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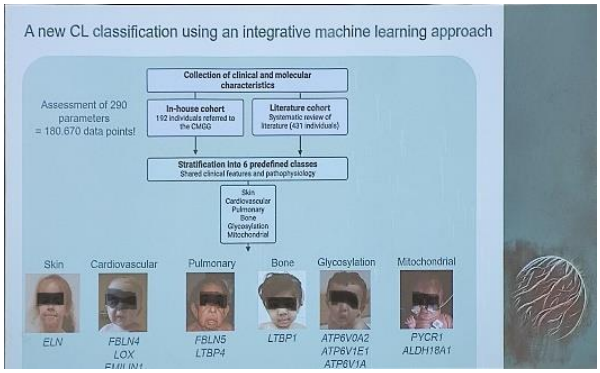
CLI ~ SPECIAL ISSUE ~ 7TH CUTIS LAXA DAYS ~ FEBRUARY 2026

4th to 6th FEBRUARY 2026 in GHENT – BELGIUM

On Tuesday February, 3rd, before the Conference where presentations had been adapted and put into lay language to give patients a better understanding of their disorder, researchers met for a scientific afternoon. The topics covered : Facial gestalt analysis of Cutis Laxa syndromes and related disorders using gestaltmatcher ; A genetic mouse model of Cutis Laxa that reveals immune-driven descending and abdominal aortic aneurysms and Hemicentins as new regulators of elastogenesis. These topics were followed by a discussion about the « COST project » presented by Gerhard Sengle and a wider discussion on access to European fundings. These two discussions are progress reports in the creation of the Consortium of Research on Cutis Laxa initiated during the previous days in 2022 .

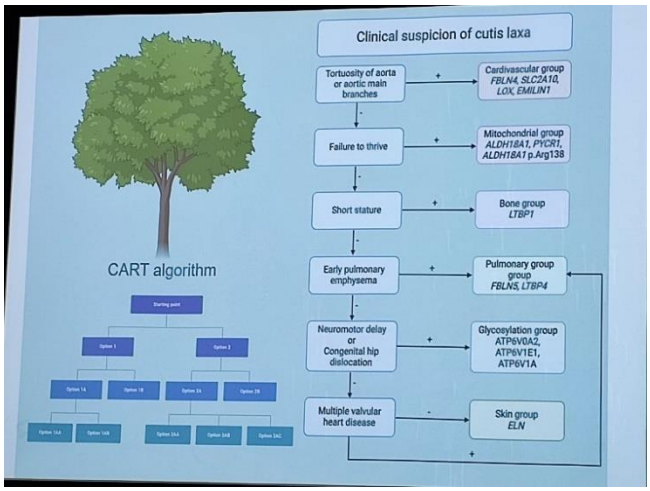
4TH FEBRUARY: CONFERENCE

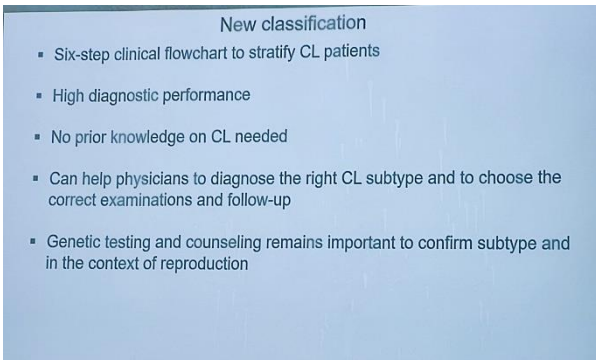
Welcomed in Ghent Unniversity Hospital Auditorium, patients and their families coming from every continent appreciated the effort made by researchers in presenting their work in a simple and clear language all could understand. It is very important for patients to be informed about the latest research findings and, then, learn more about their disorder and be active in its management. The topics discussed were rich in lessons and hope.



New classification of Cutis Laxa types (Dr Aude BEYENS)

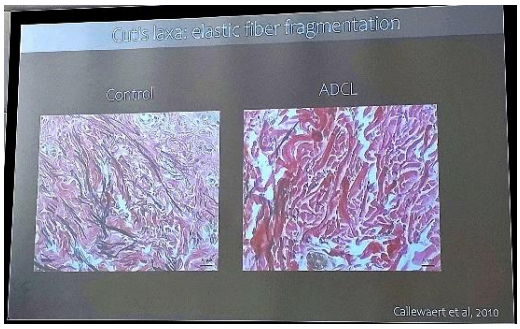
Dr A.Beyens presented the long piece of work that analizedg the different symptoms of all Cutis Laxa types. The files from the 192 patients of the in house cohort studied by Pr Bert Callewaert's team as well as the cases published in literature were screened by Artificial Intelligency (AI) in order to group major symptoms from all types.



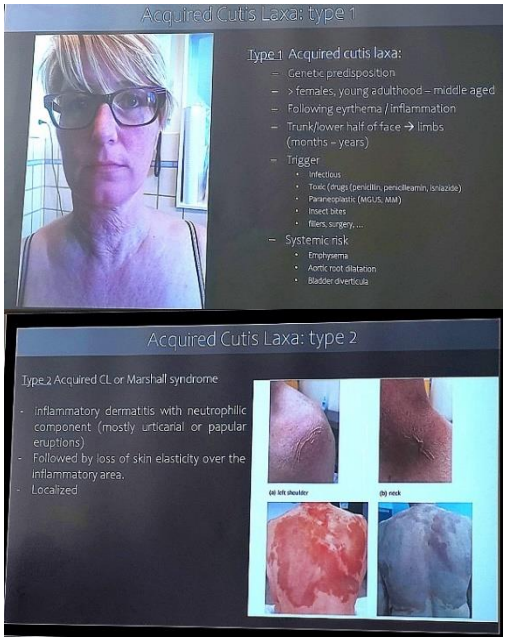


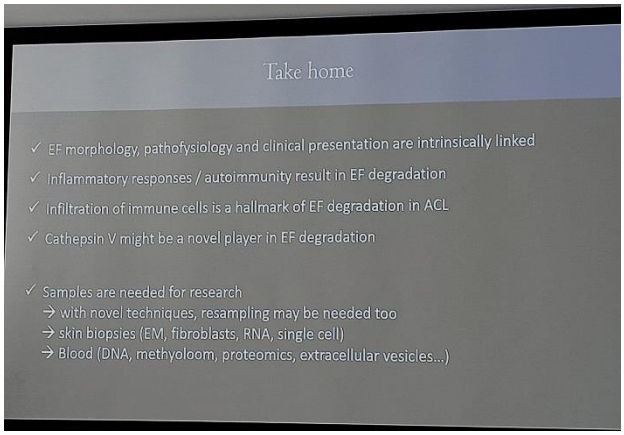
623 files were thus analysed. Clinical and molecular features, plus 290 parameters were taken into account which allowed AI to define 6 groups which share clinical ad pathophysiologic features : Skin, Cardiovascular, Pulmonary, Bone, Glycosylation and Mithocondrial. Moreover, these groups show significant differencies in the elastic fibers degradation.
Thanks to this study, it is now possible to build a decision tree (CART Algorithm) that, depending on the clinical and pathophysiological signs, can determine a suspicion of the type of Cutis Laxa from which the patient is suffering. The results obtained have a reliability of nearly 90%. This does not diminish the need for genetic/molecular testing to confirm this suspicion. But, it allows to immediately organize the care and follow up needed depending on the type, without waiting for the 6 to 8 months needed for the genetic test results. It is a significant improvement to diagnostic delay and improved care for the patients.

Acquired Cutis Laxa (Pr Bert CALLEWAERT)



This type of Cutis Laxa still remains the worst known. Not included in the genetic forms, it can nevertheless be said that there is a predisposition to develop it or not. If, for a long time, we have been talking in a general way about Acquired Cutis Laxa Acquise, today we know that there are at least two different types, depending on the context in which it starts and the clinical signs it induces.

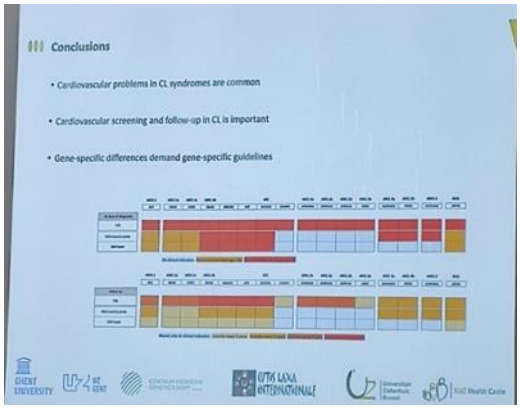


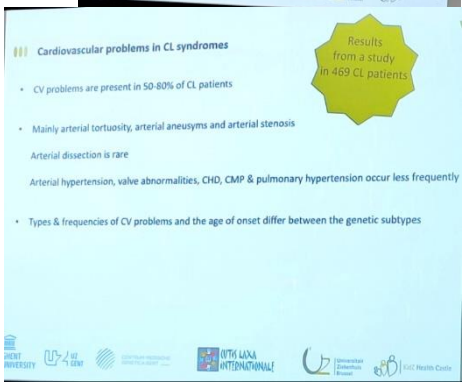


Unlike the genetic types that show a defect on various stages of the « creation » of elastic fibers, Acquired Cutis Laxa Acquise shows as a destruction of those fibers. It is therefore a different process resulting from either an inflammatory or an autoimmune context. A lot remains to be discovered about Acquired Cutis Laxa Acquise but one must keep in mind that :

- The morphology of Elastic Fibers, the pathophysiology and the clinical presentation are intrinsically linked,
- An inflammatory response/autoimmunity can result in the degradation of elastic fibers
- The infiltration of immune cell is a hallmark of the degradation of elastic fibers in the acquired form
- The Cathepsin V protein might be a new player in the degradation of elastic fibers

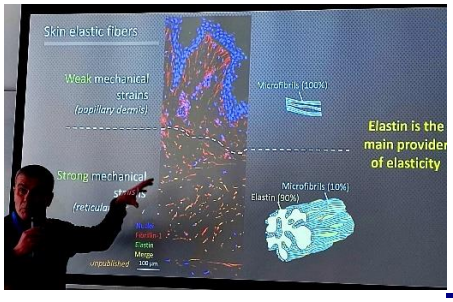
Cardiovascular problems in Cutis Laxa (Dr Ilse MEERSCHAUT)

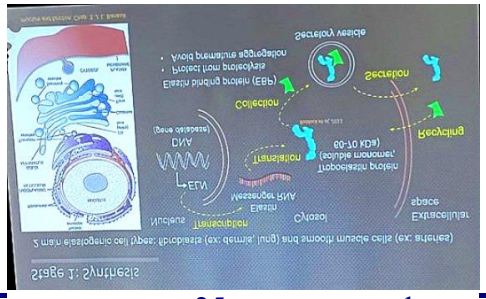


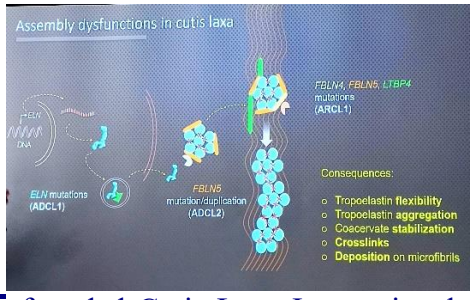


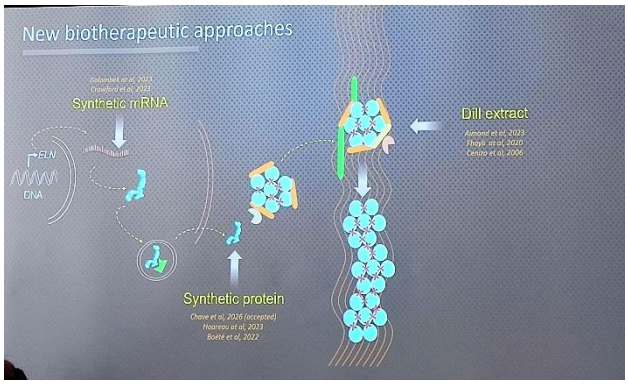
According to a study of 469 patients with CL, cardiovascular disorders are present in 50 to 80% of these patients, mainly tortuosity, arterial aneurisms or arterial stenosis. Several types of Cutis Laxa are specifically concerned : mutations FBLN4, SLC2A10, LOX et EMILIN1 with aortic and main aortic branches tortuosity and mutation ELN with multiple heart valve disorders. All these types need a specific cardiovascular follow-up. When suspecting one or the other type with those mutations in the new classification, it is mandatory to organise this follow-up without any delay. Blood pressure must be controlled, and it is also necessary to evaluate and follow up closely any heart or vascular trouble (echocardiography, MRI of the heart, MR/CT angiography head to pelvis). The frequency and age for these tests must be carried out depending on the type of CL. Difference in necessary follow up depending on genetic mutations demand gene-specific guidelines to be established for each known mutation..

Tropoelastin deposition to treat elastic fiber diseases ? (Dr Romain DEBRET)



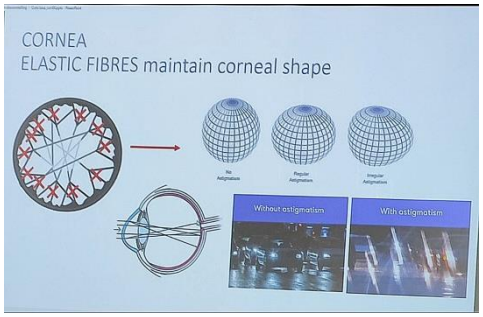




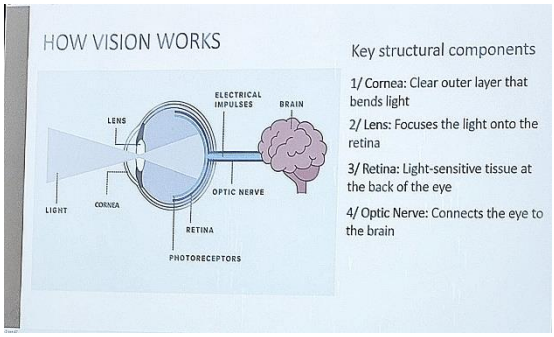


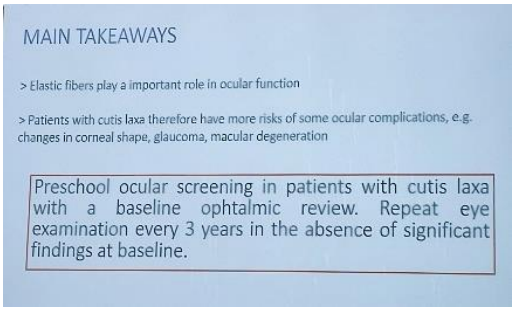
25 years ago, when we founded Cutis Laxa Internationale, access to a therapy seemed to be an unaccessible dream. Today thanks to researchers such as Romain Debret this hope is getting closer and therapeutic avenues are emerging.
After recalling the elements that make up the structure of Elastic Fibers, and the place that troposelastin holds in them, he shared the fruit of his labors: Creating a synthetic tropoelastin that could replace the faulty one in Cutis Laxa. In vitro results are encouraging.
Yet we are still far from a possible therapy for humans, but hope starts to take shape.

Ophtalmologic issues in Cutis Laxa (Dr Lana HOEBEKE)



Elastic Fibers are present in almost all parts of our body, all our organs. Their absence, degradation or malfunction may then have consequences at all levels. This is how our vision can be impacted by Cutis Laxa. Dr Hoebeke explained how eyes are functionning and how Cutis Laxa can alter it.

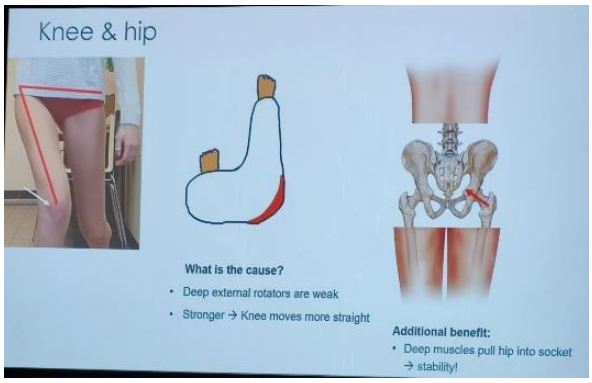




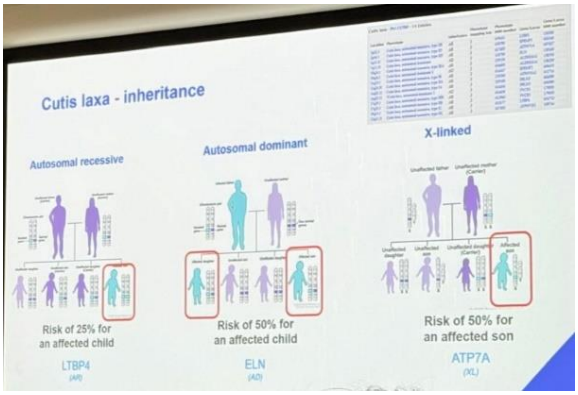
It is at the level of the cornea that the elastic fibers intervene to maintain its shape thanks to an element that could be compared to a trampoline. The appearance of glaucoma and macular degeneration are all possible consequences of Cutis Laxa in ophthalmology. This is why preschool children must be tested early. In case of absence of signs, the evaluation must be made every 3 years.

Physiotherapy and Cutis Laxa (Dr Inge DEWANDELE)

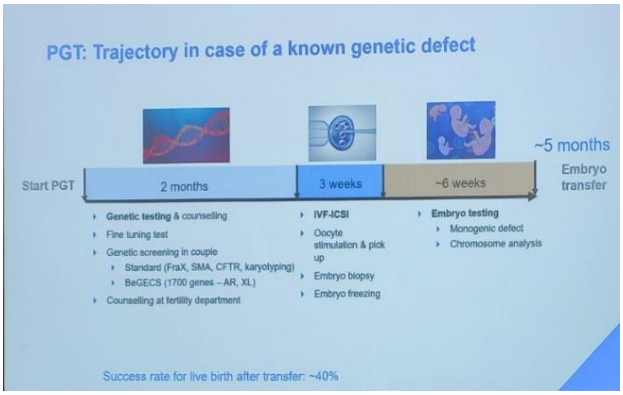
Our joints allow our body to move: waking, climbing up and down, kneeling, eating, washing, writing,etc, all these actions solicit our body and our 4 limbs. Hypermobility or weakness of our joints lead to poor positioning and bad postures. Muscle strengthening and physiotherapy can overcome these difficulties. However, not all sports are accessible to patients with Cutis Laxa due to other associated symptoms. Thus, for patients with cardiovascular disorders, certain sports are too demanding and not recommended. There are alternatives and the choice of sport must take them into account.



Transmission and testing during pregnancy in case of a genetic disorder (Dr Candy KUMPS et Dr Sofie SYMOENS)



For all young people with Cutis Laxa, girls or boys, parenthood raises many questions: Can I transmit my disease? How? What are the risks? In the event of pregnancy, can I find out if my future child could be affected? etc.



All these questions and many others are rarely highlighted in multidisciplinary consultations for rare diseases. We were fortunate at this conference to have Dr. Kumps and Dr. Symoens address them clearly. To begin with, they recalled the differences in transmission depending on whether the disease is dominant or recessive. These differences imply a percentage of risk from simple to double. They then moved on to the process and procedure of a preimplantation analysis in the event of a known mutation, when future parents wish not to transmit the mutation. It is a process that can last about 5 months with 40% success of a viable pregnancy after implantation of the embryo.

Before closing this first day….

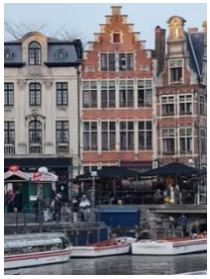
….the floor was open to the audience – patients and family members, and we heard a dialogue between doctors, researchers and patients in order to better understand their needs and how they might relate to research. Their opinions will enrich the list of projects to be carried out by the consortium to improve their daily lives and their experience with the disease.

FEBRUARY 4: FESTIVE EVENING

After this day of conference where we all learned a lot about the consequences of Cutis Laxa, an evening of relaxation was welcome.

Ghent Covered Boat Tour

From the Lieve to the Lys, via the Ringvaart and the Coupure *:* rivers and canals crisscross the city of Ghent and its surroundings. These rivers are navigable and we were able to enjoy nice tour of the city in a covered boat with commentary from a very friendly guide.



Ghent is a beautiful city whose medieval architecture surprises us at every corner, day and night.

Families and Speakers Dinner

After this nice walk, we all met up, doctors, researchers and patients for a very nice dinner in the warm atmosphere of a restaurant in the heart of the old town.

FEBRUARY 5 AND 6: CONSULTATIONS

The next two days were devoted to medical consultations. Genetics, pulmonology, cardiology, ophthalmology, blood tests and biopsies, everyone's program was very busy. A large room had been reserved for patients and their companions and, between appointments, the children played and the adults chatted. For those who had come with their families, the presence of the volunteers of Cutis Laxa International was welcome to take care of the siblings and take charge of siblings and free parents.

The support of everyone was necessary. All these appointments are very exciting and allow patients to take stock of the necessary care and to learn more about their disease. In addition, these consultation days are an opportunity for patients to participate in the research program so that Cutis Laxa is better known and patients better monitored.

BEAUTIFUL ENCOUNTERS

The Cutis Laxa Days are beautiful encounters, an exceptional opportunity to exchange, as the days go by, with those who share the same daily worries, the same concerns, the same experience.

In the hotel, in the city, in the hospital, over a meal, the members of our Cutis Laxa Family enjoyed this unique time together.

Coming from all corners of the planet, abolishing borders, and across oceans, Japan met Colombia, Greece befriended Sweden, Canada and Germany laughed together, France and Lebanon chatted, the United States and the United Kingdom walked around.....






18 patients were present. Some happily reconnected from previous Cutis Laxa Days, others got to know each other.

TESTIMONIES

They all say it, these days are unforgettable and we are lucky to have an exceptional medical and scientific team on our side.

Meeting with other patients is always a wonderful experience. I also would like to thank all the doctors and health professionals who are so dedicated to their research and still show great care for their patients

It was all very useful and in a very easy and understandable language. I learnt thing about my daughter's disease which I didn't know. I was very happy to meet you

Thank you very much for these days and for the welcome. They were really beneficial and allowed me to meet other people with the disease, which is very valuable. The medical staff really took the time to answer all of my questions. I leave with a better understanding of the disease, with the feeling of being less alone. I sincerely thank you for the organization and these moments of sharing

Fantastic few days with « Family » which wouldn't ever have happened without Marie-Claude and all the team

Through my conversation with the professor, I was able to gain a much clearer understanding of my condition, which I had not fully understood before. I am very happy to have participated in this meeting for the first time

Cutis Laxa Days are a blessing for us patients. The exchange with other patients, the exchange with the medical staff, who are very qualified and very friendly, is a gold mine for us! information. Only positive. A HUGE THANK YOU!

It's really good to be able to exchange with people who have, or have had, the same experience. You feel less alone, it's very beneficial. My daughter really appreciated being surrounded by people

Thank you for all the hard work you have been doing all this time to make the CL Days successful and in order to help all the patients and parents connect, share ideas and stories.
We feel blessed by all your doings

Your engagement for rare diseases and Cutis Laxa over years is so outstanding and your commitment has been a true source of strength for us as parents.

The CL Days have become enormously important for my life and it is always healing when I spend time with you guys. Lots of love

GOODBYE

Alas!! The best things must come to an end and you have to leave each other, get back to everyday life. However the energy gathered through meeting other patients and the information received during the conference and consultations make it possible to face difficulties. Hope is there and we trust our doctors and researchers. Their expertise is a real gift in the face of such a rare disease. Their listening and kindness are precious.

If all goes well, we will meet again in September 2029 for the 8th Cutis Laxa Days. Thank you to all those who, through their commitment or their donations, have enabled us to make these days a success:

SEMPLICEMENTE AMICI
VII° Edizione

Glisse en Coeur 17e Edition

COURSE DES HEROS LYON

Pastourelle

10ème Triathlon du Pont Sireuil Charente