Education and capacity building
- Policy shaping

02

Equitable access for all people living with NCDs

- Multi-disciplinary care
- Integration of psoriatic disease within NCD frameworks
- Collaborative campaigns and education initiatives

03

Collaborative research for bridging knowledge gaps and improving care

- National and regional registries
- Robust data and evidence
- Regional collaboration and networks

PRIORITY ACTION AREAS

01

Equitable access to early diagnosis and treatment

The challenge

Across the Americas, people face persistent and often overlapping barriers to the care they need. Socioeconomic disparities, geographic and fragmented health systems contribute to deep inequities, especially among vulnerable communities, resulting in delayed diagnoses and poorer health outcomes for many living with psoriatic disease.

Our regional commitment

We are united in our commitment to championing timely diagnosis and comprehensive care, including effective treatment, for all people living with psoriatic disease. This means tackling systemic barriers and strengthening healthcare systems to deliver equitable, person-centered care.

PRIORITY ASKS

Early diagnosis and integrated care

Implement strategies that promote early identification of psoriatic disease and ensure access to affordable treatment. Care must be patient-centered, coordinated and responsive to the complex, lifelong nature of the disease.

Empowerment and public awareness

Recognize psoriatic disease as a systemic condition affecting multiple organs and aspects of daily life. Actively include people with lived experience in shaping policies and services that impact them.

Education and capacity building

Invest in healthcare systems and ensure that providers have the training, tools and resources to effectively detect and manage psoriatic disease. Strengthening clinical capacity is essential to improving care.

Policy shaping

Support local advocates in voicing community needs to healthcare authorities. Foster the creation of national and regional strategic alliances that can speak with one voice for people living with psoriatic disease.

PRIORITY ASK 1

Early diagnosis and integrated care

Recommended actions

Establish detailed, primary care-specific guidelines for detecting and managing psoriatic disease that support transparent referral processes and align with regional guidelines.

Who to involve

01. People with psoriatic disease and their associations
Identify who is responsible for developing, issuing and updating national clinical practice guidelines for psoriatic disease in your country – whether it is a dermatology society, health authority, patient organization or another stakeholder. Check whether people living with psoriatic disease were involved in their development, and explore opportunities to contribute to future updates.

02. Medical societies and other stakeholders
If national guidelines do not exist or need improvement, consider leading their development. The International Psoriasis Council (IPC) can help develop national or regional guidelines and fill gaps with insights from its global expert network. Also, be aware of any ministry of health regulations or protocols that could affect official recognition or implementation.

At a regional level, the Latin American Psoriasis Society (SOLAPSO) has developed guidelines for the systemic treatment of psoriasis. Published in 2019 and currently under revision, these guidelines aim to standardize and improve the management of psoriatic disease in Latin America, serving as a valuable reference.

Measuring progress

Track whether guidelines are included in national or regional health policies or used in practice. Identify the extent to which people with lived experience are enlisted in advisory boards and other decision-making platforms.

PRIORITY ASK 2

Empowerment and public awareness

Recommended actions

Develop educational guides and public awareness campaigns to promote recognition and understanding of psoriatic disease.

Campaign for official national recognition of World Psoriasis Day. Develop national and regional initiatives to mark the annual event.

Who to involve

01. Healthcare providers, people living with psoriatic disease and caregivers
Engage healthcare professionals to create and distribute educational guides for individuals with psoriatic disease, sharing them with patient support groups and caregivers. Use targeted social media campaigns to reach specific audiences, selecting channels best suited to groups such as young people or older adults.

02. Media agencies and journalists
Summarize key messages from guidance materials for journalists and inform media agencies about scheduled campaigns.

03. IFPA member organizations
Consult with advocates in other countries about how they achieved official recognition of World Psoriasis Day by their governments, and collaborate with them to create a regional awareness or educational campaign.

Measuring progress

Conduct a public awareness survey to evaluate the effectiveness of the key messages communicated. This survey can be conducted at regular intervals, such as annually, or before and after an awareness or educational campaign.

PRIORITY ASK 3

Education and capacity building

Recommended actions

Educate healthcare providers and policy decision-makers about psoriatic disease to promote early detection and increase awareness of available therapies, to improve health outcomes for people living with psoriatic disease.

Who to involve

01. Partner organizations
The IPC offers various country-focused programs to improve psoriatic disease care. It also has a Latin American Working Group of healthcare professionals from across the region practicing in public and/or private care who have advocacy and research experience.

02. Health authorities
Provide healthcare decision-makers with the information and evidence they need to motivate changes within the healthcare system. Ensure that the information is delivered in a format that helps them easily understand the key message.

Measuring progress

Conduct surveys to assess whether healthcare providers' knowledge has improved as a result of capacity-building activities. Additionally, tracking attendance and the level of engagement of healthcare professionals who attend educational workshops can provide further insight into the demand for the knowledge being shared.

PRIORITY ASK 4

Policy shaping

Recommended actions

Empower patient advocates with the skills they need to successfully represent and create positive change for people living with psoriatic disease within their communities.

Who to involve

01. IFPA and its members
Organize local and regional skill-building workshops that focus on developing advocates' abilities to effectively communicate on behalf of people living with psoriatic disease. Experienced advocates involved with IFPA may also be available to assist and share insights at workshops.

02. Advocacy organizations
Engage experts who have experience of developing coalitions or alliances. The expertise may be with another country-level patient association, someone within the skin disease community, another specific disease area or someone operating more generally in NCDs.

When seeking to form partnerships, it is important to define what would make the alliance beneficial to the organization being approached and align with its goals.

Measuring progress

Track the number of local and regional workshops organized over a set period. Use surveys or evaluations to assess participants' advocacy and public speaking skills before and after the workshops. Gather qualitative feedback on workshop content, delivery and usefulness.

PRIORITY ACTION AREAS

02

Equitable access for all people living with NCDs

The challenge

Psoriatic disease puts people at higher risk of developing comorbidities, particularly NCDs. These diseases pose complex health challenges due to their chronic nature and multifaceted symptoms.

Our regional commitment

We advocate for policies that ensure fair healthcare access for individuals with NCDs and strive to create an inclusive environment where everyone can receive the care they need to improve their health outcomes.

PRIORITY ASKS

Multi-disciplinary care

Ensure that healthcare providers know and understand that psoriatic disease is a systemic and inflammatory condition associated with various comorbidities and, as such, requires multi-disciplinary care.

Collaborative campaigns and education initiatives

Promote public awareness of psoriatic disease and its link to other NCDs, to ensure timely detection and treatment.

Integration of psoriatic disease within NCD frameworks

Advocate for NCDs to be acknowledged as a national and regional healthcare priority, to prevent and control them. This includes recognition of psoriatic disease as an NCD associated with other comorbidities.

PRIORITY ASK 1

Multi-disciplinary care

Recommended actions

Educate healthcare providers about psoriatic disease, its inflammatory nature and the long-term damage inflammation can cause to the eyes and organs such as the lungs, liver and kidneys, resulting in comorbidities.

Who to involve

01. Healthcare professionals
Educate all specialties that contribute to holistic care, including general practitioners, dermatologists, rheumatologists, nurses, psychologists and nutritionists, about psoriatic disease.

02. Advocacy organizations
Partner with psoriatic disease and NCD patient associations operating within your country to build further recognition of the interconnected relationship between the disease and its related comorbidities.

Measuring progress

Metrics may include recording how many educational programs, workshops or continuing medical education sessions are delivered.

PRIORITY ASK 2

Integration of psoriatic disease within NCD frameworks

Recommended actions

Draw up an advocacy plan outlining how psoriatic disease can be prioritized within national strategies, plans and frameworks on preventing and controlling NCDs.

Who to involve

01. Civil society organizations
Identify any gaps within national and regional NCD agendas. Reflect on possible opportunities for improving recognition of psoriatic disease within the strategic documents on NCDs produced by the Pan American Health Organization (PAHO), and consider how to raise this with PAHO.

Decide whether to form an NCD coalition or alliances with other organizations to advocate collectively for recognition of NCDs, including psoriatic disease, at the local or regional level of health.

The NCD Alliance is a global umbrella advocacy organization with national and regional membership that could be a strong partner to help elevate the priority of psoriatic disease at various levels of health.

The Alliance is a key civil society partner of the World Health Organization and the United Nations. At a national and regional level, its flagship programs build demand for including NCDs in health agendas and with people who have lived experience.

The NCD Alliance provides national and regional advocacy grants and coalition grants. In low- and middle-income countries, partnerships with the NCD Alliance network are encouraged, to drive national/regional momentum and commitment for NCDs.

Measuring progress

Monitor how many national and regional policy documents, frameworks or action plans on NCDs have included psoriatic disease as an indicator to reflect the success of integration with the NCD agenda. Building recognition at national level can also drive impetus for global advocacy efforts.

PRIORITY ASK 3

Collaborative campaigns and education initiatives

Recommended actions

Foster partnerships and develop initiatives that align with national and regional healthcare agendas focused on addressing psoriatic disease and NCDs.

Who to involve

01. Healthcare professionals
Enlist the support of healthcare professionals regarded as key opinion leaders, to champion the inclusion of psoriatic disease within policy decisions and documents.

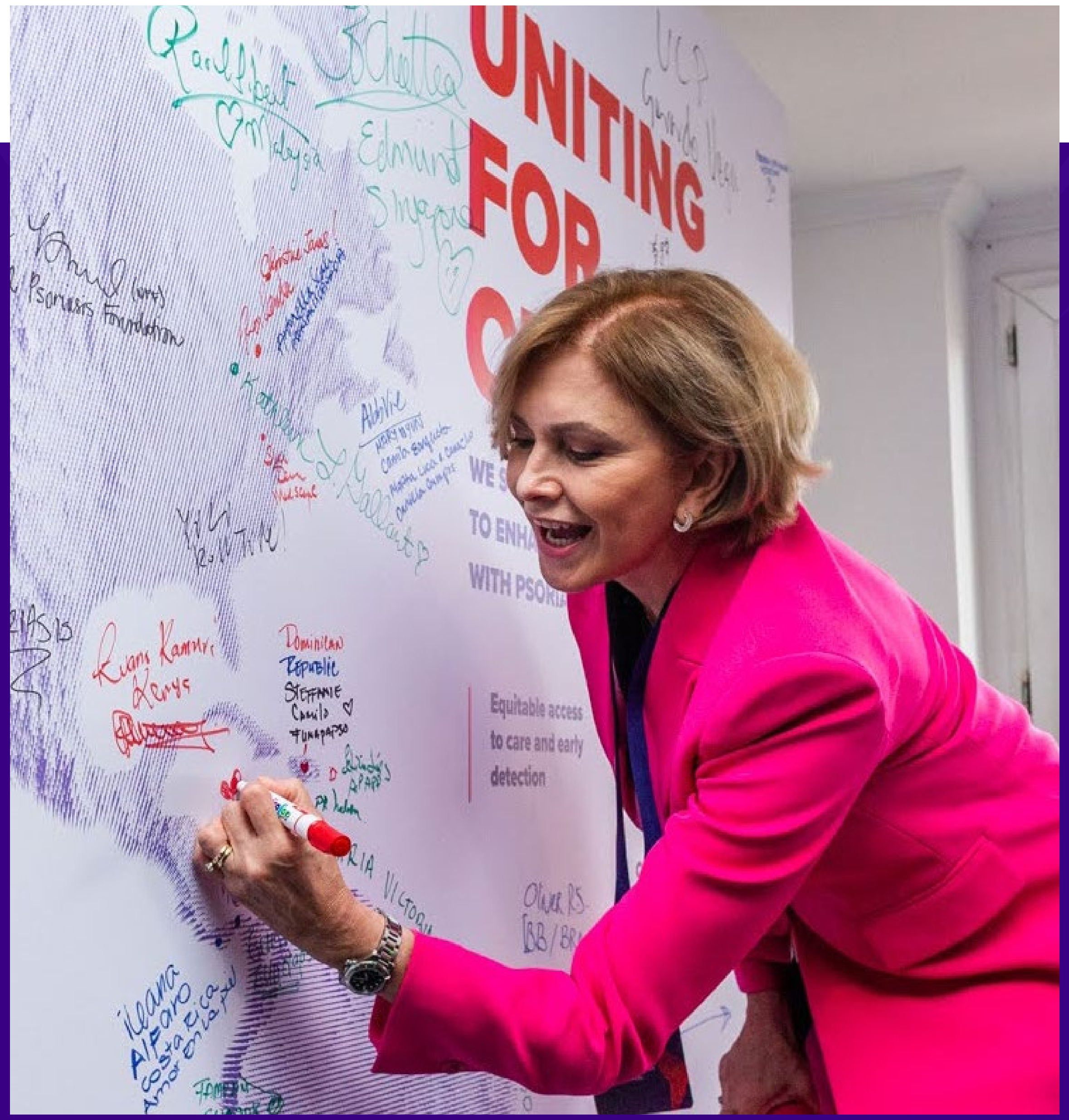
02. Regional health authorities
Collaborate with patient groups and organizations seeking to prevent and control NCDs, to run regional awareness or educational campaigns. PAHO has activities focused on raising awareness about NCDs and publishes reports on the health topic. Try to identify the PAHO country office representative and enquire about their activities. Timing your campaigns or activities with their initiatives can help to make them more impactful.

03. Civil society organizations
Work with other disease umbrella organizations and cooperate with them to organize workshops and meetings on common subject areas. Emphasize the economic burden of NCDs and find common ground with other NCDs by highlighting the impact of not treating psoriatic disease adequately. Psoriatic disease is associated with several comorbidities, including diabetes, cardiovascular disease, certain types of cancer, obesity and mental health issues. These diseases have gained significant public recognition as the major NCDs driving the disease burden, with psoriatic disease contributing as a relevant factor that needs to be acknowledged.

There may also be local synergies with other civil society organizations, such as those concerned with upholding human rights, that may be interested in partnering on a particular issue, such as the rights of people with psoriatic disease and NCDs in the workplace.

Measuring progress

Track the number of regional campaigns conducted with partner organizations, formal partnerships or memoranda of understanding.



> "I advise you to join other foundations, because a single entity can't create significant change. However, as a federation with other NGOs, like the one we've established in Panama to discuss medicines for chronic, critical and degenerative diseases, you can make an impact and become the benchmark for decision-making."
>
> **Mónica Chapman**
> Panama Psoriasis Foundation

PRIORITY ACTION AREAS

03

Collaborative research for bridging knowledge gaps and improving care

The challenge

The Americas face knowledge gaps and a lack of data on psoriatic disease. Additionally, several obstacles prevent effective data sharing and unified efforts to address regional health priorities. Typical barriers or gaps include inadequate data collection and monitoring systems to support quality data, the use of standard indicators or guidelines, and funding.

Our regional commitment

We are committed to partnering with researchers, healthcare providers and patient organizations to advance the understanding of psoriatic diseases, bridging knowledge gaps and fostering innovative solutions for better regional patient care.

PRIORITY ASKS

National and regional registries

Establish real-life national and regional registration databases to systematically collect data on the burden and impact of the disease. Identify key variables for uniform data collection across countries and ensure that the data is accessible to all healthcare professionals.

Robust data and evidence

Ensure access to robust and recent data to support high-quality studies for evidence-based decision-making in health. Gather other forms of knowledge, such as survey data, to build a coherent understanding of psoriatic disease, identify gaps in care and assess the broader health environment.

Regional collaboration and network

Promote joint research efforts that include sharing resources and knowledge, and creating regional networks that foster community support and united advocacy. These types of collaborative effort are vital for strengthening health systems and improving care and health outcomes for individuals with psoriatic disease.

PRIORITY ASK 1

National and regional registries

Recommended actions

Improve data collection through registration databases that identify national psoriatic disease prevalence. These databases collect information about people living with psoriatic disease that can be accessed by healthcare providers. Determine shared data points to enhance regional data sharing and strategies.

Who to involve

01. Healthcare professionals
Seek to collaborate with healthcare professionals, including medical and administrative staff, on a project to establish a psoriatic disease registry.

02. Industry
Clinical research business partners have the expertise and resources to set up and run technical projects. Investigate whether there are relevant organizations in your country or region that can be approached to establish a national or regional registry. Existing registries can also be referenced for a summary list of key variables.

03. Funding bodies
The National Psoriasis Foundation (NPF) funds a wide range of research on psoriatic disease and related conditions. Government agencies and private organizations also support psoriatic disease research. Speak to people within your network, including IFPA, to contact the right people who can assist you in sourcing funding.

Measuring progress

Publicly available data on psoriatic prevalence, including national and regional estimates published regularly, is essential for identifying health system gaps and improving care. Recognition from policymakers or mentions of prevalence estimates in the media serve as another way of measuring success.

PRIORITY ASK 2

Robust data and evidence

Recommended actions

Conduct research, including surveys, to improve the understanding of psoriatic disease in the local population. Encourage data sharing between researchers and highlight best practices for disseminating the findings and learnings.

Who to involve

01. Academia
Work with academics to formulate and conduct research projects investigating psoriatic disease-related comorbidities, the impact of biological therapies on the disease, pediatric cases, precision medicine, including identifying and using biomarkers for selecting the ideal treatment, and developing more affordable drugs. Pursue scalable research pilot projects in individual countries.

02. IFPA member organizations
Ask IFPA members who have developed surveys or have experience of setting up research projects to share their knowledge, expertise and learnings from the experience, to help you determine what approach to follow with your own project. There may also be an opportunity to collaborate, to establish a multi-country project.

03. Industry
Pharmaceutical companies or other industry partners are often willing to provide resources, expertise and infrastructure to support projects. Align with sponsor priorities to secure partners and funding. Members of the American Federation of the Pharmaceutical Industry (FIFARMA) promote scientific research in Latin America, and FIFARMA also has a Regional Observatory that provides data and analysis for the pharmaceutical industry.

Measuring progress

Published research outcomes, such as the number of papers, citations and other scholarly outputs, are commonly used metrics to assess the impact of research efforts. There are also ways to measure the reach and engagement via response rates, downloads, social media shares, or adoption or implementation feedback from the target audience.

PRIORITY ASK 3

Regional collaboration and networks

Recommended actions

Investigate and motivate for projects with international organizations, as well as regional and national partners, that improve evidence and knowledge about psoriatic disease.

Who to involve

01. Research institutions and medical societies
Organizations such as the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA), the Latin American Psoriasis and Psoriatic Arthritis League (LAPPAS), the Pan American League of Associations for Rheumatology (PANLAR) and SOLAPSO are actively involved in supporting psoriatic disease research and education. These groups work together to provide resources and knowledge to clinicians and academic researchers, ultimately aiming to improve the understanding and management of psoriasis and psoriatic arthritis in the region.

Measuring progress

Tracking the number of projects initiated or completed in collaboration with partners can also build confidence in scaling up partnership initiatives or considering novel alliances.

> **“We’re not alone. There are millions of people like us working passionately around the world trying to do the same work that we’re doing, and it makes so much sense for us to all work together.”**
>
> **Christine Janus**
> Formerly with Globalskin, Canadian Skin Patient Alliance (CSPA) and Canadian Psoriasis (CAPP)

IMPLEMENTATION

Milestones

Establishing key milestones is essential for effective project management and ensuring successful outcomes. The advocacy journey can be long, with many ups and downs. Milestones help keep the momentum and end goal in sight.

Setting goals for the short term (up to two years), medium term (up to four years) and long-term (five years and beyond) will help you stay on track.

IFPA's support

Another important factor to consider is involving the right people or organizations at the right time in a project. Projects are an important part of IFPA's work. IFPA has projects on its own and in collaboration with others. Present your project ideas to IFPA to ask for its collaboration, which may include funding for a project. IFPA can further provide access to an extensive network of expertise and resources, including tools for training advocates.

The following considerations can assist you when setting goals and planning milestones that align with the actions proposed in this Roadmap:

Short term

2 years

Focus on increasing awareness of psoriatic disease as an NCD. Ensure there is widespread recognition of the interconnected relationship between psoriatic disease and other NCDs, including mental health, metabolic syndrome, diabetes, obesity and cardiovascular disease.

Medium term

4 years

Focus on enhancing early diagnosis, improving treatment access and integrating psoriatic disease management into broader NCD prevention efforts.

Long term

5+ years

Focus on ensuring equitable access to personalized, multi-disciplinary care, advancing early diagnosis and fostering increased research funding for regional knowledge-building and innovative treatments that address the physical and mental health aspects of the disease.

IFPA Forum
Americas 2025
Bogotá, Colombia

CALL TO ACTION

Let’s get to work!

United in action, we can drive meaningful change for the millions living with psoriatic disease across the Americas.

We invite you, our dedicated community of advocates, to get to work.

Your involvement can make a significant difference in transforming lives and improving outcomes for those affected by psoriatic disease:

- **Advocate for equitable access to early diagnosis and treatment.**
- **Educate your communities about psoriatic disease and its impact on individuals’ lives.**
- **Collaborate with local organizations to amplify our voices and ensure that no one is left behind.**

Let us unite our efforts, share our knowledge and commit to achieving the milestones outlined in this roadmap.

Every action counts. As one collective voice, we can ensure that psoriatic disease is recognized and addressed at all levels of healthcare policy.

Never give up!

CONTACTS

IFPA member associations in the Americas

FULL MEMBERS

ARGENTINA
AEPSO
Asociación Civil para el Enfermo de Psoriasis
Website / Facebook / X / Instagram / YouTube

BRAZIL
Psoríase Brasil
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CANADA
Psoriasis Canada
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COLOMBIA
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DOMINICAN REPUBLIC
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EL SALVADOR
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APAPSO Peru
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UNITED STATES
National Psoriasis Foundation
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URUGUAY
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ASSOCIATED MEMBERS

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OUR PARTNERS

International Psoriasis Council
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Follow IFPA online

At IFPA, we encourage you to follow our social media channels and keep us informed about the initiatives, collaborations and achievements you are involved in, so that we can show our support and amplifyyour messages.

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