CUTIS LAXA INTERNATIONALE
Organisme d' Intérêt Général Loi 1901.

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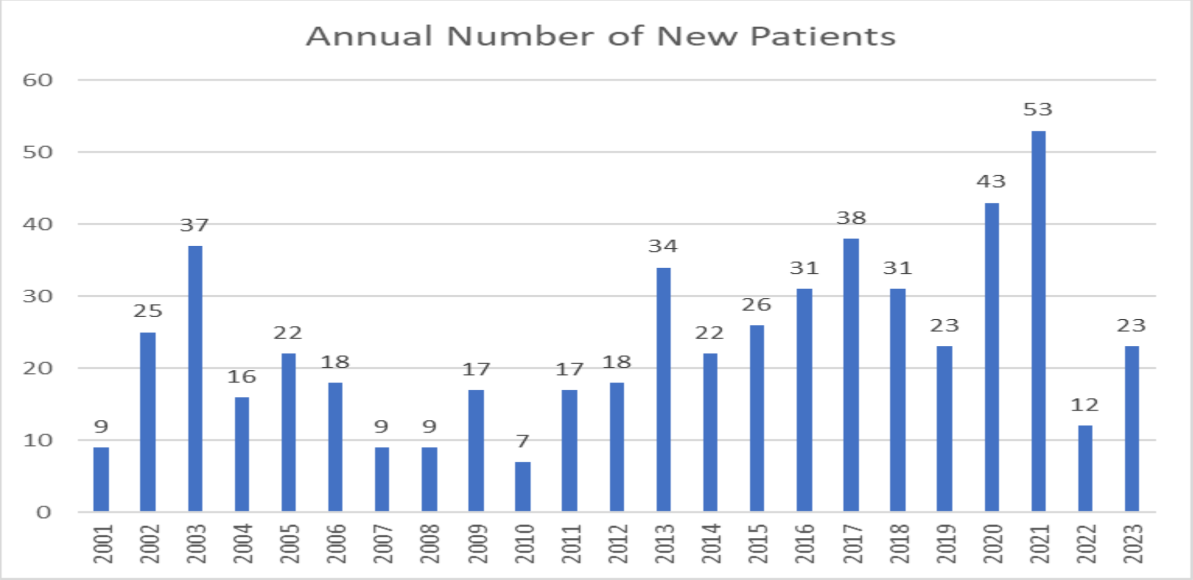
ANNUAL REPORT FOR THE YEAR 2023

SUFFERERS and FAMILIES

Identifying sufferers

On 1st January 2023, we knew of 517 sufferers. By the end of 2023 they were 540. Thus 23 newly diagnosed patients joined us in 2023.The number of patients joining us each year varies a lot and we can never really determine why some years show a higher, or lower, number. Nevertheless, on average, 23 patients have found and joined the CLI family every year for the past 23 years. 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.



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. As new mutations were discovered in 2022, precision prescribing is of the utmost importance for all patients.

THE MEDICAL WORLD

We are always at the researchers' disposal to answer their queries and always do our best to help them implement their projects, either with our sufferers' census or with supporting their calls for grants.

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 2022, 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 professionnals 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.

In 2023, after ERN-Skin was re-approved by the EU, we established our roadmap. Mapping expertise throughout Europe; Patients' mental Health; Palliative Care; Awareness of Dermatology; Burden; Pediatric Specificities; Therapeutic Training Programs. All these topics which are of deep concern to Rare Skin Disorders will be worked out over the coming years (2024-2027) .

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 leaders of organisations concerned by FIMARAD allow us to push forward some national issues. Whether for the reassessment of the Reference Centres, or the improvement of diagnosis, or recognizing the work we do, our small organisations dedicated to rare disorders need this unity, this common work to improve patients' quality of life and limit the risks of us disappearing from the health landscape in France.

On the other hand, the work group "Diagnosis roving and impasse" set up in FIMARAD continues its work to improve the speed of diagnosis for all rare skin disorders. In the continuity of the work done for Cutis Laxa, a new survey has been sent to organisations members of FIMARAD to establish concordance charts of symptoms and identify health professionals (Nurses, Physiotherapist, etc) who could raise the "alert" of possible rare disorders. The analysis of the answers to this survey will continue in 2024 and could be the subject of a scientific publication.

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 2023, FFP and its chair, Marie-Claude Boiteux, carried out two projects that were initiated almost two years ago :
  - ❖ The Skin Disability Guides : The workgroup of patients, health and medico-social professionals as well as the National Benefit Office for Solidarity and Autonomy (CNSA) decided to write and publish two guides. One in for Professionals and the general public to raise awareness and understanding of Skin Disability. The other aims to help patients voice the impacts of their Skin Disability. A form to fill in with the patient's doctor has been added to the two guides to complete any application for social care support.

- A Booklet for Children: Thanks to a workgroup and to « Little Citizens », and designed like a comics, the booklet explains what skin disorders are and is destined for children from age 7. It is an educational tool that opens a conversation with children, raises awareness and aims to stop bullying that children suffering from skin disorders are often subject to.

- **Locally :** In 2022, 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

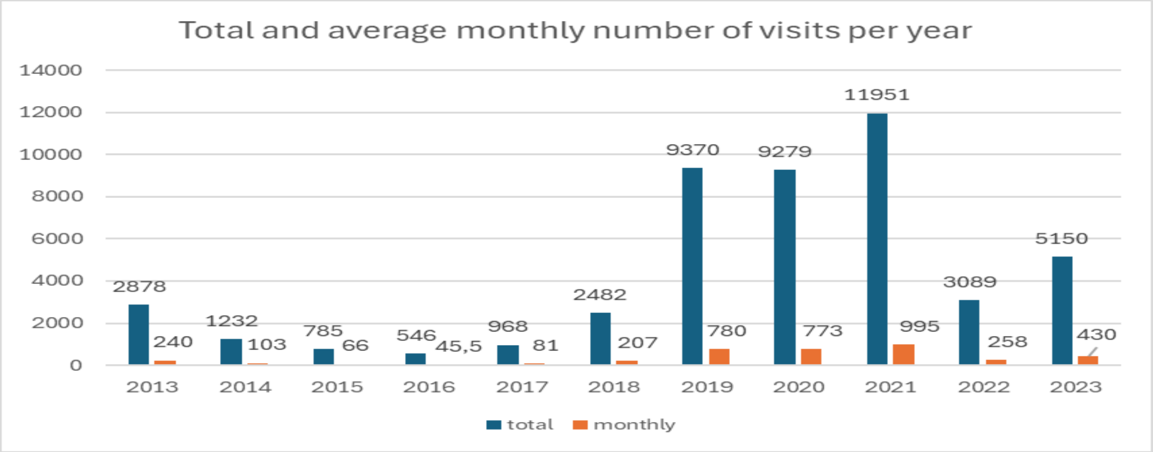
Communicating patients' voice and complying with national and European laws regarding private life and personal data protection is very important. We are especially sensitive to those issues : they are at the heart of our work.

ROUTINE WORKLOAD IN 2023

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 indicated 65,040 visits in early January 2023, and 70,190 by the end of December 2023. An increase of 5,150 visits during 2023 or an average of 430 visits per month. In 2023 our website recovered a good number of visitors. The two annual updates, associated with communicating what information has been updated, are really a high point in visitor numbers and our website being referenced by third parties.



✓ 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: Published at the end of 2020, many people were interested in these patients' testimonies in 2021. We will continue to sell it to the benefit of CLI in the coming years.

✓ « 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 2023, 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).

Wether in France or abroad, these annual meetings are always opportunities to share and work we other patient organisations' representatives. They enable the implementation of common and consistent actions to the benefit of patients.

And also this year, thanks to the Booklet for Children made by the FFP, Marie-Claude Boiteux spoke at the Bons en Chablais college to raise awareness of skin disorders in general and Cutis Laxa in particular.

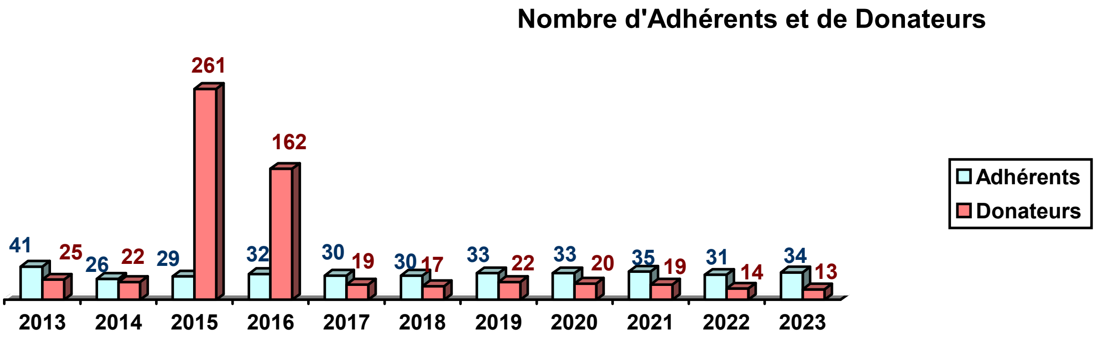
There were many other National, European, International and Organisational events online, so the 2023 diary was very full.

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-lexperience-patient/
June 2023 : ERN-Skin News : ERN-Skin Patient Representatives attended the Conference « Elevate » in Brussels. Two of them were honored with the awards « Champion » and « Innovator ».
Summer 2023 : Rare Revolution Magazine : Interview with Dave Jacob, founder of Thinkgenetic , diagnosed with Cutis Laxa
14th September 2023 : Skin Day : Round table with Marie-Claude Boiteux for the French Society of Dermatology (https://365.sfdermato.org/revivez-la-table-ronde-de-la-journee-mondiale-sante-de-la-peau/?utm_source=brevo&utm_campaign=FLASH%20INFO%20-%20Journe%20mondiale%20Sant%20de%20la%20peau%2014%20Septembre%202023%20-%20070923_copy_copy&utm_medium=email)
5th December 2023 : Roud tables and presentations of the FFP 5th Conference are now online on the YouTube channel at https://www.youtube.com/channel/UCvbExcayClnIRh7Vw99itLg

I would like to put this Annual Report for 2023 to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 20th May 2024 and the attendees' vote.

FINANCIAL REPORT 2023



The number of members and donors has remained stable for the past 10 years. The years 2015 and 2016 were exceptional in regard to the number of donors after taking part in the Solidarity Walks organized by Groupama. The usual average number of members is 32 and for donors it is 19. That is an average total of 51. Thus, with 47 in 2023, it is a bit low.
Our savings remain stable at almost € 21,000, but we must plan for bigger fundraising events to be able to guarantee the expenses of the next Cutis Laxa Days.
You will find hereunder all the figures from the 2023 balance sheet.

ATTESTATION

CUTIS LAXA INTERNATIONAL

Du 01/01/2023 au 31/12/2023

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 01/01/2023 au 31/12/2023

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	**5 519.88 €**
Résultat net comptable	**-41.08 €**
Total du bilan	**23 595.69 €**

Fait à MAURIAC,
Le 21/02/2024.

BEAUDONNET GEORGES,
Expert-comptable.

COMPTE DE RÉSULTAT

CUTIS LAXA INTERNATIONAL

Du 01/01/2023 au 31/12/2023

	Du 01/01/23 au 31/12/23	Du 01/01/22 au 31/12/22	Du 01/01/21 au 31/12/21
PRODUITS D'EXPLOITATION			
Cotisations	2 479.88	3 995.11	2 372.22
Ventes de biens et services			
Ventes de biens	50.00	186.11	100.00
Dont ventes de dons en nature			
Ventes de prestations de service	2 890.00	8 977.69	6 287.96
Dont parrainages			
Produits de tiers financeurs			
Concours publics et subventions d'exploitation	100.00	500.00	200.00
Versements des fondateurs ou cons. dotat. consomptible			
Ressources liées à la générosité du public			
Dons manuels			
Mécénats			
Legs, donations et assurances-vie			
Contributions financières			
Reprises sur amorts, dépr., prov., transf. charges			
Utilisations des fonds dédiés			
Autres produits		240.00	
TOTAL PRODUITS D'EXPLOITATION (I)	**5 519.88**	**13 898.91**	**8 960.18**
CHARGES D'EXPLOITATION			
Achats de marchandises			1 312.20
Variation de stock	92.92	531.84	-2 141.24
Autres achats et charges externes	4 027.64	19 180.30	5 329.41
Aides financières			
Impôts, taxes et versements assimilés			
Salaires et traitements	1 548.00	1 792.00	1 698.00
Charges sociales			
Dotations aux amortissements et aux dépréciations			
Dotations aux provisions			
Reports en fonds dédiés			
Autres charges			
TOTAL CHARGES D'EXPLOITATION (II)	**5 668.56**	**21 504.14**	**6 198.37**
RÉSULTAT D'EXPLOITATION (I - II)	**-148.68**	**-7 605.23**	**2 761.81**
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	107.60	53.83	14.36
Produits nets sur cessions de val. mobilières de placement			
TOTAL DES PRODUITS FINANCIERS (III)	**107.60**	**53.83**	**14.36**
CHARGES FINANCIÈRES			
Dotations aux amortissements, aux dépr. et aux prov.			
Intérêts et charges assimilées		0.09	
Différences négatives de change			
Charges nettes sur cessions de val. mobilières de placement			
TOTAL DES CHARGES FINANCIÈRES (IV)		**0.09**	
RÉSULTAT FINANCIER (III - IV)	**107.60**	**53.74**	**14.36**

COMPTE DE RÉSULTAT

CUTIS LAXA INTERNATIONAL

Du 01/01/2023 au 31/12/2023

	Du 01/01/23 au 31/12/23	Du 01/01/22 au 31/12/22	Du 01/01/21 au 31/12/21
RÉSULTAT COURANT AVANT IMPÔTS (I - II + III - IV)	**-41.08**	**-7 551.49**	**2 776.17**
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 dépr. et aux prov.			
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)	**5 627.48**	**13 952.74**	**8 974.54**
TOTAL DES CHARGES (II + IV + VI + VII + VIII)	**5 668.56**	**21 504.23**	**6 198.37**
EXCÉDENT OU DÉFICIT	**-41.08**	**-7 551.49**	**2 776.17**

I would like to put this Financial Report for 2023 to the vote. Feel free to ask questions, if any, before we count the votes, totalling the ballot papers and proxies sent before the 20th May 2024 and the attendees' vote.

SETTING THE MEMBERSHIP FEE FOR 2025

As we established, I propose that we agree the membership fee for next year that is for 2025. I propose that is maintained to € 30 for the year 2025.

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 20th May 2024 and the attendees' vote.

PROJECTS AND DRAFT BUDGET FOR 2024

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 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 20th May 2024 and the attendees' vote.

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MINUTES OF THE ANNUAL GENERAL MEETING TUESDAY 04th JUNE 2024

Mrs Marie-Claude BOITEUX, Chair, opened the debate at 2:00 pm. As notified by post to the members, the agenda is:

- **ANNUAL REPORT 2023 and VOTE**
- **FINANCIAL REPORT 2023 and VOTE**
- **ELECTIONS TO THE BOARD OF DIRECTORS**
- **FIXING THE 2025 MEMBERSHIP FEES**
- **PROJECTS and DRAFT BUDGET 2024 and VOTE**
- **GENERAL ISSUES**

Present :

Mrs M.C. Boiteux, Mr M. Senaud (appointed Secretary of the Meeting)

That is 2 votes

Voted by mail or email :

Mrs Hélène Boiteux, Mrs Valérie Decoux, Mrs Nathalie Fournier, Mrs Marion Lassalle, Mrs Martine Richemont, Mrs Mireille Tessier, Mr Pierre Ancelin, Mr Chris Boisseaux, Mr Serge Richemont, Mr Romain Rousseau.

That is 10 votes

Apologies with proxy granted to Mrs Marie-Claude Boiteux :
Mrs Cécile Boiteux-Gueye, Mrs Véronique Fustier, Mr Antonio Da Silva and Mr Jean Garidou

Apologies with proxy granted to Mr Michel Senaud:
Mrs Sophie Khalilpour.

This totals 5 votes by proxy.

In 2023, there were 34 members. The total number of votes from members being present, voting without being present or represented by proxy is 17 (2+10+5). Therefore, the meeting is quorate to vote on the agenda items (at least 1/3 of the members).

ANNUAL REPORT

The 2023 Annual Report had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0 No: 0 Yes : 17

The Annual Report was unanimously approved.

FINANCIAL REPORT

The 2023 Financial Report had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0 No: 0 Yes :17

The Financial Report was unanimously approved.

ELECTIONS TO THE BOARD OF DIRECTORS

Counting votes and proxies gives the following results:

BEAUDONNET Georges, outgoing Treasurer
Abstentions : 0 No : 0 Yes : 17

Mr Georges Beaudonnet was unanimously elected to the Board of Directors.

FIXING THE 2025 MEMBERSHIP FEES and VOTE

It had been previously proposed to fix the membership fee for 2025 at € 30. Counting votes and proxies gives the following results:

Abstentions : 0 No : 0 Yes : 17

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

PROJECTS 2024

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

Abstentions : 0 No: 0 Yes : 17

The Projects for 2024 were unanimously fixed

DRAFT BUDGET 2024

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

Abstentions : 0 No: 0 Yes : 17

The Draft Budget for 2024 was unanimously fixed

As all votes and proxies had been counted and no other question had been asked, the Chair closed the meeting at 3:00 pm.

The Chair
Marie-Claude Boiteux

The Secretary for the meeting
Michel Senaud