138 impasse de Champs Gervais - 74890 Bons en Chablais - France - 33 (0)4 56 30 74 43 - mcjlboiteux@aol.com - www.cutislaxa.org
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CLI ~ NEWS N° 44 ~ FEBRUARY 2026

I hope this new issue of our CLI-News will find you well and that the new year will bring you happiness and good times with your beloved.
The attached Special Issue covers our 7th Cutis Laxa Days, their importance and enrichment for all participants. Wishing you a great time reading it.

Marie-Claude Boiteux, Chair

NEW CONTACTS, FAMILIES' NEWS

Sara and her sister Abeer, Bennett, Tucker, Eileen, Youssef, Ella, Catarina, Rory, Malak, Carolina and Gabriel joined us over the last six month. Including them, there are now 581 patients worldwide who our Big Cutis Laxa Family helps, supports and accompanies in their search for answers to their questions.
We also sometimes know about other patients, especially when they take part in reports posted on social media. Thanks to BBC Africa, this is how we knew about an African family. Unfortunately, despite our approaches to the channel, the doctors interviewed and the directors of this report we couldn't contact them or, at least, let them know we are here. I am so sorry about that.

We are so sad, our Big Cutis Laxa Family has just lost two of its youngest members, Oceane and Rory. It is never acceptable to see our children die so young. All our thoughts to their parents and families.
Vonda left us too on 1st January 2026. She had joined CLI in 2009 and was diagnosed with ACL. Rest In Peace Vonda.

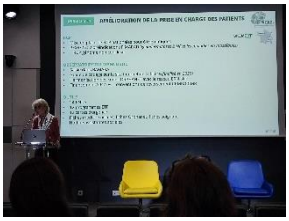
MEETINGS, EVENTS AND EXHIBITIONS

13th September : We travelled back to Bergame for an evening of information and exchanges about what it is like to live with Cutis Laxa. Roxanne and her parents were with us for this second Italian event with partners and authorities who had organised « Semplicemente Amici ». Exchanges and questions were very interesting and increased understanding of what Cutis Laxa is and how it impacts patients' lives.

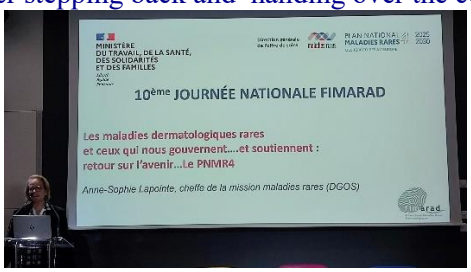
16th September : Globalskin Europe members met in Paris about Advocacy Strategies, working on opportunities and challenges when interacting with national and/or European policy makers.

17th-20th September: The European Academy of Dermatology-Venerology (EADV) held its annual conference in Paris. Besides the possibility to have a booth increase the visibility of Cutis Laxa, Marie-Claude Boiteux spoke about the successes and projects led by the Patient Representatives (ePAGS) during the session dedicated to the work done in ERN-Skin.

3rd October : The annual meeting of FIMARAD (French Network for Rare Skin Disorders) took stock about projects and advances in the network regarding diagnosis, therapeutics and follow-up. The forthcoming publication of an article written together by patients and health professionals on the diagnostic odyssey is of special interest to health authorities. We were also celebrating the network's 10th anniversary, an important step



marked by Pr Christine Bodemer stepping back and handing over the coordination to Pr Smaïl Hadj-Rabia.



14th Novembre : Regional e-Health Days at the Convention Centre of Dijon, Bourgogne-Franche-Comté. The Regional Agency of Health (ARS-BFC) held this first conference dedicated to new ways to practice medicine thanks to new technologies. During the roundtable on « Tele-Expertise », Marie-Claude Boiteux presented the first results of the study she led with the French Federation for Skin and ARS-BFC and supported by A-Fluence Consulting. Compensating for desertification in dermatology, allowing patients to have rapid access to a consultation when necessary, promoting the development of the skills of general practitioners, while participating in the care pathway, while this new tool is certainly not the universal panacea, it prevents symptoms from worsening and patients from missing opportunities.
(see the replay : Journées régionales de la e-santé 2025 : https://vimeo.com/showcase/11984104?video=1138122731)

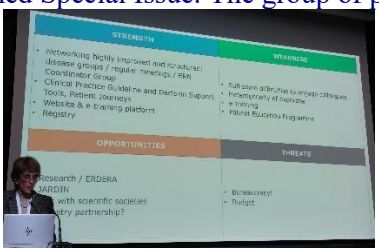
16th Novembre : The traditional St Martin's Fair was cold and wet, but it did not prevent us from running the stand for Cutis Laxa Internationale as long as we could for children to come and play « fishing for ducks» before selecting one of the proposed gifts. It was a great occasion to meet with Roxanne and her parents again.

19th November: We had the great luck and honor to be selected to benefit from a donation given by the Endowment Fund for Children, which organizes « Glisse en Cœur » which will take place from 20 to 22 March in Le Grand Bornand (A ski resort in the French Alps). During the inaugural evening of this festive, sportive and solidarity event, we were given a € 6,000 cheque to allow us to fund part of the travel costs for patients to attend the 7th Cutis Laxa Days. An evening full of emotions and joys with « Mercotte » (renowned French food critic) and ski champions.

2nd December: The 7th Conference of the French Federation for Skin (FFP) was held, as usual, in Paris Convention Center, as a preamble of the Dermatology Days of Paris (JDP). Therapeutic revolutions, Clinical Trials, Alternatives to Desertification and Integrative Health: 4 themes developed in the round table discussions. They captivated the audience and highlighted the work carried out by the FFP to improve patients' quality of life.

3rd-6th December : Having a stand in the village of associations during the Dermatological Days of Paris (JDP) is an opportunity, every year, to increase Cutis Laxa's visibility. It is also an opportunity to meet doctors, researchers and laboratories interested in our pathology and the projects we are carrying out. AND it's always nice to meet up with our colleagues and friends from the associative world. This year, our visibility increased even more with our poster alongside those of doctors and researchers.

11th-12th December : Members of ERN-Skin got together for the annual Board Meeting that takes stock of what was done over the year and future projects. Cutis Laxa was honored thanks to the method of classification established with AI that allows a reduction the diagnosis odyssey. This new classification is more detailed in the attached Special Issue. The group of patient representatives (ePAGS) was extended with new members in attendance.





RESEARCH – MEDICINE – GENETICS

The latest news regarding research on Cutis Laxa and elastic fibers are in the attached Special Issue dedicated to the 7th Cutis Laxa Days.

In addition, we have updated the Cutis Laxa Patient Journeys. Two important documents, one for the types with cardiovascular and lung symptoms, the other for the types with neurological and skeletal symptoms. These that will be used as documentation when writing guidelines for Cutis Laxa.

Can cognitive behavioural group therapy help people living with a rare disease?

People living with a rare disease (PLWRD) often experience significant psychological burden, that results from a number of factors including physical pain, reduced income and increased medical expenses, and reduced social interactions. In addition, chronic physical conditions, as in most rare diseases, often occur alongside depression which can further exacerbate other mental health effects of the disease itself. In order to address this issue, a study was recently published in Intractable & Rare Diseases Research that investigates the effects of a mindfulness-based cognitive behavioural group therapy program for patients with a rare disease and deep depression.
The program described in the article consisted of three monthly sessions, each lasting 2 hours. Overseen by a clinical psychologist, it was designed to reduce psychological stress and improve quality of life in People Living With a Rare Disorder. (©Orphanews international 2025.10.06)

THE MEDIA

8th October : Doctissimo press release : « Skin Diseases - A public health issue that is still underestimated, a collective to make things happen »
27th November : Charente Libre : « A €2,000 cheque for Cutis Laxa International»
8th December : Le Monde : « The rise of cosmetic surgery accentuates the lack of dermatologists»
3rd February : RMC Life. "Let's talk about" : What has become of Cécile since September 12, 2001? (First time in the TV broadcast) (https://www.tiktok.com/@rmc.life/video/7602344973836569889)
28th February : Rare Disease International « Mapping Rare » : CLI is in the spotlight (www.rarediseaseinternational.org/mapping rare/)

Our website : Almost 81,500 people visited our website since its opening in February 2002. That is 6,676 in 2025.
Our website gives Cutis Laxa the best possible visibility worldwide.

On 21st November 2025, the town of Sireuil handed a €2,000 cheque thanks to the profits made by the Triathlon and the Brin d'Aillet run

Three new national plans for rare diseases in the world :

Malaysia : This is the nation's first ever strategy for rare diseases. It aims to address critical gaps and strengthen the delivery of comprehensive healthcare solutions for PLWRD in Malaysia. The policy defines a disease as rare if it affects fewer than 1 in 4,000 people, and identifies 9 key pillars of action to improve rare disease care, diagnosis and awareness

Ireland : the Irish Department of Health unveiled their National Rare Disease Strategy 2025-2030. This strategy builds on the foundation of the previous National Rare Diseases Plan for Ireland 2014-2018, and addresses issues encountered by PLWRD throughout all stages of life. The result of multi-stakeholder collaboration between patients, clinicians, researchers, and government representatives, the strategy puts forward 11 recommendations to reinforce rare disease care and awareness in Ireland.

Luxembourg : The Ministry of Health adopted the country's second national plan for rare diseases, the "Plan National Maladies Rares Luxembourg" 2025-2029 (PNMRL). This plan represents a continuation of the first national plan, which was in place from 2018 to 2023. It aims to promote a reinforced, coordinated healthcare system for PLWRD in Luxembourg. It takes a holistic, person-centred approach to the challenges facing the rare disease community across five thematic areas.

They all are in line with the recent adoption of the World Health Assembly (WHA)'s Resolution on Rare Diseases, which recognises the global challenges faced by PLWRD. (© Orphanews 2025.10.06)

Following the vote on the resolutions on dermatological diseases and rare diseases by the WHA, the work continues. The next step will be drafting of a Global Plan of Action. We participate in the working group dedicated to it within the World Skin Health Coalition (WSHC).

The role of ERNs in boosting EU competitiveness through public-private partnerships

Together for Rare Diseases (Together4RD) has published a report on the use of public-private partnerships (PPPs) in rare disease research, and the role ERNs have to play in this context in order to boost European competitiveness and drive change for the rare disease community. The report was developed following a high-level conference hosted by MEPs Stine Bosse (Renew Europe, Denmark) and András Kulja (EPP, Hungary), in collaboration with Together4RD, at the European Parliament on 24 September.

Drawing on the discussions held during the conference, the report puts forward a number of action items to facilitate ERN-industry collaboration, thereby accelerating innovation and improving the availability of treatments and care for patients. Some of the actions outlined in the report are:

- Ensure the Biotech Act, Life Sciences Strategy and Multiannual Financial Framework promote collaborative research and provide resources for ERNs and industry to enter research partnerships.
- Revise the 2019 ERN Board of Member States (BoMS) statement to explicitly allow and encourage ERN-industry research and data collaboration.
- Develop and deploy a standardised EU-wide contracting and data-sharing framework for ERN-industry partnerships.
- Support ERNs in becoming legal entities or forming shared-governance structures to streamline partnerships.
- Establish an EU Rare Disease Action Plan with measurable targets and stable funding.

By combining the expertise of ERNs, the capabilities and resources of industry, and the input of patient communities, this type of PPP has the potential to deliver concrete change and improved health outcomes for all Europeans living with a rare disease. (© Orphanews 2025.11.25)

ASSOCIATION'S FINANCES Do Not Forget Us Think about renewing your fees and donations in 2026. You will find attached a membership and/or donation form. 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/

I hope this brand New Year started nicely !!

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

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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**

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☐ **Sending a cheque to**

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