



## **OUR PROJECTS FOR 2020**

Following our usual presentation, you will find below our projects for 2019 grouped under three main headings.

### **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 will still be done in 2020.

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.

###### **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 he/she only knows his/her own language.

##### **Branches or Chapters abroad**

During 2019 we will carry on our collaboration/partnership to the projects and actions that will be organised in the United States 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**

### **ERN-Skin-Mendelian Connective Tissue Disorders**

Our ERN activities are growing in intensity. 2020 will be a tough year regarding meetings, physical or on-line. Two documents will mainly draw our attention during 2020 :

- ✚ Finalising the Patient's satisfaction questionnaire after consulting in one of the European Reference Centre of ERN-Skin;
- ✚ Establishing the "Patient Journey" for those with CL. The various CL types are so different that we might need several documents to cover all difficulties CL patients face according to the type they are suffering from.

### **EPAG (European Patient Advocacy Group) : Patient Representative in ERNs**

As for ERN-Skin, and linked with its implementation, the work we achieve in the EPAG will become more and more important. Speaking with one voice, getting trained, sharing successes and difficulties are the leading aims of our participation in the EPAGs

### **FIMARAD**

FIMARAD (French Rare Cutaneous Disorders Channel) continues to work with the French Centers of Reference and French Centers of Competence. We will remain involved with it and as active as possible.

### **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 : We took part in the reactivation of the French Federation for Skin. It will allow a better visibility for issues faced by patients suffering from dermatologic syndroms.

✓ LOCALLY : The CLI official address moved to Haute-Savoie 10 years ago. Our local network is widening further, we have more opportunities for sharing, working together and regrouping our efforts. Through these exchanges, relationships and workgroups with other support groups we can share our experiences and add to our knowledge and competences in the health and rare disorders fields.

These are also a friendly way to get Cutis Laxa known and recognised, and the opportunity to have a stall and sell various objects to CLI's benefit at local group events.

### **Visibilty**

Our publications as well as our website will remain the main communication tools for public visibility. Nevertheless, in 2020, we will study the possibility of editing a book and/or organising an exhibition gathering patients' photos taken by a professional photographer.

### **Being an actor in the evolution of Society**

To achieve this we will insist on attending and participating in as many local, national, European and international events as possible. Being patients' voice in order to get society to evolve means a lot of work, perseverance and personal involvement. Be assured that we have the skills.

## **RESOURCES REQUIRED IN 2019**

### **FINANCES**

#### **Researching new financial means**

- ✓ Crowdfunding websites
- ✓ Foundations
- ✓ Taking part in local, national and international events (Rare Disease Day, Our little Stars, Musical Summer, etc)
- ✓ Gospel concert to the benefit of CLI

#### **Sales during events**

- ✓ Knitting given by members of the Group « Friends Group Malakoff Mederic » (RAMM74)
- ✓ New objects to be sold

### **TRAININGS**

- ✓ Winter School Programme of Eurordis
- ✓ Webinars EPAGs

### **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 (500 in French, 200 in English, 50 in Spanish )
- ✓ New Medical Leaflet : printed as and when needed.
- ✓ New General Information Leaflet : printed as and when needed

#### **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

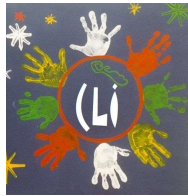
### **OTHER**

#### **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 2020

	2020	31.12.2019	31.12.2018
<b>INCOMES</b>			
Sales & events	4 500,00 €	4 184,36 €	4 104,42 €
Grants	500,00 €	- €	900,00 €
Donations & Fees	5 000,00 €	8 478,21 €	2 562,82 €
<b>Total incomes</b>	<b>10 000,00 €</b>	<b>12 662,57 €</b>	<b>7 567,24 €</b>
<b>COSTS</b>			
Purchasing	- €	21,00 €	255,33 €
Operating costs	6 000,00 €	5 202,70 €	6 343,98 €
Volunteers costs (travels)	1 500,00 €	1 180,00 €	1 516,00 €
Depreciations	- €	- €	13,14 €
Exchange differences	- €	- €	18,16 €
Interests	- €	- €	0,23 €
<b>Total costs</b>	<b>7 500,00 €</b>	<b>6 403,70 €</b>	<b>8 146,84 €</b>
<b>RESULT</b>	<b>2 500,00 €</b>	<b>6 258,87 €</b>	<b>(579,60) €</b>