

Second meeting: Sophia-Antipolis, InterPSO

France 4–5 April 2002

The second meeting of InterPSO, The International Network of People with Psoriasis, took place in April 2002, and was attended by representatives of patient associations from Belgium, France, Germany and the UK. Representatives from Galderma (France) were also present.

As you may recall from the previous report on InterPSO, it provides a forum for patient groups to discuss topics of common interest and to achieve common goals. Giving patients a chance to influence the development of psoriasis treatments at an early stage, and should increase the likelihood of obtaining treatments to suit patients' lifestyles. It also gives Galderma a unique opportunity to enhance their understanding of patients' needs.

The Patient Associations

United Kingdom

David Chandler outlined the work of the Psoriatic Arthropathy Alliance (PAA).

France

The activities of the Association pour la Lutte Contre le Psoriasis (APLCP, France) were described by Michèle Corvest. The APLCP was founded in 1983 and now has more than 15,000 members in 15 regional chapters. The APLCP produces four bulletins per year and holds many regional conferences and a national congress, every 2 years.

Belgium

Eddy Swolfs summarized the work of the Vlaamse Vereniging

van Psoriasis Patiënten (VVPP, Belgium), which was founded in 1982, and now has 1500 members. Association activities include a three-monthly information bulletin, two films, meetings and information sessions. The VVPP supports patients and defends their interests in various ways including organizing social events (e.g. swimming sessions) and visits, listening to patients, working with families, cooperating with physicians and pharmacists, contacts with the ministry of social affairs and supporting the creation of daycare centres. The VVPP tries to counter the taboo of a skin disease through publicity activities, and encourages research.

Germany

The work of the Deutscher Psoriasis Bund (DPB, Germany) was presented by Hans-Detlev Kunz. This national self-help group for psoriasis patients was founded in 1973 by doctors and now has more than 9000 members. DPB achievements include acceptance by the professional dermatology association as the voice of people with psoriasis, increasing the range of treatments available under statutory health insurance, supporting genetic research, producing a 3-monthly journal for members and dermatologists, producing treatment calendars and providing patient brochures for psoriasis treatment products. More than 45 local groups enable members to meet, and regular

events include a psoriasis day every 2 years.

Formulation in dermatology

(Laurent Fredon, Sandrine Orsoni, Alain Brzokewicz)

Members of the formulation team at Galderma discussed the principles of formulating products for topical treatment. The most important considerations are pharmaceutical requirements and 'cosmetic' acceptability to patients. Formulations for psoriasis, include solutions, shampoos or foams for the scalp, and lotions, creams, ointments, or perhaps gels for the body; the advantages and disadvantages of such formulations were considered. A better understanding of patient needs would assist the development of improved treatments.

Galenics wish list

Delegates discussed their ideas about the best topical formulations. Different formulations are needed for different lifestyle needs. Twice-daily treatment is not always practical since time is limited in the morning, and dermatologists appear to be unaware of this preference for once-daily treatment. Patients should discuss these aspects with dermatologists but there is not always time to do so. Delegates considered safety to be a priority. They noted that they are not given details of all the products available when they visit their doctors and that doctors themselves are not always aware of all the options. Some patients find alternative treatments more attractive, regardless of their effectiveness, perhaps because of their perceived lack of side-effects and ready availability.

Checklist for patients

The patient delegates were asked to think about what should be included in a checklist for patients going to their doctors. They listed questions patients should not forget to ask and suggestions of relevant information patients should tell doctors. These suggestions will be amalgamated to form a comprehensive checklist.

Observational study of compliance with topical treatments for psoriasis

It was proposed that a study of the adherence of patients to topical treatments, carried out by sending out questionnaires to the patient members, would be a valuable joint venture for InterPSO. Medications are dispensed with the expectation that they will be taken exactly as prescribed, but most patients do not follow their doctors' directions. For example, 77% of patients comply with oral medication regimens when the treatment is designed to cure a disease (e.g. antibiotics for an infection) and only 50% comply when medication is to be taken over a long period. The figures for topical drugs might be worse or better depending on various factors. The reasons why patients do not comply with their treatments may be related to the nature of their disease, the medication and its side effects, and a variety of other factors. Compliance is difficult to assess since patients tend to exaggerate their own compliance or non-compliance. The proposed study would evaluate patient compliance with their topical treatments for psoriasis.

A questionnaire would be completed by psoriasis patients, aged at least 18 years, who were currently using topical treatments for psoriasis. The aim would be to obtain completed questionnaires from around 200 patients from each of the five countries currently included in InterPSO (Belgium, France, Germany, the Netherlands and the UK) questionnaires. The results would be analysed for each individual country and for all of the countries together. The questionnaire will be short to encourage patients to complete it, and would include questions in the following categories:

- sociodemographic characteristics
- your disease
- topical treatment characteristics
- adherence to treatment
- additional questions

It was agreed that questionnaires would be sent out in the autumn.

Galenics laboratory demonstrations and testing of formulations

Delegates saw demonstrations in the galenics laboratory of the

preparation of emulsions, ointments and gels. They were asked to test these formulations, to evaluate their sensory qualities (e.g. greasiness, ease of spreading, oily effect) and to give their preferences.

Galderma research on psoriasis treatments in brief

Galderma researchers are using sophisticated up-to-date techniques to identify the many genes involved in psoriasis, each of which is a potential target for future treatment. Galderma also has other drugs in development, in addition to their new natural vitamin D drug, calcitriol (Silkis®), and are researching potential immunological treatments.

Summary

The delegates found it valuable to meet and exchange ideas, and were enthusiastic about the prospect of the joint activities. Suggested topics for the next meeting included presentations (from patient delegates) on how the healthcare systems of their countries work for psoriasis patients, together with discussions on developing future treatments for psoriasis and psoriatic arthritis.

