

**IFPA STRATEGY 2021 - 2030**

**Unite.  
Strengthen.  
Lead.**

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# Introduction

# Unite. Strengthen. Lead.

## **Driving advancements for people living with psoriatic disease**

IFPA is a nonprofit organization uniting psoriasis and psoriatic arthritis associations worldwide. The organization was founded in 1971 to advance efforts to improve the lives of people with psoriatic disease and improve methods of research and treatment for finding the ultimate cause and cure for the disease. Today, the organization comprises 63 organizations in 53 countries and represents the voice of more than 60 million people living with psoriatic disease.

## **United burden**

Psoriatic disease is a systemic condition affecting multiple body sites. It is a chronic, noncommunicable, painful, disfiguring and disabling disease for which there is no cure. It can have a significant, negative impact on patients' quality of life (QoL)<sup>1</sup>. Psoriatic disease is an immune-mediated disease whose cause remains unclear. It is associated with significant comorbidities, including cardiovascular diseases, metabolic syndrome, inflammatory bowel disease, depression and arthritis<sup>1</sup>. Up to 35% of people living with psoriasis develop

psoriatic arthritis, a chronic, inflammatory arthritis that leads to joint deformations and disability<sup>2,3</sup>.

According to the 2020 Global Psoriasis Atlas, it is estimated that at least 60 million people worldwide are living with psoriasis<sup>4</sup>. However, the prevalence appears to vary depending on genetic background and geographic location, and more than 80% of countries lack epidemiological data on psoriatic disease<sup>4</sup>.

## **Determined success**

For the last 50 years, IFPA has been at the forefront of improving life for people with psoriatic disease and has achieved success in raising the profile of psoriatic disease on the global agenda.

This includes World Psoriasis Day, which has been driven by IFPA since 2004. The day is marked on October 29, with activities worldwide. The World Psoriasis & Psoriatic Arthritis Conference also attracts a global audience. This renowned scientific event presents the latest psoriasis and psoriatic arthritis research and explores psoriatic disease from different perspectives. The conference, which is held every three years, is hugely popular and attracted

more than 1,100 delegates from across the world when it was last held in 2018. IFPA also plays a significant role in improving knowledge and understanding of the burden of psoriasis. IFPA was the main initiator of the Global Psoriasis Atlas (GPA), which was first published in 2019. The GPA provides detailed, open-access information about the worldwide epidemiology of psoriasis and is a partnership between IFPA, the International League of Dermatological Societies (ILDS) and the International Psoriasis Council (IPC). The GPA is the world's most extensive systemic review of psoriasis and a vital source for IFPA's advocacy work.

A decade ago, psoriasis was largely absent from the international agenda. Very few policymakers had ever heard about the disease. The World Health Organization (WHO) website provided almost no information about it. To change this, IFPA set itself an ambitious target – to get the World Health Assembly (WHA) to approve an official resolution on psoriasis.

After several years of work by a dedicated team at IFPA, Resolution WHA 67.9 was approved. The resolution is the only international resolution focusing solely on psoriasis. The resolution highlighted that psoriasis should be viewed as a serious noncommunicable disease (NCD).

A Global Report on Psoriasis succeeded Resolution WHA 67.9 in 2016. Several IFPA staff, board members and member association representatives contributed extensively to the report. The global report explores the challenges of

psoriasis and psoriatic arthritis in depth and outlines concrete recommendations for action.

### **The time to act is now**

Despite many achievements over the past 50 years, people living with psoriatic disease continue to experience significant unmet needs. IFPA has worked hard to gain political support and recognition for people living with psoriatic disease and has received it. Now, it is time to act and implement. IFPA advocates for greater psoriatic disease recognition and pushes for countries to deliver on the recommendations set out in the Global Report on Psoriasis.

As the only global organization uniting people with psoriatic disease worldwide, IFPA is the global leader in fighting psoriatic disease.



### **Unleashing IFPA's greatest strengths**

- **Together, for everybody:** IFPA is the only organization that brings a unified global voice to fight for all people living with psoriatic disease in the global arena.
- **Powerful history and track record:** IFPA has a 50-year track record of uniting the psoriatic disease community and elevating the psoriatic disease on the global agenda.
- **Independence and integrity:** Decisions are exclusively driven by the needs of people living with psoriatic disease.

### **Psoriatic disease**

IFPA represents all people living with psoriatic disease, regardless of their geographic location and type of psoriatic disease or how the disease impacts their lives. To reflect this inclusive approach and illustrate that no one is left behind, IFPA has adopted the term 'psoriatic disease.' Psoriatic disease covers all types of psoriasis and psoriatic arthritis – the full spectrum of psoriatic diseases. A more detailed description of the term is available on IFPA's website.

# A strategy to unite, strengthen and lead the global psoriatic disease community

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

## **Vision**

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

## **Mission**

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





### Strategic goals

IFPA has formulated five strategic goals to inform change toward a future where all people living with psoriatic disease enjoy good health and wellbeing. The interrelated goals are equally important and support each other.

- **Goal 1 – Ensure global representation:** Boost the voices of everyone living with psoriatic disease, everywhere.
- **Goal 2 – Lead global advocacy:** Fight for the interests of people affected by psoriatic disease. Demand representation on global health and development agendas.
- **Goal 3 – Strengthen member capacity:** Strengthen IFPA members. Raise national support for people living with psoriatic disease.
- **Goal 4 – Share knowledge:** Close the gap between knowledge and action. Unleash findings to trigger breakthroughs for people living with psoriatic disease.
- **Goal 5 – Unite stakeholders:** Build alliances with psoriatic disease stakeholders. Transform global, regional, and national collaboration.

## Value proposition

IFPA is the global voice dedicated to advancing psoriatic disease policy. IFPA is the trusted convener of psoriatic disease stakeholders across sectors and geographies, partnering to strengthen national and regional capacity and leadership. IFPA works with others to generate and share evidence to inform change that can address the unmet needs of people living with psoriatic disease.

## Motivating principles

- **Person-centered:** Ensure that people living with psoriatic disease are at the heart of everything that IFPA does.
- **Collaborative:** Work together and openly with members and partners.
- **Accountable:** Be responsible for all actions.
- **Bold:** Have the confidence and courage to lead the global psoriatic disease community.



## Priority issues

Psoriatic disease is a complex disease, and the issues associated with it are equally complex. According to context, priority issues are those cross-cutting issues that influence the strategic goals and vary in relevance and importance. IFPA will continuously highlight selected priority issues in campaigns, toolkits, etc. The priority issues will be reviewed annually to ensure the impact of IFPA's work, relevance and ability to respond to any new issues of concern identified by IFPA or its national member associations.

The priority issues below were identified by IFPA and its stakeholders during the strategy development process and reflect the issues set out in the WHO Global Report on Psoriasis.

- **Equal access to treatment, specialists and individualized care**  
People living with psoriatic disease require access to appropriate treatment and care, including trained healthcare professionals and medicines. However, inadequate access to healthcare is a challenge in many countries across the world.
  - **Early diagnosis of psoriatic disease**  
People living with psoriatic disease can experience unnecessary suffering, irreversible deformities of the joints and disability due to late diagnosis and lack of appropriate treatment. One standard global guideline to help promote early diagnosis of and appropriate treatment for people living with psoriatic disease.
  - **Making healthcare providers aware of psoriatic disease**  
Lack of adequate training for healthcare practitioners and providers results in low awareness of psoriatic disease. Increased awareness and understanding of psoriatic disease among those responsible for providing care can help facilitate early diagnosis and appropriate treatment.
  - **Stop stigma**  
People with psoriatic disease still experience stigmatization and discrimination. Public misconceptions
- **Change the perception of psoriatic disease and call for consensus on categorizing severity**  
Psoriatic diseases are complex and unpredictable conditions with varied manifestations and associated diseases that affect individuals differently. The misperception that psoriatic disease is a mere skin condition and the lack of consensus on categorizing the severity levels of the condition can lead to inadequate treatment and care.
  - **Multidisciplinary care**  
People living with psoriatic disease require access to multidisciplinary care to identify and manage common comorbidities that already exist or may develop, including cardiovascular and metabolic diseases (such as diabetes) and psychological conditions. Multidisciplinary care teams include primary care physicians, dermatologists, rheumatologists, psychologists, psychiatrists, pediatricians, cardiologists and endocrinologists.
  - **Link psoriatic disease and mental health**  
Psoriatic disease causes great physical, emotional and social burdens, all of which may impair an individual's quality of life and be psychologically devastating. Increased awareness and focus on the link between psoriatic disease and mental health can help improve quality of life and wellbeing for people living with psoriatic disease.
  - **Join forces with family and community**  
Psoriatic disease affects relationships at home, school, and work, as well as intimate relationships. Community support, caretakers, and families should be included in the fight against psoriatic disease.

about psoriasis, for example the myth that it is a contagious disease, result in people with psoriatic disease being excluded from everyday life and foster low self-esteem, depression and even suicidal thoughts.

# Strategy roadmap

## Vision

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

## Mission

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

### Performance indicators

STRATEGIC GOALS	2024	2030
<b>Ensure global representation</b>	85 member organizations	133 member organizations
<b>Lead global advocacy</b>	Collaboration with WHO regional offices	Psoriatic disease represented on the global agenda
<b>Strengthen member capacity</b>	Member satisfaction rate 4+ out of 5	IFPA capacity leaders in all regions
<b>Share knowledge</b>	Robust channels for systematic knowledge sharing in place	IFPA perceived as the global knowledge hub for psoriatic disease
<b>Unite stakeholders</b>	Annual psoriatic disease forum established	IFPA regarded as the global convener for the psoriatic disease community

# Strategic goals and outputs

## Goal 1

### Ensure global representation

*Boost the voices of everyone living with psoriatic disease, everywhere.*

IFPA works with and through member associations to drive positive change for people living with psoriatic disease, everywhere. To represent people with psoriatic disease in all regions of the world and facilitate as many people with psoriatic disease as possible having access to support and resources, IFPA will work to scale up its member base and grow its organization. This includes welcoming already established patient organizations that are not yet members of IFPA and supporting the formation of new patient organizations in countries where none exist.

IFPA will broaden its reach in regions such as Africa and the Middle East where IFPA has low/no representation today.

#### 2024 performance indicator

IFPA's membership base is expanded, with 22 national member associations by 2024 (total membership by the end of 2024 should be 85).

#### 2030 performance indicator

IFPA's membership base is expanded, with an additional eight members each year to reach 133 national member associations by 2030.

## Activities and roles

ACTIVITIES	PRIORITIES AND ROLE OF IFPA	ROLE OF MEMBERS AND PARTNERS
Promote IFPA and its offerings to national associations	Develop a straightforward membership offering that member associations can relate to and derive value from	Promote IFPA regionally and nationally and support the establishment of new member associations within each region
Accelerate the development of national psoriatic disease associations	Develop a clear strategy for establishing national psoriatic disease patient associations in countries where none exist	Identify potential new national associations
IFPA start-up funding pool	Establish an IFPA start-up funding pool to help finance the establishment of national psoriatic disease associations in low-resource settings	Support IFPA in advocating for the funding pool Administer the local funding pool and report back to IFPA on progress

## **Goal 2**

### **Lead global advocacy**

*Fight for the interests of people affected by psoriatic disease.  
Demand representation on global health and development agendas.*

IFPA has had significant advocacy achievements, including the WHA Resolution on Psoriasis (2014) and the WHO Global Report on Psoriasis (2016).

Working toward these milestones has provided the entire IFPA organization with a common purpose. IFPA will continue to use the mandate awarded through the WHA Resolution and WHO Global Report to systematically advocate regionally and support national and regional members in advocating for local implementation of the recommendations set out in the global report.

IFPA will redefine its Global Psoriasis Coalition as IFPA's advocacy function and not a standalone advocacy body. Coalition members will continue to support IFPA in raising awareness and advocating for meeting the unmet needs of people with psoriatic disease.

To reach its goal to lead the global advocacy, IFPA has defined a triple A (AAA) Action plan: Act, Amplify, and Align. A tool for continuing the policy conversation on psoriatic disease by cooperating across borders, across disease areas, and across sectors.

#### **2024 performance indicator**

All six WHO regional offices are engaged in dialogue and partnership regarding the local implementation of the recommendations of the WHO Global Report on Psoriasis using the regional roadmaps generated.

#### **2030 performance indicator**

The interests of people living with psoriatic disease are adequately represented in any new development and global health agenda put forward in 2030, for example through a broader view of NCDs and the inclusion of clear universal health coverage goals.

## Activities and roles

ACTIVITIES	PRIORITIES AND ROLE OF IFPA	ROLE OF MEMBERS AND PARTNERS
<b>Formalize IFPA's engagement with the WHO</b>	Establish official relations with the WHO globally to facilitate ongoing dialogue and be included as an official civil society member	Support IFPA in establishing official relations
<b>Regional and national implementation of recommendations from the WHO Report on Psoriasis (2016)</b>	<p>Initiate partnerships and discussions with the WHO and WHO regional offices about the national implementation of recommendations from the global report</p> <p>Engage relevant organizations to support advocacy and implement recommendations from the WHO Report on Psoriasis at national level</p>	Work together to translate and implement recommendations from the WHO Report on Psoriasis (2016)
<b>World Psoriasis Day</b>	<p>Coordinate advocacy activities</p> <p>Increase participation and reach</p>	Support and deliver World Psoriasis Day by implementing local activities
<b>Transform global agendas into national actions through collaboration with members and partners</b>	<p>Develop clear position papers and resources for national actions</p> <p>Hold regional dialogues to highlight psoriatic disease priorities in different geographies and use key opinion leaders to engage local stakeholders</p> <p>Participate in global events and report back to members on events held by other stakeholders</p>	Engage in national action to advocate and implement psoriatic disease policies, and provide information on such engagements and implementations to IFPA

### Goal 3

#### Strengthen member capacity

*Strengthen IFPA members. Raise national support for people living with psoriatic disease.*

IFPA's ability to deliver on its vision of a future where all people living with psoriatic disease enjoy good health and wellbeing is directly influenced by the ability of its member associations to demand change locally. It is critical to boost national members and help strengthen their capabilities.

IFPA will join forces with its members and adopt a more systematic approach to ongoing dialogue about local needs and priorities. The engagement is bidirectional and also requires member associations to systematically report feedback to IFPA. To accelerate local action, a strong understanding of local needs will provide the best basis to develop effective tools and resources.

As IFPA grows, there will be an increasing need to develop regional centers of excellence with regional capacity leaders that can pass on skills and mentor capacity building, thereby supporting IFPA's overall strengthening of member capacity.

#### 2024 performance indicators

Ongoing member surveys show a satisfaction rate of 4+ out of 5 when asked if IFPA has helped strengthen local capacity.

#### 2030 performance indicator

A network of regional capacity leaders is established in all regions where IFPA is active. Capacity leaders actively support member associations in their regions.

### Activities and roles

ACTIVITIES	PRIORITIES AND ROLE OF IFPA	ROLE OF MEMBERS AND PARTNERS
<b>Evaluate member needs and satisfaction</b>	Systematically evaluate member needs and satisfaction on an ongoing basis and actively respond to address gaps	Provide systematic and regular feedback to IFPA Support IFPA in addressing and overcoming gaps
<b>Capacity development services</b>	Continue developing tools and guidance documents, training workshops and networking initiatives	Implement IFPA toolkits and resources at national level and support IFPA initiatives Contribute with knowledge and resources to help strengthen the global IFPA community
<b>IFPA Accelerator</b>	Facilitate the execution of IFPA Accelerator	Support the program with mentorship and resources

## **Goal 4**

### **Share knowledge**

*Close the gap between knowledge and action. Unleash findings to trigger breakthroughs for people living with psoriatic disease.*

Closing the gap between knowledge and action is one of the major challenges related to psoriatic disease. This is relevant for treatment and applies to priority issues such as timely diagnosis, stigma, discrimination, equality and general understanding.

IFPA will stay abreast of the latest research and be a trusted source of information for the psoriatic disease community. In addition, the emphasis will be on sharing and delivering high-quality priority policy issues and good practice cases from member associations.

IFPA will provide platforms that facilitate knowledge sharing across stakeholder groups, including member associations, medical associations, and the private sector. In collaboration with partners and member associations, IFPA will demand that the patient's perspective and experience are always represented to inform action.

#### **2024 performance indicators**

IFPA has robust and established systems and channels for sharing knowledge systematically, including best practice cases and the latest research, throughout its network of member associations, partners and relevant stakeholders.

#### **2030 performance indicator**

IFPA is regarded as a global knowledge hub for the psoriatic disease community and the preeminent source for accessing people's views and opinions on living with psoriatic disease.

## Activities and roles

ACTIVITIES	PRIORITIES AND ROLE OF IFPA	ROLE OF MEMBERS AND PARTNERS
<b>Policy analysis, publications and briefings</b>	<p>Map national policies and generate report cards, publications and briefings</p> <p>Support advocacy efforts with timely briefings and evidence-based messaging</p>	<p>Provide information to IFPA proactively and as requested</p> <p>Use and distribute IFPA materials locally</p>
<b>Knowledge hub</b>	<p>Develop IFPA’s website into a global knowledge hub for the psoriatic disease community</p> <p>Organize regular webinars focused on relevant and pertinent themes, with case studies and good practice cases</p>	<p>Actively participate and share knowledge with IFPA and other stakeholders from the psoriatic disease community</p>
<b>Research agenda</b>	<p>Insist on the person-centered approach of the research agenda</p>	<p>Contribute with expertise and skills and facilitate national research initiatives</p>
<b>Patient perspective</b>	<p>Speak up for the patient experience in all aspects of psoriatic disease, including treatment, product development and policies</p>	<p>Facilitate and collaborate on capturing a representative patient perspective</p>
<b>Best practice sharing</b>	<p>Develop a platform where member associations can share their success stories, challenges and general key learnings. The sharing should include ad campaigns, materials and papers.</p>	<p>Actively contribute with knowledge sharing</p>

## **Goal 5**

### **Unite stakeholders**

*Build alliances with psoriatic disease stakeholders. Transform global, regional, and national collaboration.*

A primary role of IFPA is to unite psoriatic disease stakeholders, including member associations, NGOs, scientific and medical organizations, governments, and the private sector, in order to stimulate sharing, identify synergies and opportunities and, ultimately, accelerate action towards positive change.

IFPA will continue driving global scientific research, conducting the world's leading multidisciplinary conference on psoriatic disease, the IFPA Conference.

IFPA will develop a new patient forum focused on highlighting the perspectives of people affected by psoriatic disease. The forum will bring together cross-sector stakeholders to speak up for the unmet needs of people living with psoriatic disease and enable global change.

Both the IFPA Conference and the IFPA Forum will serve as excellent platforms for profiling IFPA, its vision and mission, and for attracting attention from regions and nations where IFPA does not currently have any member associations.

#### **2024 performance indicators**

IFPA has established an annual psoriatic disease forum and successfully hosted three forums.

#### **2030 performance indicator**

IFPA is regarded as the global convener for the psoriatic disease community and has several established channels, events and projects for bringing together stakeholders and driving collaboration.

## Activities and roles

ACTIVITIES	PRIORITIES AND ROLE OF IFPA	ROLE OF MEMBERS AND PARTNERS
<p><b>IFPA Conference</b></p>	<p>Host the World Psoriasis &amp; Psoriatic Arthritis Conference every three years</p> <p>Maintain the conference as a unique cross-specialty forum with CME accreditation, and leverage and develop networking opportunities across the psoriatic disease community</p>	<p>Identify and propose topics to be presented at the conference</p> <p>Promote the conference among national stakeholders</p> <p>Participate and actively engage</p>
<p><b>IFPA Forum</b></p>	<p>Convene a forum annually</p> <p>Work with stakeholders and partners to identify key topics and priorities</p>	<p>Serve on the steering committee</p> <p>Propose topics and priorities</p> <p>Participate and actively engage</p>
<p><b>Stakeholder networks</b></p>	<p>Boost networks for stakeholders, including people living with psoriatic disease and the scientific and medical communities</p> <p>Raise capacity for new networks and focus on regions where there is little or no IFPA representation as well as on topics that need increased coverage</p>	<p>Participate and actively engage in IFPA networks and events</p> <p>Lead networking and dialogue nationally</p>

# Flagship programs

IFPA has four strategic flagship programs that transcend the strategic goals and spearhead determined change toward improving health and wellbeing for people living with psoriatic disease.



## World Psoriasis Day

*Uniting for action*

World Psoriasis Day (WPD) is the annual day dedicated to people living with psoriatic disease. The day is celebrated on October 29, with the overall aim to:

- Make the world aware of psoriatic disease
- Spread information about psoriatic disease, refuting common misconceptions and increasing knowledge among people living with the condition
- Call on health ministers, governments, and decision-makers to improve access to treatment
- Join forces with people living with psoriatic disease for advocacy and knowledge exchange

World Psoriasis Day is a powerful opportunity to mobilize advocacy for a shared theme and goal. On October 29th IFPA unites the global community to unleash loud action and achieve targeted breakthroughs, together.

## IFPA Forum

*Speak up for psoriatic disease*

The IFPA Forum is organized by IFPA and brings together stakeholders from across the psoriatic community. Whereas the IFPA Conference is centered around the latest scientific research, the forum is about the people living with psoriatic disease and what it takes to address their unmet needs. The forum aims to:

- Establish consensus around the unmet needs of people living with psoriatic disease
- Discuss roadmaps for action on how to implement the recommendations of the WHO Report on Psoriasis
- Demand inclusion of the patient perspective when developing solutions (in policy, research, etc.)
- Fuel knowledge sharing across countries and stakeholder groups
- Strengthen relations across countries and stakeholder groups



## **IFPA Accelerator**

### *Boosting national leadership*

A vital part of IFPA's work is to unleash the potential of a growing network of national patient organizations. With an ambitious growth target, there will be an increasing need to develop regional centers of excellence with regional capacity leaders to pass on skills and mentor capacity building in their regions. IFPA Accelerator is an extension of IFPA's existing Mentoring Program and Peer Coaching Program. The program aims to:

- Accelerate the growth of IFPA
- Leverage the skills and capacities of selected member associations in each region
- Strengthen regional alliances and facilitate best practice sharing within regions



## **IFPA Conference**

### *Calling for breakthroughs*

IFPA is driving global scientific research. Organized by patients, we conduct the world's leading multidisciplinary conference on psoriatic disease. The IFPA Conference presents the latest developments in psoriasis and psoriatic arthritis research. Because medical professionals from both the dermatology and rheumatology field attend, the conference provides a unique cross-specialty forum. The conference aims to:

- Increase global recognition of psoriatic disease and its severity
- Unite stakeholders to strengthen international collaboration
- Share the latest scientific and clinical developments in psoriatic disease
- Encourage new research projects
- Highlight the patient perspective so that the conference ultimately improves quality of life for the global psoriatic disease community

# Enablers

Delivering on this strategic plan requires optimizing how IFPA operates and adapts to a rapidly changing world. The focus on sustainable development and COVID-19 have irreversibly impacted everyday business. Several cross-cutting areas need to be strengthened toward 2024 and beyond. These areas have a direct impact on our ability to realize the strategic plan.

## Financial resources

This strategic plan will only be realized by securing adequate financial resources for us to leverage available opportunities. This strategy will be supported with a financial plan focused on growth and a fundraising strategy for maintaining and developing existing revenue streams. This includes identifying new revenue streams to realize many of the priorities outlined in this strategic plan.

## Organization

The structure and governance of IFPA will be reviewed and optimized to ensure that the organization is prepared to deliver on the strategic plan and meet the ever-developing needs of different stakeholder groups, particularly member associations. We will continuously investigate mechanisms for improving governance, streamlining decision-making processes and optimizing processes to ensure timely delivery of all IFPA initiatives and programs.

## Communication

The world of communication has evolved rapidly over the past decade, and this has been further expedited under COVID-19 to deliver a 'new normal' of digital communication and engagement. IFPA will transition to a 'digital first' mindset and leverage all available platforms to raise awareness about psoriatic disease. We will strive to develop a more diverse and engaged audience to ensure the reach and penetration of our cause and messages. This includes expanding the number of languages in which IFPA communicates. Furthermore, we will develop a strong narrative, including updated language for referring to people living with psoriatic disease.

## **Profile and brand**

Strengthening IFPA's profile and brand is critical to achieving its mission. IFPA's brand and profile will be updated to signal a revitalized organization that can function and engage in a modern world, and speak and resonate with an increasingly diverse audience. The brand will reflect that IFPA is people-centered and dedicated to amplifying the voice of people living with psoriatic disease.

## **Relations with member associations**

To ensure the greatest impact, we will strengthen relations with its member associations. This will foster a better understanding of the needs of member associations and help mobilize a sense of unity between diverse organizations working toward a shared goal.

## **Partnerships**

Partnerships are fundamental to IFPA's work. IFPA will continue expanding and developing strategic partnerships with UN agencies, civil society, NGOs, governments, the private sector and other like-minded organizations. Partnerships are critical to developing and delivering new programs and initiatives.

## **Monitoring and evaluation**

Accountability and transparency are cornerstones in terms of unifying and representing the global patient voice. IFPA will introduce robust and systematic processes for monitoring and evaluating its programs and initiatives and reporting back to stakeholders.

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## Appendix:

# Recommendations from the WHO Global Report on Psoriasis

The WHO Global Report on Psoriasis outlines the public health impact of psoriasis and provides concrete recommendations for actions by different stakeholder groups. The action recommendations from the report are outlined below.

## Actions for governments and policymakers

- Member States should ensure that people suffering from psoriasis have access to professional medical care. It is essential that psoriasis is diagnosed as early as possible. Early diagnosis and appropriate therapy give the best chance to prevent patients from unnecessary suffering, uncontrolled disease, irreversible deformities of the joints and disability. Optimum therapy also reduces mental health and societal costs of the disease.
- Patients suffering from psoriasis should have access to comprehensive, individually adapted treatment. At a minimum, public and private facilities should provide the drugs included on the WHO Model List of Essential Medicines, including systemic therapies. Universal health coverage schemes should cover the costs of these treatments for newer biological therapies, more needs to be done to reduce the price of these medicines, if they are to present a sustainable and affordable treatment option for patients with psoriasis. The development of biosimilars may help in this regard. Governments should take cost-effectiveness of treatment options into account when developing national guidelines.
- Optimum treatment of psoriasis, and its comorbidities, require shifting to a model of people-centered and integrated health services, as outlined in the WHO global strategy on people-centered and integrated health services. All people with psoriasis should have access to health services that are provided in a way that responds to their preferences, are coordinated around their needs and are safe, effective, timely, efficient and of an acceptable quality. This is essential not just to improve the lives of people with psoriasis, but also for all other chronic complex conditions.
- Governments and nongovernmental organizations should provide

education on common chronic skin conditions to health-care professionals, including undergraduate medical and nursing curricula and in service training for physicians in primary care. There is a great need to raise awareness and knowledge about psoriasis among general practitioners to increase early diagnosis and prevent disability. Governments also have a role in supporting psoriasis research.

- Governments have a key role in reducing stigma and discrimination. Society, not psoriasis, causes the exclusion and discrimination faced by people with this disease. This situation can change through campaigns to raise awareness of psoriasis among the population and by condemning discrimination of patients who suffer from it. Active steps by Member States include anti-discrimination legislation and enforcement of existing legislation.

### **Actions for health systems and health professionals**

- All health professionals, especially clinicians working in primary health care, should be aware of psoriasis, its management, and its comorbidities. Health care professionals' associations should provide training, for example, via the Internet for physicians from low- and middle-income countries regarding prompt diagnosis and effective treatment of psoriasis. Patients with psoriasis need access to primary health care that responds to their individual needs and coordinates with any additional specialist care.
- In settings with adequate resources, health-care professionals and health systems must strive to provide patients with comprehensive care from multidisciplinary teams of specialists, including dermatologists, rheumatologists, psychologists, psychiatrists, paediatricians, cardiologists and others. Clinicians must inform patients about the possible consequences of the

disease and collaborate with them to identify barriers to adherence and help address these barriers to achieve optimal management.

- Associations of medical specialists have a role in seeking consensus on the classification of psoriasis and standardization of the collection of epidemiological data using a unified methodology.
- There is a great need to develop guidelines regarding the diagnosis of psoriasis and its treatment. Furthermore, certain standards relating to medical care such as adequate assessment of progress of therapy, using uniform tools to assess the severity of the disease and patient QoL should be implemented. Doctors should establish objectives of care and plan therapy in collaboration with their patients.

### **Actions for patients' organizations and civil society**

- Patients' organizations must continue advocating for the rights of individuals suffering from psoriasis. They should be involved in raising awareness of psoriasis among the population in collaboration with governments and policymakers.
- Patients' organizations have a key role in providing support to people suffering from psoriasis and in creating networks to foster mutual support and exchange of experiences.
- Patients' organizations have a responsibility to encourage the formation of patients' associations where currently none exists.
- Patients' organizations and civil society have a key role in holding governments and policymakers to account on global commitments, and in fighting discrimination of people with psoriasis.

## Priority areas for research

- There are many unmet needs for psoriasis, including epidemiology, etiology, treatment and ways to improve health care. Researchers should investigate the etiology of psoriasis and therapies to prevent as well as to manage the symptoms of the disease. It is vital to create low-cost effective treatment options that can be made widely available.
- Research on new treatments should focus on options which can be applicable globally, on a large scale. New treatments need to be affordable, effective and safe in the long term, stable in hot and humid climates and require minimal monitoring.
- Prospective, controlled studies are needed to further clarify the association between psoriasis and cardiovascular disorders on a pathogenic level and to substantiate the beneficial effect of treatment for skin/joints and associated disorders.
- In clinical research, there is a need for comparative effectiveness research in order to identify the benefits and efficiency of treatments.
- For research outcomes that are more reliable, the currently used clinical outcome parameters, including PASI and patient-reported outcomes such as DLQI, need to be improved.
- Health services research needs to be better used in identifying specific needs of health care, unmet patient needs and barriers of guideline-compliant treatment. Health services research should monitor and provide feedback on the actions taken to improve quality of care and investigate efficiency of care. Psoriasis care could thus become a model for the management of other chronic (skin) diseases.
- A key area of health-care research is the epidemiology of psoriasis and its incidence and prevalence on the global level. Research methods need to be harmonized and reflect cultural as well as geographical differences.

