



CUTIS LAXA INTERNATIONALE
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cli ~ NEWS n° 10 ~ June 2007

It is already the 10th issue of our newsletter, yet it seems only yesterday that I was writing the very first letter..... All together we have started a great story which will lead to a cure, one day....

There is still a long road ahead but, as we shout during the Walk for Rare Disorders : “Abandon, no, no, no, Optimism, yes, yes, yes, Hope makes us walk.....”. A network has been set up; research is ongoing; gene mutations have been identified; contacts have been established between sufferers. Isolation and loneliness are no longer the sad reality for those who suffer from Cutis Laxa. We no longer just have to bear it, we fight it with all our strength. The disorder will not win.

This 10th issue is a bit different from the previous ones. It mainly covers the results of the survey we sent to sufferers who have joined with us to evaluate the work of more than 5 years now to ensure we meet their expectations, their needs.

Marie-Claude BOITEUX, Chair of the association

New Contacts, New Families

132, that's the number of sufferers who are with us today. Deyanira (Mexico), Ben, Hanna and Dylan (USA), as well as Gavin (Sri Lanka) are now part of our great « family ». Comfort, support, mutual help, advice and exchanges, they were welcomed at once by the sufferers and families of our global network. How many pains avoided for young parents who have just received the diagnosis for their very young child! What a relief not to be or remain alone! What peace to be able to recognise oneself in someone else's face ! What a comfort to know there is someone, somewhere, who can understand you, with whom you can share your laughter and your tears!

MEETINGS, EVENTS AND EXHIBITIONS

9th February : Towns' Collective (CDC) of the Ile de Ré and the Association AREI gave us a cheque of over € 207 for collecting bottle tops in 2005.

15th February : Orphanet celebrated its 10th anniversary. Nathalie represented Cutis Laxa Internationale

19th March : I met Pr Christine Bodemer, coordinator of our Centre of Reference. This first contact was very interesting and we laid the foundations for our future collaboration.

14th April : At our Annual General Meeting, we welcomed Noriko who came from Japan to spend a few days with her friend Raga who lives in Bordeaux (France). The first time we meet a new sufferer is always a moment of



deep emotion. Thanks to Raga's presence, the language barrier was not insurmountable and we were able to exchange and share this working day in a very pleasant way. We parted with promises of meeting again one day.

1st May : Brin d'Aillet Run in Sireuil

12 mai : The Groupama Foundation had organised a seminar on the theme : « Ehlers-Danlos, Marfan, Rendu-Osler : diagnose early, treat in time ». There, I met the Chairs of the associations concerned by these « cousin » disorders of Cutis Laxa.

3rd June : Triathlon in Sireuil

RESULTS OF THE SURVEY ABOUT SUFFERERS

This survey was sent, by post or by email, to all the sufferers we are in contact with worldwide. It was written in French, English and Spanish, depending on the country it was sent to. Among the answers we received, 43% were in French, 43 % in English and 13% in Spanish, which corresponds with the distribution of these languages among the sufferers we know. It was mainly the sufferers themselves (41%) or their mothers (55%) who answered the survey. And the number of answers from both sexes (M : 41% et F : 59%) was nearly equal. Our questions were gathered under 5 headings : General Questions, CLI~News, Information Day on Cutis Laxa, Health and Social Care and Other Questions.

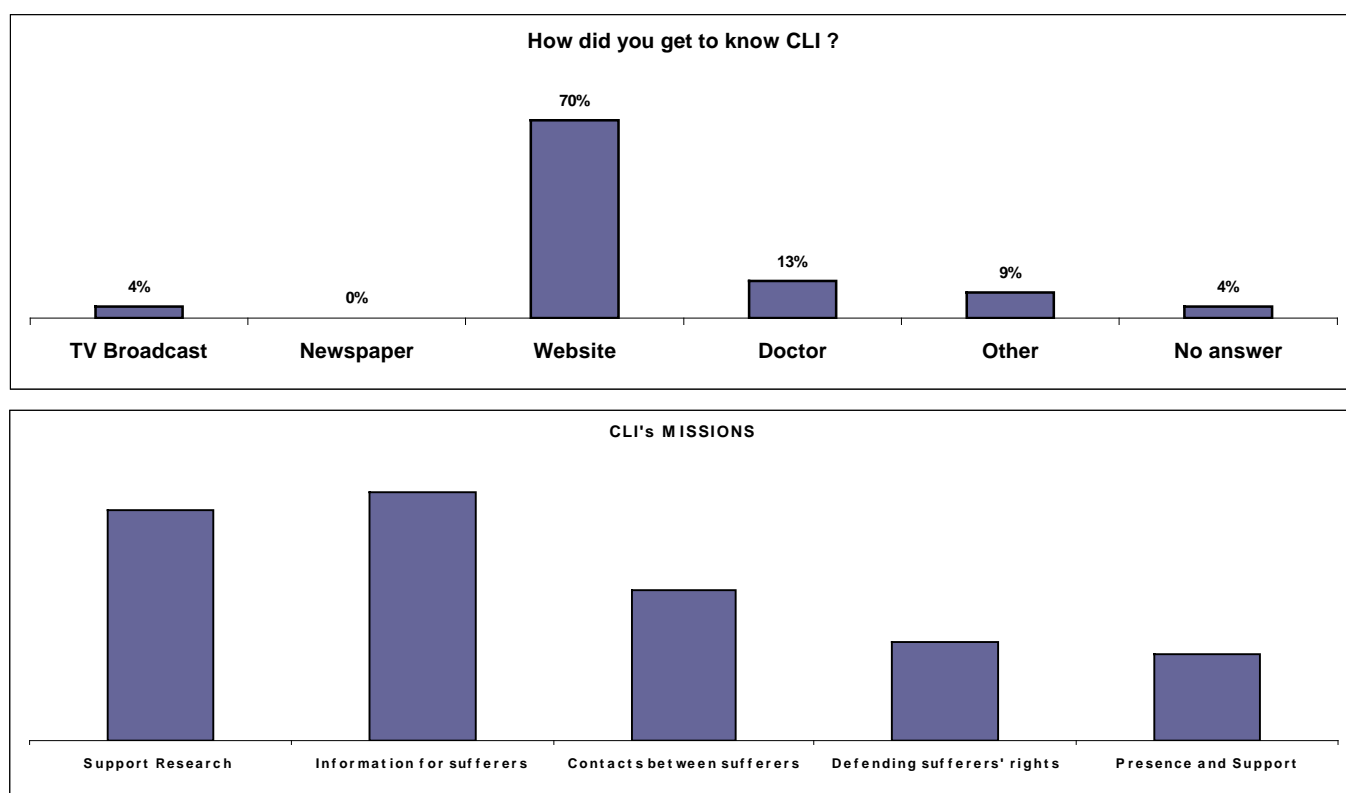
1. GENERAL QUESTIONS

Through these questions we wanted to know first how sufferers knew about us and second what were, for them, the main missions of Cutis Laxa Internationale.

With absolutely no doubt, our website is the way to get in touch with us. 70% of the people who answered the survey knew about us thanks to the internet. This reinforces our conviction that regular maintenance and updates of our website are the best guarantors for breaking sufferers' isolation.

Concerning CLI's missions, the answers may vary whether the sufferer lives in France or not. This is more notable regarding our aim of « Defending Sufferers' Rights ».

The two graphs below will explain much better than any words the distribution of the answers to these questions.



2. CLI~News

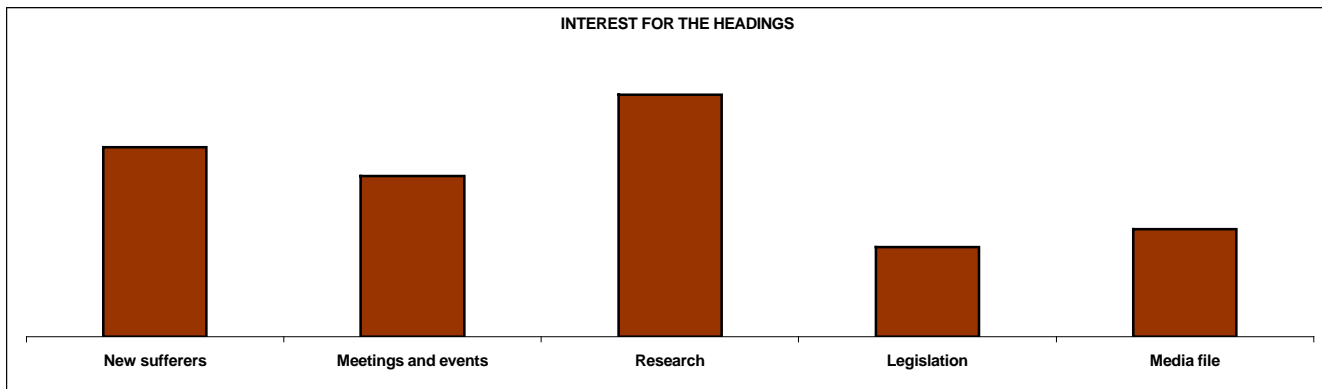
CLI~News is unanimously appreciated (very interesting : 55% and interesting : 45 %). And we thank you for this general approval. Many moving comments insisted on the importance of CLI~News for sufferers :

« I love reading these pages, they give us hope and a feeling of being part of it »,

« Thank you, you make a great job keeping us informed »,

« Obviously this is of far more relevance to those sufferers living in Europe and especially in France. Some of the issues do not mean a lot to me but I admire the work you are doing. I mainly joined CLI to discover more and to be in communication with others struggling with the problems of such a rare disorder ».

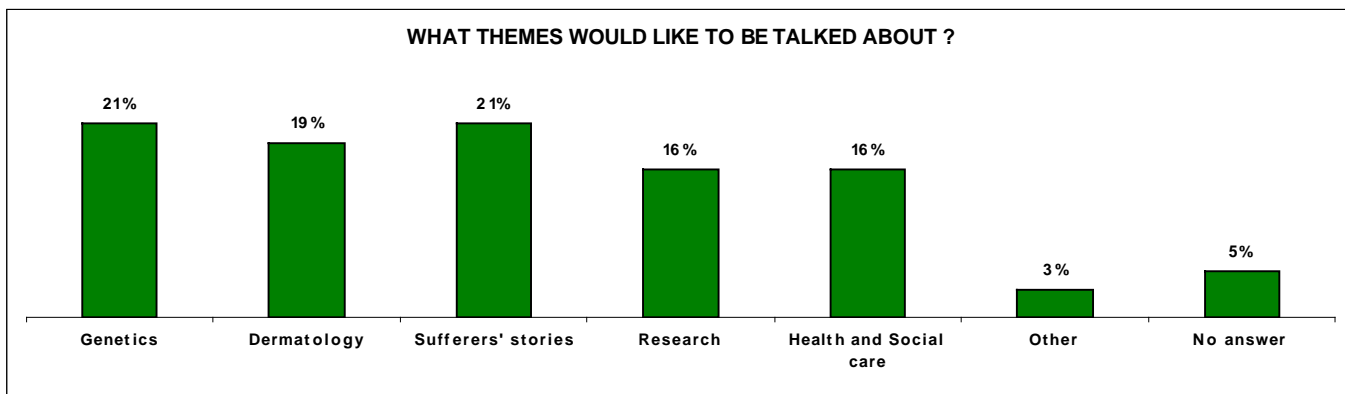
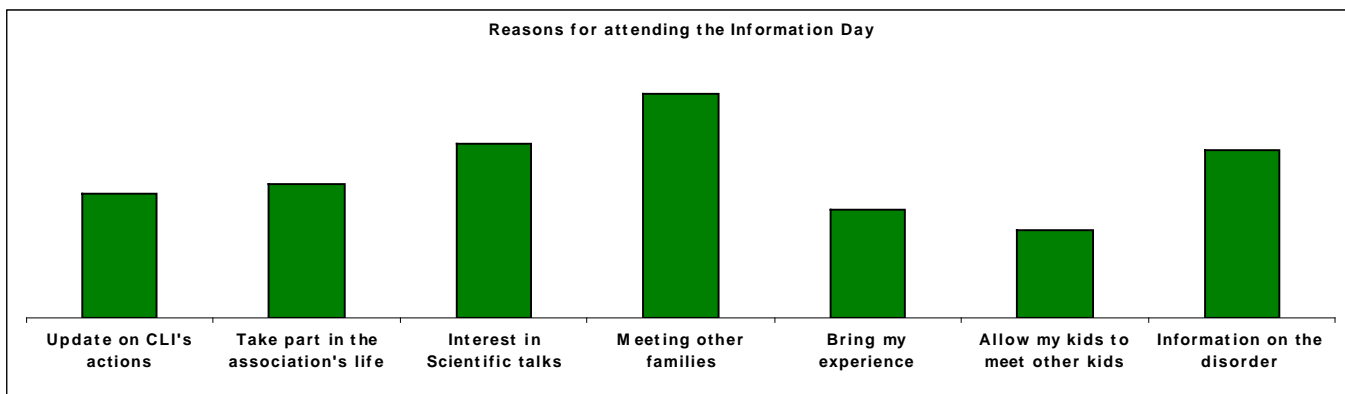
Research is the heading which wins everyone’s approval. Nevertheless, information about newly known sufferers, as well as meetings, events and exhibitions we take part in are also important headings. The lack of interest for legislation issues must be seen within the context of a high number of answers coming from abroad.



It was suggested that we add new headings such as « Recommendations or Advice for those who have psychological problems due to the disorder », « Information on good plastic surgeons for patients suffering from CL ». Thus we will consider a heading entitled « Practical Advice to best manage living with Cutis Laxa » which could be supervised by a health professional.

3. INFORMATION DAY ON CUTIS LAXA

Answers to the survey confirmed that distance (46 %) is the main obstacle preventing sufferers from attend, whereas cost accounts for only 18 % of answers. Concerning the main reason for attending, it is essentially the opportunity to meet other sufferers, other families. Among the themes arousing interest, besides medical and scientific issues, answers show great interest for sufferers’ stories and issues related to the acquired form of Cutis Laxa.

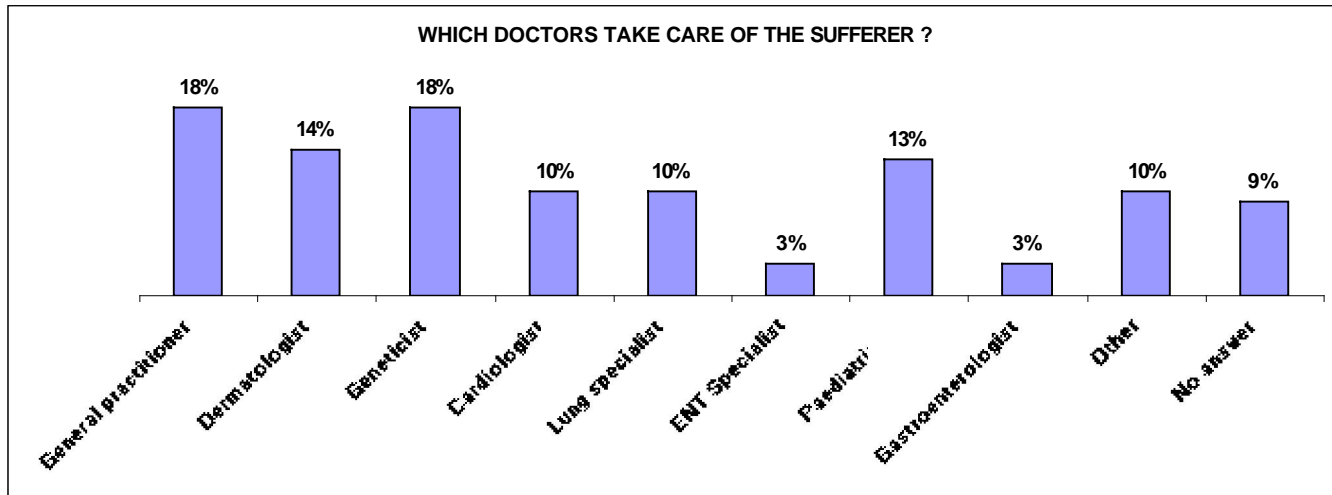


4. HEALTH AND SOCIAL CARE

This heading addressed two issues. The first covered questions aimed at identifying the different specialists who take care of Cutis Laxa sufferers. The second was, for French sufferers, aimed at evaluating if they know their

rights in terms of medical and social care, whilst for sufferers from abroad, the questions aimed at evaluating, if possible, what kind of medical and social care exist in other countries.

❖ Even if it is mostly general practitioners (18 %) and geneticists (18 %) who take care of Cutis Laxa sufferers, all the different specialised area of medicine are represented. It is somehow surprising that dermatologists represent only 14 % when the most obvious symptom is cutaneous. It is also notable that, on the one hand, some patients have only one doctor (geneticist or dermatologists or general practitioner) when, on the other, some are under many more than one. It is also important to notice the high number of “no answer” (9 %) to this question.



❖ Regarding Social Care, on the whole, French sufferers know their rights well and all the applications they made (ALD, CDES, COTOREP, etc) have been accepted. However, only 22 % of the respondents know where their Local Resource Centre for the Disabled is located. Thus we have a great deal of information work to do.

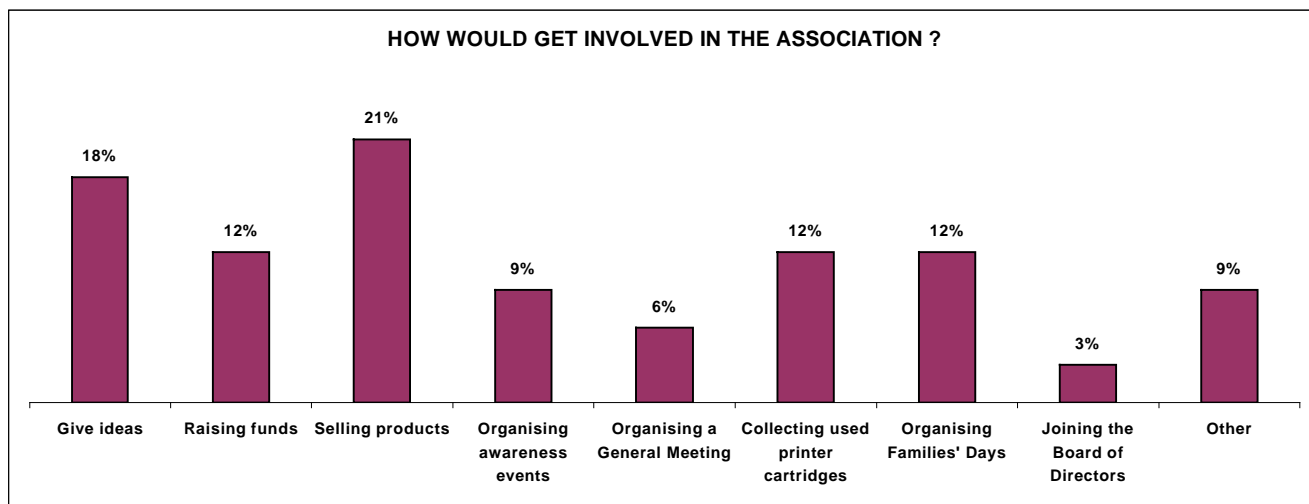
❖ Concerning foreign countries, state medical and social care, especially for rare disorders, is low or little known by sufferers themselves.

5. OTHER QUESTIONS

The questions in this heading aimed at evaluating the use of internet as well as the will to get involved in the association’s life.

Concerning the internet, 100% of the people who answered the questionnaire know Cutis Laxa Internationale’s website and 65 % among them go and visit it more than once every three months or more. This confirms its importance as a communication tool between sufferers and the association.

Over half of Cutis Laxa sufferers (57%) who answered the questionnaire are willing to get involved in the association’s life. We had suggested different ways to get involved. It is obvious that the location of residence (in France or not) had a great impact on the answers given.



CONCLUSIONS

The results of this survey confirm the importance of our website to allow sufferers to know about us (70%) as well as to keep them informed on everything concerning Cutis Laxa (65% of the respondents visit it between less than once a month and once every three months). We have here a tool of the utmost importance to break sufferers' isolation and which meets their expectations.

Nonetheless CLI~News is also an important communication tool, particularly for those who do not have a computer. Even if it needs to be supplemented with some new headings (Practical Advice, list of names and addresses, etc) it meets sufferers' needs.

The privileged occasion when we meet each other on our Information Day on Cutis Laxa answers a real need, a real expectation for sufferers and their families. Nevertheless, our geographical scattering, nationally and internationally, creates important problems. It is difficult to attend, physically, in concrete terms. Distance (46%) and cost (18%) are the main obstacles. Thus we must take sufferers' wishes into consideration and choose a more accessible, more central venue. We must also make an effort of information about the reimbursement of travel expenses . Only 26 % of the answers mentioned knowing that we can cover part of the travel expenses to attend the Information Day.

A large majority of the answers to the survey (57 %) want to get involved in the association's life and help develop it. This involvement can take different forms, not only for personal reasons but also depending on geographical distance : selling products (21%), giving ideas (18%), raising funds (12%),etc.

To bring a first answer to this desire for involvement, you will find enclosed an « order form » of various products and communication tools we can send you.

We want to thank all those who took a little of their time to answer our questionnaire. The results of the survey are a working tool. They will permit us to further improve the actions we set up to satisfy as best we can the needs and expectations of Cutis Laxa sufferers.

LEG ISLAT ION

❖ The first parliamentary meetings on bioethics were organised on 7th February 2007, in anticipation of the review of Bioethic Laws scheduled for 2009. On this occasion, the Biomedicine Agency (<http://www.agence-biomedecine.fr>) published the first national survey on French opinion on these issues.

❖ The Law on Loans for people with an increased health risk, voted on 31th January 2007, gathers together, in legal terms, the principles agreed in the AERAS convention. In this context CABIP consultants, specialised in loan insurances and mortgage opened on its website CREDIASSUR (<http://www.crediassur.fr>), a forum about AERAS convention. You can also go and visit the convention's official website <http://www.aeras-infos.fr>

❖ The Universal Convention on the Rights of Disabled People, welcomed as a « marker » treaty on social rights was adopted on 13th December 2006. 80 countries as well as the European Community signed it on 30th March in the UN headquarters, in New York. Kofi Anan, former UN General Secretary declared that this Convention is « The first treaty on human rights adopted in the 21st century » whilst Handicap International spoke of « historical progress ».

MEDIA FILE

26th Januray : Le Réveil de Mauriac : Tribute to Jean-Louis Boiteux

Januray 2007 : SCI Infos (Newsletter of the association for Cohen Syndrome) : Tribute to Jean-Louis Boiteux

14th February : Le Phare de Ré : Cheque presentation from the association AREI and the Towns Community of the Ile de Ré

21st March : Sud-Ouest : Contest « 50 student writers ». Cécile's school friends win a price for the article they have written about her. The article is published in « Sud-Ouest ».

11th April : TEVA (TV Channel) : « The 100th broadcast of TEVA's Files », broadcasting an extract of the film « Reports » (2004) and interviewing Cécile and Marie-Claude. What happened in Cecile's life since shooting « Reports » ?

30th April : CLOSER Magazine: Real Life Experiences : Cécile : « I am 16 but people think I am over 30. I have a rare disorder. »

Environment and Solidarity :

From the beginning of the year onwards, Nicole Héger has gathered a team to collect cartridges at the collecting points. I want to thank here all those who help us in this way. Over 1,800 cartridges had been collected by the end of March. We do not know yet the exact number of the last mailing to recyclers, but this project keeps on growing. In this way we hope to be able to help more families to come to our coming Information Day, in 2008.

Internet :

At the end of May, nearly 14,000 visitors had turned over the pages of our website. We carried out a comprehensive update in January and the next one is in the pipeline....

Linda(Belgium) left this world on 10th February. Suffering from the acquired form, she had had a transplant of both lungs. Unfortunately, complications occurred and the transplant was rejected. She was 38. To her husband and to her little 8 year old daughter we send our sympathy and deepest condolences.

Thanks

To all those who give their help and support for Cutis Laxa Internationale to go on developing and breaking sufferers' isolation. A special thank to Florence who took charge of our website's maintenance and its updates.

Fees, donations and grants :

Thanks to all those who have already renewed their financial help in 2007. Thanks to the villages of Martho (16-France) and Saint Bonnet de Salers (15-France) who faithfully remain at our side in the fight against the disorder. If you have not yet sent your fee or your donation, there is still time to do it. **Do not forget us in 2007. The sufferers need you.**

Investments :

Thanks to the grant we received from the AGIR Foundation of the Crédit Agricole Bank, we bought a new, high-performance, printer and a new lap-top. These new tools better fit our needs and increase our efficiency.

The Board of Directors wishes you a happy summer and great holidays.



Thank you for sending back this form with your membership fee and/or your donation to the address mentioned below

**CUTIS LAXA INTERNATIONALE ASSOCIATION
35, route des Chaignes - 17740 Sainte Marie de Re - France**

NAME..... FIRST NAME.....

ADDRESS.....

ZIP CODE..... TOWN.....

COUNTRY..... Email.....

Wants to support Cutis Laxa Internationale by sending his/her membership fee : € 23 (when paid in Euros) ; due to the very high cost of foreign currency exchange for small sums, if you cannot pay in Euros we require the equivalent of € 50 in your own currency.

Wants to send a donation. Amount.....

As indicated in French law "Freedom and Computers" 06 July 1978, you have the right to have access and to rectify your personal mentions. If you want it, write to our Association.

"ORDER FORM " SALE OR RETURN

Mrs,Ms,Mr.....
 Adresse.....
 Zip Code.....Town.....
 Country.....
 Email.....
 Tel.....Mobile.....

Asks the Association "Cutis Laxa Internationale" to send him/her the products listed below, by post, for the enclosed lump sum of € 10 postage and packing.

Description	Quantity
Communication material and posters <u>not for sale</u>	
Poster 40x60cms	
Poster 30x40cms	
Poster 21x29,7cms	
Leaflet "We are starting a great story.....all together"	
CLI~News N°8	
CLI~News N°9	
CLI~News N°10	
Products <u>for sale</u>	
T-Shirt , white or navy blue, size S to XL, price € 10 each	
Inflatable Beach Bag , convertible in pillow, price € 5 each	
Key Holder , price € 1 each	
"Kit for sale" consisting of : 14 matched T-Shirts (colors and sizes), 3 beach bags, 5 key holders, worth a total of € 160	

Except for the lump sum of € 10 postage and packing, I do not send any money now. All the products for sale will be sold at the price mentionned above. The total amount of sales will be entirely transfered to "Cutis Laxa Internationale". All the unsold products will be posted back to "Cutis Laxa Internationale" at my own expense.

Dated this day of 200
 Signature

For Cutis Laxa Internationale use only	
Commande reçue le.....	Invendus retournés le.....
Paiement des frais de port <input type="checkbox"/> oui <input type="checkbox"/> non	Montant des ventes
Commande envoyée le.....	Reçu le.....