European Federation of Psoriasis Associations – EUOPSO

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A Short History

Common confidence in the possibilities of a European cooperation led to the foundation of EUOPSO by the psoriasis associations of the Netherlands, Great Britain, France, Germany, and Belgium in 1988. The organisation was registered in Rotterdam. After this, the activities led to launching the annual conferences with themes such as some special type of treatment (e.g. fumaric acid), or the problems of a special group (elderly people, children). In the years that followed, more and more associations became members of EUOPSO. At the beginning of 2004, EUOPSO included, in addition to its founding countries, associations from Spain, Italy, Slovakia, the Czech Republic, Estonia, Latvia, Finland, Norway, Sweden, Iceland, Denmark, Poland, Switzerland, and Bulgaria.

During these years, the organisation has published circular letters for members and booklets about its conferences; in 1993 'Fumaric Acid Compound Therapy', in 1996 'Nursing Psoriasis'.

Over a period of 2 years, EUOPSO participated in the Helios 2 programme of the European Commission. Otherwise, financing of the organisation has relied on sponsoring.

In 2002, the organisation initiated a wide survey on psoriasis and its treatment in various European countries. The results of the widest study so far concerning psoriatic patients in the world (90,000 patients) throw light on the treatment and situation of patients all over Europe. Publication of the results of the EUOPSO Quality of Life Survey still continues.

Organisation of the Associations

EUOPSO arranges its General Assemblies every third year. The next General Assembly will be in Helsinki in June 2004. Between these meetings, the Board is leading the Federation. In addition to the circular letters to its members, EUOPSO

maintains a website (www.euopso.org). The rules, booklets and meetings of EUOPSO are in English.

On the Associations

The largest member association in EUOPSO is the 40-year-old Swedish Psoriasis Association, with about 20,000 patient members, the smallest one is the Estonian Psoriasis Association with 160 members. Due to different reasons, there are two psoriatic associations in Belgium, Italy, and Spain, each. Taken together, about 100,000 psoriasis patients are organised. EUOPSO is member of the European Disability Forum.

Scientific Council

The members of the EUOPSO Scientific Council are Prof. Annamari Ranki, Helsinki, Prof. Louis Dubertret, Paris, Prof. Ulrich Mrowietz, Kiel, Prof. Peter van de Kerkhof, Nijmegen, Prof. Jean-Marie Naeyaert, Gent, and Prof. Sergio Chimenti, Rome. These people, invited as experts, have also shown their great mindfulness towards patient activities at the respective national levels.

Vision

EUOPSO has the vision to act as the voice, ambassador and negotiator of the psoriasis patient associations, especially at the supranational level of health authorities and their organisations, of health-related professions, associations and enterprises, and of the media. EUOPSO has given strong support to the European Dermatology Forum, EDF, and its agenda. EUOPSO has received generous support from the European Academy of Dermatology and Venereology, EADV, in connection with its annual conferences.

Mission

In order to see its visions fulfilled, EUOPSO sees as its outbound mission to raise awareness among all Europeans of the psychosocial, medical and financial needs of psoriasis patients, and to influence the political and administrative policies and the decision makers.

The inbound mission of EUOPSO is to bundle and boost the efforts of the member associations, acting as their inspirer, stimulator, coordinator, and point of exchange, as a necessary basis for the outbound mission.

Measures and Objectives of the Years to Come

According to its objectives, EUOPSO tries to help found associations for psoriasis patients in every European country. These objectives also include the growth of the respective patient associations.

At its meeting in Rome, EUOPSO paid special attention to the fact that, at the European level, there is no institute specialized in psoriasis. To establish such an institute, as well as to obtain cheap literature aimed to European psoriatic patients, are further objectives of EUOPSO. Enhancing research on and treatment of psoriasis arthritis is also considered very important. Among the organised psoriatic patients, one out of three has a diagnosed arthritis, and more than half of them are known to suffer from its symptoms.

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