

# ISAD-OPENED

## TASK FORCE



**Present:** AAMAR KHODJA Aomar, AOKI Valeria, BELLONI Anna, BLESSMANN WEBER Magda, De RAEVE Linda, DELEURAN Mette, EICHENFIELD Lawrence, EL HACHEM Maya, GELMETTI Carlo, LUNA Paula Carolina, MARCOUX Daniele, MERY Sophie, MISERY Laurent, MOSCA Ana, MURASHKIN Nikolay, ORTIZ-BRUGES Ariana, RAMIEN Michele, SAINT AROMAN Marketa, STALDER Jean François, SUE John, VESTERGAARD Christian, WOLLENBERG Andreas

### *The ISAD OPENED meeting in Milan was a success*

A very fruitful meeting took place at the NH Hotel in Milan during the 24th World Congress of Dermatology. Each of the members present had the opportunity to exchange their ideas and experiences over a round table. You'll be able to read the minutes of their interventions below.

We would like to extend a special thanks to all the people who were able to come, a larger number more than ever before, with new members from Russia and Algeria. For those who couldn't make it, we were thinking of you and hope this minutes allow you to keep updated on our progress.

We hope to see you all in the near future...

## ROUND TABLE COMMENTS AND UPDATES

	Last Name First Name	Country	Comments and updates
1.	<b>AAMAR KHODJA</b> <b>Aomar</b>	ALG	4 atopy schools created in 2018-2019
2.	<b>AOKI Valeria</b>	BR	The Sao Paulo support group is very dynamic on the internet and Instagram. They include art in their educational approach especially with teenagers who appreciate this artistic approach. Big advantage on a psychological point of view.
3.	<b>BELLONI Anna</b>	IT	They organize TPE sessions separately for children and adults with the help of a dedicated nurse.
4.	<b>BLESSMAN - WEBER Magda</b>	BR	They have asked themselves why it is so difficult to convey patient to TPE sessions. So they have decided to invite an external speaker to give a 15 min talk during the TPE session, then they start the discussion.
5.	<b>De RAEVE Linda</b>	BE	They organize TPE sessions separately for French speaking patients and Dutch speaking patients. They don't propose too many sessions otherwise patients don't attend all of them. They face difficulties for the patients to come to attend sessions during the day (working hours).
6.	<b>DELEURAN Mette</b>	DEN	A facebook (FB) page has been created by a young nurse at the hospital for the patients to be informed about the TPE sessions. It is very successful for the recruitment. A lot of demands comes from the FB, no need to be a patient from the hospital, all patients are accepted even if not followed by doctors from the hospital. They propose Children eczema schools + Teenagers. Teenagers enjoy creative activities.

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7.	<b>EICHENFIELD Lawrence</b>	USA	<p>Training allergy with nurses</p> <p>Creation of education tools</p> <p>They use an audio powerpoint to explain AD management to patients</p> <p>15 pediatricians have been trained and are now “mini-experts” : they use education tools</p> <p>Need to train primary care who is poorly trained</p> <p>They teach how to calculate the quantity of treatment to be used at the beginning of the ttt.</p> <p>Industry send 25 people to the center to show what TPE is : very beneficial.</p>
8.	<b>EL HACHEM Maya</b>	IT	<p>Patients have the possibility to book their eczema class through the website of the hospital. The registration fee is 20 euros/class.</p> <p>They have stopped collective session for individual sessions only.</p> <p>A psychologist and a game assistant (anti itching games) are involved in the class.</p> <p>They provide a bag to each patient (family) containing :</p> <p>Books, information brochure and anti-scratching distraction technics.</p> <p>They organize 1 Openday every year open to all patients and HCP : testimonies, open discussions and other activities (sports).</p>
9.	<b>GELMETTI Carlo</b>	IT	TPE is not a waste of time but gain of time
1. 0	<b>LUNA Paula Carolina</b>	ARG	<p>TPE is not structured in Argentina, there is a recent patients association for 2 years.</p> <p>Open group : 3 meetings every 3 months on Saturdays : one to one meeting.</p> <p>Very rewarding but evaluation is needed.</p>

	Last Name First Name	Country	Comments and updates
11.	<b>MARCOUX Daniele</b>	CAN	<p>7 dermatologists involved in the atopy school.</p> <p>Close work with Amanda Crosswell from the patients' association.</p> <p>They have created a program called "Optimum care in Eczema" and have written a list of FAQ coming from the patients, Caroline Jacques a new dermatologist answers the patients' questions.</p> <p>Project : to make a video for eczema like the one made by Abbvie about psoriasis with a little teddy bear.</p>
12.	<b>MISERY Laurent</b>	FR	<p>Long term experience in TPE.</p> <p>Main concern : lack of time of doctors and nurses.</p>
13.	<b>MOSCA Ana</b>	BR	<p>No nurse. TPE is conducted by dermatologists, allergologists and psychologist.</p> <p>They have started yoga sessions against itching and gym sessions for the children + a therapeutic garden close to the hospital (= TPE outside the walls)</p>
14.	<b>MURASHKIN Nikolay</b>	RU	<p>Works in a pediatrician institute.</p> <p>They receive groups of parents.</p> <p>Project to develop a mobile app for the management of AD to collect patients big data.</p>
15.	<b>ORTIZ-BRUGES Ariana</b>	ESP	<p>18 teams of TPE in Spain.</p> <p>They conduct an evaluation study using the PASECI and the TOPICOP that are completed immediately after TPE , then 1 month and 3 months after the last TPE sessions.</p>
16.	<b>RAMIEN Michele</b>	CAN	<p>They have developed the Eczema Action Plan, and now they conduct a study to assess the interest of using the action plan. The action plan follows the patient all along his patient's journey : from atopy school to Pharmacy and to family doctors, so that every HCP is aware of the personalized TTT and AD management of the patient.</p>

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17.	<b>SUE John</b>	AUSTR	<p>Practice in a dermatological clinic and a general clinic.</p> <p>Nurses organize late workshops with 5 to 6 patients with an education nurse. They also organize group sessions of 20 people.</p> <p>TPE is organized every 2 months in the evening during the week, with a nutritionist and a psychologist.</p> <p>Difficulty : to find the right psychologist who can manage and understand the psychological impact of skin disease.</p> <p>They work with the Australian support group who has a facebook page and a website (John is not very familiar with that).</p>
18.	<b>VESTERGAARD Christian</b>	DEN	Same as Mette DELEURAN.
19.	<b>WOLLENBERG Andreas</b>	GER	<p>Difficulty in acceptance of the full German TPE program for patient / family who are very busy or single person : 12H training, from 6.00 to 8.00pm .</p> <p>Test run for a compact model of TPE : a lighter educational program of only 4H TPE . A study comparing the people who receive the 4H TPE versus no TPE at all will be conducted to demonstrate the benefit of a compact TPE program. The protocol has just been approved by the Ethics Committee. The results of the study are expected by Q2 2020.</p>
20.	<b>STALDER Jean François</b>	FR	CHAIRING
21.	<b>SAINT AROMAN Marketa</b>	FR	PFDC
22.	<b>MERY Sophie</b>	FR	FDA

## **PROGRESS OF THE 4 WORKING GROUPS (WG)**

### **Management of itch (Coord : L. Misery)**

This first project has remarkably progressed

1<sup>st</sup> draft nearly written, 2 parts missing

L. Eichenfield will review it.

### **Nurse and TPE (Coord. H. Aubert)**

- ✧ Helene Aubert is leading with Kathrin Thormann (CH) Three chapters are planned:

1. literature review about the role of nurses in TPE in AD (in progress)
2. inventory of existing practices: the experiences worldwide, collected using an online Survey 15 questions for nurse and physicians (addressed to the OPENED members) <https://www.surveymonkey.com/r/PP6L35M>
3. Synthesis, perspectives

A monkey survey questionnaire will be sent by with 15 questions about the roles and difficulties of the nurses and how to improve them.

Nikolay Murashkin will take part to this WG.

Suggestion : to include patients association to join this WG : USA (Julie), CANADA (Amanda)

### **e-Health (Coord. Michèle Ramien and Laura Von Kobylewski)**

- ✧ A systematic review will be undertaken to evaluate E-health tools for children, parents to children with AD, adults with AD and health care professionals.
- ✧ **Systematic literature search** in Medline, EMBASE, Cochrane...
- ✧ also be performed in Google and Google Scholar search engines.
- ✧ END points: description, feasibility
- ✧ Validity: improvement of knowledge, patient symptoms, health care efficacy...
- ✧ Agenda: a lot of things have been done but there is still a lot left!
- ✧

**Guidelines for pharmacies (Coord. JF Stalder and J. Sue)**

Guidelines for the management of atopic dermatitis for pharmacists: academic version

**What a pharmacist need to know about atopic dermatitis (AD)**

1. [Definition](#)
2. Epidemiology
3. Pathophysiology
4. Diagnosis
5. Course of the disease
6. Local and general treatment
7. Practical management : daily care and flare prevention

**Guidelines for the management of atopic dermatitis for pharmacists with the help of US and French pharmacists as co-author and the experience of POP Training in France**

1. What a pharmacist need to know about atopic dermatitis (AD)
2. The role of pharmacists
3. The pharmacist and the caregivers
4. The pharmacist in the “Eczema Patient Journey”

Suggestion of A. Wollenberg : to write a A4 sheet format to give instructions about what is expected from the pharmacists.

Guidelines to be enlarged to what a pharmacist should or shouldn't say to customer : Dos' and Dents'.

**PREPARATION OF THE NEXT ISAD OPENED TF MEETING IN MADRID**

A-DERMA Brand has already booked the date : THURSDAY OCTOBER 10<sup>th</sup> 2019 . 8.00 TO 10.00.

Place to be confirmed by Marketa Saint Aroman.

Objective : invitation of companies representatives interested in TPE (ie : AbbVie, LEO, Sanofi...)

Among the questions to address:

What TPE means in AD? And Who is the ISOP Task Force?

What TPE means to industrial actors?

What experiences companies have it in this area?

What is the logic behind the firms actions for TPE?