

Newsletter #1 February 2011

Dear friends,

Welcome to the first newsletter of the OPENED network. We hope to use this newsletter as a (twice yearly) platform for exchange and information. We will update you with what has been happening recently in the field of TPE, we will inform you of ongoing projects and we will try to outline where we are going in the future. We will launch pertinent questions now and then in the hope of having your feedback and of course we welcome any contributions in the form of news, events, comments. This newsletter with your comments will be included in the opened web site next month.

Best regards,

Jean-François Stalder.

During the AAD meeting in New Orleans, USA this month we held an OPENED Dermatology meeting with 14 participants at the Marriott Hotel on Saturday morning 05 February.

This brunch meeting was kindly organised by A-DERMA.

At this meeting we discussed various points:

What has been going on since 2010 ?

- The first international TPE workshop in Toulouse, in 2010, brought together the majority of the participants of the previous meeting in Miami. This meeting was a success concerning both the objective of sharing experiences and the quality of the exchanges. Two articles, inspired by this meeting are in progress at this time.
- After a round the table survey, we found that three different formats are generally used in education programmes today:
 1. Individual consultations:
 - In some centers this is the first contact the patient has with the eczema center (San Diego, Nantes, Milan).
 - In other centers the individual consultations follow a collective meeting (Chicago).

These individual sessions are often linked with a nurse's demonstration.

2. Collective sessions with structured teams (German model) developed in Brussels, Montreal, Nantes...

3. Larger meetings with more participants; organised monthly (Chicago) or twice a year (Denmark).

What is ongoing today?

After the first enthusiastic step there is general consensus that it is difficult to motivate patients to participate in educational programs. Despite proposing different time slots and types of session, the patients are more and more reluctant to come and participate in these sessions.

Suggestions made:

- Integrate education workshops into a one-day hospitalisation.
- Propose other programs dedicated to Allergic contact dermatitis or food allergy.
- Use video demonstration
- Constitute groups mixing new participants and patients who have already participated in workshops.
- Rename the process; “education” is not an attractive concept for patients.
- Develop a marketing approach to find a better way to convince patients and their families to participate in education programs.

Other issues:

- Working with teenagers is often difficult.
- Use NTIC; using Web 2.0 with teens has good results in Diabetes and the integration of Web 2.0 and social networks among known patients has been proposed (Chicago, Nantes)
- The PO-SCORAD tool is still only available on CD format but it will soon be possible for patients to download the widget in order to carry out a self-assessment. This program is carried out by A-DERMA.

Evaluation tools (of which PO-SCORAD is a part) should also be developed and shared. A Cortico-phobia index is in the process of being created (Italy, France). This point is important and needs to be developed in the future...

And where are we going?

- Future events:
 - **WCD 2011**, Seoul, Korea, 26 May. “Atopic dermatitis educational program for parents and patients”
 - **2nd International meeting for TPE in AD**: Rome, 29/30/31 June.
 - **HOME meeting**, 6/7 June, Amsterdam.
 - **Journée Dermatologique de Paris**, December. “Education thérapeutique en pratique libérale”
- The pending publications:
 - “Patient-Oriented SCORAD (PO-SCORAD): a new self assessment scale in atopic dermatitis validated in Europe”, in press at “Allergy” (2011),
 - “Therapeutic education in atopic dermatitis: worldwide experiences”, submitted to the British Journal of Dermatology
 - “Recommendations for therapeutic education in atopic dermatitis: position paper”, in process for Paediatric Dermatology.
- The creation of a newsletter attached to the OPENED-Dermatology network. This report is the first “edition” of the newsletter!
- Create a contact with Julie Block of the National Eczema Association, as suggested by Magdalene Dohil.

Feedback : Please share your ideas/suggestions on this matter with us:

What about your ideas for maintaining the patient's/parent's motivation to participate in the workshops/sessions?

Which convincing argument do you use for promoting your patient education program ?

Do you use video demonstration ? If Yes : Are these videos available and where ?

Working with teenagers is often difficult. Do you have any experience or suggestion ?

Thank you for your reply