

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° 39 ~ JUNE 2023

Cutis Laxa is a rare and complex disorder requiring multidisciplinary care.

Looking at it from the outside, many people think the problem is only “aesthetic” and “not so severe”. Only those who are directly impacted really know what it means to live with Cutis Laxa, whatever the type.

It may be very difficult to make people, employers, health authorities and even some doctors understand that Cutis Laxa is a severe, disabling disorder and that it can even be lethal.

A lot remains to be done for CL, and also many other skin disorders, to be recognised and receive the necessary care they deserve.

This has been our fight for over 20 years. There is still a long way to go, but we will stay strong.

Marie-Claude Boiteux, Chair

NEW CONTACTS, FAMILIES' NEWS

Mc Kenna Rose, Magali, Ezra, Hudson, Amelia, Maui Rose, Julie, Lennox, Aaxel, Eric and Harlyn joined us since the beginning of the year. A new country was added : Dominican Republic

There are now 533 patients gathered together and allowed to share their distress, their questions, but also their challenges and successes living with Cutis Laxa. We are here to help them.

It is with deep sorrow that we learned that Chiara, in Italy, and Dave, in UK, passed away.

For both of them, lung issues due to Cutis Laxa got the better of their energy and will to fight. Chiara was supposed to attend the Days in Ghent and Dave had attended the Days in Annecy. We send their families our thoughts and condolences, as well as lots of courage to face this hard time.

MEETINGS, EVENTS AND EXHIBITIONS



24th & 25th November 2022 : National and Scientific Days of the FIMARAD network for rare skin disorders. Besides the important progress made by the network's members, together with patient representatives in the workgroups, it was the opportunity to strengthen the collaboration between FIMARAD and the French Federation for Skin (FFP).



29th November 2022 : 4th Conference of the FFP on the theme « Health Journey in Dermatology » - Pr Dupin, Chair of the French Society of Dermatology (SFD) and Pr Beylot-Barry, presented the challenges and prospects, further developed by Dr Sulimovic, Chair of the National Union of Dermatologists-Venereologists (SNDV), specifically regarding access to dermatologists in town (rather than in hospital). For this part, Pr Bodemer focused on issues regarding Paediatric Dermatology. We ended the morning with a roundtable dedicated to “Holistic care of the Patient”. We spent the afternoon in workshops to reflect on



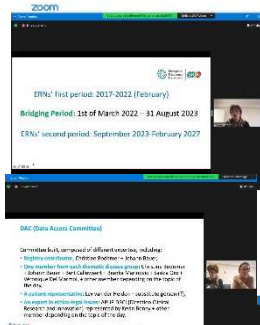
the synthesis of local meetings organised around the review of the Local Projects for Health. A great, rich, participative and interesting day, as speakers and attendees said in their comments.



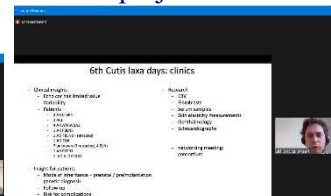


29th November – 3rd December 2022 : Dermatology Days of Paris (JDP). Pr Dupin opened the « Associations' Village ». This year, CLI not only had a stall, but we also took part in « Canal JDP » for a cross-interview with Pr Ludovic Martin « Cutis Laxa : Hope for the patients ».

Our poster was also part of the official exhibition.



13th January 2023 : ERN-Skin Board Meeting. 2023 is a transitional year for all ERNs. The first 5-year period ended in 2022. 2023 will therefore be a transition and evaluation year before a new validation by the EU for a new 5-year period to 2028. The meeting was an opportunity to take stock of what was done and present future projects.



2nd & 3rd March 2023 : SNDV organised a Dermatology Venerology Meeting (RDV 2023) in “La Cité des Sciences” in Paris. The FFP stall was held by Hélène Raynal, the Secretary. During the roundtable « Information and awareness : Prevention a priority, at last », Marie-Claude Boiteux spoke as patients' representative et brought forward patients' contribution to further raise awareness.

These two days ended beautifully with a cabaret show offered by the SNDV.



RESEARCH – MEDICINE – GENETICS

The ethics of prenatal diagnosis

A recent article published in “Maternal Health, Neonatology, and Perinatology” describes various ethical issues associated with prenatal diagnosis. “Prenatal diagnosis” is an umbrella term encompassing a range of genetic tests which are conducted prior to birth. These procedures vary in risk level and invasiveness, but all aim to detect any genetic disorders present in the foetus. They can be divided into two categories: preimplantation genetic testing, and prenatal diagnostic procedures during pregnancy. These procedures generate a large amount of data which may not be well-communicated to couples. Prenatal diagnostic procedures findings can be difficult for parents to interpret and their decisions may therefore be made on the basis of misconceptions about the likelihood or potential severity of a condition. Moreover, many of the applications of prenatal diagnosis are themselves ethically controversial, and are the subject of significant debate. Overall, there is a need for clear guidelines on the use of prenatal testing. (orphanews 2023.02.28)

On 28th March, the National Union of Dermatologists Venerologists (SNDV) published a press release about « **Taking stock of the dermatology care in France** » : unlike generally accepted ideas, amplified by the distorting mirror of social medias, medical activities of private dermatologists are above all clinical and surgical. Thus, over 2,500,000 medical treatments are made each year by 3,600 dermatologists, of which 2,700 are private, according to statistics published by the National Board of Health Insurance (CNAM). These medical treatments mostly concern the care of skin cancers and chronic inflammation skin disorders.

20th & 21st April 2023, ERN-Skin organised its Scientific Days on the topic: **“Patient Education Program (PEP)”**. As defined by the OMS-Europe report it « *aims to help patients gain or keep the competencies they need in order to better manage their life with a chronic disorder. It is an integral part, and on a permanent basis,, of patient care* ». Since 2009, PEP has been legally defined in France. The long French experience in this field could be an example to implement PEP in other European countries.

LEGISLATION ~ SOCIETY

Inter-Organisations’ contribution to the Local Projects for Health (PRS)

The French Federation for Skin (FFP), the French Society of Dermatology (SFD), the National Union of Dermatologists Venereologists (SNDV), the Network for Rare Skin Disorders (FIMARAD), the French Federation for Continuous Training and Evaluation in Dermatology Venereology (FFCEDV), as well as the association of Future Dermatologists Venereologists in France (FDVF) pulled the communication cord :

Dermatology is on the brink, an alarming situation in France. The WHO (World Health Organisation) has classified skin disorders as the 4th most impacting disorders regarding patients’ quality of life. Yet, anywhere in French, skin disorders encounter an intersectional group of difficulties : No access to care in several regions, several months’ delay to get an appointment in town and in hospital, alarming medical and paramedical demography, therapeutic and diagnostic roving leading to loss of opportunities and refusal of care, social inequities in health, and more.

A recent study led in 316 Prefectures and Sub-prefectures (*both local regional political and administrative centres*) showed that dermatology is one of the first specialist area of medicine for which getting a first appointment is almost impossible.

Patients and their families feel like they are left behind et health professionals feel helpless when face with growing difficulties. Yet, in the past few years, dermatology treatments have seen a real revolution and should allow, with correct care, to cure many conditions efficiently and much earlier.

Despite these alarming findings, skin disorders are totally absent in today’s main local health priorities. The coming review of the PRS is a unique opportunity to correct this omission and finally take into account the needs of the populations concerned.

Action must be taken urgently !

3 headings and 14 propositions are included in this contribution to turn this crisis around.

-1- Make access to care a Priority

- ☐ Train more dermatologists venereologists by increasing the number of interns in dermatology.
- ☐ Re-establish skin healthcare in hospitals in all French regions.
- ☐ Create the post of Advanced Practice Nurse (IPA) in all hospital dermatology departments.
- ☐ In areas where skin care is limited, encourage retired private dermatologists to pursue their activities for a few years beyond retirement age.
- ☐ Develop online dermatology expertise, and prioritise the worst regions where care is very limited or absent.
- ☐ Create positions for psychologists in hospital dermatology departments.
- ☐ Re-assess upward the complexity of skin treatments that nurses are allowed to deliver.

-2- Make dermatology care pathways more fluid

- ☐ Co-develop, together with health professionals and patient organisations, care pathways more readable and clarify the various levels of intervention (1st consultation, specialised care, complex care).
- ☐ Train « 1st step » health professionals in dermatology and provide them with the minimum equipment necessary (dermatoscope, biopsy equipment, online tools, etc.)
- ☐ Strengthen the co-ordination between 1st consultation and specialised care based on local measures and systems that were already well-tested (especially online expertise, specialised skincare teams)
- ☐ Reinforce the link town-hospital, especially supporting and increasing the fees for hospital consultations delivered by private dermatologists.
- ☐ Lead, with the support of patient organisation, advertising campaigns and awareness raising for patients to encourage them use the health system in a more responsible way :
 - o reduce the number of missed appointments.
 - o Limit the number of annual « check-up » appointments for people who are not at risks or with no particular symptom.

-3- Provide greater support to health professionals and patients

- ☐ Support the deployment of medical assistants to give doctors more medical time for patients.
- ☐ Set up, together with professional organisations, a support system for health professionals facing working difficulties (preventing chronic work-related stress, work-life balance, etc).

Teachers'role in the inclusion of students with rare diseases

A new study published in "Frontiers in Psychology" investigated the different teaching variables which affect the inclusion of students with rare diseases. In education, as in other fields, those students have specific needs. These needs are often unmet, due to a general lack of education of teachers and the wide variety of rare diseases. Data collected from the questionnaire filled in by teachers in La Mancha (Castille-Spain), shows that while they were in favor of including students with rare diseases, as a whole, they lacked the requisite knowledge about their specific needs. These results indicate that specific training and resources to offer bespoke educational responses to students with rare diseases are needed. If teachers are more aware of the specific challenges facing these students, their needs will be better addressed and their wellbeing will be improved. (orphanews 2023.01.31)



England recently published its 2nd Rare Diseases Action Plan: the main aims of this Action Plan are to implement the key priorities outlined in the 2021 UK Rare Diseases Framework. : to help patients get a final diagnosis faster; to increase awareness among healthcare professionals; to improve the coordination of care; to improve access to specialist care, treatment and drugs. (orphanews 2023.03.30)

THE MEDIA

28th November 2022 : Public.fr : Sophie Davant, French journalist, tells how the Telethon 2001 supported the first research on CL

1st December 2022 : Canal JDP (see link on the CLI website) cross-interview with Marie-Claude Boiteux and Pr Ludovic Martin

3rd December 2022 : Daily newspaper « Charente Libre » : The Triathlon of Sireuil presented CLI with a cheque

3rd December 2022 : Weekly newspaper « Télé7jours » : Sophie Davant remembers the 10th Cutis Laxa patient discovered during Telethon 2001.

19th December 2022 : Handicap.fr - Podcast « Rare Disorder and I live with it » episode 9 : Cécile's testimony

6th January 2023 : Social medias : « TiboInShape on Instagram » : Interview with Cécile

28th February 2023 : Daily newspaper « Le Monde » Grand Angle : dossier on Rare Disease Day

28th February 2023 : Monthly newspaper « Le Trombinoscope » - dossier on Rare Disease Day « patients face taxing times and their organisations too ! »

March 2023 : Podcast « Visible disorders of the skin » : <https://www.youtube.com/watch?v=UEhLvNiiZic>

11th March 2023 : Daily newspaper « Le Monde » editorial « Dermatology is on the brink »

28th March 2023 : 20 minutes Brut on line : « Suffering from Cutis Laxa, Amélie, 18, looks like a 60 y.o. woman »

3rd -10th April 2023 : Monthly Magazine « Maxi » : Cécile's testimony « My disorder didn't stop me finding love »

20th April 2023 : Radio « Europe1 », free antenna with Olivier Delacroix, Cécile's interview (see link on the CLI website)

24th April 2023 : Radio « France Bleu » : Interview with Cécile

11th May 2023 : Radio « VivreFM » : Health expert, Marie-Claude Boiteux's interview:

<https://www.vivrefm.com/posts/2023/05/les-experts-sante-une-maladie-rare-la-cutis-laxa>

24 Mai 2023 : Podcast Pierre Fabre-Kapcode « How Social Networks can help better understand Patient's experience ? » <https://techtomed.com/comment-les-reseaux-sociaux-permettent-de-mieux-comprendre-l'experience-patient/>



We lost a very dear friend and everlasting support. Our very first « Supporter », Eric Molinié, died on 21st December 2022.

Thanks to him, former Chair of the AFM-Téléthon, the very first research project on Cutis Laxa was carried out. Rest in Peace Dear Eric.

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**

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/>

Have a Great Summer !

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.