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Dear Friends,

2019 has been a landmark year for the International Federation of Psoriasis Associations. IFPA has launched several new initiatives in our Capacity Development Program. We have stacked up several productive meetings with our partners around the world. We have evolved in our approach to project development, communications, and science. With all of these areas bubbling, we are beginning to feel more connected to our regional and national members, partners, and sponsors than ever before. We hope that you are feeling progress too!

There have been so many stand-out moments in 2019. In terms of advocacy, we have had the pleasure of participating in several important events in the past quarter. In February, members of both our Board and Secretariat were glad to attend the annual meeting of the American Academy of Dermatology. There, we were able to host an animated Skin Matters reception with our friends at IADPO. We engaged with stakeholders through our booths at the World Congress of Dermatology in June and EADV in October. Furthermore, at the UN High Level Meeting in September, IFPA and our Global Psoriasis Coalition hosted a side event in partnership with the NCD Alliance. This month, IFPA has launched a new Advocacy Toolkit for Universal Health Coverage to coincide with the global focus on UHC, and to respond to our members’ requests for practical support in defining advocacy campaigns. These are only a few highlights from our packed schedule of advocacy work in 2019. As we make progress towards the next action points on our advocacy journey, we already have many exciting projects on the horizon that we look forward to sharing with you soon!

In early July, at the General Assembly and Members Meeting in Barcelona, IFPA hosted a variety of activities including capacity building workshops, regional meetings, and the election of a new Board. One of the exciting outcomes of this meeting was our new three-year strategy for the World Psoriasis Day themes that will coincide with the tri-annual World Psoriasis & Psoriatic Arthritis Conference. The themes of our current three-year cycle are CONNECTED (2019), INFORMED (2020) and UNITED (2021). For those who were in attendance, we thank you for coming and for sharing your input about IFPA’s new direction. It was a productive and fun meeting, that has led to much growth in our strategies.

With regards to World Psoriasis Day, our Federation membership has impressed us yet again. From marches to flash mobs to mobile clinics and more, your action has made worldwide echoes. The creativity and drive in our psoriasis community is boundless. We can’t congratulate you enough on your fantastic efforts. We look forward to learning more about the planning process of this excellent work in your World Psoriasis Day Reports. Until then, I would like to express just how honored we are to be “connected” with you.

Next year, we look forward to our first-ever regional members meetings. It will be an exciting opportunity to meet with our members in each of IFPA’s four regions, and to engage with them in the real contexts that they represent. We also look forward to launching new initiatives under our Capacity Development Program...
When you have no tools, you have to invent your own

*The first step toward curing PsA is building a diagnostic test.*

by Randy Beranek
*President and CEO*
*National Psoriasis Foundation*

There is a lot we do not know about psoriatic arthritis (PsA). But here is one thing we do know: The more time it takes to reach a diagnosis, the more time PsA can run unchecked through your body.

People with PsA can experience pain, joint stiffness and swelling, and extreme fatigue. If we can reduce the average time to diagnosis, we can reduce the damage untreated PsA does to your joints.

Why do so many people report lengthy delays in getting a diagnosis of psoriatic arthritis? The problem is not necessarily the health care provider. The problem is more likely the health care provider’s lack of tools. There are tests for rheumatoid arthritis and osteoarthritis, but not for psoriatic arthritis. Waiting years to be diagnosed through a process of elimination is not an effective treatment strategy.

The National Psoriasis Foundation is deepening our commitment to finding a cure for psoriasis and psori...
atic arthritis. We cannot yet envision all the mileposts on the road to a cure for PsA, but the first one has to be the creation of a diagnostic test. If your doctor can order a blood test to check your cholesterol or diabetes, why not a similar test to check you for PsA? We call this the PsA Diagnosis Project.

To achieve this, NPF is committed to funding research that will get us to a cure, or as a first step a diagnostic test. Pursuing an interesting idea just because it is interesting is not enough. We need researchers who are willing to take risks. They may fail, but their failures will bring us closer to tools that succeed and treatments that cure.

Are we raising your expectations? Yes. Are we being unrealistic? We do not think so. Improving health outcomes for people with psoriatic disease is at the heart of our mission. To do that, we have to aim higher.

PAINTING THE WORLD ORANGE AND BLUE: IFPA advocacy in 2019

by Elisa Martini
Advocacy and Policy Officer

This year was filled with exciting advocacy moments from IFPA and the Global Psoriasis Coalition on multiple levels. Universal health coverage was the thread binding IFPA advocacy activities together. We presented the theme during the spring webinar, explored the possibilities to use it to advocate for psoriasis during the advocacy workshop at IFPA Members’ Meeting, and ended the year with the publication of the campaign toolkit released on Universal Health Coverage Day on December 12. In terms of events, the highlight of the year was the side-event organized by IFPA and the Global Psoriasis Coalition, in collaboration with the NCD Alliance and in connection with the United Nations high-level meeting on universal health coverage. This side-event featured a panel discussion where panelists explored ways to optimize the health workforce to address shortages and provide adequate and person-centered care for non-communicable diseases. Kathleen Gallant, IFPA Board member, presented psoriasis as a test-case for universal health coverage, as psoriasis requires lifetime care optimally managed by a diverse team of healthcare providers including specialists as well as primary healthcare practitioners. Steven Biskhoff, patient representative from the National Psoriasis Foundation, reported his experience in living with psoriasis while navigating the complexity of the health system. The side-event served as platform to launch a White Paper on Psoriasis and Primary Care, detailing practical recommendations for improving primary care support systems for people living with psoriasis and psoriatic arthritis, and providing case studies on existing innovative models to improve psoriasis care.

Next year, our focus will be on developing the potential that regional networks of IFPA member associations have to offer, and at the same time we will continue the efforts to raise the profile of psoriasis on the global stage. We are planning to extend the toolkit available for psoriasis advocates by introducing a follow-up paper to the psoriasis and primary care report published this year. The upcoming white paper will focus on recommendations on how to build a person-centered type of care for psoriasis. Moreover, we are expecting
the Psoriasis Readiness Index shape and be ready for the end of 2020: the Psoriasis Readiness Index, a deliverable of the Global Psoriasis Coalition, will map the ability of selected health systems to address psoriasis, making it a valuable tool for advocates in the conversation with policymakers.

We are very proud of the successes obtained in 2019 and equally excited to continue this journey together in 2020.

IN THE WORDS OF IFPA: a year in review

by Camille Lancelot
Communications Manager

As 2019 draws to a close, IFPA's Communications department would like to reflect upon everything we have accomplished with you over the past year.

At the start of the year, IFPA revamped its communications strategy, tweaking the roles of each of our communications channels, and even incorporating an Instagram account into our social media portfolio. We shared these updates with our members in March as a part of the IFPA Webinar Series of 2019. On this occasion, we also began discussions with our members about how we could best communicate with our network, and work together to increase all of our communications capacity. The suggestions brought up in March decided our plans for the rest of the year. As requested, we collaborated with Celgene and Novartis to host W2O at the Members Meeting in July. The social media experts at W2O provided one-on-one consultations to our members, advising them in creating campaigns and building enticing content. W2O also joined the IFPA Webinar Series ahead of World Psoriasis Day to give our members useful tips for their social media celebrations.

To expand on World Psoriasis Day, 2019 was also a milestone year in our communications to prepare for October 29th. The toolkit for our 2019 Theme, CONNECTED, came out in April. For the first time, it also included pillars and subthemes designed to make the theme more relevant to each of our member’s contexts. We also distributed a series of prefab graphics and messages for social media to assist in aligning our collective voice. IFPA was thrilled with the remarkable unity and diversity that our community exemplified on World Psoriasis Day. We hope you were too! Furthermore, the WPD Committee created a three-year strategy to respond to our members’ suggestions that the themes and toolkits should come out earlier in the planning process. We are pleased to announce that the themes in 2020 and 2021 will be INFORMED and UNITED, respectively. The logos and toolkits will be revealed shortly after the new year.

As the 2019 closes, we would like to call your attention to a few final productions. The Members Meeting and General Assembly Event Report has already been made available on the Members Page of the IFPA website.
THE NEXT STEP IN PSORIASIS ADVOCACY: Updates on the Global Psoriasis Atlas

by Sicily Mburu

Scientific Officer

The Global Psoriasis Atlas is one of the International Federation of Psoriasis Associations´ (IFPA) long-term project in collaboration with two others leading organisations: The International League of Dermatological Societies (ILDs) and the International Psoriasis Council (IPC). In the past couple of months, the result of our dedicated work with support from researchers and experts at the University of Manchester as well as the University Medical Centre Hamburg-Eppendorf, led to a landmark accomplishment – the online launch of the Atlas.

The grand launch of the Global Psoriasis Atlas website was preceded by engaged discussions headed by the Director-Global Psoriasis Atlas and IFPA was not left behind. Led by our President, Board Members, and Secretariat team we participated in a series of meetings at the 28th EADV (European Academy of Dermatology and Venereology) Congress in Madrid Spain, early October. Further, the Board of Governors, Steering Committee, and Funders partners´ meetings, held side events at the same venue for an in-depth planning of the next phase of the GPA. We also engaged with multiple stakeholders in productive discussions and received updates on the progress of two research Work Streams whose findings support the development of the Atlas. It was a great chance to meet various GPA regional coordinators who presented country-level research highlights, all with the aim to uncover the prevalence of psoriasis and how it affects the individual and society at large.

Finally, the long-anticipated launch of the Global Psoriasis Atlas website took place on World Psoriasis Day, 29th October 2019, and attracted a lot media interest. This launch represents a major milestone following the World Health Assembly resolution in 2014 and WHO publication of the Global Report on Psoriasis in 2016. For the first time, people living with psoriasis and experts in the disease will have a valuable source of information on the latest data and insights on the global burden of psoriasis.

One of the GPA’s aims leading to the launch date has been to improve the understanding of psoriasis among different groups of people globally, while meeting the highest scientific standards of epidemiological data collection and estimation. This first edition of the web-based Atlas goes one step further to present the human face of psoriasis. Esteemed psoriasis advocates from the IFPA community shared their stories on camera to be included with the epidemiological results. IFPA member associations provided feedback after the GPA went online, with one member stating that, “it has been an emotional week since the website went online. The World Psoriasis Day Report is also available on the IFPA website. Finally, our brand new Advocacy Toolkit on Universal Health Coverage was launched on UHC Day last week. We strongly encourage you to explore this resource when designing your upcoming advocacy strategies.

Thank you all for a spectacular year! We wish you seasons greetings, and look forward to exciting communications in 2020.
EXPANDING OUR COMMUNITY: Introducing the Mentorship initiative

by Alice Titialii
Program Officer - Capacity Development

Do you want to be an active part of building the Psoriasis and Psoriatic arthritis community worldwide?

As part of IFPA’s expansion effort to extend the capacity and reach of the Psoriasis and Psoriatic Arthritis community, IFPA is now launching a mentorship initiative to support newly formed PsO/PsA associations.

You can play an important role in expanding our community by being a mentor for new associations applying to be members of IFPA or individuals who are just starting to build a new Psoriasis community in their country! You will be able to share information from your own and your country’s experience and share information on methods, successes and experiences with a mentee through this initiative.

What does it mean to be a mentor?

You will be a contact and support person for someone in the process of starting up a new association, or a newly started association applying to be an IFPA member. You will have one introduction meeting (online or via telephone) with IFPA to get introduced with being a mentor, IFPA will also provide you with information materials that you can share with your mentee. You will then get partnered up with a mentee and form a mentor pair. Each mentor couple should have a minimum of three contact points over the course of one year (each pair will decide for themselves if three is enough or if they want more meetings) and provide IFPA with a short update after each contact.

Find out more about the Atlas on their website:

globalpsoriasisatlas.org
This year’s theme in the global health arena is universal health coverage. Universal health coverage essentially ensures that everyone has access to quality healthcare without suffering financial hardship. This “quality healthcare” insists on acceptable standards in all health services, from prevention, to screening, to treatment and palliative care. On September 23, 2019, the United Nations convened for a high-level meeting on universal health coverage to evaluate the progress and the shortcomings on the path of achieving health for all.

In the 2019 World Psoriasis Day campaign we saw a variety of messages calling for equal access to healthcare and illuminating the cost burden of psoriasis and its co-morbidities. These messages are specifically linked to the theme of universal health coverage. For people with psoriasis, equal access to healthcare means the possibility for everyone, no matter where they live or what their socio-economic status, to have access to healthcare professionals that are prepared to manage psoriasis and its co-morbidities within a reasonable amount of time. One of the problems that must be addressed is the uneven distribution of dermatologists in different regions of the world or even between different regions within one country. A strengthened primary healthcare system or the use of telemedicine can help tackle these disparities.

Another aspect of particular relevance connecting psoriasis and universal health coverage is financial hardship. It is known that psoriasis is associated with high out-of-pocket expenses. Suffering from multiple conditions, especially if these conditions are chronic, further amplifies the individual’s health expenditures,
In response to the global attention on universal health coverage, IFPA has launched an Advocacy Toolkit to guide our community in campaigning for psoriasis and psoriatic arthritis within this arena. You can access the toolkit by visiting the News section of the IFPA website at ifpa.pso.com/news.

All across the globe, many people living with psoriasis experience the lack of adequate distribution of dermatologists and high out-of-pocket expenses. 2020 is the chance for our community to include psoriasis in the global conversation on universal health coverage. Every country can and must do more to improve the lives of people living with psoriasis.

Health is a human right.

MEMBERS IN ACTION: Anniversaries

Remembering to celebrate the big milestones in life is important. Many IFPA members had big anniversaries this year, here is a closer look at how a few of our members celebrated their many years of hard work:

HONG KONG

By Gary Lai

President of Hong Kong Psoriasis Patients Association

Time flies. It is already the 5th anniversary of Hong Kong Psoriasis Patients Association. To celebrate, we launched our first Psoriasis Run/Charity Walk to arouse public awareness and promote World Psoriasis Day in Oct/Nov 2019.

This 5th year marked our first milestone to “build something from nothing”. Five years ago, we started from scratch with no psoriasis patient support group to focus on skin problems. Hong Kong has an unique feature where dermatology services belong to Department of Health while Rheumatology services are provided by the Hospital Authority. The “one country, two systems” phenomena also resembles Hong Kong psoriasis patients plight. When we complain to the Department of Health for biologic treatments, they refer us to the Hospital Authority for help. When we seek help from Hospital Authority assistance, they reject us because they do not provide dermatology service in Hospitals, only at the Department of Health! This situations drove us to seek Government Bureau actions. After a few years of lobbying work, the Department of Health began operating the first Dermatology Biologic clinic in mid 2018.
Acción Psoriasis (www.accionpsoriasis.org) is the Spanish association of people affected by psoriasis and psoriatic arthritis and their relatives, and has been declared a Public Usefulness Entity. Throughout its twenty-five years of existence, it has become one of the most active and participative patients’ associations in Spain.

The organization was founded in 1993 by patients, families, and dermatologists who shared a common vision to provide information, awareness, education, and support to all those affected by psoriasis, psoriatic arthritis, and related conditions.

During the 25 years of Acción Psoriasis’s existence, we have learned to understand and respect the value of local knowledge and drive to take action. We have leveraged this to create sustainable and innovative programmes/activities for the benefit of people with psoriasis and psoriatic arthritis. Identifying committed partners, funding their initiatives, and strengthening their capacity for advocacy has helped us create strong local champions, thereby ensuring political commitment and long-term sustainability.

Our core mission is and will continue being the people's voice who live with both conditions, to empower our patients with the aim of enforcing their rights, to help people to learn to live well with psoriasis and arthritis psoriasics, and to increase their quality of life.

We began the celebration of our 25th anniversary introducing an evolution of our brand identity, simplified, modernized, and optimized for use in digital contexts keeping our key symbols, the sun and the sea which represent our association's values.

On the other side, the events of the 25th anniversary celebration of Acción Psoriasis began in May in a meeting at the Pharmaceutical College of Barcelona between patients, families, and healthcare professionals to discuss psoriasis topics, share knowledge and experiences, to network and motivate each other and continues the celebration developing different activities.

Another relevant activity that Acción Psoriasis made in collaboration with Janssen was the “Buen Camino Project”: a series of documentaries to raise awareness about psoriasis and psoriatic arthritis that collected audiovisual testimonies of ten patients that crossed more than 200 kilometers of the Camino de Santiago. During the trip, two patients describe their experiences with the disease, reflecting on how to carry out daily life as best as possible.

To mark the Buen Camino campaign and coinciding with the 25th anniversary we hosted 2 events, one in Madrid and one in Barcelona to introduce and spread the Buen Camino documentaries through the society aware of these pathologies and the same time promote healthy living habits. In the course of the events, health professionals (dermatologist, a rheumatologist, a psychiatrist and patients), discussed their clinical and personal experience to gain a better multidisciplinary approach to psoriasis care. Both events were moderated by journalist Ana García Lozano, a psoriasis patient.
To celebrate PSONUVES’s 9th anniversary, we held a campaign on social networks. Prizes were given for sharing about our anniversary. These prizes were donated to us by a private company. This was a strategy to encourage the followers of these private companies to participated in this campaign, to know about our association and to like the PSONUVES page, while also learning about psoriasis.

We also celebrated with a festive afternoon with our members where we shared different typical foods from our Salvadoran tradition. Special guests and PSONUVES members attended. There were raffles of gifts and the participation of a musical group.

These 9 years of our organisation have meant the development of great work, together with the members of our association. We have grown a lot as an organisation with different pleasant and unpleasant experiences. These have not discouraged or stopped us in the execution of our work.

It has not been easy to face so much ignorance about this disease and the indifference of health authorities. However, we had many achievements which makes it worthwhile to continue working. In the end, we will improve the quality of life of people with psoriasis and psoriatic arthritis in our country.

We are very satisfied with the achievements we have obtained during the past 9 years. These include:

- 2012 Approval of the National Day of Psoriasis in the year according to Decree 209
- 2013 Phototherapy booth center project in El Salvador presented to Technical Secretary of the Presidency and to the Embassy of Taiwan China as part of our objective “Access to medicines” obtained the donation of 3 phototherapy booths for the three departmental areas of Oriental, Wester, and Central. This treatment is prescribed for psoriasis and 18 other skin diseases.
- 2014 Letter of understanding is presented as an instrument to establish a working alliance between the Ministry of Health of El Salvador and PSONUVES with the objective of working together to benefit people with psoriasis and psoriatic arthritis in El Salvador.
- 2017 First National Congress Human Right to Health focused on psoriasis
- 2018 Signature of letter of understanding on June 8 of this year and development of a clinical guide for psoriasis prepared by the Ministry of Health as a result of a working agreement between PSONUVES and MINSAL. This was published in July of this year.
- 2nd Expert Congress on Autoimmune Diseases associated with psoriasis
- 2 pronouncements in the national and world day of the person with psoriasis of Mrs. Procurator Lic. Raquel Caballero de Guevara

PSONUVES celebrates 9 years with members
Contact Details

Patrik Vuorio
Executive Director
Email: patrik.vuorio@ifpa-pso.com
Tel: +46 70 749 58 20

Sicily Mburu
Science Officer
Email: sicily.mburu@ifpa-pso.com
Tel: +46 73 699 70 05

Elisa Martini
Program Officer - Policy and Advocacy
Email: elisa.martini@ifpa-pso.com
Tel: +46 70 433 73 08

Alice Titialii
Program Officer - Capacity Development
Email: alice.titialii@ifpa-pso.com
Tel: +46 73 940 22 52

Camille Lancelot
Communications Manager
Email: camille.lancelot@ifpa-pso.com
Tel: +46 73 961 15 65

Janina Kostiukaite
Project Developer
Email: janina.kostiukaite@ifpa-pso.com
Tel: +46 73 663 5203

CELEBRATING A MILESTONE YEAR

by Patrik Vuorio
Executive Director

Dear IFPA Friends,

We send you many thanks for a milestone year from the IFPA Secretariat. The close of 2019 represents a key step in our next level journey to create synergies and connections with our members, partners, and stakeholders that will allow us to facilitate maximum impact for the millions of people living with psoriasis and psoriatic arthritis.

We have a new alignment that will carry our work forward in 2020. We anticipate with excitement the great successes that are promised from our digital transformation and our platform of initiatives that will be launched under our portfolio of programs in 2020. We continue growing with a long-term perspective on our next level journey with you.

Thank you for your continued support and hard work for the people living with psoriasis and psoriatic arthritis, and happy holidays.