

# IFPA MEMBER SURVEY 2019

Summary report, including IFPA comments and follow-up  
May 2020



INTERNATIONAL FEDERATION  
OF PSORIASIS ASSOCIATIONS

# IFPA's Member survey

During April of 2019, all IFPA members were invited to complete a 31-question long member survey. The 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. The survey was open during the entire month of April and yielded 32 responses (out of 55 members).

This survey was conducted to gain a better understanding of member priorities, areas that may need further support from IFPA and overall satisfaction with their IFPA membership. The responses are planned to be used for planning future activities and programs for members.

This report contains the original survey summary, updated with responses, comments and an update on how IFPA has responded to member input and requests as of May 2020, as well as current plans. If you have further suggestions or questions, you are as always welcome to contact the IFPA Secretariat.

We would also 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.

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# About IFPA members

## Countries represented in this survey

The survey got 32 responses (out of 55 members), that came from the following countries:

Russia, France, Hong Kong, Greece, Ireland, Finland, Korea, Panama, South Africa, Czech Republic, El Salvador, Denmark, Indonesia, Germany, Japan, Iceland, Brazil, Belgium (Flanders), Slovenia, Israel, Singapore, Portugal, Puerto Rico, Philippines, Slovakia, Canada, Estonia, Vietnam, Belgium (Wallonia), Argentina, Spain and Taiwan.

## Employed staff

More than half of respondents reported that their association has employed staff (17 reported they have staff, while 14 reported they have no staff).

Of those that reported having staff, the number of staff ranged between 1-13.

## Communication channels used

Top three answers: Website, Facebook and E-mail.

Most members, 77,5%, reported that they use some form of social media.

About half (14/31) have some type of newsletter

## Main challenges

The survey asked members: What is your associations main challenge?

The question was originally intended to ask members about their association's main struggles or difficulties, however many respondents interpreted the question as "what is the mission of your association?".

### Challenges:

The top challenges reported by members were financial and fundraising difficulties, difficulties in recruiting and retaining members and a lack of volunteers. Other challenges reported less frequently included political difficulties, for example challenges with reaching their national ministries and a lack of knowledge and/or correct and updated information.

## **Mission:**

The most frequently reported missions of IFPA members are:

1. **Raising awareness**  
Educating the general public about Psoriasis and Psoriatic Arthritis, highlighting ignorance and building knowledge to reduce discrimination and stigmatization.
2. **Access to treatment**  
Working towards their national governments and health care systems, to improve access to treatment and ensure the access is equal for all. Many members also work to get improved medical care for people living with Pso and/or PsA, and to have more drugs included in national health plans.
3. **Support for people living with Psoriasis and Psoriatic Arthritis**  
Uniting people who live with Pso and/or PsA, offer mental support and therapy groups and helping people live better lives with Psoriasis.

Other missions of IFPA members are implementing national guidelines and/or the resolution on Psoriasis, encouraging medical research, finding a cure, improving quality of life, and educating patients about Psoriasis and Psoriatic Arthritis.

### **IFPA Response, comments and follow up**

#### **Fundraising**

IFPA will, from 2020, consider models for liaising with regional sponsors in connection with regional meetings (through contacts with our global sponsors), facilitate sponsor contact on member portal, invite experts to discuss fundraising during webinars/member meetings

#### **Recruiting and retaining volunteers**

Webinars and workshops will be planned to cover the topics, collect best practices from members to be shared

#### **Recruiting and retaining members**

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# Examples of successful campaigns

The following section contains examples of campaigns delivered by different IFPA Members, described by the associations that conducted them.

## Partnering with other diseases

*"We did a study on expenses chronic disease cause together with three other organizations (allergy-, skin- and asthma, Crohn's and Colitis, and Rheumatism association). Many articles in newspapers were published based on that. Since then we've been able to use the results of the study in our advocacy work."*

## Access to healthcare

*"A big success was in September 2018, when we succeeded in getting government funding for a new national centre focusing on developing better treatments for people with autoimmune disease, psoriasis included. The centre is to focus on creating holistic treatment methods and coherent patient course of treatment and follow-up in the system."*

## Education

*"In 2018 we started a campaign in primary schools over the country where we are educating children from age 9 to 15 about psoriasis and living with the disease. In this matter, we made a cartoon, a mascot and we published a book. We formed a quiz, which we are having at the end of the lecture and which allows us to measure the success of the lecture and passing on the information. In the campaign, we are having tattoos in the shape of psoriasis flake, which we are giving to children to see how psoriasis looks like their own skin."*

## Art and Media

*"PsoPortugal had a disease awareness campaign that joined several stakeholders: PSOPortugal, Theatre Company, TV station. Railways stations and a pharmaceutical partner. Real Life Psoriasis Patients contributed through their testimony, helping build the narrative. Dermatologists helped guarantee the scientific accuracy. A pioneering campaign including:*

*Theatre Tour - 12 shows in 8 cities - Theatres and train stations - Play based in patients stories - 1780 spectators*

*Soap Opera Character - Live at a national TV station - Script based in patients testimonies - 3.8 million viewers*

*Music - Part of play and soap opera - Gives voice to the feelings of patients - 52 radio stations"*

### **Supporting the community**

*“We train and transform patients to become Psoriasis Coaches who will guide newly diagnosed patients in their journeys. By giving them proper lectures conducted by our partner organizations and experts in their fields like Philippine Dermatological Society (PDS), Philippine Rheumatology Association (PRA), life coaches, psychiatrists, dieticians, etc., these psorcoaches are able to guide other patients dispensing the right information about the disease. PsorCoaches are also taught how to handle mental health issues, particularly suicidal ideation. Navigating the available health systems are also taught to the coaches with emphasis on how to access medicines and other resources available.”*

### **Campaigns related to Psoriatic Arthritis**

72% of the respondents to this question have had/or plan to have a project/campaign/initiative related to Psoriatic Arthritis.

*“We've had a project on climate therapy on people with psoriatic arthritis in 2009. Based on the results of the project we've been able to send people with psoriatic arthritis to south. Before the study we mostly were able to send those people, who had severe psoriasis on their skin.”*

*“We have conducted free skin and bone/joint clinics for patients to have access to doctors of dermatology and rheumatology for proper diagnosis, prevention and care for both psoriasis and psoriatic arthritis.”*

# Scientific updates

Only 4/28 of respondents said they do not provide scientific information to their members, meaning the majority of IFPA members provide some sort of scientific information to their members.

The most common places for IFPA members to get scientific information are:

1. Direct contact with medical professionals
2. Scientific conferences
3. Pharmaceutical industry contacts

All respondents said it would be useful for them if IFPA provided scientific updates. The most requested topics were:

- Biologics
- Treatments and therapies
- Co-morbidities (especially mental health)

Other topics requested included information on clinical trials, Quality of life, Social Return of Investment, Psoriatic Arthritis, Abstracts from WPPAC, interesting studies, pregnancy, psoriasis in children, and more information on psoriasis (for example psoriasis on nails and genitals).

## **IFPA Response, comments and follow up**

It is clear that updates on scientific progress would be appreciated by IFPA Members. To meet this request, IFPA added a Scientific Officer as a new staff function in 2018. The work scope of the Scientific Officer includes providing members with major updates in the science of psoriatic disease and information on what IFPA is doing in the science arena. We will appreciate continued feedback from our members (feel free to contact the Scientific Officer) with suggestions on how this function and IFPA overall can best continue development of our support efforts for IFPA members in this area.

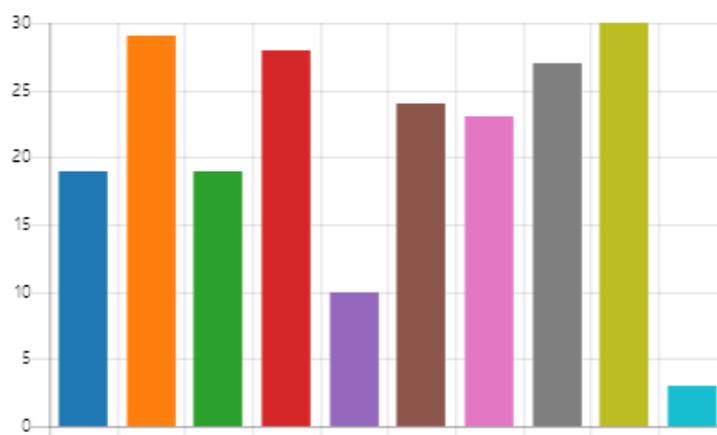
# IFPA Membership value

## Reasons for being an IFPA member

Top three reasons for being an IFPA member:

1. Being part of the global federation strengthens our credibility
2. Ability to connect and share experiences with other IFPA members
3. Representation at global level

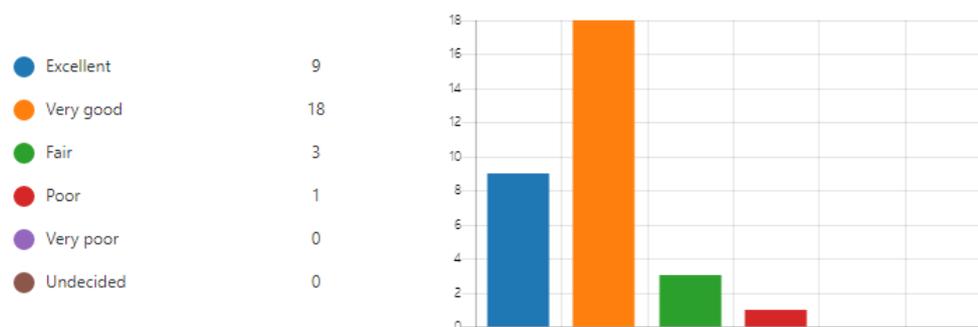
● Up-to-date information on sci...	19
● Ability to connect and share e...	29
● Access to education resources...	19
● Representation at global level	28
● Access to IFPA Solidarity fund	10
● Ability to attend the World Ps...	24
● Annual members meeting	23
● To support the mission of the ...	27
● Being part of the global feder...	30
● Annat	3



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 Conference, Annual members meeting, To support the mission of the federation, Being part of the global federation strengthens our credibility, Other.

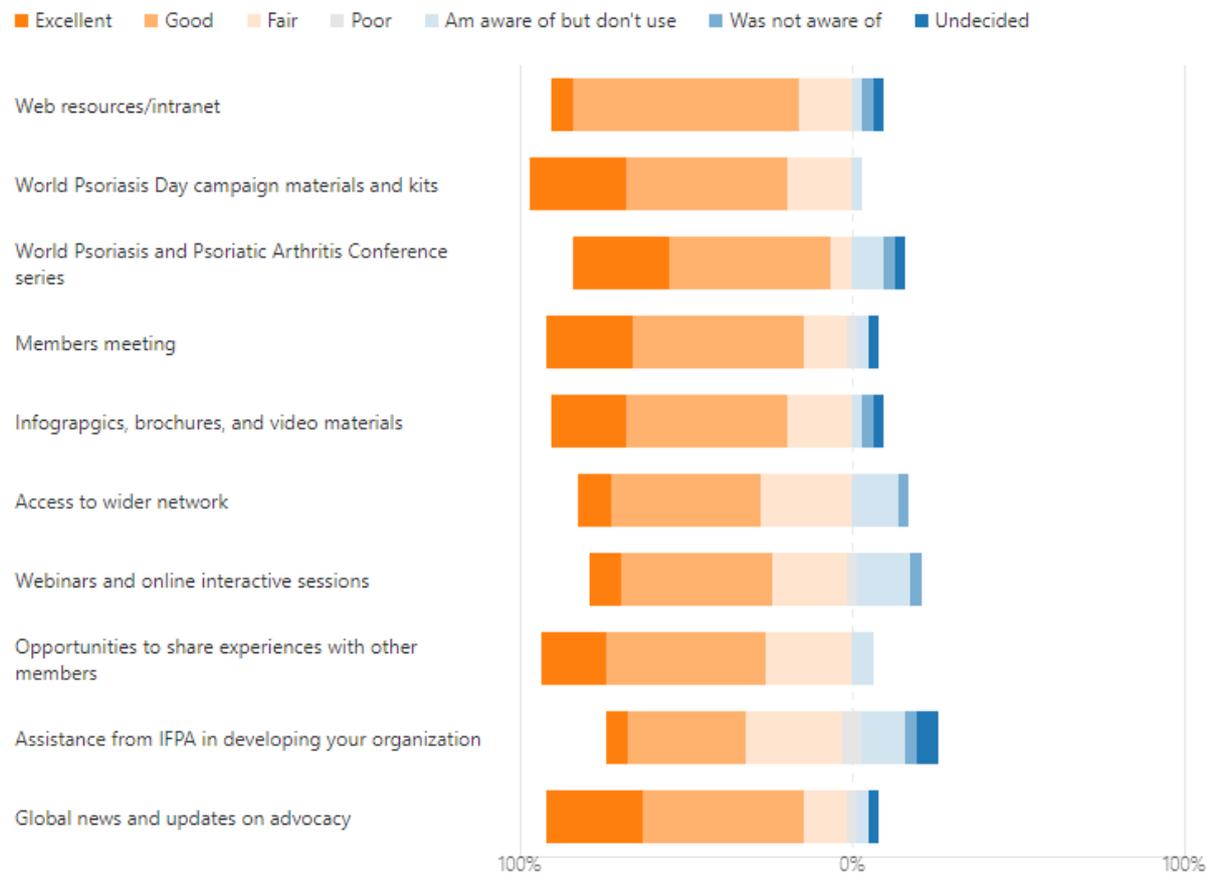
## Value of IFPA membership

When asked how they would rate their IFPA membership, 87% of respondents answered “Excellent” or “Very good”.



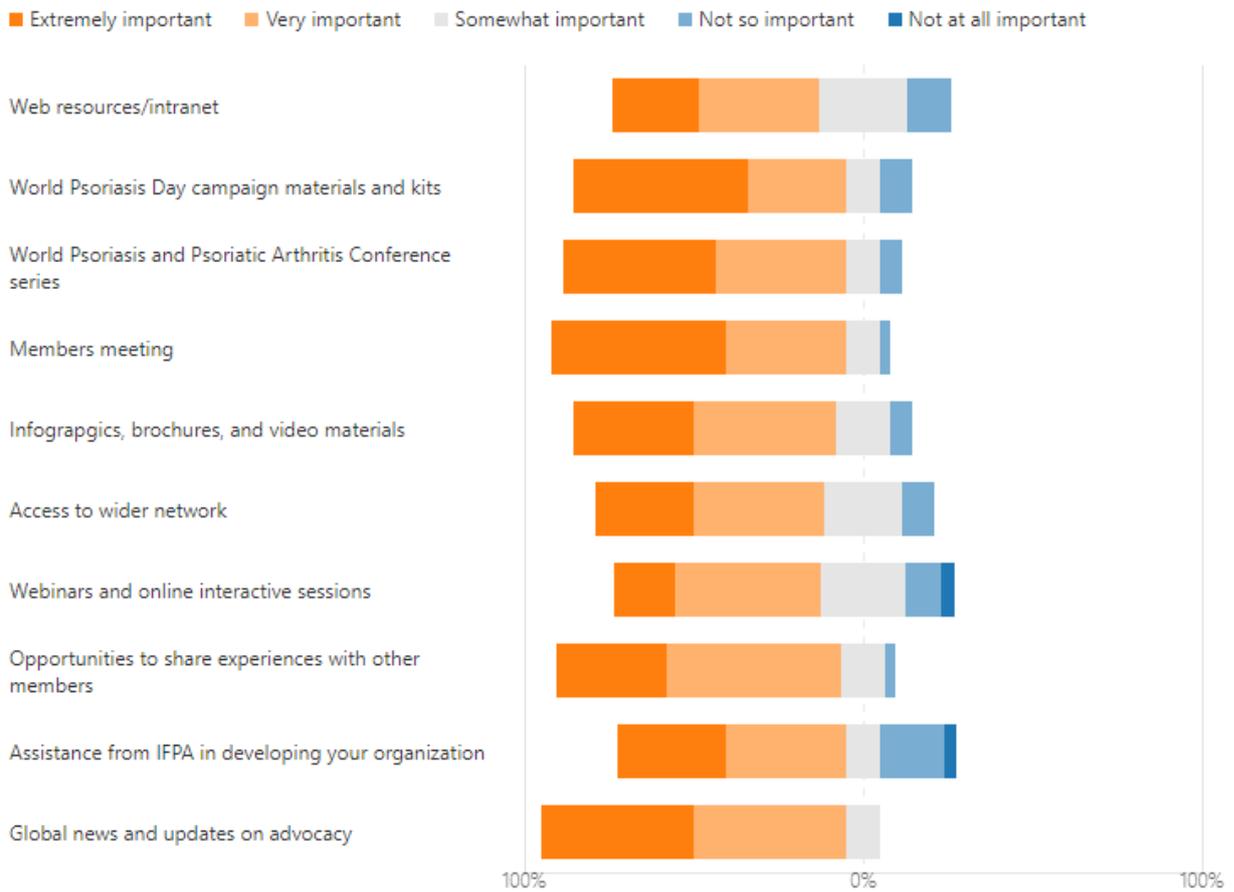
## Members ratings on quality of IFPA membership benefits

The most highly rated member benefits were World Psoriasis Day campaign materials and kits, Global news and updates on advocacy and World Psoriasis and Psoriatic Arthritis Conference series.



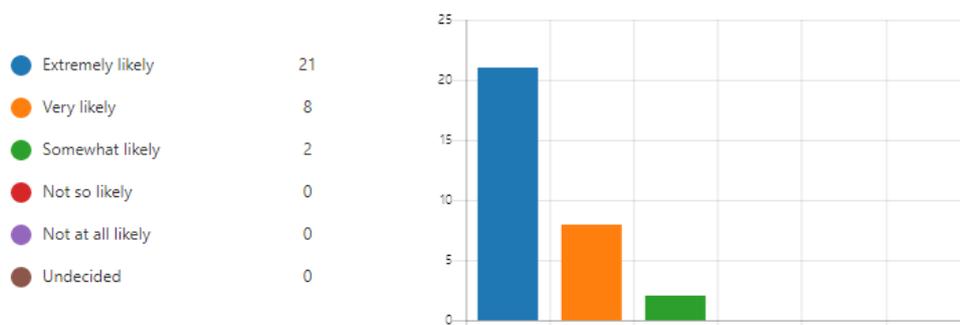
## Members ratings on importance of IFPA membership benefits

The membership benefits that are rated as most important by members are Global news and updates on advocacy, Members meetings, Opportunities to share experiences with other members and World Psoriasis and Psoriatic Arthritis Conference series.



## Membership renewal

When asked how likely they are to renew their membership, 93,5% responded they are either “Extremely likely” or “Very likely” to renew their membership.



## What would increase the membership value?

Generally, members want to be more connected both with each other and with the work going on at the global level. Many would also like more sharing of information and resources, especially for members in resource poor countries.

Two additional often mentioned suggestions were financial aid from IFPA (either via the solidarity fund or direct funding for conference participations) and material for campaigns translated to more languages (for example French, Slovak, and German).

Other suggestions include starting regional chapters (ex the greater China region), position papers on scientific issues, concrete advocacy ideas, training courses, badges for member meetings and webinars in Spanish.

### IFPA Response, comments and follow up

#### Member involvement on global level

During 2019, IFPA Working Groups were launched. This initiative allows members from all levels of IFPA to come together and be involved in projects on a global level.

#### Stronger member to member connections

More connections between IFPA Members is encouraged through initiatives such as the IFPA Working Groups, or the IFPA Peer-Coaching program scheduled to launch 2020. IFPA also facilitates contacts between members by organizing member meetings.

#### Sharing information and resources

IFPA is working on a new member platform, which would allow for a more extensive resource library where both IFPA and its members can share information and resources.

#### Creating avenues for more regular contacts

IFPA will work to develop a number of mechanisms where members can connect together, and with IFPA, to be more involved with processes throughout each year.

## Good things about being an IFPA member

What members value most about being an IFPA member is the ability to connect and share experiences with a Global community. Networking, sharing experiences and being in contact with other (sometimes more advanced) countries is the best thing about being a member according to the survey respondents.

Other things mentioned were the World Psoriasis and Psoriatic Arthritis Conference, the members meeting, recognition gained from being part of a global federation and getting more knowledge and information.

## Improvement suggestions

When asked what could be improved when it comes to being a member of IFPA, the following suggestions were reported:

- Having a joint international project
- Connections that can be relayed on national level
- Solidarity fund should be an annual thing
- Changing the travel policy - limited travel expenses are unfair and prevents certain members from joining meetings
- Members meetings should not always be in Europe
- Advocacy work should better help advocacy on national level
- WPPAC should be planned from a layman's point of view and understanding
- More online interactions
- Webinars that can be shared with patients
- New visual identity for WPD material

### **IFPA Response, comments and follow up**

The above comments are being considered in connection with planning of IFPA events. For example, the travel policy reimbursement levels has been increased somewhat as of 2020.

#### **Members meetings**

During the IFPA member meeting in Barcelona 2019, a new meeting format was presented and, based on feedback from members, eventually approved by the IFPA Board, aiming to arrange regional meetings rather than one big global meeting during 2020. One member meeting is intended to be held in each region during 2020 (subject to review depending on COVID-19 impact).

#### **Advocacy work should better help advocacy on national level**

One of IFPA's main objectives in advocacy is to offer support to its member organizations for their national advocacy work. In 2019, the focus was on the theme in global health that was under the spotlight at the international level: universal health coverage (UHC). We believe that sharing information from the international arena gives member organizations the opportunity to align the national agenda to the global conversation, with the result of being more effective in their advocacy work. We organized a webinar on UHC in April and a workshop on UHC during the IFPA Members Meeting on July 7. Moreover, we produced a toolkit on UHC tailored to the needs of psoriasis advocates, that was published and distributed to all IFPA member organization on December 12 (UHC day). The Global Psoriasis Coalition produced a report on Psoriasis and Primary Care, publicly available ([globalpsoriasiscoalition.org](http://globalpsoriasiscoalition.org)), that includes solutions and best practices for advocating for a primary care-led management of psoriasis. We have also began a conversation with IFPA Regional members on how to better support their work. As an example, the Pan American Coalition met ahead of the IFPA Members Meeting to discuss common needs and evaluate opportunities for action at the regional level. We also opened up for supporting the national advocacy efforts of our

member organizations by providing material upon request. Some organizations already contacted us and we hope they are satisfied with the level of support we provided. Continued development of IFPA's advocacy efforts will be aimed at considering and connecting synergies on global, regional and national level.

### **WPPAC should be planned from a layman's point of view and understanding**

WPPAC organized by IFPA is among few international conferences which has a scientific program with a patient focus.

The WPPAC is designed to include a complementary program designed for patient leaders and allied health professionals that meet psoriasis patients in their daily work. This program has previously included patient participation and focused on topics such as; doctor/patient relationship, patient safety, advocacy, daily life problems for Pso/PsA patients.

In view of the above request the WPPAC 2021 organizing team is also considering the following for the next conference:

Need for more patient inclusion in the program one way would be to have `management sessions` where there would be one specialist and one patient discussing real-life experiences with patient expert input and to offer different perspectives.

A plan to have (in the above sessions) active audience participation in panel discussions that will be moderated by patient experts.

At the end of each presentation - speakers there are plans to provide a short summary of what the research work actually means for the patient.

There will be multiple sessions where people living with psoriatic disease can discuss policy and advocacy issues and present their work to other member associations and patient groups

### **More online interactions**

More online interactions were had during 2019, compared to the previous year. IFPA held online webinars twice a month, giving IFPA members the opportunity to come together and discuss different topics. Online interactions will be further strengthened with the IFPA Member Portal.

### **Webinars that can be shared with patients**

During 2019 the IFPA Webinar Series was open for IFPA Members only. At the end of the year IFPA chose to open the series up for the public as well (certain presentations may still remain available for members only), meaning IFPA Member associations can invite their members and psoriasis and psoriatic arthritis patients are welcome to attend.

### **New visual identity for WPD material**

The WPD 2019 campaign had a logo with a recognizable element - a puzzle, which represented the theme "Let's get connected". Also, it was the first year we produced a visual theme document (the puzzle of the messages), and series of social media posts for our members to share on their social media channels.

## Areas that need more support

Members were asked if there are any areas that they need support in, where they are not currently getting any support. Most responded that they are getting at least some support where it is needed, there were a few requests listed:

- Preparations for WPD one year in advance
- Workshops on specific topics, for example communication skills
- Regional exposure
- Pay from IFPA
- Assistance with getting support from pharmaceutical companies
- Medical aids
- Website support
- Travel budget is not enough for some regions
- Translation to other languages

### IFPA Response, comments and follow up

#### Preparations for WPD one year in advance

IFPA Secretariat is doing their best to create a quality material every year based on your inputs. In 2019, we provided the theme and the logo early in the year, thanks to the working group and IFPA team efforts. The general themes for 2020 and 2021, Informed and United, were provided when the three-year theme was presented in 2019. The theme development for the 2020 campaign has been affected by the covid-19 pandemic but the goal is for moving the process forward significantly in 2021.

#### Workshops on specific topics, for example communication skills:

During 2019 IFPA, in collaboration with two pharmaceutical industry partners, offered several workshops on communication skills, more specifically social media skills. Experts in the topic were invited to the annual member's meeting and help a plenary session as well as individual coaching sessions. These sessions were then followed up with two webinars given by the same external experts. Workshops on other topics are continuously planned and offered to members.

#### Regional exposure:

To promote more exchange within each region IFPA is aiming to arrange Regional Member meetings instead of one global meeting during 2020.

#### Travel budget is not enough for some regions:

In the event that an IFPA Member's travel expenses while attending an IFPA event surpasses the reimbursement amount, members should contact the IFPA Secretariat to active procedures to assess individual cases.

Other feedback is also incorporated in considerations as to IFPA's continued development.

# World Psoriasis Day

## Members on the WPD toolkit

24 of 29 respondents reported they find the WPD toolkit useful.

When asked how the toolkit could be improved, the most common requests were

- The toolkit must be easy to adapt to local context
- Translated or easy to translate
- Receiving WPD material earlier (including vector files)

### **IFPA Response, comments and follow up**

#### **The toolkit must be easy to adapt to local context**

The WPD toolkit has the necessary information about the communications that can be used in any country despite their budget. Also, it includes lobbying and advocacy tips not only if you are starting an association but if you are already advanced in the field too. IFPA Members are most welcome to contact the IFPA Secretariat for further advice.

#### **Translated or easy to translate**

All WPD material in 2019 was created by an international IFPA team using simple English. Also, we created a Spanish logo version by your request due to a large number of Spanish speakers among our members. Further information will be forwarded in connection with each year's campaign as applicable.

#### **Receiving WPD material earlier (including vector files)**

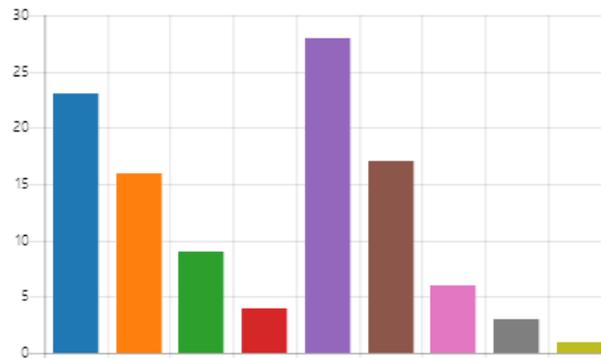
IFPA Secretariat is doing their best to create a quality material every year based on your inputs. In 2019, we provided the theme and the logo early in the year, thanks to the working group and IFPA team efforts. Due to a small number of our members using vector files, we send them upon your request.

# Communication

## IFPA communication channels

Members are most likely to check their e-mail or IFPA's website to find updated information from/about IFPA.

IFPA website	23
IFPA Facebook	16
IFPA Twitter	9
IFPA Instagram	4
Email	28
World Psoriasis Day website	17
Global Psoriasis Coalition web...	6
Global Psoriasis Coalition Twit...	3
Annat	1



## Satisfaction with ability to communicate with other IFPA members

45% "Very satisfied"

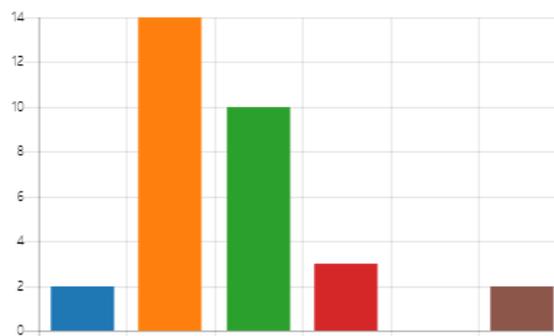
32% "Somewhat satisfied"

10% "Not so satisfied"

6,5% "Extremely satisfied"

6,5% "Undecided"

Extremely satisfied	2
Very satisfied	14
Somewhat satisfied	10
Not so satisfied	3
Not at all satisfied	0
Undecided	2

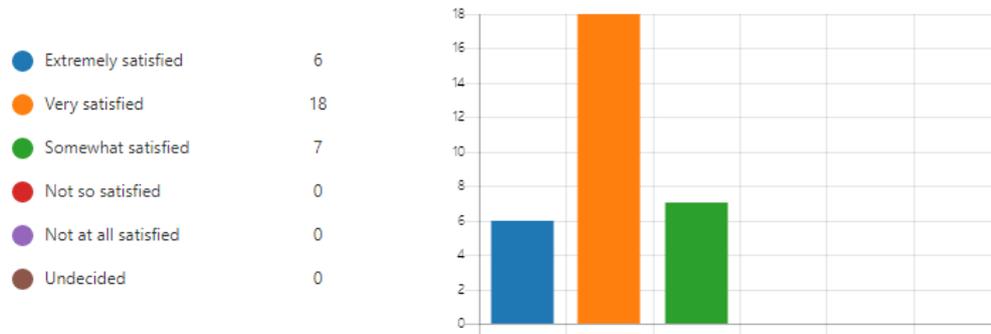


## Satisfaction with ability to communicate with IFPA

58% "Very satisfied"

23 % "Somewhat satisfied"

19% "Extremely satisfied"



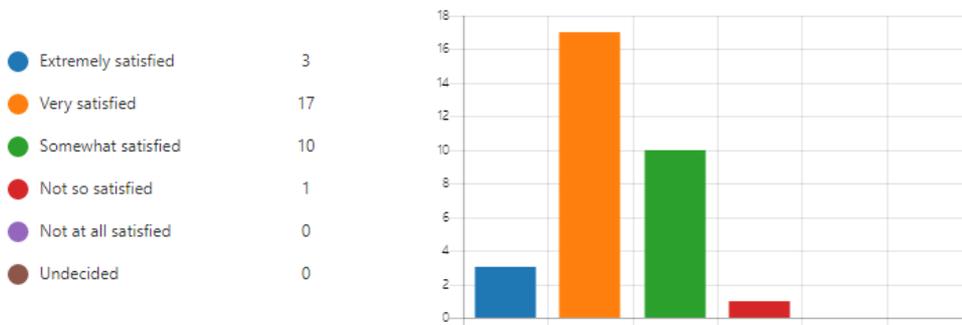
## Satisfaction with IFPA's communication to members

55 % answered "Very Satisfied"

32% said "Somewhat satisfied"

10% "Extremely satisfied"

3% "Not so satisfied"



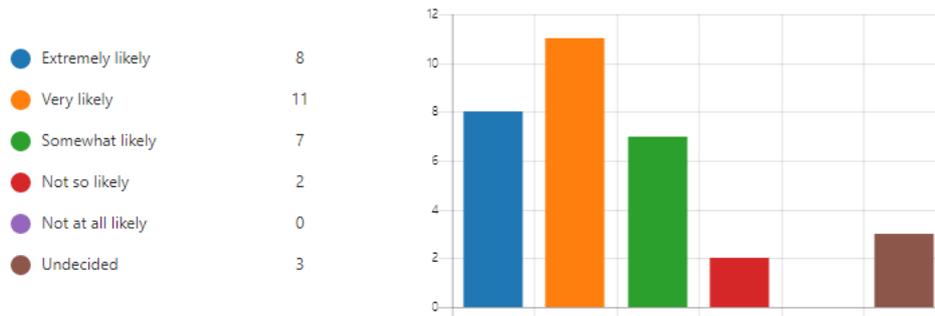
### IFPA Response

IFPA is happy to have seen an increase in engagement through our communication platforms and we happily encourage all IFPA Members to follow IFPA's channels on social media as well as following other IFPA Members and continue connecting and building a strong and visible online community.

# Training opportunities

## IFPA Webinar series

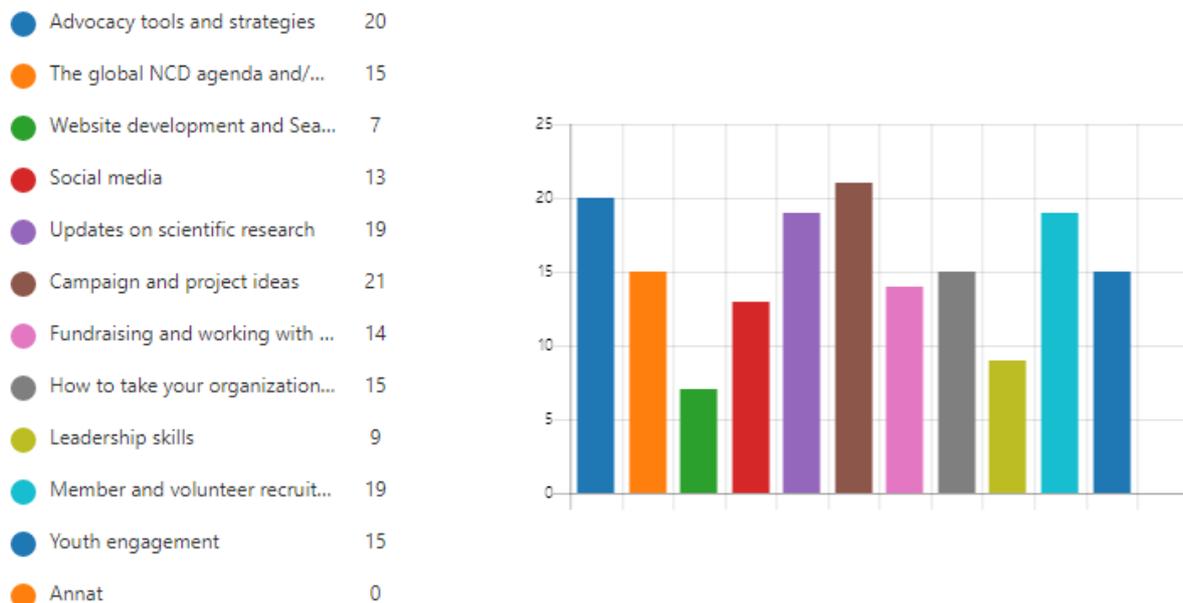
When asked how likely they are to join an IFPA webinar, 61% responded they are extremely or very likely to join.



## Requested topics for workshops or webinars

The most requested topics members would like to learn more about through workshops or webinars were:

1. Campaign and project ideas
2. Advocacy tools and strategies
3. Updates on scientific research AND Member and volunteer recruitment



Poll options in order: Advocacy tools and strategies, The global NCD agenda and/or the UN sustainable development goals, Website Development and Search Engine Optimization, Social Media, Updates on scientific research, Campaign and projects ideas, Fundraising and working with sponsors, How to take your organization to the next level, Leadership skills, Member and volunteer recruitment, Youth engagement, Other.

## **IFPA Response**

We are grateful for the participation and engagement with the webinar series throughout 2019 and 2020. During the 2019 series, all three top requested topics were covered in webinars (recordings available to view for IFPA Members, contact the secretariat if interested). We welcome all IFPA Members to continue joining our webinar series and encourage members to share the invitations to other functionaries within your associations, so more can benefit from these opportunities.