The road to the WHO psoriasis resolution: advocating for a better understanding of psoriasis as a global health challenge

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International Federation of

Psoriasis Associations

INTERNATIONAL FEDERATION OF PSORIASIS ASSOCIATIONS

IFPA – The creation of a global organization

INTERNATIONAL FEDERATION OF PSORIASIS ASSOCIATIONS

Priority 1: Becoming a trustworthy and respected international psoriasis patient organization

Priority 2: Changing the view of psoriasis as a disease to reflect its high impact on the individual and on society

Priority 3: Assisting the development of national psoriasis patient associations

Priority 4: Raising awareness of psoriasis among the general public, policy makers and healthcare professionals

Priority 1: creating the organization

1972: The Nordic psoriasis patient associations together with the UK association form the **International Federation of Psoriasis Associations** to advance all efforts made to lessen the suffering of people with psoriasis and to improve the methods of treatment and research for finding the ultimate cause and cure for the disease.

2007: IFPA creates a permanent Secretariat in Stockholm, Sweden to administrate and further develop a rapidly growing organization

2015: IFPA has 55 national member associations in 53 countries, covering all geographic regions

Priority 2: changing the view of psoriasis

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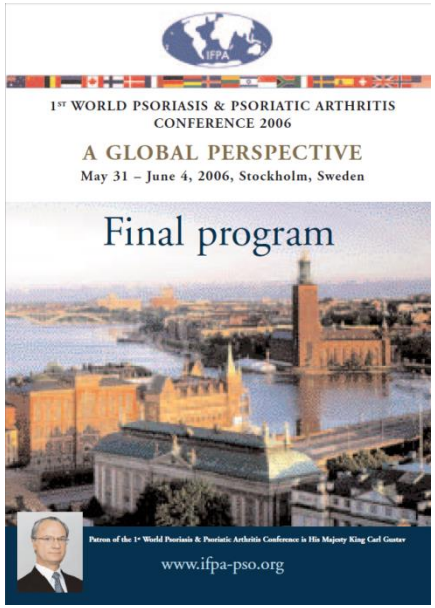
- IFPA identified a need for a forum to discuss all aspects of psoriasis
- Decided in 2003 to create a new platform for medical education on psoriasis and psoriatic arthritis
- 1st World Psoriasis & Psoriatic Arthritis Conference held in Stockholm 2006
  - Quality of life, function and participation
  - Clinical research including treatment and epidemiology
  - Immunology and biology



World Psoriasis & Psoriatic Arthritis Conferences

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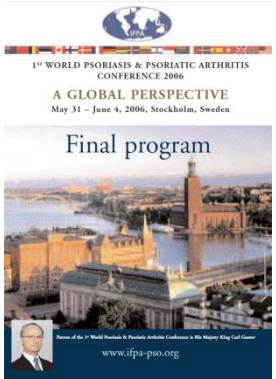
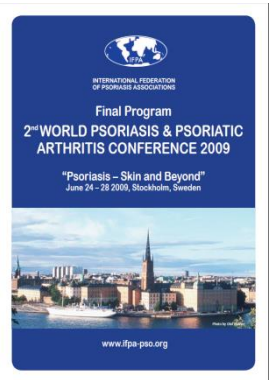
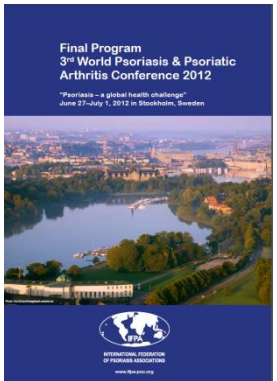
Objectives:

- To **increase global recognition of the seriousness of the diseases** and to develop a broader international perspective of psoriasis and psoriatic arthritis
- To **encourage collaboration** on developing future research and advocacy initiatives
- To **increase awareness** by medical professionals and industry of the role of IFPA and its members in assisting the medical advancement in psoriasis and psoriatic arthritis







Priority 3: Assisting the development of national psoriasis patient associations

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2002-2003

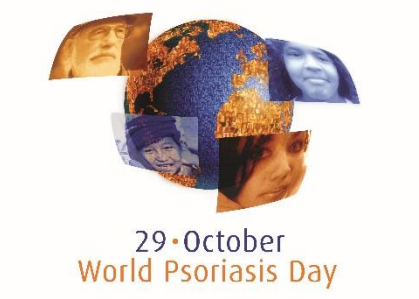
- IFPA's Executive Committee decides that IFPA's main activity should be to promote formation of new national psoriasis patient associations
- Partnership with Swedish psoriasis associations on a twinning project in Africa. Letter to the Swedish embassies in Africa and Asia in order to find interested doctors who could help IFPA to start patient associations in the region.
- First meeting in Sydney with patient representatives from African countries and Singapore and Australia/New Zealand.
- IFPA holds a General Assembly and a psoriasis conference for doctors and patient representatives in Cape Town

2004

- First annual **World Psoriasis Day Supporters Training meeting** is held to help psoriasis patient associations with strategies for raising awareness of psoriasis and national advocacy

Priority 4: Raising awareness of psoriasis

- **General public**
  - **2004:** **World Psoriasis Day**, October 29, is celebrated for the first time



- **Policy makers, UN and WHO**
  - **2006:** IFPA identified need to advocate for psoriasis on a national and global level, to gain recognition of psoriasis as a serious, chronic noncommunicable disease

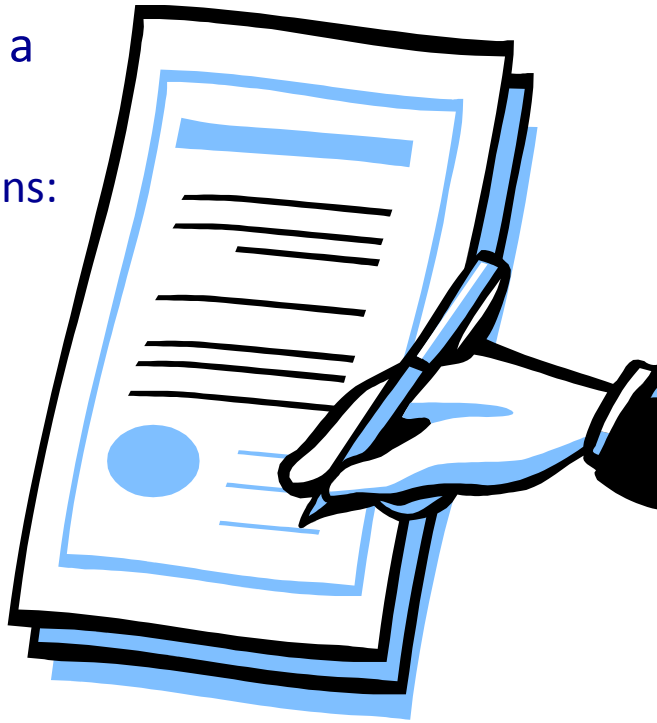
What is a resolution?

- A resolution is a **motion** within an organization that seeks to **address** and **resolve** important issues

Why is it important?

- A WHO resolution is a **powerful recommendation** to the WHO member states to **address issues** within a **specific disease area**

  Examples of other disease areas addressed by resolutions:
  - Viral hepatitis
  - Diabetes
  - Autism Spectrum Disorders



Why was the WHO Psoriasis resolution needed?

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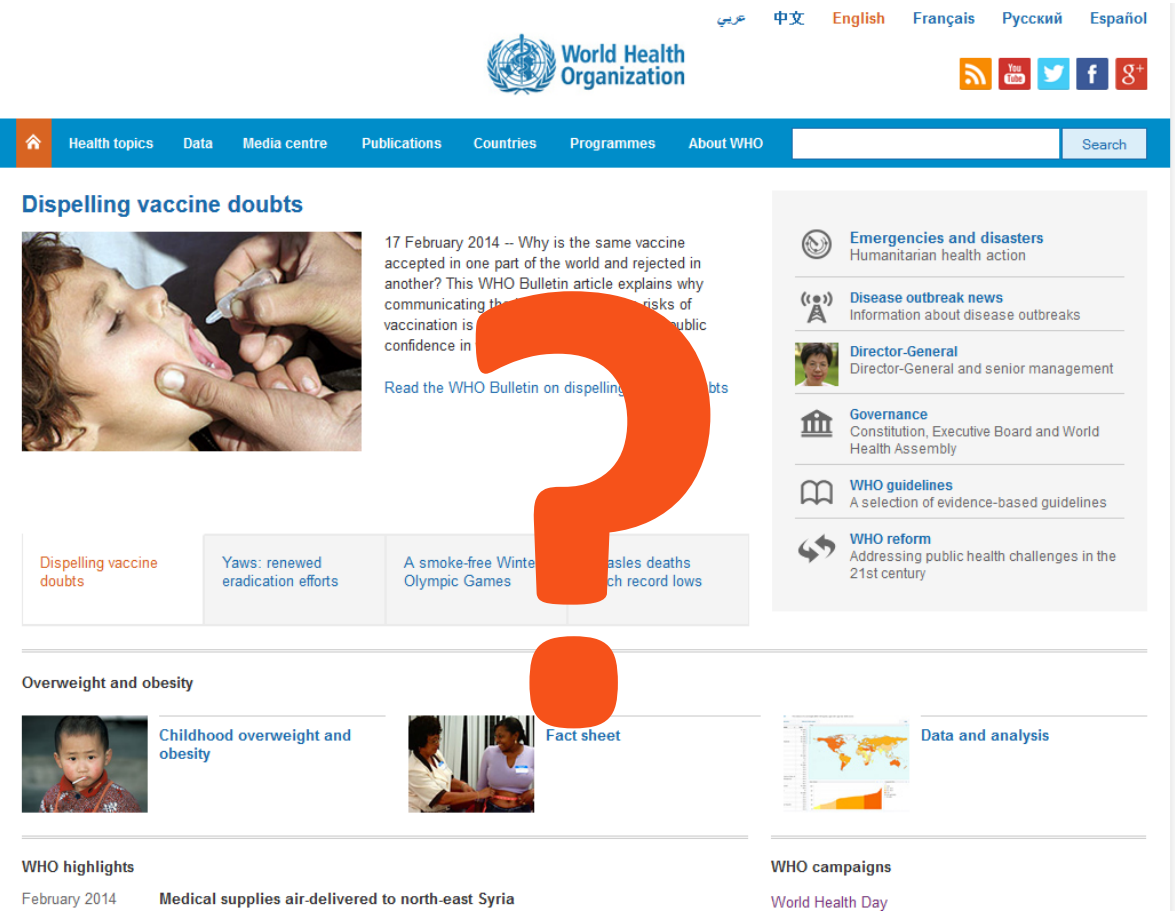

1. Psoriasis could not be found on the global agenda
2. There was very little knowledge of psoriasis on among WHO Member States
3. There was no information on psoriasis on WHO websites
4. There was no official recognition of psoriasis as a serious, non-contagious, chronic disease with big impact on both the individual and society

Why were the World Psoriasis & Psoriatic Arthritis Conferences vital for success?

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- **2006** conference reached consensus on the connection between psoriasis and psoriatic arthritis, and the systemic nature of the diseases
- **2009:** Sent IFPA/Psoriasis report and requests to, based on new research/evidence presented at 2nd World Psoriasis & Psoriatic Arthritis Conference
- **2012:** IFPA launched campaign to ”Put psoriasis on the agenda now” at 3rd World Psoriasis & Psoriatic Arthritis Conference
- 3rd World Conference gave even more evidence of the systemic nature of the disease and confirmed that it is indeed a global health challenge

There is hope for a better future

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Great advances have been made – both in diagnostics and therapeutics

Scientific

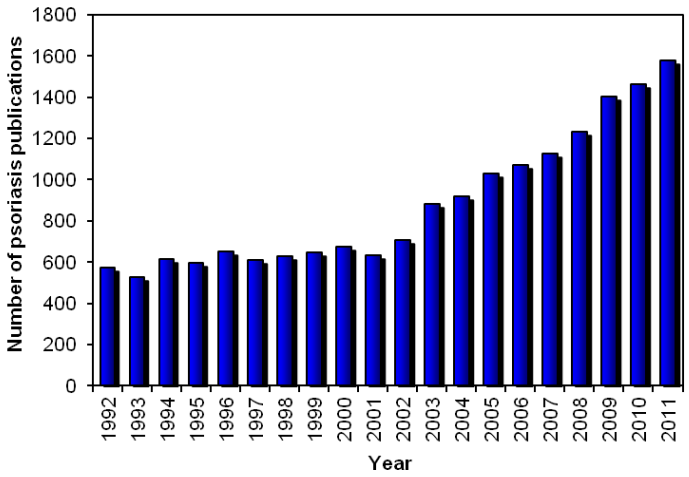
Genetics, immunology, comorbidities

Medical

Breakthrough treatments for psoriasis and psoriatic arthritis

Technological

Screening and scanning methods



M Ståhle, presentation at the 3rd World Psoriasis & Psoriatic Arthritis Conference, 2012

1916 Dithranol/cignolin
1958 Methotrexate
1971 PUVA
1979 Cyclosporin
1980 Fumal Acid
1986 Vitamin D
2003 Biologics
2012 Small molecules

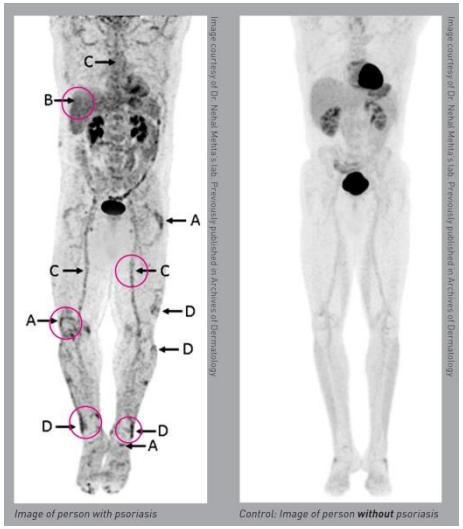


Image: Courtesy of Dr Nehal Mehta's lab and the National Psoriasis Foundation

New evidence

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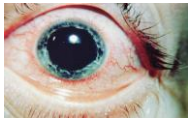
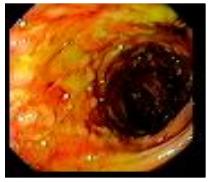
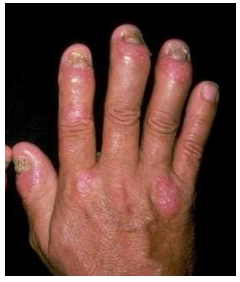
Eye inflammation
Iritis/uveitis, episcleritis

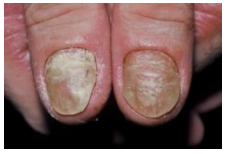




Crohn's disease **9.6–11%**
Ulcerative colitis **5.7%**

Psoriatic arthritis **7–30%**
- Peripheral arthritis
- Spondylitis/sacroileitis
- Dactylitis/tenosynovialitis
- Enthesitis
- Osteitis/periostitis





Nail involvement

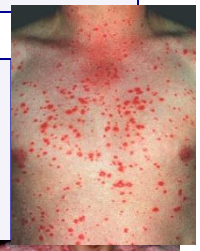
Psychological effect:
- Reactive depression
- Suicidal ideation
- Alcoholism
- Stigmatization

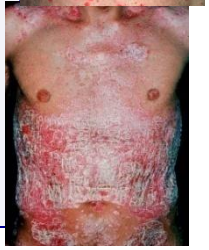
Metabolic syndrome:
⇒ Increased cardio-vascular mortality

Lipometabolic disorders
- Cholesterol
- Triglycerides
- Apolipoproteins

Psoriasis vulgaris
- Guttate psoriasis
- Chronic plaque psoriasis

Special forms
- Psoriasis pustulosa generalisata
- Acrodermatitis continua supp
- Psoriasis pustulosa palmoplantaris
- Psoriatic erythroderma
- Inverse psoriasis





The resolution timeline

Panama – the first national ”psoriasis champion”

HE Ambassador of the Panama Permanent Mission to the UN in Geneva, Alberto Navarro-Brin;

IFPA: President Lars Ettarp and IFPA EC Secretary and Chair Task Force on NCDs Kathleen Gallant

Dr. Felix Bonilla, Secretary General of Panama Ministry of Health;

Panama Psoriasis Foundation: President Monica de Chapman and Director Ana Teresa Meneses

May 2013 – WHA Psoriasis Side Event

INTERNATIONAL FEDERATION OF PSORIASIS ASSOCIATIONS

66th World Health Assembly Side Event:

Recognizing psoriasis as a serious, chronic autoimmune, non-communicable disease of high impact in people's lives

The role of the WHO Executive Board and the World Health Assembly in putting psoriasis on the global health agenda
H.E. Mr Alberto Navarro Brin, Permanent Representative of Panama

Understanding psoriasis as a chronic non-communicable disease
Dr. Shanthi Mendis, Director a.i., Department of Management of Noncommunicable Diseases, World Health Organization

Living with psoriasis – the patient's view on a global issue
Ms. Barbra Bohannan, Director of Communications, International Federation of Psoriasis Associations

Why is psoriasis a global health challenge?
Prof. Dr. Peter van de Kerkhof, President of the International Psoriasis Council, Radboud University, Nijmegen

Psoriasis – more than skin deep
Prof. Dr. Henning Boehncke, President of GRAPPA (Group for Research and Assessment of Psoriasis and Psoriatic Arthritis), Université de Genève, Geneva

World Psoriasis Day gives psoriasis patients a voice and lets them know they are not alone
Mr. Lars Ettarp, President of International Federation of Psoriasis Association

Questions and answers – panel

Closing remarks

May 27, 2013
Room XXIV, Palais des Nations, Bldg E
12.30 - 14.00
A light snack lunch will be served from 12.00
Translation: English, French and Spanish

Resolution co-sponsors Argentina, Ecuador and Panama arrange a side event on psoriasis together with IFPA

The adoption of the psoriasis resolution – a historic step for the international psoriasis community!

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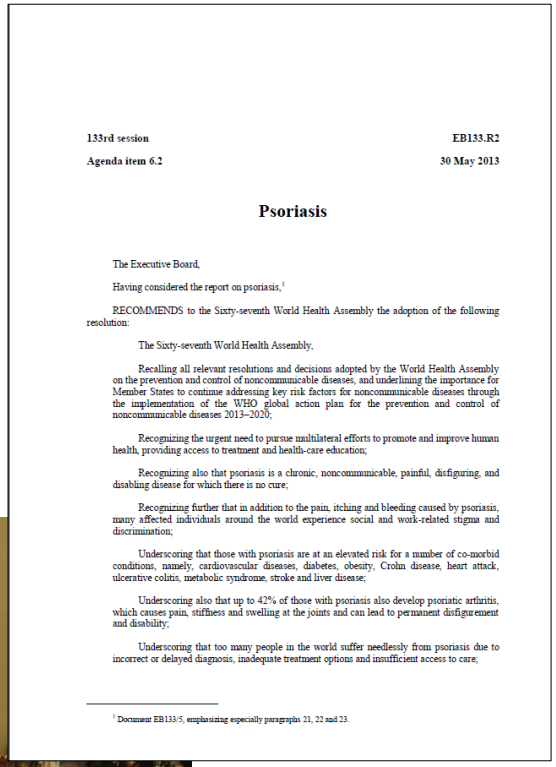


133rd session EB133.R2

Agenda item 6.2 30 May 2013

Psoriasis

The Executive Board,

Having considered the report on psoriasis,[1]

RECOMMENDS to the Sixty-seventh World Health Assembly the adoption of the following resolution:

The Sixty-seventh World Health Assembly,

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;

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;

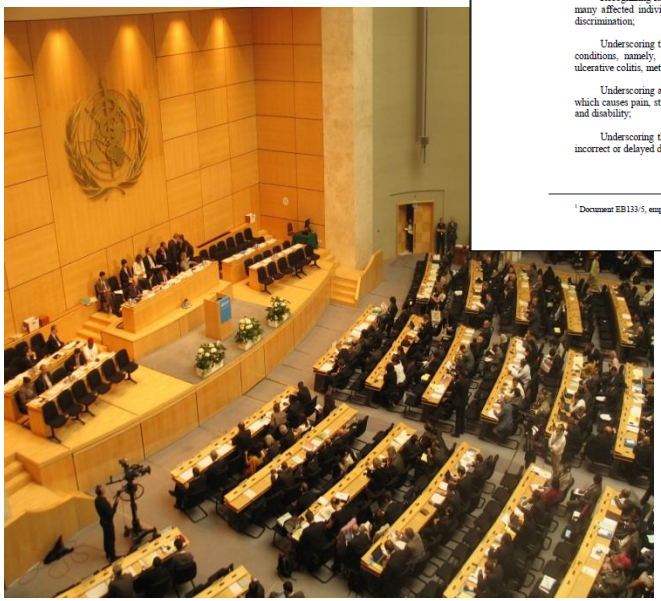
Recognizing further that in addition to the pain, itching and bleeding caused by psoriasis, many affected individuals around the world experience social and work-related stigma and discrimination;

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;

[1] Document EB133/5, emphasizing especially paragraphs 21, 22 and 23.



In May 2014, the 67th World Health Assembly adopted the Psoriasis resolution!

The Psoriasis resolution was under the leadership of Panama, Ecuador, Argentina, and Qatar.

The resolution was co-sponsored by Algeria, Angola, Barbados, Chile, Costa Rica, El Salvador, Egypt, Georgia, Guatemala, Honduras, Indonesia, Libya, Maldives, Morocco, Nigeria, Paraguay, Philippines, Sudan, Suriname, Timor-Leste, Uruguay, Venezuela and Viet Nam.

What is the psoriasis resolution?

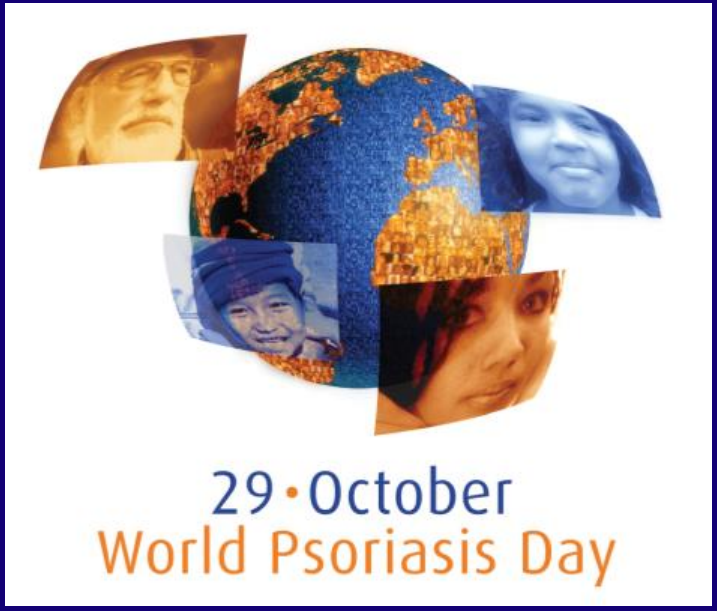
Recognizes psoriasis as a **"chronic, noncommunicable, painful, disfiguring, and disabling disease for which there is no cure."**

Acknowledges the **physical**, **psycho-social** and **socio-economic** impacts of psoriasis.

Acknowledges the connections to disabling **psoriatic arthritis** and the elevated risk of other, serious **co-morbid conditions**

Acknowledges the needless suffering due to **insufficient access to care**.

What's next?



IFPA monitors and stays in contact with WHO to ensure that the WHO Secretariat implement the resolution (WHO psoriasis report and information about psoriasis on its website)

IFPA member associations work actively around the world to ensure that the resolution is implemented in their national health policies and frameworks

The resolution calls to action by

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recognizing the many activities for psoriasis awareness that are carried out all over the world on **29 October** and encourages the WHO member states to further engage in advocacy efforts to raise awareness

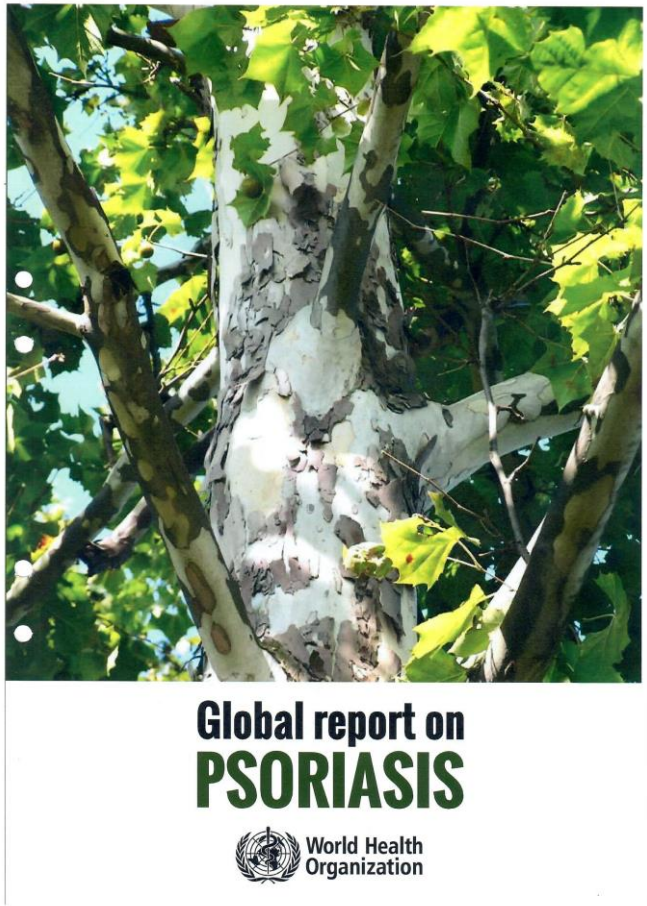
requesting WHO to publish a global report on psoriasis, including the global incidence and prevalence and identifying approaches for integrating the management of psoriasis into existing services for noncommunicable diseases

requesting WHO to include information about psoriasis, its treatment and care on the WHO website to further the awareness and knowledge of psoriasis

Encourages governments to partner with patient associations to **raise awareness** about psoriasis, thereby prompting the Health Ministry to see how psoriasis and psoriatic arthritis affects citizens and society, i.e. economically

A report will **activate WHO to collect data on psoriasis**, producing a true picture of incidence, prevalence, access, and therefore health economics

Information about psoriasis and psoriatic arthritis **on WHO's website will be accessible to all**. Information on the website will help raise awareness, elevate the priority of psoriasis and be a resource to inform patients, the general public, health care providers and governments.



Acknowledgements

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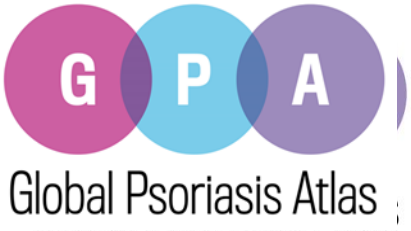
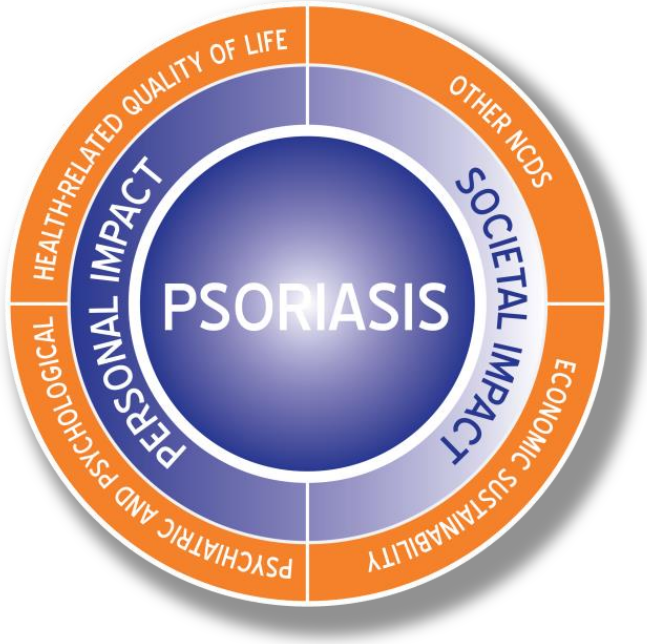


- The need is underlined in the WHO Psoriasis resolution
- International Atlas Consortium formed between IFPA, International League of Dermatological Societies (LDS) International Psoriasis Council (IPC)
- Long term project
- Almost all large and recognized NCD:s diseases Global Atlas
- Reports: Prevalence of the World, different types of the disease, severity, comorbidities, etc.
- Diabetes is the most elaborate Atlas. Has now published version 7th
- The need is illustrated in the WHO resolution
- Consortium agreed between IFPA, International League of Dermatological Societies International Psoriasis Council (IPC)
- Long term Project. Almost all large and well recognized NCD diseases have their own Global Atlas . Reports: Prevalence of the World, regions and countries, different types of the disease, severity, comorbidities,
- Diabetes is the most elaborate Atlas currently, has now published version 7th.

Four main areas of still unmeet needs :

1. Implementation of the WHO Psoriasis resolution in national laws / regulations
2. Proper diagnosis of psoriasis and psoriatic arthritis
3. Effective and affordable treatment of psoriasis and psoriatic arthritis
4. Managing the burden of disease



In conclusion

- Build up a credible and recognized international organization.
- Have a clear, understandable and consolidated message.
- Build up the scientific support in order to underpin your demands.
- Create alliances.
- Please be patient, many obstacles are waiting along the road.

INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

Thank you