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## CLI ~ NEWS N° 40 ~ JANUARY 2024

This is the 40<sup>st</sup> issue of our CLI-News ! I can't believe it ! With an average number of two issues per year, we have been sending you information on what we felt important for, and about, Cutis Laxa for 20 years. Our headings remain the same : new members, meetings and events, research, legislation, the media and various information.

It is a huge amount of work to compile that information, format it, translate it and prepare it for posting.

I sincerely hope that reading CLI-News is of interest, is useful and that you find in it all information you may need. If it is not the case, thank you for letting us know. Thank you for suggesting other headings to us or specifying those that are the most useful. We must improve it to ensure it is exactly how you wish it to be.

I wish you all a beautiful year in 2024.  
 Marie-Claude Boiteux, Chair

### NEW CONTACTS, FAMILIES' NEWS

Aaxel, Javiel, Lylio, Yamani, Ovinga, Mina, Gisely, Thomaz and Alice have recently joined us. We are now in contact with 540 patients and families. Their isolation and loneliness facing Cutis Laxa has disappeared.

Welcome to all of you. We are glad you joined the Big Cutis Laxa Family.

We have just heard, with great grief, about Abdulaziz's passing. Born in Yemen, he was able to emigrate to Canada with all his family. He was 11. May he Rest in Peace.

### MEETINGS, EVENTS AND EXHIBITIONS FACE-TO-FACE



1st – 4th June 2023 : Globalskin brought us together in Brussels for its Congress « Elevate » and the forum « Rare Derm » . What a joy to meet in person, to learn, exchange and share during three days. Putting Rare Skin

Diseases in the agenda of policy makers, working for the development of innovative therapies, building alliances with new partners, raising funds, recruiting and retaining volunteers, efficiently using communication tools, listing unmet needs of patients living with rare skin disorders,..... all those topics were tackled and our individual experiences in the fields allowed each of us to outline new issues to work

on. Two of the Patient Representatives from ERN-Skin Patient Advocacy Group were honored during the festive dinner.

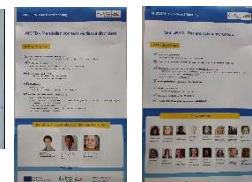
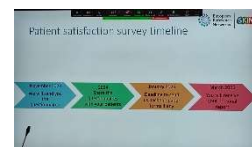


14th September 2023 : World Skin Health Day, organised by the French Society of Dermatology (SFD). The first part of the day was dedicated to Skin Disability and Marie-Claude Boiteux testified during the round table on this subject. It also was the occasion of an interview for the SFD.





**6th Novembre 2023 :** ERN-Skin Annual Board Meeting. It really was a great pleasure to meet again in person with all members of ERN-Skin. Whether we are Health professionals, doctors, researchers or patient representatives, a real common will drives us : improving Skin Patients' quality of life throughout Europe. The new roadmap for the coming years (2023-2027) has many signposts along the way, whether for health professionals or Patients' representatives.



**16th November 2023 :** Following a first online meeting on 22nd June, SpotInfoPatients, organised by BMS Laboratory, gathered together several patient representatives for a workshop on the role of decision-makers in the health sector.

**17th November 2023 :** In the beautiful setting of the « House of Latin America » in Paris, the French Network FIMARAD had organised its 8th National Day. During their presentation, Patient Representatives shared their concern about the survival of patient organisations. The latter, especially small organisations such as CLI, always sinned to fight to achieve their aims because they lack both volunteers and funding. The non-existence of funding from the government and from health authorities when they ask for greater participation in health activities is a crucial topic.



**5th-8th December 2023 :** On 5th december, the French Federation for Skin organised its 5th National Conference, in preparation for the Dermatology Days of Paris (JDP). It was a great success with the opening by Senator Philippe Mouiller, Chair of the Commission for Social Affairs, and the presence of representatives from various



authorities in the field of Health. Four round



tables allowed an exchange on the future of dermatology, teledermatology, democracy in health and patients' role in research. It was also the occasion to present the achievements of the FFP in 2023 : Disability Guides and Booklet for children.

After such a day full of contacts and information, it was time to run the booths for FFP and CLI during the three days of the JDP. The “Village of Patient Organisations” where all our organisations are gathered together, inaugurated by Pr Gaëlle Qureux, new chair of the French Society of Dermatology, provides great visibility and the opportunity for interesting contacts.



**9th December 2023 :** For the first time, the Fair Committee organised the Téléthon in Bons en Chablais. Cutis Laxa Internationale was present and offered children a range of activities, e.g. drawing hands to make a fresco i.e. our logo and face painting. € 3,050 were collected for the Téléthon



**18th and 19th December 2023 :** Marie-Claude Boiteux presented to children aged 11-12 at the Bons en Chablais secondary school: 200 children attended this awareness raising talk about skin disorders. The aim was to reduce the stigma and bullying that children with a skin disorder may face at school. Each child was given the booklet edited by the French Federation for Skin : « What about talking.... about skin disorders »



## ON-LINE ACTIVITIES

Today, a great number of meeting, working groups, workshops, etc are on line. Here is a list of what happened during the last 6 months of 2023 :



9th June Working Group  
« Pregnancy »



26th June Eurordis  
Patient Partnership



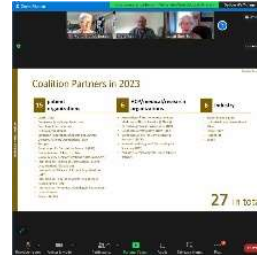
28th June Pfizer Club  
« Real Life Data »



28th June Pierre Fabre  
« Associations' funding »



10th October  
G5 Health



11th September and 14th December  
World Skin Health Coalition



20th October Webinar  
« lobbying »



13th November  
ePAG Steering Committee



28th November Webinar  
« Connective Tissue Disorders (PXE) »

## RESEARCH – MEDICINE – GENETICS



**CONECT Project (Cardio-Ocular Network ConnEctive Tissue)** gathers together several organisations dedicated to connective tissue rare disorders with cardiovascular involvement : Arterial Tortuosity Syndrome, Marfan Syndrome, Ehlers-Danlos Syndrome, Cutis Laxa, Loeys-Dietz Syndrome, etc...

Initiated by the American Patient Organisation for Arterial Tortuosity (ATOF-ATS), it aims to build a collaboration to evaluate the common issues in a population with similar patients, to inform on possible treatments that are not widely known, to ensure that patients have a minimum of scientific and clinical knowledge on their disorder to be able to give their informed consent to take part in research programmes and to improve their quality of life. Online webinars have already been set up, for patients as well as health professionals.

**Raising a child with a rare disease: Parental quality of life and family functioning :** A new study in the International Journal of Rare Diseases and Disorders showed that parents of children with rare diseases had a significantly lower quality of life and family functioning. It also points to the need for including support for parents and families in the holistic provision of health care services. (orphanews international 2023.09.15)



**Japan: Recent advances in rare skin diseases :** A new article has been published in the Keio Journal of Medicine providing an overview of recent advances in clinical research on rare hereditary skin diseases in Japan. It shows efforts to uncover their pathogeneses, potential new treatment methods, current progress on establishing clinical practice guidelines and activities which have been undertaken to raise public awareness. Collecting scientific evidence also aims to inform the creation and revision of evidence-based Clinical Practice Guidelines. (orphanews international 2023.07.26)



**What about talking ... about skin disorders ? :** As I mentioned above, the French Federation for Skin (FFP) has just published a booklet for children. Fruit of work with children with or without a skin disorder, with an adapted design made by the organisation « The Little Citizens », it perfectly answers the children's questions about skin disorders and aims to get rid of bullying for those who suffer from those disorders.

**Skin Disability Guides :** After two years of collaborative work with patients, medical professionals, medico-social professionals and the National Office of Solidarity for Autonomy (CNSA), here is another concrete result of the work led by the FFP. Because the skin is the biggest organ of our body and to understand the impacts of skin disorders, the Skin Disability Guides provide the urgent keys to evaluate the disabilities patients are facing. The Patient Guide help them correctly fill the form to assert their rights. These documents will soon be downloadable on our website.



**Another booklet recently published :** This is for schools and communities to welcome a child with a skin disorder. It lists the consequences the disorder may have, the specific needs, the possible or necessary layouts, as well as the role and place of the education team. You can download it from Fimarad website ([www.fimarad.org](http://www.fimarad.org))



**World Skin Health Coalition (WSHC) :** It gathers together all stakeholders concerned with the health of the skin : patient organisations, health professionals, medical and research societies and industrial partners, to strengthen our collective power in order to raise awareness on the global impact of dermatological disorders and conditions and put them at the top of health policies' agendas. We are members of the coalition.

**Psychosocial needs of children with rare diseases and their families :** A new article has been published in the Orphanet Journal of Rare Diseases which explores the day-to-day experiences of children living with rare diseases and their parents, as well as their needs and current pathways to psychosocial supports. Five main themes : daily life with an RD; experiences with the health care system; psychosocial support; difficulties and barriers; and improvements for patient-oriented support were addressed during semi-structured interviews with young people with RD and parents of children with RD. Overall, diagnostic delays and a lack of physician education, as well as time, socio-legal, and organisational problems all caused stress and negatively affected mental wellbeing. Despite recent advances in awareness and care, RD still represent a great challenge for all those affected by them and their families. (Orphanews International 2023.10.16)



**The economics of delayed diagnosis in the United States:** The EveryLife Foundation for Rare Diseases has published a new study on the economic implications of delayed diagnosis of rare diseases. Timely diagnosis of rare diseases is key for patients to be able to access potentially life-saving treatment and improved quality of life. Beyond the health benefits, however, delayed diagnoses also come with greater costs for health systems. (orphanews International 2023.09.29)



**Canada establishes rare disease Advisory Group :** The Government of Canada has announced the establishment of an Implementation Advisory Group (IAG) for drugs for rare diseases. The creation of the National Strategy for Drugs for Rare Diseases will aim to improve consistent access and affordability of effective drugs for rare diseases. Over the next three years, the IAG will provide a forum for patients and stakeholders to exchange information, provide patient-centered advice and exchange, and establish best practices for the implementation of the National Strategy. (orphanews International 2023.11.20)



**« United for Health » :** is a Parliamentary club established after a survey made by the NGO « Action Santé Mondiale » ( <https://www.actionsantemondiale.fr/enquete-parlementaire-inedite-menaces-sanitaires/> ) This parliamentary club wants to be a link between national representatives and civil society actors by proposing :

- ✓ A place to meet and dialogue with health and world challenges experts : scientists, leaders of UN Organisations, NGO or Think Tanks agencies, activists and other stakeholders.
- ✓ A better framework to watch at the heart of the problems, thanks to visiting Health International Organisations and taking part in study travels.
- ✓ A platform offering contents and tools to help deputies' work.



**Reaffirming at all levels the commitment to and participation of users** : In an article published on 12th December 2023 on the occasion of the National Health Strategy, the High Authority for Health identified four topics which require much effort and progress :

- 1) Promoting the commitment to and the participation of users with health professionals ;
- 2) Effectiveness of individual rights recognised in the laws of 2002 and those adopted afterwards;
- 3) Representation of users by agreed organisations ;
- 4) Reinforcement of users' knowledge.

For us, CLI, these four topics, to which must be added the lack of volunteers and financial means, are the main topics to work on during the coming years if we want to protect the survival of all voluntary organisations.



**Virginie BROS-FACER, new CEO of Eurordis** : In September 2023, Yann Le Cam announced his decision to retire from the position of CEO of Eurordis. Virginie Bros-Facer will then take over in March 2024. She had previously worked with Eurordis as Scientific Director before joining various organisations where she worked in the field of research and patient engagement for rare disorders.

In her own words, she is delighted to be back in Eurordis.

## THE MEDIA

**June 2023** : ERN-Skin News : ERN-Skin Patient Representatives attended the Conference « Elevate » in Brussels. Two of them were honored with the awards « Champion » and « Innovator ».

**Summer 2023** : Rare Revolution Magazine : Interview with Dave Jacob, founder of Thinkgenetic , diagnosed with Cutis Laxa

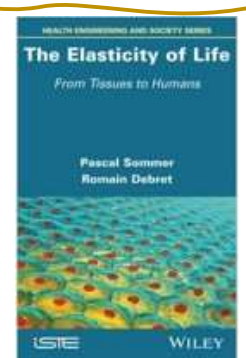
**14th September 2023** : Skin Day : Round table with Marie-Claude Boiteux for the French Society of Dermatology ([https://365.sfdermato.org/revivez-la-table-ronde-de-la-journee-mondiale-sante-de-la-peau/?utm\\_source=brevio&utm\\_campaign=FLASH%20INFO%20-%20Journe%20mondiale%20Sant%20de%20la%20peau%2014%20Septembre%202023%20-%20070923\\_copy\\_copy&utm\\_medium=email](https://365.sfdermato.org/revivez-la-table-ronde-de-la-journee-mondiale-sante-de-la-peau/?utm_source=brevio&utm_campaign=FLASH%20INFO%20-%20Journe%20mondiale%20Sant%20de%20la%20peau%2014%20Septembre%202023%20-%20070923_copy_copy&utm_medium=email))

**5th December 2023** : Round tables and presentations of the FFP 5th Conference are now online on the YouTube channel at <https://www.youtube.com/channel/UCvbExcayClnIRh7Vw99itLg>



### **The Elasticity of Life :**

This is the title of the book recently published, in French and in English, by Dr Pascal SOMMER, Emeritus Research Director of the French National Center for Scientific Research (CNRS). He has been following Cutis Laxa and our association for more than 20 years. The book is available online, printed or downloadable: [https://www.istegroup.com/fr/produit/lelasticite-du-vivant/?utm\\_source=brevio&utm\\_campaign=Sommer%200712&utm\\_medium=email](https://www.istegroup.com/fr/produit/lelasticite-du-vivant/?utm_source=brevio&utm_campaign=Sommer%200712&utm_medium=email)



**VDS (Visible Disorders of the Skin) Programme** has been set up by the “Patient Relationship” Department of Pierre Fabre Laboratories.

Living with a visible disorder of the skin on your face and/or hands, means been continuously under the gaze of others, embarrassment and reactions that are sometimes disconcerting and even hurtful from people just passing by or met daily. The gaze, even covert, can have unsuspected impacts on the life of people living with a visible disorder of the skin. Let's become aware of the power of a gaze that, if it can damage the daily life, can also illuminate it!

Listen to the podcast with patients' interviews and try the « e-motion experience », a unique moment « in the skin of a patient ».

Enjoy visiting it, in French or English : <https://www.changer-de-regard.com/>





Marie-Claude Boiteux took part in writing a new scientific publication : « *Testimonies, feelings, complaints and emotional experiences of patients suffering from dermatosis on social medias : French Infodemiologic\* Study of patients' uncensored words* ».

Stemming from a work led by Pierre Fabre Dermo-Cosmetic & Personal Care together with the society Kap Code specialised in the analysis of real-life data in health who listened for 3 years to patients' uncensored words as publicly expressed on social media.

The internet offers a forum to those for whom the skin disorder bridges their social relationships. Through social media, they share their real-life experience and reveal what they do not say - because they do not dare to or because of lack of time - in medical consultations: Self-image, physical and psychological impacts, therapeutic roving, etc. Collected, analysed and related verbatims, this work shows the emergency and need to « change our gaze on visible disorders of the skin ». <https://www.changer-de-regard.com/#ecoute-reseaux>

\*Infodemiology was defined by Gunther Eysenbach in the early 2000s as information epidemiology. It is an area of science research focused on scanning the internet for user-contributed health-related content, with the ultimate goal of improving public health. It is also defined as the science of mitigating public health problems resulting from an infodemic

**Survey ALL :** Carried out between January and April 2023, together with EMMA Society, this international survey evaluates the prevalence (number of cases among a defined population), impacts, behaviours and needs of different skins and skin disorders depending on geographical areas, countries or complexion.

It included 50,552 participants (adults ≥16 yo) in 20 countries (China, USA, Brazil, India, Australia, France, Italy, Canada, Denmark, Germany, Israel, Kenya, Mexico, Poland, Portugal, Senegal, South Africa, South Korea, Spain and United Arab Emirates) distributed across the 5 continents.

It is therefore the biggest private database in dermo-cosmetics.

Take a look at all the results on this page : <https://www.changer-de-regard.com/#all>



### Our Website :

By 31st December 2023, on our website, there had been over 70,000 visitors (exactly 70,190) since its opening in February 2002 .... Almost 22 years ago.

That represents an average of over 3,190 visitors per year.

They mostly come from European countries and North America.

### ASSOCIATION'S FINANCES

Think about renewing your fees and donations **in 2024**.

### 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.

*Happy New Year  
To all of you !*

**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 :**

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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**

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

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