

**IFPA**

GLOBAL LEADER IN FIGHTING  
PSORIATIC DISEASE

**IFPA org no 802428-5986**

**Annual  
Accounts  
2022**

# Director's Declaration 2022

Founded in 1971, IFPA is the international federation of psoriatic disease associations. We are the psoriatic disease community. Our members represent over 60 million people living with psoriatic disease. Together, we advocate for progress.

## Purpose of the Federation

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 unmet needs for people living with psoriatic disease.

- **Legitimacy to represent people living with psoriatic disease:** IFPA is the only organization that brings a unified global voice of people living with psoriatic disease to the global agenda.
- **History and track record in the psoriatic disease community:** IFPA has been unifying the psoriatic disease community and has a proven track record of elevating psoriatic disease onto the global agenda.
- **Independence and integrity:** Decisions are exclusively driven by the needs of the people living with psoriatic disease.

## 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.

## Goals

**Ensure global representation:** Boost the voices of everyone living with psoriatic disease, everywhere.

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

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

**Share knowledge:** Close the gap between knowledge and action. Trigger breakthroughs for people living with psoriatic disease.

**Unite stakeholders:** Build alliances. Transform global, regional, and national collaboration.

The interrelated goals are equally important and support each other. The strategic goals are further broken down in different activities with performance indicators set for 2024 and for 2030.

In addition to goals, four core values are identified, as well as a number of priority issues, those cross-cutting issues that influence the strategic goals and vary in relevance and importance. The priority issues identified by IFPA, and its stakeholders, very much reflect the issues set out in the WHO Global Report on Psoriasis in 2016.

## Values

**Person-centered:** Ensure that people living with psoriatic disease are at the heart of everything 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

**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 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.

**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.

# 2022

## Theme of the year: Mental Health

In 2022, IFPA tackled psoriatic disease from the inside, out. By joining forces with members and global stakeholders, IFPA emphasized mental health, boosted diverse voices, and forged new trends in advocacy and research.

Depression and anxiety are increasingly recognized as a significant part of psoriatic disease. IFPA uncovered the endogenous and exogenous reasons for this link in a report titled "Inside Psoriatic Disease: Mental Health".

The theme acted as a red thread, uniting IFPA's advocacy priorities and project choices for the year, as well as World Psoriasis Day. IFPA representatives also participated in different interviews, video recordings, podcasts, conferences and presentations on the Mental Health theme.

Below follows a description of IFPA's activities and achievements during the year.

## Governance

### General Assembly

The General Assembly, consisting of IFPA's full Members, is the highest decision-making body of IFPA. The meeting of the General Assembly is held every three years, and was held on September 4 in Milan, Italy.

The General Assembly elected a new Board composed of a President and six members. The Board governs IFPA in accordance with its objectives and its regulatory and statutory obligations. The Board represented by its President shall have the overall responsibility for ensuring the well- functioning of IFPA and compliance by the organization until a new Board is elected at next General Assembly. An extraordinary meeting of the General Assembly can be convened on the recommendation of the Board or one-third of the full members.

### Board Meetings

In 2022 the IFPA Board had ten (10) Board meetings, of which one was physically conducted.

## Secretariat

During 2022 the IFPA Secretariat consisted of the:

- Executive Director
- Finance & Administration Manager
- Marketing Manager, from September 1
- Communications Manager
- Scientific Officer
- Program Officer – Advocacy and Policy
- Program Officer – Capacity Development, until August 15
- Project Developer
- Scientific Coordinator, part-time, until September 30

The number of full-time staff positions at the Secretariat was 7. In addition to the above staff positions, IFPA also had one intern focusing on communications in the spring and one focusing on member education and science in autumn.

## Members

By December 31, 2022, IFPA had 59 national member organizations in 55 countries and 3 regional member organizations.

## IFPA Member Meeting 2022

The Member Meeting was held in the afternoon of September 4 and brought together 63 onsite patient advocates and psoriatic disease stakeholders from all over the world. In addition to the onsite participants 22 persons were following the meeting online. The meeting consisted of four sessions:

- Impact presentations by IFPA Members
- Classification of disease severity session IPC
- Unveiling of IFPA's new strategy and branding
- Current Themes in Advocacy by Health & Happiness Foundation
- Discussion on Mental Health
- Presentation of IFPA's projects and programs, how can members get involved?

The meeting was followed by a celebratory dinner for members and stakeholders.

## Impact reporting

Every year, IFPA members report the impact of their national work. Through these Impact Reports, IFPA can build a picture of progress in the global psoriatic disease space. Notable actions from this year include a new bill to include psoriasis care in the Philippines and a traveling clinic in Argentina.

## Member Survey

As a federation made up of membership associations, it is important for IFPA to continually gauge the level of satisfaction member associations feel with their membership. Each annual member survey therefore includes questions on how members value their membership, as



well as questions on what they appreciate and what they do not currently appreciate about IFPA's work. In IFPA's global strategy, 'Strengthen member capacity' is one of the five main goals. Member satisfaction is crucial to IFPA and by 2024 we set out to have a satisfaction rate of 4+ out of 5. The member survey for 2022 was conducted early in 2023 and results are not yet available.

## Solidarity Fund

The IFPA Solidarity Fund was created to address the funding gap faced by many of IFPA's members, by awarding grants to support advocacy, education and awareness-raising in psoriatic disease. During 2022, the Solidarity Fund had two calls for application, where applying organizations could receive a maximum of 2500 EUR each.

First round was closed in early January, with seven projects elected:

- Croatia – Education Program for Psoriasis Patients
- Greece – Comorbidities Campaign with focus on Depression
- Hong Kong – Psoriasis Patients Registry
- Kenya – Symposium for Patients and Caregivers
- Russia – 7-day Knowledge Marathon
- South Africa – Poetry for Inclusion and Diversity
- Vietnam – Reporter Training for PsorViet Podcast

Second round was closed in August, with three projects elected:

- Iceland – EADV Attendance
- Peru – Psychology and Coping Program
- South Africa – Mental Health Webinars

## Webinars

Designed for the psoriatic disease community, IFPA's webinar series provided updates on research, deep dives into life with psoriatic disease, and advocacy achievements. IFPA Webinars were open live for everyone, and on demand for our members through the IFPA Member Website.

- Diversity and Inclusion
- Wellbeing and Psoriatic Disease
- International Dermatology Outcome Measures
- World Psoriasis Day 2022

## IFPA Accelerator Program

IFPA officially launched the Accelerator program in 2022. It is one of our four flagship programs, a training program that supports organizations to expand their work and guides new advocates in establishing patient associations.

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



A part of the Accelerator Program is the new Member Portal, a resource to meet the members' needs that is:

- A knowledge hub hosting the latest psoriatic disease research
- A collaborative space for communication between members
- A learning center to continue building capacity and skills
- A place to showcase national work
- A library of resources

So far, lessons have been created on topics like:

- How to start a patient organization
- Running a General Assembly
- Strategic planning
- How to plan a successful campaign
- A GPP training package
- Community support

The course offering will continue to expand in coming years. The press release associated with the program launch “Boosting Leadership in Psoriatic Disease: IFPA Accelerator” had 31.8K recorded views with a potential reach of 95.4M.

## Communications

### Communication channels

#### IFPA Update and Newsletters

IFPA continued with the IFPA update, an internal newsletter to communicate more frequently with IFPA members and keep them informed of developing projects and opportunities.

IFPA sent four Quarterly Newsletters to members, stakeholders, and partners. These illuminated such topics as information about the IFPA Conference (7<sup>th</sup> WPPAC), Global Psoriasis Atlas, Coalition activities, Solidarity Fund, PsoProtectMe, IFPA Webinars, IFPA Ambassadors, World Psoriasis Day, IFPA Forum, Accelerator Program and other actions in 2022.

#### Website

IFPA's website in numbers 2022 (2021):

- Users: 33,752 (49,141)
- Page views: 95,461 (94,029)
- Top four countries frequenting the IFPA website:
  - USA 21.73% (India 19.9%)
  - India 6% (USA 17.9%)
  - UK 5.3% (UK 6.4%)
  - China 4.62% (Indonesia 5.73%)
- Top five webpages visited:
  - Homepage: 17,862 (17,804)
  - World Psoriasis Day: 9,145 (9,182)
  - Resources & Tools: 5,554



- World Psoriasis Day 2022 Toolkit: 4,091
- Now Act Petition: 3,640

### Social media

IFPA continued to invest in video content for social media channels, and to develop a following on TikTok.

Top posts included links to a World Psoriasis Day Livestream on Twitch, a video testimonial from an IFPA Ambassador living with erythrodermic psoriasis, and an article on the IFPA website discussing coverage of Cara Delevingne's psoriasis at the MET Gala.

By the end of 2022 we had this many followers on each account (2021):

2.3K Instagram (1.6K)

900 LinkedIn (430)

7.2K Twitter (6.9K)

14K Facebook (14K)

975 TikTok (0)

## World Psoriasis Day

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

- Raising awareness about the severity of the disease and the everyday challenges faced by people living with psoriatic disease
- Spreading information about psoriatic disease, refuting common misconceptions and increasing knowledge among people living with the condition
- Improving access to treatment by targeting health ministers, governments and decision-makers
- Creating a united platform to empower people living with psoriatic disease

World Psoriasis Day provides a unique opportunity for IFPA to take action, drive advocacy, and demonstrate leadership among multiple stakeholder groups. IFPA uses World Psoriasis Day to mobilize enthusiasm for a shared theme and goal.

For World Psoriasis Day 2022, IFPA's global community raised awareness of the mental health impact of psoriatic disease, and how to protect wellbeing for everyone living with it. The message was that no one should be left alone with psoriatic disease and that time had come to put down the emotional burden and #UnloadPSO.

Read more about the World Psoriasis Day campaigns by IFPA's members [here](#).

The press release "Unload Psoriatic Disease: World Psoriasis Day" had 207.8K recorded views with a potential reach of 2.7B.



## Now Act Petition

In 2021 IFPA launched the Now Act Petition. In 2022, we moved the petition to a separate page on our website and it was available for World Psoriasis Day and signatures.

The psoriatic disease community united in the petition to demand following actions:

- Change the perception of psoriatic disease
- Ensure equal access to medicines
- Stop stigma
- Advance holistic care
- Prepare the health workforce

The petition will be live until the UN High-Level Meeting on Noncommunicable Diseases in 2025. [Sign the petition here.](#)

## Advocacy and Policy

### IFPA Coalition

By collaborating across borders, sectors and disease areas, IFPA uses the Coalition to generate support to implement the recommendations outlined in the Global Report on Psoriasis, developed by the World Health Organization in 2016. To reach its goal to lead global advocacy, IFPA has defined a triple A (AAA) Action plan: Act, Amplify, and Align. The Coalition convened four times in 2022: March, July, September and December. During these meetings, the main initiatives in advocacy were discussed, namely the IFPA Forum and the report on mental health. Coalition members gave helpful input and contributions to discussions to further amplify IFPA's advocacy work. Moreover, Coalition members worked on indicators based on the WHO Global Report on Psoriasis to be utilized for producing the Psoriatic Disease Response Index Asia, planned for 2023.



In 2022, the IFPA Coalition counted 14 members from civil society, industry, and medical professionals' organizations.

## Reports

IFPA developed and launched one advocacy report:

- Inside Psoriatic Disease: Mental Health, April 28, 2022

As part of the resources developed for IFPA's year with focus on mental health, IFPA produced a report on psoriatic disease and mental health, available in English, Spanish and Japanese. A social media toolkit with messages related to the report was made available together with the report in the following languages: English, Arabic, Spanish, French, Russian, and Chinese (mandarin). The webpage received over 2.8K views by December 31, 2022. The press release associated with the launch of the report had 83.9K recorded views, with a potential audience of 2.1B people. In connection with the report launch, IFPA attended the Wellbeing conference in London.

## Relationship with international policy bodies

IFPA representatives followed the 75th World Health Assembly remotely as the limited number of seats available for the in-person event impeded our participation. IFPA contributed to the proceedings of the assembly by submitting a statement together with other organizations, as part of the Global Health Council delegation.

IFPA continued the communications with a contact from the WHO, as part of the efforts to establish official relations. Unfortunately, the communications were interrupted shortly after the beginning of the year as the contact person was suddenly unavailable.

## IFPA's network in advocacy

IFPA renewed its membership in the International Alliance of Patients' Organizations (IAPO), the Global Health Council and the NCD Alliance, in which IFPA is an active member of the Inclusive Agenda program, a project promoting inclusivity in the non-communicable disease sphere. IFPA is also a member of the Civil Society Engagement Mechanism for Universal Health Coverage (CSEM).

IFPA continued its collaboration with the International Alliance of Dermatology Patient Organizations (IADPO/GlobalSkin) and three joint workshops/webinars were held for our members.

IFPA formalized its relationship with the International Psoriasis Council and had several meetings and a few activities together.

During 2022, IFPA became members in the Rare Diseases International alliance.

## IFPA Forum

The IFPA Forum is a new program of IFPA designed to put the needs of people living with psoriatic disease at the center of the policy discourse at the regional level.

Ahead of the first Forum, a Briefing Book was developed to investigate five pressing needs for people living with psoriatic disease in Europe. IFPA also did a press release one month before the Forum with 10.7K recorded views, and a potential reach of 95M. The Forum was



held in Milan, Italy, on September 5, 2022, and brought together 95 patient advocates, policymakers and allies from industry and civil society to speak up for psoriatic disease in Europe and find solutions to the needs outlined in the briefing book. The outcome was a roadmap based on the discussions from the Forum, and an active collaboration with the European organization Europso. In December we started to develop a toolkit that will support the members to implement the actions from the roadmap.

## Science

2022 was a turn back to normal after the pandemic in regards of general physical events, and scientific conferences in particular.

### External science events

#### **AAD Annual Meeting, Boston, March 25-29**

The 2022 Annual Meeting of the American Academy of Dermatology took place in Boston in March. This was the first live AAD Annual Meeting since 2019, the largest dermatology meeting in the world, and an event that has perennially showcased the depth and breadth of dermatology in all its broad topics and fascinating minutiae. Over 15,000 registrants showed up at the Boston Convention & Exposition Center.

#### **EULAR, Copenhagen, June 1-4**

The European League Against Rheumatism (EULAR) Congress with 14,500 registrations, was held as a hybrid event, IFPA joined onsite and followed live updates on the EULAR recommendations on management of Psoriatic Arthritis, use of social media and digital resources in rheumatology. IFPA Representatives held meetings with national members from Canada and Denmark.

#### **WCRSD, Paris, June 7-9**

The 1<sup>st</sup> World Congress on Rare Skin Diseases aimed to boost the collaboration between specialists from different centers and countries and to increase research and clinical trials in order to improve the care and quality of life for patients with rare skin disorders. IFPA both hosted a patient booth and held a symposium alongside clinical experts.

#### **GPP Forum, Amsterdam, June 30-July 1**

IFPA joined the multistakeholder Forum focusing on generalized pustular psoriasis (GPP) to discuss, consolidate, and collaborate on fresh ideas to instigate a positive change for people living with GPP. The attendees comprised dermatologists, clinicians, patients, patient advocates and rare disease policy experts from around the world meeting for the first time. They shared their experiences to create the building blocks of an innovative approach to GPP. Every aspect of GPP was discussed to reach a consensus leveraging different expert perspectives. At each step of the condition's journey, the resulting GPP Charter will revolutionize how the condition is viewed and supported moving forward.

#### **SPIN, Paris, July 6-8**

This 7th edition of SPIN (Skin Inflammation & Psoriasis International Network) was hybrid for the first time with an ambitious scientific program covering 5 IMIDs. The scope of SPIN and its triennial congress was to pursue its broadening with the objective to transfer the know-how acquired on psoriasis (highest standard in issues such as quality of life, high burden and



co-morbidities) to other chronic inflammatory skin diseases, in particular atopic dermatitis, vitiligo, alopecia, and hidradenitis suppurativa. IFPA joined onsite, had a booth and hosted a symposium.

### **EADV, Milan Sep 7-10**

It was the 31<sup>st</sup> edition of the European Academy of Dermatology and Venereology Congress, showcasing the latest innovations in dermatology and venereology and providing a platform for deep scientific exchange within the dermato-venereology community. IFPA attended sessions and co-hosted the joint patient booth provided by EADV. Ahead of EADV, IFPA was actively collaborating with EADV's Task Force and Policy round table sessions to expand patient organization participation at the congress and recorded a podcast on mental health and psoriatic disease.

## **IFPA Conference**

The 7<sup>th</sup> IFPA conference will take place **June 27-29, 2024**, with the theme:

### **Uncovering the broad spectrum of psoriatic disease.**

Scientific Executive Committee:

- Chairperson - Prof. April Armstrong
- Co-Chair in Rheumatology - Prof. Laura Coates
- Co-Chair in Dermatology - Prof. Ulrich Mrowietz
- Secretary - Barbra Bohannon

Planning for the global scientific conference addressing psoriasis and psoriatic arthritis is well underway.

## **The Global Psoriasis Atlas (GPA)**

The Global Psoriasis Atlas is an international project launched in 2016 by IFPA, International League of Dermatological Societies (ILDS) and the International Psoriasis Council (IPC). It has made incredible progress and is delivered by global experts and an academic project team led by the University of Manchester. The vision is that the GPA will become the leading epidemiological resource globally on psoriasis and psoriatic arthritis providing the common benchmark on the burden of psoriasis in all countries and regions throughout the world. The Atlas will seek to: drive continuous improvement in understanding the natural history of psoriasis; uncover how it affects the individual and society; understand how healthcare can be improved for those living with the disease.

The GPA website is the first-ever comprehensive online epidemiological resource database tool. It contains data on the number of psoriasis cases, healthcare data and looks in depth at the experiences and faces behind people living with psoriasis.

In 2022 the Global Psoriasis Atlas advanced epidemiological data with:

- 3 publications
- A new frontpage displaying ongoing research in 8 countries
- A new heatmap visualizing prevalence of psoriasis around the world

Further information is available on [www.globalpsoriasisatlas.org](http://www.globalpsoriasisatlas.org).

## PsoProtect & PsoProtectMe

In 2022, IFPA continued its partnering with PsoProtect, a global registry collecting de-identified data from health care professionals caring for patients with psoriasis and COVID-19. There is also a registry for self-reported data by patients through PsoProtectMe. By collecting data, the team at PsoProtect can analyze many facets of the pandemic's impact, including outcomes of COVID-19 in people who have psoriasis, the mental health burden of living through the pandemic, and psoriasis flares because of stress or reduced access to treatment.

2022 in numbers:

- 9 publications detailing the burden of COVID-19
- 5479 cases reported to PsoProtectMe
- 1652 cases reported to PsoProtect

The results are not only important for scientific reasons. IFPA and other organizations will also be able to use these results to advocate for better provisions for people living with psoriatic disease through this pandemic and in future crises.

## Psoriasis and Beyond

Psoriasis and Beyond is a joint research initiative between IFPA, 16 national psoriasis organizations and Novartis Pharma AG. The study is overseen by a Steering Committee of patient advocates, dermatologists and rheumatologists.

By understanding the patient experience, including patient awareness of their own disease, our community will be better equipped to design meaningful interventions. The results of the study are hosted on IFPA's website for easy access to patient advocates.

In 2022, Psoriasis and Beyond received high commendation from the Communiqué Awards for "Excellence in Communicating and Using Data". Global data was published in December 2022.

The data exploration tool is live on IFPA's [website](#), sharing information and resources to help people learn more about their own illness.

## Projects 2022

### IFPA Ambassadors

IFPA has often received requests to contribute patient testimonials, survey participants, and stars for photo and video assets. Unfortunately, IFPA often struggled to find participants available, with thoughtful messaging, representing the full spectrum of people living with psoriatic disease and their caregivers in terms of race, age, body type, gender, and severity of disease.

Through the Ambassador Training program IFPA recruited a group of 20 ambassadors and gave them training on advocacy messaging. The program aims to unite a team of skilled ambassadors, reliable and ready to speak up for psoriatic disease and its comorbidities in



the global arena. Their expert perspectives boost the diverse needs and experiences of people living with psoriatic disease, everywhere.

In 2022 the Ambassadors:

- Presented their stories at conferences and on panels
- Directed personal initiatives to address mental health
- Collaborated for World Psoriasis Day
- Spoke up at IFPA Forum
- Submitted photos to All the Colors We Are
- Ran IFPAisland videogame and livestream

## IFPA Island

As the first patient organization IFPA used Nintendo's Animal Crossing to share knowledge. The purpose was to increase knowledge and interact with the younger population of people living with psoriatic disease and creating a space to connect and share experiences with each other.

The channel **JoelvsArthritis** on Twitch built a supportive community of people living with chronic illness. Joel Nelson – one of IFPA's ambassadors and owner of the channel – livestreamed and shared his story with psoriatic-associated Juvenile Idiopathic Arthritis while gaming and creating the IFPA Island together with the community.

Highlights from the project include:

- Live stream event at the EADV Congress promoting the project
- Free in-game giveaways to promote the community and share awareness
- World Psoriasis Day marathon showcasing the completed island and raising awareness of mental health
- Step-by-step guide for IFPA members interested in exploring video gaming for awareness raising and community support

## All the Colors We Are

IFPA's project addressing diversity and inclusion was launched in November. IFPA Members and Ambassadors from around the world submitted photos of visible psoriatic disease to the virtual library. These images are available for free download to raise awareness of psoriatic disease on every skin. In the next phase of the project, IFPA calls for better training of doctors and more research into care for people of color living with psoriatic disease.

## Psoriatic Arthritis Awareness

In 2022, IFPA identified the need to increase awareness of Psoriatic Arthritis – a joint manifestation of Psoriatic Disease associated with high burden and significant comorbidities. Recent progress in understanding the course of psoriatic arthritis (PsA) has led to breakthroughs in therapies. Yet the needs of many people living with PsA are still unmet. Through this project, in 2023 IFPA aims to join forces with rheumatologists and the patient community to raise awareness of new treatment guidelines, and ultimately improve quality of life for people with PsA around the world.



## Project Rare GPP

During 2022, IFPA started up the foundation to meet the needs of those affected by GPP. The Project Rare GPP fund is an opportunity for patient organizations to reach those in their region living with GPP (Generalized Pustular Psoriasis). National patient organizations are crucial to the fight against psoriatic disease, and often lack resources to carry out all the projects they wish for. With the financial assistance from this fund, they can realize some of these projects.

## Corporate Partners

In 2022, IFPA received support from AbbVie, Almirall, Amgen, Boehringer Ingelheim, Bristol-Myers Squibb, Eli Lilly, Janssen, LEO Pharma, Novartis, Pfizer and UCB.

The support covered all from IFPA Partnership Program and Flagship programs to various projects and initiatives within science and advocacy to improve the lives of all people affected by psoriatic disease. Project sponsors are revealed under the project description on IFPA's website.

# Administration report

The Board of IFPA hereby delivers the annual accounts for the full year of 2022.

Regarding the result and financial positions, please refer to the attached statements.



**President**  
Hoseah Waweru, M.D.  
Nairobi, Kenya



**Vice President**  
Ingvar Ágúst Ingvarsson  
Reykjavik, Iceland



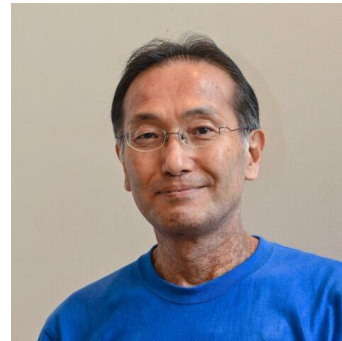
**Secretary**  
Kathleen Gallant  
Pittsburgh, USA



**Treasurer**  
Josef de Guzman  
Manila, Philippines



**Board Member**  
Silvia Fernandez Barrio  
Buenos Aires, Argentina



**Board Member**  
Masanori Okuse  
Yokohama, Japan



**Board Member**  
Helen Crawford  
Ottawa, Canada

# IFPA

## Org no 802428-5986

### Profit and loss account

Income	2022-01-01 2022-12-31		2021-01-01 2021-12-31	
	SEK	EUR 11,1283	SEK	EUR 10,2269
Membership fees	95 876	8 615	73 122	7 285
Rounding- off to whole SEK	0	0	2	0
IFPA Conference	0	0	4 154 082	413 856
AbbVie	1 570 282	141 107	929 183	92 571
Almirall S.A.	1 296 026	116 462	99 254	9 888
Amgen	1 547 260	139 038	1 033 491	102 963
Boehringer Ingelheim	2 738 610	246 094	1 826 026	181 920
Bristol-Myers Squibb	1 735 803	155 981	1 044 297	104 040
Eli Lilly	1 139 029	102 354	787 054	78 411
Janssen	1 055 452	94 844	101 590	10 121
LEO Pharma A/S	1 101 240	98 959	1 039 857	103 597
Novartis	1 346 084	120 960	1 073 749	106 974
Pfizer	936 855	84 187	707 847	70 520
UCB	1 353 699	121 645	1 858 333	185 139
Other operating income	34 279	3 080	7 773	774
<b>Total income</b>	<b>15 950 495</b>	<b>1 433 327</b>	<b>14 735 659</b>	<b>1 468 061</b>

## Profit and loss account

2022-01-01  
2022-12-31

2021-01-01  
2021-12-31

Costs	SEK	EUR 11, 1283	SEK	EUR 10,2269
Outgoing donations	-224 511	-20 175	-120 304	-11 985
Translations	-227 715	-20 463	-79 618	-7 932
Office rental agreement	-330 000	-29 654	-426 220	-42 463
Software programs	-161 181	-14 484	-89 874	-8 954
Freight and transport	-15 309	-1 376	-21 942	-2 186
Conference costs	-764 418	-68 691	-21 304	-2 122
Travel costs	-758 420	-68 152	18 883	1 881
Refund members	-214 489	-19 274	0	0
Hotel costs	-521 104	-46 827	-5 820	-580
Food	-191 585	-17 216	-302	-30
Reimbursement	-32 276	-2 900	0	0
Printing costs	-116 398	-10 460	-4 463	-445
PR-Marketing	-603 737	-54 252	-658 982	-65 652
News service, PR	-225 834	-20 294	-72 675	-7 240
Entertainment	-4 966	-446	-53	-5
Gifts	-5 099	-458	-11 823	-1 178
Office material	-62 790	-5 642	-73 220	-7 295
Phone	-30 234	-2 717	-46 534	-4 636
Insurance for the organization	-15 481	-1 391	-15 125	-1 507
Losses on receivables	-44 766	-4 023	0	0
Honorariums for external	-85 163	-7 653	-32 946	-3 282
Accountant and audit	-66 800	-6 003	-118 101	-11 766
Consultants	-2 856 842	-256 719	-2 495 139	-248 582
Web	-76 106	-6 839	-7 155	-713
IT-costs	-54 081	-4 860	-57 141	-5 693
Bank fees	-13 241	-1 190	-9 319	-928
Membership fees	-261 656	-23 513	-218 315	-21 750
Other operating expenses	-631 324	-56 731	-630 735	-62 838
Staff costs	-5 748 514	-516 567	-5 319 453	-529 958
Interest income tax account	28	3	0	0
Interest taxes and fees	-31 898	-2 866	-1 644	-164
Exchange profit/loss	24 324	2 186	-88 772	-8 844
<b>Total costs</b>	<b>-14 351 585</b>	<b>-1 289 648</b>	<b>-10 608 098</b>	<b>-1 056 847</b>
<b>Profit (+) / Loss (-)</b>	<b>1 598 910</b>	<b>143 680</b>	<b>4 127 562</b>	<b>411 214</b>

## Costs per activity

2022-01-01  
2022-12-31

2021-01-01  
2021-12-31

<b>20. Income</b>	SEK	EUR 11,1283	SEK	EUR 10,2269
Bank fees	-735	-66	-1 244	-124
Losses on receivables	-44 766	-4 023	0	0
Exchange profit/loss	92560	8 318	-47 273	-4 710
<b>Total costs</b>	<b>47 059</b>	<b>4 229</b>	<b>-48 518</b>	<b>-4 834</b>

<b>30. Governance</b>				
Software Programs	-2 728	-245	-1 941	-193
Freight and transport	-3 919	-352	-7 603	-757
Conference costs	-123 871	-11 131	0	0
Travel costs	-123 763	-11 121	0	0
Refund members	-119 691	-10 756	0	0
Hotel costs	-149 615	-13 445	0	0
Food	-96 330	-8 656	0	0
Reimbursement	-4 789	-430	0	0
Printing costs	-4 714	-424	0	0
Gifts	-1 599	-144	0	0
Office material	-11 888	-1 068	0	0
Phone	-2 221	-200	-2 033	-203
Insurance for the organization	-7 500	-674	-7 500	-747
Consultants	-134 857	-12 118	0	0
Bank fees	-868	-78	0	0
Membership fees	-13 007	-1 169	-9 807	-977
Staff costs	-5 968	-536	-5 586	-557
Exchange profit/ loss	254	23	-427	-43
<b>Total costs</b>	<b>-807 072</b>	<b>-72 524</b>	<b>-34 898</b>	<b>-3 477</b>

<b>40. Members</b>				
Outgoing donations	-224 511	-20 175	-120 304	-11 985
Software programs	-56 815	-5 105	-1 828	-182
Freight and transport	0	0	-989	-99
Printing costs	-3 385	-304	0	0
Gifts	0	0	-798	-80
IT-costs	0	0	-688	-69
Staff costs	-674 213	-60 585	-815 860	-81 281
Exchange profit/loss	-1 377	-124	0	0
<b>Total costs</b>	<b>-960 301</b>	<b>-86 294</b>	<b>-940 467</b>	<b>-93 695</b>



**Costs per activity**2022-01-01  
2022-12-312021-01-01  
2021-12-31

<b>45. Accelerator</b>	SEK	EUR 11,1283	SEK	EUR 10,2269
Software programs	-46 375	-4 167	0	0
News service, PR	-32 071	-2 882	0	0
Web	-163	-15	0	0
Other operating expenses	41 875	3 763	-41 875	-4 172
Staff costs	-265 770	-23 882	0	0
<b>Total costs</b>	<b>-302 504</b>	<b>-27 183</b>	<b>-41 875</b>	<b>-4 172</b>

<b>50. Secretariat and Staff</b>				
Office rental agreement	-330 000	-29 654	-426 220	-42 463
Software programs	-15 878	-1 427	-62 570	-6 234
Freight and transport	0	0	-859	-86
Conference costs	-28 607	-2 571	0	0
Travel costs	-24 894	-2 237	25 560	2 546
Hotel costs	-58 231	-5 233	-2 800	-279
Food	-9 888	-889	0	0
Printing costs	0	0	-3 869	-385
Entertainment	-213	-19	0	0
Gifts	-410	-37	0	0
Office material	-42 722	-3 839	-43 924	-4 376
Phone	-27 851	-2 503	-44 501	-4 433
Insurance for the organization	-7 981	-717	-7 625	-760
Accountant and audit	-66 800	-6 003	-118 101	-11 766
Consultants	-57 069	-5 128	-14 519	-1 446
Web	-47 371	-4 257	-366	-36
IT-costs	-54 081	-4 860	-56 453	-5 624
Bank fees	-11 638	-1 046	-8 075	-804
Interest income tax account	28	3	0	0
Interest taxes and fees	-31 898	-2 866	-1 644	-164
Staff costs	-1 611 459	-144 807	-1 828 000	-182 117
Exchange profit/loss	-270	-24	-488	-49
<b>Total costs</b>	<b>-2 427 231</b>	<b>-218 113</b>	<b>-2 594 455</b>	<b>-258 476</b>



## Costs per activity

2022-01-01  
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2021-12-31

<b>60. Communication</b>	SEK	EUR 11,1283	SEK	EUR 10,2269
Software programs	-39 196	-3 522	-22 668	-2 258
Travel costs	-3 782	-340	0	0
Hotel costs	-2 999	-270	0	0
Printing costs	-26 581	-2 389	0	0
PR-Marketing	-20 202	-1 815	-165 420	-16 480
News service, PR	-15 486	-1 392	-1 984	-198
Office material	-5 990	-538	-22 867	-2 278
Consultants	-71 625	-6 436	0	0
Web	-12 742	-1 145	-4 174	-416
Staff costs	-266 943	-23 988	-433 600	-43 198
Exchange profit/loss	-160	-14	0	0
<b>Total costs</b>	<b>-465 706</b>	<b>-41 849</b>	<b>-650 713</b>	<b>-64 828</b>

<b>65. World Psoriasis Day</b>				
Translations	-42 792	-3 845	-54 737	-5 453
Travel costs	-4 275	-384	0	0
Hotel costs	-1 428	-128	0	0
Food	-1 282	-115	0	0
Printing costs	-10 716	-963	0	0
PR-Marketing	-263 694	-23 696	-290 064	-28 898
News service, PR	-76 809	-6 902	-69 038	-6 878
Consultants	-112 375	-10 098	0	0
Web	-11 286	-1 014	0	0
Staff costs	-485 807	-43 655	-372 999	-37 161
Exchange profit/loss	-989	-89	0	0
<b>Total costs</b>	<b>-1 011 453</b>	<b>-90 890</b>	<b>-786 838</b>	<b>-78 390</b>

<b>70. Advocacy &amp; Policy</b>				
Travel costs	-32 566	-2 926	-5 672	-565
Hotel costs	-15 937	-1 432	-3 020	-301
Food	-202	-18	-302	-30
Gifts	0	0	-151	-15
Membership fees	-243 270	-21 860	-208 508	-20 773
Staff costs	-381 935	-34 321	-509 360	-50 746
Exchange profit/loss	6 100	548	-3 090	-308
<b>Total costs</b>	<b>-667 809</b>	<b>-60 010</b>	<b>-730 102</b>	<b>-72 737</b>



## Costs per activity

2022-01-01  
2022-12-312021-01-01  
2021-12-31

<b>71. IFPA Forum</b>	SEK	EUR 11,1283	SEK	EUR 10,2269
Software programs	-190	-17	0	0
Freight and transport	-8 261	-742	0	0
Conference costs	-60 715	-5 456	0	0
Travel costs	-187 784	-16 874	0	0
Refund members	-94 798	-8 519	0	0
Hotel costs	-81 167	-7 294	0	0
Food	-58 343	-5 243	0	0
Reimbursement	-4 789	-430	0	0
Printing costs	-45 061	-4 049	0	0
PR-Marketing	-96 585	-8 679	0	0
News service, PR	-33 822	-3 039	0	0
Gifts	-3 090	-278	0	0
Office material	-337	-30	0	0
Consultants	-870 365	-78 212	-16 658	-1 660
Web	-163	-15	0	0
Other operating expenses	85 937	7 722	-85 937	-8 562
Staff costs	-453 610	-40 762	0	0
Exchange profit/loss	-23 540	-2 115	-309	-31
<b>Total costs</b>	<b>-1 936 684</b>	<b>- 174 032</b>	<b>-102 904</b>	<b>-10 252</b>

<b>75. IFPA Coalition</b>				
Translations	-29 026	-2 608	-21 788	-2 171
Conference costs	-14 888	-1 338	0	0
Travel costs	-31 968	-2 873	0	0
Hotel costs	-10 882	-978	0	0
Food	-4 405	-396	0	0
News service, PR	-61 015	-5 483	0	0
Consultants	-738 888	-66 397	-359 403	-35 806
Web	-3 820	-343	-2 614	-260
Staff costs	-191 658	-17 223	-251 540	-25 060
Exchange profit/loss	-5 723	-514	-1 568	-156
<b>Total costs</b>	<b>-1 092 272</b>	<b>-98 153</b>	<b>-636 913</b>	<b>-63 453</b>



## Costs per activity

2022-01-01  
2022-12-31

2021-01-01  
2021-12-31

<b>80. Science</b>	SEK	EUR 11,1283	SEK	EUR 10,2269
Freight and transport	-481	-43	0	0
Conference costs	-356 403	-32 027	-21 304	-2 122
Travel costs	-149 657	-13 448	0	0
Hotel costs	-135 325	-12 160	0	0
Food	-7 999	-719	0	0
Reimbursement	-22 699	-2 040	0	0
Printing costs	-6 313	-567	0	0
Entertainment	-1 876	-169	0	0
Office material	-140	-13	0	0
Phone	-162	-15	0	0
Web	-211	-19	0	0
Staff costs	-646 007	-58 051	-298 395	-29 728
Exchange profit/loss	-534	-48	0	0
<b>Total costs</b>	<b>-1 327 807</b>	<b>-119 318</b>	<b>-319 699</b>	<b>-31 850</b>

<b>85. IFPA Conference / WPPAC</b>				
Translations	0	0	-3 094	-308
Software programs	0	0	-867	-86
Freight and transport	-642	-58	-12 491	-1 244
Conference costs	-4 000	-359	0	0
Travel costs	-8 244	-741	0	0
Food	-329	-30	0	0
Printing costs	-7 414	-666	-594	-59
PR-Marketing	-184 100	-16 543	-162 137	-16 153
News service, PR	-6 631	-596	-1 653	-165
Entertainment	-2 877	-259	-53	-5
Gifts	0	0	-10 874	-1 083
Office material	-965	-87	-234	-23
Honorariums for external	0	0	-517	-52
Consultants	-81 250	-7 301	-65 896	-6 565
Web	-350	-31	0	0
Other operating expenses	627 922	56 426	-223 069	-22 224
Staff costs	-330 453	-29 695	-636 493	-63 412
Exchange profit/loss	-670	-60	-2 844	-283
<b>Total costs</b>	<b>0</b>	<b>0</b>	<b>-1 120 816</b>	<b>-111 663</b>



## Costs per activity

2022-01-01  
2022-12-312021-01-01  
2021-12-31

	SEK	EUR 11,1283	SEK	EUR 10,2269
<b>90. Projects</b>				
Translations	-155 897	-14 009	0	0
Freight and transport	-2 006	-180	0	0
Conference costs	-175 934	-15 810	0	0
Travel costs	-191 488	-17 207	-1 005	-100
Hotel costs	-65 520	-5 888	0	0
Food	-12 808	-1 151	0	0
Printing costs	-12 214	-1 098	0	0
PR-Marketing	-39 156	-3 519	-41 361	-4 121
Office material	-749	-67	-6 195	-617
Honorariums for external	-85 163	-7 653	-32 429	-3 231
Consultants	-790 412	-71 027	-2 038 663	-203 105
Membership fees	-5 380	-483	0	0
Other operating expenses	-1 387 058	-124 642	-279 854	-27 881
Project management	-434 692	-39 062	-167 620	-16 699
Exchange profit/loss	-41 326	-3 714	-32 772	-3 265
<b>Total costs</b>	<b>-3 399 802</b>	<b>-305 510</b>	<b>-2 599 900</b>	<b>-259 019</b>



**Balance sheet**2022-01-01  
2022-12-312021-01-01  
2021-12-31

<b>Bank assets and claims</b>	<b>Note</b>	SEK	EUR 11,1283	SEK	EUR 10,2269
Outstanding claims	1	4 501 344	404 495	3 881 730	379 561
Other claims		28	3	1 000	98
Prepaid expenses and accrued income	2	738 862	66 395	108 481	10 607
Cash		2 623	236	2 374	232
Bank Nordea		14 157 762	1 272 230	11 429 163	1 117 559
<b>Total bank assets and claims</b>		<b>19 400 619</b>	<b>1 743 359</b>	<b>15 422 749</b>	<b>1 508 057</b>

2022-01-01  
2022-12-312021-01-01  
2021-12-31

<b>Capitals and creditors</b>	<b>Note</b>	SEK	EUR 11,1283	SEK	EUR 10,2269
Capital		7 670 012	689 235	3 542 451	346 386
Profit or loss		1 598 910	143 680	4 127 562	403 599
Outstanding debts		108 870	9 783	283 611	27 732
Other debts		1 046 381	94 029	2 468 261	241 350
Prepaid income	3	7 049 705	633 493	4 518 191	441 795
Accrued costs and fees paid in advance	4	1 926 740	173 139	482 674	47 196
<b>Total capital and creditors</b>		<b>19 400 619</b>	<b>1 743 359</b>	<b>15 422 749</b>	<b>1 508 057</b>



## Notes

2022-01-01  
2022-12-312021-01-01  
2021-12-31

	SEK	EUR 11,1283	SEK	EUR 10,2269
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**Note 1 Outstanding claims**

AbbVie	1 520 554	136 638	1 089 539	110 000
Amgen	1 206 722	108 437	1 143 930	114 377
Eli Lilly	1 206 722	108 437	0	0
UCB Biopharma	534 383	48 020	1 611 061	159 390
Almirall	14 305	1 285	0	0
SPOEX Iceland	6 132	551	0	0
CSN Canada	3 066	276		0
PsorPhil Philippines	2 873	258		0
Boehringer Ingelheim	2 500	225	37 200	3 637
Psoriasisliitto Finland	2 044	184	0	0
Europso	2 044	184	0	0
<b>Total</b>	<b>4 501 344</b>	<b>404 495</b>	<b>3 881 730</b>	<b>387 405</b>

**Note 2 Prepaid expenses and accrued income***Prepaid expenses*

IFPA Conference 2024	627 922	56 426	0	0
Helioworks rent	82 500	7 414	82 500	8 067
Membership GHC 2023	11 212	1 008	8 617	843
Membership IAPO 2023-2024	8 779	789	0	0
Lisa Technologies	2 619	235	4 500	440
Fortnox	2 280	205	1 865	182
Scrive	2 063	185	2 063	202
Söderberg & Partners Insurance Consulting	1 301	117	1 275	125
Loopia	186	17	161	16
Europeiska ERV	0	0	7 500	733
<b>Total</b>	<b>738 862</b>	<b>66 395</b>	<b>108 481</b>	<b>10 607</b>



## Notes

2022-01-01  
2022-12-312021-01-01  
2021-12-31

	SEK	EUR 11,1283	SEK	EUR 10,2269
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**Note 3 Prepaid income**

AbbVie	1 520 554	136 638	1 565 642	153 091
UCB	1 332 125	119 706	554 862	54 255
Bristol Myers Squibb	1 206 722	108 437	1 351 846	132 185
Eli Lilly	1 206 722	108 437	262 351	25 653
Novartis	979 101	87 983	0	0
Amgen	804 481	72 291	732 776	71 652
Boehringer Ingelheim	0	0	50 714	4 959
<b>Total</b>	<b>7 049 705</b>	<b>633 493</b>	<b>4 518 191</b>	<b>441 795</b>

**Note 4 Accrued costs and fees paid in advance***Accrued costs*

IFPA Projects	1 666 912	149 790	0	0
Credit card purchases dec	180 861	16 252	35 008	3 423
Hummelklappen	45 000	4 044	40 000	3 911
Iriam Productions	30 000	2 696	0	0
Membership fee Italy, to be returned	472	42	0	0

*Fees received in advance*

Singapore 2023	936	84	0	0
Uruguay 2023-2026	826	74	0	0
Kenya 2023-2025	741	67	0	0
Malaysia 2023	506	46		
Croatia 2023	258	23	0	0
Brazil 2023	227	20	0	0
<b>Total</b>	<b>1 926 740</b>	<b>173 139</b>	<b>482 674</b>	<b>47 196</b>



## Signatures

Stockholm, May 3, 2023

Hoseah Waweru  
President

Ingvar Ingvarsson  
Vice President

Kathleen L. Gallant  
Secretary

Josef de Guzman  
Treasurer

Silvia Fernandez Barrio  
Board Member

Masanori Okuse  
Board Member

Helen Crawford  
Board Member

My auditor's report has been issued on May 4, 2023

Hummelkläppen i Stockholm AB

Tommy Nilsson  
Authorized Public Accountant





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