

IFPA Global action for WPD 2011

IFPA Stigmatization and Discrimination Survey

- Gathering stories on how the human rights of people with psoriasis are being violated all over the world through stigmatization and discrimination
- Help them talk, so we can take action!
- Connects WPD theme 2011: "Let's talk about psoriasis – and take action" with the theme for both WPD and WPC 2012: "Psoriasis – a global health challenge"



Stigma:

Problems of knowledge (ignorance), attitudes (prejudice) and behaviour (discrimination). Stigma is a mark or sign of disgrace usually eliciting negative attitudes to its bearer.

Thornicroft et al, British Journal of Psychiatry (2007)

[S]tigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them.

Link & Phelan, Annu. Rev. Sociol. (2001)

[A] dynamic process of devaluation that 'significantly discredits' an individual in the eyes of others.

Goffman (1963) quoted in UNAIDS/05.05E (2005)



Discrimination:

Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatized. [...] Any form of arbitrary distinction, exclusion, or restriction affecting a person [...] irrespective of whether or not there is any justification for these measures.

Discrimination can occur on many levels:

Family and community settings

Institutional settings

At a national level

Discrimination is a violation of the UN universal human rights!

UNAIDS/05.05E (2005)



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Purpose of the survey

- Investigate and map how stigma and discrimination affect people with psoriatic disease all over the world
- Show how this difficult disease impacts its sufferers both in public and private domain
- Present results to the UN, WHO, policy makers, health care professionals, the media and the public on local, national and global levels



Presentation of results

- Results to be presented at the 3rd World Psoriasis & Psoriatic Conference in Stockholm, June 2012
- Preliminary results and/or parts of the survey may be presented prior to this



Why it will be worth the effort

- 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 psoriasis recognition.
- 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.
- At a local level this information 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.



Why it will be worth the effort

- At all levels we can use the facts, figures and, especially, the compelling stories to gain media attention and reach out with our key communication messages.

And most importantly:

- We give a voice to those who might otherwise go unheard.



How to perform the survey

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



How to perform the survey

- Experiences must 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.
- Clear definitions on the terms stigmatization and discrimination should be included in, or visible in conjunction with, the questionnaire.
- Results of the survey must be made accessible to IFPA and whomever IFPA authorizes to take part of the survey results.



Timeline

- “Soft” deadline, WPD 2011 (October 29) – gathered information can be used locally / nationally in gaining media attention for WPD
- “Hard” deadline, December 31, 2011. Complete information sent to IFPA.
- Information collated by IFPA.
- Preliminary results presented mid-term 2012
- Results presented at 3rd WPC & later on WPD



Questionnaire

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

Please indicate in which area/s you have experienced stigmatization:

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.

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

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



Questionnaire

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

Please indicate in which area/s you have experienced discrimination:

School

Work

Family and social relations

Health care

Public* or private† amenities

If yes:

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).



Questionnaire

You can be completely anonymous, but we would appreciate the possibility to contact you if we need more information. If so, please provide contact information.

Thank you for your contribution!



Thank you!



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