CUTIS LAXA INTERNATIONALE
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OUR PROJECTS FOR 2022

Cutis Laxa Internationale celebrated its 20th anniversary in November 2021. Unfortunately the pandemic prevented us from organising a celebration. But 2022 will be a festive year with the 6th CLI Days held in Ghent (Belgium) in September. Festive days where patients will meet each other, and receive informative and work together. These days are key times in the life of Cutis Laxa Internationale. They put into effect the aims stated in our constitution and the work done by so many to get Cutis Laxa known, recognised and better understood.

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 2020.

Regarding the contacts we have with Cutis Laxa patients, whether these take place one-to-one, essential to break loneliness, or via our website or social networks, all personal data we might be gathering will be used in compliance with regulations on personal data protection.

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.

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
- ✓ The book « Cutis Laxa, Story of a rare disorder » published in late 2020, gathers together patients'and families' testimonies from the early days of Cutis Laxa Internationale to date.

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.

Cutis Laxa Days

These will be the main event in 2022, to be held from 13-16th September in Ghent University Hospital.

The programme will be as follows :

Tuesday 13th September : 1st Clinical Consultations Day for patients
Wednesday 14th September : 2nd Clinical Consultations Day for patients
Thursday 15th September : Conference with all the latest findings on Cutis Laxa
Thursday 15th September : Festive evening with a boat tour in Ghent old town and dinner in a restaurant
Friday 16th September: Working Day on research and establishing a Patient Advisory Board for Research

As with previous CLI Days, CLI will fund part of the travel costs and all accommodation costs for patients over the period. Other expenses (conference room hire, catering during the conference, etc) will be funded by Ghent University Hospital.

It represents a huge amount of work and, fortunately, they will be organised together with Pr Bert Callewaert and his team.

Branches or Chapters abroad

During 2022 we will carry on our collaboration/partnership to the projects and actions that will be organised in France, Europe 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

LE MONDE MEDICAL

ERN-Skin

Besides the usual activities in our ERN and its subthematic groups that will continue in 2021, new transversal groups have been organised to allow common issues in all ERNs to be visible. In 2022, ERN-Skin, together with Fondation René Touraine, will organise the 1st World Congress on Rare Skin Disorders. As Patient Representative we will take part in the organisation of a patient-led session.

EPAG (European Patient Advocacy Group) : Patient Representatives in the ERNs

As for ERN-Skin, and linked to its development, the work done among the epags will grow. Speeking with one voice, getting trained, sharing successes and difficulties are the mainstays of being in an epag. Set up in 2017 at the same time as the ERNs, it is now necessary to agree the Terms of Reference that detail their rights and duties.

FIMARAD

The FIMARAD network continues its coordination work with the French Centres of reference and Centres of Competencies. The will to stimulate this work is becoming a reality in the workgroups. We will focus our engagement in the workgroup « Diagnosis Roving and Impasse » to be continued in 2022.

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 : The election of Marie-Claude Boiteux as Chair of the French Skin Federation (FFP) in late 2021 will allow Cutis Laxa Internationale to strengthen its visibility in 2022. Many cross-discipline projects will lead to actions that are beneficial to Cutis Laxa that CLI could not achieve alone. For instance : Local Plans for Health (PRS) will be reviewed in 2022. Today, they do not even mention the word « dermatology » ! It will give us the opportunity to organise seminars gathering all stakeholders in the field : Health Professionals, Institutions, Patients and Elected Officials. The FFP will then be able to submit a written contribution to the PRS review.

✓ LOCALLY : Our local network is widening further and further, we have more opportunities for sharing, working together and regrouping our efforts.

We are now member of the CCAS (Town Center for Social Support) and of the Commission for Accessibility of Public Buildings for the town of Bons en Chablais.

Unfortunately, the health and safety constraints due to the pandemic prevent us from taking part in local events.

Visibilty- Communication

Our publications as well as our website will remain the main communication tools for public visibility. We had planned for patients' portraits to be taken by a professional photographer with a view to an exhibition in 2020, but this was halted for the second year because of the pandemic. We do hope to be able to start working on it again in 2022 on the occasion of the CL Days in Ghent

Commitment to Social Change

To achieve this we will insist on attending and participating in as many local, national, European and international events as possible as soon as the virus will allow us to travel. Nevertheless, and until then, new online communication methods do allow us to be the patients' voice to get society to evolve. It means new working methods, new way of managing time, but we remain present and activ, and this is the most important.

RESOURCES REQUIRED IN 2021

FINANCES

Researching new fiancial means

- ✓ Crowdfunding websites, online fundraising
- ✓ Foundations
- ✓ Taking part in local, national and international events as soon as the pandemic allows us to
- ✓ Grant application submitted to European Institutions to support the CL Days in Ghent.

Sales during events

- ✓ New objects to be sold

Cutis Laxa Days in Ghent expenses

- ✓ 70% of patients' travel costs
- ✓ Accommodation and catering for patients over the 3 days
- ✓ The festive evening on Thursday 15th September

TRAININGS

- ✓ Webinars EPAGs
- ✓ Webinars Eurordis
- ✓ Webinars Globalskin
- ✓ Webinars RDI

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 sent by post or via the internet
- ✓ New Medical Leaflet : printed as and when needed.
- ✓ New General Information Leaflet : printed as and when needed
- ✓ New leaflet on symptomic treatments : printed as and when needed
- ✓ Book « Cutis Laxa, Story of a rare disorder, Patients' testimonies » on sale to CLI's benefit

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
- ✓ Paper posters
- ✓ Visiting cards

Public Relations

- ✓ Covering expenses (travel, accommodation, etc) to attend events…. When organisers are not proposing grants or funding to attend

OTHER

Sending documents

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

Taking part in setting up the Triathlon in Sireuil

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

CUTIS LAXA INTERNATIONALE
Draft Budget 2022

	2022	31.12.2021	31.12.2020
INCOMES			
Sales & events	4 500,00 €	2 472,22 €	1 518,91 €
Grants	2 500,00 €	200,00 €	200,00 €
Donations & Fees	6 000,00 €	6 287,96 €	11 291,21 €
Total incomes	13 000,00 €	8 960,18 €	13 010,72 €
COSTS			
Purchasing	- €	- 829,04	1 326,52 €
Operating costs	35 000,00 €	5 329,41 €	3 945,53 €
Volunteers costs (travels and time)	2 500,00 €	1 698,00 €	1 570,00 €
Depreciations	- €		- €
Exchange differences	- €		- €
Interests	- €		- €
Total costs	37 500,00 €	6 198,37 €	6 842,05 €
RESULT	- 24 500,00 €	2 761,81 €	6 168,67 €

I would like to put this Projects and Draft Budget for 2022 to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 20th May 2022 and attendees' vote.