IFPA
Member
Survey
2020

Summary Report

IFPA

INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

IFPA Member Survey 2020

IFPA’s Member Survey is sent out annually to all IFPA Members.

This survey was created using Microsoft Forms and a link was shared with all members via email. The question format was a mix between short text answers and multiple-choice questions.

IFPA’s Member Surveys are conducted to gain a better understanding of member priorities, areas that may need further support from IFPA and overall satisfaction with the IFPA membership. The responses collected through this survey will be used for planning future activities and programs for members.

IFPA would like to extend a sincere thank you to all members that have responded to the survey. The information we have received helps us better understand member needs and continue building IFPA as an organization.

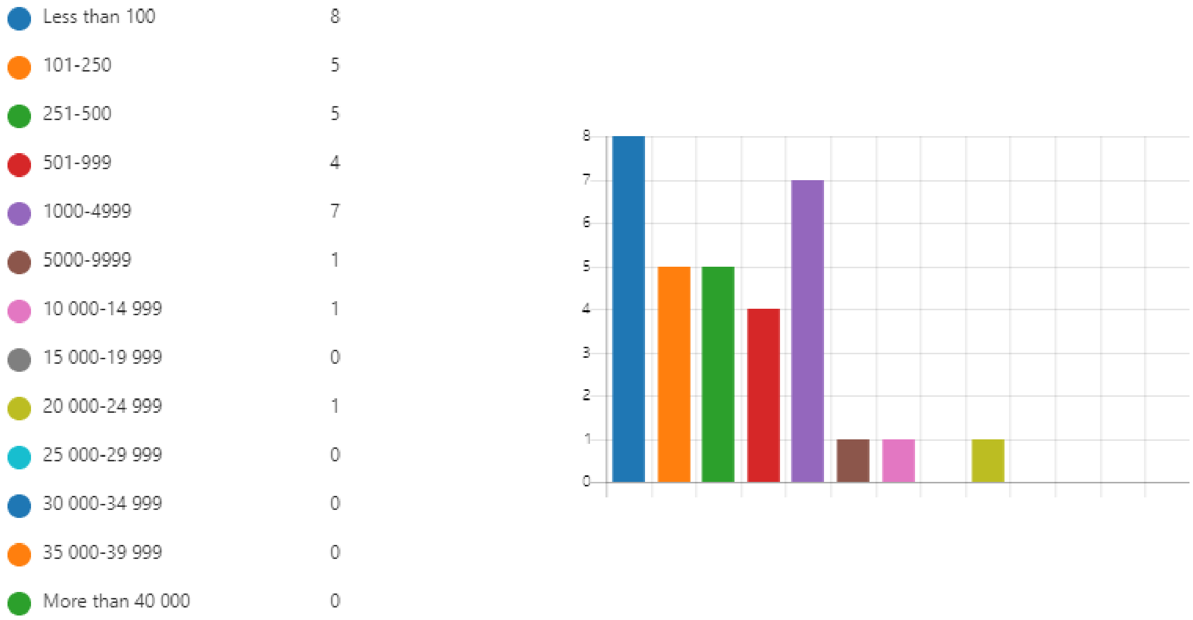
IFPA Member organizations

Countries represented in this survey

Out of IFPA's 62 Member organizations, 32 members responded to this survey. The members that responded to the survey represent the following countries: Denmark, Singapore, Austria, Japan, Colombia, Vietnam, Canada, France, Argentina, Portugal, Hong Kong, Philippines, Russia, Peru, El Salvador, Taiwan, Dominican Republic, Czech Republic, Puerto Rico, Belgium – Flanders, Finland, Panama, Indonesia, Spain, Germany, Brazil, Turkey, Korea, South Africa, and Italy.

Size of IFPA Member Organizations

Number of members each IFPA Member Organization had as of May 2020. A majority (90%) of IFPA Members that responded to this survey have between <100 and 4999 members.

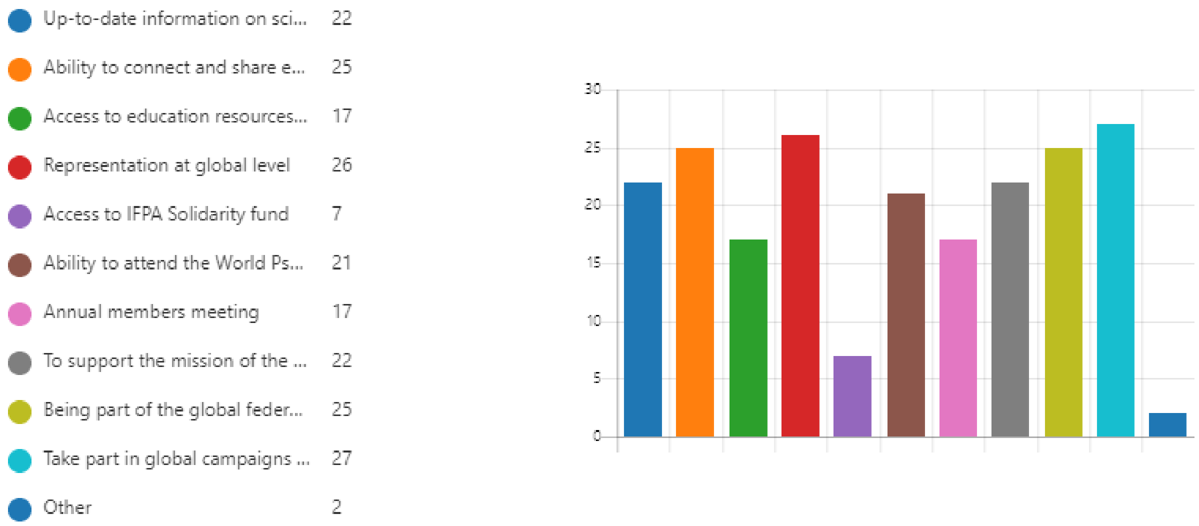


●	Less than 100	8
●	101-250	5
●	251-500	5
●	501-999	4
●	1000-4999	7
●	5000-9999	1
●	10 000-14 999	1
●	15 000-19 999	0
●	20 000-24 999	1
●	25 000-29 999	0
●	30 000-34 999	0
●	35 000-39 999	0
●	More than 40 000	0

IFPA Membership

Reasons for being a member

IFPA Members were asked what their main reasons for being an IFPA Members are, their responses are illustrated in the graph below.



Poll options listed in order: Up-to-date information on scientific research, Ability to connect and share experiences with other IFPA Members, Access to education resources (webinars, workshops etc.), Representation at global level, Access to IFPA solidarity fund, Ability to attend the World Psoriasis and Psoriatic Arthritis Conferences, Annual members meeting, To support the mission of the federation, Being part of the global federation strengthens our credibility, Take part in global campaigns like World Psoriasis Day, Other.

The top reasons for being an IFPA Member, as reported by members, are as follows:

1. Take part in global campaigns like World Psoriasis Day
2. Representation at global level
3. Ability to share experience with other IFPA Members AND Being part of the global federation strengthens our credibility

Value of IFPA Membership

IFPA Members rating the value of IFPA Membership:

A vast majority (87,5%) of IFPA Members rated their IFPA Membership as Very Good or Excellent.

IFPA Members on how the value of membership has changed over the past years (since 2018).

A majority (66%) of IFPA Members responded that they feel the value of their IFPA Membership has increased during the past years. One fourth (25%) of members feel the value of their membership has stayed the same, and 9% were undecided of felt the value had decreased.

Likelihood of renewing IFPA Membership

A majority (87,5%) of respondents said they were very likely to renew their IFPA Membership.

Positives about IFPA Membership

IFPA Members were asked what they find to be particularly positive about being an IFPA Member. Two main themes emerged from the members responses: Being part of a global organization and Connecting with other member organizations.

Being part of a global organization

Members report that they are happy to be part of a global community with global leadership. Many also reported that being able to participate and stay involved in global advocacy, and a global movement that supports patients is particularly positive.

Connecting with other IFPA Members

Many members mention the connection to other IFPA Members as a particularly positive aspect of being an IFPA Member. This presents an opportunity to share experiences with organizations working on similar issues all over the world and share ideas and learn from each other. Participating in IFPA's annual member meetings was also highlighted as a positive aspect.

Other positive aspects of IFPA Membership

Less frequently reported aspects were taking part in global campaigns, such as World Psoriasis Day and other advocacy and awareness campaigns, getting advocacy tools from IFPA, more confidence in communication with government agencies, strengthened credibility, and the Global Psoriasis Atlas.

Things that would improve the value of IFPA Membership

IFPA Members were asked what could improve the value of their IFPA Membership.

More opportunities for collaboration

- International collaboration for research projects
- Partnerships between IFPA Members
- Strategic alliances
- Sharing resources within IFPA
- Opportunities for members to work on global level, for example through working groups
- A space where members can share projects with each other

Facilitating communication

- Communication of a clear strategic direction
- Organize more teleconferences
- Clear responses to questions from members
- Translate messages and materials to different languages
- Sharing member activities through IFPA's communication channels

Member support and learning opportunities

- Sharing more information on research
- Share published articles on psoriasis from all over the world
- More training and workshops to strengthen capacity of IFPA Members
- Opportunity to learn more about advocacy strategies
- Financial support for members

IFPA’s recent development and direction

Members were asked how they feel IFPA has developed as an organization during the past years (since 2018), and weather they feel the organization is moving in the right direction.

A majority of respondents stated that they feel IFPA has been developing in the right direction in the past years, the main reasons given are listed below:

- More opportunities to connect digitally
- IFPA listening to its members
- Integration with the NCD agenda
- The Global Psoriasis Coalition
- Active and professional team at IFPA
- Better focus on questions important for the Psoriasis community
- Webinars
- Communication to members

A few members gave suggestions on what they would like IFPA to continue working on, listed below:

- IFPA could find ways to connect to governments and ministries of health
- It is important for IFPA continue to collaborate with the other organizations like NCD Alliance, IDLS, IPC and so on in order to realize global advocacy

Two respondents said they did not feel the organization is moving in the right direction but did not provide further explanations.

IFPA Members opinion on organization focus

Members were asked what they would like IFPA’s focus as an organization to be. The following section summarizes the responses from members and reflect their opinions on what IFPA as an organization should focus on. It does not necessarily reflect the current priorities of IFPA.

Awareness

IFPA should be a global voice for people living with psoriasis and psoriatic arthritis to raise the awareness on global level and make psoriasis important and visible. IFPA should continue the work to ensure the disease is recognized accordingly.

Advocacy and policy

Members want IFPA to continue to work on global advocacy and the work with the World Health Organizations and connecting to Non-Communicable Disease networks. IFPA should be the leader of advocacy on behalf of psoriasis and psoriatic arthritis patients. IFPA Members also want IFPA to disseminate information on what is going on in the global advocacy arena to make it available for members.

IFPA should work towards the implementation of health policies that affect the lives of psoriasis and psoriatic arthritis patients. IFPA should promote easier access to treatment, reduced costs of modern treatments, and greater access to biosimilars.

Global psoriasis community

IFPA should create a global community for people living with psoriasis and psoriatic arthritis. Many IFPA Members responded that they would like to see IFPA focus on supporting patients and patient associations. Members want to see education for members and opportunities for them to strengthen their capacity, particularly in advocacy work, provided by IFPA. They also want IFPA to be a link between members and their projects and facilitate platforms and chances for members to connect and learn from each other.

Patients and physician relationship

IFPA should work to facilitate a strong relationship between patients and physicians.

Research on psoriasis and psoriatic arthritis

IFPA should improve the research field for psoriasis, as well as make updated research and developments within psoriasis and psoriatic arthritis available to its members.

Capacity Development

IFPA Member strengths

IFPA Members were asked what their strengths as an organization is, their reported answers are compiled in a list below:

- Membership focus,
- Strategic development
- Advocacy
- Communication
- Organizing campaigns and events
- World Psoriasis Day
- Open air bath for patients
- Visibility
- Credibility within the psoriasis community
- Known and appreciated by health professionals and partners
- Social media
- Website and app development
- Awareness
- Education
- Patients assistance program
- Leadership development
- Political incidence
- Training and workshops
- Member engagement
- Youth and volunteer development
- Government engagement
- Volunteers team
- Stakeholder relationships
- Patient attendance and access to information
- Online counselling for doctors for questions about psoriasis
- Magazine
- Organizing meetings
- Fundraising
- A will to help each other
- Collaboration with other psoriasis and NCD organizations

Support from IFPA

IFPA Members were asked what they would like IFPA to support them with. Their responses have been compiled in the list below:

- Attracting and retaining volunteers, Volunteer development, Creating voluntary team leaders
- How to get members to join events

- How to organize national awareness campaigns, developing campaign materials, World Psoriasis Day support is appreciated, sharing campaign and project materials, and social media campaigns
- Funding and fundraising
- Help developing an advocacy strategy
- Strengthening regional advocacy efforts
- Provision of education materials
- Coaching
- Materials provided in different language or materials that can be translated by members easily while keeping original graphical elements
- Help to connect with national NCD groups
- For IFPA to promote member projects on social networks
- Information on treatments and alternative diets
- Organizational development, building an efficient workplace

Requested topics for workshops and webinars

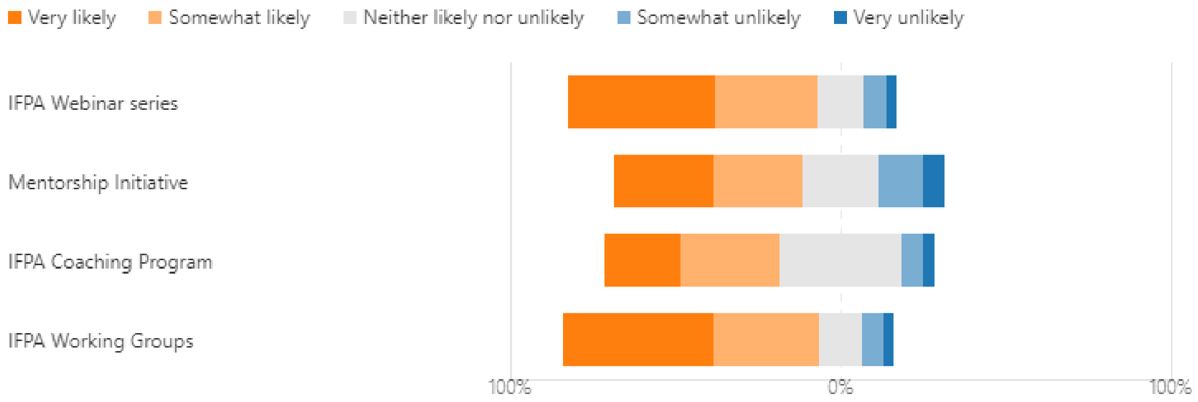
IFPA Members were asked which topics they would like to see covered in IFPA's organized workshops and webinars. The topics they requested have been compiled in a list below:

- Digital transformation of patient organizations
- Mental health related to psoriasis and psoriatic arthritis
- Website management
- Self-sustainability
- Health policies
- Communication tools
- How to access policy makers
- How to build an advocacy strategy on national level
- Working with social media platforms
- Stress management and psoriasis
- Covid-19 and psoriasis
- Negotiation skills with government officials
- Policy making
- HTA
- Fundraising
- Projects to do for people living with psoriasis
- Coaching
- Pathology of psoriasis and psoriatic arthritis
- New treatments
- Information from other IFPA members
- Psoriasis in children
- How to present psoriasis to an institution or health ministry
- Updates in psoriasis and comorbidities
- Cell therapies

- Nutrition information
- Affordable and accessible treatment options
- Coping with psoriasis
- Does diet make a difference?
- What are other associations doing globally?
- What opportunities exist for collaboration with psoriasis organizations around the world

Likelihood of participating in IFPA Capacity Development activities

IFPA Members were asked how likely they are to participate in IFPA's Capacity Development activities. The activities included in the question were: IFPA Webinar series, Mentorship Initiative, IFPA Coaching Program, IFPA Working Groups.

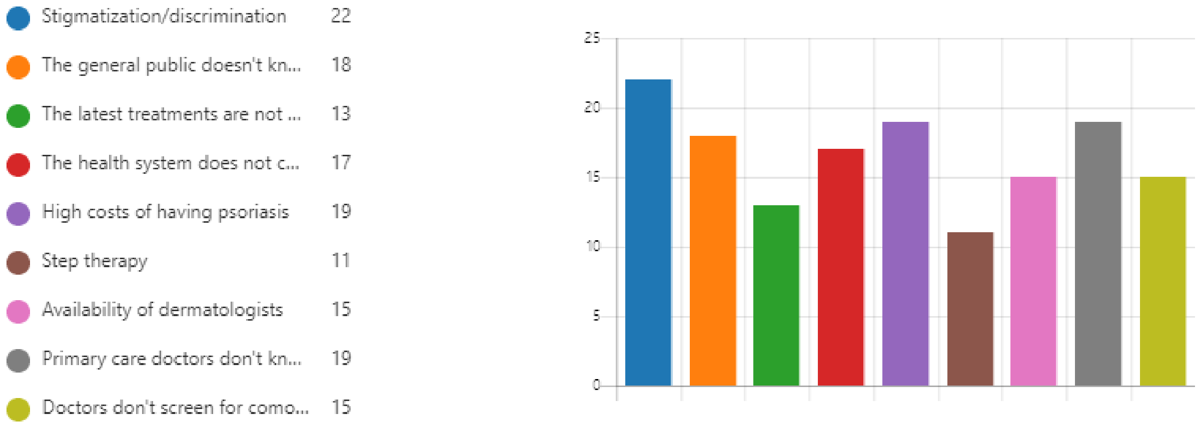


Members reported that they are most likely to join IFPA Working Groups and the IFPA Webinars series and are less likely to join the Mentorship initiative and Coaching program.

Advocacy and Policy

Main challenges for people living with psoriasis

IFPA Members were asked what they perceive to be the main challenge for people living with psoriasis and/or psoriatic arthritis in their respective countries.



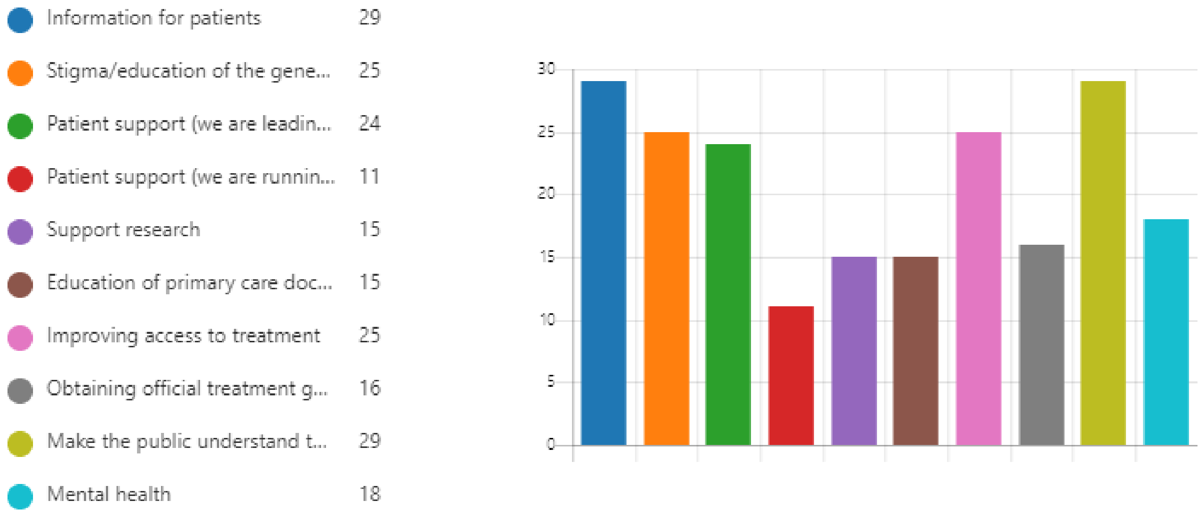
Poll options listed in order: Stigmatization/discrimination, The general public doesn't know about psoriasis, The latest treatments are not available, The health system does not cover the cost of treatments, High costs of having psoriasis, Step therapy, Availability of dermatologists, Primary care doctors don't know about psoriasis, Doctors don't screen for comorbidities.

The mains challenges for people living with psoriasis and/or psoriatic arthritis reported by IFPA Members:

1. Stigmatization/discrimination
2. High costs of having psoriasis AND Primary care doctors don't know about psoriasis
3. The general public doesn't know about psoriasis

Current work of IFPA Members

IFPA Members were asked what they are currently working on.



●	Information for patients	29
●	Stigma/education of the gene...	25
●	Patient support (we are leadin...	24
●	Patient support (we are runnin...	11
●	Support research	15
●	Education of primary care doc...	15
●	Improving access to treatment	25
●	Obtaining official treatment g...	16
●	Make the public understand t...	29
●	Mental health	18

Poll options listed in order: Information for patients, Stigma/education of the general public, Patient support (we are leading patient support groups), Patient support (we are running clinics), Support research, Education of primary care doctors on psoriasis and its comorbidities, Improving access to treatment, Obtaining official treatment guidelines for psoriasis and psoriatic arthritis, Make the public understand that psoriasis is not just a skin disease, Mental health.

The top responses regarding the current focus of IFPA Member organizations were:

1. Information for patients AND Make the public understand that psoriasis is not just a skin disease
2. Stigma/education of the general public AND Improving access to treatment
3. Patient support (we are leading patient support groups)

Additional work reported by IFPA Members

IFPA Members were asked if the had additional work not listed in the options for the previous question. Their responses are compiled in the list below:

- Running and open-air bath
- Early stage diagnosis
- Connect to other patient groups to bring the voice to society
- Working on national campaigns
- Patient education program
- Telemedicine project for dermatology/psoriasis consultation
- Promoting exercise
- Strengthening the health policies for NCDs
- Engaging the government and policy makers in creating better healthcare for psoriasis
- Rehabilitation courses for people with psoriasis
- Opportunities for mutual support
- Preparing a project for patients with the new regulations established by the health institutions for the care of the patient who attends medical appointments in hospitals
- Providing information on healthy diets with nutrition experts
- WhatsApp support group
- Analyzing the impacts of Covid-19 on psoriasis community

Advocacy lessons of IFPA Members

IFPA Members were asked if there was anything they had learned during advocacy work that they felt would be useful for other IFPA Members to know. Their advice for other members has been compiled in a list below:

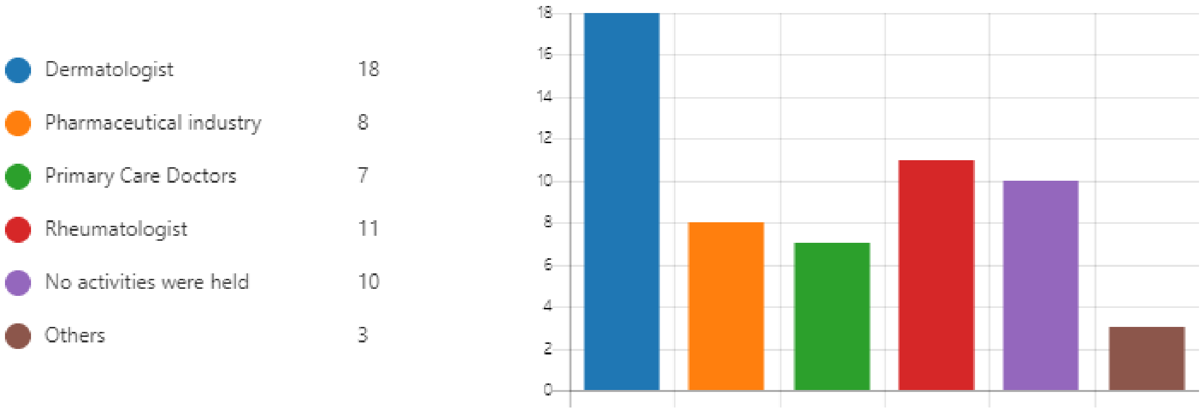
- Find the psoriasis specialists among the dermatologists and inform patients with this knowledge.
- Working with pharmaceutical companies is helpful not only in funding but also in learning their knowledge or experience.
- Create good relationships with hospitals and mass media.
- Many issues are common to several chronic diseases. Join with other patient associations to get faster and better results.
- Patient perspective reinforces our message of the importance of addressing psoriasis and why creating a health policy for psoriasis is necessary.
- Cooperate with other sectors for projects, such as artists and musicians.
- Maintain alliance with other NGOs and patient associations helps a lot.
- Be systematic, having a advocacy program tells us what we have to focus on.
- Persistence and continuity. Our national WPD campaign is well known because we use the same format but with updated materials and themes.

- Respect each other.
- Work with a national legislative power.
- The mental health issues connected to psoriasis tend to be sidelined, which is unhelpful.

Science

Medical training activities

IFPA Members were asked if they organized any medical training activities during 2019 with different professions, their responses are illustrated below.



A majority of IFPA Members organized activities with dermatologists, one third of respondents organized activities with rheumatologists, and one third reported no medical training activities were organized during 2019.

IFPA Members were asked, if medical training activities were organized, which topics were covered

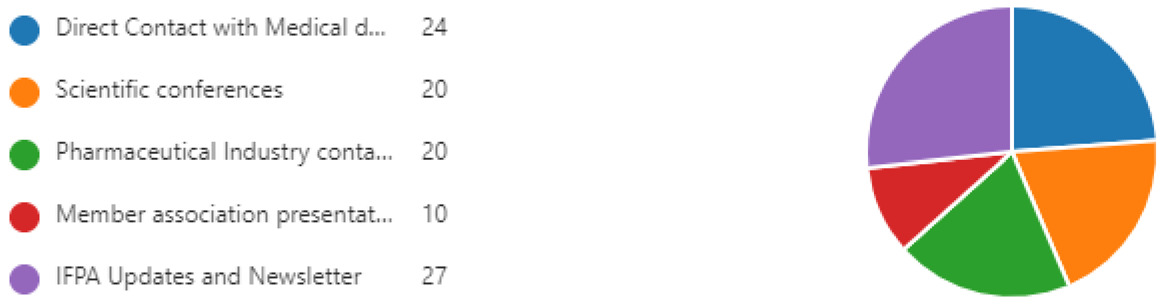
Topics IFPA Members have covered in medical training activities:

- The importance of treating patients with psoriatic arthritis early, it reduces the cost for the health care system.
- Update on psoriasis treatments.
- Lectures about psoriasis and psoriatic arthritis.
- The psychological aspect of psoriasis.
- Available treatments and primary care for psoriasis.
- The impact of psoriasis on the patient's quality of life and the actual state of psoriasis in our country.
- Biological treatments.
- We had a survey on mental well-being and how it is addressed during doctor-patient interaction during consultations.
- The difference between biologicals and biosimilars.
- Psoriasis internal effects and the effects on eyes.
- Training for health professionals in psoriasis.

- Medical student round tables geared toward medical students and cover a broad session about psoriasis and psoriatic arthritis delivered by a dermatologist and patient.

Sources for scientific information

IFPA Members were asked what the most common place is for them to get scientific updates or information on psoriasis and psoriatic arthritis, their responses are illustrated below.



A majority of respondents reported the most common place to look for research updates was IFPA Updates and Newsletters, the second most common source was direct contact with medical doctors/health care providers.

Other sources for scientific updates and information on research reported by IFPA Members:

- Pubmed
- Health Care Boards (Health insurance, industries, etc.)
- Their scientific committees
- Other patient associations such as Europso, National Psoriasis Foundation, Global Skin
- Pharmaceutical companies
- Countries national recommendations on psoriasis
- Medical journals
- International Psoriasis Council
- Dermatology societies

Requested research topics for IFPA to cover

IFPA Members were asked which topics within the fields of psoriasis and psoriatic arthritis care and research they would like to see highlighted by IFPA more, their responses are illustrated below.

Expectations for the World Psoriasis and Psoriatic Arthritis Conference 2021

IFPA Members were asked if they had any expectations or suggestions, they would like to share ahead of the upcoming World Psoriasis and Psoriatic Arthritis Conference. Their responses have been compiled in the list below:

Topics suggested for presentations:

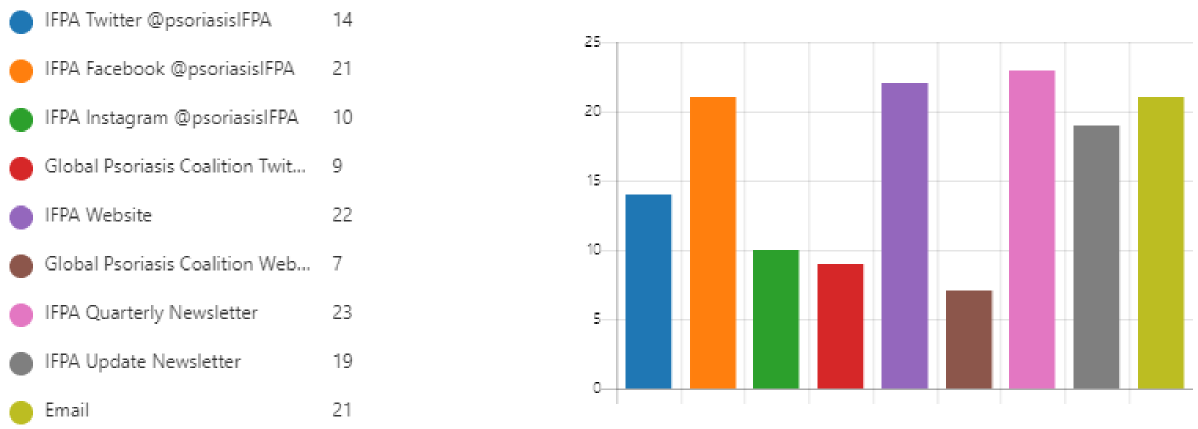
- Psoriasis as a Non-Communicable Disease
- Information about side effects (especially cancer, higher age) appearing during treatment with biologics
- Newer treatment options beyond biologics
- Mental health
- Care for biologic treated patients who have been infected with Covid-19
- The importance of telemedicine
- More on mental health, comorbidities and new available medicine, treatments and therapies
- Importance of patient doctor partnership in pushing change in the proper primary care for psoriasis and psoriatic arthritis
- More research related to psoriasis presented during the conference
- Communication and public health policies

Suggestions regarding the structure of the conference

- Opportunity for members to share their experience with all attendees
- More patient participation as a resource
- To have a thorough and interesting program to those people that are not doctors
- A broader patient organization component beyond the basics – most in the room are aware of the challenges and would benefit from more sessions on relevant training on improving your organization

Communications

Channels used to find updates from IFPA



●	IFPA Twitter @psoriasisIFPA	14
●	IFPA Facebook @psoriasisIFPA	21
●	IFPA Instagram @psoriasisIFPA	10
●	Global Psoriasis Coalition Twit...	9
●	IFPA Website	22
●	Global Psoriasis Coalition Web...	7
●	IFPA Quarterly Newsletter	23
●	IFPA Update Newsletter	19
●	Email	21

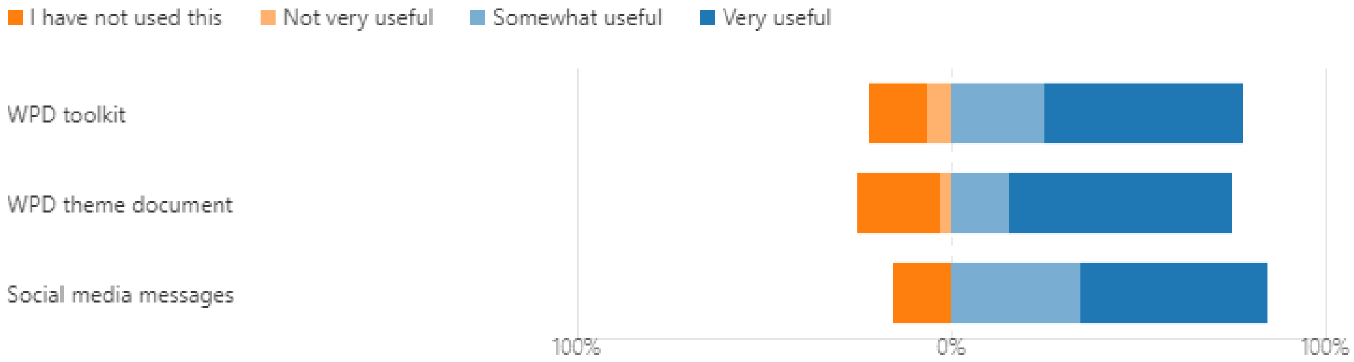
Poll options listed in order: IFPA Twitter, IFPA Facebook, IFPA Instagram, Global Psoriasis Coalition Twitter, IFPA Website, Global Psoriasis Coalition Website, IFPA Quarterly Newsletter, IFPA Update Newsletter, Email.

The top place IFPA Members use to look for updates from IFPA are through the IFPA Quarterly Newsletters, followed by IFPA's Website, Email, and IFPA's Facebook.

World Psoriasis Day

IFPA’s World Psoriasis Day material

IFPA Members were asked how useful they find the different World Psoriasis Day materials provided by IFPA, their responses are illustrated below.



Collaboration with other associations

IFPA Members were asked if they collaborate with other associations around World Psoriasis Day.

A majority (62%) of members reported that they collaborate with other associations around World Psoriasis Day. Below is a list of the different type of associations IFPA Members report collaboration with:

- Other psoriasis associations
- Other psoriatic arthritis associations
- Dermatological societies
- Rheumatology associations
- Health care professionals’ associations
- Scientific societies
- Other IFPA Members

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OF PSORIASIS ASSOCIATIONS