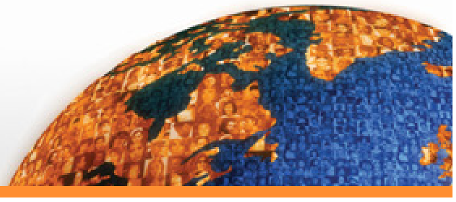
INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

IFPA ACTIVITY REPORT
2015



IFPA ACTIVITY REPORT 2015

Dear friends,

The Executive Committee of the International Federation of Psoriasis Associations is pleased to hereby present the activity report for 2015.

2015 was a tremendous year for IFPA, its members and the psoriasis community. IFPA has been very active on many different platforms in order to achieve recognition of psoriasis as a serious, inflammatory, chronic, non communicable disease. IFPA has been represented at numerous international conferences/congresses and meetings all over the world, to mainly promote the conference and its advocacy work towards the WHO and UN.

IFPA's advocacy strategy for 2015 mainly focused on how to further implement the WHO Psoriasis Resolution WHA 67.9 adopted in 2014, using the IFPA's advocacy tools. The strategy involved action plans on the national, regional and global level. Aligned with the WHO resolution, IFPA was asked by the WHO Secretariat to make contributions, provide comments and expert technical reviews on the draft of the WHO Global Report on Psoriasis to be published early 2016. IFPA was honored to contribute and to be recognized as a vital actor in the Psoriasis community.

The main activity for the year was the extremely successful 4th World Psoriasis and Psoriatic Arthritis Conference, organized in Stockholm in July 2015. Over 1 000 delegates from 70 countries in Stockholm attended the conference with its theme "Psoriasis – new insights and innovations". The program featured a number of developments within the treatment and care of psoriasis and psoriatic arthritis, where delegates were treated to a number of excellent presentations by world-leading experts, advancing the knowledge of the epidemiology, genetics, epigenetics, diagnostics and associated comorbidities, as well as treatments currently available and under development for psoriasis and psoriatic arthritis. All IFPA's members were invited to the conference and also to a specific advocacy workshop as well as IFPA Member Meetings, in conjunction to the conference.

All activities in 2015 resulted in strengthening the voice of IFPA as a unique global patient organisation in the psoriasis sphere and it could not have been achieved without its member's commitment and engagement.

The IFPA Executive Committee wishes to direct a special thanks to its member associations for their wonderful work in helping to improve the quality of life for patients living with psoriasis. IFPA could not have achieved so much without the support from healthcare professionals, allied organizations, partners, media and other stakeholders – Thank you to you all!

On behalf of the IFPA Executive Committee,

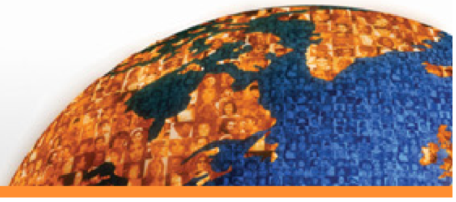
Lars Ettarp
President
IFPA

Hoseah Waweru
Vice President
IFPA

Sophie Andersson
Head of Operations
IFPA Secretariat

INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

Worldwide unity for people living with psoriasis



IFPA ACTIVITY REPORT 2015

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:

- 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.
- Provide advice and consultation on the problems associated with psoriasis to member organizations or other communities and organizations worldwide.
- Provide the basis for closer liaison and the free exchange of information among psoriasis organizations and related organizations worldwide.
- Encourage and assist the establishment of new national organizations of people with psoriasis.
- Contribute to the improvement of the quality of health and social life of people suffering from psoriasis and psoriatic arthritis.
- 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. To further 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 July 2015 such a meeting was called and a vote was held on an addition to the IFPA Constitution, under Paragraph 2 “Purpose”, proposed by the IFPA EC. The addition concerning regarding IFPA´s strategic advocacy work towards the UN and WHO, with focus on the disabling aspects of psoriasis, and which approach to take was adopted by the General Assembly by vote on July 12, 2015. In 2015 the IFPA EC had six meetings, of which four physical and two telemeetings.

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. In 2015, the Secretariat was comprised of three permanent members of staff and one temporary member of staff. The Secretariat was managed under agreement with the Swedish Psoriasis Association, Psoriasisförbundet, and shared its office. By the decision taken in June 2015, the agreement with the Swedish association was not prolonged between the two parties, IFPA and the Swedish Psoriasis Association, and contract to end December 31st. This was motivated by IFPA´s expansion of advocacy projects and the increase of number of member associations, and the consequent need for IFPA to run the organization independently and take over the employer liability. Negotiations was held in autumn on how the transition was to be processed and which practicalities needed to be solved. IFPA decided to look for new office premises and moved in December to a new office suitable to IFPA´s needs and requirements.

Main activities 2015:

The theme for World Psoriasis Day 2015 was: “Hope. Action. Change.” The field in which IFPA is active has undergone immense changes and developments, and giving people with psoriasis hope for the future is a priority for the psoriasis community. But IFPA cannot do it alone, which is why it is necessary for all to take action, in order to effect change. This was done through the global World Psoriasis Day campaign that gathers individuals, patient organizations, healthcare professionals and other stakeholders to take action on behalf of people with psoriasis and psoriatic arthritis; action that can drive change – change that gives hope for a better future. That is one of the many reasons that IFPA encouraged people to “Have hope. Take action. Make a change.” These messages have been underlined in the following main activities/projects, acted as the focus of IFPA’s efforts during 2015:

Focus areas 2015: Advocacy, Awareness, Education, Organization
Main activities:

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

IFPA Advocacy project (UN/WHO)


IFPA’s Program Officer Advocacy & Polic, Susanne Hedberg, at the WHO.

The advocacy strategy towards the United Nations, UN, and World Health Organization, WHO, authorities to gain global, regional and national recognition for psoriasis as a serious non-communicable and disabling disease stepped into its next phase as the WHO psoriasis resolution was adopted at the 67th World Health Assembly in May 2014. IFPA has continued its activities in the area and have been represented at several meetings, summits and conferences organized by the WHO, the UN as well as IFPA’s regional members and partner meetings. The need for IFPA to continue working actively in this field motivated the prolongation of the contract for the Program Officer for Advocacy and Policy, whose main task was to carry on and further develop the coordination and administration the IFPA Advocacy Project. The most prominent focal point for the IFPA Advocacy work 2015 was the follow-up on the implementation of the WHO psoriasis resolution. A number of activities was arranged by IFPA, such as:

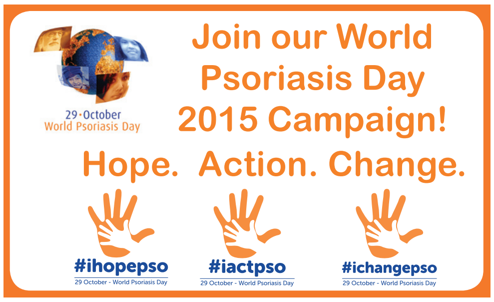
- Educational online seminars “webinars” with State Actors, Non-State Actors within the WHO system.
- Frequent stakeholder meetings with patient organizations, medical societies and industry representatives, participation in medical/scientific congresses and conferences and presentations/lectures in varied settings, to ensure the psoriasis community is represented.
- Frequent contact and meetings with Permanent Missions representatives in both the WHO and UN forum.

- Development of toolkits for different stakeholders, 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, for example: toolkit geared towards the Ministries of Health.
- Capacity building and advocacy workshops ensuring 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 during the IFPA Informal member meeting in conjunction to the 4th World Psoriasis & Psoriatic Arthritis Conference, in Stockholm, Sweden.
- Support given to national health ministries to implement the resolution in their countries (where there is no patient association).
- Development of issue brief on psoriatic arthritis for raising awareness on its impact on the individual and society.
- The results of the call for action initiative, an IFPA online global survey launched in 2014 to identify strategic activities to cope with unmet needs of patients with psoriasis, were presented at the 4th World Psoriasis & Psoriatic Arthritis Conference.
- First time attendance at the World Innovation Summit for Health which is seeking influence areas like development of health policies and health care both in relations to international organizations, such as IFPA. Great opportunity for networking and highlighting the patient perspectives in health issues.


Board Member Kathleen Gallant at CoSP with the Panamaian delegation.

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 2015, such as the Conference of State Parties (CoSP) on the Convention of Rights for Persons with Disabilities (CRPD). IFPA submitted a quadrennial report to the ECOSOC in June and a written statement to ECOSOC High-Level Segment (HLS) in July.

World Psoriasis Day 2015



The theme for World Psoriasis Day in 2015 was “Hope. Action. Change”. It is a day when people with psoriasis from all over the world unite in a call for awareness and greater understanding of the impact of a complex and challenging disease. But World Psoriasis Day is more than a day for awareness, it is a global campaign that gathers individuals, patient organizations, healthcare professionals and other stakeholders to take action on behalf of people with psoriasis and psoriatic arthritis; action that can drive change –change that gives hope for a better future. That is one of the many reasons that IFPA encouraged people to “Have hope. Take action. Make a change.”, in the campaign 2015. The campaign was launched during the 4th World Psoriasis & Psoriatic Arthritis Conference given IFPA a great opportunity to communicate the supporting messages: every year we understand more about psoriasis – research gives us hope, everyone can take actions to raise awareness about psoriasis, every positive action can lead to positive change.

IFPA created an online digital wall of hope which was launched, at the 4th World Psoriasis & Psoriatic Arthritis Conference. People were asked to answer the question: what gives you hope for a better future for people with psoriasis and psoriatic arthritis? where social media posts using the hashtags #ihopepso, #iactpso and #ichangepso were shared. Delegates could also post their messages directly.

IFPA's Wall of Hope on World Psoriasis Day.

In addition, IFPA also had a physical World Psoriasis Day wall of hope, in the IFPA booth, where people could write directly on the wall: what gives them hope for a better future for people with psoriasis and psoriatic arthritis? The objective was to showcase to the delegates that the wall could easily be set up at World Psoriasis Day activities in clinics, hospitals, town centers, squares etcetera, and campaign feasible everywhere in the world, no matter the resources. To help create a World Psoriasis Day social media buzz, IFPA launched a Thunderclap in which people couldvery easily "take action" to show their WPD support by simply signing up with their Facebook, Twitter or Tumblr account to help spread the WPD message globally.

The 4th World Psoriasis & Psoriatic Arthritis Conference 2015

Over 1 000 delegates from 70 countries joined us in Stockholm this summer for the 4th World Psoriasis & Psoriatic Arthritis Conference, organized by IFPA. The conference theme "Psoriasis – new insights and innovations" was well reflected in the program, as it featured a number of developments within the treatment and care of psoriasis and psoriatic arthritis. The conference dele-gates were treated to a number of excellent presentations by world-leading experts, advancing the knowledge of the epidemiology, genetics, epigenetics, diagnostics and associated comorbidities, as well as treatments currently available and under development for psoriasis and psoriatic arthritis.

Congress attendees at the Waterfront Congress Center, Stockholm.

Professor Mona Ståhle being interviewed by SVT television.

Based upon feedback from the previous conference in 2012, the program featured more case-based learning than ever, and the audience also had the opportunity to ask questions to the faculty via their smartphones/ PDAs – making the conference more interactive and dynamic than ever. The featured keynotes highlighted important issues such as the relationship between psoriasis and psoriatic arthritis, the treatment of psoriasis from an international perspective, and treatment guidelines and recommendations, such as the recently updated EDF guidelines. The clinical case sessions featured a number of interesting and challenging cases, such as treating psoriasis with hepatic comorbidity, pustular psoriasis and psoriatic arthritis with widespread pain.


Dr. Hoseah Waweru and Mrs Kristine Bukhave.

The conference also featured a short Complementary program every day, mainly targeted towards general practitioners, allied health professionals and representatives of patient organizations. The Complementary program committee, led by IFPA's Vice President Dr Hoseah Waweru, had developed a program focused on patient needs and outcomes, featuring presentations and panel discussions with both healthcare professionals and patient representatives. The Complementary program featured, among other things, a special symposium on how to treat the whole patient, giving the view on treatment from a dermatologist, a rheumatologist, a psychodermatologist and a specialist skin care nurse.

A highly appreciated part of the program was also the panel discussion on "The ideal treatment – what would it be and is it possible?" featuring panelists IFPA Executive Committee members Kathleen Gallant (US) and Josef de Guzman (Philippines) and dermatologist April Armstrong (US) and rheumatologist Sergio Toloza (Argentina) and moderated by Randy Beranek (US). A short clip from this discussion can be viewed on IFPAs Facebook page. In the Complementary program the delegates could also learn more about the importance of close collaboration between the medical societies and the patient organizations to improve patient outcomes, through given examples of global, regional and national collabo-ration projects or programs, such as IFPA's joint Global Psoriasis Atlas project with the International Psoriasis Council and the International League of Dermatological Societies.

The first satellite symposium of the conference was presented by IFPA and had the theme "We need to talk! Improving patient outcomes through communication and collaboration." The symposium's objective was to address the need for good communication between the patients and their treating physicians, and to give examples of both bad and excellent communication. The delegates attending the symposium were first treated to a performance by an improvisation theatre group on the subject, which, even though light-hearted and very entertaining, proved the point of how difficult it can be to communicate, and also how important it is to think about how and what we communicate. The improv session was followed by a panel discussion featuring IFPA Executive Committee members Silvia Fernandez Barrio (Argentina) and Josef de Guzman (Philippines), and dermatologist Prof. Mahira El Sayed (Egypt) and rheumatologist Dr Sergio Toloza (Argentina).

Since 2012, IFPA has endeavored to keep its followers on social media up to date with recent developments in psoriasis and psoriatic arthritis research, by covering relevant congresses and symposia. To enable people around the world to follow the discussions from the 4th World Psoriasis and Psoriatic Arthritis Conference (WPPAC15), IFPA provided live updates from all the conference sessions on Twitter. In total, IFPA provided more than 460 tweets from the scientific and complementary programs, allowing the followers of @PsoriasisIFPA or the hashtag #WPPAC15 insight into the many important topics discussed at the conference.

IFPA also conducted two tweet chats with participating medical experts, Dr Liv Eidsmo (dermatology) and Dr Elaine Husni (rheumatologist) giving followers the opportunity to ask questions by using the hashtag #ChatWPPAC. To ensure that the patient perspective came across also in IFPA's twitter coverage of the conference, IFPA conducted three interviews via Twitter, so called twinterviews, with patient organization representatives Silvia Fernandez Barrio (IFPA/Latinapso), Josef de Guzman (IFPA/PsorAsia) and Julie Emilie Petersen (Psoriasisforeningen, Denmark).

The conference delegates had the opportunity to view art featured in the project "Perspectives – art, inflammation and me", courtesy of AbbVie. This very powerful art exhibit featured pieces of art inspired by people with psoriasis and psoriatic arthritis, giving the dele-gates a unique and emotional insight into what it is like to live with these complex diseases.

IFPA members at the WPAAC 2015.

IFPA is indeed a global organization, which became quite obvious to the delegates who visited the IFPA member booth at the conference, featuring a huge map over the IFPA member countries. In the booth, the members were invited to share information about their organizations and activities with the delegates and to interact with doctors from their countries and regions. The IFPA booth highlighted the World Psoriasis Day 2015 theme "Hope. Action. Change" and functioned as a "Wall of Hope" where delegates were invited to share their hopes and visions for a better life for people with psoriasis and psoriatic arthritis. In the booth delegates also found information about IFPA, our activities and tools to help raise awareness of and advocate for psoriasis.

The result of IFPA´s online global survey which was launched in June of 2014, was presented at the conference. It was developed by IFPA to gain insights on which activities, or "tools", patients, physicians, family members and friends find to be the most valuable in improving the situation for people with psoriasis all over the world. When the survey closed, more than 4 600 individuals from 120 countries had each voted for the five tools out of a total of seventeen they believed will help build a better world for people with psoriasis. The aggregated results from all respondent groups clearly indicate that education must be prioritized. The five tools that received the most votes are all within the education category, showing that this is an area where the survey respondents see a clear need for improvement and development. Primarily, the needs seem to be the greatest regarding education about treatment options, both for the patients and the physicians, but also in educating policy makers about the socioeconomic and psychosocial impact of psoriasis.

INTERNAL MEETINGS

IFPA Member meetings in Stockholm - highlights

In conjunction to the 4th World Psoriasis & Psoriatic Arthritis Conference, IFPA had the great pleasure of welcoming the IFPA members to the IFPA Member workshop, for one full day of IFPA member meetings of workshops, seminars, presentations and for the Extraordinary Meeting of the IFPA General Assembly.

IFPA Member workshop, July 8

One of the European groups present their greatest successes and challenges

The representatives from IFPA's member associations were invited to participate in a special advocacy workshop. The members were divided into groups, as per the WHO regions, in order to enable discussions on how to work nationally and regionally with the WHO psoriasis resolution and with patient advocacy in general. The attendees were asked to list their greatest successes as well as their challenges, prompting fruitful discussions within the groups on how to adapt successful activities to other countries/regions and how to overcome the many challenges that we face as non- profit organizations.

Extraordinary meeting of the IFPA General Assembly, July 12

The IFPA Members Meetings was opened by Lars Ettarp welcoming the IFPA members to the Extraordinary meeting of the IFPA General Assembly. He went through the formal agenda of the meeting which was followed by a presentation held by Kathleen Gallant. She spoke about the background and past discussion held at the IFPA member meeting in 2012 and IFPA General Assembly in 2013 regarding IFPA´s strategic advocacy work towards the UN and WHO, with focus on the disabling aspects of psoriasis. Question: which approach should IFPA take? Two perspectives were presented, International Classification of Functioning, Disability and Health (ICF) and the Human Rights Model, with the latter focusing on interaction of the person and society.

In view of this, Kathleen Gallant presented the suggested addition to the IFPA Constitution put forward by the IFPA Executive Committee. It was recommended to the Extraordinary General Assembly that the IFPA constitution be amended by adding clause "g" at Paragraph 2.1 to read as follows: "g) Promote the rights of people with psoriasis and break the barriers that bar them from fully and effectively participating in society by supporting international treaties on disability, such as the Convention on the Rights of Persons with Disabilities (CRPD) that protect and ensure the full enjoyment of people with the physical, or emotional, impairment that psoriasis causes."

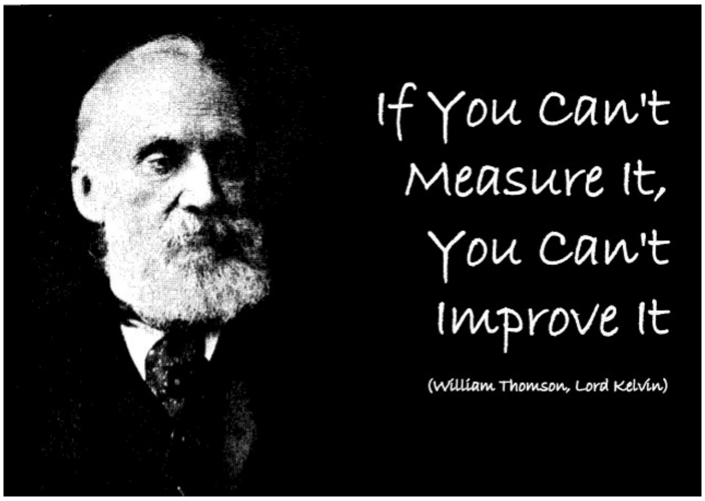
An open discussion was then held and Psoriasis Vereeniging Nederland, Netherlands, suggested that the new addition be included in paragraph 2.1 as clause “f” in the IFPA Constitution. Hoseah Waweru, suggested not amending the existing wording in paragraph 2.1 but adding the wording as clause “g” as suggested to clarify that this is an addition to the IFPA Constitution.

Chairman, Lars Ettarp, asked if the Extraordinary General Assembly was ready to vote on the suggested addition to the Constitution based on the information given and the Assembly concurred. Lars Ettarp then asked the Extraordinary General Assembly if all were in favor of the suggested addition to the IFPA Constitution put forward by the IFPA Executive Committee. The Assembly concurred unanimously and the suggested addition was thereby approved by the Extraordinary General Assembly for inclusion in the IFPA Constitution.

IFPA Informal member meeting, July 12

The Extraordinary Meeting of the General Assembly was followed by an IFPA informal member meeting. Updates on IFPA’s projects, activities and finances were presented by Lars Ettarp and Josef de Guzman. Kathleen then held the next presentation about a new activity report form for IFPA’s members. The purpose of the activity report was that it will enable the IFPA members to showcase its main activities, work, to learn about and be inspired from other members’ activities and to be used as a base to assure that each member association fulfills the requirement of full membership in IFPA, in accordance to IFPA Constitution 4.1. Following that, Hoseah Waweru, held an excellent presentation about the reflections and key learnings from the 4th World psoriasis & Psoriatic Arthritis Conference 2015.

The attendees also had the privilege of listening to one of IFPA´s younger member representatives, as Paul Mendoza from the PsorPhil youth board was interviewed, by Susanne Hedberg, on the topic of “Building for the future – how to engage the youth in your organization”. A presentation held by Barbra Bohannan, on why patient organizations need to work with metrics and outcomes measures was followed by two work-shops – one on “Building membership engagement” and one on “How using metrics and outcomes measures can help your advocacy work and fundraising”. New for this member meeting was that the attending members had the opportunity to choose which workshop to participate in, depending on the special needs of the organization represented. Both workshops were well attended and featured many lively and highly engaging discussions.



World Psoriasis Day Supporters Training Meeting, July 12

During the second half of the day IFPA had its World Psoriasis Day Supporters Training Meeting and the attendees were given a report on the World Psoriasis Day activities in 2014, by Josef de Guzman. The meeting also featured a presentation of the World Psoriasis Day theme and campaign for 2015. As 2015 was a monumental one in terms of global development goals, the attendees were also given a presentation on the Sustainable Development Goals, and how health in general and psoriasis in particular fits into this agenda.

After these presentations the attendees were welcome to choose from two separate workshops, one with focus on PR and communications and the other on advocating for national treatment guidelines and recommendations; with the latter facilitated by Jens Sloth-Nilsen and Julie Emilie Petersen from the Danish Psoriasis Association. These interesting and engaging workshops gave the attendees much food for thought and hopefully some inspiration on how to continue to work with awareness and advocacy as a patient organization.

After this followed a session where the attending representatives of the World Psoriasis Day Corporate Supporters were invited to present themselves and their initiatives to raise awareness of psoriasis and actively engage in World Psoriasis Day. The meeting concluded with a presentation on IFPA's Strategic Plan for 2015-2017, which is focused on four main areas: Advocacy, Awareness, Education and Organization, and has as its goal "To improve the lives of people with psoriasis and psoriatic arthritis by actively contributing to awareness, understanding, and action".

Members

On December 31, IFPA had fifty-four Full member organizations and one Associated member organization. In 2015, IFPA was delighted to welcome three new members to the IFPA family! The new members are Slovenia (Drustvo Psoriatikov Slovenije), Taiwan (Psoriasis Association Taiwan) and Greece (Epidermia).

Photo by Daymin.

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.

The Global Psoriasis Atlas

The Board of Governors, IFPA, the International League of Dermatological Societies (ILDS) and the International Psoriasis Council (IPC), initiated the Global Psoriasis Atlas, GPA, in 2015. Actions made since the first Steering Committee meeting held in 2014, has been the examination of three purposed structures: legal entities, academic institution alignment, contractive and flow and indicative budgets. Work streams been developed with mission to focus on: conduct systematic review of current literature, determine globally accepted methodology to serve as framework for compiling the Global Psoriasis Atlas. A GPA leaflet was developed to provide brief information about the project and discussions with partners have been ongoing to inform about the progress of the project and garner interest/support. At the World Psoriasis & Psoriatic Arthritis Conference 2015, in July, a presentation was made with the theme: "Collaborating to improve patient outcomes on all levels – the Global Psoriasis Atlas Project", with its purpose to inform the conference delegates of the GPA joint partnership and the project's potential for effecting change for the psoriasis patients worldwide.

G P A
Global Psoriasis Atlas

Corporate partners/Fundraising

In 2015 IFPA received project sponsorships from the following corporate partners: AbbVie, Celgene, Janssen, LEO Pharma, Lilly, Novartis and Pfizer. In alignment with IFPA´s Strategic Plan 2015-2017, to ensure financial and organizational stability, IFPA decided to explore opportunities for fundraising and donations to IFPA with the objective to broaden and develop new options of financial income. A first meeting was held with PricewaterhouseCoopers AB about the advantages and disadvantages for various alternatives to organize fundraising, especially direct donations.

EXTERNAL MEETINGS

United Nations – ECOSOC

In February Kathleen Gallant, Secretary of the IFPA Executive Committee and Chair of the IFPA Task Force on NCDs Committee, participated in UN Meetings in New York in February where the post-2015 agenda was discussed. At the end of 2015, the Millennium Development Goals (MDGs) are expiring and discussions are ongoing in regards to what framework and priorities will be set for the successor of the MDGs. IFPA saw it was a great opportunity to lift health and noncommunicable diseases, including psoriasis, in these discussions. IFPA are to continue to monitor the discussions and inform state representatives about the need for further awareness of psoriasis and its impacts.


IFPA President Lars Ettarp at WISH in Doha, Qatar.

World Innovation Summit for Health, WISH

Lars Ettarp represented the global psoriasis community at the 2nd World Innovation Summit for Health in Doha, Qatar. The Summit gathered 800 specially invited thought leaders within health to discuss the best evidence-based ideas on how to improve healthcare globally. Seven specific Forums were created for the 2015 meeting, focusing on subjects such as “Communicating complex health messages”, “Patient safety”, and “Universal Healthcare Coverage”. Each Forum published a report in advance of the meeting.

Medical Transparency Alliance Forum

IFPA Executive Committee Treasurer and President of Psorphil and PsorAsia, Josef de Guzman, was invited to participate in and speak at the WHO-initiated Medical Transparency Alliance Forum that was held in the Philippines. The Forum was an excellent opportunity to ensure inclusion of psoriasis in these forums and Josef gave a presentation on “The Filipino Patient: Perspectives, Aspirations and Commitments.”

EADV Spring Symposium

The IFPA Secretariat, represented by Annika Rastas and Linnéa Lindström, attended the EADV Spring Symposium in Valencia, in March. IFPA was given a prime booth location and it was a constant great flow of delegates passing. Approximately 300 -350 conference invitations and 200-250 conference programs were handed out at site and IFPA also had 1200 inserts in the congress bags and an article, middle page, in the EADV news, about the conference 2015. Annika and Linnéa also had many interesting meetings with delegates regarding IFPA´s work and activities.

Global Health Conference

Kathleen Gallant, attended the Unite for sight/Global Health Conference at Yale University. There, experts talked around topics of “Health is a human right” and the Sustainable Development Goals.

68th World Health Assembly

According to the adopted psoriasis resolution, by the end of 2015, the WHO are to publish a report about the prevalence and incidence on psoriasis as well as publish information about the disease on the WHO website. Kathleen Gallant and Susanne Hedberg went to Geneva in May to attend the 68th World Health Assembly, WHA. Their mission was to monitor and remind WHO and its member states on the resolution and follow discussions on health and the new Global Sustainable Development Goals, SDG´s. At site they attended several side-events such as: Delivering on NCDs and health in the post-2015 era and Leave no one behind: Ensuring UHC for marginalized and key populations. Kathleen and Susanne also participated in the NCD Alliance NGO Briefing ahead of the WHA, which gave them the opportunity to meet other NGO´s, learn about official WHA NCD agenda items and side events, and strategize on advocacy and priority messages.

Conference of States Parties

In conjunction with the 8th session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities in New York, Kathleen Gallant from IFPA met with the delegate from Panama, Nelida Ortiz de Loiza, Directora General Secretaria Nacional de Discapacidad. Kathleen and Nelida Ortiz de Loiza discussed how psoriasis fits in the disability agenda as people with psoriasis often have to face many barriers to full inclusion and participation in society.

23rd World Congress of Dermatology June

In June, Lars Ettarp and Kathleen Gallant were in Vancouver, Canada, attending the 23rd World Congress of Dermatology and the International Dermatology Patient Organization Conference, IDPOC, held in conjunction to the World Congress. At IDPOC, Kathleen made a presentation on: Highlighting Excellence in Awareness Campaigns. Practical tips to be inspired! She also led a panel from around the world to present pointers from successful awareness-raising campaigns. Lars held the presentation: “The road towards recognition of psoriasis as a global health challenge”, at a special IDPOC session for dermatologists: Best-in-Class – Featuring patients, patient groups and organizations that have made a difference in worldwide advancement of dermatology patient education, support and care. Both Lars and Kathleen were also invited as speaker at a roundtable event and in a session: From Global to Local: The journey leading to the WHO Resolution on Psoriasis and what are the next steps on a global level? Presentation made focused on: How IFPA mobilized patients and succeeded in bringing psoriasis on the WHA agenda.

UN High-Level meeting

As the Millennium Development Goals expired this year, Kathleen Gallant, from IFPA, attended UN meetings this spring and summer to ensure that the psoriasis community is represented in the discussions and work on the successor agenda, known as the post-2015 development agenda.

Seminar in Almedalen, Sweden

In late June, Barbra Bohannan was invited to participate in a panel discussion, in a seminar during the annual political week in Almedalen, Sweden. The basis for the discussion were: how health care should suffice for psoriasis patient's needs, based on the WHO resolution on psoriasis.

Barbra Bohannan at the annual political week in Almedalen, Sweden.

Global Alliance for Musculoskeletal Health of the Bone and Joint Decade World Summit 2015

Kathleen Gallant got the opportunity to attend the Bone and Joint Decade, BJD, World Summit in Oslo, October 8-9. Presentation on the BJD was given on what has been done in the past – transition - current position? Information was given that the WHO wanted to partner with them and have asked the BJD to apply for official relations with the WHO. Kathleen and the President of the BJD, Tony Woolf had fruitful discussions on the topic and it was a great opportunity to exchange knowledge and information.

EADV Congress

IFPA was of course present at the 24th EADV Congress in Copenhagen October 7-11. For the first time ever, the EADV had arranged for a special "Patient Society Village" which gathered patient organizations from a number of different disease areas and countries. IFPA was truly grateful for the opportunity to share information about psoriasis and to also raise awareness of the need for more psoriasis patient organizations. The IFPA team were able to share both information material with the congress delegates as well as the new psoriasis awareness ribbons.

REPORTS FROM IFPA REGIONAL MEMBERS

Africa – PsorAfrica

In February a meeting in Tanzania was arranged with its purpose to strengthen psoriasis sufferers position in Africa. Participants of the meeting were: Lars Ettarp, IFPA, Hoseah Waweru, PAK, Chebet Karago, PAK, Yassin Mgonda, PSORATA, Dorothy Malecela, PSORATA, Veronica Mitchell, SAPSA and Alister Porthen, SAPSA. Each IFPA national member association got the opportunity highlight its activities, achievements and specific challenges. This was followed by an open discussion centered around a couple of questions:

- Is there a need for a closer collaboration between the national psoriasis associations in Africa?
- Should the collaboration be formalized, and if so how?
- How can a regional collaboration in Africa be made visible within the IFPA community?
- What kind of collaboration project should be given the top priority?
- Identification of new/possible psoriasis patient organizations.

The meeting was successful and it was determined that capacity building and support is needed in the region. Discussions were made of the importance of recruiting new members in the region and to form a legal entity. To set up a formal agreement between the three associations stating that they are the founders of the regional organization.

The next regional meeting took place at the World Psoriasis & Psoriatic Arthritis Conference 2015, where the member associations continued to discuss the need for support and capacity-building in the region.

Asia Pacific – PsorAsia Pacific

Political actions

2015 was a busy year in the Asia Pacific region and PsorAsia had many activities throughout the year focusing primarily on the implementation of the resolution.

World Psoriasis Day

A large amount of World Psoriasis Day activities was arranged in the region, reaching many thousands of people. Among the activities arranged in the region were: Several radio interviews and TV appearances, awareness walks, psoriasis week, press conferences, articles published online and in printed media, seminars, educational meetings etcetera.

WPD activities in Singapore .

Europe – EUROPSO

Conferences

During 2015 EUROPSO were represented at several conferences such as the EADV Spring Symposium in Valencia and the EADV Congress in Copenhagen etcetera. Information and material about EUROPSO´s work and activities were distributed at these meetings.

2nd EUROPSO Youth Round Table

EUROPSO hosted a second Youth Round Table in Barcelona March 13-15. The meeting gathered young people between the ages of 18 and 30 from all over Europe, who have psoriasis and/or psoriatic arthritis. Meeting was very successful and full of inspiration and fruitful discussions took place.

World Psoriasis Day

Also in the European region a large number of activities were organized on and in conjunction to World Psoriasis Day. The activities varied from educational conferences, videos, interviews in printed media, psoriasis schools and media events to arranged lectures for the general public, psoriasis cafés and participation at Health Fairs.

Participants at the 2nd EUROPSO Youth Round Table.

Latin America – LATINAPSO

Regional member meeting

At the end of August 2015 LATINAPSO held the seventh Annual Meeting in Panama City. It was very successful event where member associations from Argentina, Brazil, Panama, Venezuela and Uruguay, together with officials and technical advisers of the network exchanged experiences, discussed action plans for further implementation of the WHO Psoriasis Resolution and presented the First Latin American Map of pathology. Dr. Eva Maria Ruis De Castilla, leader in consulting patient organizations and member of the Board of IAPO (International Alliance of patients' Organizations) was the guest of honor at the event.

During the meeting members of LATINAPSO continued to discuss and plan their work in alignment with the principles of the Network focusing on patient care, in order to fight for the rights of patients with psoriasis and psoriatic arthritis in order to improve their quality of life.

World Psoriasis Day

The Latin American member associations of IFPA were highly active in arranging activities for World Psoriasis Day. Also in this region the activities were diverse but mainly social media actions/campaigns as well as focus on educational and awareness activities such as walks, urban actions, conferences, seminars and press conferences etcetera that draw a lot of attention and were well noticed by the general public, policy makers, media and other stakeholders.

29 DE OCTUBRE
Día Mundial de la Psoriasis
ABRAZOS Y CAMINATA
Con la compañía de profesionales médicos
HORARIO: 12H A 14H
LUGAR: Estación Saludable del Rosedal
Av. Iraola y Av. Sarmiento - CABA
Vení con remera blanca, o azul eléctrico o naranja
ESTÁN TODOS INVITADOS

1er MAPA ARGENTINO DE PSORIASIS HACÉ CLICK Y SUMATE
www.aepso.org

IFPA

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