



## **OUR PROJECTS FOR 2024**

Our participation to the work led by the French Skin Federation remains an essential element across all the projects we run. Everything that puts dermatology at the core of National, European and International concerns and stakes will be of undeniable benefit for all Cutis Laxa patients, improving their care pathways and financial support. In this way, the official launch of the Skin Disability guides at the end of 2023 and their dissemination, as wide as possible, in 2024 will allow a more comprehensive recognition of the impacts of skin disorders and an improved medico-social assessment of patients' needs.

### **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 2024.

Regarding the contacts we have with Cutis Laxa patients, whether these 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.
- ✓ The Booklet for Children « Let's talk about Skin Disorders », edited by the French Skin Federation, will facilitate more interventions with year 8 students from Junior High School of Bons en Chablais to raise awareness and prevent bullying.

###### **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 is now an essential place of exchange and support for all sufferers. Thanks to the online translation websites, each one can talk with all the others, whatever their countries are, even if they only knows their own language.

## Cutis Laxa Days

Working together with Pr Bert Callewaert from Ghent University Hospital, it was decided to organise this event every three years. It gives us time to accumulate the necessary funds to enable a high number of patients to participate. This means that the 7th Cutis Laxa Days will take place in September 2025. Until then, we must do everything possible to grow our funds. 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 2024 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 as an important medical specialty, but mostly just an aesthetic wish and for comfort. In 2024, our main aim will be to advocate to Health Authorities (WHO) and political authorities for dermatology to be added to health priorities and for sufferers' voice to be heard in each and every country.

## THE MEDICAL WORLD

### LE MONDE MEDICAL

#### ERN-Skin

Besides the usual activities in our ERN and its subthematic groups that will continue in 2024, new transversal groups have been organised to allow common issues in all ERNs to be visible.

As the European Commission re-approved the ERNs for a 5-year period, there is a lot of work ahead of us. The thematic groups will be re-organised to improve efficiency.

### 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

The FIMARAD network continues its coordination work with the French Centres of reference and Centres of Competencies. The will to stimulate this work is becoming a reality in the workgroups. The one dedicated to « Diagnosis roving and impasse » continues to be very productive.

2024 will see the continuation of the analysis of the survey given to patient associations. The results of the first analysis are very promising and interesting. They could lead to a scientific publication on ways to improve diagnosis roving by training and involving other health professionals.

#### 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.

Regarding our sufferers' census, and following the new European GDPR, we will take all necessary steps to gather patients' consent for their data to be, eventually, and with their agreement, forwarded to research projects.

## SOCIETY

### Relationship with other Support Groups

✓ INTERNATIONALLY : We will stay involved with the EPAGs and be member of Rare Disease International, Eurordis, Geneticalliance 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 : The actions led by Marie-Claude Boiteux, as Chair of the French Skin Federation, allow for real collaboration in many transversal projects. These actions are beneficial for Cutis Laxa patients. CLI would not be able to lead on them alone. In 2024, the preliminary work to create the « House

of Skin » benefiting organisations and patients themselves will take on a new dimension with the hope of opening it by the end of the year.

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

We will stay as member of the CCAS (Town Center for Social Support) and of the Commission for Accessibility of Public Buildings for the town of Bons en Chablais.

### 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 2024.

## **RESOURCES REQUIRED IN 2024**

### 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 as soon as the pandemic allows us to

#### - **Sales during events**

### 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, symptomatic 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.

#### - **Other communication tools**

- ✓ Roll-up posters, Paper posters, Visiting cards

#### - **Public Relations**

- ✓ Covering expenses (travel, accommodation, etc) to attend events.... When organisers are not proposing grants or funding to attend

### OTHER

#### - **Sending documents**

- ✓ Postage costs, Envelopes, paper, stationery, etc

#### - **Taking part in setting up the Triathlon in Sireuil**

- ✓ T-Shirts, caps, Miscellaneous communication tools



**CUTIS LAXA INTERNATIONALE**  
Draft Budget 2024

	2024	31.12.2023	31.12.2022
<b>INCOMES</b>			
Sales & events	2 500,00 €	2 479,88 €	3 995,11 €
Grants	100,00 €	100,00 €	500,00 €
Donations & Fees	5 000,00 €	2 940,00 €	9 163,80 €
Other Income		- €	240,00 €
<b>Total incomes</b>	<b>7 600,00 €</b>	<b>5 519,88 €</b>	<b>13 898,91 €</b>
<b>COSTS</b>			
Purchasing	100,00 €	92,92 €	531,84 €
Operating costs	5 500,00 €	4 027,64 €	19 180,30 €
Volunteers costs (travels and time)	1 700,00 €	1 548,00 €	1 792,00 €
Depreciations	- €	- €	- €
Exchange differences	- €	- €	- €
Interests		- €	- €
<b>Total costs</b>	<b>7 300,00 €</b>	<b>5 668,56 €</b>	<b>21 504,14 €</b>
<b>RESULT</b>	<b>300,00 €</b>	<b>-148,68 €</b>	<b>-7 605,23 €</b>

**I would like to put this Projects and Draft Budget for 2024 to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 20<sup>th</sup> May 2024 and attendees' vote.**