CUTIS LAXA INTERNATIONALE
Organisme d' Intérêt Général Loi 1901.

138 impasse de Champs Gervais - 74890 Bons en Chablais - France - 33 (0)4 56 30 74 43 - mcjlboiteux@aol.com - www.cutislaxa.org
IBAN : FR76 1810 6000 4296 7525 0578 892 BIC : AGRIFRPP881

CLI ~NEWS N° 43 ~ AUGUST 2025

The 7th CUTIS LAXA DAYS will be held in GHENT – BELGIUM
4th to 6th FEBRUARY 2026

In France and in Italy, sportsmen and sportswomen, volunteers, patients as well as members of the board spent a lot of energy into raising funds so patients from around the world can attend the 7th Cutis Laxa Days in 2026 in Belgium where they will also benefit from consultations with experts.

I am forever grateful to them. Without them we would not have the necessary funds.

We are the only organisation worldwide dedicated to Cutis Laxa and we represent patients from 68 countries. Our financial means only come from private citizens, from their fees and/or donations. No industry or laboratory supports us. We do not receive any funding from the French Government, nor from the European Union. We are very cautious about our expenditure.

Yet, only French people, with one or two other European countries on an ad hoc basis, organise fundraising events towards the cost of patients attending from all over the world. **Others must rally in support of CLI's actions.**

I eagerly wish for CLI members in other countries to step up and fundraise to help Cutis Laxa Internationale fulfil its missions, to keep our Big Cutis Laxa Family alive.

Marie-Claude Boiteux, Chair

NEW CONTACTS, FAMILIES' NEWS

Rebecca, Sami, Robert, Anna, Zoé, Mercédes, Sarah, Emily, Elena, Tawn, Ember, Mariam, Giulano, Quentin, our Big Cutis Laxa Family is here to help and support you and to answer your questions.
Counting you, we are now 567 patients worlwide, suffering from Cutis Laxa.

Alas ! more deaths plunged us in mourning: Nathan, Maui, Tony and Tasha.
Adults or children, new members or those we've known for years, we always hear with great sadness that one of our members has left this world. They meet all those who have already left. They remain in our hearts and thoughts forever. May they Rest In Peace.

MEETINGS, EVENTS AND EXHIBITIONS

The attached Special Issue tells you about the events we attended in 2025 in France and in Italy. These special events allowed us to raise the necessary funds to organise the 7th Cutis Laxa Days next year and to give a financial help for worldwide patients to attend them.

OTHER FACE-TO-FACE MEETINGS AND ON-LINE ACTIVITIES

30th-31st January 2025 : Dermatology-Venerology Meeting organised in Paris by the National Union of Dermatologists-Venerologists (SNVD). It gave CLI the opportunity to speak during a round table dedicated to partnerships between patient organisations and SNDV.

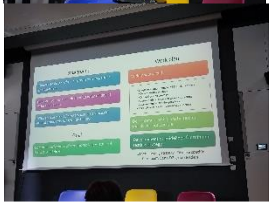
3rd April 2025 : Patient organisations representatives met up in Paris to take part in the Stakeholders' National Conference.of Dermatology organised by the French Society of Dermatology (SFD).

23rd-26th April 2025 : Globalskin had chosen Prague to held its biannual conference. It is always a great pleasure to meet again with patient representatives colleagues coming from every part of the world. Three days of work, exchange, reflections and building projects united us and gave us the necessary energy to advocate for patients. This year had a special taste as Marie-Claude Boiteux received the collaboration award during the closing diner. It is a great recognition of the work she is doing for Cutis Laxa patients and for all those who are concerned by a rare skin disorder.

21st-22nd May 2025 : Marie-Claude Boiteux was in Geneva to support two important resolutions to be voted by the World Health Assembly (WHA). The first one, presented by **Globalskin**, is asking **for Skin Disorders** to be placed as a global public health priority. The second one, presented by **Rare Disease International** for its part, asks **for Rare Disorders** to be placed as a global public health priority Cutis Laxa is a rare and skin disorder. These two resolutions, unanimously voted by WHA in its 24th May 2025 session, are then essential for our patients worldwide. They open the path to global action plans focused on prevention, early diagnosis, efficient treatment and long term care for all people suffering from rare cutaneous disorders worldwide. They also promote equitable access to affordable and quality services and integrate skin health in larger healthcare systems. Healthcare professionnals have not been forgattent as the resolutions also call for promoting research on skin disorders in collaboration with academic and research institutions, and for improving data collection, research and monitoring on rare disorders to developp strategies to enhance understanding, timely and confirmed early identification, including screening, diagnosis and treatment options; We must now carry on working for those Global Action Plans to be implemented and fit with patients' needs worldwide.

23rd June 2025 : The scientific medias « Psychologies » « Doctissimo » « et « Science & Vie » welcomed us in Paris to take part in « Let's talk about Dermatology » and more specifically to share our experience with Tele-expertise during the roundtable that was dedicated to it.

2nd-3rd July 2025 : ERN-Skin had organised its Scientific Days in Paris to present the latest research on each pathology, clinical cases and the work of young researchers so we would be updated on the work and projects led in our European network. The work done by patient representatives was also honored with Marie-Claude Boiteux's presentation of the publication « Pregnancy and Family Planning in Rare Disorders – A Heathcare Professionals survey » (see the details of this study under the heading "Research – Medicine – Genetics".



…………. And many other meetings, working sessions, video conferences that kept us busy for days, weeks, months since January......

RESEARCH – MEDICINE – GENETICS

Orphanet Journal of Rare Diseases the results of the survey for heathcare professionals « Pregnancy and Family Planning in Rare Diseases :. The European Reference Networks (ERNs) transversal working group brings together patient representatives (EPAGs) (of which Marie-Claude Boiteux) and healthcare professionals (HCP) from 20 ERNs published in the. After identifying 7 transversal domains to be explored in the survey (Fertility preservation, Pre-conceptional counseling, Family Planning counseling, Pre-implantation diagnosis, Prenatal diagnosis, Pregnancy monitoring, Post pregnancy monitoring/ lactation monitoring/counseling/newborn management), the group established closed and open-ended questions for each domain. These questions explored the level of importance, the activities performed by the center, the clinical challenges, the good practice and the educational activities related to the selected topics.
197 HCP, from 24 different countries answered the survey.
"Pre-conceptional counselling" and "pregnancy monitoring" were mentioned as important/very important at 83.3% and 75.6%, respectively. And « Family Planning Counselling » was considered very important/important at 71,6%.

The conclusions of this survey are pointing unmet needs for HCPs, including the need to improve communication between different HCPs, the lack of predefined organizational pathways, the lack of availability of expert HCPs for some pregnancy-related issues and the need to streamline the care provided among different European countries.

In addition, the survey underlined the need to improve the educational activities provided to rare disease patients.

Overall, the results pointed out the need to educate both physicians and patients on the basis of the emerging unmet needs. Online resources can be an excellent educational tool, they may help in disseminating and standardizing educational activities in order to homogenize the information for HCPs and patients.
Therefore, initiatives in this direction by scientific societies, ERNs and patient associations should be promoted and encouraged

A second questionnaire had been sent to patients. The answers are being analysed and should be soon published. It will then be possible to compare HCPs' and patients' views.

LEGISLATION ~ SOCIETY

On 25th Février, the **4th National Plan for Rare Disorders was finally launched in France.** Long awaited, but delayed due to the political context, it aims to widen and pursue the work done with the previous Plans. It is based on 4 axes :

- Improving the life and care pathway (strengthening city-hospital links, strengthening Therapeutic Patient Education, developing specific actions for transition periods, raising awareness, training and informing, mobilizing investigator centers in research);
- Facilitating and accelerating diagnosis (support "L'Observatoire du Diagnostic" (French statutory organisation promoting diagnostic optimisation), Integrate fetopathology into the patient's pathway, strengthen foresight in the field of genetics, promote antenatal and neonatal screening, give a diagnosis to each patient, promote new technologies and health data.
- Promoting access to treatments (strengthen access to innovative treatments, strengthen the development of new therapies, organize real-life data collection for early and compassionate access, support access to therapeutic innovation coordinated with Europe);
- Developing databases and biobanks (improve the collection and reuse of health data, strengthen biobanks and their use for research purposes, use health databases for research purposes, strengthen the sharing of health data in connection with Europe).

THE MEDIA

January: CNRS Micro-Conference « Elasticity of life » especially with Pr Romain Debret on youtube (in French) : https://www.youtube.com/watch?v=IxHnivefeTs
28th February: Teaser of Rare Disease Day with CLI's Logo
28th February: Le Monde: Grand Angle, Special Rare Disease Day
30th March: Facebook Page «Dermato Info», presenting CLI
15th April: ERN-Skin Newsletter: Announcing the scientific publication « Pregnancy and Family Planning in Rare Disorders ».
03rd May: Charente Libre: Walking for CLI on 1st of May
May 2025: La Pastourelle: Brochure and Facebook page announcing the « Night Fever in Salers » to the benefit of CLI

July 2025: Taking stock of the « Heroes Run » : CLI won the prize for the best costumes.

Recognising Disabilities and Barriers in rare skin disorder : key-findings of the Rare barometer survey

- 7 / 10 people with rare skin disorders live with disabilities;
- 66% of respondents have difficulties with at least two of the following activities: seeing, hearing, walking/climbing stairs, remembering/concentrating, selfcare, communicating;
- 59% find it difficult or very difficult to obtain publicly funded support such as attendant care support, home support, financial support, assistive technology, mobility aids or other support;
- 52% experienced discrimination related to the rare disease or disability in healthcare, in employment, in education, in housing, in public accommodations and in other places;
- 14% of people with a rare skin disorder are unemployed (in comparison, the unemployment rate in the general population was 6,1% in the European Union in 2023)

Our Website : Over 77,300 people visited our website since its opening in February 2002. Thanks to our website Cutis Laxa is better and better known.

ASSOCIATION'S FINANCES Think about renewing your fees and donations **in 2025.** **Do Not Forget Us,** do not forget the patients who count on you, without you we would not be able to help them anymore. You will find a membership and/or donation form at the end of this newsletter.**MANY THANKS IN ADVANCE**

FOLLOW US ON FACEBOOK

The Facebook Private Group : Is dedicated to patients, their parents, doctors and researchers. If you need to share with other sufferers, other parents, what Cutis Laxa means in your life, come and join our private group: http://www.facebook.com/groups/62977351521/

The Facebook Public Page : If you wish to follow us and get all the news from the rare diseases and disability world, in France and worldwide : https://www.facebook.com/CutisLaxaAssociation/

Privacy Policy : You receive this newsletter because you are on our list. Send us a request to the address mentioned below if you wish to be taken off our mailing list.

I hope you had a Beautiful Summer

Thank you for filling and sending back this form with your membership fee and/or your donation

NAME……………………………………………………………………………………………………

FIRST NAME…………………………………………………………...…………………...…………….

ADDRESS………………………………………………………………………………………………

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

COUNTRY…………………………………………………………………………………….……………

☐ **Wants to support Cutis Laxa Internationale** by sending his/her membership fee : **€ 30** (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…………………..

☐ **Orders the book « Cutis Laxa, Story of a rare disorder, Patients' testimonies » and I add the amount of ☐ 25 € to my membership fee and/or donation**

☐ **Bank Transfer :** IBAN : FR76 1810 6000 4296 7525 0578 892 BIC : AGRIFRPP881

Name of the Bank : Crédit Agricole Bons en Chablais

Please don't forget to mention your name and complete address with the transfer, as well as the details of the amount (membership fee, donation, book,..) so we can send you a receipt and the book if you ordered it.

☐ **Sending a cheque to**

CUTIS LAXA INTERNATIONALE ASSOCIATION - 138 impasse de Champs Gervais - F-74890 Bons en Chablais - France

Do you want to receive CLI~News via Email ? yes ☐ no ☐

Email address……………………………………………………………..…………………………………

The data we collect here is necessary for administrative management of you membership fee and/or donation. The collected data is kept and processed on computer for Cutis Laxa Internationale's secretaryship use only. As indicated in French law "Freedom and Computers" on 06 July 1978, you have the right to have access and to rectify your personal data. If you want it, write to our Association (see address above). You can also, at any time, unsubscribe to our electronic newsletter by sending an email mentioning "unsubscribe" to: mcjlboiteux@aol.com.