



OUR PROJECTS FOR 2021

Cutis Laxa Internationale will celebrate its 20th anniversary in November 2021. We had planned a well-deserved celebration which the pandemic forced us to cancel. Following our usual presentation, you will find below our projects for 2021 grouped under three main headings.

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 2021.

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.

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During 2019 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.

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THE MEDICAL WORLD

LE MONDE MEDICAL

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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 ».

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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.

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- ✓ Knitting given by members of the Group « Friends Group Malakoff Mederic » (RAMM74)
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TRAININGS

- ✓ Webinars EPAGs
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Other communication tools

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

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CUTIS LAXA INTERNATIONALE

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