



Oriented Patient Education Network in Dermatology

www.opened-dermatology.com

Report OPENED meeting AAD Miami March 2010

Park Central Miami Beach, 06 March 2010.

Present : L Eichenfield, (San Diego, US), R Takaoka, (Sao Paulo, Brazil), C Paul, (Toulouse, France), JF Stalder, S Barbarot, JM Chavigny, (Nantes, France), Danielle Marcoux, (Montreal, Quebec), C Henry (Lyon, France), P Vabre (Dijon, France), N Beneton (Le Mans, France), M Ambonati (P. Fabre, France) ? Excused : P Lio (Chicago, US).

Present : L Eichenfield, (San Diego, US), R Takaoka, (Sao Paulo, Brazil), C Paule, (Toulouse, France), JF Stalder, S Barbarot, JM Chavigny, (Nantes, France), Danielle Marcoux, (Montreal, Quebec), C Henry (Lyon, France), P Vabre (Dijon, France), M Ambonati (P. Fabre, France)
Excused : P Lio (Chicago, US).

This meeting was made possible by the Fondation Dermatite Atopique and the help of **Dr Marco Ambonati**, medical director of Aderma-Ducray, who was present at the meeting.

After the initial presentations, the objective of the meeting was to exchange information on each other's experience and to reflect on possible common projects in the field of TPE. For the first time we met our US colleagues (Larry and Peter). They talked about their experience.

At San Diego, for example, **Larry Eichenfield** runs weekend sessions every 2 months. Larry emphasised the central role that the family support groups and patient associations play, as well as the web site www.eczemacenter.org. This web site proposes information on eczema and assistance for patients : reinforcement of the medical team's message, specific training, wet wrapping... The funding of this program depends entirely on the help of the families and

the associations as neither the hospital nor the university fund the program. The information and the communication is handled by the associations and they exploit social networking tools such as Facebook to this effect. The team is composed of doctors and nurses. There are no psychologists involved.

Peter Lio, from Chicago, who couldn't make the meeting, met **JF Stalder** the next day. He has developed a collective education program which has involved more than 100 patients in the last year. Sessions are organised mixing children and adults, also combining siblings and spouses. Doctors, nurses and guest speakers give the workshops. The content includes basic understanding of eczema, treatment, answering basic questions, and even support. He has created a nice web site, www.eczemacarecenter.com, and his team also work with the allergy team.

Roberto Takaoka organises a collective education session one Saturday per month. He underlined the difficulty of involving dermatologists in these sessions. However he has no problem filling his sessions with patients thanks to the key rôle the patient associations play.

Carle Paul in Toulouse, brought his experience in the field of Psoriasis to the meeting. His team is made up of doctors and nurses who are trained in patient education. He is at the origin of a clinical research project in the field of Patient Education for Psoriatic patients.

Danielle Marcoux has been developing an Atopic school in Quebec, modelled on the German schools, for many years now. She has obtained the recognition of her education program within her hospital department at St Justine with the help of pharmaceutical labs.

Sébastien Barbarot and **Jean-Marc Chavigny** brought their experience in Nantes where individual and collective education sessions are organised with the help of trained nurses and psychologist. The education workshops are organised by age group which sometimes results in there not being enough participants. The centre is recognised as an « educational functional unit » within the Dermatology department. Atopic dermatitis, psoriasis and food allergy are the themes involved.

Pierre Vabre is a paediatric dermatologist and is concerned specifically by patients with genodermatosis. He is in touch with patient associations and would like to develop education in the management of genodermatosis patients.

Catherine Henry works in the Lyon University Hospital in the Allergy department. Education is carried out for atopic dermatitis patients in the context of daycare.

To summarise

The following principles were agreed :

- Experience in TPE varies according to each country and culture.
- There is no perfect model of patient education and TPE is not really integrated into the care process (except maybe in France), even though the concept of TPE for chronic dermatoses is consensual worldwide.

- Today, in most countries we lack evaluation methods to evaluate the impact of education programs and so we lack (except maybe in Germany) a clear medico-economic approach to education.

Future perspectives

- The development of the POSCORAD tool could be a pertinent patient-centred way to evaluate the impact of patient education. In the next few weeks/months, a software dedicated to patient self scoring will be available and will be distributed by the lab Aderma-Ducray. A multi-centre study could be envisaged in the near future.
- In the meantime, all participants have agreed to produce an overview of the state of TPE around the world to be submitted for publication to «Paediatric Dermatology ». This article would summarise the survey of the various worldwide centres operating TPE programs. This survey is already available on the web site <http://opened-dermatology.com>. Peter Lio and Larry Eichenfield agreed to answer this survey.

Agenda

- The next meeting, organised by the « Fondation Dermatite Atopique », will take place at Toulouse, the 24-25 June 2010. It would be interesting for the group to meet again at this occasion to formalise the previous mentioned article.
- During the next Rajka meeting in Munich (22-23 July 2010), Roberto Takaoka suggests to organise a joint meeting as he had done for the previous Kyoto meeting.
- Marco Ambonati proposes to send the English version of the POSCORAD software as soon as it's available.

Many thanks to all concerned for a fruitful exchange.

Jean-François Stalder, Alan Ball

Nantes, March 16 2010.