



OUR PROJECTS FOR 2008

Following our usual presentation, you will find below our projects for 2008 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). Some continents or countries remain difficult to reach (Africa, Asia, Eastern European countries, The Middle East, etc).

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 2008.

Information

1. To Sufferers

✓ CLI-News will remain our first information tool for sufferers and their families with its 2 annual issues. From the first 2008 issue (June 2008) onwards, we will start sending it in .pdf file via the internet, thus reaching two aims : Reducing its production (time, ink, paper, etc) and postage (envelops, stamps) costs while protecting the environment and reducing waste.

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

✓ Our Leaflet will be completely updated; the new issue that could not be done in 2007 will be presented during the Information Day (May 2008).

2. From Sufferers

We will also keep on calling for sufferers' stories to allow us to complete our "White Book".

Family Days

Thanks to the funds raised with "Environment and Solidarity, 2008 will see the greatest Family Days we have ever organised since we set up the Association. It will be our most important work for the year, either preparing and organising them beforehand, or writing and formatting the reports afterwards. Our main criteria of success will be the number of sufferers (from France and abroad) we will welcome in Paris and also our capacity to balance the budget.

Branches or Chapters abroad

We have been hoping to set up this project for many years. It often comes up in our daily work. In some countries, especially the USA, we now know a real “group” of sufferers and not only isolated sufferers, alone in their country. In 2008 American sufferers should start “structuring”. Of course, Cutis Laxa Internationale will help them getting organised and give them all the documents and information they might need. Cutis Laxa sufferers’ voice needs to be heard by the Authorities in every countries.

THE MEDICAL WORLD

Partners in the Research Project

2008 will be a transition year for the Cutis Laxa research network started with AFM-Généthon. In France, the network will be a little “sleepy” as the two years’ support from the INSERM has ended and reserachers are waiting for new funding for new research projects. Nevertheless, Pascal Sommer’s work is going on and will be developed with new aims and research targets. On the other hand, several research teams work on Cutis Laxa, abroad. Of course, in 2008, we will keep on working with these teams, helping them with the sufferers’ census and supporting their call for grants.

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. It is therefore of the utmost importance that we attend as many as possible. In 2008, we will do it as often as possible, in human and financial terms.

SOCIETY

Relationship with other Support Groups

In 2008, we will pursue our work with those associations or federations we are members of, especially with Alliance Rare Disorders’ decentralisation in Poitou-Charente and the organisation of the working group “Home Help” in the CISS-PC. Beyond sharing our experiences, it is through inter-association exchanges and working groups that we are in the best position to learn of changes in the Health world. This is also how Cutis Laxa will be increasingly 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, more than ever in 2008, the last year of the National Plan for Rare Disorders. We already called on our deputy,

asking them to become an advocate with the Ministry of Health for an Improvement Plan to start in the early days of 2009.

Campaign work

In 2008, we will remain active and vigilant in regards to legislative and social issues. We will start working on the review of the Bioethic Laws which, theoretically, should take place in 2009. We will know how to advocate with deputies (members of the Lower Chamber) and senators so that they do not forget to work on this review. Each time we have the opportunity to do so, we will carry the sufferers' voice to all levels, not only in France, but also in Europe and all over the world. 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 2008

Publications

(All issues are printed in French, English, Spanish and some in German)

- ✓ CLI~News : 2 issues a year (500 in French, 200 in English, 50 in Spanish)
- ✓ Leaflet : A new print run with a chapter about research as well as usefull addresses. We will print 5,000 copies in French, 3,000 in English and 2,000 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, pre-paid 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 20 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

Organising the Annual General Meeting

- ✓ Invitations and press-books
- ✓ Printing and postal costs
- ✓ Funding 80 % of the travel costs of sufferers and their families coming from abroad
- ✓ Lunch and coffee break
- ✓ Funding speakers' travel costs
- ✓ Funding the accomodation costs of all sufferers and families coming from abroad.
- ✓ Organising a festive closing evening
- ✓ Hiring the room as well as presentation and equipment for speakers



COMPTE PREVISIONNEL ANNEE 2008 CUTIS LAXA INTERNATIONALE MIS A JOUR LE 17/06/2008

35 route des Chaignes 17740 Sainte Marie de Ré France Tel/Fax : 33 (0)5 46 55 00 59

BUDGET GENERAL ANALYTIQUE REGROUPANT TOUTES LES ACTIVITES

	ACTIVITE ASSOCIATION	ACTIVITE CARTOUCHE	ACTIVITE CLI~Infos	ACTIVITE JOURNEES des 9 et 10/05/2008	ACTIVITE GLOBALE
PRODUITS/RECETTES					
ACTIVITE CARTOUCHES					
SUBVENTIONS					
Ministère de l'Environnement	Réponse négative				- €
Fondation ANGELFLIGHT	Réponse négative				- €
RECETTE CARTOUCHES COLLECTEES		5 000,00 €			5 000,00 €
pour memoire identique au reversement accorde					
ACTIVITE JOURNEE du 10 Mai					
SUBVENTIONS					
Fondation RONALD Mc DONALD	Réponse négative				- €
Mairie de Paris	Réponse négative				- €
Ministère de la Santé	Réponse négative				- €
Fondation AIR France	Réponse négative				- €
Hypermarchés CARREFOUR	Réponse négative				- €
INSCRIPTIONS					
100 ADULTES A 20 € (hors malades)				2 000,00 €	2 000,00 €
CLI~Infos					
SUBVENTIONS					
Fondation GROUPAMA			800,00 €		800,00 €
Commune de Sireuil			150,00 €		150,00 €
Commune de Marthon			100,00 €		100,00 €
Commune de Saint Bonnet de Salers			100,00 €		100,00 €
ASSOCIATION					
SUBVENTIONS					
DRASS/GRSP Poitou Charentes	500,00 €				500,00 €
GROUPAMA (Nouvelle Brochure)	845,00 €				845,00 €
Dons	7 000,00 €				7 000,00 €
Dons en nature membres du bureau	3 200,00 €				3 200,00 €
COTISATIONS	2 000,00 €				2 000,00 €
TOTAL	13 545,00 €	5 000,00 €	1 150,00 €	2 000,00 €	21 695,00 €

CHARGES/DEPENSES					
Activité Cartouches					
DOSSIERS PRESSE					
10 DOSSIERS A 4 €		40,00 €			40,00 €
MATEREL AFFICHAGE					
50/20*60		100,00 €			100,00 €
RENCONTRE DES MALADES					
Soirée festive 10 Mai		3 523,00 €			3 523,00 €
Frais de Transport venue des Familles	9 et 10 Mai	4 600,00 €			4 600,00 €
FRAIS ADMINISTRATIF		170,00 €			170,00 €
TELEPHONE	120				
COURRIER	45				
DIVERS	5				
Activité Journée du 10 Mai					

LOCATION SALLE		gratuité par Hôpital Necker			0,00 €
IMPRESSIONS DOCUMENTS				950,00 €	950,00 €
FRAIS POSTAUX				450,00 €	450,00 €
FRAIS DE TRANSPORT					
- INTERVENANTS				500,00 €	500,00 €
- Familles métro sur Paris				45,00 €	45,00 €
FRAIS HEBERGEMENT		Total 3 catégories ci-dessous		3 850,00 €	3 850,00 €
- INTERVENANTS					
- FAMILLES					
- MEMBRES DU CA					
RESTAURATION					
- COLLATIONS 9 Mai					
- PAUSE 10 Mai				145,00 €	145,00 €
- DEJEUNER 10 Mai				1 385,00 €	1 385,00 €
LOCATION VIDEO		gratuité par Hôpital Necker			0,00 €
LOCATION MATERIEL BUFFET				380,00 €	380,00 €
FRAIS DIVERS (teleph. ;;)				160,00 €	160,00 €
PRISE EN CHARGE ENFANTS PENDANT LA JOURNEE = BENEVOLES					0,00 €
CLI~Infos					
Impression (2 éditions)			800,00 €		800,00 €
Frais Postaux					
France					
500 enveloppes x 0,04			20,00 €		20,00 €
500 Timbres x 0,54			270,00 €		270,00 €
Etranger					
100 enveloppes x 0,04			4,00 €		4,00 €
100 Timbres x 0,90 en moyenne			90,00 €		90,00 €
FRAIS ADMINISTRATIF			170,00 €		170,00 €
ASSOCIATION					
Frais Confection impression	1 100,00 €				1 100,00 €
Papeterie	600,00 €				600,00 €
Informatique	160,00 €				160,00 €
Frais Postaux	160,00 €				160,00 €
Téléphone	480,00 €				480,00 €
Internet	500,00 €				500,00 €
Adhésions Associations	500,00 €				500,00 €
Assurance	200,00 €				200,00 €
Représentation Association	1 200,00 €				1 200,00 €
BENEVOLAT	3 200,00 €				3 200,00 €
AMORTISSEMENT					
MATERIEL	2 000,00 €				2 000,00 €
IMPRESSION NOUVELLE BROCHURE					
Photocomposition	505,00 €				505,00 €
Impression 10000 ex (F+GB+ES)	845,00 €				845,00 €
TOTAL	11 450,00 €	8 433,00 €	554,00 €	7 865,00 €	28 302,00 €

RESULTAT	Association	Cartouches	CLI~Infos	Journée CLI	GLOBAL
	2 095,00 €	3 433,00 €	596,00 €	5 865,00 €	6 607,00 €