



RARE DISEASES INTERNATIONAL

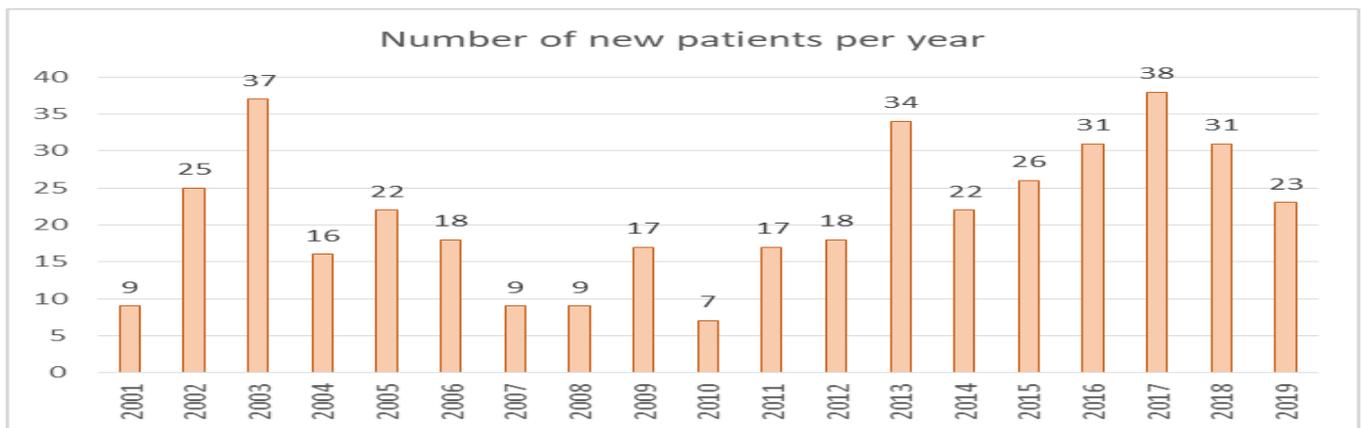


ANNUAL REPORT FOR THE YEAR 2019

SUFFERERS and FAMILIES

Identifying sufferers

On 1st January 2019, we knew of 386 sufferers. At the end of the year, 409 had joined us, meaning that 23 new patients found us in 2019.



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 had 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 was 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. These year's attendance at many meetings enabled us to take stock of the findings from doctors and researchers, especially the new clinical classification of Cutis Laxa now a major element in the improvement of the diagnosis and care for patients. This is the first concrete result of the work on Cutis Laxa in our ERN.

Our collaboration with medical and scientific professionals brings a real added value benefit to patients. As an example, creating the "satisfaction questionnaire for patients after a consultation" essentially relied on patients' representatives' work. In this way evaluating the quality of European Reference Centres will really show patients' expectations and experiences.

E-PAG (European Patient Advocacy Group) : Patient Representative in ERNs

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

In 2019 we got to the heart of the matter after only a year of being set up. Bi-monthly online calls, « homework », face to face meetings, board meetings, our involvement as patient representative really set the pace this year.

Concretely we presented the patients' representation during ERN-Skin Board Meeting. We also took part in a roundtable discussion on the topic "Patients' burden: What do healthcare professionals need to know?" during a training session for young healthcare professionals. Regarding the background work, besides the creation of the Patient's satisfaction questionnaire, we started working on the « Patient Journey » that will allow healthcare professionals to better understand patients' burden and needs.

Moreover, in order to acquire the skills needed to carry out this patient representative's work, we took part in a training session organised by Eurordis.

In addition, Marie-Claude Boiteux, already a patient representative in the sub-thematic group for Cutis Laxa in ERN-Skin (Mendelian Connective Tissue Disorders), accepted in 2019 to become the coordinator of all EPAGs as well as being a patient representative on the Executive Committee of ERN-Skin.

Accepting those responsibilities gives Cutis Laxa Internationale visibility and legitimacy for healthcare professionals, Europe-wide.

FIMARAD

The Health Channel for Dermatology Rare Disorders (FIMARAD) can be seen as the French equivalent of ERN-Skin. This is why we have also taken part in it as much as possible in 2019, even if the lack of fully active volunteers led us sometimes to privilege the work in ERN-Skin because of our international presence.

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 gives a new dimension to our national work as we are members of the newly elected board and represent "Rare Disorders".

- ✚ **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

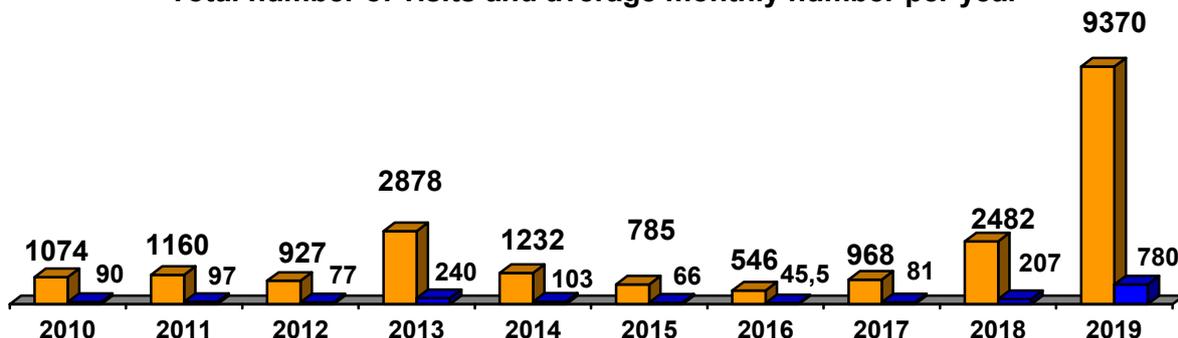
Communicating patients' voice and complying with national and European laws regarding private life and personal data protection is very important. We are especially sensitive to those issues : they are at the heart of our work.

ROUTINE WORKLOAD IN 2019

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 31,351 visitors in January 2019. It showed 40,721 by the end of December 2019, or 9,370 visitors during 2019 and an average of almost 780 visitors per month.

Total number of visits and average monthly number per year



Thus 2019 was the best year since we opened our website in 2002. The second best year is 2003 with 3,110. 2019 has been an exceptional year. Our good place on Google, our regular updates and the recent big update with the new design are all paying off.

- ✓ Leaflets : Our two leaflets are printed at home and on demand. This gives us a great flexibility, no need to find space to hold stocks, and it saves money.
- ✓ Roll-up Posters/Kakemonos : Always present at all the events we take part in, they are a mandatory communication tool.
- ✓ 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 the two new volunteers who now look after the Spanish translations.

Projects in the pipeline

- ✓ Photos exhibition and/or book : late in 2019 we started working with a professional photographer. Nice projects might result from this in 2020/2021.

Celebrations and events

Besides events allowing us to have an information and sales stall, there were international and national important events in 2019.

28th Februray : Rare Disease International Day. “Macarons Show” with local patissiers.

17th March : Once again this year, « Our Little Stars » gathered together the local organisations dedicated to suffering and disabled children.

11th April : The Annual General Meeting of France Assos Santé – Auvergne-Rhône-Alpes in Lyon

15th Juin : The Annual General meeting and Annual Conference of Solhand in Paris.

26th Juillet : Musical’Eté festival in Fantasia Park in Annemasse.

30th August : Second Musical’Eté festival in Fantasia Park in Annemasse.

3 – 4th October : ERN-Skin Board Meeting in Necker Hospital in Paris. Two days of intense work.

26 – 27th November : Last days of the Leadership School organised by Eurordis in Barcelona.

29th November : We received the cheque from the Triathlon of Sireuil

03rd December : First Conference on Skin and Annual Meeting of the French Federation of Skin during the Dermatology Days of Paris.

09th December : We met the Gospel Choir... some projects for 2020...

16th December : ERN-Skin, training session in Ghent (Belgium)

The Media

01st December : Voralberger Nachrichten (Germany) : « Despite a very rare disorder, Mohammed is a real scamp »

02nd February : Video with Cécile announcing the article in the Swiss media « L’illustré »

<https://www.facebook.com/1081337022/posts/10215330750396949/>

02nd Février : « L’illustré », online article : http://www.illustre.ch/magazine/jai-28-ans-peau-65?utm_source=facebook&utm_medium=share&utm_campaign=article&fbclid=IwAR27c8ecTEHOaRzGt12jXDGMitKrjSBgL6zmGnfbfZAHS3VQaEQkRqZ_rzLk

06th February : « L’illustré » (Swiss magazine) : issuing the paper version « I am 28, but my skin is 65 »

26th February : Le Dauphiné Libéré (France) : Announcing the Rare Disease Day

28th February : Le Messager du Faucigny (France) : International Rare Disease Day

28th February : Le Messager Pays du Mont Blanc (France) : International Rare Disease Day

21st March : Le Messager genevois (France) : « Our Little Stars » event

05th May : Caffè.ch, Swiss on line media (Italian Switzerland) « Cécile suffers from a rare disorder » (in italian)

[\(http://www.caffe.ch/stories/Storie/62873_ho_appena_28_anni_ne_dimostro_il_doppio/\)](http://www.caffe.ch/stories/Storie/62873_ho_appena_28_anni_ne_dimostro_il_doppio/)

27th September : « Free Channel », Europe 1, French radio, Isabelle’s testimony

<https://www.europe1.fr/emissions/La-libre-antenne/isabelle-est-atteinte-de-cutis-laxa-une-maladie-orpheline-qui-accelere-le-veillissement-3922012?fbclid=IwAR3jUjNjHLCprKN2nR51F6hBSsOPTXzAhYtXgPr-HKYMduWNXGReMlmimk>

01st December : Newspapers « De Morgen » (Belgium) and « De Volkskrant » (Austria) article in Dutch about Mohammed « Who helps Mohammed ? How charity stifles a Syrian family in Austria »

<https://www.demorgen.be/nieuws/wie-helpt-mohamad-hoe-liefdadigheid-een-syrisch-gezin-in-oostenrijk-verstikte~b0765328/>

02nd December : Newspaper, Charente Libre (France) article on receiving the cheque from the Triathlon of Sireuil

10th December : TV Show, Turkey, report with Zeynep, a little girl recently diagnosed with CL

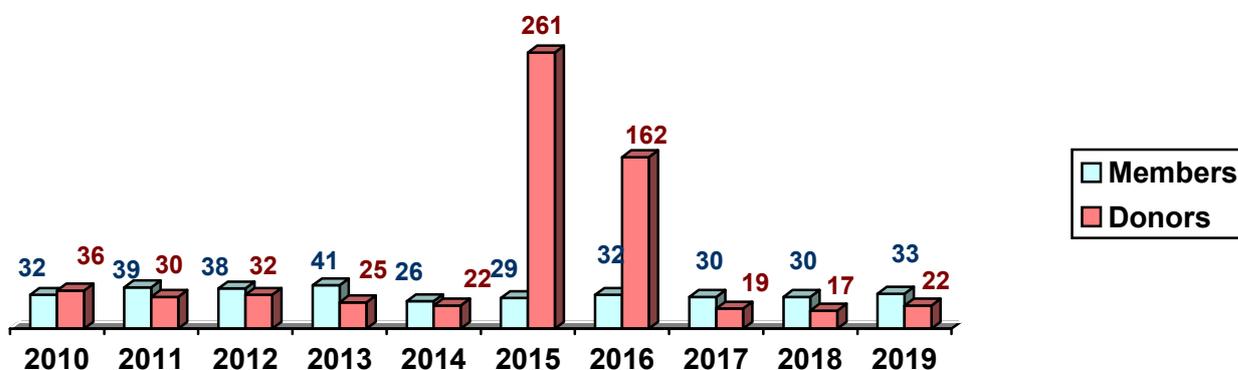
<https://www.facebook.com/showtv/videos/2554386797988359/UzpfSTEwMDA0MDQ0OTc0MjlyMjpWSzoxMDE1ODA3OTkwOTQ4MTUyMg/>

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 25th March 2020 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 2019 Annual General has either already been cast, digitally or by post, or will be cast on 6th June by proxy to the Chair.

FINANCIAL REPORT 2019

The year 2019 remained steady at a good level with 33 members and 22 donors. The various events we organised or took part in allowed us to keep a good financial balance with a positive result. We can thus think about rising our saving in anticipation of the next Cutis Laxa Days.

Number of Members and Donors



You will find hereunder all the necessary details in the numbers of the 2019 Financial Report.

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

CUTIS LAXA INTERNATIONALE
Pour l'exercice du 01/01/2019 au 31/12/2019

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	22 191.70 €
- Chiffre d'affaires	9 516.72 €
- Résultat net comptable	6 258.87 €

Fait à MAURIAC,
Le .
BEAUDONNET GEORGES,
Expert-comptable.

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

Cutis Laxa Internationale
for the year from 01/01/2019 to
31/12/2019,

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
CPTÉ DE RÉSULTAT DÉTAILLÉ

Du 01/01/2019 au 31/12/2019

	Du 01/01/19	Du 01/01/18	Du 01/01/17	Variation N / N-1 (*)	
	Au 31/12/19	Au 31/12/18	Au 31/12/17	en valeur	en %
Produits d'exploitation (1)					
Ventes de marchandises	122.00	671.04		-549.04	-82
70730000 VENTES OBJETS	122.00	671.04		-549.04	-82
Production vendue (biens et services)	9 394.72	3 433.38	3 778.60	5 961.34	174
70610000 MEMBRES ADHERENTS	1 095.00	900.00	895.00	195.00	22
70620000 MEMBRES BIENFAITEURS	2 826.60	2 284.39	2 400.00	542.21	24
70650000 DONATEURS	1 410.76			1 410.76	
70651000 DONS COMITE FETE SIREUL	1 200.00			1 200.00	
70660000 DONS OBSEQUES JONNY ANDERSON	434.85			434.85	
70801000 PARTICIPATION FANTASIA	754.16			754.16	
70810000 PARTICIPATION MANIFESTATION	1 673.35	140.00		1 533.35	
70830000 PARTICIPATION ASSOCIATIONS COM			137.10		
70840000 PARTICIPATION ERN SKIN 05.2017			346.50		
70850000 PARTICIPATION JOURNEE APHP		108.99		-108.99	-100
Montant net du chiffre d'affaires	9 516.72	4 104.42	3 778.60	5 412.30	132
Subventions d'exploitation		900.00	375.00	-900.00	-100
74350000 SUBVENTION CNE SIREUIL		900.00	300.00	-900.00	-100
74352100 SUBV CNE ST MARTIN VX			75.00		
Autres produits	3 145.85	2 562.82	2 277.06	583.03	23
75615000 DONS ENVIRONNEMENT			86.55		
75640000 BENEVOLAT TEMPS	1 180.00	1 516.00	950.00	-336.00	-22
75641000 BENEVOLAT DEPLACEMENT	1 965.85	1 046.82	1 240.51	919.03	88
TOTAL DES PRODUITS D'EXPLOITATION (1)	12 662.57	7 567.24	6 430.66	5 095.33	67
Charges d'exploitation (2)					
Achats de marchandises		645.33		-645.33	-100
60710000 ACHAT BIJOUX		400.00		-400.00	-100
60730000 ACHATS SOIREE FANTASIA		245.33		-245.33	-100
Variation de stocks	21.00	-390.00		411.00	105
60371100 VARIATION STOCK OBJET REVENET	21.00	-390.00		411.00	105
Autres achats et charges externes	5 209.42	6 343.98	5 951.29	-1 134.56	-18
60640000 FOURNITURE DE BUREAU		1 271.27	425.20	-1 271.27	-100
61540000 ENTRETIEN MATERIEL		110.40		-110.40	-100
61550000 ENT MAT INFORMATIQUE	195.20	210.06	137.60	-14.86	-7
61600000 PRIMES D'ASSURANCES	158.69	100.36	99.66	58.33	58
61810000 DOCUMENTATION ET ABONNEMENT	48.00	48.00	48.00		
62310000 PUBLICITE ANNONCES	797.91	475.92	253.18	321.99	68
62510000 FRAIS DE DEPLACEMENT		12.00		-12.00	-100
62512000 DEPLT CA BOITEUX	1 965.85	1 046.82	1 240.51	919.03	88
62516000 FRAIS DEPLACEMENT ASSOCIATION	57.36	559.08	631.49	-501.72	-90
62600000 TIMBRES AFFRANCHISSEMENT	1 127.39	1 618.70	2 116.00	-491.31	-30
62610000 TELEPHONE INTERNATIONAL			26.23		
62620000 AOL INTERNET	397.22	346.27	359.40	50.95	15
62700000 FRAIS BANCAIRES	68.30	102.85	72.80	-34.55	-34
62800000 COTISATION	393.50	442.25	541.22	-48.75	-11
Salaires et traitements	1 180.00	1 516.00	950.00	-336.00	-22
64140000 BENEVOLAT TEMPS	1 180.00	1 516.00	950.00	-336.00	-22

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

CUTIS LAXA INTERNATIONAL
CPTE DE RÉSULTAT DÉTAILLÉ

Du 01/01/2019 au 31/12/2019

	Du 01/01/19	Du 01/01/18	Du 01/01/17	Variation N / N-1 (*)	
	Au 31/12/19	Au 31/12/18	Au 31/12/17	en valeur	en %
Dotations aux amortissements et dépréciations					
Sur immobilisations : dotations aux amortissements		13.14	124.50	-13.14	-100
68110000 DOTATIONS AMORTISSEMENTS		13.14	124.50	-13.14	-100
TOTAL DES CHARGES D'EXPLOITATION (II)	6 410.42	8 128.45	7 025.79	-1 718.03	-21
RÉSULTAT D'EXPLOITATION (I - II)	6 252.15	-561.21	-595.13	6 813.36	
Quotes-parts de résultat sur opérations faites en commun					
Produits financiers					
Différences positives de change	18.66	18.16	28.01	0.50	3
76600000 INTERET CSL CRCA	18.66	18.16	28.01	0.50	3
TOTAL DES PRODUITS FINANCIERS (V)	18.66	18.16	28.01	0.50	3
Charges financières					
Intérêts et charges assimilées (4)	11.94	0.23		11.71	
66150000 INTERET CPTE COURANT	11.94	0.23		11.71	
TOTAL DES CHARGES FINANCIÈRES (VI)	11.94	0.23		11.71	
RÉSULTAT FINANCIER (V - VI)	6.72	17.93	28.01	-11.21	-63
RÉSULTAT COURANT avt impôts (I+II+III-IV+V-VI)	6 258.87	-543.28	-567.12	6 802.15	
Produits exceptionnels					
TOTAL DES PRODUITS EXCEPTIONNELS (VII)					
Charges exceptionnelles					
TOTAL DES CHARGES EXCEPTIONNELLES (VIII)					
RÉSULTAT EXCEPTIONNEL					
TOTAL DES PRODUITS (I+III+V+VII)	12 681.23	7 585.40	6 458.67	5 095.83	67
TOTAL DES CHARGES (II+IV+VI+VIII+IX+X)	6 422.36	8 128.68	7 025.79	-1 706.32	-21
Bénéfice ou Perte	6 258.87	-543.28	-567.12	6 802.15	

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

Due to the exceptional health situation and due to Orders N°2020-321 and 2020-318 of 25th March 2020 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 2019

Financial Report have either already been received via electronic or postal mail, or will be cast on 6th June by proxy to the Chair.

ELECTIONS TO THE BOARD OF DIRECTORS

Mrs Marie-Claude Boiteux, Nathalie Fournier, Martine Richemont, and Mr Chris Boisseaux and Serge Richemont's mandates expire this year.

Thus, the whole Board of Directors has to be renewed, except Mrs Justine Sergeat, Assistant-Treasurer and Mr Georges Beaudonnet, Treasurer, whose mandates expire in 2021.

Standing for election to the Board of Directors :

Mrs	Mr
BOITEUX Marie-Claude, outgoing Chair	BOISSEAUX Chris, outgoing Administrator
FOURNIER Nathalie, outgoing Secretary	RICHEMONT Serge, outgoing Vice-Chair
RICHEMONT Martine, outgoing Administrator	

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 25th March 2020 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 to elect Directors to the Board has either already been cast, digitally or by post, or will be cast on 6th June by proxy to the Chair.

SETTING THE MEMBERSHIP FEE FOR 2021

As we established, I propose that we agree the membership fee for next year that is for 2021. I propose that is maintained to € 30 for the year 2021.

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 25th March 2020 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 2021 membership fee has either already been cast, digitally or by post, or will be cast on 6th June by proxy to the Chair.

PROJECTS AND DRAFT BUDGET FOR 2020

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 25th March 2020 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 project and Draft Budget for 2020 has either already been cast, digitally or by post, or will be cast on 6th June by proxy to the Chair.

MINUTES OF THE ANNUAL GENERAL MEETING MONDAY 15th JUNE 2020

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

- ANNUAL REPORT 2019 and VOTE

- **FINANCIAL REPORT 2019 and VOTE**
- **ELECTIONS TO THE BOARD OF DIRECTORS**
- **FIXING THE 2021 MEMBERSHIP FEES and VOTE**
- **PROJECTS and DRAFT BUDGET 2020**
- **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 :

Ms Cécile Boiteux, Mr Chris Boisseaux, Mr Guillaume Boiteux, Mr Jean-Claude Boutron, Mrs Nathalie Fournier, Mrs Nicole Héger, Mr Richard Héger.

That is 7 votes

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

Mrs Hélène Boiteux, Mrs Marie-Thérèse Bourgeois, Mrs Véronique Fustier, Mrs Martine Richemont, Mr Serge Richemont, Mr Pascal Sommer, Mrs Mireille Tessier, Mr Moctar Wane

This totals 8 votes by proxy.

In 2019, there were 33 members. The total number of members present or represented by proxy is 17. Therefore, the meeting is quorate to vote on the agenda items (at least 1/3 of the members).

ANNUAL REPORT

The 2019 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 2019 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:

BOITEUX Cécile, outgoing member of the board

Abstentions : 0 No : 0 Yes : 17

BOITEUX Marie-Claude, outgoing Chair

Abstentions : 0 No : 0 Yes : 17

FOURNIER Nathalie, outgoing Secretary

Abstentions : 0 No : 0 Yes : 17

RICHEMONT Martine, outgoing member of the board

Abstentions : 0 No : 0 Yes : 17

BOISSEAUX Chris, outgoing member of the board

Abstentions : 0 No : 0 Yes : 17

RICHEMONT Serge, outgoing Vice-Chair

Abstentions : 0 No : 0 Yes : 17

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

FIXING THE 2021 MEMBERSHIP FEES and VOTE

It had been previously proposed to fix the membership fee for 2021 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 2020

The Projects for 2020 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 2020 were unanimously fixed

DRAFT BUDGET 2020

The Draft Budget for 2020 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 2020 was unanimously fixed

As all votes and proxies had been counted and no other question had been asked, the Chair closed the meeting at 10:30 am.

The Chair
Marie-Claude Boiteux



The Secretary for the meeting
Michel Senaud

