

IFPA

INTERNATIONAL FEDERATION OF PSORIASIS ASSOCIATIONS

NEWSLETTER

No.3 2011

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ENCLOSED DOCUMENTS:

IFPA Stigmatization & Discrimination Survey (Two documents)

IFPA Stigmatization & Discrimination Survey presentation

Reports and presentations from the member meetings can be found on the IFPA website under [Activities](#).



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OF PSORIASIS ASSOCIATIONS

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Dear IFPA Friends,

First of all we would like to warmly thank all the members, speakers and supporters who attended the IFPA Member meetings in Amsterdam! It was a wonderful experience to meet you all and to learn more about your hard work in making the world a better place for people with psoriasis.

For those of you who weren't able to make it this year, know that you were sorely missed and that we hope to see you next year in Stockholm, instead!

In this newsletter you will find a short report from the Amsterdam meetings, as well as information about the IFPA Stigmatization & Discrimination survey—a most important action that we hope all our members and partners can take an active part in.

Wishing you all a very pleasant summer,
IFPA Executive Committee & Secretariat



IFPA Member meetings June 17-19

On June 17-19 IFPA arranged three days of member meetings which gathered participants from all over the world to hotel NH Schiphol just outside Amsterdam in the Netherlands.

The presentations made during the meetings can be found on IFPA's website, under Activities.

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IFPA Informal Member's Meeting, June 17

The meeting was held from 15.00 – 19.00, Friday June 17, 2011. 47 IFPA Member representatives from 30 IFPA countries participated in the meeting. The IFPA Informal Member meeting was opened by Lars Ettarp, President of IFPA, who also gave a presentation with a report of IFPA's activities and development during 2010. He also warmly welcomed the new IFPA Members: Portugal, Colombia, Puerto Rico, Turkey and Venezuela to IFPA. Treasurer of IFPA, Joachim Barth, presented the economy of IFPA and gave an overview of the financial situation and also presented the collaborative partners of IFPA. Annika Rastas and Barbra Bohannan from the IFPA Secretariat gave an introduction to the upcoming IFPA activities and next steps that are planned, and presented the IFPA calendar for 2011 – 2013.

A report of the development work with the upcoming 3rd World Psoriasis & Psoriatic Arthritis Conference 2012 was then presented by Lars Ettarp and Joachim Barth.

IFPA's regional development was presented in the form of regional reports by Silvia Fernandez Barrio for LATINAPSO, Josef de Guzman for PsorAsia, Ottfrid Hillmann for EUROPSO and by Hoseah Waweru regarding the development of the African region. Short reports from the IFPA Member associations were given by all 30 countries represented at the meeting on the theme "the greatest suc-

cess and challenge in your organisation during the past year".



Ragnar gives the Norwegian report

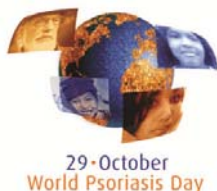
World Psoriasis Day Supporters Training Meeting, June 18

The WPD Supporters Training Meeting was held as a full day meeting Saturday June 18. 61 persons from 30 IFPA member countries and collaborative partners to IFPA participated. The meeting was opened by Lars Ettarp, President of IFPA, with an IFPA Advocacy report and strategy for 2011-13, specifically regarding the WHO. Josef de Guzman, Chairman of the WPD Steering Committee, continued with a report and presentation of the World Psoriasis Day activities 2010. The WPD concept 2011 with the theme: "Let's talk about psoriasis – and take action" with key communication messages and suggested advocacy actions were introduced and explained by Barbra Bo-

hannan from the IFPA Secretariat. Josef de Guzman then gave a presentation of ideas for awareness-raising activities and events. The meeting continued with a part dedicated to IFPA's supporters and collaborative partners. This was a unique opportunity to meet the pharmaceutical companies who are supporting WPD on a global level and to learn more about how collaboration can be done also on a national level. Abbott, Janssen and LEO Pharma each held presentations where they introduced their companies and gave their view on partnership with patient organisations on both a global and national level.

An introduction to the IFPA Survey of stigmatization and discrimination of people with psoriasis was held by Barbra Bohannan. IFPA then had the pleasure of welcoming the first of the eminent guest speakers for the day: Dermatologist Patrick Kemperman, Dept of psychodermatology Erasmus MC, Rotterdam. Dr Kemperman held a presentation about psychodermatology with focus on psoriasis in relation to stigma and discrimination.

After lunch the floor was given to the next guest speaker, Anna Korving, healthcare public relations and educational media specialist, who held a most appreciated presentation about easy and effective ways to reach and engage the media with the focus of nonprofit organizations with low budgets. Many tips and tricks on how to attract the media were shared with the audience.



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The afternoon continued with two workshops, where the participants could discuss the subjects in smaller groups. The first workshop was on the theme Stigmatization and Discrimination and the groups shared thoughts and experiences on how to prevent stigmatization and discrimination. The second workshop focused on media and events under the theme "Raising awareness of WPD – how to use media and other channels." The groups were asked to present the most successful WPD activity of their own organisation and also come up with new ideas for WPD activities. All the results from the workshops can be found in the attached document that summarizes the results presented by the groups. The WPD Supporters Training meeting was highly appreciated and the participants found the content of high educational value to bring home and share in their own organisations.



Kuzma, Monika and Vojtech were the representatives from Ukraine, Poland and the Czech Republic

The introduction of the new activity with the IFPA Stigmatization and Discrimina-

tion Survey was warmly welcomed and the IFPA Member representatives found this as an interesting and important activity which can be conducted in all IFPA Member countries and where the result will be of great value on a local, national and global level. It is an activity that encourages and supports the theme of WPD 2011 "Let's talk about psoriasis and take action" and that also open the doors and builds a platform for the upcoming theme of WPD next year "Psoriasis – a global health challenge".

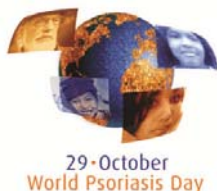
Under the spotlight meeting, June 19

The Under the Spotlight Information Meeting was held 08.30 – 12.30, Sunday June 19. The meeting was an integrated part of the IFPA Informal Member meetings 2011. 61 persons from 30 IFPA member countries and collaborative partners to IFPA participated. The meeting was opened by Lars Ettarp, President of IFPA and the Under the Spotlight 2nd International Documentary from 2010 was showed to the audience. The viewing of the film was followed by an introduction by IFPA to the UTS program and progress presented by Annika Rastas & Barbra Bohannan from the IFPA Secretariat. The Abbott view of the Under the Spotlight Program was given by Camilla Lauritzen, Abbott International. The next point of the agenda was "Guidance from the Director's chair" were International film director Alex Wykes gave a presentation about creating the Under the Spotlight documen-

taries where he also provided some valuable tips and advices to the teams in the process of making the films. The meeting program continued with an appreciated presentation from Denmark who have been part of the Under the Spotlight program from the very beginning:

"Denmark – 2009 : 3 years with UTS: An evolutionary perspective". Then Spain entered the stage and presented the successful implementation in their country "Spain - 2010 - A campaign that impacted the 3Ms in just one year". The newest part of the UTS program and the regional pilot version of the project in Latin America was presented by Silvia Fernandez Barrio "LATINAPSO/Argentina – 2011 - BREAKING NEWS: UTS arrives in Latin America!" The meeting was concluded by showing the Under the Spotlight trailer from 2010 that has been successfully used in various activities by IFPA and shown for both WHO and at the IFPA Satellite Symposium that was arranged in October 2010 at the EADV Congress.

The Under the Spotlight meeting in Amsterdam was highly appreciated of both IFPA members that is already in the program, but also by the new IFPA members and those who have not yet entered the project for various reasons. The striving and work for making the UTS program a global program and open up for all IFPA members to participate and be part of the successful development was well met from all stakeholders.



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IFPA Stigmatization & Discrimination Survey 2011

Stigmatization and discrimination remain huge problems for many people with psoriasis. As we feel that it is of the utmost importance that we bring these issues to light both at a national and international level, IFPA now asks all members to please participate in the IFPA Stigmatization & Discrimination Survey. The survey is made up of two main questions and the respondents will also be asked to share their personal experiences of being stigmatized and/or discriminated against. The questionnaire provided is an example of how it could look, but feel free to add /include any texts, definitions and/or examples that you believe might help the respondents understand more exactly what we are asking them.

Regarding the distinction between stigmatization and discrimination, one example can be visiting a public swimming pool. If you visit such a place and people behave strangely towards you, perhaps staring, whispering behind your back or pointing a finger at you—that is *stigmatization*, something that points you out as not being part of the norm, not belonging, and the consequent feelings of shame and anxiety that comes with this type of isolation of one individual or group. If you on the other hand would be denied access to the pool by officials, because you have psoriasis, that would be a case of *discrimination*. As stigmatization often leads to discrimination, it is

important to try and map what the biggest problem areas are in your society, so that you can move forward and contact the relevant policy makers, business owners and others and point out the need for legislation, information and education.

As this has the potential of being a very strong and useful tool in our work, both at a local and at a global level, we ask our member associations to please do all they can to participate in this survey.

Please see the enclosed documents for more information. A Spanish version of the survey will be available at the IFPA Secretariat. Many thanks to AEPESO for helping us with translating the survey into Spanish!

New member—welcome Venezuela!

It is our great pleasure to announce that Venezuela is the newest IFPA member, through AVEPSO, the Venezuelan Association of Psoriasis.

President of the association is Luisa Herrera Gómez and we warmly welcome her and AVEPSO to the IFPA family, that now has 43 members!

Membership fees 2011

Dues are based on each organization's membership size. The dues structure is as follows:

Up to 100 members USD 25.00
(minimum fee)
101-250 USD 50.00

251-500 USD 100.00
501-999 USD 200.00
1,000-4,999 USD 300.00
5,000-9,999 USD 500.00
10,000-14,999 USD 700.00
15,000-19,999 USD 1,000.00
20,000-24,999 USD 1,200.00
25,000-29,999 USD 1,400.00
30,000-34,999 USD 1,600.00
35,000-39,999 USD 2,000.00
More than 40,000 USD 2,500.00
(maximum fee)

Bank fees are to be paid by sender. Not by IFPA. Do not send bank checks – the handling and cashing of checks are very expensive for IFPA!

Please transfer your membership fees to the IFPA account in Sweden:

Nordea Bank Sverige AB
Box 7434
103 93 Stockholm
SWEDEN

Account nr: 4104 13 07825
Include the following IBAN number and Swift/BIC code on your money order:

IBAN: SE37 3000 0000 0410 4130 7825

Swift/BIC code: NDEASESS

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If you have any news that you would like to share with our readers all over the world, please contact us at ifpa@pso.se.

