CUTIS LAXA INTERNATIONALE
Organisme d' Intérêt Général Loi 1901.

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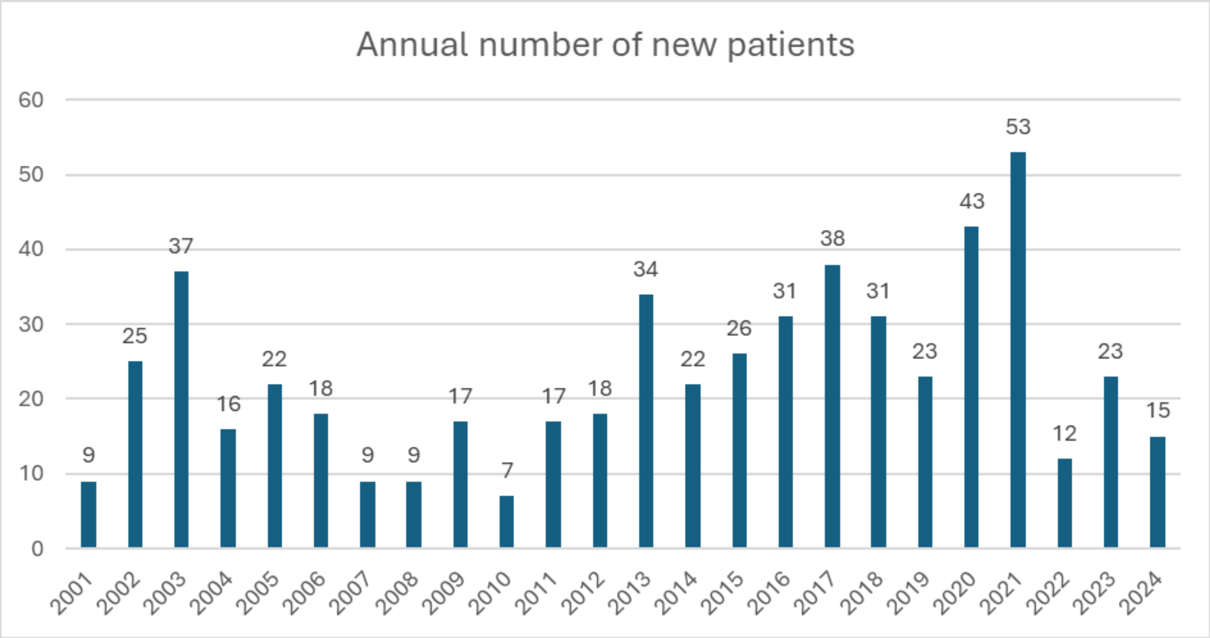
ANNUAL REPORT FOR THE YEAR 2024

SUFFERERS and FAMILIES

Identifying sufferers

On 1st January 2024, we knew of 540 sufferers. By the end of 2024 they were 555. Thus 15 newly diagnosed patients joined us in 2024. For every patient joining us, we have fulfilled our first aim : To Break their loneliness and isolation. Whatever their country, thanks to our website and our private Facebook group we allow them to have contacts with other patients.
Unfortunately, we were mourning in 2024 following the death of several patients: Abdulaziz, Lucille and Safaa left this world. To their mourning families we give all our support and thoughts in this very difficult time.
Since we set up CLI in 2001, 27 patients left this world. They remain in our hearts and thoughts.



Access to information

- **General :** Thanks to our various media (website, newsletter, leaflet) sufferers and their families have access to information that enable them to know and assert their rights, to ease their daily life and find their way in society.

- **Medical and Scientific :** The rarity of Cutis Laxa means that information and data related to it are also rare, difficult to find. Our role is and will always be to centralise them, edit them, and make them easy to find for sufferers and their families, especially through our newsletter and our website.

Putting you in touch with expert clinicians

That is a request made more and more often, and regularly, from sufferers. Whatever the country they come from, they ask us to put them in touch with expert clinicians for Cutis Laxa. Even if they have been given the diagnosis by their local geneticist or doctor, when a symptom occurs or worsens, they ask us to put them in contact with a clinician who « knows the disorder well ». Moreover, as of today over 35% of the people diagnosed with “Cutis Laxa” do not know the exact type they are suffering from because they have not been genetically tested. It is such a pity that they cannot receive the follow up and care they deserve since each type of Cutis Laxa needs such specific support. This is why we do as much as possible to connect patients and doctors beyond borders.

Helping with access to healthcare

This is an important part of the work done at the European level to organize and set up cross-border care. The rarity of Cutis Laxa means that the experts are also rare and patients are spread worldwide.

Thus it is vital for patients to benefit from the expertise of doctors who know Cutis Laxa, regardless of the country the patient and the doctor live in, precision prescribing is of the utmost importance for all patients.

THE MEDICAL WORLD

We are members of several workgroups, in France and in Europe. Through them we work together with health professionals and patients. Whether it is to improve the diagnosis odyssey or to show evidence of specific issues linked to pregnancy and family planning, all this work will lead to scientific publications where the expertise of patients, co-authors of these publications, will be in evidence.

ERN-Skin

Taking part in the European Reference Network (ERN) as Patient Representative remains the central pillar of our activities with the European medical world. Thanks to the new habits of meeting virtually, it is now possible that we « meet » in Brussels in the morning, in Paris in the afternoon and in New York in the evening….. And this way, all along 2024, we took part in workshops and webinars organised worldwide. It would not have been possible if those meetings had been held onsite.

Our collaboration with medical and scientific professionals brings a real added-value to the benefit of patients and improvement of their quality of life.

EPAG (European Patient Advocacy Group) : Patient advocates in ERN-Skin

EPAG carries out its work in parallel with ERN's.

En 2024, We have continued to work according to our roadmap for the period 2024-2027: Mapping expertise throughout Europe; Patients' mental Health; Palliative Care; Awareness of Dermatology; Burden; Pediatric Specificities; Therapeutic Training Programs. All these topics are of deep concern to Rare Skin Disorders.

FIMARAD (French Network for Rare Skin Disorders)

The Health Channel for Dermatology Rare Disorders (FIMARAD) can be seen as the French equivalent of ERN-Skin.

Fruitful exchanges and regular collaboration with the leaders of the associations concerned by FIMARAD make it possible to advance national issues. This joint work aims to improve the quality of life of patients and limit the risk of seeing us disappear from the health landscape in France.

In addition, the "Errance et Impasse Diagnostic" (Diagnostic Odyssey and Impasse) group continued to analyse responses to the questionnaire sent to all FIMARAD member associations to establish symptom concordance tables and identify health professionals (nurses, physiotherapists, etc;) who could be "alerters" of a possible rare disease. These results should be available for publication in 2025/2026.

OUTREACH WORK

Relationship with other Support Groups

- **Internationally :** Our growing in-depth engagement at the European level allows us to have regular and fruitful contacts with other dermatologic patient organizations, as our memberships in Rare Disease International (RDI) and in Globalskin (International Alliance of Dermatology Patient Organisations) also do.

- **Nationally :** Being members of national umbrella organisations (Solhand, Alliance Rare Disorders, etc), and being member for "Rare Disorders" of the elected Board of the French Skin Federation (FFP), gives Cutis Laxa a great visibility. In 2024, the last year of Marie-Claude Boiteux's presidency of the French Skin Federation, projects were initiated:
  - ❖ The Maison de la Peau (House of Skin): this ambitious project should provide visibility, a place of exchange and resources for all the member associations of the FFP.
  - ❖ Study of Tele-Expertise in Bourgogne-Franche-Comté: This region has a good precedent in the implementation of Tele-Expertise in its territory, where the medical desertification is very important, making access to dermatologists almost impossible depending on the patient's place of residence. Carried out in consultation with the Regional Health Agency, this study should produce interesting figures.
- **Locally :** In 2024, Cutis Laxa Internationale strengthened its commitment in local actions as member of the Local Committee for Social Action of the Town of Bons en Chablais. Those local projects allow us to develop personal contacts that increase the visibility of the disorder.

Visibility

Being known and recognised means being visible by the greatest number. All the projects we lead have the sole aim of making the disorder visible to the greatest number. Building networks is one of the tools.

Involvement in Society and Compliance

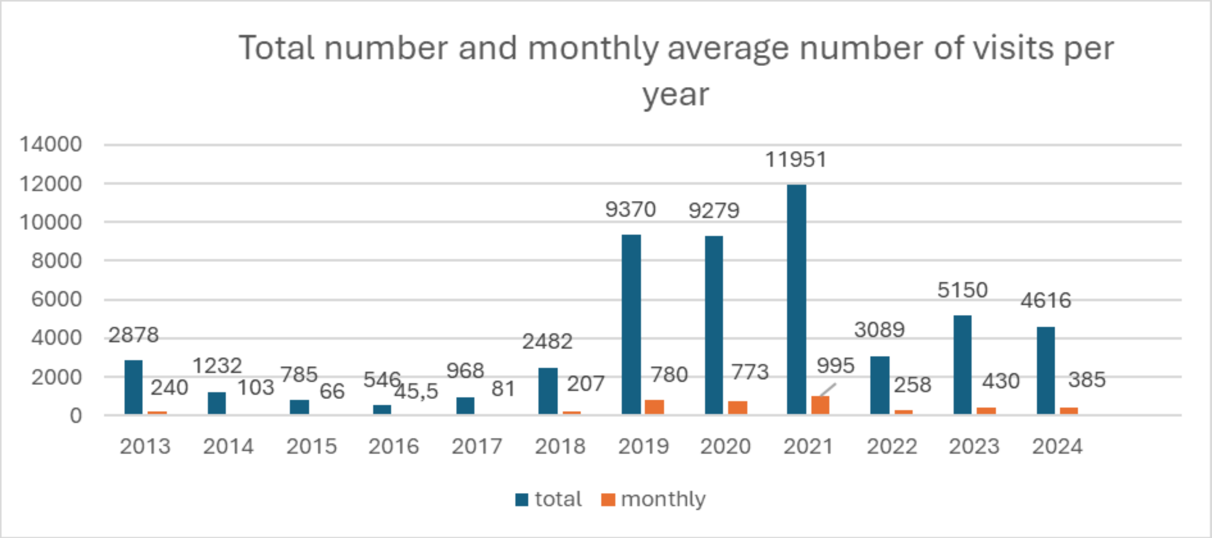
Communicating patients' voice and complying with national and European laws regarding private life and personal data protection is very important. We are especially sensitive to those issues : they are at the heart of our work.

ROUTINE WORKLOAD IN 2024

Disseminating Information

✓ The Internet remains the fastest and cheapest communication tool we have to disseminate information and to help sufferers connect with us worldwide. There are now three ways of contacting us: our website, the public page on Facebook and the private group on Facebook.

✓ Our Website : The counter showed 70,190 visits at the beginning of January 2024. We had reached 74,806 visits at the end of December 2024, i.e. 4,616 visits during the year, so this is a monthly average of nearly 385 visits. Our two annual updates, combined with the dissemination of information about these updates, are really a major element in increasing visits and referencing of our site. The main searches concern genetic transmission, the definition of Cutis Laxa and photos.



✓ Leaflets: Still topical, our three leaflets are regularly distributed; Being printed "on demand" allows us to keep them updated as and when needed;;

✓ CLI BOOK: This book of patient testimonies has continued to interest many people in 2024 and its sale, 100% to the benefit of CLI, continues.

✓ « CLI ~News » : An important communication tool, we continue to publish our newsletter twice a year, in French, English and Spanish. Totally home-made it is sent to all our contacts via email and postal mail. Many thanks to our volunteer-translators.

Celebrations and events

Throughout 2024, we attended, face-to-face or online, events planned by partners or organisations that we are member of : ERN-Skin (Eropean Reference Network for Skin), FFP (French Skin Federation), FIMARAD (French Network for Rare Skin Disorders), Globalskin (International Alliance of Dermatology Patient Organisatio), SFD (French Society of Dermatology), SNDV (National Union of Dermatologists-Venerologists).
We can note in particular our presence:
✓ in Geneva (Switzerland) to support the submission of two resolutions (skin diseases and rare diseases) to the WHO (World Health Organisation);
✓ in Paris (France) during the World Congress on Rare Dermatological Diseases, of which we were co-organisers;
✓ in Philadelphia (USA) for the conclusions and future prospects of the CONECT project in which we collaborated for 2 years;

- ✓ in Reims (France) during the European Elastin Meeting where we met all the scientists working on Elastin;
- ✓ in Paris (France) again for various events, including the Journées Dermatologiques de Paris (Paris Dermatological Days) where we had a stand.

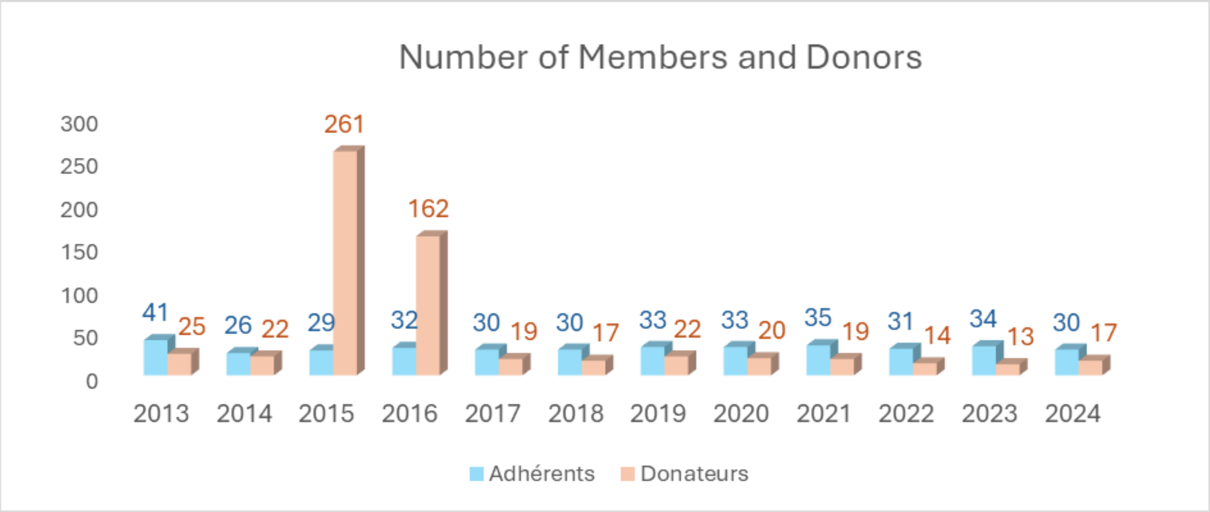
Wether in France or abroad, these meetings are essential because we are the only association worlwide dedicated to Cutis Laxa. They are always opportunities to share and work with other patient organisations' representatives. They enable the implementation of common and consistent actions to the benefit of patients. They give a unique visibility to Cutis Laxa.
There were many other National, European, International and Organisational events online, so the 2024 diary was very full.

The Media

12th June 2023 Doctissimo : interview with Pr.Bert Callewaert : All you need to know about Cutis Laxa (in French) : https://www.doctissimo.fr/sante/maladies/maladies-de-la-peau/cutis-laxa-la-maladie-de-la-peau-relachee/a89563_ar.html
30th January Patient Stories: Dave Jacob : A late diagnosis of Cutis Laxa and creating ThinkGenetic (in English) : https://www.greygenetics.com/a-late-diagnosis-of-cutis-laxa-and-the-creation-of-thinkgenetics/
February 2024 Patient View : The growing role of patient groups in healthcare research. (in English) : https://www.patient-view.com/2024/the-growing-role-of-patient-groups-in-healthcare-research/
06 Mars Le Monde : Rare Disorders - the Challenge of Diagnosis
15 Mars Festival de la Communication Santé : Interview with Catherine Baissac, Patient relationship – Pierre Fabre Dermato-Cosmetics (in French)
28 Avril Charente Libre : The « Brin d'Aillet » run in Sireuil (France) to the benefit of Cutis Laxa Internationale (in French)
02nd September 2024 : Info-Chalon Official opening of the resource center for tele-expertise in dermatology in Chalon-sur-Saône.
10th September 2024 : Le Journal de Saone et Loire Official opening of the resource center for tele-expertise in dermatology in Chalon-sur-Saône.
15th November 2024 : Masterclass at La Sorbonne recording of an interview with Marie-Claude Boiteux for the videos used during the Masterclass at the University for Patients in La Sorbonne (in French) (https://universitedespatients-sorbonne.fr/)
29th November 2024 : Charente Libre Handing over the € 2,500 check to the benefit of Cutis Laxa Internationale by Triathlon de Sireuil
Autumn 2024 : la Gazette Bonsoise Cutis Laxa Internationale, beyond the frontiers of Bons en Chablais (in French)

I would like to put this Annual Report for 2024 to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 10th Juin 2025 and the attendees' and online votes.

FINANCIAL REPORT 2024



The total number of members and donors in 2024 is the same as in 2023, that is 47, so the number of people supporting our actions remains stable. It would be desirable if we could increase this number. The

difficulty we have is our worldwide geographical dispersal. In fact, only members and donors living in France can benefit from a tax rebate. We have been working on that for a long time. The first and obvious solution would be to create “chapters” in other countries…... but, to do so, we must find enough local, volunteers willing to commit to put enough time and effort in these organisations and to keep them running……..
Our savings remain stable, but we must plan for bigger fundraising events to be able to guarantee the expenses of the next Cutis Laxa Days, scheduled in 2026.
You will find hereunder all the figures from the 2024 balance sheet.

Dans le cadre de la mission de présentation des comptes annuels qui a été réalisée pour le compte de :

CUTIS LAXA INTERNATIONAL
Pour l'exercice du 01/01/2024 au 31/12/2024

et conformément aux termes de notre lettre de mission, nous avons effectué les diligences prévues par la norme professionnelle du Conseil National de l'Ordre des Experts-Comptables applicable à la mission de présentation des comptes qui ne constitue ni un audit ni un examen limité.

Sur la base de nos travaux, nous n'avons pas relevé d'éléments remettant en cause la cohérence et la vraisemblance des comptes annuels pris dans leur ensemble.

Ces comptes annuels sont joints à la présente attestation, ils sont paginés conformément au sommaire figurant en tête du présent document, ils se caractérisent par les données suivantes :

Total ressources	**10 867.46**	**€**
Résultat net comptable	**1 295.12**	**€**
Total du bilan	**25 013.67**	**€**

Fait à MAURIAC,
Le 08/02/2025.

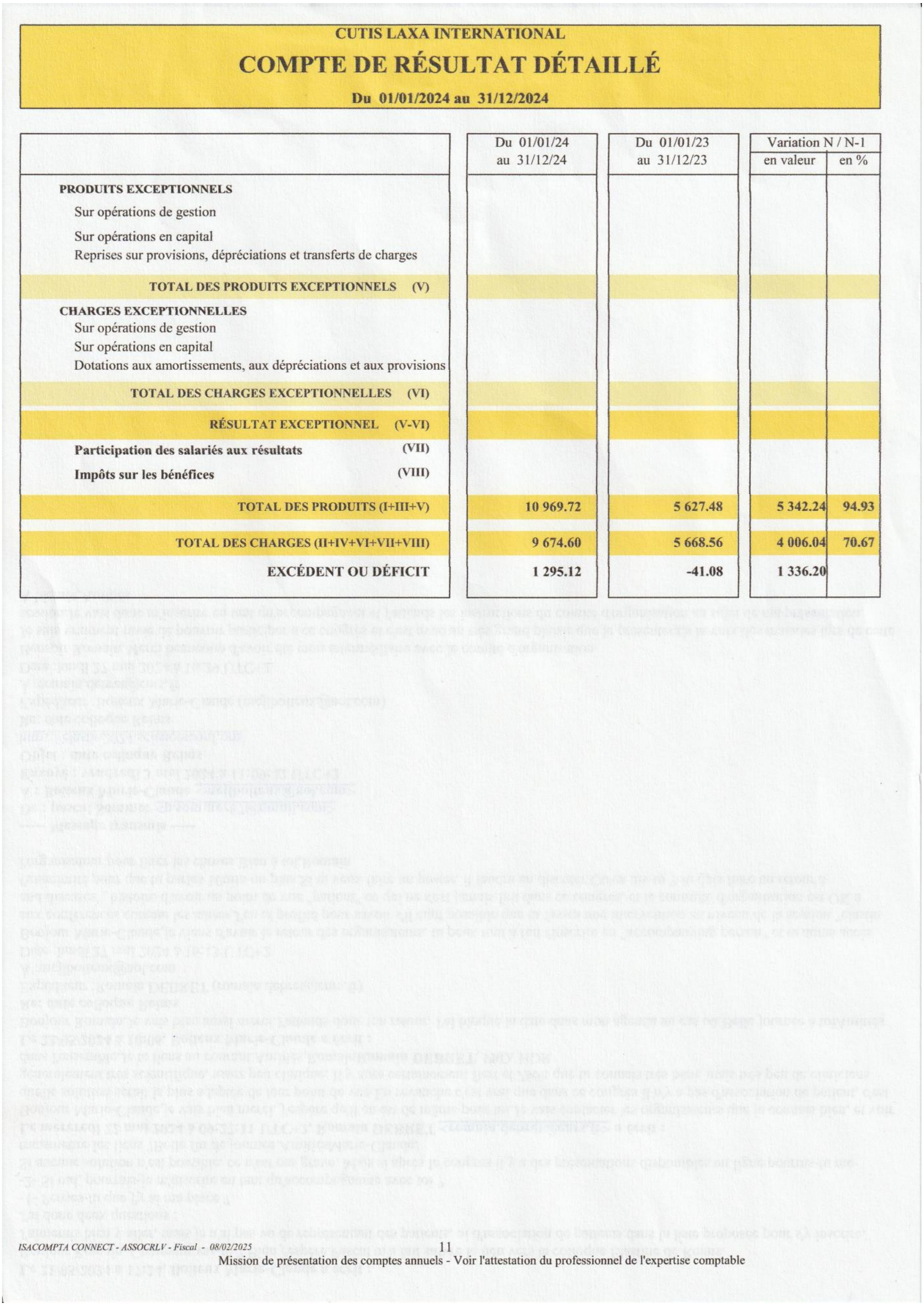
BEAUDONNET GEORGES,
Expert-comptable.

CUTIS LAXA INTERNATIONAL

COMPTE DE RÉSULTAT DÉTAILLÉ

Du 01/01/2024 au 31/12/2024

	Du 01/01/24 au 31/12/24	Du 01/01/23 au 31/12/23	Variation N / N-1 en valeur	Variation N / N-1 en %
PRODUITS D'EXPLOITATION				
Cotisations	3 223.82	2 479.88	743.94	30.00
Ventes de biens et services				
Ventes de biens		50.00	-50.00	-100.00
Dont ventes de dons en nature				
Ventes de prestations de service	4 843.64	2 890.00	1 953.64	67.60
Dont parrainages				
Produits de tiers financeurs				
Concours publics et subventions d'exploitation	2 800.00	100.00	2 700.00	
Versements des fondateurs ou cons. de la dotation consomptible				
Ressources liées à la générosité du public				
Dons manuels				
Mécénats				
Legs, donations et assurances-vie				
Contributions financières				
Reprises sur amortissements, dépréc., prov. et transferts de charges				
Utilisations des fonds dédiés				
Autres produits				
TOTAL PRODUITS D'EXPLOITATION (I)	**10 867.46**	**5 519.88**	**5 347.58**	**96.88**
CHARGES D'EXPLOITATION				
Achats de marchandises				
Variation de stock	18.68	92.92	-74.24	-79.90
Autres achats et charges externes	7 959.92	4 027.64	3 932.28	97.63
Aides financières				
Impôts, taxes et versements assimilés				
Salaires et traitements	1 696.00	1 548.00	148.00	9.56
Charges sociales				
Dotations aux amortissements et aux dépréciations				
Dotations aux provisions				
Reports en fonds dédiés				
Autres charges				
TOTAL CHARGES D'EXPLOITATION (II)	**9 674.60**	**5 668.56**	**4 006.04**	**70.67**
RÉSULTAT D'EXPLOITATION (I-II)	**1 192.86**	**-148.68**	**1 341.54**	**902.30**
PRODUITS FINANCIERS				
De participation				
D'autres valeurs mobilières et créances de l'actif immobilisé				
Autres intérêts et produits assimilés				
Reprises sur provisions, dépréciations et transferts de charges				
Différences positives de change	102.26	107.60	-5.34	-4.96
Produits nets sur cessions de valeurs mobilières de placement				
TOTAL DES PRODUITS FINANCIERS (III)	**102.26**	**107.60**	**-5.34**	**-4.96**
CHARGES FINANCIÈRES				
Dotations aux amortissements, aux dépréciations et aux provisions				
Intérêts et charges assimilées				
Différences négatives de change				
Charges nettes sur cessions de valeurs mobilières de placement				
TOTAL DES CHARGES FINANCIÈRES (IV)				
RÉSULTAT FINANCIER (III-IV)	**102.26**	**107.60**	**-5.34**	**-4.96**
RÉSULTAT COURANT AVANT IMPÔTS (I-II+III-IV)	**1 295.12**	**-41.08**	**1 336.20**	



CUTIS LAXA INTERNATIONAL

COMPTE DE RÉSULTAT DÉTAILLÉ

Du 01/01/2024 au 31/12/2024

	Du 01/01/24 au 31/12/24	Du 01/01/23 au 31/12/23	Variation N / N-1 en valeur	Variation N / N-1 en %
PRODUITS EXCEPTIONNELS				
Sur opérations de gestion				
Sur opérations en capital				
Reprises sur provisions, dépréciations et transferts de charges				
TOTAL DES PRODUITS EXCEPTIONNELS (V)				
CHARGES EXCEPTIONNELLES				
Sur opérations de gestion				
Sur opérations en capital				
Dotations aux amortissements, aux dépréciations et aux provisions				
TOTAL DES CHARGES EXCEPTIONNELLES (VI)				
RÉSULTAT EXCEPTIONNEL (V-VI)				
Participation des salariés aux résultats (VII)				
Impôts sur les bénéfices (VIII)				
TOTAL DES PRODUITS (I+III+V)	**10 969.72**	**5 627.48**	**5 342.24**	**94.93**
TOTAL DES CHARGES (II+IV+VI+VII+VIII)	**9 674.60**	**5 668.56**	**4 006.04**	**70.67**
EXCÉDENT OU DÉFICIT	**1 295.12**	**-41.08**	**1 336.20**	

I would like to put this Financial Report for 2024 to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 10th June 2025 and the attendees' vote.

SETTING THE MEMBERSHIP FEE FOR 2026

As we established, I propose that we agree the membership fee for next year that is for 2026. I propose that is maintained to € 30 for the year 2026.

I would like to put this to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 10th Juin 2025 and the attendees' and online votes.

PROJECTS AND DRAFT BUDGET FOR 2025

The document covering these is enclosed and I suggest that you take a look at them. Feel free to ask any question or explanation about them before we proceed to the vote. They are in line with the work we have done since we set up « Cutis Laxa Internationale ».

I would like to put the Projects and Draft Budget 2025 to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 10th Juin 2025 and the attendees' and online votes.

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MINUTES OF THE ANNUAL GENERAL MEETING WEDNESDAY 25th JUNE 2025

Mrs Marie-Claude BOITEUX, Chair, opened the debate at 6:00 pm. As notified by post to the members, the agenda is:

- **ANNUAL REPORT 2024 and VOTE**
- **FINANCIAL REPORT 2024 and VOTE**
- **FIXING THE 2026 MEMBERSHIP FEES**
- **PROJECTS and DRAFT BUDGET 2025 and VOTE**
- **GENERAL ISSUES**

Present face-to-face:

Mrs M.C. Boiteux, Mr M. Senaud (appointed Secretary of the Meeting)
That is 2 votes

Present online via the zoom link :
Mrs Cécile Boiteux-Gueye, Mrs Marion Lassalle, Mr Romain Rousseau
That is 3 votes

Voted by mail or email :
Mrs Martine Richemont, Mr Serge Richemont, Mr Jean Garidou
That is 3 votes

Apologies with proxy granted to Mrs Marie-Claude Boiteux :
Mrs Sophie Khalilpour and Mr Antonio Da Silva
Apologies with proxy granted to Mr Michel Senaud:
Mrs Véronique Fustier and Mr Pierre Ancelin.

This totals 4 votes by proxy.

In 2024, there were 30 members. The total number of votes from members being present, voting without being present or represented by proxy is 12 (2+3+3+4). Therefore, the meeting is quorate to vote on the agenda items (at least 1/3 of the members).

ANNUAL REPORT 2024

The 2024 Annual Report had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0 No: 0 Yes : 12

The Annual Report 2024 was unanimously approved.

FINANCIAL REPORT 2024

The 2024 Financial Report had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0 No: 0 Yes :12

The Financial Report was unanimously approved.

FIXING THE 2026 MEMBERSHIP FEES and VOTE

It had been previously proposed to fix the membership fee for 2026 at € 30. Counting votes and proxies gives the following results:

Abstentions : 0 No : 0 Yes : 12

Therefore the fee will not change and remains at the actual amount of € 30.

PROJECTS 2025

The Projects for 2025 had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0 No: 0 Yes : 12

The Projects for 2025 were unanimously fixed

DRAFT BUDGET 2025

The Draft Budget for 2025 had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0 No: 0 Yes : 12

The Draft Budget for 2025 was unanimously fixed

As all votes and proxies had been counted and no other question had been asked, the Chair closed the meeting at 8:15 pm.

The Chair
Marie-Claude Boiteux

The Secretary for the meeting
Michel Senaud