



INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

IFPA Stigmatization and Discrimination Survey

The purpose of the survey

This survey is being carried out by IFPA and its member associations to investigate and map how stigma and discrimination affect people with psoriatic disease all over the world. The results of the survey can then be presented, in part or in full, to psoriasis stakeholders, to the WHO and UN, policy makers and health care professionals, as well as the media and public on local, national and global levels.

It is of great importance that IFPA and its members are able to show how this difficult disease impacts its sufferers both in the private and public domain, and that, in some instances, their human rights are being violated.

How to perform the survey

IFPA asks that its member associations conduct the survey in any way they see fit, as long as the results are made accessible to IFPA and whomever IFPA authorizes to take part of the survey results.

The survey can be conducted via post, e-mail, a website, by personal interview, telephone, text messaging or any other media; the important part is that it is carried out in a way that ensures the privacy and integrity of the respondents. It is also vital that the respondents understand that their answers will be used for the purposes stated above, and that they give their consent to this (for example by checking/clicking a box or by written statement).

It must also be clearly corresponded to the respondents that the experiences have to be strictly first-hand, not hear-say. The answers can be completely anonymous, but we encourage you to ask for contact information should it be necessary to obtain more information or clarification of details, and also to ensure against duplicates. Clear definitions on the terms stigmatization and discrimination should be included in or visible in conjunction with the questionnaire.

How will the results be presented?

The results of the survey will be presented by IFPA in connection with the 3rd World Psoriasis & Psoriatic Arthritis Conference in June 2012, as part of its theme – “Psoriasis – a global health challenge”. Parts of the survey may be presented prior to this. The survey ties into both the theme for WPD 2011: “Let’s talk about psoriasis - and take action” as well as the theme for WPD and the Conference in 2012: “Psoriasis – a global health challenge”.



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Timeline

As this survey is an important part of World Psoriasis Day 2011, we ask that you gather as much information as possible between now and October 29, 2011, as any preliminary results can be successfully used in gaining local and national media attention for World Psoriasis Day. The absolute deadline for the survey is **December 31, 2011**.

Benefits of the survey – why it is well worth the effort

1. We can use the information on an international level by presenting the results to the United Nations and the WHO, strengthening the IFPA Strategy and global campaign for worldwide psoriasis recognition.
2. At a national level you can use the information when petitioning Ministries of Health/Social Affairs/Work and Education, and other policy makers, to improve the conditions for people with psoriasis in your country.
3. At a local level these issues can be used as a base for discussions with policy makers, Boards of Education, business owners and other employers to educate them on the many difficult aspects of living with psoriasis, and so hopefully creating a better environment for people with psoriasis in schools and daycare, at the work place, and in both communal and social settings.
4. At all levels we can use the facts, figures and compelling stories to gain media attention and reach out with our key communication messages.
5. Lastly, and most importantly – we give a voice to those who might otherwise go unheard.

The survey – step by step

1. Read through the survey carefully and translate it into your local language – make sure to include definitions of the words “stigma” and “discrimination” so that it is easy for the respondents to understand the distinction.
2. Decide on how the survey shall be carried out. How can you reach as many people with psoriasis as possible in your country with the survey? Contact your sponsors/corporate partners as well as other partners, such as medical societies, to see if they can help in any way – for instance with funding, marketing and/or spreading the survey to psoriasis patients.
3. Set a date for when you need the results. Make sure to allow enough time for the results to be collected, counted and translated into English, so that IFPA receives the results at the latest December 31.
4. Choose the stories that you feel best represent the stigmatization & discrimination situation in your country/region, and translate them into English. (Note: You do not have to translate all the case stories you receive, what is important is to try and show how these problems manifest themselves in your area.) Please try to ensure that the chosen stories can in some way be verified and that they are told first-hand.
5. Send the statistics and the stories to ifpa@pso.se. Use the enclosed Excel-file for the statistics part of the survey. Name the e-mail “Survey”.

Thank you for your kind cooperation!



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Questionnaire

1. Have you ever experienced stigmatization of some kind because of your psoriasis?

- Yes
- No

Please indicate in which area/s you have experienced stigmatization (several areas may be indicated):

- School
- Work
- Family and social relations
- Health care
- Public* or private† amenities

If yes, please provide example/s of this in as much detail as possible.

2. Have you ever been discriminated against because of your psoriasis?

- Yes
- No

Please indicate in which area/s you have experienced discrimination (several areas may be indicated):

- School
- Work
- Family and social relations
- Health care
- Public* or private† amenities

If yes:

- a) Please provide example/s of this
- b) Did you or anyone affiliated with you take any action as a result of the discriminating act, such as legal action, contacting the media, addressing local or national politicians, contacting your local or national psoriasis association? If yes, please explain what action was taken, by whom, and with what result (if known at this time).

You can be completely anonymous, but we would appreciate the possibility to contact you if we need more information. If so, please provide your contact information below. All information will be handled confidentially and will not be used for any other purpose.

Name:

E-mail:

Tel.:

- I understand that the results of this survey can and will be used in aggregated and anonymous form by [insert name of national association] and the International Federation of Psoriasis Associations in any way that they see fit.

Thank you for your valuable contribution!

*Such as communal swimming pool, bath house, recreation area, and other.

†Such as café, restaurant, gym, spa, and other.



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