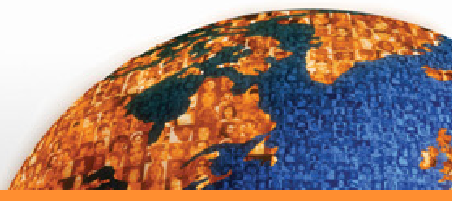
INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

IFPA ACTIVITY REPORT
2014

INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

Worldwide unity for people
living with psoriasis



IFPA ACTIVITY REPORT 2014

Dear friends,

Together we can look back on a historic year for the global psoriasis community. In May the World Health Assembly adopted a resolution on psoriasis, for the first time ever, opening doors and creating possibilities for our members and all stakeholders within our disease area as never before. The year 2014 also marked the 10th anniversary of World Psoriasis Day—the largest psoriasis awareness campaign there is!

Without our member associations, partner organizations, industry partners and other stakeholders neither the resolution nor World Psoriasis Day would be a reality. It is thanks to your efforts, your encouragement and your support that we can now truly all say that we have helped build a better world for people with psoriasis. We are also so very grateful to all the state actors and WHO/UN Permanent Missions who have guided and supported us on the long, but exciting, road towards global recognition of psoriasis as a serious, chronic noncommunicable disease.

But it doesn’t end there. Now we must continue to work for the national and regional implementation of the WHO psoriasis resolution and we shall always strive to do all that we can to raise awareness of, and thereby hopefully alleviate, the challenges that people with psoriasis encounter in their daily lives. Thank you for helping us with this important work!

We have also been participating in, or leading, a number of other activities, and we hope that you will find this activity report of interest.

On behalf of the IFPA Executive Committee and Secretariat we wish to thank you all for your continued commitment to the psoriasis community and for the trust that you have put into us as we endeavor to improve the lives of more than 125 million people with psoriasis.

Your friends,

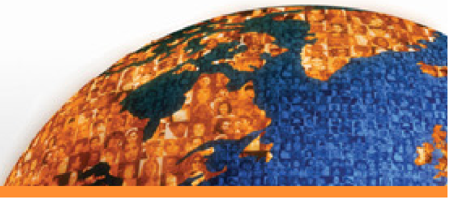
Lars Ettarp
President
IFPA

Hoseah Waweru
Vice President
IFPA

Barbra Bohannan
Head of Operations and Strategic Communications
IFPA Secretariat

INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

Worldwide unity for people living with psoriasis



International Federation of Psoriasis Associations
Activity report 2014

Purpose:

The purposes for which the Federation is formed are to advance efforts to lessen the suffering of people with psoriasis and to improve methods of treatment and research for finding the ultimate cause and cure of the disease. In order to realize its purposes, the Federation shall:

a) Represent the interests of its member associations in international forums such as the World Health Organization, the World Congress of Dermatology and international psoriasis symposia. IFPA shall also in close cooperation with other relevant international organizations organize international conferences, symposia and other events related to psoriasis/psoriatic arthritis, e.g., The World Psoriasis Day.

b) Provide advice and consultation on the problems associated with psoriasis to member organizations or other communities and organizations worldwide.

c) Provide the basis for closer liaison and the free exchange of information among psoriasis organizations and related organizations worldwide.

d) Encourage and assist the establishment of new national organizations of people with psoriasis.

e) Contribute to the improvement of the quality of health and social life of people suffering from psoriasis and psoriatic arthritis.

f) The Federation shall not supersede or contravene the autonomy of national or other member organizations.

Goals:

IFPA's goals as an organization are to:

SECURE universal access to treatment, to raise awareness and understanding of psoriasis and to change the treatment paradigm and end discrimination

GROW the IFPA national psoriasis association membership base to encompass all representative psoriasis associations

COOPERATE and become active partners with all relevant psoriasis and psoriatic arthritis stakeholder groups including medical associations, pharmaceutical companies and other relevant organizations

INITIATE and communicate all relevant market and clinical research in psoriasis, psoriatic arthritis and related diseases.

Governance:

IFPA is governed by the General Assembly (GA) of its Full members. The meeting of the General Assembly is held every three years, with the next to be held in 2016. In furtherance of the objectives of the Federation, the Executive Committee (EC) shall implement IFPA policies and management between official General Assembly meetings.

The IFPA EC may also call an Extraordinary General Assembly meeting, either as a physical meeting or by postal/ online vote, should any urgent amendments to or clarifications of the IFPA Constitution or Bylaws be deemed necessary. In March of 2014 such a meeting was called and an online vote was held on a Bylaw proposed by the IFPA EC. The Bylaw, concerning national representation, was adopted by the General Assembly by online vote on March 26, 2014. In 2014 the IFPA EC had five meetings, of which four physical and one telemeeting.

Secretariat:

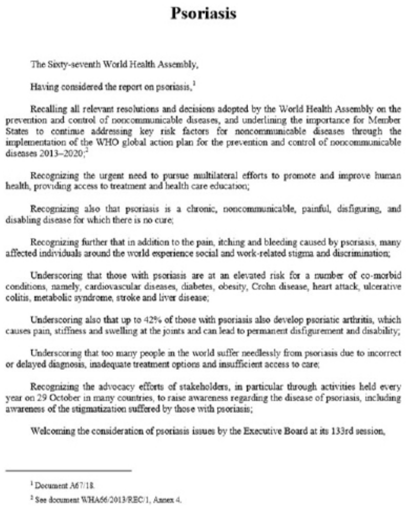
In order to assist the EC in its management of the Federation and its projects, a Secretariat was formed in 2007, and placed in Stockholm, Sweden. The Secretariat is managed under agreement with the Swedish Psoriasis Association, Psoriasisförbundet, and shares its offices. In 2014, the Secretariat was comprised of three permanent members of staff and one temporary member of staff.

Main activities 2014:

The theme for World Psoriasis Day 2014: “Building a better world for people with psoriasis” is without doubt a strong reflection of the main IFPA vision of a world without human suffering from psoriasis. As our organization represents millions of people all over the world, it is crucial that we develop a true understanding of their unmet needs; that we get a better picture of the demographics of psoriasis and that we, as an organization, move the agenda forward to meet the challenges people with psoriasis face, as individuals and as a community.

To reflect this, the following four main activities/projects acted as the focus of IFPA’s efforts during 2014:

- The IFPA Advocacy project
- World Psoriasis Day 2014
- The Global Psoriasis Atlas
- The 4th World Psoriasis & Psoriatic Arthritis Conference 2015



Psoriasis

The Sixty-seventh World Health Assembly,

Having considered the report on psoriasis,[1]

Recalling all relevant resolutions and decisions adopted by the World Health Assembly on the prevention and control of noncommunicable diseases, and underlining the importance for Member States to continue addressing key risk factors for noncommunicable diseases through the implementation of the WHO global action plan for the prevention and control of noncommunicable diseases 2013–2020;[2]

Recognizing the urgent need to pursue multilateral efforts to promote and improve human health, providing access to treatment and health care education;

Recognizing also that psoriasis is a chronic, noncommunicable, painful, disfiguring, and disabling disease for which there is no cure;

Recognizing further that in addition to the pain, itching and bleeding caused by psoriasis, many affected individuals around the world experience social and work-related stigma and discrimination;

Underscoring that those with psoriasis are at an elevated risk for a number of co-morbid conditions, namely, cardiovascular diseases, diabetes, obesity, Crohn disease, heart attack, ulcerative colitis, metabolic syndrome, stroke and liver disease;

Underscoring also that up to 42% of those with psoriasis also develop psoriatic arthritis, which causes pain, stiffness and swelling at the joints and can lead to permanent disfigurement and disability;

Underscoring that too many people in the world suffer needlessly from psoriasis due to incorrect or delayed diagnosis, inadequate treatment options and insufficient access to care;

Recognizing the advocacy efforts of stakeholders, in particular through activities held every year on 29 October in many countries, to raise awareness regarding the disease of psoriasis, including awareness of the stigmatization suffered by those with psoriasis;

Welcoming the consideration of psoriasis issues by the Executive Board at its 133rd session,

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[1] Document A67/18.

[2] See document WHA66/2013/REC/1, Annex 4.

IFPA Advocacy project (UN/WHO)

The strategic advocacy towards the UN and WHO authorities to gain global, regional and national recognition for psoriasis as a serious noncommunicable, and disabling, disease moved up to the next level as the WHO resolution on psoriasis came up for the vote at the 68th World Health Assembly (WHA) .

In order to expand IFPA’s efforts in this area, the Secretariat was strengthened with a Program Officer for Advocacy and Policy, whose main task was to coordinate and administrate the IFPA Advocacy Project. In order to gain support of the WHO resolution, a number of activities were carried out by IFPA, such as educational online seminars (“webinars”, meetings with State Actors and Non State Actors within the WHO system, frequent stakeholder meetings with patient organizations, medical societies and industry representatives, participation in medical/scientific congresses and conferences and presentations/lectures in varied settings.

Toolkits for different stakeholders were also developed, ensuring that patient organizations and medical societies were informed about the WHO resolution and given resources to advocate for its adoption on a national and regional basis.

A side event at the 68th WHA was also planned and carried out in collaboration with the core sponsor group of the resolution – Argentina, Ecuador, Panama and Qatar. The side event featured expert physicians and patient representatives who were able to share with the WHA delegates the need for recognition of psoriasis as a serious noncommunicable disease. They also informed the public about the phsyical and psychosocial impacts of psoriasis.

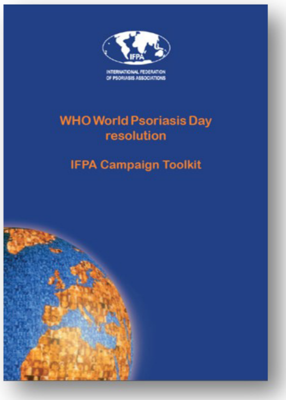
As a result of this side event and IFPA’s advocacy, the WHA finally adopted Resolution 67.9, entitled “Psoriasis.”

World Health Assembly gathering in Geneva.

After the resolution was adopted at the WHA, the IFPA Advocacy project moved into its next phase, focused on the implementation of the resolution. During the remainder of 2014, this entailed ensuring that the IFPA members were given the necessary training, information and resources to advocate for national implementation of the resolution and on how to use it as a platform for national advocacy and policy issues. This was done both by written information but also through presentations and training workshops at the annual IFPA informal member meeting in Frankfurt, Germany.

As IFPA holds Special Consultative status with the United Nations Economic and Social Council (UN ECOSOC), IFPA was also represented at several UN meetings during 2014.

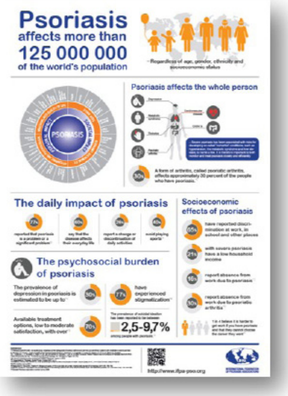
Finally, in 2014 IFPA developed a range of educational and awareness-raising resources for its members - including a Campaign Toolkit, an Infographic poster, a Policy Brief and various Tips for implementing the WHA resolution.



INTERNATIONAL FEDERATION OF PSORIASIS ASSOCIATIONS

WHO World Psoriasis Day resolution

IFPA Campaign Toolkit



Psoriasis affects more than 125 000 000 of the world's population

Psoriasis affects the whole person

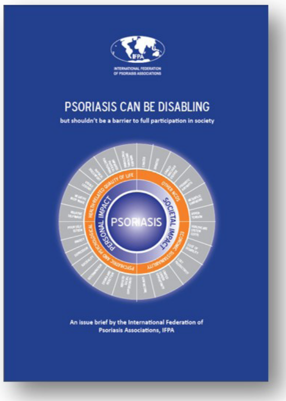
The daily impact of psoriasis

Socioeconomic effects of psoriasis

The psychosocial burden of psoriasis

2,5-9,7%

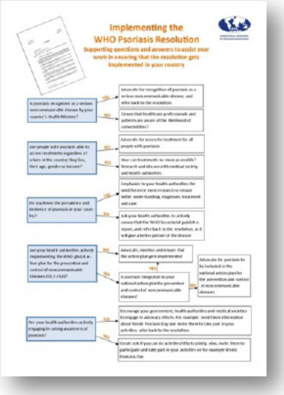
http://www.ifpa-pso.org



PSORIASIS CAN BE DISABLING

but shouldn't be a barrier to full participation in society

An issue brief by the International Federation of Psoriasis Associations, IFPA



Implementing the WHO Psoriasis Resolution

Supporting questions and answers to assist your work in ensuring that the resolution gets implemented in your country

World Psoriasis Day 2014

INTERNATIONAL FEDERATION OF PSORIASIS ASSOCIATIONS

29 October World Psoriasis Day

IFPA global survey – "Building a better world for people with psoriasis"

Which tools do you believe are the most important when building a better world for people with psoriasis? You can choose up to five tools and also leave your own suggestions. Your participation is vital for IFPA and for psoriasis patient associations all over the world to help us identify effective strategies to cope with unmet needs for people with psoriasis.

Thank you for your participation!

IFPA | Contact | Valid until: 2015-05-31 | Legal notice

Netigate - Advanced Surveys Made Simple

The theme for World Psoriasis Day in 2014 was "Building a better world for people with psoriasis". In order to help bring about a better world for people with psoriasis, it is imperative that IFPA as the representative of the global psoriasis community truly understands the unmet needs and challenges of people with psoriasis and what they themselves perceive to be useful tools and methods to improve the situation. IFPA therefore launched an online survey at the annual World Psoriasis Day Supporters Training Meeting in Frankfurt, Germany, in the form of 17 different tools within advocacy, awareness and education.

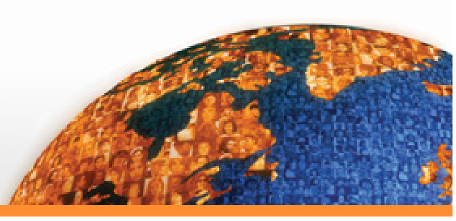
On World Psoriasis Day 2014, IFPA announced preliminary results of the survey in the official World Psoriasis Day press release, showing that the top three tools voted for all concerned the need for education – of the patients, the healthcare professionals and the policy makers. The preliminary results of the survey were closely reviewed by the IFPA EC and have been an important factor in the development of IFPA's Strategic Plan for 2015-2017.

World Psoriasis Day 10th Anniversary

2014 marked the ten-year anniversary of World Psoriasis Day, which was initiated in 2004. Psoriasis patients associations, medical societies, hospitals and other stakeholders were asked to:

1. Choose a photo that illustrated their most successful or inspiring World Psoriasis Day-activity during the ten years.
2. To send the photo to hap00middle@photos.flickr.com.
3. The photo was automatically included in the World Psoriasis Day photo gallery.

To mark and highlight the ten-year anniversary of World Psoriasis Day in social media a global Thunderclap campaign was launched on October 29. The campaign with the World Psoriasis Day messaging reached over 360 000 people. As one of many World Psoriasis Day celebrations a special "birthday" cake was made and was highly appreciated by the attendees at the World Psoriasis Day Training Meeting, held by IFPA in June, 2014.



29•October
World Psoriasis Day

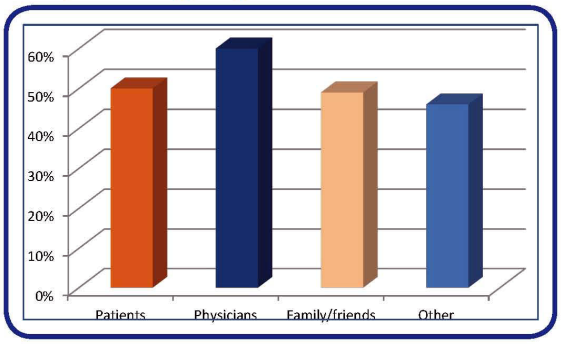
Building a better world for people with psoriasis

Psoriasis
affects more than
125 000 000
of the world's population

– Regardless of age, gender, ethnicity and socioeconomic status

In June 2014, the International Federation of Psoriasis Associations launched an online survey, where people with psoriasis, physicians and friends and family are invited to vote for up to five different tools for building a better world for people with psoriasis. Preliminary results show that the tool deemed as most effective by all respondents is "Educating the patients about treatment options" and the top five tools voted for all concern education. The survey is open until end of May, 2015, and can be found at www.netigate.se/ifpa.

Percentage of votes for "top tool" by respondent group:

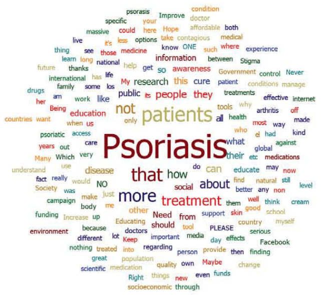


Top 5 tools voted for by all respondents:

- Educating the patients about treatment options - 50%
- Educating the patients about serious comorbid conditions - 42%
- Educating the patients about psoriasis as a serious, inflammatory, noncommunicable disease - 39%
- Educating doctors and other healthcare professionals about treatment options - 32%
- Educating policy makers about the socioeconomic and psychosocial impact of psoriasis - 32%

- Respondents from 90 countries have participated in the survey
- 60% of the responding physicians found it valuable that the patients are educated about treatment options
- The largest group of respondents (68%) are psoriasis patients
- The survey features 17 suggested tools within advocacy, awareness and education

90 countries represented in the survey



Most common suggestions for other tools:
"supportive initiatives for psoriasis patients"
"more research be conducted on the treatment strategy regarding psoriasis"

The Global Psoriasis Atlas project

In 2014, IFPA, the International League of Dermatological Societies (ILDS) and the International Psoriasis Council (IPC) formed a partnership to develop a Global Psoriasis Atlas to fill the gaps in the understanding of the prevalence and burden of psoriasis. While studies over the recent years have contributed to an improved understanding of psoriasis, there are still significant gaps in knowledge related to the epidemiology of psoriasis and trends in incidence over time. The project's initial task therefore will be to establish a credible and reliable database recording the prevalence of psoriasis worldwide and by country.

While gathering detailed information on prevalence, the initiative will undertake to build a framework for improved collection of data on the burden of psoriasis. In the long-term, the aim is to look at incidence over time and the burden associated with comorbidities as well as the economic impact of psoriasis.

The first meeting of the GPA Steering Committee was held in IFPA's offices on July 7, 2014, where IFPA was represented by Lars Ettarp and Barbra Bohannan.

The 4th World Psoriasis & Psoriatic Arthritis Conference 2015

IFPA has been organizing the World Psoriasis & Psoriatic Arthritis Conferences since 2006 and the next one will be held in Stockholm, Sweden July 8-11, 2015. In 2014, IFPA marketed the conference heavily at a number of international meetings, such as the EADV Congress in Amsterdam, the Netherlands and at the "Psoriasis: Gene to Clinic" meeting in London, UK, and also through a number of direct email marketing campaigns and through scientific journals and websites.

In 2014 IFPA also led the development of the Complementary program of the conference, through its Vice President Hoseah Waweru, who acts as Chairman of the Complementary Program Committee. Barbra Bohannan, acting as Secretary of the conference's Scientific Executive Committee and also as liaison between the SEC and the Organizing Committee, administrated the development of the conference program and interactions with faculty.

Collaborations

In 2014 IFPA collaborated with EUROPSO, the National Psoriasis Foundation and The Arthritis Society Canada on a joint statement on unmet needs of people with psoriasis and psoriatic arthritis. The statement is available for download from the IFPA website.

Memberships

IFPA is a Full member of the International Alliance of Patients' Organizations (IAPO) since 2012 and a member of the Noncommunicable Diseases Alliance Common Interest Group since 2011.

Corporate Partners

In 2014 IFPA received project sponsorships from the following corporate partners: AbbVie, Amgen, Celgene, Janssen, LEO Pharma, Lilly, Novartis and Pfizer.

Internal IFPA Meetings

IFPA Member Meeting in Frankfurt, Germany, in June 2014

in June, IFPA members from all over the world gathered for the IFPA Informal member meeting which was this year held in Frankfurt, Germany. The IFPA Executive Committee, Secretariat and members were especially happy to welcome our new members from Russia, for whom this was the very first IFPA meeting.
The meeting commenced with everyone, especially the new members and representatives who hadn't before participated in an IFPA meeting, being welcomed by IFPA President Lars Ettarp. After the welcome, he proceeded to present the IFPA Activity report from 2013, which was indeed a momentous year, as the resolution on psoriasis was adopted by the WHO Executive Board, as IFPA held a very successful General Assembly, and as it also saw the conclusion of the award-winning Under the Spot-light project. Josef de Guzman, IFPA's Treasurer then presented the financial report for 2013.

After this, it was the IFPA region's turn to present their 2013 activities. Silvia Fernandez Barrio spoke about the many political and public activities in Latinapso, Hoseah Waweru presented the actions taken in the African region towards strengthening the relationship between the psoriasis associations and the dermatological societies, Josef de Guzman spoke about the many and varied activities throughout the Asia Pacific region and Celia Marin from EUROPSO concluded with a report covering, among other things the first EUROPSO youth round table and the event at the European Parliament.

After the IFPA regional members had presented, a few member associations who don't belong to an official region were given the floor to present briefly, so that the delegates could learn more about the main activities during 2013 from members in Canada, the US, Russia, Chile, Colombia, Mexico and El Salvador.
Barbra Bohannan, IFPA Head of Operations and Strategic Communications, presented the main present and upcoming activities of IFPA, with focus on the Global Psoriasis Atlas, which is a joint project with the International League of Dermatological Societies and the International Psoriasis Council and the 4th World Psoriasis & Psoriatic Arthritis Conference in 2015.

One of the highlights of the day's program was the presentation by Kathleen Gallant, IFPA Secretary, and Susanne Hedberg, IFPA Program Officer Advocacy & Policy as they shared the journey of the psoriasis resolution from its conception to its adoption by the WHO 67th World Health Assembly. The presentation was followed by a Q & A session where the delegates were able to ask questions about the resolution and its implementation. After lunch, the delegates were split into two groups to attend two work-shops running in parallel. One work-shop, headed by Josef de Guzman, focused on organizational development and the need for mission statement to live and work by and how to identify different areas for interaction and collaboration.

IFPA members from all over the world gathered at the IFPA Member Meeting in Frankfurt, Germany, in June 2014.

The other workshop was led by Kathleen Gallant and Susanne Hedberg and served as a training workshop on how to approach government officials, such as Ministers of Health. The workshop featured two scenarios—one where the representatives from the patient association are poorly prepared and have little understanding of political protocol (a special thank you here to our dear friends Evans, Antoinette, Christine and Riika for their outstanding performances), followed by one where the representatives are well prepared and well versed in how to conduct a proper meeting with a policy maker. After the workshops, two very inspiration and important projects were presented. The first, the IDEOM project, was presented by Dr. Andy Robertson from the National Psoriasis Foundation. IDEOM is a patient-centered project focused on outcomes to enhance research and treatment of psoriasis and other dermatological conditions.

Lars Ettarp then presented the Swedish Psoriasis School, which has proven to be a very effective instrument to improve the quality of life for people with psoriasis and psoriatic arthritis. The program features specialists, nurses, dieticians and physiotherapists to ensure a holistic approach and has been a great success in a number of different locations in Sweden. After this presentation Lars Ettarp concluded the meeting for the day.

World Psoriasis Day Supporters Training Meeting

On Sunday IFPA welcomed the IFPA members and other supporters of World Psoriasis Day to the annual World Psoriasis Day Supporters Training Meeting.

The meeting was opened by Lars Ettarp, and started with a presentation of the 2013 World Psoriasis Day activities by Josef de Guzman, Chair of the World Psoriasis Day Steering Committee. The theme for World Psoriasis Day 2014” Building a better world for people with psoriasis” was then elaborated on in a presentation by Barbra Bohannan. The main campaign for this and next year was the IFPA online survey, where respondents will be able to vote for which” tools” they find the most effective in building a better world for people with psoriasis. All attendees were asked to share the link to the survey in all their channels—in newsletters, on their respective websites and in social media— it was explicitly stated that IFPA need to hear what people from all over the world wish for IFPA as well as the regional and national psoriasis associations to focus on in their strategic work for the future! Preliminary results of the survey were to be presented on World Psoriasis Day 2014, and the final results at the world conference next summer, in 2015. The importance of creating awareness for the resolution on and around World Psoriasis Day was also highlighted.

IFPA also had the pleasure to present the theme for World Psoriasis Day 2015, “Hope. Action. Change”, as in “Have hope, take action, make a change”. After this presentation, the World Psoriasis Day supporters present at the meeting were able to present themselves. After a break the psoriasis treatment symposium followed, with an introduction and historical overview by Lars Ettarp. Hoseah Waweru then discussed the challenges of treating psoriasis in developing countries and that cost-effective treatment is possible with educated doctors and patients communicating openly with each other about treatment goals and treatments available. The patient associations play a big part in patient education and empowerment.

Dr. Andy Robertson then gave an overview of the psoriasis treatments that are new to market or in the pipeline, such as the PDE-4 inhibitors (”small molecules”) and biologics targeting IL-17 and IL-17A. He also discussed both efficacy and safety as issues of great importance for the patient organizations to engage themselves in and advocate for. Barbra Bohannan held a brief presentation on biosimilars, which are essentially biologics that will be coming to market based on treatments whose patents have expired. The International Alliance of Patients’ Organizations, IAPO, have created an excellent tool kit for patient organizations, and IFPA would like to encourage all members to download this tool kit and educate themselves and their members on the issue of biosimilars. The symposium concluded with Silvia Fernandez Barrio talking about a successful case in Argentina where the patient association had helped an individual receive proper treatment, and Evelyn de Aguirre from El Salvador presented the important work that they have done to provide light therapy treatment to people with psoriasis in El Salvador.

After lunch two parallel workshops were held, with the delegates split into two groups, just as the previous day. One workshop focused on the World Psoriasis Day theme for 2014," Building a better world for people with psoriasis", and was led by Josef de Guzman and Annika Rastas, IFPA Director Global Corporate Relations and Project Development. This workshop was highly interactive and let the delegates use their creativity to come up with good examples on how to communicate the theme as efficiently as possible and sui-table activities for World Psoriasis Day. The other workshop was designed to assist the member organizations in creating and disseminating policy papers on their most important issues. IFPA's own policy paper" Psoriasis is a serious disease deserving global attention" was used as an example by workshop facilitators Barbra Bohannan and Susanne Hedberg.
After a brief summary of the workshops, Lars Ettarp concluded the meeting by giving an exposé of the ten years of World Psoriasis Day and how it has grown from being an isolated activity in a handful of countries to the global awareness campaign it is today.

EXTERNAL MEETINGS

IFPA Media Event at the 72nd meeting of the AAD

The first major congress of the year was the annual meeting of the American Academy of Dermatology (AAD) in Denver, Colorado. IFPA was represented by Lars Ettarp and Kathleen Gallant who had the opportunity to meet with a number of different stakeholders from all over the world to discuss support for the psoriasis resolution. On the last day of the congress, IFPA hosted a panel discussion at a media event together with the Center for Medicine in the Public Interest and the Society for Women's Health Research with the theme "Easing the Burden of Psoriasis and Psoriatic Arthritis Through Medical Innovation".


IFPA signing the GPA Agreement at the AAD in Denver, Colorado.

IAPO – 6th Global Patients Congress

Lars Ettarp and Kathleen Gallant had meetings with both key opinion leaders and medical societies to discuss the resolution at the 6th IAPO Global Patients Congress.

Dubai Dermatology Conference

Kathleen Gallant has also travelled to Dubai and met with key opinion leaders from that region to advocate for people with psoriasis and for the resolution.

The Asia-Pacific League of Associations for Rheumatology

Heading East, IFPA's Treasurer and President of IFPA regional member PsorAsia, Pacific, Josef de Guzman, represented IFPA at two scientific meetings. During the APLAR 2014, the Asia Pacific Rheumatology Congress in Cebu, the Philippines, Josef and his associate Paul welcomed delegates from all over the region to the joint IFPA/PsorAsia/PsorPhil booth to inform them about our organizations and the psoriasis resolution. Several ex-pressed interest in helping to form patient organizations in their countries and Josef provided his contact details to ensure that they get the support they need for such an important initiative.

The Regional Conference of Dermatology

Just a few days later, Josef travelled to the Regional Conference of Dermatology (Asia-Australasia) in Danang, Vietnam, to meet with regional key opinion leaders to advocate for the resolution and to inform about the upcoming world conference. Danang was also the setting for the annual meeting of PsorAsia, so patient leaders from the whole region gathered for this very important event, as well.

IFPA in Geneva to advocate for the WHO resolution on psoriasis

Kathleen Gallant and Susanne Hedberg visited Geneva in April to meet with representatives from national Permanent Missions and advocate for the WHO resolution on psoriasis. They there discovered that some European countries still seem to believe that the resolution is about establishing an official World Health Day on Psoriasis; however IFPA wished to make it clear that this is not the case. Therefore, it is even more important that we continue to raise awareness of the resolution to make sure that governments around the world, and especially in Europe, know that the resolution is primarily about recognition of psoriasis as a serious noncommunicable disease, encouraging awareness activities, initiating a WHO report on the prevalence of psoriasis and ensuring that information on psoriasis is readily available on the WHO websites.

In Geneva, they also found out that some of the government officials are viewing psoriasis association's websites in their country when preparing for the discussions on psoriasis that will take place during the WHA. IFPA encouraged all its members inform about the resolution on their respective website, and why it is so important to people with psoriasis

EADV

At the 23rd Congress of the EADV, in Amsterdam, the Netherlands, IFPA had a number of activities. In the IFPA booth, the congress delegates were invited to participate in IFPA's survey and, upon leaving a business card, also in a raffle for a prize, namely a beautiful book about the historic Swedish warship, the Vasa. Over 1 200 invitation programs for the 4th World Psoriasis & Psoriatic Arthritis Conference 2015 were handed out in the booth, which shows the great interest there is among the dermatologists for this important scientific meeting. IFPA also hosted a well-visited joint partner meeting for our corporate partners, as well as an exhibitor meeting to inform about the exhibition and sponsorship opportunities for the upcoming world conference.

IFPA President Lars Ettarp at the 23rd EADV Congress in Amsterdam.

WPD Event Geneva

In late October to early November, Kathleen Gallant was in Geneva and met with the Psoriasis Resolution core group to strategically discuss the implementation of the WHO psoriasis resolution. Previously it was also discussed to host an event on World Psoriasis.

4th Continental Congress of Dermatology

In November the 4th Continental Congress of Dermatology was held for the first time in the Philippines in collaboration with the Philippine Dermatological Society. The theme for the congress was "Advance in Dermatology- A Jour-ney Across Nations", and IFPA was of course well represented by the participation of Josef de Guzman, IFPA Treasurer and President PsorAsia Pacific. In IFPA's booth the delegates could learn more about our activities and receive the invitation programs for the 4th World Psoriasis & Psoriatic Arthritis Conference.

12th Annual Congress of International Drug Discovery Science & Technology
In November IFPA was also represented at the 12th Annual Congress of International Drug Discovery Science & Technology in Suzhou, China, by Lars Ettarp, President of IFPA. Lars gave an overview of the medical history of psoriasis and how the development of new treatments has revolutionized the care of psoriasis patients during the last half century. Special focus was also given to the advanced learning opportunities which will be given within the fields of psoriasis and psoriatic arthritis at next year's world conference.

Meeting with Permanent Missions
In December Kathleen Gallant, IFPA's Secretary, visited New York City to meet with representatives from a number of countries' permanent missions to the United Nations. The objective with the meetings was primarily to discuss the WHO psoriasis resolution and its implementation and the many challenges that people with psoriasis encounter all over the world. These meetings also gave IFPA the opportunity to share the new issue brief on psoriasis and disability

SOLAPSO 2nd Psoriasis Congress
December also saw two important scientific meeting with focus on psoriasis: the 2nd Congress of Psoriasis and Psoriatic Arthritis in Latinamerica, organized by SOLAPSO in Cancún, Mexico and the Psoriasis: Gene to Clinic conference in London, UK. IFPA was present at both meetings with a booth to share information about IFPA's activities and to invite delegates to the conference next summer. At the SOLAPSO congress IFPA Executive Committee member Silvia Fernandez Barrio also gave a presentation on the important of patient advocacy both regionally and globally and the WHO resolution, in particular.

7th International Congress of Psoriasis: From Gene to Clinic
In December 2014 IFPA were represented at the 7th International Congress of Psoriasis: From Gene to Clinic, in London, by Susanne Hedberg, Program Officer Advocacy & Policy. IFPA had a booth with information and material about IFPA´s work and activities. Invitation programs about the upcoming World Psoriasis & Psoriatic Arthritis Conference 2015 were distributed to the attendees at the Congress. Several participants came up to IFPA´s booth wanting to receive/share information about various activities and especially for next year´s World Psoriasis Day 2015. Susanne made an excellent work in reporting from the Congress, in London via IFPA´s Twitter account.

NEW MEMBERS

In 2014 IFPA was delighted to welcome three new members to the IFPA family! The new members are the Union of Psoriasis Associations of Brazil, The Hong Kong Psoriasis Patients Association and Korea Psoriasis Association.

REPORTS FROM IFPA REGIONAL MEMBERS

Asia Pacific – PsorAsia Pacific

Regional meeting

PsorAsia arranged a regional meeting in conjunction to the Regional Conference of Dermatology, RCD (Asia-Australia) in Danang, Vietnam. The key opinion leaders were encouraged to advocate for the resolution and to inform about the upcoming World Psoriasis & Psoriatic Arthritis Conference 2015. Danang was also the setting for the annual meeting of PsorAsia and patient leaders from the whole region gathered for this very important event.

A lot of promotion for the conference 2015 was done throughout 2014. For example, PsorPhil volunteers promoted the conference at the APLAR Congress in Cebu in February and at the Continental Congress of Dermatology in Manila, in November.

Promotion at the Continental Congress of Dermatology in Manila.

World Psoriasis Day campaign

A lot of World Psoriasis Day activities were arranged in the region and among these were: psoriasis presentations, awareness health walks, women´s seminar, healing walk day, informational and educational awareness seminars for the public, patients, family, healthcare professionals etcetera. As for the media activities many radio interviews were made, several articles featured in printed media, campaign broadcasts etcetera. Extensive social media activities were organized resulting in large media coverage.

Political campaigns

2014 marked a very important year for advocacy as PsorPhil won against the Cebu Pacific Airline who did not allow Rev. Magnolia Mendoza to fly because of Psoriasis. This was a clear case on discrimination and Rev. Mendoza received full support from the psoriasis association in the Philippines, PsorPhil, as well as from IFPA and a number of psoriasis associations around the world and went on to sue the airline for discrimination. Legal actions were taken with PsorPhil taking the lead and the outcome was very positive as the case was settled where the verdict ruled in the plaintiff’s favor. The court saw this as a clear case of discrimination that led to a great amount of personal suffering for the Rev. Mendoza.

PsorAsia´s members were highly active in taken actions and arranging several meetings, events to inform, discuss and implement the psoriasis resolution in the region on all levels, regionally, nationally and locally.

Europe – EUROPSO

IAPO

Europso were represented at the 6th Global Patient Congress, IAPO in March, 2014.

EADV

EUROPSO had a stand at the EADV Congress in Amsterdam. At site they informed the numerous specialists in dermatology and other fellow patients associations present about their work, projects and upcoming activities related to psoriasis in the European context and spoke about the latest research on psoriasis and psoriatic arthritis.

The EADV Congress took place in Amsterdam, The Netherlands.

Consensus statement

Together with IFPA, the National Psoriasis Foundation and The Arthritis SocietyCanada, EUROPSO collaborated on a joint statement on unmet needs of people with psoriasis and psoriatic arthritis. The statement also included recommendations in order to address the needs of the patients:

1. Diagnosis of psoriasis and PsA

Patients need to be diagnosed with psoriasis and PsA more quickly, and in order to tackle these unmet needs in the diagnosis of patients with psoriasis and PsA, the following are recommended:
a. Educate patients to recognize the symptoms of and comorbidities associated with psoriasis and PsA
b. Educate GPs and other HCPs to recognize the symptoms of and co-morbidities associated with psoriasis and PsA
c. Highlight the importance of early diagnosis

2. Treatment of psoriasis and PsA

a. Provide early and appropriate access to treatment
b. Establish a multidisciplinary approach to treatment
c. Educate patients about treatment options
d. Address the issue of under- and mistreatment

3. Managing the burden of disease

Psoriasis and PsA need to be recognized by health organizations, physicians, other stakeholders, and the public as serious diseases. Without this wider understanding, the burden of these diseases on the lives of the patients and their families cannot be recognized and they will continue to suffer. The following recommendations have been made:
a. Raise awareness of psoriasis and PsA as serious diseases
b. Provide support to cope with the social and psychological
burden of disease
c. Address the reasons behind treatment discontinuation

Latin America – LATINAPSO

Latinapso held its General Assembly in 2014 for the period 2014-2017. New board members were elected. Latinapso worked extensively on prioritizing global guidelines on supporting the actions taken by WHO to include psoriasis on the agenda.

World Psoriasis Day Campaign

Argentina, Brazil, Panama, Puerto Rico and Uruguay had very successful local and regional campaigns with the objectives to empower the associations using the psoriasis resolution towards governments, policy makers and other stakeholders. Among the many activities arranged were, awareness walks, lottery, distribution of informational material, social media campaigns etcetera.

Political Actions

Uruguay and Peru stated their effort to make psoriasis visible to all community through mass awareness events. Uruguay, after its political restructuration, conducted massive campaigns and strengthened its participation in medical specialists' networks in the region and in meetings of patient organizations. Peru conducted a mass media campaign and in government agencies facing the possibility that some medicaments were discontinued and achieved the prolongation. Venezuela made an effort to achieve visibility through mass media as their urban actions were constrained by the situation in their country in these days. Argentina, Puerto Rico and Panama showed outstanding political actions and made an impressive awareness in different levels of their government. Argentina signed an agreement with the Minister of Health in the province of Buenos Aires for the first registry of patients with psoriasis in the region. Puerto Rico won Senate approval to make visible the disease through the turnin on of the lights on the Capitol for three days. Turn the newsletter "Let's talk about Psoriasis" is highlighted. Panama conducted its IX annual walk awareness and the first contest of journalism psoriasis. Brazil remarked regionalization efforts and professionalism, efforts that took advantage in the second segment of the hand of their coach Jonas Flores, who was hired to guide and advise the process.

Latinapso coached the leaders in respective member association in implementing the resolution. The Latinapso secretary coached every leader to organize round tables with their Health Ministers. For example, the roundtable meetings were organized in Argentina on October 28, in Brazil on November 13th.

In the region during 2014 the following actions were organized:

- 12 urban campaign
- 27 publications in printed media
- 54 appearances on TV
- 40 interventions on Radio
- 11 presentations in regional medical conferences

As for the social media coverage Latinapso increased its Facebook account with 144 followers and the Twitter account with 168 new followers. Many people were reached by a Map on psoriasis organized for the first time via Facebook.

LATINAPSO
den 13 oktober 2014

Ayudanos a crear conciencia sobre la psoriasis y su impacto. Si tenes psoriasis, o amigos/familiares que la padecen firma en el siguiente link http://thndr.it/1xWVXal . Los resultados se van a difundir a nivel mundial para que se conozca en todos los ámbitos su impacto y se incentiven mas acciones de concientización y educación. MUCHAS GRACIAS!

Visa översättning

World Psoriasis Day 2014
I just supported World Psoriasis Day 2014 on @ThunderclapIt // @PsoriasisIFPA
THUNDERCLAP.IT

INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

The International Federation of Psoriasis Associations (IFPA) is a non profit organization made up of psoriasis associations from around the world.

IFPA unites psoriasis associations so that their global campaign for improved medical care, greater public understanding and increased research will improve the lives of people who live with psoriasis and psoriatic arthritis and explore the challenges psoriasis presents to the international psoriasis community.

Worldwide unity for people living with psoriasis
IFPA gives nonprofit psoriasis associations a global voice to campaign on behalf of people who have psoriasis and psoriatic arthritis. IFPA provides the unity that strengthens everyone's ability to support research that will someday find a cause and a cure for these diseases.

IFPA Vision
A world without human suffering from psoriasis

IFPA Mission
To be the unifying global voice of all psoriasis associations, supporting, strengthening and promoting their cause at an international level

For more information about IFPA and our activities, please visit
www.ifpa-pso.com and www.worldpsoriasisday.com.

Follow us on Twitter: @PsoriasisIFPA
Like us on Facebook:
www.facebook.com/internationalfederationofpsoriasisassociations