



## **OUR PROJECTS FOR 2015**

Following our usual presentation, you will find below our projects for 2015 grouped under three main headings.

### **THE THREE MAIN HEADINGS**

#### **SUFFERERS**

##### **Identifying sufferers**

Of course we will pursue our work in identifying sufferers worldwide, whether through the internet or by any other means (contacts with other associations, with the medical and scientific world, sending documents, etc). It remains difficult to establish communication with some parts of the world (Africa, Asia, Eastern Europe, South America, the Near and Middle East), but we already have a few contacts.

##### **Individual Contacts**

Our phone line often becomes a helpline. It is an important element of our involvement with sufferers. All of them know they can call 7 days a week. Even if a relay can be made via the internet, direct contact remains the most important in difficult moments. This will go on in 2015.

##### **Information**

###### **1. To Sufferers**

✓ CLI~News will remain our primary information tool for sufferers and their families with its 2 annual issues.

✓ Our Website will still be part of our main mission regarding the dissemination of information, with its usual 2 updates.

✓ 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.

###### **2. From Sufferers**

We will also keep on calling for sufferers' stories so that, in time, we can publish our "White Book".

##### **Family Days**

Regarding this issue, 2015 will be a calm year as the next International Days on Cutis Laxa have not yet been completely planned. They should be held in 2017, at the latest.

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

We will keep on supporting this group lead Susan Dickinson-Nuner and Angela Glazner. During 2014 we will carry on our collaboration/partnership to the projects and actions they will organise in the United States.

Cutis Laxa sufferers' voice needs to be heard by the Authorities in every country.

#### **THE MEDICAL WORLD**

##### **Partners in Research Projects**

In 2015 we will continue to collaborate with the different research team (France, Europe, United States) we already know. Not to rule out discussions with team from other countries if they should appear.

##### **Disseminating Information**

Our website is the essential tool for disseminating information to the medical world. Therefore, we will update all the information in our "Health Professionals" page as and when necessary.

Nevertheless, not every doctor and consultant has the time or the possibility to surf the web, so we will go on posting our documents to any new doctor we hear of who is concerned by or interested in Cutis Laxa. We will continue to seek the most cost effective means for the widest dissemination of our existence and information.

### **Conferences, Congresses and Seminars**

Conferences, Congresses and Seminars are main events in the medical world. We will try as much as possible to attend them in 2015. Nevertheless, we must be very cautious in choosing which to attend. The criteria of choice will of course be the direct link with Cutis Laxa, but also accommodation and fee costs.

## **SOCIETY**

### **Relationship with other Support Groups**

In 2015, we will pursue our work with those associations or federations we belong to.

We will get in contact with the local representatives of Rare Disorders Alliance and with sufferers' support groups in Haute Savoie to pursue our inter-association work.

It is through inter-association exchanges, relationships and working groups that we are able to share experiences and share knowledge and competencies in the Health and Rare Disorders Field.

This is also how Cutis Laxa will increasingly be better known and recognised.

### **Advocacy for sufferers**

Even if Cutis Laxa is not always a severely disabling disorder, some of our members may have day to day difficulties. We must offer them advocacy and support in their dealings with government departments (Education, Health Care, Acknowledgement of the disability, etc). We fulfil an important role of information and support in these areas.

### **Campaign work**

In 2015, we will remain active and vigilant in regards to legislative and social issues. We will continue working with think tanks and seminars we are already connected to, and will never miss the opportunity to take part in new ones.

## **RESOURCES REQUIRED IN 2015**

### **Publications (All issues are printed in French, English and Spanish )**

- ✓ CLI~News : 2 issues a year (500 in French, 200 in English, 50 in Spanish )
- ✓ White Book : about 50 pages size 11x18 (1000 in French, 500 in English, 150 in Spanish)
- ✓ List of Doctors : 1doubled sided A4 sheet
- ✓ Various products : posters, prepaid envelopes, .....

### **Updating the website**

- ✓ Updating the scientific and medical information
- ✓ Creating new pages (press cuttings and reviews, projects and new actions, etc)

### **Public Relations**

- ✓ Covering expenses (travel, accommodation, etc) for attending events, about 10 times a year.

### **Sending documents**

- ✓ Postal expenses
- ✓ Envelopes, paper, stationery, etc

### **Taking part in setting up the Triathlon and the "Brin d'Aillet run" in Sireuil**

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

**COMPTE PREVISIONNEL ANNEE 2015 CUTIS LAXA INTERNATIONALE MIS A JOUR LE 24/06/2015**

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**BUDGET GENERAL ANALYTIQUE REGROUPANT TOUTES LES ACTIVITES**

	ACTIVITE	ACTIVITE	ACTIVITE	ACTIVITE
	ASSOCIATION	CARTOUCHE	CLI-Infos	GLOBALE
<b>PRODUITS/RECETTES</b>				
<b>ACTIVITE CARTOUCHES</b>				
SUBVENTIONS				
RECETTE CARTOUCHES COLLECTEES pour memoire identique au reversement accorde		300,00 €		300,00 €
<b>CLI-Infos</b>				
SUBVENTIONS				
Fondation GROUPAMA			800,00 €	800,00 €
Commune de Marthon			150,00 €	150,00 €
Commune de Saint Bonnet de Salers			100,00 €	100,00 €
<b>ASSOCIATION</b>				
SUBVENTIONS				
Triathlon de Sireuil	1 000,00 €			1 000,00 €
Dons	2 500,00 €			2 500,00 €
Dons en nature membres du bureau	600,00 €			600,00 €
COTISATIONS	1 200,00 €			1 200,00 €
<b>TOTAL</b>	<b>5 300,00 €</b>	<b>300,00 €</b>	<b>1 050,00 €</b>	<b>6 650,00 €</b>

<b>CHARGES/DEPENSES</b>				
<b>Activité Cartouches</b>				
FRAIS ADMINISTRATIF		60,00 €		60,00 €
COURRIER	50			
DIVERS	10			
<b>CLI-Infos</b>				
Impression (2 éditions)			800,00 €	800,00 €
<b>Frais Postaux</b>				
France				
500 enveloppes x 0,15			75,00 €	75,00 €
400 Timbres x 0,7			280,00 €	280,00 €
Etranger				
100 enveloppes x 0,15			15,00 €	15,00 €
200 Timbres x 1,6 en moyenne			320,00 €	320,00 €
FRAIS ADMINISTRATIF			60,00 €	60,00 €
<b>ASSOCIATION</b>				
Frais Confection impression	350,00 €			350,00 €
Papeterie	350,00 €			350,00 €
Informatique	160,00 €			160,00 €
Frais Postaux	300,00 €			300,00 €
Internet et Téléphone	500,00 €			500,00 €
Adhésions Associations	600,00 €			600,00 €
Assurance	200,00 €			200,00 €
Représentation Association	200,00 €			200,00 €
BENEVOLAT	600,00 €			600,00 €
AMORTISSEMENT				
MATERIEL	1 500,00 €			1 500,00 €
<b>TOTAL</b>	<b>4 760,00 €</b>	<b>60,00 €</b>	<b>1 550,00 €</b>	<b>6 370,00 €</b>

<b>RESULTAT</b>		<b>Association</b>	<b>Cartouches</b>	<b>CLI-Infos</b>	<b>GLOBAL</b>
		<b>540,00 €</b>	<b>240,00 €</b>	<b>500,00 €</b>	<b>280,00 €</b>