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(Li ~ NEWS ~ SPECIAL EVENTS ~ AUGUST 2025

I am very happy to share with you the best moments of the events that allowed us to raise the necessary funds for the 7th Cutis Laxa Days.

Thanks again to the organisers and participants of these festive and supportive events. Marie-Claude Boiteux, Chair

IFT MAY IN (HARENTE (FRANCE)

DOUZAT

The Festival Committee and the association for the "Blood Donations" had chosen us to be the beneficiaries of their annual walk. Good weather guaranteed on this first day of May and beautiful energy with all participants.

Mélissa and her father Serge, our Vice-Chair, shared their expertise by experience of living with Cutis Laxa. € 684 were raised.





<u>Sirevil</u>

For many years Serge has been involved in the organisation of the "Trail du Brin d'Aillet" in his town of Sireuil. Every year, Cutis Laxa International receives the benefits of this friendly event which welcomes many participants. The financial statement is not yet finalized.





30 MAI À BERGAME (ITALY)

Thanks to Roberto Trapletti, several towns in the Region of Bergame mobilized for

Daniel, suffering from Cutis Laxa, to organize events to the benefit

of Cutis Laxa Internationale. The Chair,

Marie-Claude Boiteux together with Cécile

travelled to Bergame to support this great





initiative and answer

jounalists' questions for the local television channel. It was a beautiful first event and a strong commitment from the region's authorities that generated € 5,900 in grants and donations.



8TH MAY IN SALERS (FRANCE)



For its 25th edition, La Pastourelle, a renowned sporting event bringing together more than 6000 participants around trail and mountain bike events and a hike, chose Cutis Laxa International to be honored



During the 3 days dedicated to mountain sports, not only did we have

a stand at our disposal with information about Cutis Laxa, but also, an exceptional race "The Salers Night Fever" was dedicated to us.





On the stand, in the nighttime atmosphere of the streets of the magnificent village of Salers and during the races among the extinct volcanos of the Massif Central, Roxanne and her family as well as Marie-Claude Boiteux and Cécile were able to make Cutis Laxa known and show that despite the disease, life can be rich and beautiful. A cheque for €2,500 was given to us and we sold €360 worth of merchandise on the stand

18TH MAY IN LYON (FRANCE)

A great festive moment in the heart of the city of Lyon, the "Heroes' Race" took over the Parc Gerland. This event brings together volunteers from many associations, each one responsible for collecting donations for their association from their relatives, families, friends and colleagues.









We had 7 "Heroes": Roxanne's father, mother, aunt and great-aunt, Cécile's husband and sister-in-law, as well as one of our researchers in Lyon, Professor Romain Debret. They all worked hard to raise more than €5,700. A thousand BRAVOS to all of them.



To top it off, thanks to Roxanne's mom and the fabulous costumes she made and brought, we won the Best Costume Award: an extra \in 500 in our kitty.



A joyful, friendly day, full of laughter, joy, shared happiness and a picnic under the cool of the trees.







<u> 25# MAY ÎN SAINT PIERRE DE (HANDIEU (FRANCE)</u>

Roxanne's parents once again put all their energy into running the Cutis Laxa Internationale stand during the flea market organized in their town.

Information on the disease, various contacts and sale of merchandise; another great day for the benefit of CLI with nearly 170 €.

22ND JUNE IN SIREVIL (FRANCE)



Second annual event organized in Sireuil, where our Vice-

President and his daughter Mélissa live. Every year as usual, the triathlon offers a competition in three sports: cycling, swimming and running. Cutis Laxa International has been a long-time beneficiary



of this event. The two sporting events in Sireuil

meant we received €2,500 in 2024. The assessment is underway for 2025, so we do not yet know the final total.

AND FUTURE EVENTS.....

13TH SEPTEMBER IN BERGAME (ITALY)

A second event is scheduled in Bergame, following the one held in May. Roxanne and her parents, as well as Marie-Claude Boiteux, will meet again with Daniel's family to get Cutis Laxa even better known.

<u> 16TH NOVEMBER IN BONS EN (HABLAIS (FRANCE)</u>

The fair of Saint Martin is a multi-centenarian tradition in the town where we have our head office The organisations that are in Bons en Chablais have the opportunity to have an information stand and to sell branded merchandise.

We will therefore be present together with Cécile and Roxanne and her family.

We will tell you about these events in our next CLI-News. Once again, from the depth of my heart, I want to thank organisers, participants, volunteers, patients and their families as well as members of the Board who give their energy to allow us to fulfill our missions and support patients. The Chair, M.C. Boiteux