

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

(LI ~NEWS N° 45 ~SEPTEMBER 2026

I hope you all had a nice summer break and that you have not suffered too much from the heat waves and fires that have raged in several countries. Here we are starting the last term, having a look in our agendas and getting organized for the many events scheduled until the end of the year... Time goes by so quickly. 2027 is already pointing its nose I wish you a beautiful autumn to those living in the Northern Hemisphere and a beautiful spring to those living in the Southern Hemisphere.

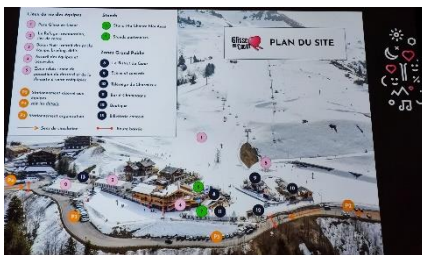
Marie-Claude Boiteux, Chair

NEW CONTACTS, FAMILIES' NEWS

Marie, Rachel, Gavin Du, Meryem and Hassan Ali, Atayaf, Adam, Sahylin, Stephanie, Inaya, Zimi, Youssif and Ahmed, Roqaya, Mohamed and Ahmed, and Josué joined us over the last six month. Including them, there are now 596 patients worldwide who our Big Cutis Laxa Family is helping, supporting and accompanying in their search for answers to their questions.

Alas, our Cutis Laxa Family is once again in mourning. Tammy passed away on September 12th. Rest in Peace

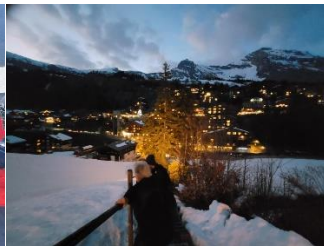
MEETINGS, EVENTS AND EXHIBITIONS



3rd, 20th and 22nd march : The « Glisse en cœur » days were busy. In the beautiful ski area of Le Grand Bornand (France) 24 hours of skiing was dedicated to children's associations. We had had the great luck to receive €6,000 in November 2025 to help us fund the Cutis Laxa Days. In March



2026 we were thus present, with volunteers on the tracks to support and encourage all those thanks to whom this amount had been given to us.



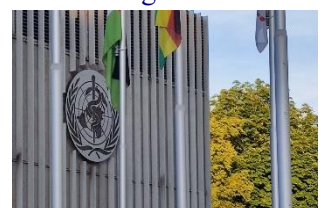
After a bright sunny first day, the last relay skiers went down the slope under snowfall. Two days of joy, solidarity and support for associations.



20th May : Rare Disease Internationale (RDI) had organised an event in Geneva , on the occasion of the 79th World Health Assembly (WHA). Following the adoption, last year, of the resolution for Rare Disorders, it is now necessary to work on the Global Action Plan (GAP) that will implement the recommendations of the resolution.



21st May: The next day, still in Genève, but this time in the World Health Organisation (WHO) building, Globalskin had the opportunity to talk in the parallel session « From



Resolution to Action : Implementing WHA Resolution on Skin diseases » organized by the WHO to hear patient organisations' voices. It was an honor to attend it together with ERN-Skin and Globalskin members.



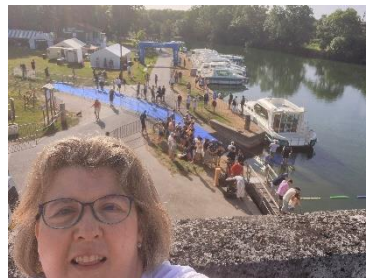
12 Juin :

International

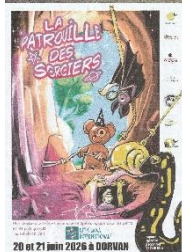
Forum of Dermatology organised in Lisbon by Pierre Fabre Laboratories. Marie-Claude Boiteux's talk about the results of the study on Tele-expertise in Dermatology in Bourgogne Franche Comté had been registered beforehand as she couldn't attend in person.



13th June : For its 20th edition, the Sireuil Triathlon ran was again dedicated to Cutis Laxa International. Always as festive, as sporty as ever, this faithful event by our side helps us to finance our projects. Thank you to all the organizers, thank you to all the volunteers, thank you to all the runners.



20th and 21st June : Roxanne's parents are passionate about potholing/caving and, with their club, they organized a weekend of discovery of this original sport, to the benefit of Cutis Laxa Internationale. Entitled "The Sorcerers' Patrol", intended for young and old, it was a hunt



for underground treasures in the depths of the Torcieu forest in Dorvan (Ain-France). A great opportunity to get Cutis Laxa known.



1st-3rd July : The 3rd World Congress on Rare Skin Disorders (WCRSD) was held

at the Palais des Congress in Versailles. For this 3rd edition, a plenary session was entirely dedicated to patients. As members of the organizing committee, we had decided to highlight the work that associations do.

The theme of this session was mental health in rare dermatological diseases. Six speakers presented the publications and work done by the organisations : Mental Wellbeing in Rare Disease; PRIDD: Validating the Mental Health Impact of Living with a Rare Skin Disease ; Psychological States of Loneliness, Social Isolation and Psychological Deprivation in



Patients with Albinism. ; The Profound Impact on Mental Health when Living with Ichthyosis: A Qualitative Study ; Interaction of Psychosocial Factors and Well-Being of Women Caring for a Sick Child: The Impact of the Child's Level of Dependency ; Addressing the Mental Health Needs of Rare Skin Disease Patients: Generalized Pustulous Psoriasis Care Network. A very rich session, of great interest to the audience.



A congress as interesting as ever: moments of exchange with associative "colleagues", enriching presentations, a stand introduce ourselves, a poster, a session dedicated to the Cutis Laxa



and a magnificent evening in the stables of the castle. It was also an opportunity to meet members of Globalskin for a working session on rare dermatological diseases



12th September: The 7th Cutis Laxa Days sometimes have very positive and quite unexpected effects. They allowed Sayaka's mother to overcome her fears and certain prejudices and to agree to share her testimony during a mini-conference that welcomed about sixty people. Bravo!

September 22nd: Marie-Claude Boiteux moderated the "Coffee-Chat" of Globalskin on the theme "Communicating with members of the association through cultural differences". She shared her experience within Cutis Laxa International



RESEARCH – MEDICINE – GENETICS

Mental Health Figures in Rare Skin Diseases

In June 2026, RareBarometer, Eurordis' polling organisation, published the results of the survey conducted in 17 European countries from 11th September to 14th December 2025. 130 people representing 13 rare diseases responded. The figures speak for themselves:

- ✚ 7 out of 10 people living with a rare skin disease and their families report poor mental health.
- ✚ 50% report moderate to severe depressive symptoms (8 times more than the European population (6.1%))
- ✚ 44% report significant clinical symptoms of anxiety (8 times more than the European population (5.4%))
- ✚ 39% feel lonely (4 to 20 times more than the European population (2 to 10%))
- ✚ 37% report suicidal thoughts in the last 6 months (6 to 12 times more than the European population (3 to 6%))
- ✚ 48% report at least 2 severe mental health difficulties
- ✚ 28% report at least 3 severe mental health difficulties
- ✚ 14% report at least 4 severe mental health difficulties
- ✚ While 76% say they need professional psychological support, only 46% receive it
 - ✓ 25% of a general practitioner or nurse taken care of
 - ✓ 21% of a professional not reimbursed, or paid by themselves (psychologist, psychotherapist, psychiatrist)
 - ✓ 17% of a professional fully or partially reimbursed (psychologist, psychotherapist, psychiatrist)
 - ✓ 11% of a Centre of Expertise (multidisciplinary care team specialising in rare or undiagnosed diseases)

THE MEDIA

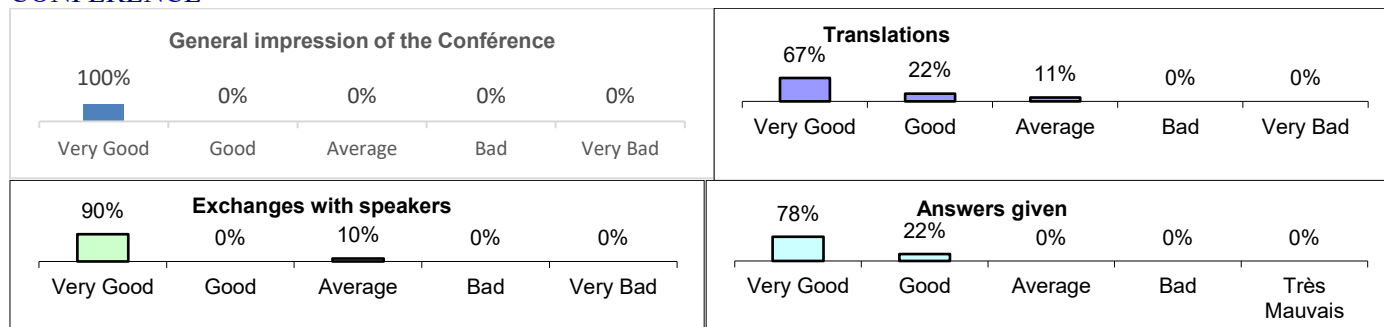
June 2026: Young Dermatologists Review: "From loneliness to an international organization" the story of Cutis Laxa International

Autumn 2026: Gazette de Bons : report of the 7th Cutis Laxa Days

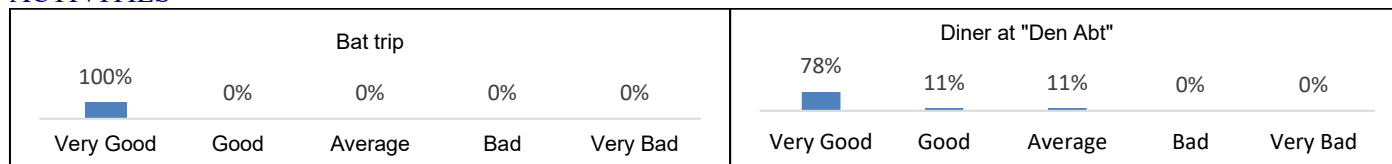
12th September 2026: Article in the Japanese media on the 7th Cutis Laxa Days.

Our website : Over 92,000 people visited our website since its opening in February 2002. Our website gives Cutis Laxa the best possible visibility worldwide.

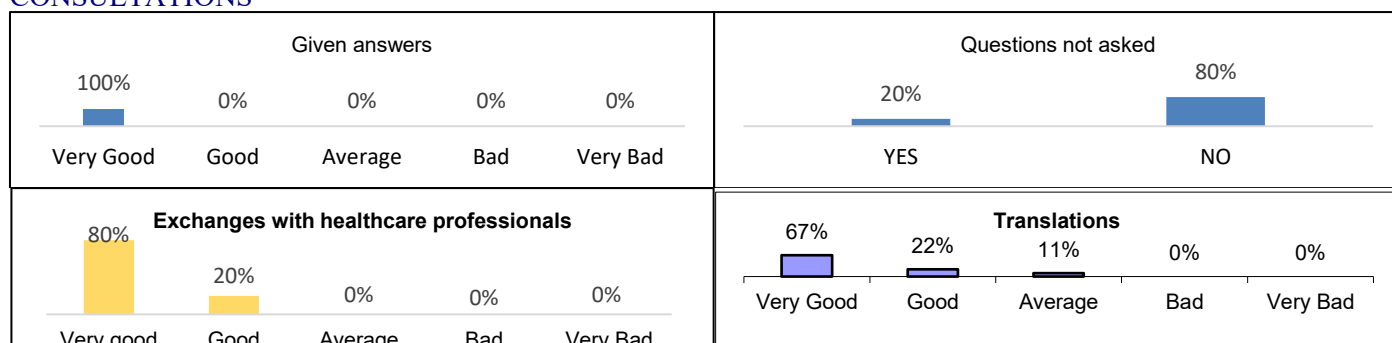
RESULTS OF THE SATISFACTION QUESTIONNAIRE FOR CUTIS LAXA DAYS CONFERENCE



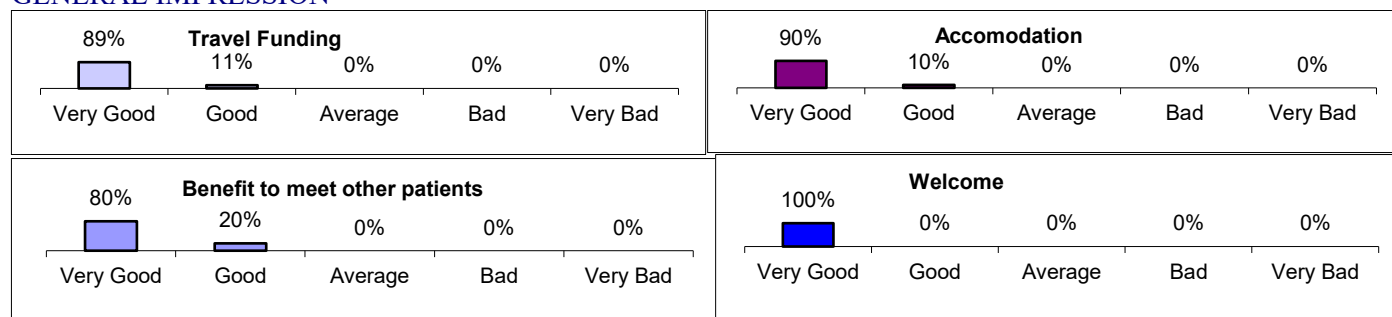
ACTIVITIES



CONSULTATIONS



GENERAL IMPRESSION



Orphanet in Figures

It is a network spreading over **40 countries** in Europe and beyond. The site is accessible for free in **9 languages**. **28 million pages** were visited in 2025. **6,622 rare disorders with a unique identifier** : ORPHA Code. **25,883 healthcare professionals** referenced. **2,798 patient organisations** and **31 National Alliances** of rare disorders. **8,512 Expert Centers**. **31,742 Diagnosis Tests**, **5,605 Patient Registries**, **181 biobanks**, **1,013 medical laboratories dedicated to diagnosis**. and so many other ressources.... <https://www.orpha.net/> (©Orphanews 2026.06.03)

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/>

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.

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.