



4 ongoing publishing projects...

Management of itch and pain in AD

Working group: Valeria Aoki Anna Belloni Fortina, Pavel Chernyshov, Maya El Hachem, Annice Heratizadeh, Laura von Kobyletzki, Danielle Marcoux, Laurent Misery (coordinator)

Guidelines for pharmacists

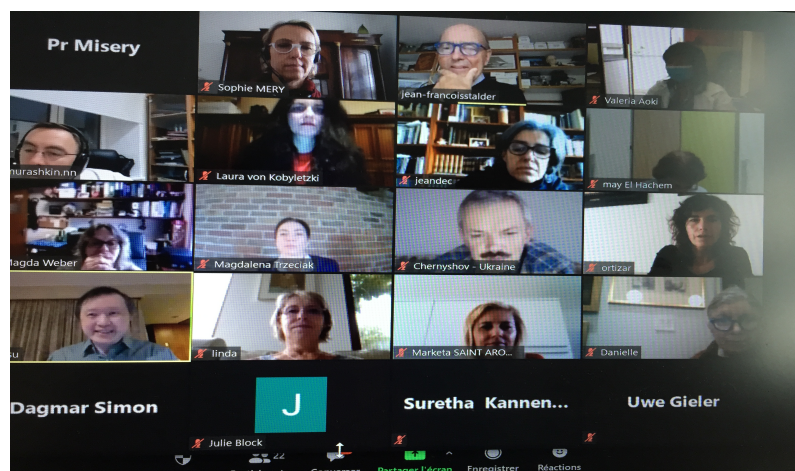
Working group: Jean-Francois Stalder -John Su (leaders) Andreas Wollenberg, Åke Svensson, Pavel Chernyshov, Peter Lio, Dedee Murell, John Su, Audrey Nosbaum and Sebastien Faure.

E-health educative tools

Laura von Kobyletzki, Michelle Ramien, Roberto Takaoka, Jean-Francois Stalder

Nurses and TPE

Working group: Sebastien Barbarot/Hélène Aubert, Pavel Tchernikov, Maya El-Hachem, Jette de Groot and Florine Raymakers, Mette Deleuran, Linda, Dagmar Simon, Kathrin Thormann, Gabriele Wiener-Hemme, Fiona Cowdell.



Adapting to the "new normal"...

Despite everyone's efforts, it was not easy to get connected and to be able to exchange views as we were used to enjoyed in previous meetings. I personally had difficulty recognizing each one on the screen and I apologize to those I might have forgotten

The round table reported on the devastating effect of Covid-19 on our care and education organizations in each of our countries

The impact concerns the reduction of beds and the almost complete elimination of consultation activity. Clinical research has also been affected due to the decrease in physician and resident availability. The therapeutic education activity has been suspended or replaced by telephone interaction or remote consultations or even Zoom meetings, which have shown their limits in terms of peer to peer quality interaction.



ISAD-OPENED Website

Our new website is up and running. Make sure to pay a visit at www.isad-opened.com

Your suggestions are welcome. Please contact David Troya: david.troya@univ-nantes.fr

Future Projects:

1. **Ideation Project**
2. **Coalition or consortium project**

IDEATION PROJECT

The objective is to reflect about how to improve communication tools so that they become more adapted to TPE particularly given the limits and constraints of COVID

The survey that is done for patients and healthcare providers will allow us to organize an innovative workshop

We're going to use the design thinking approach for the ideation project and is addressed to volunteers from ISAD-OPENED as well as patient associations and healthcare providers.

The objective being to present one or more prototypes of Digital TPE tools that could then be validated the ISAD-OPENED Taskforce

Projects discussed...

Management of itch and pain in AD

A position paper on the management of itch and pain in atopic dermatitis from the International Society of Atopic Dermatitis (ISAD)/ Oriented Patient-Education Network in Dermatology (OPENED) taskforce

Laurent Misery¹, Anna Belloni Fortina², Maya El Hachem³, Pavel Chernyshov⁴, Laura von Kobyletzki⁵, Annice Heratizadeh⁶, Danielle Marcoux⁷, Valeria Aoki⁸, Mariana Colombini Zaniboni⁸, Jean-François Stalder⁹, Lawrence F. Eichenfield¹⁰

This project has been well managed by Laurent and the coauthors After having been rejected by the JACI and after a very complete overhaul; finally, it's the article was accepted by the JEADV journal and will be published in one of the next issue.

Congratulations to all authors!

Guidelines for pharmacists

As global data is lacking, an international survey has been undertaken of pharmacists across 4 continents, examining pharmacist AD-related knowledge, experience, and attitudes. (Participating countries have included France, Italy, Russia, China, Mexico, Colombia, Argentina, and Australia). Data currently being compiled, analysed and drafted for the OPENED pharmacist education workgroup

Potential next steps for discussion:

1. We propose a short research letter to address the results of the international survey. A draft is in preparation and will be submitted to the working group for review; the tentative target journal is JAAD.
2. We propose a position paper on what a pharmacist needs to know and what information they should transmit to their customers. We would appreciate offers of help for writing this article and suggestions for a suitable journal for publication."

CONSORTIUM OR COALITION PROJECT

Rational:

The idea we developed during the Paris meeting in 2018 was to create a coalition as a consortium to enlarge the TaskForce with other pharma companies, patients associations and additional stakeholders (private insurance, Public health organization).

TF members are solicited by the different pharma companies launching drugs in atopic eczema to better develop projects in the field of therapeutic education for atopic patients.

Enlarging the eczema expert Task Force by creating a coalition with other pharma companies, patients organizations and payers.

Sophie, the Eczema Foundation and the Pierre Fabre group have worked hard to set up this broad coalition with other pharma companies, patients organizations and payers.

This innovative coalition has patients in its mind and contributes to the optimization of costs.

E-health educative tools

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.

Regarding the gray literature, there is an exponential number of tools proposed and never validated, a huge job which can appear out of reach for our small team ?

The judgment criteria are to be written ...

Should we spend our energy running after this crazy train?

Nurses and TPE

The role of nurses in the management of Atopic Dermatitis :
what do we know, what do we do, where can we go?

- Literature review about the role of nurses in TPE in AD
- Inventory of existing practices: synthesis, perspectives
- Our article was unfortunately refused by the JEADV.

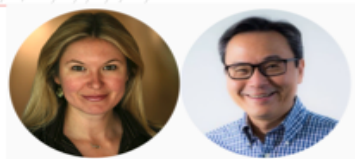
More of a pilot study than a position paper, which is not currently possible due to the differences between countries in the organization, the training and the remuneration of nurses. The objective was to report on the experiences declared and to specify the expected benefits of the nurse implication.

Next step: Propose the European Journal of Dermatology ?

Dagmar Simon informed us that she's writing an article about the role of nurses that could be complementary to this article

Innovative Ideation Workshop

"Digital Communication Tools for Therapeutic Patient Education (TPE) in Atopic Dermatitis" Education (TPE) in Atopic Dermatitis"



Eczema
Foundation

Using the design thinking approach, which uses diverse perspectives from patients, caregivers and healthcare professionals.

**on November 20th 2020,
from 3pm to 6pm CET
(online)**



Setting up an Eczema Education Coalition

HOW

Enlarging the eczema expert Task Force by creating a coalition with other pharma companies, patients organizations and payers

ADDED VALUE : innovative coalition to benefit the patients and participate to better control health cost in eczema management.

PARTNERS

- Pharma industries who market or develop topical treatments: TCS, TCI, Crisaborole and topical JAK inhibitors
- Patient associations in eczema : Global Skin
- Patient organizations : EUPATI or others
- Private health insurance
- Public payers
- WHO

HELPERS : ILDS to reach WHO , MediPaCe



Example of project:

A universal connected smart cap to improve treatment adherence

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A score to assess the performance of the Eczema Education Coalition

Each project raised by the coalition will be assessed according to the following score: 10 items : ranging from 0 to 10 → Global score /100

1. INNOVATIVE (no similar project)	
2. RETURN ON INVESTMENT	
3. PATIENT CENTRIC / PATIENT INVOLVEMENT (Patient involvement index PII)	
4. FITS HCP UNMET NEEDS	
5. BRINGS REAL CONCRETE AND QUANTIFIED RESULTS	
6. SCIENTIFIC RECOGNITION (Publication, communication in <u>medical</u> conventions, patents...)	
7. CSR (Corporate Social Responsibility) COMPLIANT, <u>with</u> respect of the <u>environment</u>	
8. INTERNATIONAL / GLOBAL INTEREST	
9. WELL DEFINED USED OF THE COLLECTED DATA	
10. TRANSVERSAL <u>INTEREST AMONG</u> THE STAKEHOLDERS	
TOTAL POINTS	SUM / 100

The score will allow to classify projects for decision support and prioritization of project management by the Eczema Education Coalition (sort of triage).

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Roadmap of the Eczema Education Coalition

Q4 2020

- Coaching of the Eczema Foundation by MediPaCe
- Recommendation for different scenari of coalition/consortium

Q1 2021

- Sharing the scenari with the ISAD OPENED TF (end January)
- Distribution of the contact with the potential stakeholders
- Selling the benefit of this coalition to the different targetted stakeholders with the help of the TF members and Patients Organizations → get their commitment

Q2-Q3
2021

- Setting the coalition/consortium : legal contract established
- Release the Financial support from the different stakeholders
- Start with the first project of the Coalition/consortium

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CONCLUSION

THIS MEETING SHOWS THAT WE ARE ALL STILL MOTIVATED BY TPE AND GIVEN THE INCREASING NUMBER OF TRATMENTS IT IS IMPORTANT TO ALLOW PATIENTS TO SELF-MANAGE THEIR DISEASE. ISAD-OEPENED TASKFORCE REMAINS MOTIVATED. WE CONTINUE TO WORK AND FINALIZE OUR PUBLICATIONS BUT ALSO DEVELOP MORE AMBITIOUS PROJECTS SUCH AS THE IDEATION PROJECT AND THE EDUCATION COALITION PROJECT