Psoriasis - a serious, and common, disease

Psoriasis has a major impact on health-related quality of life that is comparable to other major chronic diseases.

Psoriasis is associated with a variety of psychiatric and psychological difficulties.

People with psoriasis have an increased risk of other non-communicable diseases (NCDs).

Psoriasis imposes a substantial economic burden on the individual and society.
Impact on quality of life

Physical burden
- Itch
- Pain
- Discomfort
- Lack of sleep
- Painful or time-consuming treatments

Social burden
- Embarrassment
- Self-stigma
- Avoidance as coping measure
- Time-consuming
Psychosocial impact

Stigma
- 77% report stigmatisation
- Seen as unclean or contagious
- Suffer abuse, rejection

Discrimination
- 65% report discrimination
  - School and work
  - Social settings
  - Public and private amenities

Psychological impact
- Low self-esteem
- Depression
- Suicidal ideation
Comorbidities

- Psoriatic arthritis
- Hypertension
- Obesity
- Metabolic syndrome
- Cardiovascular disease
- Diabetes type II
- Crohn’s disease
- Liver disease
- ...etc...
Economic impact

- High cost of treatment
- High rate of absenteeism from school/work due to illness or time-consuming treatments
- Restricted career choices
...and a global health challenge
Where is psoriasis on the global health agenda?
Since 2009, IFPA, psoriasis associations and medical societies worldwide have been working to get the WHO to acknowledge psoriasis and recognize it as a serious disease...

...how?
A national champion steps up – and a psoriasis resolution is born

"... the Government of Panama wants to suggest that psoriasis is considered as a serious, auto-immune, non-contagious, chronic, exhausting, worldwide disease, which impacts the patient’s life. We propose to declare October 29 as World Psoriasis Day..."

Dr Eduardo Mora
Previous Director General of Public Health of Panama
65th World Health Assembly, May 2012
Resolution acknowledges burden of psoriasis

**Why is this important?**

States that the World Health Assembly has passed relevant resolutions and decisions regarding noncommunicable diseases (NCDs) and highlights psoriasis as a serious NCD, where previously psoriasis has not been mentioned.

Highlights the impacts of psoriasis and underscores that too many people are suffering from the condition, and why.

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

Acknowledges the physical, psychosocial 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.
Calls to action also important

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.

**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
What can this resolution achieve?

- Resolution accepted by 67th World Health Assembly
- Helps **raise awareness** of psoriasis as a **serious**, inflammatory, immune mediated disease and as the **global health challenge** it truly is
- Provides a platform for disseminating **information** about psoriasis
- Helps **eliminate ignorance, misconceptions** and thereby also **stigmatization** and **discrimination**
What is IFPA?

• A non-profit umbrella organisation of psoriasis associations
• Today IFPA has **50 national member associations**
• IFPA has **three regional members** – AsiaPacific, Europe and Latin America, with a regional member in Africa under development

What is our mission?
To be the **unifying, global voice** of all psoriasis associations, **supporting, strengthening** and **promoting their cause** at an international level
IFPA’s “three pillars”

**Awareness**
- World Psoriasis Day, October 29
- Outreach – printed and social media
- “Under the Spotlight” documentary project
- Media workshops

**Advocacy**
- Consultative status UN Economic and Social Council
- Frequent contacts with WHO
- Member of IAPO
- Advocacy training for members

**Education**
- Annual member meetings
- Scientific conferences every three years focused on psoriasis & psoriatic arthritis
- Information material, online and printed
Priority:
Gathering evidence by creating a Global Psoriasis Atlas

Answering a call to action

"...draw attention to the public health impact of psoriasis and to publish a global report on psoriasis, including the global incidence and prevalence, emphasizing the need for further research on psoriasis..."

Extract from draft resolution EB133/CONF./2 WHO Executive Board, 2013

"Studies on the prevalence and incidence of psoriasis have contributed to a better understanding of the burden of the disease. However, further research is required to fill existing gaps in understanding the epidemiology of psoriasis and trends in incidence over time"

Epidemiology of psoriasis states, 2013

April 2014 – official announcement of joint partnership between IFPA, ILDS and IPC to initiate Global Psoriasis Atlas project
Atlases have worked for other disease areas

Diabetes
IDF Diabetes Atlas (Print and electronic)

CVD
Global atlas on cardiovascular disease prevention and control
Global Atlas on heart disease & stroke

Mental health
Global atlas on mental health (Print)

ARI
Acute respiratory infections atlas (Print)

Other Health Atlases
WHO Global Health Expenditure Atlas
Tobacco Atlas
Cancer Atlas
Example: The IDF Diabetes Atlas over 14 years

- **2000**: 1st Edition
- **2003**: 2nd Edition
- **2005**: 3rd Edition
- **2009**: 4th Edition
- **2011**: 5th Edition
- **2012**: 5th Edition update
- **2013**: 6th Edition

**Milestones**

- **Diabetes awarded priority status by WHO**
- **2006 UN Resolution on World Diabetes Day**
- **2006 UN Resolution on World Diabetes Day**
- **WHO starts citing IDF Atlas numbers**
- **Increased global focus on prevention and access to treatment**
- **Diabetes recognised as a threat to global development**

**New WHO initiatives for prevention and monitoring**

**Countries start developing national diabetes plans**

**Increased global focus on prevention and access to treatment**

**Diabetes recognised as a threat to global development**
What do we want to achieve?

1. Build a robust evidence base
2. Encourage collection of data and research into psoriasis that could ultimately lead to better use of resources
3. Unite all stakeholders on one mutually beneficial agenda
4. Enable benchmarking within and between countries
No one can do it alone...

...but together we can build a better world for people with psoriasis!
Read more about IFPA, the WHO psoriasis resolution and what you can do to help on www.ifpa-psp.org

Thank you!