IFPA Member Survey 2021

Summary Report

IFPA
GLOBAL LEADER IN FIGHTING
PSORIATIC DISEASE

MEMBER SURVEY 2021

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.

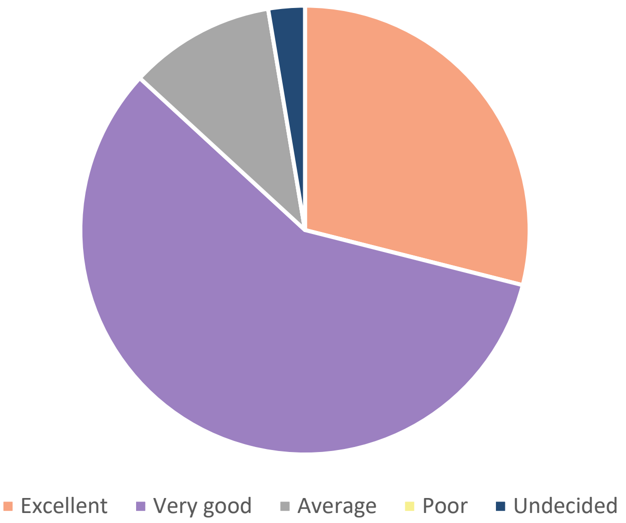
IFPA’s Member Surveys are conducted to gain a better understanding of member priorities, areas that may need further support from IFPA and overall satisfaction with the IFPA membership. The responses collected through this survey will be used for planning future activities and programs for members.
IFPA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

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 our 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.

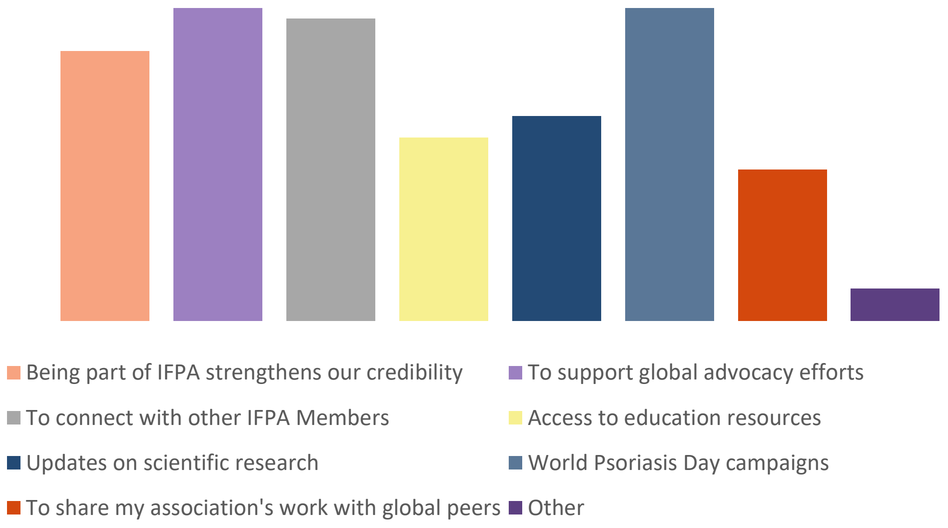
Value of IFPA Membership

Members were asked to rate the value of IFPA Membership on the scale Poor, Average, Very good, Excellent, and Undecided. A vast majority of respondents rated their IFPA Membership as either Very good (58%) or Excellent (29%).



Reasons for being an IFPA Member

Members were asked what their main reasons for being IFPA Members are, their responses are illustrated in the graph below. The two most common responses were ‘To support global advocacy efforts’ and ‘World Psoriasis Day campaigns’, followed by ‘To connect with other IFPA Members’.



Members could select multiple answers.

What members appreciate about IFPA

Members were asked what they most appreciate about IFPA. The most common responses centered around four themes: Global network, Educational activities, Global voice, and World Psoriasis Day.

Global network
Members report that being part of a global network is one of the main benefits of an IFPA membership. Members see great benefit from being part of a network where they are able to connect regularly with other psoriatic disease advocates and share ideas and best practices. Members also highlighted that they feel IFPA has grown closer to its members in recent years, which has been appreciated.

Educational Activities
Many members mentioned that the educational activities provided by IFPA are important. Being able to participate in educational activities such as the webinar series and workshops, as well as being provided with educational materials and information on research is helpful for members.

Global voice
IFPA's work in the global advocacy arena is important for members. The systematic efforts on advocacy, the continuous efforts to ensure the psoriasis resolution is enforced, and IFPA's connection with the UN were all mentioned as valuable.

World Psoriasis Day
The annual World Psoriasis Day Campaigns were highlighted as especially appreciated by members. Sharing the same message globally makes the campaign stronger and more visible.

Member concerns

Members were also asked what they do not currently appreciate about IFPA. Again, the most common responses centered around four themes: IFPA's Member Page, Unclear advocacy goals, Lack of member presentations, Lack of Latin American representation.

IFPA's Member Page
The member's only area on IFPA's website was mentioned as a concern from many members. Members feel that the member's only page is difficult to navigate and that it is unclear what type of information one can expect to find there.

How IFPA will address the issue:
We recognize the problems with the IFPA member page, and as a result of this and in support of reaching Goal 4 in our global strategy we will provide an updated website and member portal. In October of 2021, IFPA will launch its new website, including a new member's area. IFPA's secretariat will work with developers to ensure the member's area is more user friendly and meets the needs expressed by

members. The platform will be a channel for sharing knowledge systematically, including best practice sharing and the latest research.

Lack of member presentations

Members want to see more presentations and webinars by other members.

How IFPA will address the issue:

Making space for member’s work to be presented is essential. IFPA will continue to find ways to include member presentation during the annual member meetings, as well as looking for further opportunities where member work can be showcased. IFPA will also dedicate more webinars to member presentations.

Advocacy work unclear

Members report that the vision for IFPA’s advocacy work is unclear.

How IFPA will address the issue:

IFPA's focus since the final quarter 2020 until second quarter 2021 has been to unite around a clear direction. In March 2021 we presented The Coalition's Strategic Action Plan that includes clear goals and a roadmap for our advocacy. In July we presented a global strategy with updated vision and mission. With this new start and clear direction. We have what it takes to unite, strengthen and lead for another 50 years!

Lack of Latin American representation

Members from the Latin American region would like to see more representation form their countries. Members requested more studies that include Latin American countries and more Spanish materials provided by IFPA.

How IFPA will address the issue:

It is important for IFPA that all regions feel well represented. IFPA continuously advocates for diverse representation in research and other projects. IFPA also works to provide translated material. A few examples of translated material provided by IFPA in 2021 are the report ‘Inside Psoriatic Disease: Diabetes’, available in two languages, the checklist guiding people with psoriatic disease in the prevention and management of diabetes, available in 11 languages, and the material for World Psoriasis Day, available in 9 languages. Member support is important for promoting IFPA regionally and nationally and for the establishment of new member associations within each region. In our global strategy, Goal 1 - Ensure global representation, highlights how we must: Boost the voices of everyone living with psoriatic disease, everywhere.

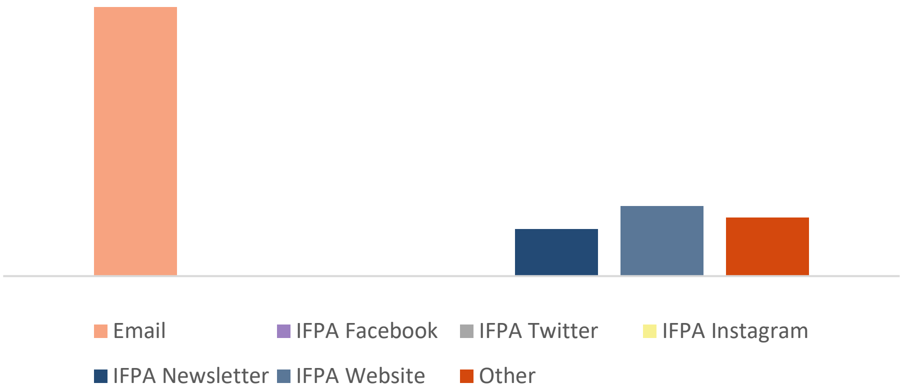
Less frequently reported concerns

Other, less reported, concerns included: lack of in person meetings, not enough best practice sharing, and high staff turnover. A few members also requested more opportunities for collaboration between members, and opportunity to discuss management issues with other members, and more rotation in the roles of the board.

NEWS AND UPDATES

Where do you look to find updates?

Members were asked where they look to find updates from IFPA. Respondents could only select one answer, and the most reported answer was ‘Email’.



Members could only select one answer.

Newsletters

Newsletters are a great way to share news and upcoming activities with the entire IFPA community. IFPA issues four quarterly newsletters each year, as well as more regular ‘IFPA Updates’ that are shared with members only. Members were asked what type of content they would like to see in IFPA’s newsletters, the responses are listed in the box below. Frequently suggested content is marked in bold.

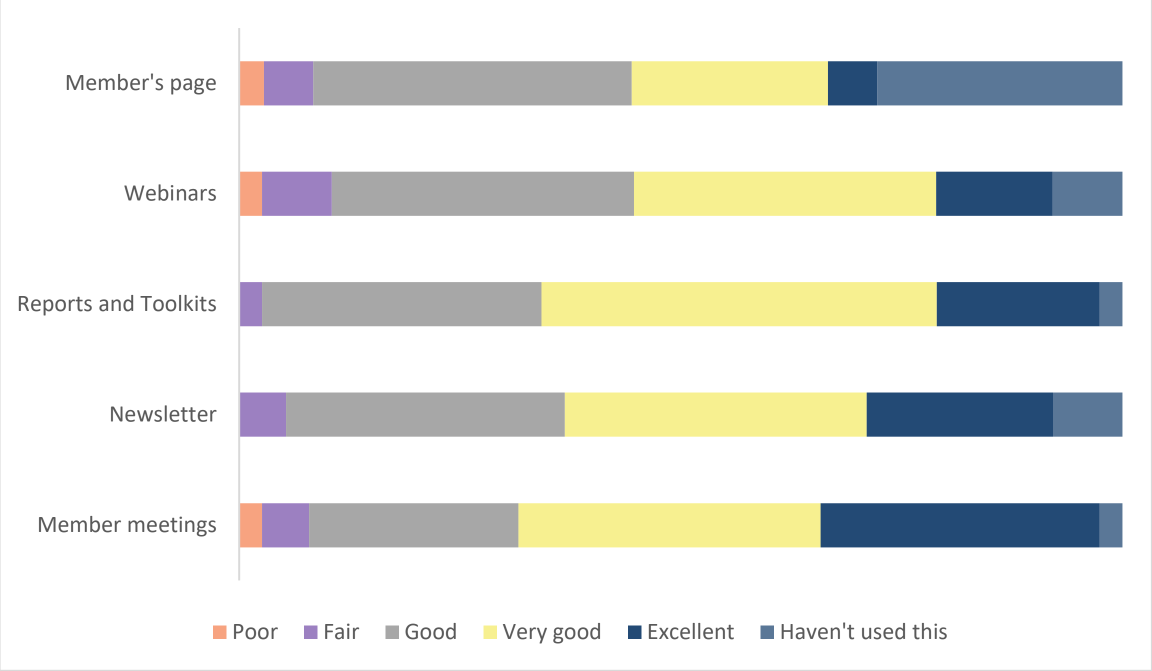
What type of content do members want to see?

- Educational resources
- **Member initiatives**
- Information on covid-19, vaccines, and psoriasis
- **Treatments**
- Regional updates
- Project ideas and upcoming activities
- Opportunities for collaboration
- **Research and medical updates**
- Achievements in advocacy work
- Healthcare policies in different countries
- Psychological aspect of psoriatic disease
- Patient support
- Examples of good campaigns
- Member spotlight
- Events calendar

MEMBER ACTIVITIES

Rating member benefits

Members were asked to rate a number of member benefits on a scale from ‘Poor’ to ‘Excellent’. When looking at the proportion of ‘Very good’ or ‘Excellent’ ratings, Member meetings were rated the highest closely followed by Reports and Toolkits. Members were least satisfied with the Member’s page.



Requested topics for educational activities

Organizing educational and skill building activities is an important part of IFPA's member support activities. It is therefore important to understand what topics members want to learn more about. Members were asked to suggest topics they would be interested to learn more about through IFPA's webinars and workshops, the suggestions are listed in the box below.

Topics for webinars and workshops

- World Psoriasis Day
- Findings from the GPA
- How organizations structure their board
- Advances in medicine
- Patient support actions
- Covid-19 and Psoriasis
- Share news and successful activities
- Treatment advances and guidelines
- Global advocacy work on psoriasis
- Patient registries
- Latest research
- Social media management
- How to make your organization stronger
- Fundraising
- Mental health
- IFPA's work with the WHO
- Coaching programs
- Health Technology Assessment
- Patient empowerment
- Leadership
- Campaign development
- Articles co-authored by IFPA
- Holistic treatment
- Engagement in healthcare policy and decision-making systems
- IFPA's work on international treatment guidelines
- Mental health
- Nutrition
- Treatment systems and functionality in different countries
- How to create a good awareness campaign
- Patient education
- Motivating volunteers
- Difficulties and achievements from members
- How to get resources

Requested brochures and toolkits

IFPA continuously creates brochures and toolkits to share with the psoriatic disease community. Members were asked what type of brochures and toolkits would be useful for them, and the responses are listed in the box below. A few members also requested to get documents sent in a format that can be edited, so they may translate for their local audience.

Useful brochures and toolkits

- New treatments
- World Psoriasis Day
- Organizational structure of patient associations
- Logos and graphics
- How to define an advocacy strategy
- How to manage psoriatic disease
- Self-advocacy resources for patients
- Pamphlets for youth
- Infographics
- Updated medical information on psoriatic disease and comorbidities
- Awareness about psoriatic disease
- Integrated medical systems
- Psoriatic disease and depression
- Information from surveys

Requested activities

Members were asked if there are any specific activities they would like to see IFPA organize. Responses are listed in the box below.

Activities

- Virtual World Psoriasis Day celebration
- On-site regional meetings
- Regular global research discussions
- In-person meetings
- Timely access to recorded webinars
- Panel discussion on advocacy work in different countries
- Data collected on advocacy work in different countries
- Share stories of people living with psoriatic disease
- Help with website development
- Forums and educational conferences that involve patients
- Drawing contest for children
- Share photos of WPD activities from all countries
- Lectures by healthcare professionals
- Social media campaigns

CAMPAIGNS

WPD theme suggestions

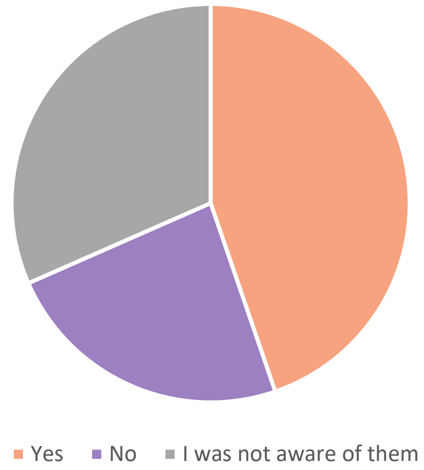
Each year IFPA organizes the World Psoriasis Day campaigns and shares a theme and theme materials with IFPA Members. Member participation in these campaigns is crucial to have a great impact. Members are therefore always consulted on which themes they would like to see, suggestions collected through the member survey are listed below. In addition to the theme suggestions, members also requested to receive campaign materials in a format that can be edited. Respondents also said that loose themes for the World Psoriasis Day campaigns are good, as it makes it easier to adapt for local contexts.

Campaign theme suggestions

- The many faces of psoriatic disease
- Childhood psoriasis
- Mental health
- Psoriasis and comorbidities
- Presentation differences in different skin types for early diagnoses
- Treating the person, not the disease
- Psoriatic disease as a family health issue
- Building awareness among health care providers
- Climate therapy
- Battling stigma and discrimination
- Patient stories
- Psychosomatic problems
- Empowerment
- Connection between IFPA and WHO
- Quality of life
- Psychological support
- ‘I have psoriasis, do you know my disease? I’ll explain what it is’
- ‘You’re not alone’
- Covid-19, psoriasis, and vaccines
- Dots day
- Access to treatment
- Campaign tied to the Global Psoriasis Atlas
- Caretakers and psoriatic disease

Participation in non-WPD campaigns

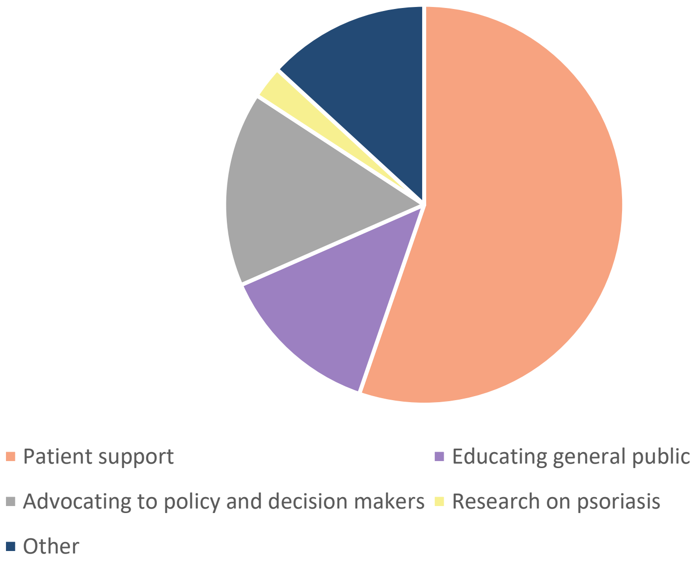
In addition to the World Psoriasis Day campaigns, IFPA also organizes other awareness campaigns. Members were asked if they participate in IFPA organized campaigns outside of the annual World Psoriasis Day campaign. Responses are illustrated in the graph below, 45% answered ‘Yes’, 24% answered ‘No’, and 32% answered ‘I was not aware of them’.



MEMBER’S WORK

Main focus

Understanding the focus of IFPA Members is important when planning activities and materials to be produced. When asked ‘If you could choose only one, what would you say your main focus is?’ 55% of respondents answered ‘Patient support’. ‘Advocating to policy and decision makers’, ‘Educating general public’, and ‘Other’ had similar response rates (16%, 13%, 13%), and ‘Research on psoriasis’ had the least number of responses (3%).



How can IFPA support members?

As a global federation, one of IFPA's main tasks is providing support for its member associations. To do this in the best way possible, it is important to understand what members feel they need in order to support their local communities. Members were asked to share what IFPA can do to assist them with their work, the responses are listed in the box below.

Requested member support

- Share materials as PDF and Word so they can be translated
- Provide translated materials
- Share educational resources
- Share best practices
- Help define an advocacy strategy
- More active participation from members
- Amplify member campaigns
- Share resources
- Share research
- Partner more with members
- Support for grant applications
- Solidarity fund
- Financial support
- Global advocacy
- Peer support on virtual platforms
- Share results from surveys
- Shared psoriasis website with sections for different countries' contributions and activities
- Share resources relating to clinical practice guidelines
- Adapting IFPA campaigns to local contexts
- Designed materials that members can put their logo on

IFPA

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