

Newsletter #3, March 2013



Dear friends,

thanks to your dedication and expertise, TPE for AD patients has continued to develop around the world in 2012. The specificities and constraints of each country, region or hospital have produced different strategies, but the general consensus is toward a combination of individual or collective workshops and/or group lectures. The opportunity to get together and share experiences face to face is a luxury that is precious in the midst of busy schedules and geographical distance. Thanks again to ADERMA we were able to propose an OPENED meeting during the AAD in Miami.

Many of you were present, and the exchanges were rich and constructive. We have outlined the main subjects covered in the meeting in this 3rd newsletter. Don't hesitate to send us your news and feedback! Best wishes for the coming months.

Regards, Jean-Francois Stalder



OPENED meeting, AAD congress, Miami, March, 2013

Thanks to Christine Coutanceau of ADERMA for the organization.

Shared developments...

In **Spain**, Antonio confirmed that the atopic school project has now been officially consolidated with widespread media attention.

In **Sweden** Ake Svensson reports that the Asthma and Allergy Association has been involved in education sessions in partnership with Dermatologists.

Peter has told us about an exciting new project in **Chicago** : the Chicago Integrative Eczema Center, which will host monthly TPE workshops and lectures.

In **France**, work has continued on the POSCORAD app which is now available for smartphone and ipad and is being used in numerous studies (see below).

The first **Mexican** atopic school was opened under Carola Duran's responsibility and a special day of training and information was organised by the Fondation Dermatite Atopique. Jean-François travelled to **Taipei** to present TPE to pediatricians and dermatologists, during the 38th annual Taiwanese Dermatological Association meeting.

In **Belgium** Marie-Anne Morren and colleagues seem to be particularly active : new TPE schools have opened and they have developed a new pruritis scale ; Leuven Itch Scale (LS), available in different languages.

In **Canada**, Danielle and her team have developed a tool « Patient's treatment reminder » which will soon be ready.

Mette has told us that all Dermatology Depts in **Denmark** now have an eczema school.

The AADA in **Brazil** created a Facebook page for patient exchange but results are inconclusive, apparently posts are often superficial. The artistic sensibility of the AADA's actions are evident in the photos of the wonderful exhibition and workshops organized in Sao Paolo around the theme of Origami (see below).

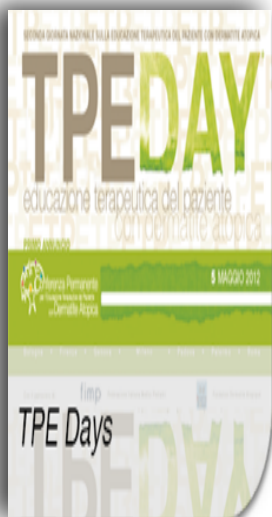
Finally, Thomas Werfel tells us that in **Germany** a prospective study on the effects of AD schools for adults ("ARNE" study) is underway (together with Uwe Gieler and 10 other German Centers). Results in 2013 or 2014. They hope that this study positively impacts the reimbursement of TPE actions by the insurance companies in Germany. Interesting!!

Launch of a new concept : TPE Day in Europe

TPE days were organized across Europe in 2012 at the initiative of the *Fondation pour la Dermatite Atopique*.

In Italy, Belgium and France events were held in 18 different cities. Over 500 participants were registered in each country, with positive feedback from all involved. Leaders in the field gave lectures and led workshops for a mixed population including private dermatologists, nurses, pharmacists, dietitians and allergologists.

The objective of the TPE day was to address the issues involved in TPE with a maximum number of caregivers, a particular emphasis being put on how to organize TPE in private dermatology clinics.



A common program was established around the following themes :

- New developments in physiopathology of AD
- The role of dermatologists and nurses in TPE
- Corticophobia and it's management
- TPE in private practice
- Multimedia aids (e.g. wet wrapping)

Link to French TPE day site: <http://www.etpday.com>



POSCORAD

The POSCORAD is now available for ipad and iphone in English, French and Taiwanese and will be translated into 16 languages for mid June 2013. The app can be downloaded from opened-dermatology.com. The tool is currently being used in the following studies:



Name	Institution	Study
Amy Tan	Discipline of Chinese Medicine, RMIT University, Australia	Evaluation of safety and efficacy of Chinese medicine in the treatment and management of AD
Marjolein de Bruin-Weller	University Medical Center Utrecht	Follow-up of adult patients with atopic dermatitis in daily practice
Lydia Govender	Durban University of Technology	Somatechniques
Gabriela Olszewska	University Warsaw	the impact of stress on the course of atopic dermatitis.
Zsuzsanna Szalai	Heim Pál Children's Hospital Budapest	
Erna Snellman	Department of Dermatology, Lahti, Finland	Does phototherapy influence on QoL? Heliotherapy and QoL
Robert A Siverman	American Medical Association- American Board of Medical Specialties	Quality assesment for Atopic Dermatitis
Chris Long	Oxagen Ltd Abingdon, UK.	Effect of X on flares on subjects with moderate to severe AD. Randomized, double blind, placebo control, parallel group study.
Peck Ong, MD	Division of Clinical Immunology and Allergy Children's Hospital Los Angeles/ USC Keck School of Medicine.	American Academy of Asthma, Allergy and Immunology in San Antonio, Texas. "Exercises and practical application" part to teach allergists how to use SCORAD

Publications

The following articles have recently been published:

- "Therapeutic Patient Education in Atopic Dermatitis: Worldwide Experiences" Ped Dermatol 1–6, 2013
- "Therapeutic Patient Education in Children with Atopic Dermatitis: Position Paper on Objectives and Recommendations" Ped Dermatol Vol. 30 No. 2 199–206, 2013

TOPICOP: FAC study H Aubert, S Barbarot, JF Stalder* Nantes University Hospital-France

In last year's newsletter we outlined the study design and called for participation...

Phase I: a prospective preliminary international multi-centric pilot study to assess the use of a corticosteroid phobia score. We propose to send a questionnaire to patients over 15 yrs, and parents of children under 15 yrs.

Primary end point (FAC): *Feasibility* of a score for CS phobia detection, tested by a questionnaire given to patients (over 15 yrs) or parents (of children under 15 yrs) before a consultation, *Acceptability* of the score, *Comprehensibility* 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.

Since last year 22 centres in 11 different countries have volunteered to be part of the study. During the meeting in Miami, the following points were discussed:

- The translation of the questionnaire into the different languages
- Defining the target population (hospital or private patients, how many patients per country)
- E-CRF, the practical organization of the study
- Ethical committee approval

The next steps:

- Translations will be carried out by one person for each country
- The questionnaire will be distributed, for the moment, in a medical setting. The participation of patient associations will be treated apart at a later date.
- Instead of a CRO there will be a E-CRF which will be managed using an online survey platform (we're testing different solutions at the moment). The idea is to provide each centre with an «ipad» to be used, either by the patients to directly access the survey online using wi-fi, or by a member of staff to recopy the data from paper questionnaires filled in by the patients.
- Each centre will need to contact their own ethics committee with the study design and the patient authorization forms, in order to obtain agreement for the distribution of the survey.

Planning:

- May 2013: we send out the documents for translation by each country
- June 2013: translations are completed and returned
- Mid-August 2013: we send out the e-crf and ipads
- Mid-September 2013: launch of the study
- March 2014: all surveys collected

Please note: there will be a TPE Symposium during the World Congress in Madrid



Last but not least: a big thanks to the Foundation for Atopic Dermatitis for their continuing investment in TPE for AD