



Newsletter #2, April 2012

Dear friends,

In San Diego, during this year's AAD meeting, we had the pleasure of organizing a meeting of the OPENED network. Each participant presented the developments in each country in the field of TPE for AD and we discussed future projects, including an exciting study to validate a steroid phobia score. Unfortunately, all of you could not make the meeting so we have outlined the main points in this newsletter. We have also added recent publications and other events. We look forward to getting

your feedback on the TOPICOP project and hearing about your ongoing actions and developments. We are also in the process of «modernising» the OPENED site (content and form), which gets very few hits at the moment! We will let you know when this is up and running and, again, will welcome your feedback.

Finally, I would like to take this opportunity to wish you and your collaborators every success in your projects for the coming months.

Best regards,
Jean-Francois Stalder



OPENED meeting, AAD congress, San Diego, March, 2012

*Thanks to Christine Coutanceau of
ADERMA for the organization.*

Shared developments...

Canada: telephone follow-up, collective sessions (cultural differences among the participants has made these sessions difficult to organize). A personalized treatment plan has also been designed (see p4).

Germany: the annual Asthma school congress, an article will soon be published on the impact of TPE 5 years after the launch of the GADIS project. Johannes talked about the Rajka meeting in Tanzania, and the existence of eczema in Africa: It is one of the most common skin diseases even though there is more super-infection than elsewhere. The next Rajka congress will be in Nottingham in 2014. In Seoul during the World Congress there was also a symposium on education.

Italy: 4 TPE congresses last year, 6 atopic schools, a TPE day, which was held in 2011, and the project to establish a consensus between pediatric and educational centers.

The **USA:** a national meeting where new education tools were presented (video teaching, websites), the development of train the trainer sessions, new tools (video and web) and the work on recommendations and the development of questionnaires for patients.

Belgium: special groups for babies and e-learning which is being developed.

Brazil: the use of a support group including a psychologist and dermatologist in Sao Paulo. Here is a link to an original origami workshop that is a success: http://www.aada.org.br/page_videos.php.

France: 17 centers now practicing TPE with 3 different programs: AD, Psoriasis, and next year hand dermatitis and epidermolysis bullosa. The French TPE day is planned for the 15 Nov 2012.



2nd International TPE workshop, Rome, June 2011

Following on from the success of the first meeting in Toulouse in 2010, the second international TPE meeting was held in Rome, in June 2011. For a summary of the meeting, including speakers' presentations, please click [here](#)

Other events...



•2nd World Congress of Dermatology, Seoul, May.

•20th EADV congress, Lisbon, October.

•Eczema School Day, Aarhus, Denmark, October.

Publications:

- A. Armstrong and P. Lio. Online video improves clinical outcomes in adults with atopic dermatitis. JAAD 2011;64 :502-7
- Topical corticosteroid phobia in atopic dermatitis: a study of it's nature, origin and frequency. BJD 2011;165 : 808-11
- POSCORAD: a new self assessment scale in atopic dermatitis in Allergy 2011 March
- Recommendations in TPE, submitted to Ped Derm... awaiting publication..

News

The POSCORAD is being developed for ipad and iphone and an applet is being developed which will allow a patient to automatically calculate the POSCORAD and export the data to the physician (Fr and Eng). A paper version of POSCORAD is now available in 15 different languages.

TOPICOP

1. Summary of the publication on corticosteroid phobia (see ref above):

Background

- Topical corticosteroids (TCS) remain the mainstay of AD therapy
- Nevertheless, many AD therapeutic failures appear to be due to poor adherence to treatment due to TCS phobia

Objectives: To assess the origins and frequency of fear of TCS use among patients with AD.

Methods: A questionnaire comprising 69 items, generated from information gathered during interviews with 21 patients and 15 health professionals, was given to consecutive patients consulting at the outpatient dermatology departments of five regional university hospitals or with 53 dermatologists in private practice.

Results: A total of 208 questionnaires were analyzed:

- 81 % of the respondents reported having fears about TCS and 36% admitted non-adherence to treatment.
- A correlation was found between TCS phobia and a prior adverse event, inconsistent information about the quantity of cream to apply and a poor treatment adherence.
- TCS phobia was not correlated with AD severity.

Conclusion: TCS phobia is a frequent and complex phenomenon, that has an important impact on adherence.

The TOPICOP study

Background: Because TCS phobia appears to be a complex phenomenon, its evaluation with binary responses is too simplistic, as it cannot detect different types of fear.

Objectives: to develop and validate a scale TOPICOP measuring excessive worries and wrong beliefs concerning TCS among AD outpatients.

Methods: The scale development process comprised an explanatory principal component analysis, Cronbach's a-coefficients and structural equation modeling.

Results:

- The validated score comprised **12 items**, covering two important dimensions relative to “excessive worries” (six items) and “wrong beliefs” (six items).
- Psychometric properties were very good.
- The final two-factor solution accounted for 47.3% of the variance.
- Cronbach's a-coefficients were, respectively, 0.79 and 0.78.
- Structural equation modeling strongly supported the possibility of calculating a global score.

Justification:

Topical corticosteroid phobia is the most important obstacle to attaining treatment adherence and one of the main causes of treatment failure in atopic patients. Detecting and scoring a corticosteroid phobia level should help practitioners to screen TCS phobia in order to improve the management and quality of care.

A tool can assess the efficiency of TPE.

Future development

Observational:

- Scale validation according to countries and cultures worldwide.
- Comparison with CS phobia in other cutaneous diseases.
- Evaluation of the relationship between TCS phobia and adherence in atopic patients.

Design of the feasibility study:

Phase I: a prospective preliminary international multi-centric pilot study to assess the use of a corticosteroid phobia score.

Primary end point: acceptability of a score for CS phobia detection, feasibility (tested by a questionnaire given by patients or parents given before a consultation), and pertinence according to language and health literacy.

Secondary end point: an analysis of the factors involved in CS phobia according to the culture, the way of dispensing corticosteroids (over-the-counter, prescription) and the social category of patients.

Conclusion

All participants at the meeting in San Diego accept on principle to participate.

The different steps: waiting for the article to be accepted by the JAAD.

We would like to know who would be interested in participating in this study and how many questionnaires you think you could return filled in.

- mail to: a.ball@me.com or jfstalder@mac.com

PLAN DE TRAITEMENT POUR LA DERMATITE ATOPIQUE

Date : ____ j / ____ m / ____ an

Notes du médecin ou de l'infirmière



Pour la peau sèche : (les hydratants)

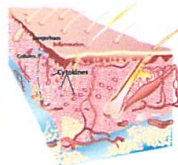
Appliquer sur toute la surface corporelle ____ fois par jour. Continuer à hydrater la peau même si l'eczéma semble guéri.

Appliquer les produits médicamenteux prescrits avant d'appliquer les hydratants.



Pour la démangeaison (le grattage): (les antihistaminiques)

- Au coucher, Médicament: _____
Dose: _____
- Pendant le jour, Médicament: _____
Dose: _____



Pour l'inflammation de la peau (l'eczéma): (les anti-inflammatoires)

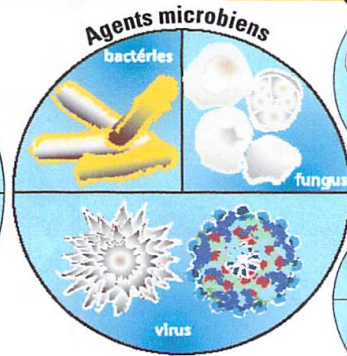
- Appliquer _____ aux endroits atteints du corps _____ fois par jour.
- Appliquer _____ aux endroits atteints du visage _____ fois par jour.
- Appliquer _____ aux endroits atteints du cuir chevelu _____ fois par jour



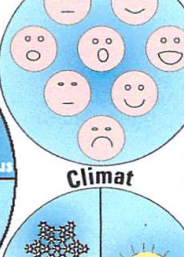
Si l'eczéma s'infecte: (écoulements, mauvaise odeur, croûtes collantes...) (les antibiotiques)

- Médicament antibiotique : _____
Dose: _____
- Bains avec Javel _____ minutes par jour fois par semaine. **Préparation:** ¼ de tasse d'eau de Javel dans un bain rempli d'eau tiède.

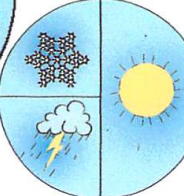
ATTENTION!



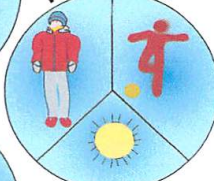
Stress et émotions



Climat



Transpiration



CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant
Université de Montréal