

REPORT



Present: Jean-François Stalder, Danielle Marcoux, Roberto Takaoka, Mette Deleuran, Sue Lewis-Jones, Valeria Aoki, Marco Ambonati.

What's been done in 2008 ?

The POSCORAD was presented to the non-European teams. For material reasons (ethics committees and launching costs) the 21 investigating centres were chosen inside Europe.

The training material for training the patients on POSCORAD was put on line and is available for everybody : « Assess your eczema » <http://opened-dermatology.com/>

A preliminary report was published in « Dermatology » (pdf).

Suggestions were made concerning extending this study in the future to different ethnic groups ; asiatic and black populations. Moreover, Sue questioned the reliability of this POSCORAD when done at different times.

In Kyoto, Roberto allowed us to share a stimulating experience with the participation of various associations. This has led to us redesigning the site with the inclusion in particular of the Brazilian experience.

We modified certain aspects of the web site : we are launching a French version and there is now a page dedicated to patients; "Patient's Page" with a presentation of "My Adorable son" <http://opened-dermatology.com/>



Workshop in Kyoto



French version of the web site



Illustrated version of "My Adorable Son"

What is on going ?

Concerning the international developments. Each person spoke about the projects of their particular teams. Mette and Sue spoke about the fact that they are training 'over the counter' pharmacists.

Valéria and Roberto have developed patient support groups who meet one Saturday per month and they are organising an International Symposium on AD organised by AADA <http://www.simposioaada2009.org.br/objetivos.php>

Danielle has organised discovery camps with the help of Stiefel Laboratories Inc. The first camp will be held this summer.

All the projects are explained in the responses to the questionnaires launched at the end of 2008 concerning the following points :

1. Have there been any new developments in patient education for atopic dermatitis, in your country, in 2008 (research programs, new atopic schools/education centres, publications, partnerships, congresses)?
2. Have there been any new developments in patient education for other dermatology pathologies?
3. Could you *briefly* describe the patient education activity in your centre in 2008?
4. Have there been any new developments/projects in your centre since the beginning of the year?
5. What difficulties have you encountered in developing patient education in your centre (recruitment, training, integration of p.e. in the hospital...)?
6. Could you *briefly* outline your objectives/projects for the coming year?

The review paper on Patient Education in Europe has not been forgotten! The EADV journal is still in the pipeline...

Where are we going ?

"SET UP Dermatology" (Practical Initiation to Patient Education for Dermatologists) has been proposed to the Pierre Fabre foundation. This is a project to introduce the practical concept of patient education to dermatologists.

The first step is a French-language self training programme. It's objective is to increase awareness of chronic cutaneous disease among dermatologists, GPs, medical students and nurses.

The material will be presented as videocasts of clinical situations and will lead to an initiation in making an educational diagnosis and proposing a care contract in clinical practice.

The proposition was made that it would be good to think about how to involve teenagers in patient education and how to use tools that they are familiar with (video clips, facebook, i-pod etc.) There is a growing demand for this group which is different to the other initiatives.

The experience of Danielle with the camps could be very interesting in relation to this question.

Clinical Research projects:

The impact of patient education on treatment adhesion was discussed. Treatment adhesion is of course a global problem, particularly concerning topical treatments. Considering the difficulty in evaluating the real adhesion to a treatment, the idea of using electronic caps was supported as a principal evaluation tool. This project is to be developed and Pierre Fabre is ready to consider helping with the setting up of this project, particularly in relation to the supply of the electronic Material.

The calendar of the next meetings :

The idea of a bi-annual meeting was agreed upon. In 2009 the two opportunities are San Francisco and Berlin.

Finally it was noted the exceptional atmosphere of mutual collaboration and sharing of experience within the group of experts involved in OPENED Dermatology. It is a sign of the commitment of all concerned to the common cause of patient education and is a good sign of future success!

Jean-François Stalder

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