INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

2020

IFPA Annual Report

Contents

2020 was marked with hardship, and particular insecurity for our international community. Though we could not physically gather, our federation remained vibrant and active throughout 2020 thanks to the hard work of IFPA members around the world. Together, we quickly responded to COVID-19, gathering responsible advice, and sharing resources like IFPA's COVID-19 Advocacy Toolkit. We launched the Mentorship Program in June 2020 to grow valuable new peer-support communities. IFPA's Global Psoriasis Coalition released the Psoriatic Disease Response Index which provides practical, evidence-based recommendations for governments to improve psoriatic disease management. World Psoriasis Day's 2020 campaign, Be Informed, achieved at least 43 million social media reach in 102 countries. Finally, we have participated in countless projects with our partners including the Global Psoriasis Atlas, the NCD Alliance's 'Turning the Tide' campaign, medical publications, and updated clinical guidelines, to mention a few.

Looking back on 2020, one thing is very clear: Our collective power as a federation is defined by the passionate contributions of each individual working at each national psoriasis association. These advocates go above and beyond the call to help their own neighbors, applying generous effort to benefit strangers living with psoriasis halfway around the globe. We are so grateful. Our united effort has ripple effects that will seep into each corner of this world. I sincerely thank the IFPA Board, staff, members, and partners for your contributions this year.

Dr. Hoseah Waweru
President of the Board

I am deeply grateful to IFPA's board, staff, members and partners for their warm welcome to this community. I had the unique pleasure of joining IFPA as Executive Director in November 2020. The optimism I witnessed in my first contacts intensified my own enthusiasm for upcoming projects. We have much to look forward to in 2021!

Psoriasis and psoriatic arthritis affect millions of people across the world. This is a serious global health challenge. People with psoriasis or psoriatic arthritis may struggle to get a correct diagnosis or adequate treatment, have limited access to care or face persistent stigma and discrimination. Throughout 2020, IFPA continued the work to resolve these challenges facing the international psoriasis community.

In this report, you will read about IFPA's 2020 actions to empower members, improve conditions for patients, raise awareness, and cooperate with fellow stakeholders. On behalf of the organization, I sincerely thank the partners and volunteers who made this work possible. In 2021, IFPA will celebrate its 50th anniversary. We look forward to growing our impact with you at the launch of IFPA's next era.

Frida Dunger Johnsson
Executive Director

Background

2020. The year of INFORMED. The year of COVID-19. 2020 challenged IFPA to change plans, grow closer to our members, and develop strategies for resilience. Uncertainty surrounding the pandemic highlighted the necessity for credible, complete information about psoriasis and psoriatic arthritis. As hunger for these answers grew, IFPA responded with the World Psoriasis Day campaign: Be Informed. As we grew to understand the pandemic, our demands sharpened. People with psoriasis and psoriatic arthritis must be included in emergency provisions. Health systems must be prepared to ensure adequate care for people with chronic illnesses, even during a crisis. IFPA called for more support at the World Health Assembly and the United Nations General Assembly. IFPA adapted, and pushed forward. The organization welcomed Frida Dunger Johnsson as Executive Director in November 2020. Her passion and drive breathe fresh inspiration into our federation. Our results for 2020 may not match our original plans, but the achievements exceeded expectations.

Sponsors

AMGEN · Boehringer Ingelheim · Bristol Myers Squibb · janssen · LEO · Lilly · NOVARTIS · Pfizer · ucb

Partners

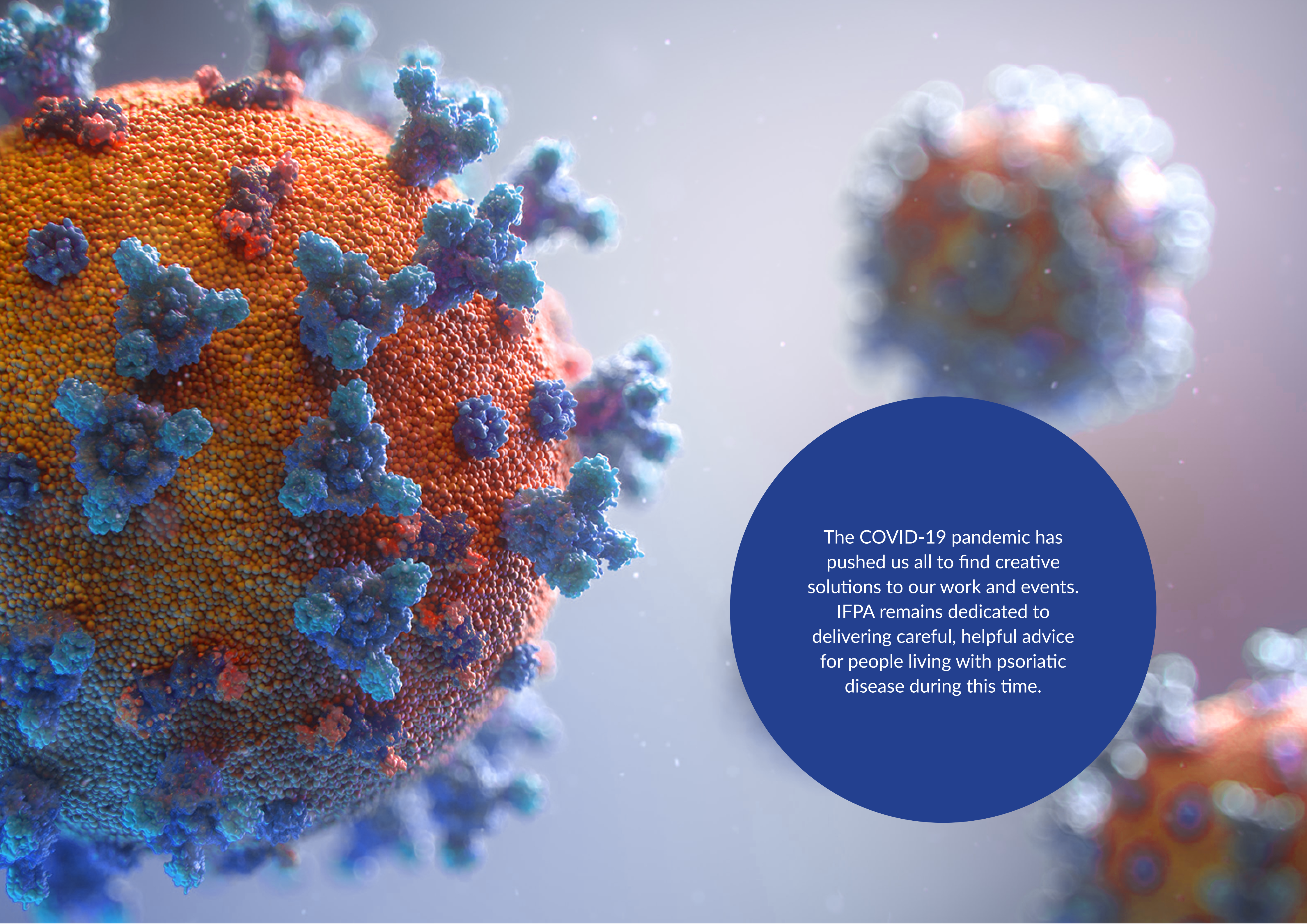
csem – Civil Society Engagement Mechanism for UHC2030

Global Health Council – The Collective Voice of the Global Health Community

International Alliance of Dermatology Patient Organizations – GLOBALSKIN.ORG

International Alliance of Patients' Organizations – A global voice for patients

NCDAlliance



The COVID-19 pandemic has pushed us all to find creative solutions to our work and events. IFPA remains dedicated to delivering careful, helpful advice for people living with psoriatic disease during this time.

COVID-19 Timeline

January 1

A novel coronavirus is identified following reports of a cluster of pneumonia cases in Wuhan, China.

January 13

Officials confirm a case of COVID-19 in Thailand, the first recorded case outside of China.

March 8

IFPA's COVID-19 Task Force is formed.

March 9

IFPA releases a statement to members regarding COVID-19. Physical meetings and travel are suspended until further notice.

March 12

The WHO formally declares the COVID-19 outbreak a pandemic.

April 1

IFPA begins researching the impact of COVID-19 on people living with psoriasis with PsoProtect.

April 14

People with psoriatic disease, and particularly those on biologics, express deep concern for their safety. Physicians and patient organizations remain uncertain about the impact of COVID-19 on people with psoriatic disease. IFPA's COVID-19 Task Force creates a series of dedicated COVID-19 web pages offering global advice, answers to FAQs, and a resource library. These web pages reassure people living with the disease, and orient anyone looking for information or ways to help.

May 6

IFPA begins campaigning for PsoProtect*Me*, encouraging anyone living with psoriasis to report their experience during COVID-19.

May 18

The World Health Assembly passes a resolution on COVID-19 Response.

COVID-19 Timeline

June 11

IFPA's Global Psoriasis Coalition releases a statement on COVID-19.

June 12

IFPA publishes an advocacy toolkit titled "Together we will overcome" to guide patient organizations in using the WHA Resolution on COVID-19 Response to advocate for people with psoriatic disease during the pandemic. People living with chronic illnesses must be able to access continued care, even during a pandemic.

September 11

The United Nations adopt a Resolution on the COVID-19 Pandemic.

October 16

First findings from PsoProtect are published. The findings show encouraging results that most people with psoriasis reported to PsoProtect taking drugs that affect the immune system fully recover from COVID-19.

October 29

IFPA incorporates COVID-19 into the World Psoriasis Day theme, "Informed". The COVID-19 pandemic highlights the absolute necessity for complete, reliable information on psoriatic disease. Together, IFPA, PsoProtect and the Global Psoriasis Atlas collect patient testimonies, putting human faces and voices to the experience of living with psoriasis during the pandemic.

December 18

IFPA publishes a joint statement regarding the safety and effectiveness of COVID-19 vaccines for people with psoriatic disease.

December 23

Findings from PsoProtect*Me* are published. These findings show that people receiving targeted treatments, such as biologics, are more likely to stay at home and minimize face-to-face contact. These strict behaviors lower their exposure to the virus and may explain why other studies report lower risk of severe COVID-19 infection in people who take biologics.

Global Psoriasis Coalition

The Global Psoriasis Coalition is IFPA's advocacy body uniting representatives from medical societies, NGOs, the corporate sector, foundations and professional societies. By cooperating across borders, sectors and disease areas, the Global Psoriasis Coalition works to implement the recommendations outlined in the World Health Organization's 2016 Report on Psoriasis. The Coalition takes action to improve the lives of millions of people living with psoriasis.

The Global Psoriasis Coalition convened twice in 2020, once in July and once December. Members of the Global Psoriasis Coalition worked together to produce a statement on COVID-19 highlighting the impact of the pandemic on people living with psoriatic disease, and recommending strategies to mitigate its effects. The statement was published on the Global Psoriasis Coalition website for members to access. 2020 marked the end of the strategic cycle in which the Coalition's primary objective was the inclusion of psoriasis in the NCD agenda. The Global Psoriasis Coalition began setting the new strategic plan for the next 3-5 years by forming a Policy Task Force. In addition, a revision of the governance will be discussed within the newly formed Governance Task Force. The two Task Forces will conclude their work at the beginning of 2021 when the Global Psoriasis Coalition strategic plan is presented.

globalpsoriasiscoalition.org

Coalition Partners

International Alliance of Dermatology Patient Organizations
GLOBALSKIN.ORG

NCDAlliance

International Alliance of Patients' Organizations
A global voice for patients

Global Health Council
The Collective Voice of the Global Health Community

Coalition Members

abbvie
AMGEN
Bristol Myers Squibb
janssen
LEO
Lilly
NOVARTIS
ucb

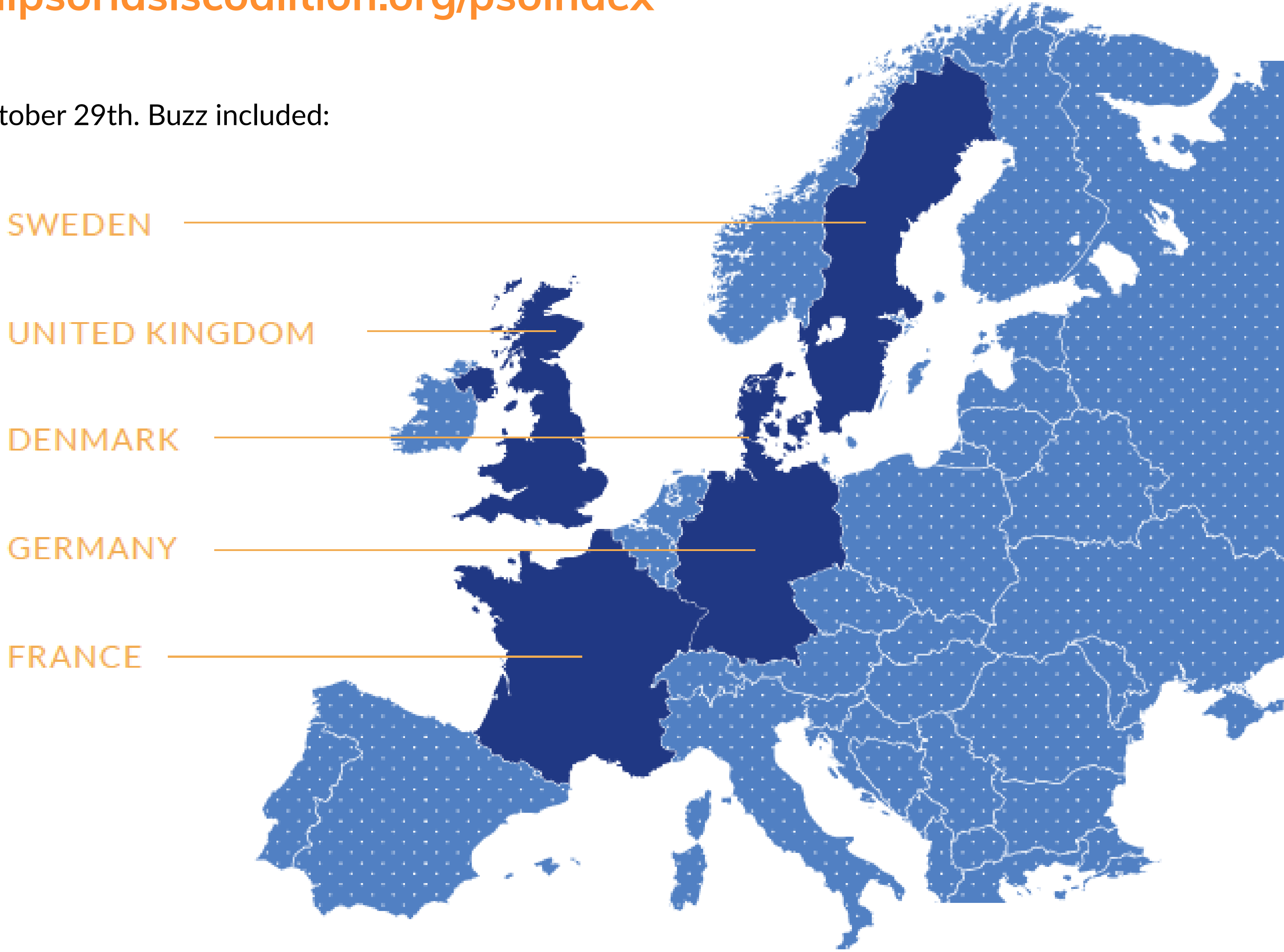
Psoriatic Disease Response Index

The primary deliverable of the Global Psoriasis Coalition in 2020 was the Psoriatic Disease Response Index (known colloquially as "the Index"). The Index is the first-ever effort to survey, quantify, and analyze health systems' responses on an international scale. By identifying five enablers and five barriers, the Index provides practical, evidence-based recommendations for each government to improve psoriatic disease management. Analyses combined desk research with expert interviews in the five countries analyzed – France, Denmark, Germany, the United Kingdom and Sweden. A steering committee was established to shape the Index, establish indicators and evaluate progress.

globalpsoriasiscoalition.org/psoindex

The Index was launched on World Psoriasis Day, October 29th. Buzz included:

- A preview webinar to present the Index to supporters and contributors, organized on October 20
- A launch event on October 29, organized during the European Academy of Dermatology and Venereology Congress
- A social media campaign, press release, presentation deck, executive summary, and video
- An article published on the NCD Alliance blog



View the toolkit

“Together we will overcome”

In early 2020, pandemic response became the major global health priority and many people with psoriatic disease experienced disturbing disruptions in their access to care. IFPA released a COVID-19 advocacy toolkit on June 12. This guide outlines how patient groups can use the World Health Assembly Resolution on COVID-19 Response (June 2020) to advocate for people living with psoriasis and psoriatic arthritis during the pandemic. People living with chronic conditions must always be able to access adequate care, especially during an emergency. National pandemic response plans must include provisions for people living with chronic conditions.

235

page views

52

downloads

International and European Association Awards

IFPA was named International Association of the Year by the Association of Association Executives (AAE) in their International & European Association Awards 2020. Competing against 102 entries in 12 categories, IFPA earned the international title. The judges said, “The organization is doing everything an international federation of associations should do.”

Without data, how can we advocate effectively for improved treatment & care? After the WHO resolution & Report, this is the next big thing!

-Kathleen Gallant
IFPA Board

Webinar Series 2020

Following the Webinar Series launch in 2019, IFPA opened 2020 with a **kick-off webinar** overviewing IFPA's planned operations for the year.

The team behind the PsoProtect and PsoProtect*Me* surveys joined for a webinar titled "**PsoProtect: Understanding how COVID-19 affects people living with psoriasis**".

Dr. April Armstrong held a presentation on **Psoriasis and its comorbidities**, a topic highly requested by IFPA Members.

International Alliance of Patients' Organizations CEO, Kawaldip Sehmi, led an interesting discussion on the importance of **patient safety**, the newly adopted WHA resolution 'Global action on patient safety,' and how patient advocates can use it in their work.

Mentorship Program

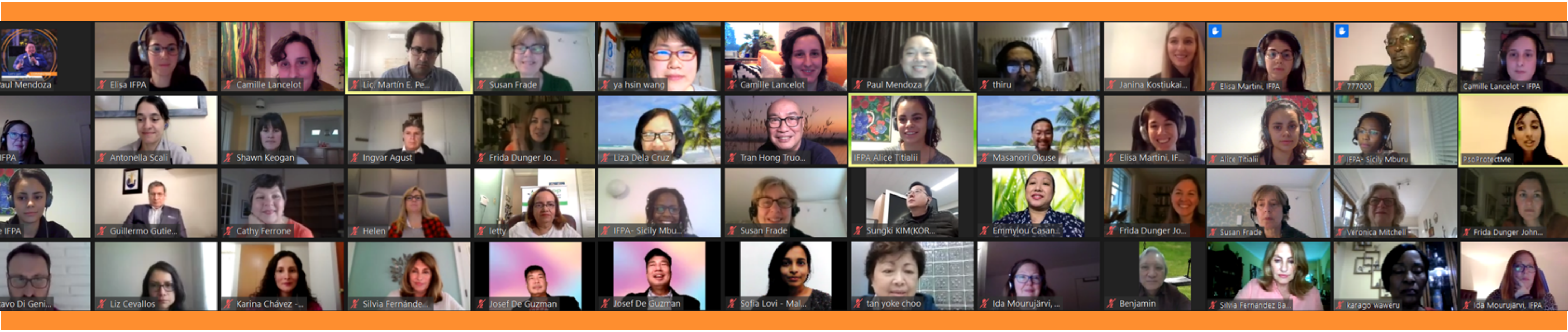
In March of 2020, IFPA launched a new Mentorship Program as part of capacity building efforts within the psoriasis community.

The mentorship initiative was designed as part of IFPA's expansion effort to extend the capacity and reach of the psoriasis and psoriatic arthritis community. The mentorship initiative will aim to support newly formed psoriasis associations.

Through the program, individuals in the process of starting new patient associations for people living with psoriasis and/or psoriatic arthritis are matched with a mentor from one of IFPA's already established member associations. Mentors share their valuable expertise as the patient advocates at the novice association begin to build a community.

This program offers IFPA members and individuals from newly formed associations a mutually beneficial opportunity to share ideas and experiences. We are confident it will bring value for both mentor and mentee. By the end of 2020, individuals from Belarus, Ghana, India, Namibia, Nepal, and Tunisia were actively participating in the mentorship program to get support in starting and building their patient associations. We look forward to announcing them as new members of IFPA!

6 new patient associations participating in the mentorship program



Member Meetings

Each year, IFPA Members gather to share their successes, evaluate IFPA's work, and discuss the strategic direction of the organization. In 2020, IFPA broke tradition for the first time, dividing the global meeting into targeted regional conferences. IFPA organized four regional meetings for members in Pan America, Africa, Europe and Asia Pacific. In total, almost 150 participants joined the four virtual meetings.

2020's member meetings represented many firsts:

- First time hosting segmented regional meetings instead of one global meeting
- First time hosting four member meetings in one year
- First time hosting member meetings virtually
- First time working with a conference platform
- First time working with live translators

The member meetings covered topics such as updates from the Global Psoriasis Atlas, PsoProtect and our work on psoriasis and COVID-19, Health Technology Assessment and how it can empower patient advocates, as well as offering models of how to structure multiple level coalitions. We were also treated to excellent presentations from many IFPA Members who shared examples and successes from all the impressive work that has been done nationally.

> *Once we truly understand the burden of psoriasis we will be able to command the recognition that people with psoriasis deserve.*
>
> -Lars Ettarp
> Former President

Event Calendar

Global NCD Alliance Forum 2020

February 9-11

Global NCD Alliance forum took place in Sharjah, organized by IFPA's partner, the NCD Alliance. Board member Josef de Guzman represented IFPA at the meeting. De Guzman spoke at the Coalition building session and participated in the launch event for the BBC series "Turning the Tide" featuring IFPA's film "More than skin deep."

73rd World Health Assembly

May 18 - 19

IFPA representatives took part in the official delegation of the Global Health Council attending both sessions of the 73rd World Health Assembly (WHA), begun in May and resumed in November. A report with key learnings from the event was shared with IFPA membership. IFPA used the Resolution on COVID-19 Response adopted at the WHA to create a toolkit. The document guides patient associations in advocating for people with psoriatic disease during the COVID-19 pandemic.

EULAR Congress

June 3 - 6

In 2020, the European League Against Rheumatism (EULAR) Congress was held as an online event. IFPA followed the virtual sessions live, hearing latest updates on new treatment options for psoriatic arthritis. In addition, sessions addressed the risk of comorbidities like cardiovascular disease, diabetes, and metabolic syndrome among people living with psoriatic arthritis.

GRAPPA Annual Meeting

July 9 - 11

The Group for Research of Psoriasis and Psoriatic Arthritis (GRAPPA) annual meeting was also held in a virtual format in 2020. IFPA was invited to attend GRAPPA's annual meeting and IDEOM's side-meeting. The meetings highlighted some of the most important developments at GRAPPA in the past year. Topics included COVID-19, outcome measures for musculoskeletal symptoms in psoriasis, trainee work, pustular psoriasis, related rheumatologic diseases, and composite measures.

74th United Nations General Assembly

September 22 - 25

IFPA followed the United Nations General Assembly and contributed to the language of the omnibus resolution through a process coordinated by the NCD Alliance. IFPA further participated in a round-table with the Dr. Tedros, Director General of the World Health Organization, organized by the Global Health Council.

IDEOM Annual Meeting

October 23 - 24

The International Dermatology Outcome Measures (IDEOM) Annual Meeting began with a pre-meeting for Patient Research Partners. Over 30 participants joined the networking session. Among these, 25 were from the psoriasis community. This was followed by a two-day series of workshops and working group discussions in multiple disease areas including psoriasis and psoriatic arthritis.

Dr Tedros speaks at the 73rd World Health Assembly.

EADV Congress

October 29 - 31

The dates of the European Academy of Dermatology and Venereology (EADV) Congress 2020 coincided with World Psoriasis Day. IFPA created a booth to bring attention to World Psoriasis Day and our cause. At the scientific meetings, there were key presentations in psoriasis care such as developments in biologics, biosimilars, and early findings on the impact of COVID-19 in people with psoriasis (presented by PsoProtect). Most importantly, it was evident that through advocacy efforts, patients' voices have been heard. Physicians and experts are more and more keen to connect psoriasis with comorbidities in multidisciplinary care.

WHO Informal Consultation on People living with NCDs

December 9-11

IFPA was invited to the 3-day digital meeting organized by the World Health Organization to involve people living with all NCDs in building an agenda that includes lived experiences. IFPA representatives actively participated in discussions. IFPA Board member Silvia Fernandez Barrio facilitated two sessions: Exploring Meaningful Engagement, and Mapping the Way Forward.

World Psoriasis Day

The theme of World Psoriasis Day 2020 was: Be Informed. The campaign emphasized reliable and useful information as a tool to empower people living with psoriasis and psoriatic arthritis, their healthcare providers, and other stakeholders in our community. Some of the highlights of the campaign:

43.8 M people reached on social media

1.1 K downloads of the World Psoriasis Day Toolkit

102 countries participated online in the global campaign

15 national monuments lighted orange in honor of World Psoriasis Day

Click to view the report!

See more results from the campaign in the World Psoriasis Day Report!

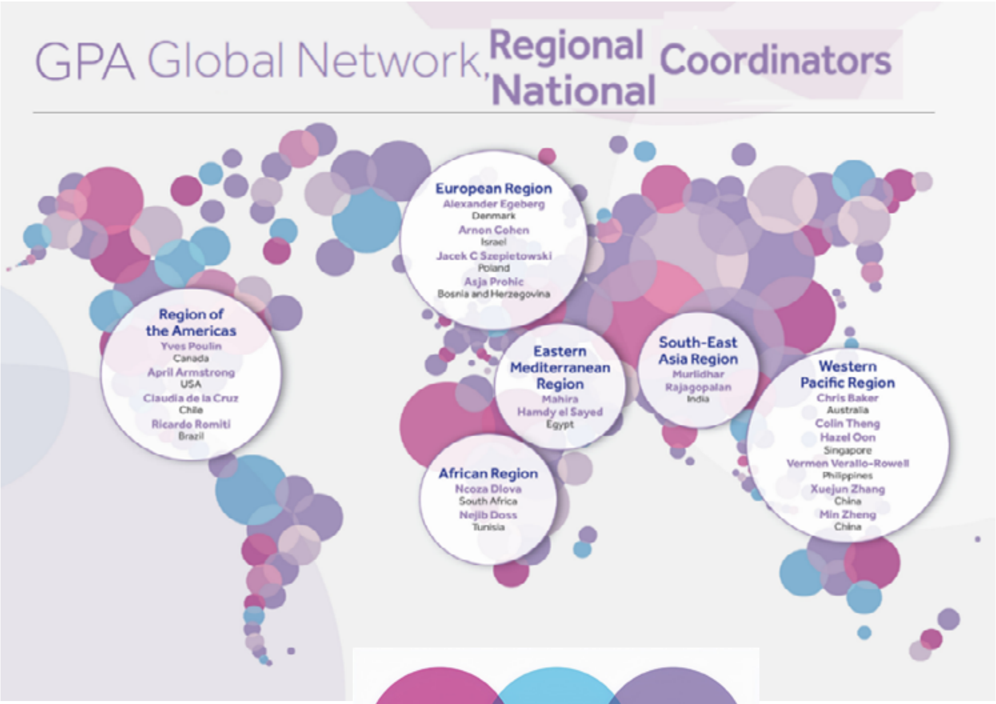
Global Psoriasis Atlas

The Global Psoriasis Atlas (GPA) is a long-term epidemiological study into the global burden of psoriasis, informing patients, advocates, and medical professionals so they can allocate resources to reduce morbidity, disability, and mortality. Along with the International League of Dermatological Societies and the International Psoriasis Council, IFPA has collaborate with the GPA since 2016. In 2020, the GPA celebrated the launch of Phase II, adding more regional coordinators and introducing national coordinators to the global research team. The GPA published the world's largest systemic review of global data on the burden of psoriasis in the British Medical Journal. The GPA further achieved 3 publications on the co-morbid burden of psoriasis.

globalpsoriasisatlas.org

In 2020, the GPA:

- Celebrated the launch of Phase II
- Added more regional coordinators and introduced national coordinators to the global research team
- Published the world's largest systemic review of global data on the burden of psoriasis in the British Medical Journal
- Achieved 3 additional publications on the co-morbid burden of psoriasis



IFPA
INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

ILDS

IPC
INTERNATIONAL
PSORIASIS
COUNCIL

GPA
Global Psoriasis Atlas

PsoProtect & PsoProtectMe

At the beginning of the COVID-19 pandemic, IFPA joined PsoProtect to investigate how people living with psoriasis are affected by the COVID-19 pandemic. By collecting data from both healthcare professionals and people with psoriasis, the team at PsoProtect are able to 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 the effect on psoriasis activity. IFPA and other organizations will be able to use these results to advocate for better provisions for people living with psoriatic disease through this pandemic and in future crises.

'Since I have psoriasis and psoriatic arthritis, and I'm taking a biologic and immunosuppressive medications, I have had some concerns about exposure to COVID-19 and who I'm around, so I've taken extra steps to protect myself.'

Jason
from the USA

'The pandemic has affected my anxiety and my financial and professional stressors. Lockdown, coupled with the fear, anxiety and uncertainty of the future heightens my anxiety and feelings of losing control.'

Jodi
from South Africa

Do you have psoriasis? Click to report!

psoprotect.org

psoprotectme.org

"I am so thankful for the global psoriasis community - knowing that I am not alone in coping with both my condition and the pandemic. In trying times like these everyone needs a family - and here it is. The world may have shut its borders, but we have never been closer."

Barbra,
from Sweden

"PsoProtectMe is such a valuable forum and one that I regularly revisit to see the updated stats on how fellow psoriasis patients are dealing with COVID-19. I'm especially keen to understand the data that refers to specifically those using biologic treatments for their psoriasis – because that's me."

Julian,
from the UK

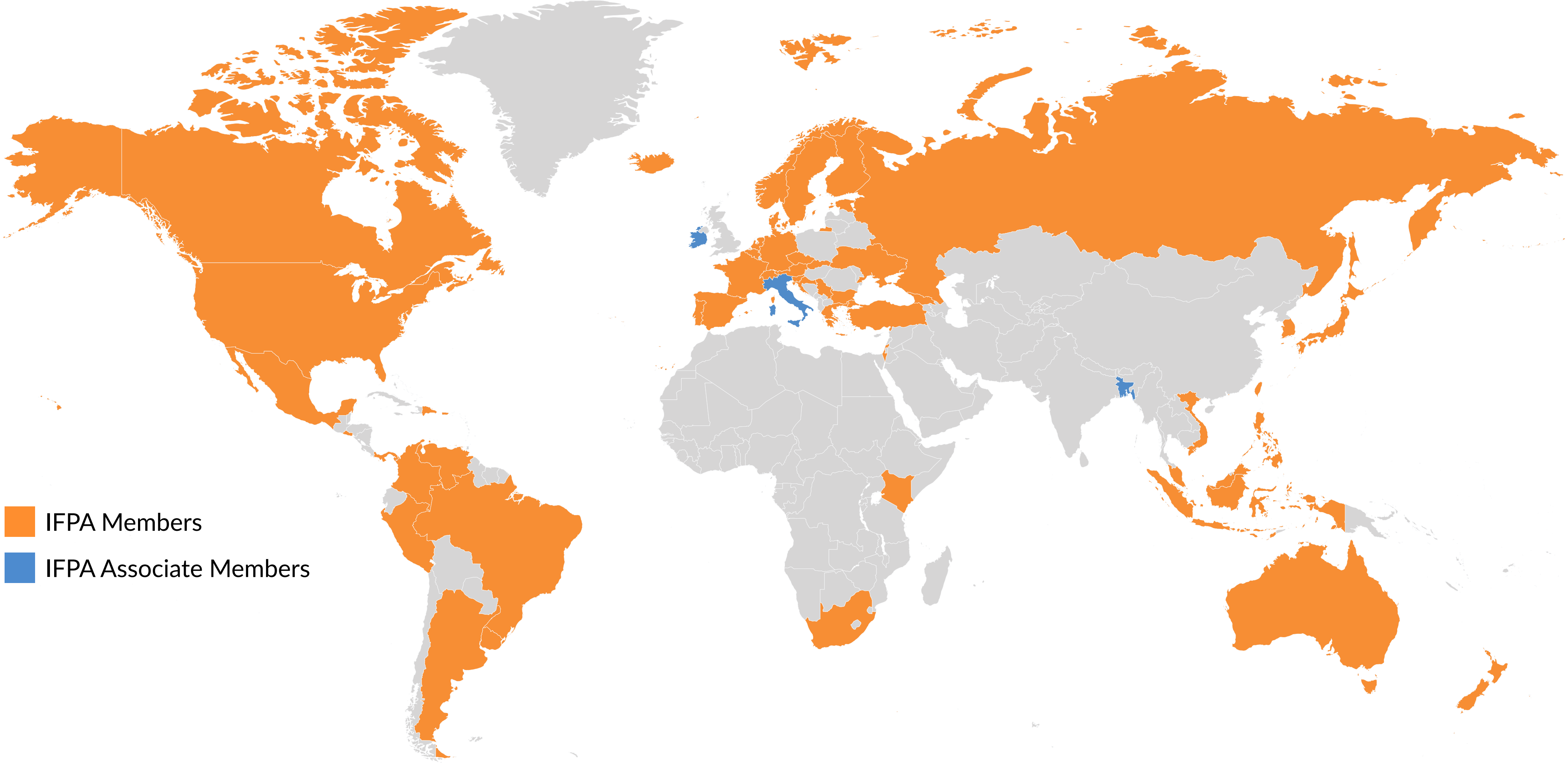
Turning the Tide

“They’re the world’s biggest killers. Non-communicable diseases like cancer, cardiovascular disease, chronic respiratory diseases, and diabetes account for 70 percent of all deaths. But many of these diseases can be prevented and the suffering from their effects, reduced. Turning the Tide is a series of short films about the bold actions being carried out by communities and organisations to take on NCDs. The stories are about the small and significant changes being made for better, healthier lives.”

NCDAlliance

Click to play!

The burden of psoriasis goes deeper than the skin to impact physical, mental, and economic wellbeing. Created in collaboration with the NCD Alliance and BBC StoryWorks, IFPA’s film “More than Skin Deep” challenges the idea of treating non-communicable diseases in silos and offers solutions.



IFPA Members

Representing **62** associations in **55** countries

Click to view our members!

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Nairobi, Kenya

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Sicily Mburu, M.D.

IFPA

INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

Gustavslundsvägen 143
167 51 Bromma, SWEDEN

info@ifpa-pso.com

ifpa-pso.com