







# Multinational Patient Advocacy Organizations Develop Framework on How to Improve the Care of People Living with Psoriasis and Psoriatic Arthritis

Consensus Statement Supports Adoption of Psoriasis Resolution by the World Health Organization (WHO) at Upcoming 67<sup>th</sup> World Health Assembly

[Stockholm, May 13, 2014]

The International Federation of Psoriasis Associations (IFPA), European Federation of Psoriasis Associations (EUROPSO), National Psoriasis Foundation (NPF) and The Arthritis Society today issued a joint consensus statement to provide a framework addressing the unmet needs faced by the over 125 million people living worldwide with psoriasis and psoriatic arthritis.

This initiative represents a first-of-its-kind collaboration between international and national advocacy organizations dedicated to psoriasis and psoriatic arthritis to address areas of unmet needs and issue a unified call-to-action. The consensus statement provides key stakeholders with a roadmap on how to improve the standards of care for people with psoriasis and psoriatic arthritis so that they may live full and healthy lives.

"The burden of psoriasis and psoriatic arthritis is significant, and yet throughout the world there is a vast variation in the quality of care patients receive," said Joanne Simons, chief mission officer, The Arthritis Society. "It is therefore critical that we raise awareness of the impact of these often debilitating diseases, and work to provide real solutions to meet the needs of people affected by them."

The consensus statement outlines how key stakeholders can come together to:

- Reduce the time to diagnosis of psoriasis and psoriatic arthritis
- Improve treatment of psoriasis and psoriatic arthritis, including access to medical specialists and medications
- Assist patients, caregivers and medical professionals in managing the burden of these diseases

The full consensus statement can be viewed for free at <a href="http://www.ifpapso.org/web/page.aspx?refid=274">http://www.ifpapso.org/web/page.aspx?refid=274</a>

"Despite the fact that psoriasis and psoriatic arthritis are serious chronic diseases with a significant impact on quality of life, they are not recognized by both global and national health authorities and their effects are often ignored," said Randy Beranek, president and CEO, National Psoriasis Foundation. "We want to send a message to healthcare organizations and professionals, regulatory bodies, industry, governments, academia and patient advocacy groups that greater attention and resources need to be allocated to this patient population."

Highlighted in the consensus statement is the need for psoriasis and psoriatic arthritis to be recognized as distinct, serious diseases by key decision makers in order to ensure appropriate support services and research funding are dedicated to this population. Specifically, the consensus statement supports adoption of a resolution that will be voted on at the upcoming 67th World Health Assembly of the World Health Organization (WHO) in May which would result in psoriasis being recognized as a serious

noncommunicable disease (NCD) that needs greater public awareness of its inflammatory nature, psychosocial impacts and shared risk factors with other NCDs.

"The passing of the WHO resolution will be an important step forward in ensuring that the actions outlined by this patient advocacy group-led consensus statement are addressed on a global scale," said Lars Ettarp, president, International Federation of Psoriasis Associations. "We encourage any group or person dedicated to psoriasis and psoriatic arthritis to take action with us to ensure these serious conditions, which often are associated with life-long complications, receive the recognition they need."

### **About Psoriasis and Psoriatic Arthritis**

Psoriasis is a chronic, autoimmune disease that appears on the skin. Up to 30 percent of people with psoriasis will develop psoriatic arthritis, a form of inflammatory arthritis that attacks the joints and tendons. There is a severe burden on people who live with psoriasis and psoriatic arthritis. Psoriasis is largely regarded by as treatable skin complaint; however, nearly 60 percent of people with psoriasis report their disease as a significant problem in their everyday life. These diseases are also associated with serious comorbidities that can reduce life expectancy such as high blood pressure and diabetes. In addition, the associated stigmas of these diseases lead to depression in many people and can heavily impact life choices, for example, career decisions and personal relationships.

### **About International Federation of Psoriasis Associations**

IFPA is the non-profit umbrella organization for the majority of psoriasis associations from around the world. Today IFPA has 50 member associations covering all regions of 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 the more than 125 million people who live with psoriasis and/or psoriatic arthritis. IFPA is actively campaigning for recognition of psoriasis as a serious, noncommunicable disease by the World Health Organization's member states. You can read more about IFPA, our members and our activities on our website www.ifpa-pso.org.

#### **About European Federation of Psoriasis Associations**

Founded in November 1988, EUROPSO is a non-profit and non-governmental umbrella organization gathering 24 national patients associations operating in Europe. EUROPSO's core mission is to raise awareness of the psycho-social, medical and financial needs of psoriasis patients in Europe. Our aims are to:

- Strive for social and economic integration of psoriasis patients in Europe by dispelling prejudices, and all other forms of discrimination against psoriasis sufferers.
- Foster and improve treatment of psoriasis, and stimulate research into the causes and consequences of psoriasis.
- Promote contacts and co-operation between the national psoriasis associations and other organizations pursuing equivalent aims.
- Improve the quality of life of psoriasis patients and their families.
- Obtain recognition from the European Union and other European or international institutions.

More information can be found at www.europso.eu.

## **About National Psoriasis Foundation**

National Psoriasis Foundation is the world's largest nonprofit organization serving those with psoriasis and psoriatic arthritis. Our priority is to provide the information and services people need to take control of their condition, while increasing research to find a cure. In addition to serving more than 2.1

million people annually through our patient and professional health education and advocacy initiatives, NPF has funded more than \$10 million in psoriatic disease research grants and fellowships. Learn more about the NPF at www.psoriasis.org or call 800.723.9166. Follow the Foundation on Facebook and Twitter.

## **About The Arthritis Society**

The Arthritis Society has been setting lives in motion for over 65 years. Dedicated to a vision of living well while creating a future without arthritis, The Society is Canada's principal health charity providing education, programs and support to the over 4.6 million Canadians living with arthritis. Since its founding in 1948, The Society has been the largest non-government funder of arthritis research in Canada, investing more than \$185 million in projects that have led to breakthroughs in the diagnosis, treatment and care of people with arthritis. The Arthritis Society is accredited under Imagine Canada's Standards Program. For more information about The Arthritis Society and to make a donation, visit www.arthritis.ca.

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