CUTIS LAXA INTERNATIONALE
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OUR PROJECTS FOR 2026

We pursue our participation to the work led by the French Skin Federation (FFP). The publication of the study on Tele-expertise in Dermatology in Bourgogne-France-Comté at the end of 2025 will have an impact in 2026. In addition, it remains very important to be included in the collaboration projects carried out by the FFP that increase CLI's visibility. Everything that puts dermatology at the core of National, European and International concerns is also representative of our commitment in society. After the vote on the two resolutions (rare diseases and dermatological diseases) at the World Health Assembly in May 2025, the follow up work remains to be done to develop a Global Action Plan that meets patients' needs. We will be present to participate in this work. Improving diagnosis, healthcare pathways and follow-up for patients suffering from Cutis Laxa in every country in the world 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 discussion, sharing and access to the most up-to-date information.

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, the 7th edition would be held from 3 to 7 February 2026. Taking into account the funds collected in 2025, we could finance 40% of patients' transport costs

(plus a companion if the patient in under 18) as well as accommodation and catering over the 3 days. The first day would be devoted to a conference on the latest discoveries of the research teams. Presentations would be in lay language for ease of understanding. The next two days would be dedicated to individual consultations. We would also offer a tour of Ghent by covered boat and a festive denier with all the doctors and researchers present.

Being present abroad

Throughout 2026 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 2026, our aims are to advocate to the World Health Organisation (WHO) and World Health Assembly (WHA) regarding the follow up work from the votes on the two resolutions (rare diseases and dermatological diseases) so that the Global Action Plans that must result from them correspond to the patients' needs around the world. Cutis Laxa is a Rare AND a Skin Disorder; we will therefore study and work on these two Global Action Plans.

THE MEDICAL WORLD

In order for Cutis Laxa International to increase its visibility and for its actions and contributions to improving the quality of life of patients be further recognized, we are committed to publishing articles, or participating in their publication, as often as possible in recognized scientific journals.

LE MONDE MEDICAL

ERN-Skin

Besides the usual activities of our ERN and its thematic groups that will be pursued in 2026, transversal collaborative working groups were set up to increase the visibility of issues that are common to all ERNs. The transversal working group of European Reference Networks (ERNs) bringing together patient representatives (EPAGs) (including Marie-Claude Boiteux) and health professionals (HCPs) from 20 ERNs has published the results of its survey of healthcare professionals in the Journal Orphanet des Maladies Rares. "Pregnancy and Family Planning in Rare Diseases"

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. Speeking 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 publication of the results of the patient questionnaire on "Wandering and Diagnostic Impasse", of which we are co-authors, was delayed in 2025. It is expected to be published in 2026.

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, in-depth 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 2026

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 : Search for new events to participate in.

TRAININGS

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

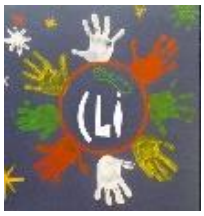
COMMUNICATION and MEDIAS

- **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**
  - ✓ Our "stock" having been renewed in 2025, we will not need to make new purchases
- **Other communication tools**
  - ✓ Roll-up posters, Paper posters, Visiting cards

- **7e CUTIS LAXA DAYS**
  - ✓ Financing of 40% of the costs of transporting patients
  - ✓ Financing of accommodation and catering costs for all the Days
  - ✓ Organization of a boat tour and a festive dinner
  - ✓ Preparation of welcome booklets and totebags

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 2026

	2026	31.12.2025	31.12.2024
INCOMES			
Sales & Events	19 400,00 €	5 000,00 €	3223,82 €
Grants	2 500,00 €	2 300,00 €	2 800,00 €
Donations and memberships	8 500,00 €	8 000,00 €	4 842,64 €
Other Income (Volunteer)	3 200,00 €	- €	- €
Total Income	33 600,00 €	15 300,00 €	10 867,46 €
COSTS			
Purchasing	950,00 €	1 500,00 €	18,68 €
Operating costs including Cutis Laxa Days	33 430,00 €	8 000,00 €	7 959,92 €
Volunteers costs (travels and time)	2 000,00 €	1 700,00 €	1 696,00 €
Depreciation	- €	- €	- €
Exchange rate differences	- €	- €	- €
Interests	- €	- €	- €
Total Costs	36 380,00 €	11 200,00 €	9 674,60 €
RESULT	- 2 780,00 €	4 100,00 €	1 192,86 €

I would like to put this Projects and Draft Budget for 2026 to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 15th June 2026 and attendees' vote.