



ANNUAL REPORT FOR THE YEAR 2025

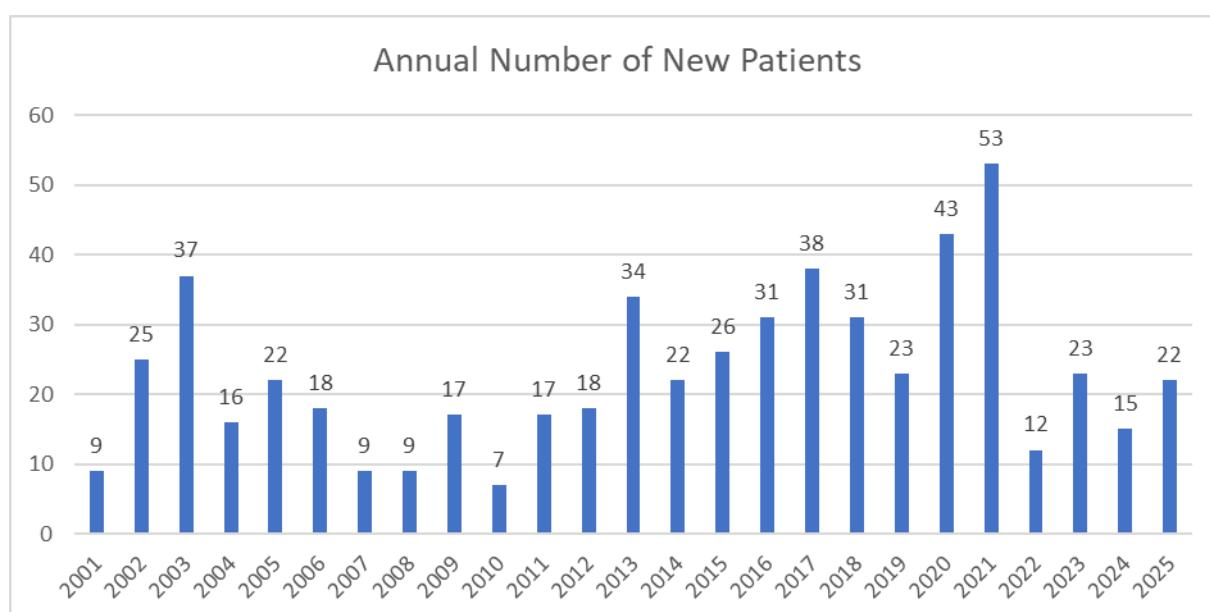
SUFFERERS and FAMILIES

Identifying sufferers

On 1st January 2025, we knew of 555 sufferers. By the end of 2025 they were 577. Thus 20 newly diagnosed patients joined us in 2025. 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 2025 following the death of several patients: Nathan, Maui, Tony et Tasha 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, 31 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 centralize 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 2025, 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 2025, 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 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 2025 the study on tele-expertise in Bourgogne-Franche-Comté has been finalised and published.

A new collective has been created:

Les Peauxcibles "Target Skins"

On several occasions, during meetings with health professionals and authorities, rare dermatological disease associations have mentioned the financial and volunteers recruitment difficulties they encounter. We were told that we should unite our votes to have more weight vis-à-vis the authorities by 2025. It has been done. We have created the collective "Peauxcibles" (Target Skins) which brings together 8 associations: Association Française Hailey-Hailey Darier (AFRHAIDA), Association Ichthyose France (AIF), Association Pemphigus Pemphigoïde France (APPF), Cutis Laxa Internationale (CLI), DEBRA – France, Enfants de la Lune, Genespoir and Incontinentia Pigmenti France (IPF). We worked on a first project that aims to make ourselves known via video clips broadcast on social networks.

- **Locally** : In 2025, 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

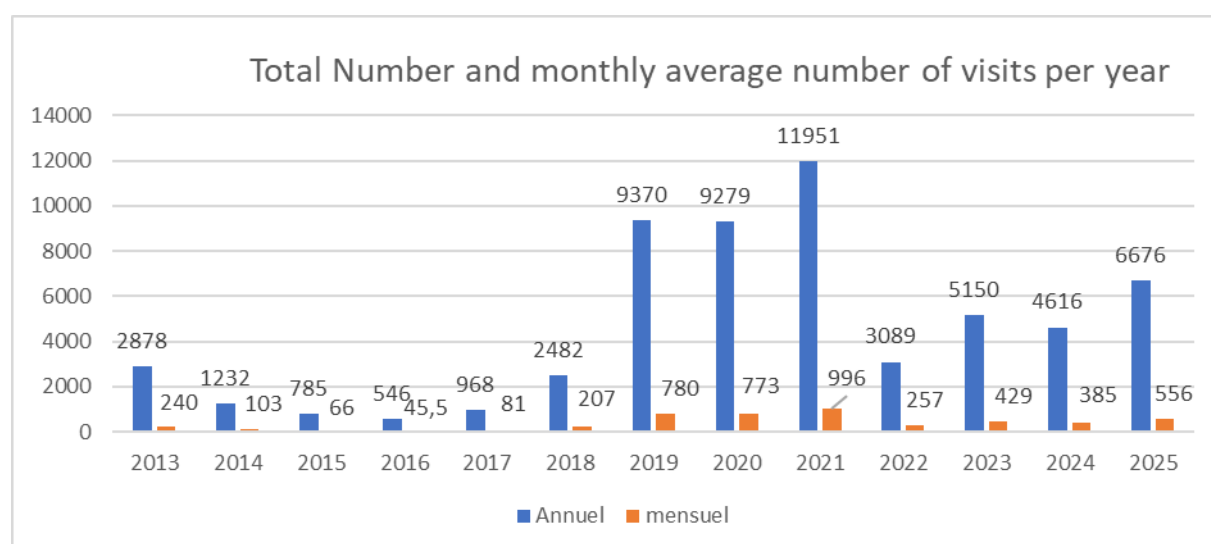
Communicating patients' voice and complying with national and European laws regarding private life and personal data protection is very important. We are especially sensitive to those issues : they are at the heart of our work.

ROUTINE WORKLOAD IN 2025

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 74,806 visits at the beginning of January 2025. We had reached 81,482 visits at the end of December 2025, i.e. 6,676 visits during the year, so this is a monthly average of 556 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 2025 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

2025 has been particularly buusy with events. In addition to the annual ones: 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),..it was mainly sporting and friendly events that kept us busy and enabled us to raise funds:

- ✓ The Douzat Hike (Charente-France)
- ✓ The Brin d'Aillet and the Sireuil Triathlon (Charente-France)
- ✓ Simply Friends (Bergame-Italie)
- ✓ La Pastourelle (Salers-France)

- ✓ The Heroes' Race (Lyon-France)
- ✓ La Brocante (Chandieu-France)
- ✓ The Saint-Martin Fair (Bons en Chablais-France)
- ✓ Glisse en Cœur (Le Grand Bornand-France)

I would like to thank all the Board members and volunteers who were involved in the preparation, participation and organization of these events. Thanks to them and all those who trusted us, we were able to raise the necessary funds for the organization of the 7th Cutis Laxa Days in February 2026 at the University Hospital of Ghent (Belgium). There were many other National, European, International and inter-association events online, so the 2025 diary was very full.

The Media

January: CNRS Micro-Conference « Elasticity of life » especially with Pr Romain Debret on youtube (in French) :

<https://www.youtube.com/watch?v=IxHnivefeTs>

28th February: Teaser of Rare Disease Day with CLI's Logo

28th February: Le Monde: Grand Angle, Special Rare Disease Day

30th March: Facebook Page «Dermato Info», presenting CLI

15th April: ERN-Skin Newsletter: Announcing the scientific publication « Pregnancy and Family Planning in Rare Disorders ».

03rd May: Charente Libre: Walking for CLI on 1st of May

May 2025: La Pastourelle: Brochure and Facebook page announcing the « Night Fever in Salers » to the benefit of CLI

July 2025: Taking stock of the « Heroes Run » : CLI won the prize for the best costumes.

8th October : Doctissimo press release : « Skin Diseases - A public health issue that is still underestimated, a collective to make things happen »

27th November : Charente Libre : « A €2,000 cheque for Cutis Laxa International»

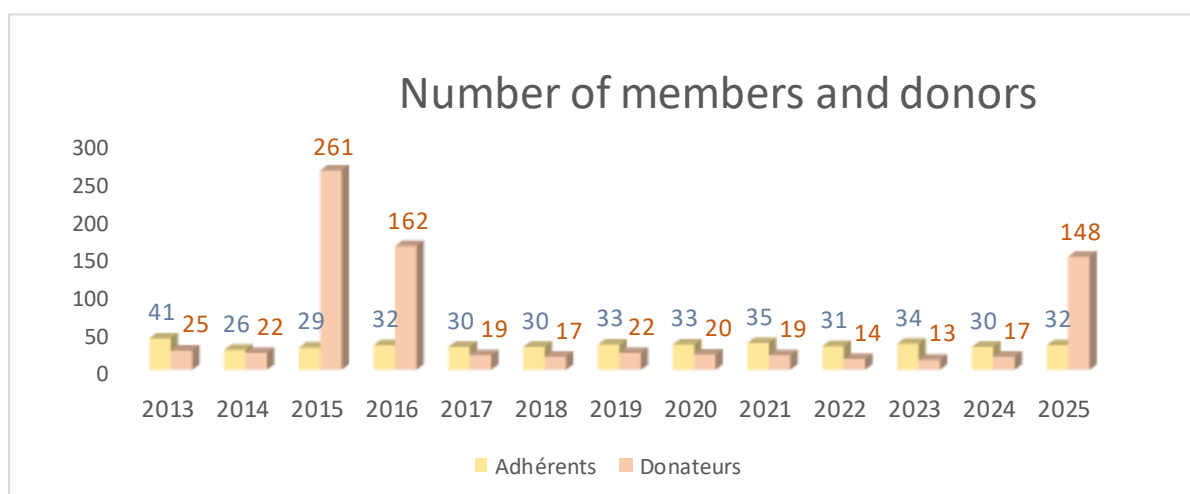
8th December : Le Monde : « The rise of cosmetic surgery accentuates the lack of dermatologists»

3rd February : RMC Life. "Let's talk about" : What has become of Cécile since September 12, 2001? (First time in the TV broadcast) (<https://www.tiktok.com/@rmc.life/video/7602344973836569889>)

28th February : Rare Disease International « Mapping Rare » : CLI is in the spotlight (www.rarediseaseinternational.org/mapping-rare/)

I would like to put this Annual Report for 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 15th Juin 2026 and the attendees' and online votes.

FINANCIAL REPORT 2025



The total number of members and donors at the end of 2025 reached 180. The number of members has remained stable for several years. The significant increase in the number of donors is linked to the

various sporting and other events we have participated in or organised. It is fully in line with the financial result presented below. It goes without saying that it is obvious that the more events we organize, the more donors we will have and the better our financial health will be. This reinforces the absolute necessity of the creation of branches in other countries... the activation of the "CLI-USA Foundation" is progressing slowly..... We finally have a volunteer to take care of financial matters and get the tax number needed to be allowed to fundraise.... There are still steps to be finalized..... If only I could announce in 2026 that this entity is finally working!!

Fortunately, our savings had increased by more than 54% thanks to the fundraising done during the year. This means the expenses of the Cutis Laxa Days were guaranteed to take place in February 2026.

You will find hereunder all the figures from the 2025 balance sheet.

CUTIS LAXA INTERNATIONAL
ATTESTATION
Du 01/01/2025 au 31/12/2025

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 01/01/2025 au 31/12/2025

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 du bilan	46 842,87 C
Total ressources	15 060,87 C
Résultat net comptable	9 763,50 C

Fait à MAURIAC,
Le 28/01/2026.
BEAUDONNET GEORGES,
Expert-comptable.

CUTIS LAXA INTERNATIONAL
COMPTE DE RÉSULTAT

Du 01/01/2025 au 31/12/2025

	Valeur au 31/12/2025	Valeur au 31/12/2024	Variation	
			en valeur	en %
Produits d'exploitation				
Cotisations	5 181,76	3 223,82	1 957,94	60,73
Ventes de biens et services				
Ventes de biens	1 370,00		1 370,00	
<i>dont ventes de dons en nature</i>				
Ventes de prestations de services	13 690,87	4 843,64	8 847,23	182,66
<i>dont parrainages</i>				
Produits de tiers financeurs				
Concours publics et subventions d'exploitation	3 100,00	2 800,00	300,00	10,71
Versements des fondateurs ou cons. dotation comptable				
Ressources liées à la générosité du public				
Dons manuels				
Mécénats				
Legs, donations et assurances-vie				
Contributions financières				
Reprises sur amortissements, dépréciations et provisions				
Produits des cessions d'immobilisations incorp. et corp.				
Utilisations des fonds dédiés				
Autres produits				
TOTAL DES PRODUITS D'EXPLOITATION (I)	23 342,63	10 867,46	12 475,17	114,79
Charges d'exploitation				
Achats de marchandises	1 771,57		1 771,57	
Variation de stocks	-1 214,11	18,68	-1 232,79	
Autres achats et charges externes	11 336,98	7 959,92	3 377,06	42,43
Aides financières				
Impôts, taxes et versements assimilés				
Salaires	1 681,00	1 696,00	-15,00	-0,88
Cotisations sociales				
Dotations aux amortissements et aux dépréciations	140,73		140,73	
Dotations aux provisions				
Valeur comptable des immob. incorp. et corp. cédées				
Report des fonds dédiés				
Autres charges				
TOTAL DES CHARGES D'EXPLOITATION (II)	13 716,17	9 674,60	4 041,57	41,78
1-RÉSULTAT D'EXPLOITATION (I-II)	9 626,46	1 192,86	8 433,60	707,01

CUTIS LAXA INTERNATIONAL
COMPTE DE RÉSULTAT

Du 01/01/2025 au 31/12/2025

	Valeur au 31/12/2025	Valeur au 31/12/2024	Variation	
			en valeur	en %
Produits financiers				
De participation				
D'autres valeurs mobilière et créances actif immobilisé				
Autres intérêts et produits assimilés				
Reprises sur dépréciations et provisions				
Différences positives de change	139,87	102,26	37,61	36,78
Produits de cessions d'immobilisations financières				
Produits nets sur cessions de VMP, d'instruments de trésor.				
TOTAL DES PRODUITS FINANCIERS (III)	139,87	102,26	37,61	36,78
Charges financières				
Dotations aux amortissements, dépréciations et provisions				
Intérêts et charges assimilées	2,83		2,83	
Différences négatives de change				
Valeur comptable des immobilisations financières cédées				
Charges nettes sur cessions de VMP, d'instruments de trésor.				
TOTAL DES CHARGES FINANCIÈRES (IV)	2,83		2,83	
2-RÉSULTAT FINANCIER (III-IV)	137,04	102,26	34,78	34,01
3-RÉSULTAT COURANT avant impôts (I-II+III-IV)	9 763,50	1 295,12	8 468,38	653,87
Produits exceptionnels (V)				
Charges exceptionnelles (VI)				
4-RÉSULTAT EXCEPTIONNEL (V-VI)				
Participation des salariés aux résultats (VII)				
Impôts sur les bénéfices (VIII)				
TOTAL DES PRODUITS (I+III+V)	23 482,50	10 969,72	12 512,78	114,07
TOTAL DES CHARGES (II+IV+VI+VII+VIII)	13 719,00	9 674,60	4 044,40	41,80
EXCÉDENT OU DÉFICIT	9 763,50	1 295,12	8 468,38	653,87
Contributions volontaires en nature				
Dons en nature				
Prestations en nature				
Bénévolat				
TOTAL DES CONTRIB. VOLONTAIRES EN NATURE				
Charges des contributions volontaires en nature				
Secours en nature				
Mises à disposition gratuite de biens				
Prestations en nature				
Personnel bénévole				
TOTAL CHARGES DES CONTRIB. VOLONTAIRES EN NAT.				
TOTAL	9 763,50	1 295,12	8 468,38	653,87

CUTIS LAXA INTERNATIONAL
BILAN ACTIF DÉTAILLÉ

Du 01/01/2025 au 31/12/2025

	Valeur nette au 31/12/2025	Valeur nette au 31/12/2024	Variation	
			en valeur	en %
Immobilisations corporelles				
Installations techniques, matériel et outillages industriels				
21540000 MAT ET OUT INDUSTRIE	103,70	103,70		
28154000 AMORT MAT OUT INDUST	-103,70	-103,70		
Autres immobilisations corporelles	288,61		288,61	
21830000 MATERIEL BUREAU	429,34	691,48	-262,14	-37,91
21840000 MOBILIER	188,72	188,72		
28183000 AMORT MAT BUREAU	-140,73	-691,48	550,75	79,65
28184000 AMORTISS MOBILIER	-188,72	-188,72		
TOTAL DE L'ACTIF IMMOBILISÉ (I)	288,61		288,61	
Stocks et en-cours	2 711,91	1 497,80	1 214,11	81,06
37110000 STOCK LIVRE REVENTE	465,62	510,68	-45,06	-8,82
37500000 STOCK OBJETRAMA	2 246,29	987,12	1 259,17	127,56
Créances				
Autres créances	715,00		715,00	
401EURORDI EURORDIS	50,00		50,00	
46270000 OBJET EN VENTE A BERGAME	665,00		665,00	
Charges constatées d'avance	6 930,00	65,04	6 864,96	
48600000 CHARGES CONSTA AVANC		65,04	-65,04	-100,00
48616000 FRAIS MANIFESTATION GAND 2026	6 930,00		6 930,00	
Disponibilités	36 197,35	23 450,83	12 746,52	54,35
51120000 CHEQUES A ENCAISSER	240,00	200,00	40,00	20,00
51211000 CRCA SAVOIE	777,46	162,55	614,91	378,29
51216000 CRCA CSL SAVOIE	35 139,87	23 052,26	12 087,61	52,44
53000000 CAISSE	38,17	34,17	4,00	11,71
53100000 CAISSE	1,85	1,85		
TOTAL DE L'ACTIF CIRCULANT (II)	46 554,26	25 013,67	21 540,59	86,12
TOTAL GÉNÉRAL DE L'ACTIF (I + II + III + IV + V)	46 842,87	25 013,67	21 829,20	87,27

I would like to put this Financial Report for 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 15th June 2026 and the attendees' vote.

SETTING THE MEMBERSHIP FEE FOR 2027

As we established, I propose that we agree the membership fee for next year that is for 2027. I propose that is maintained to € 30 for the year 2027.

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 15th Juin 2026 and the attendees' and online votes.

PROJECTS AND DRAFT BUDGET FOR 2026

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 2026 to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 15th Juin 2026 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 1 votes (2 people present on line voted online via Balotilo)

Voted online via Balotilo:

16 people, anonymous, with an individual connection link sent, no duplicates possible
That is 16 votes

Voted by mail or email :

Mr Romain Debret, Mr Antonio Da Silva, Mrs Martine Richemont, Mr Serge Richemont, Mrs Maria Keakoy
That is 5 votes

Apologies with proxy granted to Mrs Marie-Claude Boiteux :

Mrs Sophie Khalilpour, Mrs Véronique Fustier and Mr Pierre Ancelin

Apologies with proxy granted to Mrs Cécile Boiteux:

Mrs Marie-Hélène Boucand

This totals 4 votes by proxy.

In 2025, there were 32 members. The total number of votes from members being present, voting without being present or represented by proxy is 28 (2+1+16+5+4). Therefore, the meeting is quorate to vote on the agenda items (at least 1/3 of the members).

ANNUAL REPORT 2025

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

Abstentions : 3 No: 0 Yes : 25

The Annual Report 2024 was approved by a majority.

FINANCIAL REPORT 2025

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

Abstentions : 3 No: 0 Yes : 25

The Financial Report was approved by a majority.

FIXING THE 2026 MEMBERSHIP FEES and VOTE

It had been previously proposed to fix the membership fee for 2027 at € 30. Counting votes and proxies gives the following results:

Abstentions : 3 No : 0 Yes : 28

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

PROJECTS 2026

The Projects for 2026 had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 3 No: 0 Yes : 25

The Projects for 2026 were approved by a majority

DRAFT BUDGET 2026

The Draft Budget for 2026 had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 4 No: 0 Yes : 24

The Draft Budget for 2026 was approved by a majority

As all votes and proxies had been counted and no other question had been asked, the Chair closed the meeting at 8:30 pm.

The Chair
Marie-Claude Boiteux



The Secretary for the meeting
Michel Senaud

