



## **OUR PROJECTS FOR 2019**

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 2018.

Regarding the contacts we have with Cutis Laxa patients, may these contact be individual, essential to break loneliness, or via our website or social networks, all personal data we might be gathering will be used in compliance with GDPR. For that we will set up all necessary tools.

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. In this field too we will set up the tolls that comply with GDPR

##### **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 will become more intense. 2019 will be a tough year regarding meetings, physical or on-line. There will also be a fundamental hard work to support projects like classification of each form of each disease concerned by our sub-thematic group or writing guidelines/consensus for diagnosis and care.

### 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.

### Visibility

Our communication tools need a new look, an update, a huge piece of work during the first three months of 2018. Modifying our artwork, except our logo, should give impetus and a new interest into our publications.

### 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
- ✓ Taking part in local, national and international events (Rare Disease Day, Our little Stars, Musical Summer, etc)

#### **Sales during events**

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

### **TRAININGS**

- ✓ Leadership 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
- ✓ New artwork for our posters
- ✓ New visiting cards
- ✓ New Letterhead

#### **Public Relations**

- ✓ Covering expenses (travel, accommodation, etc) to attend events.

### **OTHER**

#### **Sending documents**

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

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

- ✓ T-Shirts, caps
- ✓ Miscellaneous communication tools



COMPTES PREVISIONNELS ANNEE 2019 CUTIS LAXA INTERNATIONALE MIS A JOUR LE 23/02/2019					
138 Impasse de Champs Gervais 74890 Bons en Chablais France tel : 04 56 30 74 43					
BUDGET GENERAL REGROUPANT TOUTES LES ACTIVITES					
		ACTIVITE ASSOCIATION	ACTIVITE Cartouches	ACTIVITE CLI-Infos	ACTIVITE GLOBALE
<b>PRODUITS/RECETTES</b>					
<b>ACTIVITE CARTOUCHES</b>					
SUBVENTIONS					
RECETTE CARTOUCHES COLLECTEES			50,00 €		50,00 €
pour memoire identique au reversement accorde					
<b>CLI-Infos</b>					
SUBVENTIONS					
Commune de Marthon				150,00 €	150,00 €
Commune de Saint Bonnet de Salers				150,00 €	150,00 €
<b>ASSOCIATION</b>					
Ventes lors de manifestations		1 000,00 €			1 000,00 €
Triathlon de Sireuil		1 000,00 €			1 000,00 €
Dons		1 000,00 €			1 000,00 €
Dons en nature membres du bureau		1 000,00 €			1 000,00 €
COTISATIONS		2 200,00 €			2 200,00 €
<b>TOTAL</b>		<b>6 200,00 €</b>	<b>50,00 €</b>	<b>300,00 €</b>	<b>6 550,00 €</b>
<b>CHARGES/DEPENSES</b>					
<b>Activité Cartouches</b>					
FRAIS ADMINISTRATIF			50,00 €		50,00 €
COURRIER	40				
DIVERS	10				
<b>CLI-Infos</b>					
Impression (2 éditions)				700,00 €	700,00 €
Papier + encre					
<b>Frais Postaux</b>					
Timbres France + Etranger				800,00 €	800,00 €
enveloppes				200,00 €	200,00 €
FRAIS ADMINISTRATIF				60,00 €	60,00 €
<b>ASSOCIATION</b>					
Frais Confection impression		200,00 €			200,00 €
Papeterie		300,00 €			300,00 €
Informatique		160,00 €			160,00 €
Frais Postaux		300,00 €			300,00 €
Internet et Téléphone		300,00 €			300,00 €
Adhésions autres Associations		300,00 €			300,00 €
Assurance		200,00 €			200,00 €
Représentation Association		300,00 €			300,00 €
BENEVOLAT		1 000,00 €			1 000,00 €
<b>AMORTISSEMENT</b>					
MATERIEL		1 000,00 €			1 000,00 €
<b>TOTAL</b>		<b>4 060,00 €</b>	<b>50,00 €</b>	<b>1 760,00 €</b>	<b>5 870,00 €</b>
<b>RESULTAT</b>					
		<b>Association</b>	<b>Cartouches</b>	<b>CLI-Infos</b>	<b>GLOBAL</b>
		<b>2 140,00 €</b>	<b>0,00 €</b>	<b>1 460,00 €</b>	<b>680,00 €</b>