Psoriasis in the NCD Agenda: The Road to 2018 World Health Assembly Side Event Outcomes Report June 12, 2017

At the 70th session of the World Health Assembly (WHA), the International Federation of Psoriasis Associations (IFPA) convened leaders in psoriasis and NCD advocacy, research, innovation and policy to underline the urgency for cross-sectoral action. Presentations centred around why and how to drive a comprehensive response, and the roles different actors can play to improve the lives of the 125 million living with psoriasis worldwide.

The biggest WHA in history, this advocacy stage is becoming an increasingly important platform for shaping policy and raising awareness. The following summary outlines the key takeaways from the conversation.

The Face of Psoriasis

Psoriasis is a severe, chronic, disabling NCD for which there is no cure. It affects 125 million people –roughly 3 percent of the world population – and inflicts a serious mental, emotional, social and economic toll. Psoriasis demands the attention of and action from the global community, national governments and civil society.

Psoriasis is a Serious, Accelerating Global Health Challenge: The prevalence of psoriasis has been increasing globally, and in some countries, rates have roughly doubled in the last several decades.²

"Psoriasis patients still face significant challenges today. Stigma, poor understanding of psoriasis comorbidities and unequal access to medicine remain barriers to improved living conditions for the 125 million with psoriasis." ~Lars Ettarp, President, IFPA

Intimate Link Exists Between Psoriasis and the Big 4

NCDs: There are mechanisms that link psoriasis to many comorbid diseases – among which are diabetes, cardiovascular diseases, cancers and respiratory diseases – and healthcare strategies addressing psoriasis demand a comorbidity approach.

"Psoriasis plays in the Champions League of diseases." ~Prof. Wolf-Henning Boehncke, Geneva

University Hospitals

Psoriasis Advocates Spread Hope: 125 million worldwide are living in hope for a life without psoriasis. As IFPA Treasurer and global psoriasis activist, Josef de Guzman shared, the search for hope reaches school kids being bullied for being different, parents wanting to end the suffering of their children and adults facing stigmatization while looking for work.

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Securing a Place for Psoriasis in the NCD Agenda

Growing scientific evidence and focused advocacy has led to important policy wins. The 67th WHA adopted the Resolution on Psoriasis in 2014 and the WHO released the Global Report on Psoriasis in 2016 – a relatively rare accomplishment for a single disease area. Both provide guidance for national action. But there is more to be done.

Include Psoriasis in Global and National Action Plans: Psoriasis should be included in both global and national action plans for the prevention and control of NCDs. This will help promote policies like early screening of psoriasis patients. Early screening of psoriasis patients can lead to the detection of comorbid diseases like diabetes and cardiovascular disease, creating the potential to reduce the overall burden of NCDs.

Adopt National Primary Healthcare Approach:

Tackling NCDs like psoriasis requires a patient-centred, primary health care approach that allows for interventions across the life course and promotes healthy behaviours like abstention from tobacco use, responsible alcohol consumption, healthy diets and physical activity.

"It is time to include psoriasis in the global response to NCDs. At the NCD Alliance, we are dedicated to working with IFPA and others to unite the NCD community in making NCD prevention and reduction a global priority. Psoriasis belongs in this movement."

~ José Luis Castro, President, NCD Alliance

Address Appendix III of the Director-General's Report A70/27:

Additional criteria should be used when selecting interventions, including the impact on health equity. Appendix III should also be strengthened with the recommendations and indications from the WHO Global Report on Psoriasis from 2016.

"The main goal for psoriasis advocacy efforts should be to have a more focused voice to policymakers. Look at how HIV advocacy progressed and changed policy – people with HIV were the main force to drive down the price of medicines. The WHO stands committed to support and work with the psoriasis community on achieving the goals set out in the Global Report on Psoriasis."

~Dr. Cherian Varghese, Coordinator for Management of NCDs, WHO

Invest in Psoriasis; It Pays: A study conducted in Spain concludes that for every 1 EUR invested in psoriasis, the social return on investment (SROI) is 5 EUR.³ Investing in psoriasis will not only benefit patients, but will also improve the sustainability of strained health systems.

National Approaches to Psoriasis

Many countries appreciate the human toll of psoriasis and are taking action to change the lives of their citizens living with the disease. Five Permanent Missions – Argentina, Ecuador, Panama, Qatar and the Philippines – endorsed the side event and sent representatives to signal their ongoing commitment to psoriasis advocacy. Several key policy themes emerged from the discussion:

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Increase Access and Improve Quality: A critical factor to reducing the prevalence of NCD-related deaths is increasing access to medical assistance and improving quality of care.

Evaluate Disease Impact: Conducting comprehensive evaluations of disease impact on health systems – mortality rates, disabilities, financial burden – can help countries channel limited resources in an economically and socially beneficial way.

Develop Participatory and Integrated Strategies: Solutions for tackling psoriasis must address the far-reaching impact – physical, emotional, psychological – of the disease and promote understanding and acceptance.

"It is imperative that the governments of the world support initiatives that sensitize people to psoriasis and promote awareness. In Panama, we support World Psoriasis Day in order to do more for those suffering from the disease."

~H.E. Miguel Mayo,, Minister of Health, Ministry of Health, Panama "The Ministry of my country is working hard to set priorities regarding NCDs – a critical issue at both the national and global levels."

~ Ms. Jorgelina Costanzi, Director of the National Department for International Affairs, Ministry of Health, Argentina "Our national policy motivation on NCDs is to reduce morbidity and mortality, to prioritize health promotion and to generate efficient, quality and equitable health care."

~ Dr. Fernando Cornejo, Vice-Minister, Ministry of Health, Ecuador

A Global Psoriasis Coalition Advocating for Change

To build on advocacy successes and national momentum, IFPA launched the Global Psoriasis Coalition – a targeted response to the WHO call to action that patients' organisations and civil society hold governments to account. The Coalition had its official kick-off at the WHA side event and showcased important details about its purpose, intended impact and benefits to members.

All In for 125 Million: The Global Psoriasis Coalition is a united front of diverse voices committed to focusing global health conversations on psoriasis, fostering behavioural change and creating opportunities for action that will improve the lives of the 125 million living with psoriasis worldwide.

Advocates for Action: The Global Psoriasis Coalition will promote several policy actions and targeted interventions at the individual, healthcare community, government and societal levels. Three key priorities include:

- 1. The inclusion of psoriasis in comprehensive national and global NCD strategies;
- The promotion of early screening of psoriasis patients for diabetes and cardiovascular diseases in the revision of the WHO Global NCD Action Plan (2013 - 2020); and

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3. Allocation of resources for services that holistically address the physical, functional and psychosocial disabilities related to psoriasis and its comorbid NCDs.

Benefits of Membership: Any organisation or institution interested in improving the

lives of those living with psoriasis and cooperating across borders, disease areas, and sectors should consider joining the Global Psoriasis Coalition. The benefits are many:

- 1. Engagement with a network of like-minded organisations;
- 2. Membership in an incubator for followon partnerships between members;
- 3. Being part of an expert group that takes a hands-on approach in advocacy and proactively engages in discussions at the UN/WHO level;

"While the WHO Resolution and the Global Psoriasis Report are excellent advocacy tools, they are not binding and their implementation is dependent on the moral responsibility of the Member States. The Global Psoriasis Coalition recognizes the need for global psoriasis advocacy to take the next step."

~Sophie Andersson, Executive Director, IFPA

- 4. Being part of a united and powerful voice that aims to change lives by changing policies;
- 5. Putting expertise to use in the development of resources and advocacy actions;
- 6. Access to coordinated, professional messaging for exclusive stakeholder convenings;
- 7. Elevated profile in local, national, regional and global advocacy and policy platforms; and
- 8. Elevated visibility to a wide range of NGOs, healthcare professionals and decision makers.

Next Steps

As follow-up to the convening, IFPA – in coordination with the International Alliance of Patients' Organizations – submitted a "Statement on Agenda Item 15.1 – Preparation for the third High-level Meeting of the General Assembly on the Prevention and Control of Non-Communicable Diseases, to be held in 2018."

The statement endorsed the updated Appendix III of the Director-General's report A70/27 and called for additional areas of research to be identified by the WHO that could support the further implementation of the interventions listed in Appendix III.

On the road to 2018, IFPA and the Global Psoriasis Coalition will continue their efforts to drive action on the national, regional and global stage, and will take steps aimed at successful participation at the WHO Global Conference on NCDs in October 2017 in Uruguay.

Thank You to Our Presenters

Welcome Remarks

• Lars Ettarp, President, International Federation of Psoriasis Associations

Remarks from Permanent Missions

- Jorgelina Costanzi, Director of the National Department for International Affairs, Ministry of Health, Argentina
- Fernando Cornejo, Vice-Minister, Ministry of Health, Ecuador
- H.E. Miguel Mayo, Minister of Health, Ministry of Health, Panama

Introduction – Global Report on Psoriasis

 Cherian Varghese, Coordinator for Management of NCDs, World Health Organization

Why the Global Psoriasis Coalition is the Next Step in Psoriasis Advocacy

 Sophie Andersson, Executive Director, International Federation of Psoriasis Associations

The NCD Policy Landscape: Addressing Psoriasis within a Comprehensive NCD Response

José Luis Castro, President, NCD Alliance

Psoriasis: Diversity - Comorbidity - Needs

 Wolf-Henning Boehncke, Chairman of the Division of Dermatology and Venerology, Geneva University Hospitals

Social Return on Investment in an Ideal Approach to Psoriasis: Report on Results 2016

• María Merino, Health Outcomes Research Manager, Max Weber Institute

Patients' Call for Action

Josef de Guzman, Treasurer, International Federation of Psoriasis Associations;
 Patient and Activist

About the International Federation of Psoriasis Associations

The International Federation of Psoriasis Associations (IFPA) unites 56 member organisations in 54 countries and 4 regional organisations. For the past 45 years, IFPA has sought to resolve the challenges facing the international psoriasis community. In response to developments in the global NCD agenda, IFPA recently launched the Global Psoriasis Coalition.

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About the Global Psoriasis Coalition

The Global Psoriasis Coalition joins stakeholders from medical societies, non-governmental organisations, foundations, corporate partners and other relevant associations from across borders, across disease areas, and across sectors to improve the lives of the 125 million people worldwide living with psoriasis. A programme of the International Federation of Psoriasis Associations (IFPA), the Coalition promotes the inclusion of psoriasis in comprehensive global and national NCD strategies. Members of the Global Psoriasis Coalition are committed to addressing the impacts of psoriasis by adopting an integrated approach at the intersection of policy, research, advocacy, and care, and going all in for 125 million.

¹ "Addressing NCD Comorbidities – Shared Opportunities for Action." International Federation of Psoriasis Associations and NCD Alliance. 2017.

² Global report on psoriasis. World Health Organization. 2016. http://apps.who.int/iris/bitstream/10665/204417/1/9789241565189_eng.pdf

³ "Retorno Social de la Inversion de un abordaje ideal de la psoriasis." Accion Psoriasis and Max Weber Institute. 2016. http://www.accionpsoriasis.org/vivetupiel/public/Informe-Proyecto-SROI-PSORIASIS.pdf