CUTIS LAXA (CL) - what is it?

Cutis Laxa (in Latin « loose skin ») is a rare genetic disorder. Its main visible symptom is a wrinkled, loose skin; the elastic fibers in the whole body are deteriorated or even totally missing. It affects men and women equally and its frequency is not well known. Nevertheless, the medical profession estimates that there are less than 1000 cases worldwide.

The disorder can be identified, superficially, by this characteristic loose skin. But, there are more than ten different types depending on which internal issues (cardio-vascular, digestive, respiratory, genital, ligamental…) are affected and the age of CL onset. Only genetic testing and/or a biopsy can confirm the diagnosis.

CUTIS LAXA INTERNATIONALE (CLI) - who are they?

Our organisation was set up on 11th November 2001, by Marie-Claude and Jean-Louis Boiteux, parents of Cécile who was diagnosed with Cutis Laxa in 1992. Their aims at that time, stemming from their own experience with facing the disorder, still fit today with the needs of patients and their families:

- Breaking the loneliness, induced by the rarity of this syndrome;
- Working together with the medical and scientific world to improve knowledge and research;
- Getting this unrecognized or even often unknown disorder known and recognized worldwide;

As of today we are still the only organisation worldwide. For the past 16 years, CLI has allowed 351 sufferers (as of 31st October 2017) and their families to get to know each other, to communicate and share their experiences facing the disorder. But, all over the world, sufferers and their families are still isolated.

CLI - What actions?

- Against Isolation and Loneliness
  « Cutis Laxa Days »: Over 2-3 days, we organise meetings, medical conferences, festive evening gatherings... Seriousness and recreation, all together, sufferers, families and health professionals. Those days mean a lot in the life of attendees as they allow them, at last, not to be alone anymore and to have privileged contacts with doctors and researchers who attend.

  During our 16 years we have only been able to fund 5 of them, including sufferers’ accommodation, food and travel, but thanks to those « CLI Days », 61 sufferers, 33 of them coming from abroad were able to come to France and break their loneliness.

  Breaking isolation is also done daily through the Facebook Private Group. Any patient can be a member from the first contact. We are also willing to attend to any individual issue or questions and liaise between sufferers and our worldwide network of expert physicians.

- With the Medical World
  Besides facilitating contact between sufferers and doctors, we help researchers in their research projects, through a census and liaising with sufferers as well as through administrative and legal tasks, in France (laboratory IBCP-Lyon) and abroad (Pittsburgh University-USA).

  Starting from « 0 », and after 16 years of hard work, research projects on Cutis Laxa have led to the discovery of 11 genetic mutations and to finalise 1 consumer cosmetic product.

- Facing Society
  Active at all levels in the Rare Disorders Community, after being a member of the Citizen Panel during the review of bioethic laws in France, we are now a patients’ representative in the European Reference Network for Skin (ERN-Skin) and lately became full member of the organisation « Rare Diseases International ».

  We also work directly for Cutis Laxa patients, bringing them the help and support they need in all the necessary steps to get their rights recognised.

  We distribute our information as much as possible through different medias : website, Facebook page, the press including radio and TV, conferences, meetings, congresses, etc...

  We write, translate (French, English and Spanish), edit and distribute all our documents worldwide : 2 newsletters per year, leaflets, information brochures...

CLI Our needs?

We call on your financial generosity.

We call on your network: we are looking for volunteers, new partners (helping with secretarial tasks, printing our documents, translations, social media and communications tools, etc…)

In 2016, our costs increased to over € 25,000 of which € 20,000 was related to the Cutis Laxa Days. To cover those expenses, we used all our means, hoarded during 5 years thanks to our members’ fees and donations from supporters and benefactors.

We make it clear that our volunteers’ time is not quantified.

We need you.
Support us, Talk about us, Help us getting known!
CUTIS LAXA INTERNATIONALE is member and/or partner of:

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“Ni notre peau, ni nos rides, ne symbolisent notre identité”