CUTIS LAXA INTERNATIONALE
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OUR PROJECTS FOR 2023

After an overwhelmed year in 2022, we can be sure that 2023 will be calmer. Nevertheless some topics are burning questions such as the review of the Local Programmes for Health (PRS) in France with a 2023 deadline. Our participation in the work done by the French Federation for Skin is an essential brick in building all our projects. Everything that can bring dermatology to the heart of national, European and international concerns and stakes will be of utmost benefit for all patients suffering from Cutis Laxa, improving their health pathways and care.

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 2023.

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..

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
✓ The book « Cutis Laxa, Story of a rare disorder » published in late 2020, gathers together patients'and families' testimonies from the early days of Cutis Laxa Internationale to date.

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

2023 will be a calm year regarding this topic. But the great success of 2022, as well as the active participation of Ghent University Hospital can allow us to predict that the next CL Days will not wait for 6 years to be organized …..

Branches or Chapters abroad

During 2023 we will carry on our collaboration/partnership to the projects and actions that will be organised in France, Europe and in every country where events and actions will be lead for the benefit of Cutis Laxa.
Cutis Laxa sufferers' voice needs to be heard by the Authorities in 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 2021, new transversal groups have been organised to allow common issues in all ERNs to be visible.

Early in 2023, the ERNs (European Reference Networks) will be re-evaluated by the European Commission for 5 years. We hope ERN-Skin will be confirmed in its activities.

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. Set up in 2017 at the same time as the ERNs, it is now necessary to agree the Terms of Reference that detail their rights and duties.

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. We are member of the workgroup « Diagnosis roving and impasse ». In 2022, we worked on setting up a patient survey to allow us to analyse the way their care is organised and which other healthcare professionnals are concerned by their disorder. We will continue to work on this analysis in 2023.

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 are involved with the EPAGs and we are member of Rare Disease International, Eurordis, Geneticalliance and several other support groups working internationally or based out of France. Thus we spread our links and friendship networks throughout the world.
- ✓ NATIONALLY : The actions led by Marie-Claude Boiteux, as Chair of the French Federation for Skin 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. For instance, the contribution to the review of the Local Programmes for Health (PRS) in France that was just sent to all Local Health Agencies and was the topic of an article, co-signed by main stakeholders in dermatology, professionnals and patients, aims to, at least, get the word « dermatology » written in the PRS. Likewise, creating a guide «Skin Disability» will allow a better evaluation of care files by Local Houses for Disabled People (MDPH).
- ✓ LOCALLY : Our local network is widening further and further, we have more opportunities for sharing, working together and regrouping our efforts.

We are now 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.

RESOURCES REQUIRED IN 2021

FINANCES

- **Researching new financial means**
  - ✓ Foundations
  - ✓ Taking part in local, national and international events as soon as the pandemic allows us to

- **Sales during events**
  - ✓ New objects to be sold

TRAININGS

- ✓ Webinars EPAGs
- ✓ Webinars Eurordis
- ✓ Webinars Globalskin
- ✓ Webinars RDI

COMMUNICATION and MEDIAS

- **Publications** (All issues are printed in French, English and Spanish , entirely homemade at the lowest possible cost)
  - ✓ CLI~News : 2 issues a year sent by post or via the internet
  - ✓ New Medical Leaflet : printed as and when needed.
  - ✓ New General Information Leaflet : printed as and when needed
  - ✓ New leaflet on symptomic treatments : printed as and when needed
  - ✓ Book « Cutis Laxa, Story of a rare disorder, Patients' testimonies » on sale to CLI's benefit

- **Social Networks**
  - ✓ Facebook Private Group
  - ✓ Facebook Public Page

- **Website**
  - ✓ Creating new pages as and when needed (press release, projects,etc)
  - ✓ Intermediate 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 2023

	2023	31.12.2022	31.12.2021
INCOMES			
Sales & events	2 500,00 €	3 995,11 €	2 372,22 €
Grants	200,00 €	500,00 €	200,00 €
Donations & Fees	6 000,00 €	8 977,69 €	6 287,96 €
Other Income		240,00 €	
Total incomes	8 700,00 €	13 898,91 €	8 960,18 €
COSTS			
Purchasing	400,00 €	531,84 €	- 829,04 €
Operating costs	5 500,00 €	19 180,30 €	5 329,41 €
Volunteers costs (travels and time)	1 700,00 €	1 792,00 €	1 698,00 €
Depreciations	- €	- €	- €
Exchange differences	- €	- €	- €
Interests	- €	- €	- €
Total costs	7 600,00 €	21 504,14 €	6 198,37 €
RESULT	1 100,00 €	-7 605,23 €	2 776,81 €

I would like to put this Projects and Draft Budget for 2023 to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 20th May 2022 and attendees' vote.