CUTIS LAXA INTERNATIONALE
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OUR PROJECTS FOR 2025

We pursue our participation to the work led by the French Skin Federation (FFP). Even if Marie-Claude Boiteux's mandate ended at the end of Decembre 2024, she remains member of the Board of the FFP and especially as a referent for Tele expertise in Dermatology. While the lack of dermatologists is greatly felt, Tele-expertise that allows patients to have, nevertheless, access to diagnosis and adapted care remains a priority aim for our organisations. Everything that puts dermatology at the core of National, European and International concernsis also representative of our commitment in Society. Getting Worl Health Organisation (WHO) recognise our rare and dermatological conditions as world health priorities is our aim. Improving diagnosis, healthcare pathways and follow-up for patients suffering from Cutis Laxa in all countries worldwide remains our priority and is at the heart of our work.

THE THREE MAIN HEADINGS

SUFFERERS

Identifying sufferers and Individual Contacts

Our main work is to allow people suffering from Cutis Laxa to break their isolation. Thanks to our visibility on the internet, either via our website or via social networks, they can get in contact with other people concerned by Cutis Laxa. This Fundamental work will be pursued in 2025.

Regarding the contacts we have with Cutis Laxa patients, whether this take place one-to-one, essential to break loneliness, or via our website or social networks, all personal data we might be gathering will be used in compliance with regulations on personal data protection.
Direct contact remains the most important in difficult moments, but the internet, and especially the Facebook private group, remain the preference place for talking and sharing.

Getting access to and spreading Information

1. **Global**

✓ CLI~News allows us to share with patients, members and donors the daily life of our organisation.
✓ The Public Page on Facebook is accessible to anyone. It allows us to spread useful information in the rare disease field in general and for Cutis Laxa in particular.
✓ The book « Cutis Laxa, Story of a Rare Disorder » edited in late 2020, gathers together patients' and families' testimonies since we set up Cutis Laxa Internationale up to now.
✓ Meetings and Conferences we attend in different ways allow us to spread our leaflets widely and get Cutis Laxa known.

2. **Medical and Scientific**

✓ CLI~News is our first spreading tool for this kind of information after we centralised and verified it..
✓ Our website will still be part of our main mission regarding the dissemination of information, with its regular updates.

3. **Dedicated to patients and their parents**

The Facebook Group remains an essential place for exchanges and support for all patients. Online translation tools have greatly improved and helped exchanges, whichever country they come from.

Cutis Laxa Days

Working together with Pr Bert Callewaert from Ghent University Hospital, it was decided to organise this event as regularly as possible. We need time to accumulate the necessary funds to enable a higher number of patients to participate. Therefore, whereas the 7th CL Days were initially scheduled for September 2025, we had to postpone it to February 2026. In fact, we must dedicate 2025 to the organisation of fundraising events, otherwise we will not be able to fund part of the patients' travel expenses to come to Ghent. I would encourage all readers to consider what funds they can raise for CLI and what donations they themselves could make.

Being present abroad

Throughout 2025 we will continue to collaborate / partner with projects and actions organised in France, Europe and in every country where events and actions will be led to the benefit of Cutis Laxa and skin disorders in general.
All over the world, Dermatology is not considered an important medical specialty, but mostly just an aesthetic wish and for comfort. In 2025, our aims will be to advocate to the World Health Organisation (WHO) and World Health Assembly (WHA) to vote two resolutions. The first one, presented by the International Alliance of Dermatology Patient Organisations (Globalskin), asks for the recognition of Skin Disorders as world health priority. And the second, presented by Rare Disease International (RDI) asks for Rare Disorders to be raised as a world health priority. Cutis Laxa is a Rare AND a Skin Disorder. We will then support the adoption of both resolutions.

THE MEDICAL WORLD

LE MONDE MEDICAL

ERN-Skin

Besides the usual activities of our ERN and its thematic groups that will be pursued in 2025, transversal working groups were set up to increase the visibility of issues that are common to all ERNs. One of the themes, Pregnancy and Family Planning in Rare Disorders is coming to an end and will give rise to scientific publications of which we are co-authors.

EPAG (European Patient Advocacy Group) : Patient Representatives in the ERNs

As for ERN-Skin, and linked to its development, the work done among the epags will grow. Speaking with one voice, getting trained, sharing successes and difficulties are the mainstays of being in an epag. Our roadmap is well loaded until 2027.

FIMARAD

FIMARAD network continues its coordination work with French Centers of Reference and Centers of Competencies. There is a real will to put this work into effect through workgroups. The one dedicated to « Diagnosis odyssey and Impasse » continues to be very productive. In 2025 we should, there again, come to the end of several years of work on the analysis of the survey for patients. The results should be published in the course of the year. We are co-author of this publication.

Sharing Information

Sharing information is done, and will continue to be done, in a cross-linked way, with the medical and research teams we support and help. We centralise all up to date information on Cutis Laxa and spread it in our Medias. That partnership with doctors and researchers is essential.

SOCIETY

Relationship with other Support Groups

✓ INTERNATIONALLY : We will stay involved with the EPAGs and be member of Rare Disease International, Eurordis, Globalskin and several other support groups working internationally or based out of France. Thus our links and friendship networks will continue to spread around the world.

✓ NATIONALLY : Marie-Claude Boiteux's participation in several transversal projects benefits to Cutis Laxa patients. It is a long term work and CLI could not do this alone.

- ✓ LOCALLY : Our local network is widening further and further, we have more opportunities for sharing, working together and regrouping our efforts.

Visibilty- Communication

Our publications as well as our website will remain the main communication tools for public visibility.

Commitment to Social Change

Sometimes, we need a lot of inventiveness to be able to attend and participate in a maximum of local, national, European or international events. Nevertheless, new online communication tools allow us to bring patients' voice forward to improve society. It requires new working methods and time-management, but the most important remains that we are present and actively attending. It will be the case in 2025.

RESOURCES REQUIRED IN 2025

FINANCES

- **Researching new financial means**
  - ✓ Advocacy towards national authorities to get funding for, at least, our running costs
  - ✓ Taking part in local, national and international events
  - ✓ Bigger participation to sports, charitable and support events : Brin d'Aillet and Triathlon (Sireuil-France), Semplicemente Amici (Bergame-Italie), La Pastourelle (Salers-France), La Course des Héros (Lyon-France)

TRAININGS

- ✓ Webinars (EPAGs, Eurordis, Globalskin, RDI, AMR, etc)

COMMUNICATION and MEDIAS

- **Publications**
  - ✓ CLI~News : 2 issues a year sent by post or via the internet
  - ✓ Leaflets (medical, general information, symptomic treatments) printed as and when needed
  - ✓ Book « Cutis Laxa, Story of a rare disorder, Patients' testimonies » on sale to CLI's benefit
  - ✓ Skin Disability Guides
  - ✓ Children Booklet
- **Social Networks**
  - ✓ Facebook Private Group and Public Page
- **Website**
  - ✓ Creating new pages as and when needed (press release, projects,etc)
  - ✓ Regular updates to improve our online positioning.
- **Goodies we sell during the events in which we participate include**
  - ✓ Tote Bags, Mugs, Magnets, Coloring books, etc…..
- **Other communication tools**
  - ✓ Roll-up posters, Paper posters, Visiting cards

OTHER

- **Sending documents**
  - ✓ Postage costs, Envelopes, paper, stationery, etc
- **Public Relations**
  - ✓ Covering expenses (travel, accommodation, etc) to attend events…. When organisers are not proposing grants or funding to attend

CUTIS LAXA INTERNATIONALE

Draft Budget 2025

	2025	31.12.2024	31.12.2023
INCOMES			
Sales & events	5 000,00 €	3 223,82 €	2 479,88 €
Grants	300,00 €	2 800,00 €	100,00 €
Donations & Fees	8 000,00 €	4 843,64 €	4 843,64 €
Other Income		- €	- €
Total incomes	13 300,00 €	10 867,46 €	10 867,46 €
COSTS			
Purchasing	1 500,00 €	18,68 €	18,68 €
Operating costs	5 500,00 €	7 959,92 €	7 959,92 €
Volunteers costs (travels and time)	1 700,00 €	1 696,00 €	1 696,00 €
Depreciations	- €	- €	- €
Exchange differences	- €	- €	- €
Interests	- €	- €	- €
Total costs	8 700,00 €	9 674,60 €	9 674,60 €
RESULT	4 600,00 €	1 192,86 €	-148,68 €

I would like to put this Projects and Draft Budget for 2025 to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 10th June 2025 and attendees' vote.