



CUTIS LAXA INTERNATIONALE

Organisme d'Intérêt Général Loi 1901.



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RARE
DISEASES
INTERNATIONAL

ThinkGenetic
Advocacy Partner



NORD
National Organization for Rare Disorders
Member Organization



Fédération
Française
de la Peau



Alliance
maladies rares



European
Reference
Networks

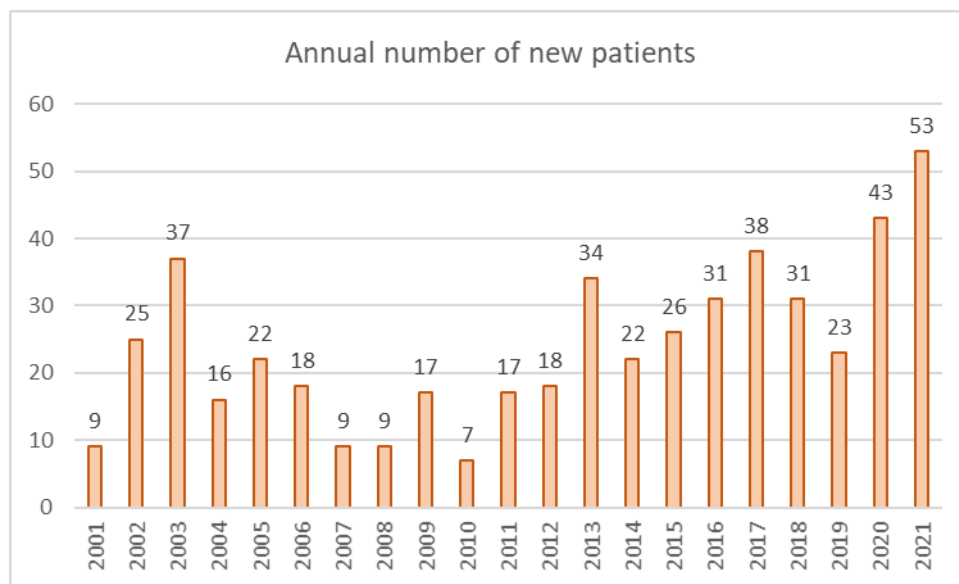


ANNUAL REPORT FOR THE YEAR 2021

SUFFERERS and FAMILIES

Identifying sufferers

On 1st January 2021, we knew of 452 sufferers. At the end of the year this number had grown by 53 new patients and families to 505. The development of social networks and access to the internet are without a doubt the main reasons for this high growth



Whatever those new patients' native country, whatever the continent they come from, thanks to our website and especially to our Facebook private group dedicated to them, we enable new and old members of CLI to contact each other, share their lives, get support and advice. We have reached our first aim : Breaking sufferers' loneliness.

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, almost 40% 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 not all in the same country 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 2021, 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 is the central pillar of our activities with the European medical world. The Covid-19 pandemic allowed to become used to working online in virtual workgroups. It is, if I can say so, one of the benefits of the pandemic. It then became possible throughout 2021 to take part in workgroups and webinars held worldwide. We would not have been able to attend if they had been face-to-face events.

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

EPAG's work is done in parallel with ERN's.

In 2021, we ensured that Cutis Laxa Internationale remained highly visible within the European institutions. A close collaboration with Pr Bert Callewaert's team, spreading the two Cutis Laxa "Patient Journeys", taking part in the transdisciplinary workgroup "Pregnancy and Family Planning for Rare Disorders", representing patients in ERN-Skin Executive Committee, all these actions have the sole goal of improving follow up and healthcare for people suffering from a rare dermatologic disorder, and especially Cutis Laxa..

FIMARAD



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

Exchanging and collaborating with leaders from organisations concerned by FIMARAD allows for transdisciplinary work. We face common issues. For instance, we are all concerned by the lack of recognition of the work done, voluntarily, by associations' leaders. Our joint reflexion and diverse personal skills enabled us to write an article calling on the French government to remedy this problem which can harm Democracy in Healthcare. Small associations dedicated to rare disorders might disappear from the Health Landscape in France.

On the other hand, the workgroups set up in FIMARAD are beginning to be productive. Thus, the group "Diagnosis roving and impasse" developed a chart on the overlapping of symptoms that could, in future, be of help for a quicker diagnosis of Cutis Laxa and its different types..

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 :** Besides being members of national umbrella organisations (Solhand, Alliance Rare Disorders, etc), the renewed activity of the French Skin Federation (FFP), of which we are a representative member for "Rare Disorders" on its elected Board, is enlarging our national work. In 2021, the FFP grew enormously, thanks to its Executive Director's hard work. The recognition of the place of the FFP as partner with French health institutions was highlighted by the French Health

Minister when he opened its 3rd Conference in November. A lot of work is required for dermatology to be taken into account by health institutions. At the end of the Annual Meeting, in December, Marie-Claude Boiteux was elected Chair of the FFP. This new leadership allows us to work on projects that CLI could not lead alone..

- ✚ **Locally** : In 2021, Cutis Laxa Internationale got more involved in local projects, such as Pink October and the Christmas Market organized by the Bons en Chablais local council. 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.

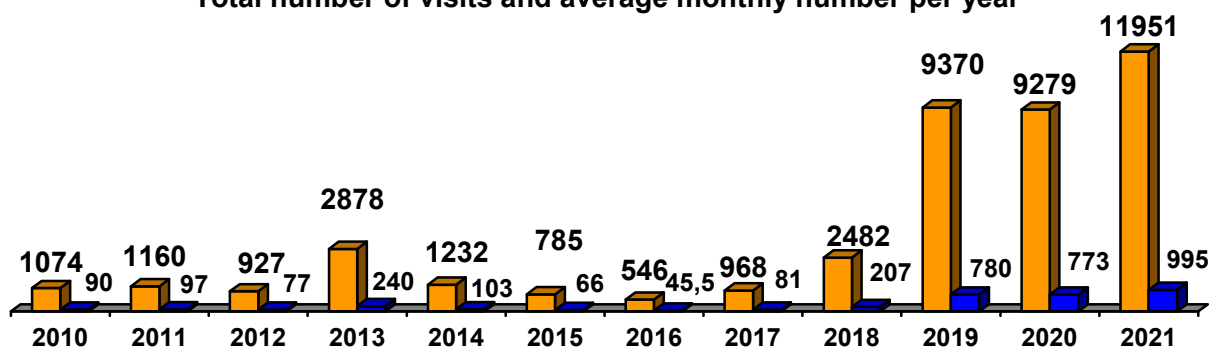
ROUTINE WORKLOAD IN 2021

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 50,000 visits in early January 2021, and 61,951 by the end of December 2021. An increase of 11,951 visits during 2021 or an average of 995 visits per month.

Total number of visits and average monthly number per year



Since we completely updated and reorganized our website, its visibility is continuously increasing. We remain in high on the list of Google search returns thanks to our regular updates. We can compare the evolution of the website with the evolution of the number of patients who contact us each year. The increase in numbers is similar and confirms that our website is an important vehicle that allows patients to know about us and not remain alone facing the disorder. This is a great way to reach our aims..

✓ 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.

Projects in the pipeline

✓ Photos exhibition and/or book : Unfortunately postponed for two years due to the Covid-19 pandemic, we hope this project will be achieved in 2022.

Celebrations and events

Once again the pandemic disturbed all the events we had scheduled in 2021. Nevertheless we took part in two face-to-face events : Pink October and Christmas Market. All the others were held online.

The Media

On 16th March, Chiara's testimony (in French and in Italian) was posted on Facebook :
<https://www.facebook.com/photo?fbid=3509557279156318&set=pcb.3509561645822548>

On 7th April, « Le Tribunal du net » edited an interview with Cécile (in French). Watch it again on our website
<https://www.cutislaxa.org/fr/quoi-de-neuf/> (videos) or on the “Tribunal du Net” page
<https://www.facebook.com/letribunaldunet/videos/1782251148618795>

In April and May, every week, Ewenlife published one of the 8 videos about Cutis Laxa. From diagnosis to medico-social care and treatments, all issues are tackled. You can watch them again (in French or with subtitles in your own language) on our website <https://www.cutislaxa.org/fr/quoi-de-neuf/> (videos) or on Youtube :
https://www.youtube.com/watch?v=XPI5X03FOEw&list=PLvUNI3idDQjTKEL_-tfQjZUE9ixRnH_aD

6th October : Le Dauphiné – Bons en Chablais : On the occasion of « Pink October » and in partnership with the local council of Bons en Chablais, Cutis Laxa Internationale held an information stall and sold various items.

11/10/21 Le dauphiné – Bons en Chablais : Pink and Blue Walk The health organisations of the town were associated with the Blue Walk dedicated to elderly people and with Pink October dedicated to Breast Cancer.

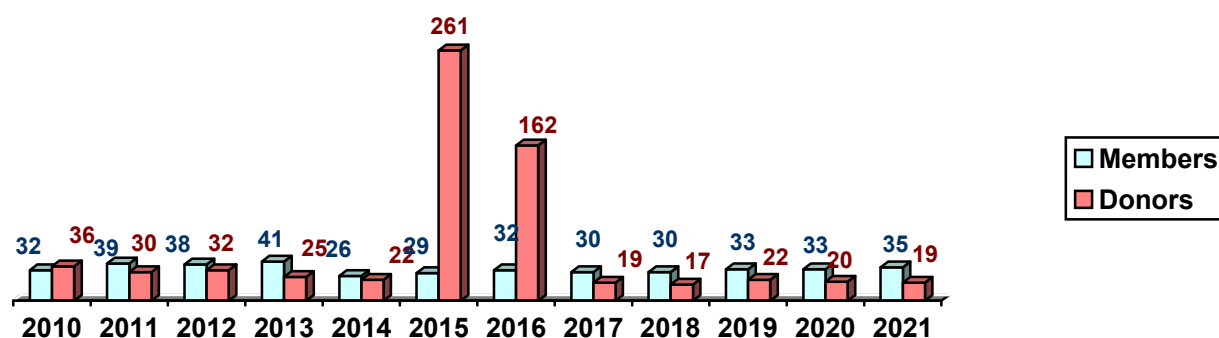
Autumn 2021 : La Gazette Bonsoise : Report of all the events organised on the occasion of « Pink October ».

I would like to put this Annual Report for 2021 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 May 2022 and attendees' vote.

FINANCIAL REPORT 2021

2021 fits in with the average with 35 members and 19 donors. Our finances remain stable and allow us to look peacefully forward to organizing the 6th Cutis Laxa Days held in Belgium in September 2022. Whereas the pandemic prevented us from raising income through fundraising events, it also meant that travel expenses were considerably reduced, thus balancing each other.

Number of Members and Donors



You will find hereunder all necessary and detailed numbers in the 2021 Financial Report.

ATTESTATION

CUTIS LAXA INTERNATIONAL

Du 01/01/2021 au 31/12/2021

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 01/01/2021 au 31/12/2021

et conformément aux termes de notre lettre de mission, nous avons effectué les diligences prévues par la norme professionnelle du Conseil Supérieur 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	8 960.18 C
Résultat net comptable	2 776.17 C
Total du bilan	31 674.92 C

Fait à MAURIAC,
Le 08/03/2022.
BEAUDONNET GEORGES,
Expert-comptable.

Within our responsibility for the presentation of the annual financial report for

Cutis Laxa Internationale
for the year from 01/01/2021 to 31/12/2021,

and in accordance with our mission, we have acted and governed in accordance with the professional ethics of the High Council of Auditors (Conseil Supérieur de l'Ordre des Experts Comptables) applicable to the presentation of accounts which are not audited nor subject to a limited examination.

Based on our accounting and financial controls, no element has arisen to cast doubt on the overall consistency and veracity of these annual accounts.

These annual accounts are published together with this certification, they are formatted according to the summary at the top of this document. They can be summarized as follows:

COMPTE DE RÉSULTAT

CUTIS LAXA INTERNATIONAL

Du 01/01/2021 au 31/12/2021

	Du 01/01/21 au 31/12/21	Du 01/01/20 au 31/12/20	Variation N / N-1	
			en valeur	en %
PRODUITS D'EXPLOITATION				
Cotisations	2 372.22	1 687.57	684.65	40.57
Ventes de biens et services				
Ventes de biens	100.00		100.00	
<i>Dont ventes de dons en nature</i>				
Ventes de prestations de service	6 287.96	11 123.15	-4 835.19	-43.47
<i>Dont parrainages</i>				
Produits de tiers financeurs				
Concours publics et subventions d'exploitation	200.00	200.00		
Versements des fondateurs ou cons. dotation consommable				
Ressources liées à la générosité du public				
Dons manuels				
Mécénats				
Legs, donations et assurances-vie				
Contributions financières				
Reprises sur amort., dépr., prov. et transf. charges				
Utilisations des fonds dédiés				
Autres produits				
TOTAL PRODUITS D'EXPLOITATION (I)	8 960.18	13 010.72	-4 050.54	-31.13
CHARGES D'EXPLOITATION				
Achats de marchandises	1 312.20	957.52	354.68	37.04
Variation de stock	-2 141.24	369.00	-2 510.24	-680.28
Autres achats et charges externes	5 329.41	3 945.53	1 383.88	35.07
Aides financières				
Impôts, taxes et versements assimilés				
Salaires et traitements	1 698.00	1 570.00	128.00	8.15
Charges sociales				
Dotations aux amortissements et aux dépréciations				
Dotations aux provisions				
Reports en fonds dédiés				
Autres charges				
TOTAL CHARGES D'EXPLOITATION (II)	6 198.37	6 842.05	-643.68	-9.41
RÉSULTAT D'EXPLOITATION (I - II)	2 761.81	6 168.67	-3 406.86	-55.23
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	14.36	12.20	2.16	17.70
Produits nets sur cessions de VMP				
TOTAL DES PRODUITS FINANCIERS (III)	14.36	12.20	2.16	17.70
CHARGES FINANCIÈRES				
Dotations aux amortissements, aux dépréc. et aux prov.				
Intérêts et charges assimilées				
Différences négatives de change				
Charges nettes sur cessions de VMP				
TOTAL DES CHARGES FINANCIÈRES (IV)				
RÉSULTAT FINANCIER (III - IV)	14.36	12.20	2.16	17.70
RÉSULTAT COURANT AVANT IMPÔTS (I - II + III - IV)	2 776.17	6 180.87	-3 404.70	-55.08

COMPTE DE RÉSULTAT

CUTIS LAXA INTERNATIONAL

Du 01/01/2021 au 31/12/2021

	Du 01/01/21 au 31/12/21	Du 01/01/20 au 31/12/20	Variation N / N-1	
			en valeur	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 dépréc. 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)	8 974.54	13 022.92	-4 048.38	-31.09
TOTAL DES CHARGES (II + IV + VI + VII + VIII)	6 198.37	6 842.05	-643.68	-9.41
EXCÉDENT OU DÉFICIT	2 776.17	6 180.87	-3 404.70	-55.08

COMPTE DE RÉSULTAT

CUTIS LAXA INTERNATIONAL

Du 01/01/2021 au 31/12/2021

	Du 01/01/21 au 31/12/21	Du 01/01/20 au 31/12/20	Du 01/01/19 au 31/12/19
PRODUITS D'EXPLOITATION			
Cotisations	2 372.22	1 687.57	3 145.85
Ventes de biens et services			
Ventes de biens	100.00		122.00
<i>Dont ventes de dons en nature</i>			122.00
Ventes de prestations de service	6 287.96	11 123.15	9 394.72
<i>Dont parrainages</i>			
Produits de tiers financeurs			
Concours publics et subventions d'exploitation	200.00	200.00	
Versements des fondateurs ou cons. dotat. consommable			
Ressources liées à la générosité du public			
Dons manuels			
Mécénats			
Legs, donations et assurances-vie			
Contributions financières			
Reprises sur amortis, dépr., prov., transf. charges			
Utilisations des fonds dédiés			
Autres produits			
TOTAL PRODUITS D'EXPLOITATION (I)	8 960.18	13 010.72	12 662.57
CHARGES D'EXPLOITATION			
Achats de marchandises	1 312.20	957.52	
Variation de stock	-2 141.24	369.00	21.00
Autres achats et charges externes	5 329.41	3 945.53	5 209.42
Aides financières			
Impôts, taxes et versements assimilés			
Salaires et traitements	1 698.00	1 570.00	1 180.00
Charges sociales			
Dotations aux amortissements et aux dépréciations			
Dotations aux provisions			
Reports en fonds dédiés			
Autres charges			
TOTAL CHARGES D'EXPLOITATION (II)	6 198.37	6 842.05	6 410.42
RÉSULTAT D'EXPLOITATION (I - II)	2 761.81	6 168.67	6 252.15
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	14.36	12.20	18.66
Produits nets sur cessions de val. mobilières de placement			
TOTAL DES PRODUITS FINANCIERS (III)	14.36	12.20	18.66
CHARGES FINANCIÈRES			
Dotations aux amortissements, aux dépr. et aux prov.			
Intérêts et charges assimilées			11.94
Différences négatives de change			
Charges nettes sur cessions de val. mobilières de placement			
TOTAL DES CHARGES FINANCIÈRES (IV)			11.94
RÉSULTAT FINANCIER (III - IV)	14.36	12.20	6.72

COMPTE DE RÉSULTAT

CUTIS LAXA INTERNATIONAL

Du 01/01/2021 au 31/12/2021

	Du 01/01/21 au 31/12/21	Du 01/01/20 au 31/12/20	Du 01/01/19 au 31/12/19
RÉSULTAT COURANT AVANT IMPÔTS (I - II + III - IV)	2 776.17	6 180.87	6 258.87
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)	8 974.54	13 022.92	12 681.23
TOTAL DES CHARGES (II + IV + VI + VII + VIII)	6 198.37	6 842.05	6 422.36
EXCÉDENT OU DÉFICIT	2 776.17	6 180.87	6 258.87

I would like to put this Financial Report for 2021 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 May 2022 and the attendees' vote.

SETTING THE MEMBERSHIP FEE FOR 2023

As we established, I propose that we agree the membership fee for next year that is for 2023. I propose that is maintained to € 30 for the year 2023.

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 May 2022 and the attendees' vote.

PROJECTS AND DRAFT BUDGET FOR 2022

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 2022 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 May 2022 and the attendees' vote.

138 impasse de Champs Gervais
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CUTIS LAXA INTERNATIONALE
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MINUTES OF THE ANNUAL GENERAL MEETING TUESDAY 3rd JUNE 2022

Mrs Marie-Claude BOITEUX, Chair, opened the debate at 10:00 am. As notified by post to the members, the agenda is:

- **ANNUAL REPORT 2021 and VOTE**
- **FINANCIAL REPORT 2021 and VOTE**
- **FIXING THE 2023 MEMBERSHIP FEES**
- **PROJECTS and DRAFT BUDGET 2023 and VOTE**
- **GENERAL ISSUES**

Physically Present :

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

That is 2 votes

Voted by mail or email :

Mrs Cécile Boiteux, Mrs Hélène Boiteux, Mrs Marion Lassalle, Mme Martine Richemont, Mr Serge Richemont, Mr Romain Rousseau, Mrs Anne-Marie Tessier, Mrs Mireille Tessier

That is 8 votes

Apologies with proxy granted to the Chair , Mrs Marie-Claude Boiteux :

Mr Chris Boisseaux, Mrs Marie-Hélène Boucand, Mr Antonio Da Silva, Mrs Valérie Decoux, Mrs Nathalie Fournier, Mrs Véronique Fustier.

This totals 6 votes by proxy.

In 2021, there were 35 members. The total number of members present or represented by proxy is 16. Therefore, the meeting is quorate to vote on the agenda items (at least 1/3 of the members).

ANNUAL REPORT

The 2021 Annual Report had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0 No: 0 Yes : 16

The Annual Report was unanimously approved.

FINANCIAL REPORT

The 2021 Financial Report had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0 No: 0 Yes : 16

The Financial Report was unanimously approved.

FIXING THE 2023 MEMBERSHIP FEES and VOTE

It had been previously proposed to fix the membership fee for 2023 at € 30. Counting votes and proxies gives the following results:

Abstentions : 0 No : 0 Yes : 16

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

PROJECTS 2022

The Projects for 2021 had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0 No: 0 Yes : 16

The Projects for 2022 were unanimously fixed

DRAFT BUDGET 2022

The Draft Budget for 2022 had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0 No: 0 Yes : 16

The Draft Budget for 2022 was unanimously fixed

As all votes and proxies had been counted and no other question had been asked, the Chair closed the meeting at 11:00 am.

The Chair
Marie-Claude Boiteux



The Secretary for the meeting
Michel Senaud

