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(LI ~ NEWS N° 38 ~ DECEMBER 2022

Of course, the main event of 2022 is, and will remain, the 6th Cutis Laxa Days held for the first time out of France. It was in Ghent, Belgium, at the heart of the European Center of Reference dedicated to Cutis Laxa, that 23 patients, coming from 11 countries with parents and siblings, gathered together to meet doctors and researchers and spend four amazing days. You will find the report and photos in the N°38 - Special Issue added to this usual one.

Have a good time reading.
 Marie-Claude Boiteux, Chair

NEW CONTACTS, FAMILIES' NEWS

Cutis Laxa Internationale now gathers 517 patients coming from all parts of the world: Stacy, Amber, Ayse, Celia, Deacon, Emmy, Scott, Anna, Em, Amelie, Patricia, Yousef, Nora Grace, Warisha and Nicole joined us since our last newsletter.

Our Big Cutis Laxa Family is glad to welcome them and give them all the help and support they need.

Very sadly I need to let you know that two of our members passed away : Anaaya, 3 ½ , in India and Dominique, 51, in France. Again, we send our deepest condolences to their families. May they Rest in Peace.

MEETINGS, EVENTS AND EXHIBITIONS

Many events and meetings have taken place since early 2022. Whether they were online or face-to-face, National, European or International, Inter-associative or with other health stakeholders, they always allow to gain knowledge, share learnings and, most of all, establish relationships within the skin disorders community and the various stakeholders we work with.

National Events

3rd February: Workshop with the National Service for Solidarity and Autonomy and the French Federation for Skin

on Support Files given to the Local Houses for Disabled People for patients to assert their rights.

8th February : Official hearing by the National Conference for Health on the occasion of the 20th anniversary of Democracy in Health. A lot still has to be done for small organisations such as ours to continue existing and working for improvements in patients' quality of life.

9th February : Associations member of FIMARAD (French Network for Rare Skin Disorders) worked on the concept of Expert by Expertise, where the Patient is rightly considered an Expert.

European Events

ERN-Skin : 14th January :
Annual Meeting, 10th March :
Scientific Day and 27th September : Webinar of the

Thematic group concerned with Cutis Laxa
AMEQUIS : 18th January : last meeting to establish the criteria on which ERNs will be re-assessed and 15th June : final document.

EPAG : 21st January meeting of the Organising Committee and 31st January Good Practice webinar

ECRD : 27th to 30th June European Conference on Rare Disorders

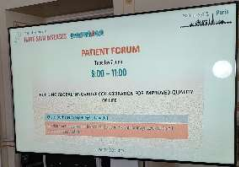
International Events

RDI, Rare Disease International : 28th February : International Day of Rare Diseases and 15th June : Annual General Meeting





1st WCRSD (First International Congress on Rare Skin Disorders) 7th to 9th June, organised by ERN-Skin, René Touraine Foundation as well as Patients Representatives and Globalskin for the Patient Session. It was the occasion to meet with other organisations. A huge success !!

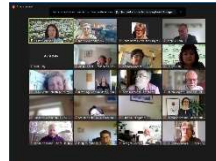


Associations' Events

IADPO (International Alliance of Dermatology Patients Organisations) 27th January : Meeting of Globalskin Europe and 18th May : Presentation of the first results of the international survey on the burden of dermatology disorders.

Our Little Stars : 10th April stall and entertainment

EURORDIS : 18th May Annual General meeting



Other Events



1st February: Pharmaceuticals Seminar

6th July : Pierre Fabre Contest, Marie-Claude Boiteux was a member of the Grand Jury that awarded the Price of the Best Patient-Centered project presented by the international chapters of the Pierre Fabre Group.

30th September and 1st October : CHAM 2022 gathered together all stakeholders of tomorrow's health : Politicians, Health Professionals, Institutional bodies, Pharma Industries and Patient Organisations.

RESEARCH – MEDICINE – GENETICS

See the most recent information in our Special Issue dedicated to the 6th Cutis Laxa Days.

LEGISLATION ~ SOCIETY



UKRAINE

As war still goes on, Ukraine faces a humanitarian crisis and rare disease patients are the most affected by the conflict. 2 million Ukrainians have a rare disease and face the sizeable challenge of meeting the complex medical needs on their own. The EU, Eurordis, ERNs, Orphanet and all the members of the European rare diseases sector joined forces and organized everything to give displaced Ukrainian patients the best help they could: list of medical centres abroad, safe transfer of patients across Europe, access to medicines and medical equipment in Ukraine despite the destruction of vital infrastructures, list of rare disease resources for refugees and displaced persons, and much more, see <https://www.standwithukraine.how/>

THE MEDIA

Winter 2022 : La Gazette Bonsoir : Associations' Life : Cutis Laxa Special

28th February 2022 : Grand Angle : Journal Radiorg (Belgique) : Testimony with Sofie's mother on the occasion of Rare Disease Day

1st March 2022 : Le Monde – Tribune Grand Angle : What about recognition for rare disorders representatives ?

April 2022 : Le Trombinoscope : Calling for recognition of rare disorders representatives

May 2022 : Social Network- French Federation for Skin : Announcing the Cutis Laxa Days

4th Juin 2022 : France 2 – Magazine « Bel et Bien » (Wellbeing) : Cécile : <https://www.france.tv/france-2/bel-et-bien/3454012-bel-bien.html>

6th Juin 2022 : Newsletter René Touraine Foundation: Announcing the Cutis Laxa Days

26th juin 2022 : Social Networks are a very good way to get Cutis Laxa known. This is how a 17yo young lady, was recognized after a report about Cécile. <https://www.youtube.com/watch?v=DYPOq2iUI-s>

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www.cutislaxa.org at Mid-October 2022, our website indicated 64,265 visitors since its opening in 2002.