



OUR PROJECTS FOR 2016

Following our usual presentation, you will find below our projects for 2016 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 2016.

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

The 5th Cutis Laxa Days will be held in Annecy (France) on 5th to 8th May 2016. As for the previous days, we will fund part of travel costs for sufferers, plus one travelling companion when they are children. We also will fund accommodation and restaurant costs during the 2 days. Thus our draft budget for 2016 is tidy

Branches or Chapters abroad

We will keep on supporting this group lead Susan Meek-Nuner. During 2016 we will carry on our collaboration/partnership to the projects and actions that will be organised 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 2016 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.

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 2016. 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 2016, 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, especially European Reference Networks, Genodermatose Network and FIMARAD (Rare Cutaneous Disorders Channel). We 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) In order to optimize its printing and reduce ours running costs we will replace our A4 printer with an A3 one.
- ✓ List of Doctors : 1 doubled sided A4 sheet
- ✓ Various products : posters, prepaid envelopes,

Updating the website

- ✓ Updating the scientific and medical information as well as those regarding the life of the association itself.
- ✓ Creating new pages (press cuttings and reviews, projects and new actions, etc)
- ✓ Intermediate updates in order to be better referenced after th change of our address.

5th Cutis Laxa Days

- ✓ Funding accomodation and travel costs for sufferers and speakers
- ✓ Organising a festive dinner
- ✓ Organising the visit of Annecy.

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 in Sireuil

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

COMPTE PREVISIONNEL ANNEE 2016 CUTIS LAXA INTERNATIONALE MIS A JOUR LE 20/12/2015

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BUDGET GENERAL ANALYTIQUE REGROUPANT TOUTES LES ACTIVITES

	ACTIVITE	ACTIVITE	ACTIVITE	ACTIVITE	ACTIVITE
PRODUITS/RECETTES	ASSOCIATION	Cartouches	JOURNEES CL	CLI-Infos	GLOBALE
ACTIVITE CARTOUCHES			5 - 8 Mai 2016		
SUBVENTIONS					
RECETTE CARTOUCHES COLLECTEES		300,00 €			300,00 €
pour memoire identique au reversement accorde					
ACTIVITE JOURNEES De Mai 2016					
SUBVENTIONS					
Groupama Marche solidaire			4 000,00 €		4 000,00 €
INSCRIPTIONS					
10 Repas Adulte à A15€ (hors malades)			150,00 €		150,00 €
10 Croisières Adulte à 50 € (Hors malades)			500,00 €		500,00 €
CSL Bons en Chablais (vente Cartouches)			10 000,00 €		10 000,00 €
Livret A Angoulême (Epargne)			13 000,00 €		13 000,00 €
CLI-Infos					
SUBVENTIONS					
Commune de Marthon				150,00 €	150,00 €
Commune de Saint Bonnet de Salers				150,00 €	150,00 €
ASSOCIATION					
SUBVENTIONS					
Triathlon de Sireuil	1 000,00 €				1 000,00 €
Dons	3 000,00 €				3 000,00 €
Dons en nature membres du bureau	600,00 €				600,00 €
COTISATIONS	1 800,00 €				1 800,00 €
TOTAL	6 400,00 €	300,00 €	27 650,00 €	300,00 €	34 650,00 €

CHARGES/DEPENSES					
Activité Cartouches					
FRAIS ADMINISTRATIF		60,00 €			60,00 €
COURRIER	50				
DIVERS	10				
Activité Journées de Mai 2016					
LOCATION SALLE			520,00 €		520,00 €
IMPRESSIONS DOCUMENTS			1 200,00 €		1 200,00 €
FRAIS POSTAUX (envoi invitations)			600,00 €		600,00 €
FRAIS DE TRANSPORT					0,00 €
- INTERVENANTS			1 360,00 €		1 360,00 €
- Bus et Trams Annecy			110,00 €		110,00 €
- Bus soirée festive			600,00 €		600,00 €
- Malades et Familles			13 000,00 €		13 000,00 €
FRAIS HEBERGEMENT			6 000,00 €		6 000,00 €
- INTERVENANTS					
- FAMILLES					
- MEMBRES DU CA					
RESTAURATION					
- Repas jeudi 5/5 (50Ax15) +			850,00 €		850,00 €

(10Ex8)						
- DEJEUNER7 Mai (60 A x 15€) +(15 E x 8)				1 100,00 €		1 100,00 €
- SOIREE FESTIVE vendredi soir				3 000,00 €		3 000,00 €
- Activités Samedi matin				1 000,00 €		1 000,00 €
FRAIS DIVERS (tel, poste, etc)				60,00 €		60,00 €
Prise en Charge Enfants vendredi 6/05				300,00 €		300,00 €
MODERATEUR/ANIMATEUR				1 000,00 €		1 000,00 €
CLI-Infos						
Impression (1 édition)					800,00 €	800,00 €
Frais Postaux						
France						
500 enveloppes x 0,1					50,00 €	50,00 €
400Timbres x 0,70					280,00 €	280,00 €
Etranger						
100 enveloppes x 0,1					10,00 €	10,00 €
200 Timbres x 1,6 en moyenne					320,00 €	320,00 €
FRAIS ADMINISTRATIF					60,00 €	60,00 €
ASSOCIATION						
Frais Confection impression		300,00 €				300,00 €
Papeterie		300,00 €				300,00 €
Informatique		160,00 €				160,00 €
Frais Postaux		200,00 €				200,00 €
Internet et Téléphone		500,00 €				500,00 €
Adhésions Associations		500,00 €				500,00 €
Assurance		200,00 €				200,00 €
Représentation Association		500,00 €				500,00 €
BENEVOLAT		600,00 €				600,00 €
RENOUVELLEMENT Imprimante		400,00 €				400,00 €
AMORTISSEMENT						
MATERIEL		2 000,00 €				2 000,00 €
TOTAL		5 660,00 €	60,00 €	30 700,00 €	1 520,00 €	37 940,00 €
RESULTAT		Association	Cartouches	Journées CL	CLI-Infos	GLOBAL
		740,00 €	240,00 €	3 050,00 €	1 220,00 €	3 290,00 €