

## THE ACTIVITY OF THE PSORIASIS ASSOCIATION IN LUBLIN

**The Psoriasis Association** is the national organisation for people affected by psoriasis including patients, families and health professionals. The Association, based in Lublin, was founded and officially registered in 1993. Its activity is based on the statutory aims. The main purpose of setting up this organisation was the co-operation with the health service in improving the knowledge about the causes of the illness its course, the modern methods of treatments (especially at home), co-operation with associations whose aim is to work for the ill, and, above all, the integration of people in need.

At the end of 1993, we began a series of cyclic meetings of members and supporters/sympathizers of the Association, at which doctors of dermatology delivered lectures on issues related to psoriasis. We share our own experience through discussing our illness and treatment cases. We endeavour to make sure that our members and supporters/sympathizers are fully informed in the questions and problems bothering them. We are learning to live with psoriasis; especially because it is easier to do so as a member of a group rather than alone.

Representatives of companies producing medication for psoriasis are invited to our meetings, at which the effectiveness of the offered products are discussed and presented. Some of the companies have supported the Association financially. We invite and establish contact with doctors of other specializations.

Another form of help for sufferers is through the media, for example: radio and television interviews, at which members of the Head Office of the Association speak about its aims and types of activity. We also talk about the tolerance and its lack in our society. We explain that it is not an infectious illness; that it belongs to a type of cosmetic illness, which makes it non-threatening to others.

We are receiving many letters from around the country, from those touched by the illness asking for help and advice on treating psoriasis. As a result of our media campaign and hard work, many branches of our Association have been set up all over the country. One of the very first branches was set up in Konin, that activity spreads all over the Great Poland district. Successive branches were set up in the following cities: Rzeszów, Białystok, Kielce, Olsztyn, and finally, in Radom. The Association's other form of activity was to organise a few sanatorium stays in Nałęczów (located in the South of Poland) for members of the Association and its supporters.

One of the Lublin Psoriasis Association's ambitions was to enter an international forum and get in contact with other countries and their related organisations. We were successful in this owing to the information about the Association's existence being published on one of the sponsor's website – *Schering* company. In June 2001, a representative of the Head Office in Lublin was invited to a plenary session in Rome. The organiser of the session was the European Federation of Psoriasis Associations (**EUROPSO**) with its head office in Helsinki. The delegate was the Chairman of the Psoriasis Association in Lublin. The purpose of the session was to elect **EUROPSO** representatives, to make changes in its statutes and admit new members.

**EUROPSO** was founded in November 1988 in Rotterdam and brings together 18 Member States of the European Union. The founding countries were Belgium, France, Great Britain, Germany and the Netherlands. One of the aims of the program was to affiliate the countries from outside the European Union to the fellowship. It was decided by a unanimous vote, that the Polish Psoriasis Association (based in Lublin) would be admitted to the body of **EUROPSO**. The advantage of the participation of the Chairman of the PPA at this meeting was the opportunity of making contact with other international associations, as well as the exchange of experience, aiming to deepen the knowledge on the issue of treating psoriasis and the activity of this type of social organisation.

In 2003, the Association received the grand prize in the prestigious competition organised by **EUROPSO** and funded by the pharmaceutical concern *Biogen*. The purpose of this competition was to present the new treatment methods and ultimately improve the quality of life of those touched by psoriasis. The project in which we propose to connect dermatological treatment with psychotherapy was unanimously selected out of nine others proposed by Associations from: Great Britain, Sweden, Denmark, Italy, Iceland, Finland, Belgium Germany and France. Due to the funds received along with the reward, we have carried out a number of meetings having a psychological-therapeutic character for all volunteers in our region.

In November 2005, a representative of our Association took part in the next **EUROPSO** report-election meeting. As a result, we have a representative in the newly established committee which works on promoting knowledge and research about psoriasis with particular emphasis on quality of life and the needs of patients. The project will be presented to the authorities of the European Union. Another representative of ours was elected for the

Committee of Associations in the Middle- and East-European countries to support Associations in these countries.

Another important decision made at this meeting was to support the setting up of the European Psoriasis Therapy Centre in Nice through **EUROPSO** (commencement of this activity was planned for the year 2007).

Since October 2006, the Lublin Psoriasis Association belongs to the organisation World Psoriasis Day (WPD). Thanks to the measures taken by WPD, the 29th October was declared as *World Psoriasis Day* and our Association contributed to the commemorations. We translated into Polish and signed a petition online, which was forwarded to the World Health Organisation in order to bring the problem of psoriasis to the public attention of the whole World.

In May 2009, we became a full member of **IFPA** (International Federation of Psoriasis Association), an organisation bringing together associations from around the world. We are the 33rd Member State.

On October 3, 2009, a nationwide conference of associations for people affected by psoriasis took place in Lublin with the participation of organisations from the following cities: Bydgoszcz, Gdansk, Poznan, Wroclaw, Konin, Radom and Kielce. Also in attendance were: National Consultant in the field of dermatology Professor Andrzej Kaszuba, Professor Wiesław Gliński, guest of honor - President Europso Otffrid Hillmann and Adam Borzęcki (Phd). As the goal is common, which is helping patients suffering from psoriasis and other skin diseases, it was decided to create a Union of Associations of people affected by psoriasis. The new organisation will mainly represent the interests of all patients and request that the Ministry of Health and the NFZ (English equivalent – NHS), provide treatment with biological drugs for psoriasis and enter psoriasis in to the registry of chronic diseases (petition).

On October 26, 2009, in Warsaw, at the PAP Press Center, a press conference was held on the occasion of World Psoriasis Day. The organiser of the conference on behalf of the Association was the National Consultant in the field of Dermatology and Venereology, Professor Andrzej Kaszuba, together with the National Team of Experts on Dermatology. The conference was focused on bringing the huge problems of patients with this disease to the public's attention and requesting that the institutions responsible for health care provide the treatment that could significantly improve the quality of life for sufferers of psoriasis. After

the conference, representatives of associations appearing as the Union of Associations on behalf of the patients signed a petition addressed to: the Minister of Health, the President of the National Health Fund and Director of AOTM, and the National Consultant for Dermatology and Venereology.

**The petition requested the following:**

- to consider the possibility of increased financial aid for the costs of the biological psoriasis drug, as it is not possible for these to be met by the patient alone because of the high price.
- the inclusion of the most seriously ill on a psoriasis drug program (NFZ) to guarantee access to treatment and reimbursement of expenses,
- the re-classification of psoriasis on the list of chronic diseases.

The Association has also sent a written appeal to the Minister of Health signed on behalf of doctors by Professor Kaszuba - National Consultant, and on behalf of patients by Janusz Jagiełło - coordinator of the Union of Associations.

**The appeal asked for:**

- the establishment in Poland of a long-term strategy for the treatment of patients with psoriasis.
- the implementation of standards developed taking into account modern therapeutic methods of treatment.
- providing Polish patients access to biological therapies.

**If you would like further information please contact us on:**

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**We invite you to cooperate !!!**

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