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° 34 ~ SEPTEMBER 2020

2020, What a difficult year !! The Covid-19 pandemic has turned everything upside down.
Many events have been cancelled or changed into online virtual meetings. We have had to learn how to work differently : teleworking, changing to part-time hours, …
Patients with « rare » conditions have been directly hit: appointments, surgeries and care have been cancelled….

As a second wave is approaching, we must remain vigilant and follow the recommendations.

But life didn't stop during all those months. We worked to keep Cutis Laxa Internationale alive and transmit patients' voices.

Several projects are ongoing, even if some of them have just been postponed :

- The Cutis Laxa white book has just been issued ;
- The 6th Cutis Laxa Days, initially scheduled in June 2021, is postponed to September 2022

And many others…

New sufferers have joined us. Alas others passed away too soon. Jaiden, almost 16, and Zeinab, 21, have gone to join the stars. I am deeply sad and, once again, send their families all my thoughts and condolences in the name of Cutis Laxa Internationale.

Marie-Claude Boiteux, Chair

NEW CONTACTS, FAMILIES' NEWS

Caetano, Tamapa, Defne, Tami,Yusuf, Tracey, William, Atay Robin, Sunusi, Hanna, Umar, Jo, Sarah, Talita, Randi, Carol, Eli, Gina, Sonia, Maria, James, Ayyaz, Mariya and Oluhle have joined us since the beginning of 2020.

Koweit, Dubai, Sierra Leone, Nigeria and South Africa are the additional colors on our map of world..

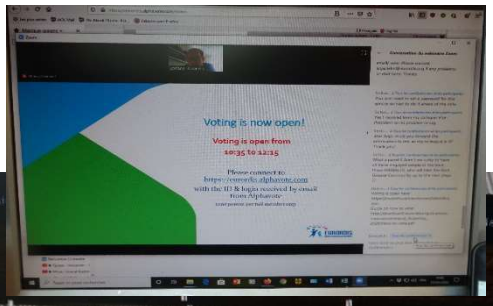
We now gather together 440 patients worldwide. Of them, 18,6 % have a Dominant type (ADCL) , 17,1 % a Recessive type (ARCL), 22 % an Acquired one and 40% do not know, or not yet, their exact type. The other types (MACS, OHS, GO,...) represent 2,3% of the total.

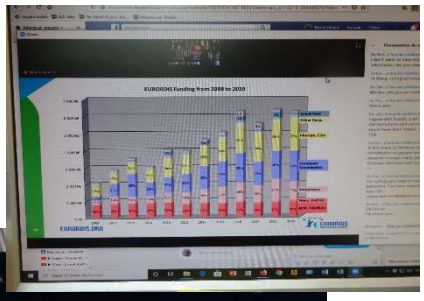
Since Cutis Laxa Internationale was set up, we have received many patients' and parents' testimonies. They are now collected in a newly published book : « **Cutis Laxa, Story of a Rare Disorder, Patients' testimonies** ». It is available in French, English and Spanish. We will send it to you on request, at €25 per copy.

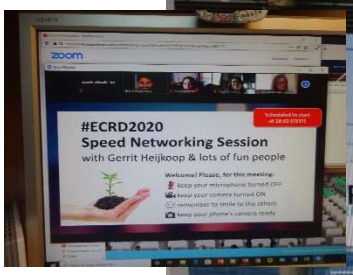
MEETINGS, EVENTS AND EXHIBITIONS

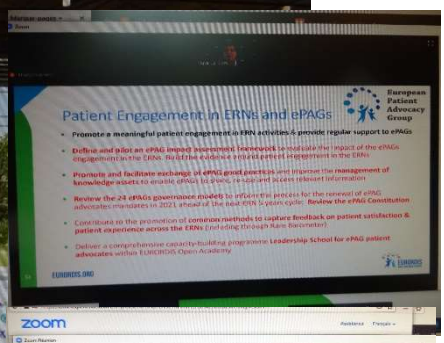
09th February : Shortly before lockdown, the Gospel choir had organized a masterclass and we were given the benefits. Cécile, together with her brother and her sister took part in this singing and joyfull afternoon.

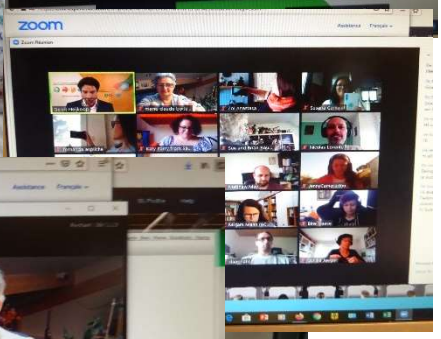
Of course, during lockdown, many events and meetings have been cancelled or replaced with online meetings due to the health constraints. It was the case for **Eurordis Annual Meeting on 13th May, European Conference on Rare Disorders (ECRD) on 14th and 15th May** which gathered together over 1,500 people from 57 countries, as well as the **Rare Disease International (RDI**) Annual Meeting and Conference on **19th May**. Here are some screenshots of those important events we attended online from CLI's home/office.

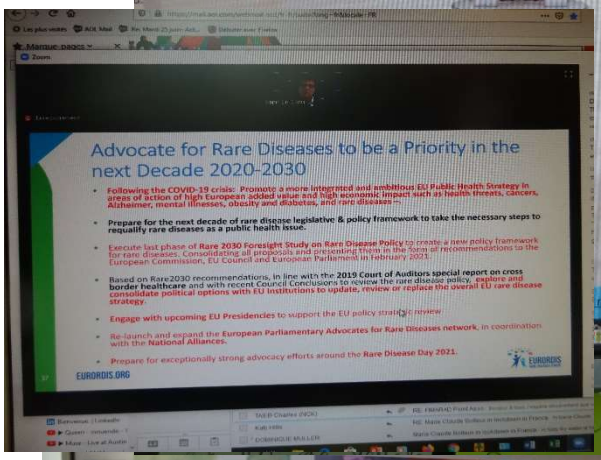


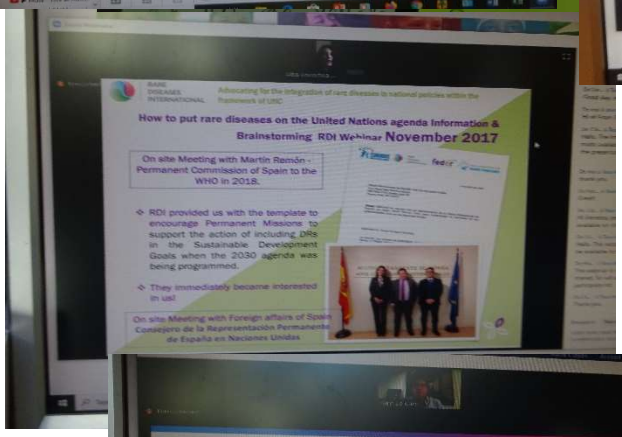


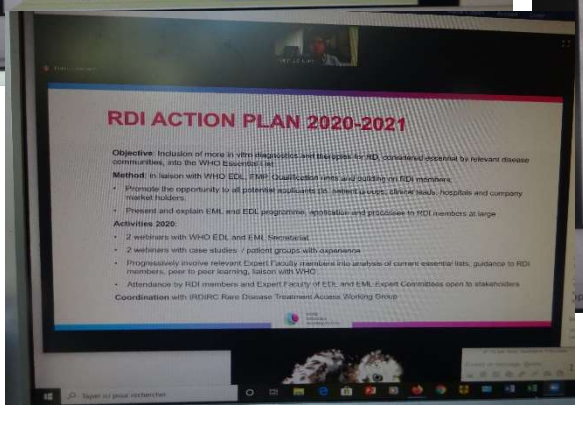


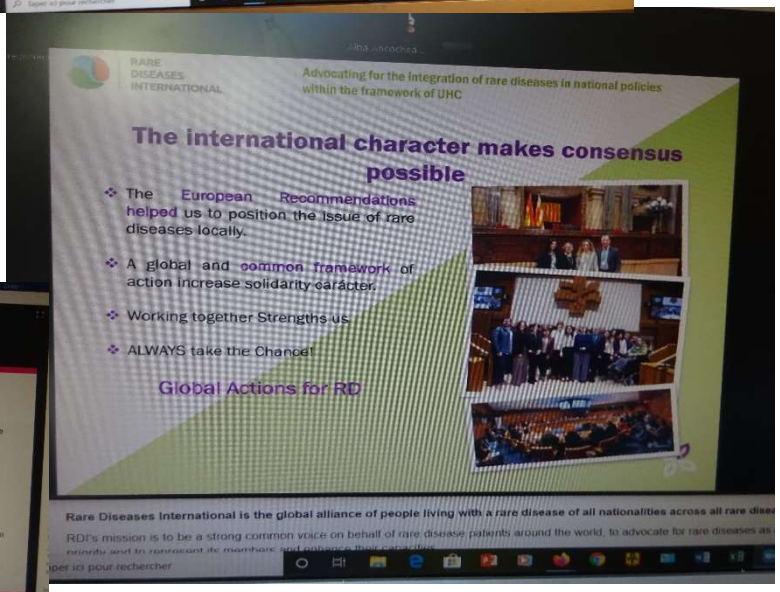












7th August : After several months in lockdown, it was a real pleasure to participate in the « Summer Music » evening in Fantasia Park in Annemasse (France).

Respecting all sanitary recommendations we were able to welcome people at our stall where they could find, besides our now usual sausages and french fries, information on Cutis Laxa as well as various jewellery and items we sell. A very friendly evening which allowed us to get some funds, more than welcomed with all our other scheduled events being cancelled.

RESEARCH – MEDICINE – GENETICS

ACQUIRED CUTIS LAXA :

- A scientific study on Acquired Cutis Laxa (ACL) will be led by Dr Bert Callewaert at University Hospital of Ghent (Belgium).

This type of Cutis Laxa has never been studied before.
It is a great opportunity to learn more about it : how it appears, what are its causes and maybe a first step to treatment.
Worldwide patients with ACL can take part in it. The doors of hope are opening up for them.

- A possible improvment of the symptoms in Acquired Cutis Laxa associated with monoclonal gammapethy or multiple myeloma: A haematologist from Sao Paulo (Brasil) has had very satisfactory results in two cases with an autolog bone marrow transplant. For those two patients the results were more than encouraging though we certainly cannot talk about treatment or cure yet. Many studies and therapeutic trials are still necessary to get there. Nevertheless this is a huge leap for those patients.

RARE SKIN DISORDERS AND COVID-19

An observational study was initiated by the European Reference Network ERN-Skin and the French Health Network for Rare Skin Disorders (FIMARAD) : « COVID-19 and rare skin diseases. European observational study (data research) during an epidemic". It concerns paediatric and adult patients with rare skin diseases and suspected or confirmed COVID-19 infection who consulted a medical team that is part of the ERN-Skin or FIMARAD. Professor Christine BODEMER (Hôpital Necker-Enfants Malades – Paris, France) is the principal investigator..

The main objective of this European observational cohort study (research data) is to determine the impact of a COVID-19 virus infection in a cohort of patients with rare skin diseases and particularly whether these rare diseases and their treatments are risk factors of infection severity

SAVE THE DATES
The 6th Cutis Laxa Days will be held at the University Hospital of Ghent(Belgium)
on **14th, 15th and 16th September 2022**

LEGISLATION ~ SOCIETY

The COVID crisis reveals how patients' and associations' role is poorly recognised (Le Monde 2020.07.06)
In this newspaper article, three members of the French association Renaloo (kidney failure) make an unanimous statement : Associations of Health Users were forgotten in the heart of the sanitary crisis :

- There were no official recommendations for « at risk » people.

- Associations had to establish themselves « Recommendations for patients » based on international recommendations or those from other countries. ;
- Nothing was set up to allow « at risk » people to stop working as soon as the crisis started ;
- Cooperation with patients and their associations was considered incidental and with no priority ;
- Despite the collective stakes we all had to face, democracy in health suffered a lot ;
- Never quoted as being part of the various parties committed to protect vulnerable people, nevertheless patient associations were working on all fronts during this period ;
- In France, except a few cases, patients associations have not yet reached the place they deserve in the medical world;
- Government communication about vulnerable people focuses only on older aged people and forgets young and active people who are fragile too.

Nothing should be done without Us !

THE MEDIA

Avril 2020 : Rare Revolution Magazine : An article about David Ross «Meet David, a true RARE Revolutionary » and another one about Dawn Laney, Dave Jacob's daughter and co-founder of « Thinkgenetic », « RARE Heroe »

WE NEED YOU :

You have got ideas, you want to help us, you want to organise fundraising events for the benefit of Cutis Laxa Internationale. Feel free to contact us and we will work together to achieve your project. We need you to be able to organise the next Cutis Laxa Days.

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.

Our Website : **www.cutislaxa.org** has had 47 642 visits since its opening in 2002, that is almost 7,000 since 1st January 2020

Rare Diseases and Covid :

According to the survey lead by **Eurordis,** 9 out of 10 people living with a rare disease experienced interruption in care because of Covid. More than half of those who need surgery or transplant have seen these interventions cancelled or postponed.
And
According to a survey in the **UK**, 72% of family carers and siblings say they had to provide **a lot more** care. Overall parents talk about extreme exhaustion, stress and sleepless nights. For many of them, professional care just stopped.

ASSOCIATION'S FINANCES:

Think about renewing your fees and donations in 2019. **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

A HUGE THANK YOU to two people - they will know who they are – for the € 6,000 they have donated. Thanks to you Ladies organising our coming Cutis Laxa Days seems more feasible.

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/

Take care of yourselves !

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……..

☐ **Bank transfer :**
IBAN : FR76 1810 6000 4296 7525 0578 892
BIC : AGRIFRPP881
Bank name: Crédit Agricole Bons en Chablais
Please don't forget to mention your name and complete address with the transfer so we can send you a receipt

☐ **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.