

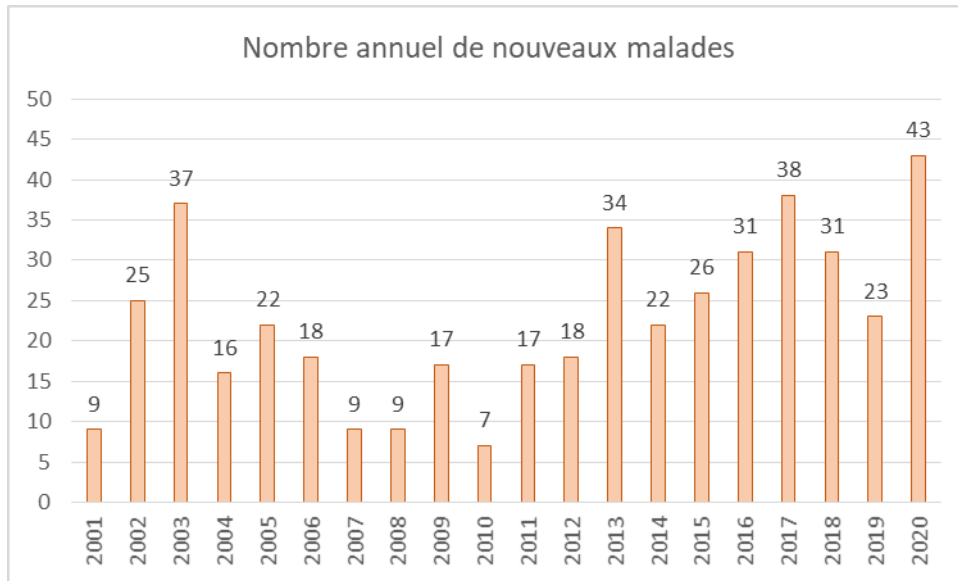


## ANNUAL REPORT FOR THE YEAR 2020

### SUFFERERS and FAMILIES

#### Identifying sufferers

On 1st January 2020, we knew of 409 sufferers. At the end of the year, 452 had joined us, meaning that 43 new patients found us in 2020. It is the highest number since we set up CLI in 2001. It surely is mainly due to the development of social networks and access to the internet.



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 ». This is how we have connected sufferers and clinicians across 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.

## 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 medical world. The Covid-19 pandemic meant that many meetings could not be attended in person. Nevertheless, thanks to online meeting we were able to keep on working. Especially all the work necessary to gather information and testimonies from patients to compile the data needed for ongoing research. This is especially how research on Acquired Cutis Laxa could be started in 2020.

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

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

In 2020 we amplified the work started in 2019. Achieving our two "Patient Journey" allowed a close collaboration with Cutis Laxa experts. Thanks to Dr Bert Callewaert's new clinical classification we established each "Patient Journey" based on the two main groups of Cutis Laxa : Cutis Laxa with Arteries and Lungs symptoms and Cutis Laxa with neurological and skeletal symptoms. These two "journeys" must become a tool that eases confirmation of the diagnosis and allows the patient to project themselves into his future.

This year we also presented the ePAGs' work during ERN-Skin Annual Board meeting and during the annual meeting of the FIMARAD network.

In order to acquire all necessary skills to achieve this patient advocacy task the best possible way, we attended a new training course thanks to Eurordis Open Academy.

Thanks to Marie-Claude Boiteux's commitment in those European organisations, Cutis Laxa Internationale is more and more visible there.

### FIMARAD

The Health Channel for Dermatology Rare Disorders (FIMARAD) can be seen as the French equivalent of ERN-Skin. We were particularly active in it in 2020, especially when representing patients on the Executive Committee. The new workgroups set up at the end of 2020 will lead to a stronger commitment in 2021 as we are now member of the workgroup « Diagnosis roving and impasse».

## OUTREACH WORK

### Relationship with other Support Groups

- ✚ **Internationally** : Our growing in-depth engagement at the European level allows us to have regular and fruitful contact with other dermatologic organization for patients, as our membership in Rare Disease International (RDI) also does.
  
- ✚ **Nationally** : Besides being members of national umbrella organisations (Solhand, Alliance Rare Disorders,..), the French Skin Federation (FFP) gives a new dimension to our national work as a member of its newly elected board to represent "Rare Disorders".  
In 2020, working with the FFP started to be more structured with the recruitment of an Executive Director in November. After the 2<sup>nd</sup> Conference on Skin, held in December, the aims for 2021 and beyond were specified. A lot of work is waiting for us.
  
- ✚ **Locally** : Creating a local network of help and support for Rare Disorders organisations is a very rich experience that boosts resolve and energy. New projects are in the making.

### Visibility

Being known and recognised means being visible by the greatest number. That is why we re-started PR and communication work with the media. This is long-term work that, today, is essential.

## Involvement in Society and Compliance

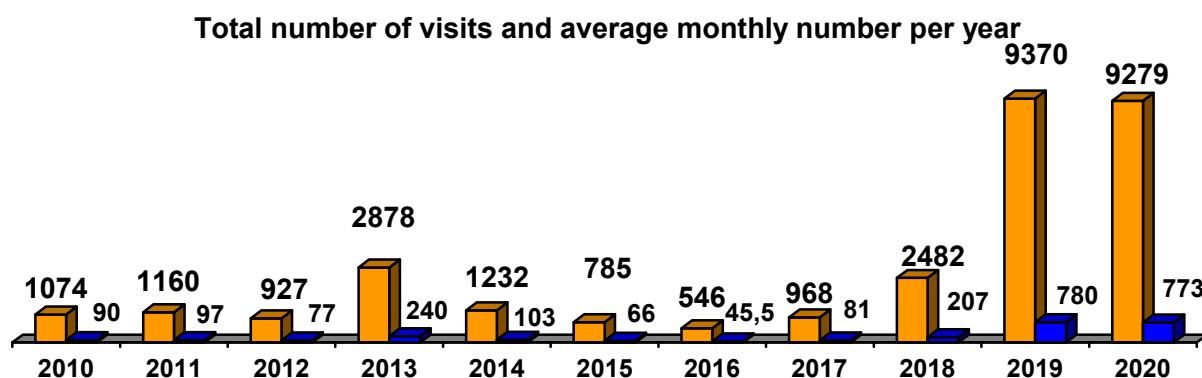
Communicating patients' voice and complying with national and European laws regarding private life and personal data protection is very important. We are especially sensitive to those issues : they are at the heart of our work.

### *ROUTINE WORKLOAD IN 2020*

#### 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 40,721 visits in early January 2020, and 50,00 by the end of December 2020. An increase of 9,279 visits during 2020 or an average of 773 visits per month.



Thus it is the second highest year in terms of visits of the website. It means that our referencing is still optimal and that people seeking information on Cutis Laxa find us more and more easily. Our regular updates and the recent big update with the new design are all paying off.

✓ Leaflets: In 2017, we thoroughly reviewed and updated our General Information Leaflet. In 2019 we added to it, with the same graphics, a Medical Leaflet describing the different types of Cutis Laxa. This year a third leaflet was edited, still with the same graphics. This new leaflet is about the various possible treatments of symptoms.

✓ CLI BOOK: At the end of 2020, to start celebrating CLI's 20th anniversary (11th November 2021), we published the book "Cutis Laxa : Story of a Rare Disorder, Patients' testimonies". Edited in French, English and Spanish, all sales will be to the entire benefit of CLI.

✓ « 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, those projects initiated in late 2019 have all been postponed due to the Covid-19 pandemic.

#### Celebrations and events

2020 was really a special year because of the pandemic. Only one event could be physically held: « Musical'summer » festival in the Park Fantasia in Annemasse (France). All the other meetings, conferences and various events were held online.

#### The Media

Avril 2020 : Rare Revolution Magazine : An article about David Ross «Meet David, a true RARE Revolutionary » and another one about Dawn Laney, Dave Jacob's daughter and co-founder of « Thinkgenetic », « RARE Heroe »

**November 2020** : « Practitioner's Magazine», French monthly magazine for healthcare professionals « Living with.....Cutis Laxa »

**11th November 2020** : Recordings from the FIMARAD annual meeting (in French):

[https://www.youtube.com/watch?v=71EwHwy5g\\_4](https://www.youtube.com/watch?v=71EwHwy5g_4)

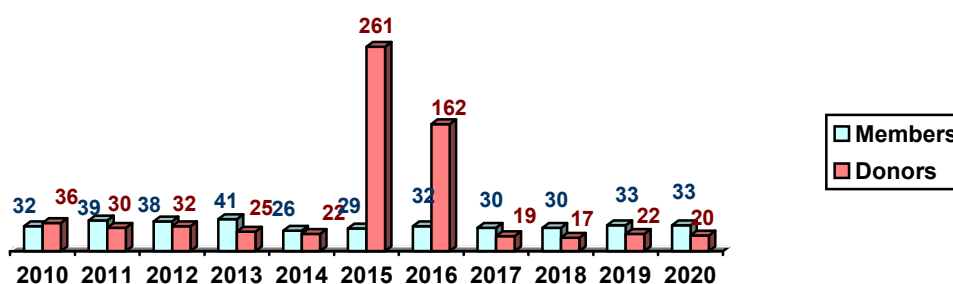
**December 2020** : How we got in contact with Solhand (in French): [https://www.solhand.org/coups\\_de\\_coeur/cecile-un-10eme-cas-a-tout-prix](https://www.solhand.org/coups_de_coeur/cecile-un-10eme-cas-a-tout-prix)

**Due to the exceptional health situation brought about by the Covid-19 crisis and the consequent orders N°2020-321 and 2020-318 published on 25<sup>th</sup> March 2020, extended by order N°2021-255 on 9<sup>th</sup> March 2021, regarding meetings and votes of councils and boards of moral entities registered under the French law that cannot take place until social isolation is lifted, voting on the 2020 Annual Report has either already been cast, digitally or by post, or will be cast on 18<sup>th</sup> Mai by proxy to the Chair.**

## **FINANCIAL REPORT 2020**

2020 fits with the average with 33 members and 20 donors. Unfortunately, the pandemic prevented us from organising and/or taking part in fundraising events. Fortunately two generous donors allowed our balance sheet to show a nice benefit. These donations were added to our savings account and we can start preparing the 6th Cutis Laxa Days for 2022 with a more confident feeling. Nevertheless we need more funds and hope 2021 will be a good year for fundraising.

**Number of Members and Donors**



You will find hereunder all necessary and detailed numbers in the 2020 Financial Report.

CUTIS LAXA INTERNATIONAL  
**COMPTE RENDU DE TRAVAUX**  
Du 01/01/2020 au 31/12/2020

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 01/01/2020 au 31/12/2020

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 du bilan	28 440.14 €
- Chiffre d'affaires	11 123.15 €
- Résultat net comptable	6 180.87 €

Fait à MAURIAC,  
Le 26/02/2021.

BEAUDONNET GEORGES,  
Expert-comptable.

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

*Cutis Laxa Internationale  
for the year from 01/01/2020 to 31/12/2020,*

*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:*



**CUTIS LAXA INTERNATIONAL**  
**Cpte de Résultat Détaillé**

Du 01/01/2020 au 31/12/2020

	Du 01/01/20	Du 01/01/19	Du 01/01/18	Variation N / N-1 (*)	
	Au 31/12/20	Au 31/12/19	Au 31/12/18	en valeur	en %
<b>Produits d'exploitation (1)</b>					
Ventes de marchandises		122.00	671.04	-122.00	-100
70730000 VENTES OBJETS		122.00	671.04	-122.00	-100
Production vendue (biens et services)	11 123.15	9 394.72	3 433.38	1 728.43	18
70610000 MEMBRES ADHERENTS	1 291.00	1 095.00	900.00	196.00	18
70620000 MEMBRES BIENFAITEURS	3 294.88	2 826.60	2 284.39	468.28	17
70650000 DONATEURS	5 097.31	1 410.76		3 686.55	261
70650100 DONATEURS EN NATURE	957.52			957.52	
70651000 DONS COMITE FETE SIREUL		1 200.00		-1 200.00	-100
70660000 DONS OBSEQUES JONNY ANDERSON		434.85		-434.85	-100
70801000 PARTICIPATION FANTASIA	232.44	754.16		-521.72	-69
70810000 PARTICIPATION MANIFESTATION	250.00	1 673.35	140.00	-1 423.35	-85
70850000 PARTICIPATION JOURNEE APHP			108.99		
<b>Montant net du chiffre d'affaires</b>	<b>11 123.15</b>	<b>9 516.72</b>	<b>4 104.42</b>	<b>1 606.43</b>	<b>17</b>
Subventions d'exploitation	200.00		900.00	200.00	
74120000 SUBVENT MAIRIE BONS EN CHABLAIS	200.00			200.00	
74350000 SUBVENTION CNE SIREUIL			900.00		
Autres produits	1 687.57	3 145.85	2 562.82	-1 458.28	-46
75615000 DONS ENVIRONNEMENT	78.95			78.95	
75640000 BENEVOLAT TEMPS	1 570.00	1 180.00	1 516.00	390.00	33
75641000 BENEVOLAT DEPLACEMENT	38.62	1 965.85	1 046.82	-1 927.23	-98
<b>TOTAL DES PRODUITS D'EXPLOITATION (1)</b>	<b>13 010.72</b>	<b>12 662.57</b>	<b>7 567.24</b>	<b>348.15</b>	<b>3</b>
<b>Charges d'exploitation (2)</b>					
Achats de marchandises	957.52		645.33	957.52	
60710000 AC MARCHANDISE 5.5%			400.00		
60730000 ACHATS SOIREE FANTASIA			245.33		
60740000 ACHAT LIVRE CLI HISTOIRE	957.52			957.52	
Variation de stocks	369.00	21.00	-390.00	348.00	
60371100 VARIATION STOCK OBJET REVENET	369.00	21.00	-390.00	348.00	
Autres achats et charges externes	3 945.53	5 209.42	6 343.98	-1 263.89	-24
60631000 PETIT MATERIEL	156.80			156.80	
60640000 FOURNITURE DE BUREAU	665.47		1 271.27	665.47	
61540000 ENTRETIEN MATERIEL			110.40		
61550000 ENT MAT INFORMATIQUE	235.20	195.20	210.06	40.00	20
61600000 PRIMES D'ASSURANCES	101.74	158.69	100.36	-56.95	-36
61810000 DOCUMENTATION ET ABONNEMENT		48.00	48.00	-48.00	-100
62310000 PUBLICITE ANNONCES	566.32	797.91	475.92	-231.59	-29
62510000 FRAIS DE DEPLACEMENT			12.00		
62512000 DEPLT CA BOITEUX	38.62	1 965.85	1 046.82	-1 927.23	-98
62516000 FRAIS DEPLACEMENT ASSOCIATION		57.36	559.08	-57.36	-100
62600000 TIMBRES AFFRANCHISSEMENT	1 293.28	1 127.39	1 618.70	165.89	15
62620000 TELEPHONE INTERNET	413.60	397.22	346.27	16.38	4
62700000 FRAIS BANCAIRES	70.00	68.30	102.85	1.70	2
62800000 COTISATION	404.50	393.50	442.25	11.00	3
Salaires et traitements	1 570.00	1 180.00	1 516.00	390.00	33
64140000 BENEVOLAT TEMPS	1 570.00	1 180.00	1 516.00	390.00	33

(\*) La variation est calculée au prorata de la durée d'exercice

**CUTIS LAXA INTERNATIONAL**  
**Cpte de Résultat Détaillé**

Du 01/01/2020 au 31/12/2020

	Du 01/01/20 Au 31/12/20	Du 01/01/19 Au 31/12/19	Du 01/01/18 Au 31/12/18	Variation N / N-1 (*)	
				en valeur	en %
Dotations aux amortissements et dépréciations					
Sur immobilisations : dotations aux amortissements			13.14		
68110000 DOTATIONS AMORTISSEMENTS			13.14		
<b>TOTAL DES CHARGES D'EXPLOITATION ( II )</b>	<b>6 842.05</b>	<b>6 410.42</b>	<b>8 128.45</b>	<b>431.63</b>	<b>7</b>
<b>RÉSULTAT D'EXPLOITATION ( I - II )</b>	<b>6 168.67</b>	<b>6 252.15</b>	<b>-561.21</b>	<b>-83.48</b>	<b>-1</b>
Quotes-parts de résultat sur opérations faites en commun					
Produits financiers					
Différences positives de change	12.20	18.66	18.16	-6.46	-35
76600000 INTERET CSL CRCA	12.20	18.66	18.16	-6.46	-35
<b>TOTAL DES PRODUITS FINANCIERS ( V )</b>	<b>12.20</b>	<b>18.66</b>	<b>18.16</b>	<b>-6.46</b>	<b>-35</b>
Charges financières					
Intérêts et charges assimilées (4)		11.94	0.23	-11.94	-100
66150000 INTERET Cpte COURANT		11.94	0.23	-11.94	-100
<b>TOTAL DES CHARGES FINANCIÈRES (VI)</b>		<b>11.94</b>	<b>0.23</b>	<b>-11.94</b>	<b>-100</b>
<b>RÉSULTAT FINANCIER ( V - VI )</b>	<b>12.20</b>	<b>6.72</b>	<b>17.93</b>	<b>5.48</b>	<b>82</b>
<b>RÉSULTAT COURANT avt impôts (I+II+III-IV+V-VI)</b>	<b>6 180.87</b>	<b>6 258.87</b>	<b>-543.28</b>	<b>-78.00</b>	<b>-1</b>
Produits exceptionnels					
<b>TOTAL DES PRODUITS EXCEPTIONNELS (VII)</b>					
Charges exceptionnelles					
<b>TOTAL DES CHARGES EXCEPTIONNELLES (VIII)</b>					
<b>RÉSULTAT EXCEPTIONNEL</b>					
<b>TOTAL DES PRODUITS (I+III+V+VII)</b>	<b>13 022.92</b>	<b>12 681.23</b>	<b>7 585.40</b>	<b>341.69</b>	<b>3</b>
<b>TOTAL DES CHARGES (II+IV+VI+VIII+IX+X)</b>	<b>6 842.05</b>	<b>6 422.36</b>	<b>8 128.68</b>	<b>419.69</b>	<b>7</b>
<b>Bénéfice ou Perte</b>	<b>6 180.87</b>	<b>6 258.87</b>	<b>-543.28</b>	<b>-78.00</b>	<b>-1</b>

(\*) La variation est calculée au prorata de la durée d'exercice

ISACOMPTA CONNECT - BICCDRD - Fiscal - 26/02/2021

11

Mission de présentation des comptes annuels - Voir l'attestation du professionnel de l'expertise comptable

**Due to the exceptional health situation and due to Orders N°2020-321 and 2020-318 of 25<sup>th</sup> March 2020, extended with order N°2021-255 of 9<sup>th</sup> March 2021, about meetings and votes of councils and boards of moral entities registered under French law that cannot take place as usual due to the**

covid-19 pandemics, individual votes on the 2020 Financial Report have either already been received via electronic or postal mail, or will be cast on 18<sup>th</sup> May by proxy to the Chair.

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### ELECTIONS TO THE BOARD OF DIRECTORS

Mr Georges Beaudonnet's mandate expires this year. Thus it has to be renewed.

**Due to the exceptional health situation brought about by the Covid-19 crisis and the consequent orders N°2020-321 and 2020-318 published on 25<sup>th</sup> March 2020, extended by order N°2021-255 on 9<sup>th</sup> March 2021, regarding meetings and votes of councils and boards of moral entities registered under the French law that cannot take place until social isolation is lifted, voting on the Elections to the Board of Directors has either already been cast, digitally or by post, or will be cast on 18<sup>th</sup> Mai by proxy to the Chair.**

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### SETTING THE MEMBERSHIP FEE FOR 2022

As we established, I propose that we agree the membership fee for next year that is for 2022. I propose that is maintained to € 30 for the year 2022.

**Due to the exceptional health situation brought about by the Covid-19 crisis and the consequent orders N°2020-321 and 2020-318 published on 25<sup>th</sup> March 2020, extended by order N°2021-255 on 9<sup>th</sup> March 2021, regarding meetings and votes of councils and boards of moral entities registered under the French law that cannot take place until social isolation is lifted, voting on the membership fee for 2022 has either already been cast, digitally or by post, or will be cast on 18<sup>th</sup> Mai by proxy to the Chair.**

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### PROJECTS AND DRAFT BUDGET FOR 2021

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 ».

**Due to the exceptional health situation brought about by the Covid-19 crisis and the consequent orders N°2020-321 and 2020-318 published on 25<sup>th</sup> March 2020, extended by order N°2021-255 on 9<sup>th</sup> March 2021, regarding meetings and votes of councils and boards of moral entities registered under the French law that cannot take place until social isolation is lifted, votings on the 2021 Projects and Draft Budget have either already been cast, digitally or by post, or will be cast on 18<sup>th</sup> Mai by proxy to the Chair.**

138 impasse de Champs Gervais  
74890 Bons en Chablais  
France



CUTIS LAXA INTERNATIONALE  
Organisme d'Intérêt Général Loi 1901.



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## **MINUTES OF THE ANNUAL GENERAL MEETING TUESDAY 18<sup>th</sup> MAY 2021**

Mrs Marie-Claude BOITEUX, Chair, opened the debate at 16:00 pm. As notified by post to the members, the agenda is:

- ANNUAL REPORT 2020 and VOTE
- FINANCIAL REPORT 2020 and VOTE
- ELECTIONS TO THE BOARD OF DIRECTORS

- **FIXING THE 2022 MEMBERSHIP FEES and VOTE**
- **PROJECTS and DRAFT BUDGET 2021**
- **GENERAL ISSUES**

**Reminder :** Due to the exceptional sanitary situation, this general meeting was held behind closed doors. Mr Michel Senaud was appointed secretary for the meeting due to the exceptional circumstances.

**Physically Present :**

Mrs M.C. Boiteux, Mr M. Senaud,

That is 2 votes

**Voted by mail or email :**

Mr Chris Boisseaux, Mrs Hélène Boiteux, Mr Jean-Claude Boutron, Mr Michel Carbonnier, Mrs Nathalie Fournier, Mrs Nicole Héger, Mr Richard Héger, Mrs Marion Lassalle, Mr Romain Rousseau, Mrs Anne-Marie Tessier, Mrs Mireille Tessier, Mrs Martine Thomasson, Mrs Trudy Tottey-Carroll.

That is 13 votes

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

Mrs Marie-Thérèse Bourgeois, Mrs Marie-Hélène Boucand, Mr Antonio Da Silva, Mrs Véronique Fustier, Mrs Sophie Khalilpour, Mrs Tifenn Hervoir, Mrs Martine Richemont, Mr Serge Richemont

This totals 8 votes by proxy.

In 2020, there were 33 members. The total number of members present or represented by proxy is 23. Therefore, the meeting is quorate to vote on the agenda items (at least 1/3 of the members).

**ANNUAL REPORT**

The 2020 Annual Report had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0    No: 0    Yes : 23

The Annual Report was unanimously approved.

**FINANCIAL REPORT**

The 2020 Financial Report had been previously sent to all members to read. Counting votes and proxies gives the following results:

Abstentions : 0    No: 0    Yes : 23

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 : 23



The above persons were unanimously elected to the Board of Directors.

### **FIXING THE 2022 MEMBERSHIP FEES and VOTE**

It had been previously proposed to fix the membership fee for 2022 at € 30. Counting votes and proxies gives the following results:

Abstentions : 0    No : 0    Yes : 23

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

### **PROJECTS 2021**

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 : 23

The Projects for 2021 were unanimously fixed

### **DRAFT BUDGET 2021**

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

Abstentions : 0    No: 0    Yes : 23

The Draft Budget for 2021 was unanimously fixed

As all votes and proxies had been counted and no other question had been asked, the Chair closed the meeting at 17:00 pm.

The Chair  
Marie-Claude Boiteux



The Secretary for the meeting  
Michel Senaud

